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REVIEW ARTICLE

Instruments to Measure Perceptions in the Emergency Department Provider-Patient with Sickle Cell Disease Interaction: Findings of an Integrative Review from a Ph.D. Project

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Abstract:

Background & Purpose:

The purpose of this review is to examine instruments that measure providers' perceptions of adult patients with Sickle Cell Disease (SCD), examine instruments that measure adult patients with SCD perceptions of providers' behaviors, and determine optimal instruments to use in evaluating the perceptions of Emergency Department (ED) providers and adult patients with SCD of one another's behaviors after an interaction in the ED.

Methods:

An integrative review was conducted searching EBSCOhost and PubMed databases using the keywords: measure [OR] measure* [OR] assess* [OR] scale [OR] survey [OR] tool [AND] stigma* [OR] stereotype [OR] prejudice [OR] bias [OR] perception [OR] attitude [OR] discrimination [OR] racism [OR] behavior [AND] interaction [OR] relationship [OR] communication [AND] sickle cell. Initial search located 256 articles, but only 15 articles were included in the final review.

Results:

Fifteen articles reporting six instruments were reviewed. Four instruments evaluated a provider's perceptions of patients with SCD behaviors, and two instruments evaluated how patients with SCD perceived provider behaviors. The two patient-focused instruments and three provider-focused instruments were found to be adequately reliable and valid according to the Psychometric Grading Framework (PGF).

Conclusions:

The findings suggest that the General Perceptions About Sickle Cell Disease Patients Scale would be an optimal instrument to evaluate ED providers' perceptions of adult patients with SCD behaviors. One patient-focused instrument, The Sickle Cell Health-Related Stigma Scale (SCD-HRSS), reported adequate reliability and validity but was not specific to measuring the patient's perceptions of ED providers' behaviors, nor was it administered in the ED environment. The SCD-HRSS Doctors subscale has potential adaptability for use in measuring patients with SCD perceptions of ED provider behaviors in the ED environment.

Keywords: Sickle cell disease, Perception, Social stigma, Attitude, Surveys and questionnaires, Emergency service, Hospital.

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1. INTRODUCTION

Sickle Cell Disease (SCD) is the most common inherited blood disorder in the United States [1]. During childhood and adolescence, many patients with SCD have disease-related symptoms treated at pediatric comprehensive sickle cell clinics [2]. Once patients with SCD reach adulthood, they transit out of comprehensive sickle cell clinics into mainstream medical care where there are instances of undertreated and potentially discordant care [3 - 6]. Due to the specialized nature of SCD, patients with SCD face poorer health outcomes due to limited access to primary care and hematologists for treatment [7, 8]. Healthcare providers report feeling unprepared to treat this unique disease process [7, 8]. Patients with SCD report difficulties in accessing primary care in a timely manner causing many patients with SCD to seek medical care delivered in the emergency department (ED) [3, 4, 9 - 12].

SCD is characterized by chronic hemolytic anemia, chronic

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pain, increased risk of infections, and eventually end-organ damage [13 - 15]. Patients with SCD can also experience intermittent acute pain from an acute Vaso-Occlusive Crisis (VOC), which is the hallmark symptom of SCD, leading to an ED visit [10, 16, 17]. Pain from acute VOC accounts for 78% of ED visits made by adult patients with SCD [18].

Treatment for an acute VOC includes evidence-based pain management with a combination of nonsteroidal anti-inflammatory medications and short- and long-acting opioids used in-home therapies [19]. When home regimens fail, aggressive analgesic management, using parenteral [intravenous or subcutaneous] opioids, should be initiated within 30 minutes of triage or 60 minutes from arrival to the ED [19, 20]. Patients with SCD wait for 25% longer to see a physician than other patients presenting to the ED [21] or 16 minutes longer when the average wait time is one hour [22]. The average wait time to initial analgesic administration is 80 minutes from the time of triage [23]. This long wait time for care has been associated with race [21]; over 90% of individuals with SCD in the United States are African American [24]. African Americans with chronic diseases suffer more negative health outcomes leading to substantial health disparities in timely access to quality care [25].

A recent survey of ED Providers reported that 75% of providers were not aware of evidence-based guidelines regarding patients with SCD, although 87% were aware that pain medication should be administered within 30 minutes of arrival to the ED [26]. Providers have reported reluctance in following guidelines due to the potential for drug addiction or suspected drug-seeking behaviors among patients with SCD when patient behaviors such as watching television or talking on the telephone seem incongruent with subjective pain scores [27 - 29]. It is common for patients with SCD to present with no outward signs of pain [30]. Physicians may expect to see signs such as redness and swelling of a joint related to the acute inflammatory process often associated with a VOC [30]. When providers do not find outward signs of pain in a patient with SCD, they report feeling frustrated and manipulated [30, 31]. These feelings of frustration and manipulation may increase, particularly when the provider reviews the medical chart and finds out that a patient has had many visits to the ED for pain and is non-adherent with medical care, such as following up with a PCP after discharge from the ED [30].

Patients with SCD are often reluctant to go to the ED for analgesic pain management due to anticipated stigma based on past negative experiences with providers [28, 32]. Patients with SCD often report feeling health-related stigma, or feelings of being discredited based on their health condition when providers doubt their quest for pain relief and label them as being drug-addicted, drug-seeking, or manipulative [33, 34]. Patients with SCD also perceive stigma when they are treated differently than other patients, making them feel undervalued and not a part of their health care decisions [34, 35]. The quality of communication with a provider can be directly associated with the ability of the patient with SCD to trust a provider during the interpersonal interaction [36].

Many providers are unaware that some patients with SCD perceive responses to their behaviors as unfavorable and stigmatizing during an interaction [28, 37 - 41]. Patients may not understand that behavioral attributions, such as requesting specific dosages of opioid pain medications or frequent visits to the ED for pain management, can lead to cognitive bias, negative behaviors and stigmatization by providers [17, 42, 43]. This discordance in the patient-provider interaction causes a communication breakdown that affects patient outcomes and may have significant clinical implications [39].

Patient-provider concordance, or a mutual understanding, in a medical interaction, can improve health outcomes [8, 44 - 48]. There is no gold standard to measure concordance (or discordance) in the shared experience of the provider and patient interaction [44, 49]. While it is challenging to measure perceptions of patients' and providers' self-reported agreement of an interaction, a paired survey method has previously been successful in measuring the patient-provider interaction for concordance (or discordance) and examining the extent of shared perceptions of behaviors during an interaction [44, 46, 49 - 52]. A dyadic or paired survey approach has not been used in current studies measuring perceptions in the provider and patient with SCD interaction. Current studies utilize instruments that measure provider behaviors such as negative attitudes and the patients' perception of health-related stigma during separate encounters [37, 53 - 66].

An examination of provider and patient with SCD perceptions of behaviors during the same ED encounter is needed in order to bring awareness to potential discordance in the patient-provider interaction and develop strategies to reduce possible discordance [57, 67 - 69]. A valid and reliable way to assess provider and patient with SCD perceptions of behaviors during the same ED encounter needs to be established in order to evaluate this interaction for possible discordance. Therefore, the purpose of this review is to: (a) identify and critically appraise instruments used to measure providers' perceptions of adult patients with SCD behaviors, (b) identify and critically appraise instruments used to measure adult patients with SCD perceptions of providers' behaviors, (c) describe the psychometric properties of these instruments, and (d) determine optimal instruments to use in a paired-survey method to evaluate the dyad immediately after an interaction in the ED.

2. METHODS

2.1. Search Strategy

EBSCOhost and PubMed databases were searched in June 2020 after consultation with a medical reference librarian. EBSCOhost includes Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, and PsychInfo databases. All databases were searched for articles reporting the psychometric properties of instruments using the following synonyms of key terms: instrument [OR] measure* [OR] assess* [OR] scale [OR] survey [OR] tool [AND] stigma* [OR] stereotype [OR] prejudice [OR] bias [OR] perception [OR] attitude [OR] discrimination [OR] racism [OR] behavior [AND] interaction [OR] relationship [OR] communication [AND] sickle cell. The PRISMA Diagram (Fig. **1**), which follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines, provides a

flow chart of the search strategy selection process that was used to identify relevant articles for review [70].

The search yielded 146 articles from EBSCOhost and 90 from PubMed. After 90 duplicates were removed, title and abstract review were conducted on 146 articles. Articles were excluded if they did not include patients with SCD aged 18 or older (n=98), did not include a licensed health-care provider (*i.e.*, Medical Doctor, Doctor of Osteopathic Medicine, Registered Nurse, Physicians Assistant, or Nurse Practitioner) and patient with SCD interaction for pain (n = 36), were not conducted in the United States (n=1), or were non-English (n = 1). Title and abstract review yielded ten articles. A secondary search was conducted within EBSCOhost, PubMed, Google Scholar, and in a hand search of references using an ancestry and descendancy method of instruments identified in the ten articles utilized previously on a different population (*i.e.*, child or adolescent with SCD, internal medicine resident, inpatient nurse), or in a different setting (*i.e.*, inpatient, provider's office). Using ancestry and descendancy methods to identify instruments helped to discover the steps used to develop an instrument and subsequent uses of an instrument to assist in the psychometric property critique of an instrument. Eleven additional articles were included using this ancestry and descendancy method to identify papers describing an instrument's development or subsequent use.

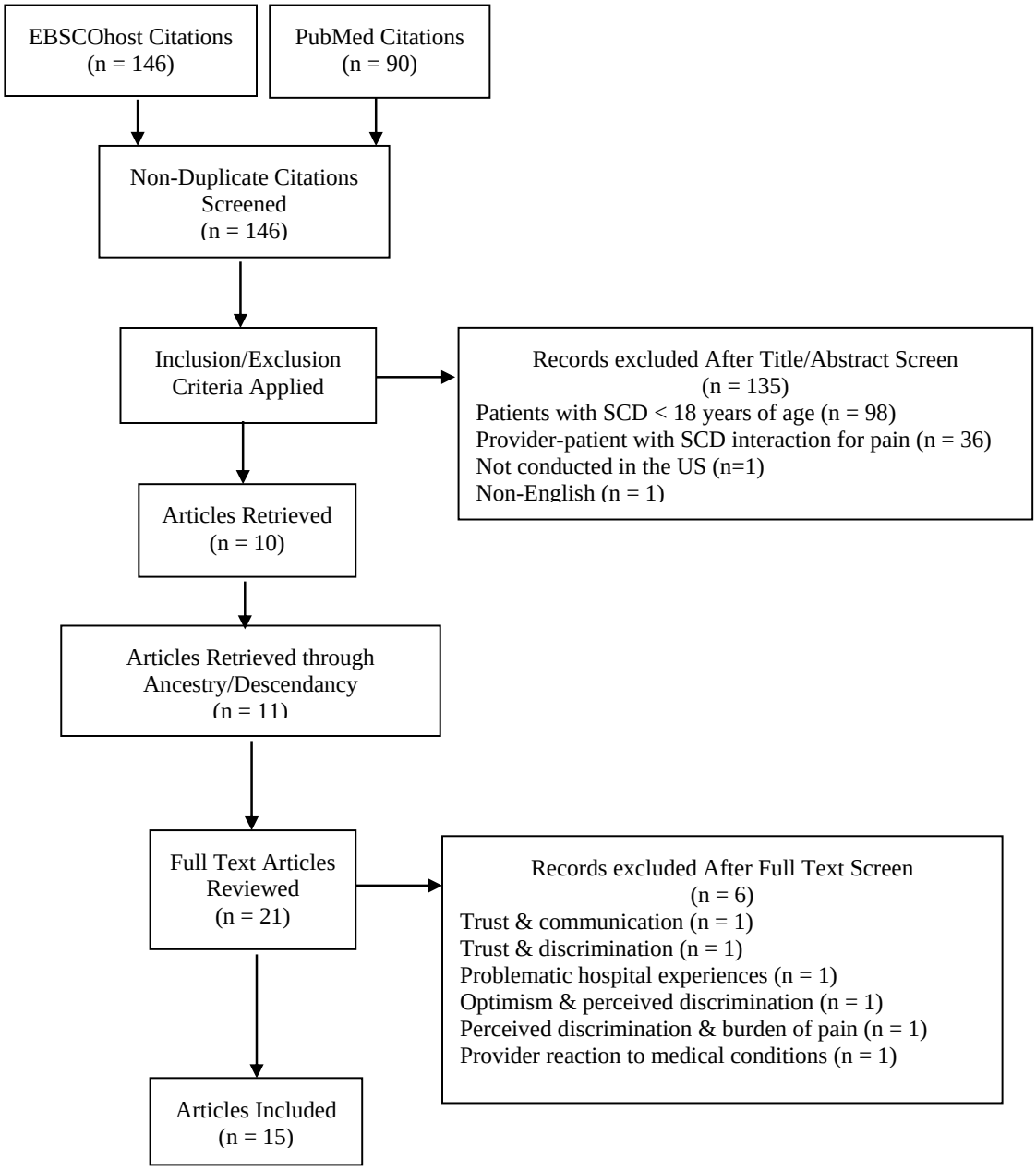

Fig. (1). PRISMA Diagram, literature search flowchart.

During the full-text review, 21 articles were examined to identify instruments that specifically measured a provider's perceptions of a patient with SCD behaviors or a patient with SCD perceptions of provider behaviors. The specificity of the instrument used in a population was chosen because instruments have been shown to have lower validity when administered outside the context for which they were developed [71]. For the purpose of this review, the behaviors associated with stigma, stereotype, prejudice, bias, attitude, discrimination, and racism, were targeted due to the high use of these terms in SCD behavioral research. While the root causes of behaviors associated with these terms are different, they are psychosocial stressors and follow similar social processes in a person's perception of them [72]. Reasons for exclusion during the full-text review included instruments not explicitly designed for the provider or patient with SCD interaction but were designed to measure patient trust in communication with a provider [36], patient trust and discrimination [73], patient experiences in the hospital as being problematic or not [74], patient optimism and perceived discrimination [75], the association of perceived discrimination with the burden of pain [76], and an instrument designed to measure provider reaction to medical conditions [65]. No date limit was set for this literature search. After full-text review, the resulting 15 articles reporting on six instruments were included in this integrative review. An overview of the 15 articles included in this review is summarized in Table **1**.

Table 1. Overview of studies included.

Author(s), Year of Publication	Title	Instrument Name	Instrument Population Focus
Ratanawongsa, N., Haywood, C., Bediako, S. M., Lattimer, L., Lanzkron, S., Hill., P. M., Powe, N. R., Beach, M. C.; 2009 [66]	Health care provider attitudes toward patients with acute vaso-occulusive crisis due to sickle cell disease: Development of a scale	Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS)	Provider
Haywood, C., Lanzkron, S., Hughes, M. T., Brown, R., Massa, M., Ratanwongsa, N., Beach, M. C.; 2011 [58]	A video-intervention to improve clinician attitudes toward patients with sickle cell disease: The results of a randomized experiment.	Clinician Attitude Scales: Negative Attitudes Scale, Positive Attitude Scale, Concern Raising Behaviors Scale, Red-Flag Behaviors Scale, Medical Condition Regard Positive Regard Subscale, Medical Condition Regard Negative Regard Subscale	Provider
Jenerette, C., Brewer, C. A., Crandell, J., Ataga, K. I.; 2012 [62]	Preliminary validity and reliability of the Sickle Cell Disease Health-Related Stigma Scale.	Sickle Cell Health-Related Stigma Scale (SCD-HRSS).	Patient
Glassberg, J. A., Tanabe, P., Chow, A., Harper, K., Haywood, C., DeBaun, M. R., Richardson, L. D.; 2013 [35]	Emergency provider analgesic practices and attitudes towards patients with sickle cell disease	General Perceptions About Sickle Cell Patients Scale	Provider
Glassberg, J., Tanabe, P, Richardson, L, DeBaun, M.; 2013 [37]	Among emergency physicians, the use of the term “sickler” is associated with negative attitudes toward people with sickle cell disease.	General Perceptions About Sickle Cell Patients Scale	Provider
Walker, P. M.; 2013 [54]	Sickle cell disease: A quality improvement initiative for emergency department providers	Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS)	Provider
Freiermuth, C. E., Haywood, C., Silva, S., Cline, D. M., Kayle, M., Sulliva, D., Thornton, V., Tanabe, P., 2014 [57]	Attitudes toward patients with sickle cell disease in a multi-center sample of emergency department providers.	General Perceptions about Sickle Cell Disease Patients Scale	Provider
Jenerette, C. M., Brewer, C. A., Edwards, L. J., Mishel, M. H., Gil, K. M.; 2014 [63]	An intervention to decrease stigma in young adults with sickle cell disease.	Sickle Cell Health-Related Stigma Scale (SCD-HRSS).	Patient
Haywood, C., Lanzkron, S., Hughes, M., Brown, R., Saha, S., Beach, M. C.; 2015 [77]	The association of clinician characteristics with their attitudes towards patients with sickle cell disease: secondary analysis of a randomized control trial.	Negative Attitudes Toward SCD Patients Scale, Positive Attitudes Toward SCD Patients Scale, Suspicion Over Concern-Raising Behaviors Scale	Provider
Jenerette, C. M., Pierre-Louis, B. J., Matthie, N, Girardeau, Y.; 2015 [60]	Nurses’ attitudes toward patients with sickle cell disease: A worksite comparison.	General Perceptions about Sickle Cell Patients Scale; Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS)	Provider
Singh, A. P., Haywood, C., Beach, M. C., Guidera, M., Lanzkron, A., Valenzuela-Araujo, D., Rothman, R. E., Dugas, A. F.; 2015 [59]	Improving emergency department providers’ attitudes toward sickle cell patients in pain.	General Perceptions about Sickle Cell Patients Scale	Provider
Bediako, S. M., Lanzkron, S., Diener-West, M., Onojobi, G., Beach, M. C., Haywood, C.; 2016 [53]	The Measure of Sickle Cell Stigma: Initial findings from the improving patient outcomes through respecte and trust study.	Measure of Sickle Cell Stigma (MoSCS)	Patient
Freiermuth, C. E., Silva, S., Cline, D. M., Tanabe, P.; 2016 [64]	Shift in emergency department provider attitudes toward patients with sickle cell disease.	General Perceptions about Sickle Cell Disease Patients Scale	Provider

(Table 1) contd.....

Author(s), Year of Publication	Title	Instrument Name	Instrument Population Focus
Jenerette, C. M., Brewer, C. A., Silva, S., Tanabe, P.; 2016 [61]	Does attendance at a sickle cell educational conference improve clinician knowledge and attitudes towards patients with sickle cell disease?	General Perceptions about Sickle Cell Patients Scale	Provider
Goddu, A. P., O'Conor, K. J., Lanzkron, S., Saheed, M. O., Saha, S., Peek, M. E., Haywood, C., Beach, M. C.; 2018 [55]	Do words matter? Stigmatizing language and the transmission of bias in the medical record.	Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS)	Provider

There is no gold standard to evaluate and interpret the quality of studies included in an integrative review, which includes various research designs [78]. Therefore, the studies presented in this paper were reviewed if they met the inclusion criteria, and no studies were excluded due to methodological criteria [79]. Heterogeneity was not assessed as the difference between instruments is under investigation, not the methodology of the studies under which they were published. To prevent publication bias in this review, multiple databases were searched, web searches conducted, ancestry and descendancy handsearching methods utilized, and grey literature included [80]. This review did not include statistical evaluation of individual studies, therefore, additional methods to prevent publication bias, such as funnel plots, were not explored [78].

2.2. Psychometric Properties

The psychometric evidence strength for each instrument included in this review was evaluated using the Psychometric Grading Framework (PGF), which was developed to evaluate self-report instruments by determining quality across six psychometric properties: content validity, construct validity, criterion validity, internal consistency, test-retest reliability, and inter-rater reliability [81]. The feasibility of each instrument was also assessed to determine the instruments' ease of use and potential administration limitations.

The PGF consists of two scales. Scale 1 is a matrix from which each psychometric property of an instrument is assigned a grade, A-D, with A at the top of the hierarchy and D at the bottom of the hierarchy. A higher grade reflects a more reliable psychometric property [81]. The graded hierarchy strength of each psychometric property was generated from the recommendations of commonly used guidelines for threshold values of statistical tests [81]. The determination of the graded hierarchy strength of each psychometric property within an instrument can be visualized in the Level of Psychometric Measures (Table **2**) [81].

Table 2. Level of psychometric measures [81].

Psychometric Measures / Levels	Content Validity	Construct Validity	Criterion Validity	Internal Consistency	Test-Retest Reliability	Inter-Rater Reliability
N/A	N/A	Convergent/divergent or discriminant. ANOVA (Cohen's f) / T-Test (Cohens' d) or Eta Squared n2 / Spearman rank-order correlation (p). Multitrait-multimethod/Factor analysis: Percentage variance explained and Kaiser-Meyer-Olkin value (KMO). Probability value (p). Cronbach's a.	Concurrent/predictive. ANOVA (Cohen's f) / T-Test (Cohen's d) or Eta Squared (n2) / Pearson product-moment correlation (r) / Spearman rank-order correlation (p). Probability value (P). Diagnostic/screening instruments: Area under curve (AUC). Positive likelihood ratio (LR+). Negative likelihood ratio (LR-).	Reliability coefficient (a). Cronbach's alpha. Kuder Richardson 20 (KR-20) / Split-half reliability.	Kappa coefficient (k): Landis's k or Fleiss's k. Intraclass correlation coefficient (ICC /Pearson correlation (r) / Probability value (P)	Kappa coefficient (k): Landis's k or Fleiss's k. Intraclass correlation coefficient (ICC / Pearson correlation (r) / Probability value (P)
A	N/A	Cohen's f ≥ .40 / Cohen's d ≥ .80 or n2 ≥ .14. r or p = ± .50 - ± 1.0. KMO ≥ .80. Percentage variance ≥ 70%. P < .05. a ≥ .90.	Cohen's f ≥ .40 / Cohen's d ≥ .80 or n2 ≥ .14. r or p = ± .50 - ± 1.0. P < .05. AUC > .9. LR+ > 10 or LR- < .10	a ≥ .90.	Landis's k ≥ .81 or Fleiss's k > .75. ICC > .75. r ≥ .95. P < .05	Landis's k ≥ .81 or Fleiss's k > .75. ICC > .75. r ≥ .95. P < .05
B	N/A	Cohen's f = .25 - .39 / Cohen's d = .50 - .79 or n2 = .06 - .13. r or p = ± .30 - ± .49. KMO = .70 - .79. Percentage variance ≥ 70%. P < .05. a = .80 - .89.	Cohen's f = .25 - .39 / Cohen's d = .50 - .79 or n2 = .06 - .13. r or p = ± .30 - ± .49. P < .05. AUC = .70 - .90. LR+ = 5.0 – 10 and LR- = .10 - .20.	a = .80 - .89.	Landis's k = .61 - .80 or Fleiss's k = .60 - .75. ICC = .60 - .74. r = .90 - .94. P < .05.	Landis's k = .61 - .80 or Fleiss's k = .60 - .75. ICC = .60 - .74. r = .90 - .94. P < .05.

(Table 2) contd.....

Psychometric Measures / Levels	Content Validity	Construct Validity	Criterion Validity	Internal Consistency	Test-Retest Reliability	Inter-Rater Reliability
C	Expert panel	Cohen's f = .10 - .24 / Cohen's d = .20 - .49 r n2 = .01 - .05. r or p = ± .10 - ± .29. KMO = .60 - .69. Percentage variance ≥ 70%. P < .05. a = .70 - .79	Cohen's f = .10 - .24 / Cohen's d = .20 - .49 or n2 = .01 - .05. r or p = ± .10 - ± .29. P < .05. AUC = .50 - .69. LR+ = 2.0 – 5.0 and LR- = .50 – 2.0	a = .70 - .79.	Landis's k = .41 - .60 or Fleiss's k = .40 - .59. ICC = .40 - .59. r = .85 - .89. P < .05.	Landis's k = .41 - .60 or Fleiss's k = .40 - .59. ICC = .40 - .59. r = .85 - .89. P < .05.
D	Group of related clinicians. Feedback from participants. Literature review.	Cohen's f < .10 / Cohen's d < .20 or n2 < .01. r or p = ± .10. KMO = .50 - .59. Percentage variance < 70%. P ≥ .05. a ≤ .69.	Cohen's f < .10 / Cohen's d < .20 or n2 = .01 - .05. r or p < ± .10. P ≥ .05. AUC ≤ .49. LR+ = 1.0 – 2.0 and LR- = .50 – 1.0.	a ≤ .69.	Landis's k < .40 or Fleiss's k < .40. ICC < .39. r ≤ .84. P ≥ .05.	Landis's k < .40 or Fleiss's k < .40. ICC < .39. r ≤ .84. P ≥ .05.

Any variable which appropriately matched a psychometric property was included in the grading of that psychometric property. Grades are not additive or averaged within a psychometric property and only assist the researcher in determining an overall grade for the psychometric property. For the purposes of this review, if multiple grades were reported for a psychometric property, the grades were assigned a number for a letter grade (A = 4, B=3, C=3, D=1, F=0) and the result averaged and rounded for determination of that psychometric property's grade. Scale 2 (Table **3**), Grading of Psychometric Strength, reviews the overall strength of the instrument is determined with the use of and the subsequent assignment of value: "good," "adequate," "weak," or "very weak" [81]. The process of determining the overall strength of an instrument can be visualized in the Grading of Psychometric Strength (Table **3**) [81]. It is up to the individual researcher to determine the PGF grade of psychometric strength level acceptable for instrument use in research [81].

3. RESULTS

The results of this review identify instrument characteristics, instrument purpose and development, psycho-metric properties, and feasibility of each provider- and patient-focused instrument. Table **1** provides a summary of the 15 studies included in this review.

3.1. Instrument Characteristics

This review included 15 articles representing six instruments. Articles were published between 2009 and 2018, and all were conducted in the United States. Twelve articles reported provider-focused instruments (n = 4) and three articles patient-focused instruments (n = 2). Table **4**, Provider-focused instrument overview 1, provides an overview of provider-focused instrument name purpose, theoretical framework, sample demographics, and setting., and Table **5**, Provider-focused instrument overview 2, provides the study design or sampling technique, number of items per subscale, scoring method, and any additional instruments, variables evaluated, or interventions discussed in provider-focused studies. Table **6**, Patient-focused instrument overview 1, provides an overview of patient-focused instrument name purpose, theoretical framework, sample demographics, and setting, and Table **7**, Patient-focused instrument overview 2, provides the study design or sampling technique, number of items per subscale, scoring method, and any additional instruments, variables evaluated, or interventions discussed in patient-focused studies.

Table 3. Grading of psychometric strength [81].

Grade of psychometric strength	Description	Example
Good	Three or more As and/or Bs ± C or D	A + A + B + C
Adequate	Two As and/or Bs ± C or D	A + B + C + D
Weak	One A or B ± C or D	B + D + C
Very weak	One or more C or D only	D + C

Table 4. Provider-focused instrument overview 1.

Instrument by Study	Purpose of Instrument	Purpose of Instrument in the Study	Theoretical Framework	Sample Demographics	Setting
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [66]	Measure provider attitudes towards patients with SCD.	Associate provider characteristic with provider attitudes.	N/A	47 adult patients (>18yo) with SCD. 84 Providers: 79% nurses, 6% PAs, 15% physician, 70% women, 26.2% African American, 57.1% White, 9.5% Asian, Hawaiian, or Pacific Islander, 1.2% Hispanic, 4.8% Other, (1.2% unaccounted for); 70% inpatient setting, 30% ED.	Urban, academic medical center.

(Table 4) contd.....

Instrument by Study	Purpose of Instrument	Purpose of Instrument in the Study	Theoretical Framework	Sample Demographics	Setting
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [54]	Measure provider attitudes towards patients with SCD.	Evaluate the effectiveness of an intervention in on provider attitudes.	Lewin's Change Management Model.	50 Providers: ED Nurses, ED Physicians, no % breakdown provided.	Emergency department.
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [55]	Measure provider attitudes towards patients with SCD.	Associate' stigmatizing language' with provider-in-training attitudes.	N/A	413 Providers: 42.8% female, 43.5% residents, 56.4% medical students, 20% emergency medicine residency, 90% internal medicine residency; 14% Hispanic/Latino, 54.7% White, 26.9% Asian, 10.4% black or African American.	Large, urban academic medical center.
Clinician Attitude Scales [58]	Measure provider attitudes towards patients with SCD.	Evaluate the effectiveness of an intervention in provider attitudes.	N/A	276 Providers: 88.5% nurses, 13.3% physician, 15% male, 53.9% White, 27.1% African American, 11.7% Asian, 7.3% Other.	Department of Medicine at a large, urban, academic medical center.
General Perceptions about Sickle Cell Patients Scale [35]	Measure provider attitudes towards patients with SCD.	Associate physician practice patterns with physician attitudes.	N/A	795 ED Physicians, 671 with complete data: 67.9% providers from academic or teaching hospital (7.5% rural teaching, 7.1% rural non-teaching, 60.2% urban teaching, 17.8% urban non-teaching), 83.2% practice in the US. 73.5% White, 5.9% Black, 16.3% Asian, 0.3% Hawaiian/Pacific Islander, 0.3% Native American/Alaskan Native, 3.8% Other. 36.6% treat primarily adults, 1.8% treat primarily children, and 61.6% treat both adults and children.	Booth at 2011 American College of Emergency Physician's Scientific Assembly.
General Perceptions About Sickle Cell Patients Scale [37]	Measure provider attitudes towards patients with SCD	Associate physician practice patterns to the term 'sickler'	N/A	655 ED Physicians: 67.9% academic, 32.1% community.	N/A - secondary analysis.
General Perceptions About Sickle Cell Disease Patients Scale [57]	Measure provider attitudes towards patients with SCD.	Associate provider characteristic with provider attitudes.	N/A	215 ED Providers, 200 with complete data: 15.4% attending, 23.4% resident, 3.7% PA, 1.4% NP, 56.1% nurse; overall 42.5% physicians, 57.5% nurses. 82.3% Non-Hispanic/Latino White, 6.5% Non-Hispanic/Latino Black, 2.7% Hispanic/Latino White, 0.6% Hispanic/Latino multiracial, 3.2% Asian, 0.6% Native American/Alaska Native, 0.4% Other.	Setting: from ED providers in a Level 1 trauma ED.
General Perceptions About Sickle Cell Disease Patients Scale [77]	Measure provider attitudes towards patients with SCD.	Associate provider characteristics with provider attitudes.	N/A	215 Providers: 57% White, percentage not provided: African American & Asian; 90% nurses, 10% physicians; 68% cared for between 1 and 10 patients with SCD in the past 3 months.	N/A Secondary analysis (58)..
General Perceptions About Sickle Cell Patients Scale [60]	Measure provider attitudes towards patients with SCD.	Associate a worksite comparison to nurse attitudes.	Theory of Self-Care Management for Sickle Cell Disease.	36 ED/ICU Nurses: 82.9% female, 16.7% male; 2.8% Black or African American, 75.0% White, 2.8% Other, 0% >1 race, 16.7% prefer not to answer; 20.6% AD, 63.9% BSN, 2.8% MN/MSN, 2.8% DNP. 41 Medical-Surgical Nurses: 97.6% female, 2.4% male; 12.2% Black or African American, 73.1% White, 2.4% Other, 4.9% >1 race, 7.3% prefer not to answer; 36.6% AD, 58.5% BSN, 4.9% MN/MSN, 0% DNP.	Two hospitals

(Table 4) contd.....

Instrument by Study	Purpose of Instrument	Purpose of Instrument in the Study	Theoretical Framework	Sample Demographics	Setting
General Perceptions About Sickle Cell Patients Scale [61]	Measure clinician attitudes toward patients with SCD.	Evaluate the effectiveness of an intervention on provider attitudes.	N/A	59 Participants at Time 1 (pre-conference), 47 completed surveys: 4% Hispanic/Latino, 96% non-Hispanic/Latino, 61% white, 34% black, 3% Asian, 2% other; 58% RN, 8% NP, 10% student, 10% social worker, 14% other; 21% treated 1-5 patients in career, 18% treated 6-10 patients in career, 43% treated >10 patients in career. 38 Participants at Time 2 (immediately post conference), 36 completed surveys: 3% Hispanic/Latino, 97% non-Hispanic/Latino, 59% white, 35% black, 3% Asian, 3% other; 74% RN, 5% NP, 5% student, 5% social worker, 14% other; 28% treated 1-5 patients in career, 14% treated 6-10 patients in career, 44% treated >10 patients in career. 30 Participants at Time 3 (2 months post conference), 20 completed surveys: 3% Hispanic/Latino, 97% non-Hispanic/Latino, 44% white, 50% black, 3% Asian, 3% other; 48% RN, 14% NP, 4% student, 17% social worker, 7% educator, 10% other; 23% treated 1-5 patients in career, 3% treated 6-10 patients in career, 50% treated >10 patients in career.	2-day SCD Education Conference.
General Perceptions About Sickle Cell Patients Scale [59]	Measure provider attitudes towards patients with SCD.	Evaluate the effectiveness of an intervention on provider attitudes.	N/A	96 Providers at T1 (pre-intervention): 57% nurses, 10% attending physicians, 25% residents, 7% midlevel providers (PAs/NPs); 72% female; 44% aged 30-39 years; 41% 2-4 years clinical experience. (Characteristics only gathered at T1). 83 Providers at T2 (post-intervention). 80 Providers at T3 (3 months post-intervention).	Urban, inner-city academic ED.
General Perceptions About Sickle Cell Disease Patients Scale [64]	Measure provider attitudes.	Evaluate the effectiveness of an intervention on provider attitudes.	N/A	216 ED Providers at T1 (Baseline): 15.4% attending, 23.7% resident, 3.7% PA, 1.4% NP, 55.8% nurse; overall 42.8% physicians, 57.2% nurses. 87.6% White, 5.7% Black, 2.9% Asian, 0.5% Native American/Alaska Native, 0.5% Native Hawaiian/Pacific Islander, 2.9% Multiracial/Other. 182 ED Providers at T2 (206 months) 21.4% attending, 20.9% resident, 3.3% PA, 2.2% NP, 52.2% nurse; overall 45.6% physicians, 54.4% nurses. 84.4% White, 7.8% Black, 3.9% Asian, 0.6% Native American/Alaska Native, 0.6% Native Hawaiian/Pacific Islander, 2.8% Multiracial/Other. 113 ED Providers at Time 3 (3-30 months): 25.7% attending, 22.1% resident, 4.4% PA, 2.6% NP, 45.1% nurse; overall 52.2% physicians, 47.8% nurses. 87.0% White, 2.8% Black, 5.6% Asian, 0% Native American/Alaska Native, 0% Native Hawaiian/Pacific Islander, 4.6% Multiracial/Other.	Emergency Department.

Table 5. Provider-focused instrument overview 2.

Instrument by study	Study Design / Sampling Technique	Number of Items / Subscale	Scoring Method	Additional Instruments / Variable Evaluated / Intervention
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [66]	Cohort Study	10 items; after analysis 7 items.	5-point Likert scale: 5 -much more than average to 1 - much less than average, 1 - strongly agree to 5 - strongly disagree, or 5 - extremely likely to 1 - not at all likely.	N/A

(Table 5) contd.....

Instrument by study	Study Design / Sampling Technique	Number of Items / Subscale	Scoring Method	Additional Instruments / Variable Evaluated / Intervention
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [54]	Pre-experimental one group pre-test/post-test quality improvement project	10 items.	5-point Likert scale: 5 -much more than average to 1 - much less than average, 1 - strongly agree to 5 - strongly disagree, or 5 - extremely likely to 1 - not at all likely.	Instrument: ED-SCANS Decision 2 Analgesic Algorithm, Provider practices of analgesia. Intervention: 8-minute video [58].
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [55]	RCT	7 items to assess provider attitudes towards patients. 3 items altered to assess participant perception of vignette physician attitudes towards the patient (vs. participant rating their own attitudes towards the patient). Specific questions not identified.	5-point Likert scale: 5 -much more than average to 1 - much less than average, 1 - strongly agree to 5 - strongly disagree, or 5 - extremely likely to 1 - not at all likely. Higher scores indicate a more positive attitude.	Instrument: Comfort in Dosing Pain Medication. Intervention: Hypothetical patient vignettes.
Clinician Attitude Scales [58]	RCT	31-Item Long Version, after analysis; 17-Item Short Version. Subscales: Negative Attitudes Scale = 6-items; Positive Attitudes Scale = 4-items; Concern Raising Behaviors Scale = 4-items; Red Flag Behaviors Scale = 3-items; Medical Condition Regard = 3-item positive regard scale and 4-item negative regard subscale derived from Medical Condition Regards Scale (MCRS).	5-point Likert scale: <5% to > 75%. 6-point Likert scale: strongly disagree to strongly agree.	Intervention: 8-minute video.
General Perceptions about Sickle Cell Patients Scale [35]	Cross-sectional convenience sample survey study	17-Item Short Version Clinician Attitude Scales. After analysis 15-items were retained: 6-item negative attitudes scale, 4 item positive attitudes scale, and 5 item red-flag behaviors scale.	5-point Likert scale: Not at all likely to extremely likely. 6-point Likert scale: strongly disagree to strongly agree. 4-point Likert scale: never to always.	Instrument: Provider practice patterns. Question about the term 'sickler'
General Perceptions About Sickle Cell Patients Scale [37]	N/A: Secondary analysis of cross-sectional convenience sample survey study [35]	N/A - Secondary analysis of General Perceptions About Sickle Cell Patients Scale [82].	N/A - Secondary analysis of General Perceptions About Sickle Cell Patients Scale [35].	N/A
General Perceptions About Sickle Cell Disease Patients Scale [57]	Convenience sample part of a larger prospective study	30 of 31-Item Long Version Clinician Attitude Scales, one item removed due to a lack of relevance in the ED setting. After analysis, 18 items were retained in 9-item Negative Attitudes subscale, 5-item Unease With Care of SCD Patients subscale, and 4-item Positive Attitudes subscale. Uneasiness With Care subscale includes 3 questions to determine if a provider was bothered by another provider's behaviors. 4 additional questions on frustration. Perception of addiction among adults with SCD compared with the general population and ED patients.	5- or 6-point Likert scale: strongly disagree to strongly agree. 0-10-point Likert scale: 0 - not frustrated to 10 – most frustrated. 0%-100%..	Instrument: MCRS
General Perceptions About Sickle Cell Disease Patients Scale [77]	N/A: Secondary analysis of RCT [58]	17-Item Short Version. Subscales: re-named in a secondary analysis: 6 item Negative Attitudes Toward SCD Patients Subscale; 4 item Positive Attitudes Toward SCD Patients Subscale; 4 item Suspicion Over Concern-Raising Behaviors Subscale.	5-point Likert scale: <5% to > 75%. 6-point Likert scale: strongly disagree to strongly agree.	N/A
General Perceptions About Sickle Cell Patients Scale [60]	Convenience sample, descriptive, comparative study	17-Item Short Version Clinician Attitude Scale. 3-items adapted from the SCD-HRSS: cause of sickle cell pain, appropriate use of pain medication, comparing patients with SCD to other patients with medical conditions. Open-ended question for comments on perceptions about patients with SCD	5-point Likert scale: <5% to > 75%. 6-point Likert scale: strongly disagree to strongly agree.	N/A

(Table 5) contd.....

Instrument by study	Study Design / Sampling Technique	Number of Items / Subscale	Scoring Method	Additional Instruments / Variable Evaluated / Intervention
General Perceptions About Sickle Cell Patients Scale [61]	Prospective descriptive survey	17-Item Short Version Clinician Attitude Scales prior to secondary analysis. Correlated with a change in 20-item Knowledge of SCD questionnaire.	5-point Likert scale: <5% to > 75%. 6-point Likert scale: strongly disagree to strongly agree.	Instrument: 20-item Knowledge about SCD survey
General Perceptions About Sickle Cell Patients Scale [59]	Pre- multi-post-test intervention	Original 31-Item Long Version Clinician Attitude Scale focusing on the 6 item negative attitudes subscale, 4 item positive attitudes subscale, and 5 item red flag behaviors subscale.	5-point Likert scale: Not at all likely to extremely likely. 6-point Likert scale: strongly disagree to strongly agree.	N/A
General Perceptions About Sickle Cell Disease Patients Scale [64]	Longitudinal quality improvement study	18-item General Perceptions About Sickle Cell Disease Patients Scale; 4 additional questions on frustration. Perception of addiction among adults with SCD compared with the general population and ED patients.	5- or 6-point Likert scale: strongly disagree to strongly agree. 0-10-point Likert scale: 0 - not frustrated to 10 – most frustrated. 0%-100%.	N/A

Table 6. Patient-focused instrument overview 1.

Instrument by Study	Purpose of Instrument	Purpose of Instrument in Study	Theoretical Framework	Sample Demographics	Setting
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [62]	Describe patient perceived health-related stigma	Associate patient characteristic with depressive symptoms and health-related stigma	The Theory of Self-Care Management for Sickle Cell Disease	77 adult patients with SCD aged 18-35.	SCD clinic
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [63]	Describe patient perceived health-related stigma	Evaluate the effectiveness of an intervention on patient perceived health-related stigma	The Theory of Self-Care Management for Sickle Cell Disease	90 adult patients with SCD aged 18-35.	Comprehensive Sickle Cell Program center
Measure of Sickle Cell Stigma (MoSCS) [53]	Measure disease-specific stigma in adults with SCD	Associate patient characteristic with health-related stigma	N/A	Initial: 19 patients with SCD, age not provided but labeled 'adults'. Follow-Up 1: 71 (70 with complete data) patients with SCD ≥ 18 years old. Setting: clinic associated with an academic hospital center. Follow-up 2: 279 (262 complete data) patients with SCD ≥15 years old.	Two comprehensive SCD centers

Table 7. Patient-focused instrument overview 2.

Instrument by study	Study Design / Sampling Technique	Number of Items / Subscale	Scoring Method	Additional Instruments / Variable Evaluated / Intervention
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [63]	Secondary analysis of a pilot intervention, convenience sample.	30 items, 3 subscales: general public, physicians, and family	Six-point Likert-type scale: 1-strongly agree to 6-strongly disagree. Higher scores indicate higher perceived stigma.	Instrument: Beck Depression Inventory-Fast Screen (BDI-FS), Chronic Pain Stigma Scale.
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [62]	Prospective, longitudinal RCT, convenience sample.	30 items, 3 subscales: general public, physicians, and family	Six-point Likert-type scale: 1-strongly agree to 6-strongly disagree. Higher scores indicate higher perceived stigma.	Instrument: Assertive communication skills using SBAR. Intervention: 8-Minute Video(58). Video on physiologic phases of SCD.

(Table 7) contd.....

Instrument by study	Study Design / Sampling Technique	Number of Items / Subscale	Scoring Method	Additional Instruments / Variable Evaluated / Intervention
Measure of Sickle Cell Stigma (MoSCS) [53]	Initial: Qualitative (focus group), convenience sample. Follow-Up 1: convenience sample. Follow-Up 2: prospective cohort study, convenience sample.	Initial evaluation of 40 items resulting in 31 items tested initially, 11 retained after analysis	Six-point Likert-type scale: 1-completely false to 6-completely true. Higher scores indicate higher levels of stigma.	Instrument: Human Immunodeficiency Virus (HIV) Stigma Scale.

Provider-focused instruments were reported to measure providers' attitudes [35, 37, 54, 55, 57 - 61, 64, 66, 77]. Provider behaviors of interest were most often adapted from extant literature and reviewed by an expert panel of providers developed by authors of a manuscript [37, 58, 66]. Expert panels most often included a provider experienced in treating patients with SCD, providers experienced in the measurement of the patient experience of care, providers experienced in bioethics, and a patient with SCD to gain the patient perspective [37, 58, 66]. Behaviors of interest often included a provider's regard for a patient, feelings of affiliation with a patient, the level of frustration a provider had with a patient, beliefs providers had about a patient's behavior, and behaviors providers associated with less than favorable attitudes toward a patient [58, 66].

Patient perceptions of provider behaviors were evaluated by measuring health-related stigma [53, 62, 63]. Health-related stigma occurs when a health-related characteristic of a patient evokes a negative reactive behavior from a provider such as a negative emotion, negative attitude, rejection, devaluation, blame, avoidance, or exclusion [33] from a person in a position of authority [83].

Forty percent [n=6] of studies reviewed were designed to evaluate the effectiveness of an intervention on behavior change by utilizing a pre- and post-test administration of the instrument [54, 55, 58, 59, 61, 63]. Sixty percent [n=9] of studies utilized an instrument to associate a demographic variable to the behavior of interest [53, 55, 57, 59 - 62, 64, 77]. Four manuscripts describe a secondary analysis correlating demographic variables to behavior change before and after an intervention [37, 59, 63, 77]. Additional study designs included randomized control trials [RCT] [55, 58, 62], cohort study designs [53, 66], quality improvement studies [54, 64], prospective studies [57, 61], a descriptive study [60], and a cross-sectional study design [35].

All of the instruments were administered through self-report using 4 to 10-point Likert-style scoring systems for between 7 to 31 items per instrument. The largest group to complete an instrument were located at a conference (n=795] [35]. All patient-focused instruments were administered in a SCD clinic or SCD center [53, 62]. No instruments were administered to both patients and providers to evaluate their perceptions of an interaction during or immediately after the encounter.

Participants numbered from 20 to 671 completed surveys with seven studies using convenience sampling [35, 53, 57, 60, 62]. In over half of the articles, the inclusion of ED providers was reported with ED physicians participating most often [35, 37, 54, 57, 59, 60, 64]. Nine studies reported female nurses as being the primary participant type, whereas nurses comprised 48% to 88.5% in mixed provider administration of an instrument [54, 57, 58, 60, 61, 64, 66, 77]. Of articles reporting race, instruments were most often administered to White providers [44%-87.6%], followed by African American providers [2.8%-50%] [35, 55, 58, 60, 61, 64, 66, 77].

While a theoretical framework can standardize and guide the development and measurement of related concepts or variables, only four articles reported the association of a theory during the administration of an instrument, one of which was a secondary analysis [54, 60, 62, 63]. The Theory of Self-Care Management for Sickle Cell Disease was used in the administration of a patient-focused instrument in two articles and a provider-focused instrument in another article [60, 62, 63]. One theory was used in the administration of a provider-focused instrument, Lewin's Change Management Model [54]. No theoretical frameworks were applied to the development of instruments.

3.2. Instrument Purpose and Development

3.2.1. Provider-Focused Instruments

All provider-focused instruments were designed to measure provider attitudes towards patients with SCD. Provider-focused instruments measured a provider's perceptions of patients' with SCD behaviors through the measurement of positive attitudes toward patients, negative attitudes toward patients, perception of patients' behaviors that raise a “red flag” for the provider, perceptions of patients' behaviors that were concerning to the provider, and in some cases the level to which observation of another providers behaviors toward patients' with SCD bothered the provider [35, 37, 54, 55, 57 - 61, 64, 66, 77]. No provider-focused instruments measured stereotype, prejudice, discrimination, or racism directly. Jenerette *et al.* (2015) adapted the General Perceptions about Sickle Cell Scale to include three stigma-related items from a patient-focused instrument to assist in measuring nurse attitudes [60]. The PASS instrument was used to associate physician attitudes with “stigmatizing language” by evaluating a provider's charting language [55]. This charting language consisted of terms that can create doubt in the reader, such as a provider charting the patient's pain score was “still a 10” instead of “still has 10/10 pain” or using the term “narcotic” instead of “opioid” [55]. Freiermuth *et al.* (2014) included an additional instrument to evaluate provider biases, emotions, and expectations, but the additional instrument was not developed to evaluate providers who care for patients with SCD [57].

Ratanawongsa, *et al.* (2009) developed a new scale, Positive Provider Attitudes toward Sickle Cell Patients Scale

(PASS), from which all future instruments derived variations of item questions [54, 55]. These instruments included: The Clinician Attitude Scales [58], the General Perceptions About Sickle Cell Patients Scale [35, 37, 59 - 61], and the General Perceptions About Sickle Cell Disease Patients Scale [57, 64].

The 10-item PASS questionnaire was initially developed using the hypothesis that providers may have believed some patient behaviors, such as the exaggeration of pain, manipulation, drug abuse, and non-compliance, were associated with provider attitudes toward patients with SCD [66]. Provider perceptions of a patient with SCD behavioral attributions may influence a provider's interpretation of patients' behaviors in a negative way [66]. The PASS was used to measure ED provider attitudes after education and the introduction of a pain algorithm specific to patients with SCD [54]. PASS was later revised with the addition of 3 questions of the 10-item PASS, to measure the influence of language used in provider charting was compared to provider-in-training attitudes [55].

Content was added to PASS by Haywood, *et al.* (2011) when developing the Clinician Attitude Scales. This content included questions to measure provider positive attitudes, provider negative attitudes, provider perceptions of concern-raising behaviors exhibited by patients, and provider perceptions of red-flag behaviors exhibited by patients [58]. In a secondary analysis of content within the Clinician Attitude Scales, the 31-item instrument was modified into a final 17-item questionnaire to measure negative attitudes, positive attitudes, and concern-raising behaviors [57].

The Clinician Attitude Scales were adapted by an expert panel consisting of ED providers who treat patients with SCD, a hematologist specializing in SCD, and a patient with SCD [35]. This new General Perceptions About Sickle Cell Patients Scale was administered by Glassberg, *et al.* (2013) to ED providers to measure negative attitudes, positive attitudes, and red-flag behaviors in order to correlate instrument results with provider practice patterns [35]. The results from the newly adapted scale were also correlated with the use of the derogatory term 'sickler,' which is a term sometimes used by providers as a label for patients with SCD [37]. This version of the General Perceptions About Sickle Cell Patients Scale was also used to measure nurses' attitudes at two different worksites [60], to determine if educating providers about SCD would change provider knowledge and attitudes toward patients with SCD [61], and improve ED providers' attitudes toward patients with SCD in pain [59].

While all other provider-focused instruments were administered to samples, which included ED providers, only one was adapted for the ED provider in the ED environment [57]. Freiermuth, *et al.* (2014) revised the initial 17-item Clinician Attitude Scales were by adding four items on provider frustration and provider perceptions of addiction among patients with SCD [57]. One item was removed due to a lack of relevance to the ED environment. Items were assessed by content experts to determine which items would be relevant for ED providers in the ED environment [57]. After factor analysis, a new 18-item General Perceptions About Sickle Cell Disease Patients Scale was developed to measure ED provider behaviors [57]. Subscales included negative attitudes, positive attitudes, and uneasiness with care in the ED environment [57].

3.2.2. Patient-Focused Instruments

Patient-focused instruments measured perceptions of providers' behaviors through instruments to measure health-related stigma [53, 62]. No patient-reported instrument measured stereotypes, prejudice, biases, attitudes, or racism directly. One instrument used the term 'expected discrimination' with a definition including 'anticipated discrimination' alluding to anticipated stigma in addition to measuring feelings of 'social exclusion' and 'disclosure concerns' [53].

The two patient-focused instruments include a 30-item Sickle Cell Disease Health-Related Stigma Scale (SCD-HRSS) [62, 63] and 11-item Measure of Sickle Cell Stigma Scale (MoSCS] [53]. Both patient-focused instruments were developed to measure how patients with SCD perceived health-related stigma [62]. Health-related stigma instruments measured how patients with SCD perceived stigma from doctors, the public, and family members [62].

Jenerette, *et al.* (2012) developed the SCD-HRSS to measure external stigma, which is an individual's awareness of unfair treatment or devaluing attitudes towards them [53, 84]. The SCD-HRSS also focuses on perceived stigma and experienced stigma through items wherein a patient is asked to reflect on incidents after they have occurred [53, 62]. To address a gap in measuring internalized stigma and anticipated stigma of a patient with SCD, the MoSCS was developed by Bediako, *et al.* (2016). The MoSCS was developed by adapting a 40-item HIV stigma scale [53]. Focus groups of patients with SCD were asked to score the items as very relevant or not at all relevant to the experiences of patients with SCD [53]. The resulting 31-item MoSCS was administered to a convenience sample and after analysis, and 11 items were retained in the scale. The MoSCS applies a multi-dimensional approach to capture a patient's social exclusion, expected discrimination, disclosure concerns, and internalized stigma based on previous experiences and possible future experiences [53]. The MoSCS is designed to capture the lived experience of a patient and does not focus on specific health interactions [53].

3.3. Psychometric Properties

An overview representation of the psychometric properties for instruments based on analysis using PGF criteria can be found in Table **8**, level of psychometric measures for provider-focused instruments; Table **9**, grading of psychometric strength for provider-focused instruments; Table **10**, feasibility found in provider-focused instruments; Table **11**, level of psychometric measures for patient-focused instruments; Table **12**, grading of psychometric strength for patient-focused instruments; Table **13**, feasibility found in patient-focused instruments. Of note, no studies reported test-retest no inter-rate reliability for the provider- or patient-focused instruments, so are not included in the tables for the level of psychometric measures. In addition, currently, no gold standard instruments are available, which could be tested against instruments for criterion validity, so they are not included in the tables for the level of psychometric measures.

Table 8. Provider-focused psychometric properties: Level of psychometric measures.

Instrument by Study	Content Validity	Construct Validity	Internal Consistency
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [66]	Literature review, experts, and a patient. **PGF Grade = C.**	Hypothesis: 1. Inpatient ($p<0.001$), nursing ($p<0.001$), female ($p=0.02$) and African American ($p=0.19$) providers would have more positive attitudes. 2. Higher patient socioeconomic status ($p <0.001$) would equal more positive provider attitudes. 3. The more severe the SCD was using as evidence by increasing the frequency of hospitalizations within the past year ($p<0.001$), the less positive attitudes. 4. concerning behaviors such as patients discharge against medical advice ($p = .04$), narcotics dependence ($p = 0.01$), and positive toxicology screen (0.04) would equal less positive provider attitudes. 5. Prior disputes with staff ($p=0.002$) would equal less positive provider attitudes. 6. No statistical significance was found in the sex of the provider. Two markers of SCD did not meet statistical significance (prior avascular necrosis and prior acute chest syndrome). Exploratory Factor Analysis: Eigenvalues above 1 = 2, retained due to lower AIC for 2- factor solution. **PGF Grade = A**. Corrected item total correlation ranges 10-item/7-item = 0.54 – 0.80/0.59-0.81. 3 items eliminated due to high uniqueness values on factor analysis. **PGF Grade = A.** **Overall PGF Grade = A + A = A.**	10-item Cronbach's alpha = 0.910. 7-item Cronbach's alpha = 0.907. **PGF Grade = A.**
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [54]	**PASS PGF Grade = C.**	Hypothesis: Pre-intervention vs. Post-intervention. 1. Triage level of pain (LOP) (no sig difference, p-value not provided). 2.LOP one-hour post analgesia administration (no sig difference, p-value not provided) 3.LOP at discharge from ED ($p<0.002$). 4.PASS scores ($p<0.001$). **PGF Grade = A.**	Not reported in the study, relied on previous reporting of 10-item Cronbach's alpha = 0.910. **PGF Grade = A.**
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [55]	**PASS PGF Grade = C.**	Hypothesis: 1. PASS scores differ in stigmatizing language vs. neutral language ($p<0.001$) in medical students and residents. 2. Stigmatizing language cohort prescribed less aggressively ($p<0.001$) and had less comfort in dosing pain medication ($p<0.04$) than neutral cohort. 3. The more training a physician had, the lower the PASS score ($p<0.001$). Perceptions of Vignette Physician attitudes: stigmatizing language note physician had a more negative attitude toward the patient ($p<0.001$). **PGF Grade = A**	10-item (altered) Cronbach's alpha = not reported. **PGF Grade = N/A.**
Clinician Attitude Scales [58]	PASS further developed or adapted from extant literature. **PASS PGF Grade = C.**	Hypothesis: Clinicians who expressed more negative attitudes toward patients with SCD would exhibit lower regard for patients as measured by the MCRS. Intervention vs. Control: Negative attitudes (Cohen's $d = 0.41$, $p = 0.001$), Concern Raising Behaviors (Cohen's $d = 0.36$, $p = 0.004$), Positive Attitudes (Cohen's $d = .27$, $p = 0.29$), Red-Flag Behaviors (Cohen's $d = 0.08$, $p = 0.511$). **PGF Grade = A.** Mean inter-item correlation = Negative attitudes scale (0.57), Positive attitudes scale (0.59), Concern raising behaviors scale (0.53), Red flag behaviors scale (0.51). Corrected item-total correlations range = Negative attitudes scale (0.59-0.82), Positive attitudes scale (0.64-0.78), Concern raising behaviors scale (0.55-0.73), Red flag behaviors scale (0.52-0.65). **PGF Grade = A.** Pearson correlation matrix bivariate associations Clinician Attitude Scales vs. MCRS: all correlations significant at $p<0.001$.**PGF Grade = A.** **Overall PGF Grade = A+A+A = A.**	Cronbach's alpha = 17- item short version (not reported). Negative attitudes scale = 0.89. Positive attitudes scale = 0.85. Concern raising behaviors scale = 0.85. **PGF Grade = B.** Red flag behaviors scale = 0.76. **PGF Grade = C.** **Overall PGF Grade = B + C = B.**
General Perceptions About Sickle Cell Patients Scale [35]	Focus on provider practice patterns, developed or adapted from extant literature. A panel of 5 experts to include a patient. Content Validation Survey. **PGF Grade = C.**	Hypothesis: 1. ED providers with negative attitudes toward patients with SCD deviate from 8 national guidelines for the management of an acute VOC. 2. Characteristics of providers will be associated with a deviation from national guidelines Pediatric providers and positive attitudes; adult providers and negative attitudes; the number of SCD patients seen per week and negative attitudes; black providers and positive attitudes and lower red flag behaviors when compared to white providers; analgesic practices and provider attitudes; all $p \leq 0.05$. **PGF Grade = A.** Mean inter-item correlation = Negative attitudes scale (0.60), Positive attitudes scale (0.61), Red flag behaviors scale (0.52). Corrected item-total correlations range = Negative attitudes scale (0.44 – 0.73), Positive attitudes scale (0.53-0.66), Red flag behaviors scale (0.63-0.72). **PGF Grade = A.** **Overall PGF Grade = A+A = A.**	Cronbach's alpha = Negative attitudes scale = 0.90. **PGF Grade = A.** Positive attitudes scale = 0.86. **PGF Grade = B.** Red flag behaviors scale = 0.86. **PGF Grade = B.** **Overall PGF Grade = A+B+B = A.**

(Table 8) contd.....

Instrument by Study	Content Validity	Construct Validity	Internal Consistency
General Perceptions About Sickle Cell Patients Scale [37]	Secondary analysis, previous study [35]. **PGF Grade = C.**	Hypothesis: Physicians who use the term 'sickler' have more negative attitudes towards patients with SCD (statistically significant, p-value not given) and less likely to adhere to national guidelines (not statistically significant). **PGF Grade = A.**	Secondary Analysis, previous study [35]. **Overall PGF Grade = A+B = A.**
General Perceptions About Sickle Cell Patients Scale [60]	Reported Clinician Attitude Scales. **PGF Grade = C.**	Reported previous construct validity with correlation to MCRS. **PGF Grade = A.** Reported previous construct validity with SCD-HRSS correlation to BDI-FS. **PGF Grade = A.** Hypothesis: ED/ICU nurses and medical-surgical nurses demonstrate different attitudes and behaviors toward patients with SCD. ED/ICU and more negative attitudes ($p = 0.342$), concern raising behaviors ($p=0.232$), red flag behaviors ($p =-0.186$), and lower positive attitudes ($p = 0.661$). **PGF Grade = D.** Hypothesis: Attitudes and behaviors vs. appropriate use of pain medication (negative $p < 0.001$, positive $p = 0.015$, concern-raising behaviors $p < 0.0001$, red-flag behaviors $p = 0.002$), comparing patients with SCD to other patients with medical conditions (negative $p < 0.001$), concern-raising behaviors $p = 0.005$, red-flag behaviors $p = 0.012$. **PGF Grade = A.** **Overall PGF Grade = A + A + A + D + A = B.**	Reported previous Cronbach's alpha scores ranging from 0.76 to 0.89 for negative attitudes, positive attitudes, concern-raising behaviors, and red flag behaviors. **PGF Grade = B.** Reported total score and subscales of SCD-HRS as ranging from 0.69 to 0.84. **PGF Grade = B.** **Overall PGF Grade = B+B = B.**
General Perceptions About Sickle Cell Patients Scale [61]	Reported Clinician Attitude Scales. **PGF Grade = C.**	Hypothesis: Change in clinician SCD knowledge and attitudes toward patients with SCD before the intervention, immediately post-intervention, and 2 months post-intervention. Overall increase in knowledge scores ($p<0.0001$), increase in overall knowledge between T1-T2 ($p<0.001$), increase in overall knowledge between T1-T3 ($p = 0.0125$) Total negative attitudes decreased between T1-T3 ($p = 0.03$). **PGF Grade = A.**	Reported previous Cronbach's alpha scores ranging from 0.76 to 0.89 for negative attitudes, positive attitudes, concern-raising behaviors, and red flag behaviors. **PGF Grade = B.**
General Perceptions About Sickle Cell Patients Scale [59]	Reported Clinician Attitude Scales. **PGF Grade = C.**	Hypothesis: Change in clinician attitudes toward patients with SCD before intervention (T1), immediately post-intervention (T2), and 3 months post-intervention (T3). All significantly different ($p \leq 0.05$) from T1 to T2 and T3. **PGF Grade = A.**	Reported Cronbach's alpha from previous administration [35]. Negative attitudes scale = 0.90. **PGF Grade = A.** Positive attitudes scale = 0.86. **PGF Grade = B.** Red flag behaviors scale = 0.86. **PGF Grade = B.** **Overall PGF Grade = A+B+B = A.**
General Perceptions About Sickle Cell Disease Patients Scale [57]	Reported Clinician Attitude Scales. **PGF Grade = C.** Additional Questions validated by content experts. **PGF Grade = C.**	Hypothesis: 1. When compared to physicians, nurses had higher levels of frustration in caring for an adult patient with SCD ($p = 0.0037$), higher perception of opioid addiction in the general population ($p \leq 0.0001$), higher perception of opioid addiction among adults with SCD ($p \leq 0.0001$), and a higher perception of ED patients with SCD believed to be addicted to opioids ($p = 0.0210$. In all cases, ratings of frustration decreased as the years of practice increased. **PGF Grade = A.** Partial Spearman correlation with subscales and MCRS total scores. MCRS vs. negative attitudes: rs = -0.65, $p \leq 0.002$. MCRS vs. positive attitudes: rs = 0.61, $p \leq 0.002$. Higher negative attitudes vs. higher frustration rs = 0.65, $p < 0.0001$. **PGF Grade = A.** Higher uneasiness scores vs. less perception of opioid addiction rs = -0.32, $p \leq 0.0001$. Higher positive attitude scores vs less frustration rs = -0.44, $p < 0.0001$. Higher positive attitudes vs less perception of opioid addiction rs = -0.31, $p < 0.0001$. **PGF Grade = B.** MCRS vs uneasiness with care: rs = 0.23, $p \leq 0.002$). **PGF Grade = C.** Higher uneasiness scores not related to frustration rs = -.05, $p \leq 0.0001$. **PGF Grade = D.** **Overall PGF Grade = A+A+B+C+D = B.**	Cronbach's alpha: Negative Attitudes = 0.93. **PGF Grade = A.** Uneasiness With Care = 0.83. **PGF Grade = B.** Positive Attitudes subscale = 0.82. **PGF Grade = B.** **Overall PGF Grade = A+B+B = B.**

(Table 8) contd.....

Instrument by Study	Content Validity	Construct Validity	Internal Consistency
General Perceptions About Sickle Cell Disease Patients Scale [64]	Reported Clinician Attitude Scales. **PGF Grade = C.** Additional questions validated by content experts. **PGF Grade = C. Overall PGF Grade = C+C = C.**	Hypothesis: ED provider attitudes would improve after an intervention and be maintained over a 2.5 year time period at two sites by attitude subscale scores, level of frustration, and perception of addiction among adults with SCD compared with the general population and ED patients. Uneasiness with care increasing as the years of provider experience increased ($p = 0.0221$); negative attitudes decreased between time 1 and time 2 ($p = <0.0001$); nurses at site 2 higher negative attitudes vs. site 2 physicians, site 1 nurses and physicians ($p < 0.0001$); site 2 physicians higher negative attitudes vs. site 1 nurses and physicians ($p<0.04$); average negative attitudes higher at site 2 than site 1 ($p<0.0001$); uneasiness with care higher in physicians than nurses ($p<0.0001$); positive attitudes increased over time ($p=0.0324$); positive attitudes increases between time 1 and time 3 ($p=0.0134$); positive attitudes higher at site 1 than site 2 ($p<0.0001$); frustration level higher at site 2 than site 1 ($p<0.0001$); frustration level higher in nurses than physicians ($p = 0.0015$); site 2 estimated higher addiction than site 1 ($p<0.0001$); nurses estimated higher addiction than physicians ($p<0.0001$); nurses at site 2 estimated higher addiction than nurses and physicians at site 1, and physicians at site 2 ($p<0.0001$); physicians at site 1 estimated lower addiction than physicians at site 2 ($p=0.0174$ and nurses at site 2 ($p<0.0001$). **PGF Grade = A.**	Reported Cronbach's alpha from previous administration [57]: Negative Attitudes = 0.93. **PGF Grade = A.** Uneasiness With Care = 0.83. **PGF Grade = B.** Positive Attitudes subscale = 0.82. **PGF Grade = B. Overall PGF Grade = A+B+B = B.**

Table 9. Provider-focused psychometric properties: Grading of psychometric strength.

Instrument by Study	PGF Strength
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [66]	C + A + A = Adequate
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [54]	C + A + A = Adequate
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [55]	C + A = Weak
Clinician Attitude Scales [58]	C + A + B = Adequate
General Perceptions About Sickle Cell Patients Scale [35]	C + A + A = Adequate
General Perceptions About Sickle Cell Patients Scale [37]	C + A + A = Adequate
General Perceptions About Sickle Cell Patients Scale [60]	C + B + B = Adequate
General Perceptions About Sickle Cell Patients Scale [61]	C + A + B = Adequate
General Perceptions About Sickle Cell Patients Scale [59]	C + A + A = Adequate
General Perceptions About Sickle Cell Disease Patients Scale [57]	C + B + B = Adequate
General Perceptions About Sickle Cell Disease Patients Scale [64]	C + A + B = Adequate

Table 10. Provider-focused psychometric properties: Feasibility.

Instrument by Study	Feasibility
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [66]	Written administration. Questions in table reporting psychometric properties. No mention of the need to request permission. No mention of a cost to use.
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [54]	Written administration. Instrument available as an appendix. No mention of the need to request permission. No mention of a cost to use.
Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) [55]	Electronic via Qualtrics. Some questions available in the literature. No mention of the need to request permission. No mention of a cost to use.
Clinician Attitude Scales [58]	Written administration. Instrument available as an appendix. No mention of the need to request permission. No mention of a cost to use.
General Perceptions About Sickle Cell Patients Scale [35]	Written administration. Instrument available as an appendix. No mention of the need to request permission. No mention of a cost to use.

(Table 10) contd.....

Instrument by Study	Feasibility
General Perceptions About Sickle Cell Patients Scale [60]	Electronic via Qualtrics. Some questions available in the literature. No mention of the need to request permission. No mention of a cost to use.
General Perceptions About Sickle Cell Patients Scale [61]	Electronic via Qualtrics. Questions not provided, referenced original authors. No mention of the need to request permission. No mention of a cost to use.
General Perceptions About Sickle Cell Disease Patients Scale [57]	Written administration. Questions in table reporting psychometric properties. No mention of the need to request permission. No mention of a cost to use
General Perceptions About Sickle Cell Disease Patients Scale [64]	Started as written administration at timepoint 1, moved to electronic administration for timepoints 2 and 3. Questions not provided, referenced original authors. No mention of the need to request permission. No mention of a cost to use.

Table 11. Patient-focused psychometric properties: Level of psychometric measures.

Instrument by Study	Content Validity	Construct Validity	Internal Consistency
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [62]	Adapted from a previously validated Chronic Pain Stigma Scale by changing the words chronic pain to sickle cell pain or sickle cell disease, process not listed but assumed. **PGF Grade = D.**	Measured against BDI-FS = significant but weak correlation (r = 0.27, p < 0.05). Did not conduct factor analysis due to small sample size. **PGF Grade = C.** Initial: 30 item subscale correlation: Doctors = -0.15-0.72. **PGF Grade = Unable to determine, range.** Family = 0.78-0.83. **PGF Grade = A.** Public = 0.66 - 0.77. **PGF Grade = A.** Total initial item-correlation for 30 item scale = 0.004 - 0.68. **PGF Grade = unable to determine, range.** **Overall PGF Grade = C+A+A = B.**	30 item Cronbach's alpha = 0.84. **PGF Grade = B.** 10 item subscales: Doctor's Cronbach's alpha = 0.68. **PGF Grade = D.** Family Cronbach's alpha = 0.82. **PGF Grade = B.** Public Cronbach's alpha = 0.73. **PGF Grade = C.** **Overall PGF Grade = B+D+B+C = C.**
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [63]	Reports adaptation from a previously validated Chronic Pain Stigma Scale by changing the words chronic pain to sickle cell pain or sickle cell disease, process not listed but assumed. **PGF Grade = D.**	Hypothesis: Patients w/ SCD who receive the intervention will have lower perceived health-related stigma from doctors compared to those in the control group measured by mean change from baseline (Time 1) on health-related stigma total score (p = 0.2297) and doctor subscale score (p = 0.0002) by Time 3. **PGF Grade = A.**	Cronbach's alpha = 0.84, 0.70, 0.69, 0.81 identification for which scale/subscale belongs with which Cronbach's alpha unclear. Subscale reporting 0.84 & 0.82. **PGF Grade = B.** Subscale reporting 0.70. **PGF Grade = C.** Subscale reporting 0.69. **PGF Grade = D.** **Overall PGF Grade = B+C+D = C.**
Measure of Sickle Cell Stigma (MoSCS) [63]	Adapted from the HIV Stigma Scale, focus group of patients with SCD assessed items for relevance. **PGF Grade = D.** HIV stigma scale developed from literature search, expert panel. **PGF Grade = C.** **Overall PGF Grade = D+C = C.**	75 Percent variance explained using eigenvalues greater than 1; KMO index = 0.83. **PGF Grade = A.**	Final 11 item scale Cronbach's alpha = 0.86 Subscales Social Exclusion Cronbach's alpha = 0.89. Internalized Stigma Cronbach's alpha = 0.84. **PGF Grade = B.** Disclosure Concerns Cronbach's alpha = 0.74. Expected Discrimination Cronbach's alpha = .76. **PGF Grade = C.** **Overall PGF Grade = B+C = B.**

Table 12. Patient-focused psychometric properties: Grading of psychometric strength.

Instrument by Study (year)	PGF Strength
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [62]	D + B + C = Adequate

(Table 12) contd.....

Instrument by Study (year)	PGF Strength
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [63]	D + A + C = Adequate
Measure of Sickle Cell Stigma (MoSCS) [53]	C + A + B = Adequate

Table 13. Patient-focused psychometric properties: Feasibility.

Instrument by Study (year)	Feasibility
Sickle Cell Stigma Health-Related Stigma Scale (SCD-HRSS) [62]	Written administration. Approximately 30 minutes to complete. Questions available upon request from the author. No cost to use.
Measure of Sickle Cell Stigma (MoSCS) [53]	Initial: Written administration. Follow Up: Electronic with audio assistance. Questions in table reporting psychometric properties. No mention of the need to request permission. No mention of a cost to use

After evaluation with the PGF, all provider- and patient-focused instruments had 'adequate' psychometric strength, the second-best overall strength in this appraisal tool [81]. One article reported adaptation of items within the PASS instrument, which led to that administration of the instrument being rated as 'weak' due to no internal consistency measurements provided for the altered questions [55]. The most consistent psychometric property reported was Cron-bach's alpha as a measure of internal consistency. All but one article reported hypothesis testing.

Content validity was determined by authors of manuscripts through literature reviews, provider expert panels, provider expert panels with patient perspectives, and a content validation survey. All but one instrument was rated a 'C' for content validity according to the PGF. The SCD-HRSS was the only scale rated a 'D' in grading strength for content validity, according to the PGF. Construct validity was demonstrated through hypothesis testing, factor analysis, or inter-item and total-item correlations. All instruments included in this review received an 'A' grading strength for construct validity based on the PGF. The PASS 10-item scale reported the highest overall internal consistency (Cronbach's alpha = 0.91] [66]. Subsequent iterations of the use of PASS items reported subscale internal consistencies only, with the provider negative attitudes subscale reporting the highest internal consistency of subscales (Cronbach's alpha = 0.91-0.93). The 11-item MoSCS reported the highest overall and subscale internal consistency (Cronbach's alpha = 0.87 overall; 0.89-0.76 subscales] and was found to be the most multi-dimensional instrument incorporating multiple types of patient-perceived stigma [53]. Criterion validity could not be measured due to a lack of a gold standard comparison for the concepts or constructs measured in this population.

The only instrument administered to ED providers in the ED environment was The General Perceptions About Sickle Cell Disease Scale [57]. This instrument was considered 'adequate' according to the PGF. Freiermuth *et al.* (2014) based content validity on the previously reported Clinician Attitude Scales and had additional questions validated by content experts earning the highest grade of 'C' for this psychometric property. The General Perceptions About Sickle Cell Disease Scale and subscales were tested using a partial Spearman correlation with MCRS total scores and had a construct validity grade of 'A,' the highest grade for this psychometric property. The sample size was at the low end of acceptable for the use of the instrument to associate provider characteristics with provider attitudes (n = 215) and to evaluate the effectiveness of an intervention (n=216), potentially affecting the stability of psychometric property results. Internal consistency was quite high for the negative attitudes subscale (Cronbach's alpha = 0.93) and acceptable for uneasiness with care (Cronbach's alpha = 0.83) and positive attitudes (Cronbach's alpha = 0.82) subscales, earning an overall grade of 'A.' The authors found an additional dimension not identified in the original administration of the instrument, administered to non-ED providers, which warranted the adaptation of the scale to meet the needs of evaluating ED providers.

Only the Doctors subscale of the SCD-HRSS met criteria for potential use in the ED environment with ED providers as the Public and Family subscales are not the populations of interest in this review [62]. The SCD-HRSS was measured against the BDI-FS for construct validity, which showed a significant but weak correlation; this suggests that those with higher levels of perceived health-related stigma have higher levels of depression. The internal consistency was acceptable with subscale Cronbach's alpha ranging from 0.68 to 0.82 and total scale Cronbach's alpha of 0.84. The Doctors subscale (Cronbach's alpha = 0.68) was hypothesized by the authors to be low due to the wording of doctor-related questions. Another factor that may affect the psychometric properties of this instrument is the small sample size for instrument development (n = 77) and for instrument use in an intervention (n = 90). A more recent iteration of the SCD-HRSS to develop a 'nurses' subscale was administered to youth and demonstrated an overall consistent face validity of 90.5% [82 - 85], but was not included in this review due to the age of the population being evaluated.

3.4. Feasibility

Ease of use of an instrument was noted through administration time, the method of instrument administration, and the availability of an instrument. Four articles were secondary analyses and thus were not included in the feasibility assessment [37, 59, 63, 77].

Only Jenerette *et al.* (2012) reported a relatively short patient-focused instrument administration time of 30 minutes [62]. No administration time estimates were reported for provider-focused instruments [35, 37, 54, 55, 57 - 61, 64, 66, 77]. The method of administration was more likely to be written [35, 54, 57, 58, 62, 64, 66] than electronic [55, 60, 61], although two studies started with paper and pencil and moved to electronic administration during follow-up to increase confidentiality and reduce the effects of social desirability bias [53, 64]. All have the capability for electronic administration.

Instruments were readily available in the appendices of four articles [35, 54, 58, 59], and instrument questions from three other articles were available in tables reporting psychometric properties but would require formatting prior to administration [53, 64, 66]. Two articles reported some questions in the literature [55, 60], and two articles did not provide questions, although the authors refer the reader to the original developer of the instrument [61, 64]. No articles reported the need to request permission to use an instrument or a cost to use an instrument. After contact with Jenerette *et al.* (2012) [62], the SCD-HRSS instrument questions and scoring were available after completion of a permission to use form.

CONCLUSION

The purpose of this integrative review was to identify and critically appraise instruments used to measure perceptions of behaviors in the provider and patient with SCD interaction, describe the psychometric properties of these instruments, and recommend optimal instruments to use in evaluating ED provider and adult patient with SCD perceptions of each other's behavior during the same interaction in the ED. By identifying and bringing awareness to potential discordant communication and perceptions in the interaction, barriers can be crossed, and health outcomes can be improved through patient-provider concordance in a medical interaction [44, 53].

When providers' perceptions of an encounter are measured using an instrument, researchers have found a discordance of provider perceptions when compared to the perceptions of the patient who has just been in the same interaction [86]. A study on dyadic interactions reported the patients' perceptions in discordant interactions were more likely to be that their provider had not listened to them, had left questions unanswered, and did not feel they had input in treatment plans [44]. Providers were also found to underestimate pain during a dyadic interaction [44], which is the primary presenting symptom for a patient with SCD in the ED. Although there is no gold standard to measure concordance [or discordance] in the shared experience [44] of the provider and patient with SCD interaction, a comparative study of both sides of the interaction is needed to understand the extent of shared perceptions during the interaction. While there are several instruments that measure provider behaviors such as negative attitudes and the patients' perception of health-related stigma during separate encounters [35, 37, 53 - 65], none have used a dyadic or paired survey approach. In addition, by understanding the shared perspective, interventions can be developed to resolve perceptions of potentially discordant care.

This review found all but one administration of provider-focused instruments had adequate reliability and validity to measure providers' perceptions of patients with SCD behaviors. All provider-focused instruments measured provider behaviors towards patients with SCD. These behaviors included positive attitudes toward patients, negative attitudes toward patients, perception of patients' behaviors which raise a red flag for the provider, perceptions of patients' behaviors which are concerning to the provider, and in some cases the level to which other providers' behaviors toward patients with SCD bother the participating provider. One provider-focused instrument was found to have adequate overall psychometric properties and was conducted in the ED environment with ED providers, the general perceptions about sickle cell disease. This scale was adapted specifically for the ED provider to measure negative attitudes, positive attitudes, and uneasiness with care for the patient with SCD. No barriers in the feasibility of administering the provider-focused instruments were identified.

All patient-focused instruments were found to have adequate reliability and validity. Unfortunately, no patient-focused instrument was administered in the ED environment measuring patient perceptions of ED provider behaviors. One instrument, SCD-HRSS, could potentially be adapted as a comparison instrument due to the inclusion of a Doctor's subscale. A barrier to the use of the SCD-HRSS could be the ability to obtain the questions and the copyright limitations in evaluating the items of the Doctor's subscale.

Directions for future research include comparing perceived behaviors of providers and patients who are part of the same interaction in order to identify concordance (or discordance) in the interaction. No studies to date were identified that evaluated both sides of the provider and patient with SCD interaction during the same encounter. In addition, the inclusion of a theoretical framework can guide and standardize research, and has been used to support the development of concordant care through the process of establishing patient goals, understanding treatment limitations, evaluating treatments received, and judging whether the care received was concordant with a patient's goals, taking into account limitations on treatment [87].

There are multiple limitations to this review. The number of articles identified for review may have been limited by the search strategy, and some instruments may not have been identified. However, several databases were searched on multiple occasions. The keyword search may have been too limiting, even after consultation with a medical reference librarian. The exclusion criteria may have eliminated articles that reported instruments that should have been included, or inclusion criteria could have been broadened to include additional parameters related to the assessment of behaviors. Hand-searching and ancestry/descendancy search methods identified many additional articles included in this review. One author reviewed articles several times to gather all relevant data to include in this review.

RELEVANCE TO NURSING PRACTICE

Communication is successful where there is a mutual agreement or concordance of perceptions during an interaction

[44, 86, 88]. For patients with SCD and patients with other conditions, the ability for the patient-provider dyad to successfully communicate in the ED is vital to achieving positive physical and psychological health outcomes leading to a shared understanding of medical goals, mutual trust, patient satisfaction, and patient adherence [44, 86, 88 - 90].

To develop interventions that may improve perceptions within the dyad, the interaction must be investigated using a provider-focused and patient-focused instrument in a paired-survey method. A paired-survey method will capture both sides of the interaction. While it is challenging to measure patients' and providers' self-reported perceptions of behaviors, the general perceptions about sickle cell disease patients scale and doctors subscale of the SCD-HRSS would be a valid and reliable way to measure perceptions of behaviors between the patient with SCD and their provider in the ED.

LIST OF ABBREVIATIONS

BDI-FS	=	Beck Depression Inventory-Fast Screen
CINAHL	=	Cumulative Index to Nursing and Allied Health Literature
ED	=	Emergency Department
HIV	=	Human Immunodeficiency Virus
MCRS	=	Medical Condition Regards Scale
MoSCS	=	Measure of Sickle Cell Stigma Scale
PASS	=	Positive Provider Attitudes toward Sickle Cell Patients Scale
PCP	=	Primary Care Provider
PGF	=	Psychometric Grading Framework
PRISMA	=	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	=	Randomized Control Trials
SCD	=	Sickle Cell Disease
SCD-HRSS	=	Sickle Cell Disease Health-Related Stigma Scale
VOC	=	Vaso-Occlusive Crisis

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CONFLICTS OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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REFERENCES

[1] NHLBI. Sickle Cell Disease: Milestones in research and clinical progress National Heart, Lung, and Blood Institute. NHLBI 2018.

[2] Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. Blood 2010; 115(17): 3447-52. [http://dx.doi.org/10.1182/blood-2009-07-233700] [PMID: 20194891]

[3] Minniti CP, Vichinsky E. Lifespan care in SCD: Whom to transition, the patients or the health care system? Am J Hematol 2017; 92(6): 487-9. [http://dx.doi.org/10.1002/ajh.24685] [PMID: 28211097]

[4] Lanzkron S. Need for specialized centers to provide acute care to adults with sickle cell disease. South Med J 2016; 109(9): 566-7. [http://dx.doi.org/10.14423/SMJ.0000000000000519] [PMID: 27598363]

[5] Harrison M, Milbers K, Hudson M, Bansback N. Do patients and health care providers have discordant preferences about which aspects of treatments matter most? Evidence from a systematic review of discrete choice experiments. BMJ Open 2017; 7(5): e014719. [http://dx.doi.org/10.1136/bmjopen-2016-014719] [PMID: 28515194]

[6] Renedo A, Miles S, Chakravorty S, *et al.* Not being heard: barriers to high quality unplanned hospital care during young people's transition to adult services - evidence from 'this sickle cell life' research. BMC Health Serv Res 2019; 19(1): 876. [http://dx.doi.org/10.1186/s12913-019-4726-5] [PMID: 31752858]

[7] Xavier Gomes LM, de Andrade Barbosa TL, Souza Vieira ED, Caldeira AP, de Carvalho Torres H, Viana MB. Perception of primary care doctors and nurses about care provided to sickle cell disease patients. Rev Bras Hematol Hemoter 2015; 37(4): 247-51. [http://dx.doi.org/10.1016/j.bjhh.2015.03.016] [PMID: 26190428]

[8] Kaur M, Brown M, Love TW, Thompson A, Treadwell M, Smith-Whitley K. Understanding sickle cell disease: Impact of surveillance and gaps in knowledge. Blood Adv 2020; 4(3): 496-8. [http://dx.doi.org/10.1182/bloodadvances.2019001000] [PMID: 32027743]

[9] Aljuburi G, Phekoo KJ, Okoye NO, *et al.* Patients' views on improving sickle cell disease management in primary care: Focus group discussion. JRSM Short Rep 2012; 3(12): 84. [http://dx.doi.org/10.1258/shorts.2012.011153] [PMID: 23476727]

[10] Blinder MA, Duh MS, Sasane M, Trahey A, Paley C, Vekeman F. Age-related emergency department reliance in patients with sickle cell disease. J Emerg Med 2015; 49(4): 513-522.e1. [http://dx.doi.org/10.1016/j.jemermed.2014.12.080] [PMID: 25910824]

[11] Paulukonis ST, Feuchtbaum LB, Coates TD, *et al.* Emergency department utilization by Californians with sickle cell disease, 2005-2014. Pediatr Blood Cancer 2017; 64(6) [http://dx.doi.org/10.1002/pbc.26390] [PMID: 28000344]

[12] Tanabe P, Crego N, Douglas C, Bonnabeau E, Earls M, Eason K, *et al.* Emergency department encounters, hospitalizations and ed reliance among medicaid eligible patients with sickle cell disease in north carolina. Blood 2019; 134(Supplement_1): 2113-. [http://dx.doi.org/10.1182/blood-2019-127196]

[13] Steinberg MH. Sickle cell anemia, the first molecular disease: overview of molecular etiology, pathophysiology, and therapeutic approaches. Scientific World J 2008; 8: 1295-324. [http://dx.doi.org/10.1100/tsw.2008.157] [PMID: 19112541]

[14] Wilkie DJ, Johnson B, Mack AK, Labotka R, Molokie RE. Sickle cell disease: An opportunity for palliative care across the life span. Nurs Clin North Am 2010; 45(3): 375-97. [http://dx.doi.org/10.1016/j.cnur.2010.03.003] [PMID: 20804884]

[15] Takaoka K, Cyril AC, Jinesh S, Radhakrishnan R. Mechanisms of pain in sickle cell disease. Br J Pain 2020. [http://dx.doi.org/10.1177/2049463720920682]

[16] Kayle M, Docherty SL, Sloane R, *et al.* Transition to adult care in sickle cell disease: A longitudinal study of clinical characteristics and disease severity. Pediatr Blood Cancer 2019; 66(1): e27463. [http://dx.doi.org/10.1002/pbc.27463] [PMID: 30251318]

[17] Lovett PB, Sule HP, Lopez BL. Sickle Cell Disease in the Emergency Department. Hematol Oncol Clin North Am 2017; 31(6): 1061-79. [http://dx.doi.org/10.1016/j.hoc.2017.08.009] [PMID: 29078924]

[18] Yusuf HR, Atrash HK, Grosse SD, Parker CS, Grant AM. Emergency department visits made by patients with sickle cell disease: A descriptive study, 1999-2007. Am J Prev Med 2010; 38(4)(Suppl.): S536-41. [http://dx.doi.org/10.1016/j.amepre.2010.01.001] [PMID: 20331955]

[19] NHLBI. Evidence-Based management of sickle cell disease: Expert panel report, 2014 National Heart, Lung, and Blood Institute (NHLBI), US Department of Health and Human Services, National Insititutes of Health. NIH 2014.

[20] Brandow AM, Carroll CP, Creary S, *et al.* American Society of Hematology 2020 guidelines for sickle cell disease: Management of acute and chronic pain. Blood Adv 2020; 4(12): 2656-701. [http://dx.doi.org/10.1182/bloodadvances.2020001851] [PMID: 32559294]

[21] Haywood C Jr, Tanabe P, Naik R, Beach MC, Lanzkron S. The impact of race and disease on sickle cell patient wait times in the emergency department. Am J Emerg Med 2013; 31(4): 651-6. [http://dx.doi.org/10.1016/j.ajem.2012.11.005] [PMID: 23380119]

[22] Pulte D, Lovett PB, Axelrod D, Crawford A, McAna J, Powell R. Comparison of emergency department wait times in adults with sickle cell disease *versus* other painful etiologies Hemoglobin 2016; 40(5): 330-4. [http://dx.doi.org/10.1080/03630269.2016.1232272] [PMID: 27677560]

[23] Lazio MP, Costello HH, Courtney DM, *et al.* A comparison of analgesic management for emergency department patients with sickle cell disease and renal colic. Clin J Pain 2010; 26(3): 199-205. [http://dx.doi.org/10.1097/AJP.0b013e3181bed10c] [PMID: 20173433]

[24] Hassell KL. Population estimates of sickle cell disease in the U.S. Am J Prev Med 2010; 38(4)(Suppl.): S512-21. [http://dx.doi.org/10.1016/j.amepre.2009.12.022] [PMID: 20331952]

[25] Wailoo K. Stigma, race, and disease in 20th century America. Lancet 2006; 367(9509): 531-3. [http://dx.doi.org/10.1016/S0140-6736(06)68186-5] [PMID: 16473131]

[26] Martin OY, Thompson SM, Carroll AE, Jacob SA. Emergency department provider survey regarding acute sickle cell pain management. J Pediatr Hematol Oncol 2020; 42(6): 375-80. [http://dx.doi.org/10.1097/MPH.0000000000001843] [PMID: 32569034]

[27] Bergman EJ, Diamond NJ. Sickle cell disease and the "difficult patient" conundrum. Am J Bioeth 2013; 13(4): 3-10. [http://dx.doi.org/10.1080/15265161.2013.767954] [PMID: 23514384]

[28] Maxwell K, Streetly A, Bevan D. Experiences of hospital care and treatment seeking for pain from sickle cell disease: Qualitative study. BMJ 1999; 318(7198): 1585-90. [http://dx.doi.org/10.1136/bmj.318.7198.1585] [PMID: 10364116]

[29] Zempsky WT. Evaluation and treatment of sickle cell pain in the emergency department: Paths to a better future. Clin Pediatr Emerg Med 2010; 11(4): 265-73. [http://dx.doi.org/10.1016/j.cpem.2010.09.002] [PMID: 21499553]

[30] Pentin PL. Drug seeking or pain crisis? Responsible prescribing of opioids in the emergency department. Virtual Mentor 2013; 15(5): 410-5. [http://dx.doi.org/10.1001/virtualmentor.2013.15.5.ecas2-1305] [PMID: 23680561]

[31] Yale SH, Nagib N, Guthrie T. Approach to the vaso-occlusive crisis in adults with sickle cell disease. Am Fam Physician 2000; 61(5): 1349-56, 63-4..

[32] Blake A, Asnani V, Leger RR, *et al.* Stigma and illness uncertainty: Adding to the burden of sickle cell disease. Hematology 2018; 23(2): 122-30. [http://dx.doi.org/10.1080/10245332.2017.1359898] [PMID: 28766464]

[33] Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. Psychol Health Med 2006; 11(3): 277-87. [http://dx.doi.org/10.1080/13548500600595053] [PMID: 17130065]

[34] Jenerette CM, Brewer C. Health-related stigma in young adults with sickle cell disease. J Natl Med Assoc 2010; 102(11): 1050-5. [http://dx.doi.org/10.1016/S0027-9684(15)30732-X] [PMID: 21141294]

[35] Glassberg JA, Tanabe P, Chow A, *et al.* Emergency provider analgesic practices and attitudes toward patients with sickle cell disease. Ann Emerg Med 2013; 62(4): 293-302 e10. [http://dx.doi.org/10.1016/j.annemergmed.2013.02.004]

[36] Haywood C Jr, Lanzkron S, Ratanawongsa N, *et al.* The association of provider communication with trust among adults with sickle cell disease. J Gen Intern Med 2010; 25(6): 543-8. [http://dx.doi.org/10.1007/s11606-009-1247-7] [PMID: 20195785]

[37] Glassberg J, Tanabe P, Richardson L, Debaun M. Among emergency physicians, use of the term "Sickler" is associated with negative attitudes toward people with sickle cell disease. Am J Hematol 2013; 88(6): 532-3. [http://dx.doi.org/10.1002/ajh.23441] [PMID: 23526459]

[38] Bulgin D, Tanabe P, Jenerette C. Stigma of sickle cell disease: A systematic review. Issues Ment Health Nurs 2018; 39(8): 675-86. [http://dx.doi.org/10.1080/01612840.2018.1443530] [PMID: 29652215]

[39] Bediako SM. Interpersonal contexts of communication between sickle cell disease patients and providers. South Med J 2016; 109(9): 573-5. [http://dx.doi.org/10.14423/SMJ.0000000000000505] [PMID: 27598366]

[40] DeLaune J, Close J, Murphy M. Addressing bias towards patients with sickle cell disease. Lancet Haematol 2020; 7(7): e508. [http://dx.doi.org/10.1016/S2352-3026(20)30183-6] [PMID: 32589975]

[41] Glassberg JA. Improving emergency department-based care of sickle cell pain. Hematology (Am Soc Hematol Educ Program) 2017; 2017(1): 412-7. [http://dx.doi.org/10.1182/asheducation-2017.1.412] [PMID: 29222286]

[42] Porter J, Feinglass J, Artz N, Hafner J, Tanabe P. Sickle cell disease patients' perceptions of emergency department pain management. J Natl Med Assoc 2012; 104(9-10): 449-54. [http://dx.doi.org/10.1016/S0027-9684(15)30199-1] [PMID: 23342819]

[43] Elander J, Beach MC, Haywood C Jr. Respect, trust, and the management of sickle cell disease pain in hospital: Comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice. Ethn Health 2011; 16(4-5): 405-21. [http://dx.doi.org/10.1080/13557858.2011.555520] [PMID: 21797726]

[44] Coran JJ, Koropeckyj-Cox T, Arnold CL. Are physicians and patients in agreement? Exploring dyadic concordance. Health Educ Behav 2013; 40(5): 603-11. [http://dx.doi.org/10.1177/1090198112473102] [PMID: 23345336]

[45] Kanter J, Gibson R, Lawrence RH, *et al.* Perceptions of US adolescents and adults with sickle cell disease on their quality of care. JAMA Network Open 2020; 3(5): e206016-. [http://dx.doi.org/10.1001/jamanetworkopen.2020.6016]

[46] Petrocchi S, Iannello P, Lecciso F, Levante A, Antonietti A, Schulz PJ. Interpersonal trust in doctor-patient relation: Evidence from dyadic analysis and association with quality of dyadic communication. Soc Sci Med 2019; 235112391 [http://dx.doi.org/10.1016/j.socscimed.2019.112391] [PMID: 31301438]

[47] Hsueh L, Hirsh AT, Maupomé G, Stewart JC. Patient-Provider language concordance and health outcomes: A systematic review, evidence map, and research agenda. Med Care Res Rev 2019; 1077558719860708107755871986070810775587198607081077558719860708 [http://dx.doi.org/10.1177/1077558719860708] [PMID: 31291823]

[48] Lorié Á, Reinero DA, Phillips M, Zhang L, Riess H. Culture and nonverbal expressions of empathy in clinical settings: A systematic review. Patient Educ Couns 2017; 100(3): 411-24. [http://dx.doi.org/10.1016/j.pec.2016.09.018] [PMID: 27693082]

[49] Röttele N, Schöpf-Lazzarino AC, Becker S, Körner M, Boeker M, Wirtz MA. Agreement of physician and patient ratings of communication in medical encounters: A systematic review and meta-analysis of interrater agreement. Patient Educ Couns 2020; 103(10): 1873-82. [http://dx.doi.org/10.1016/j.pec.2020.04.002] [PMID: 32376141]

[50] Vaichinger AM, Shields MN, Morrey ME, O'Driscoll SW. Prospective blinded evaluation of patient-physician agreement using the Summary Outcome Determination (SOD) score. Mayo Clin Proc 2019; 94(7): 1231-41. [http://dx.doi.org/10.1016/j.mayocp.2018.10.025] [PMID: 31248694]

[51] Levesque J-F, Corscadden L, Dave A, Sutherland K. Assessing performance in health care using international surveys: Are patient and clinician perspectives complementary or substitutive. J Patient Exp 2020; 7(2): 169-80. [http://dx.doi.org/10.1177/2374373519830711] [PMID: 32851137]

[52] Jácome C, Pereira AM, Almeida R, *et al.* Patient-physician discordance in assessment of adherence to inhaled controller medication: A cross-sectional analysis of two cohorts. BMJ Open 2019; 9(11)e031732 [http://dx.doi.org/10.1136/bmjopen-2019-031732] [PMID: 31699737]

[53] Bediako SM, Lanzkron S, Diener-West M, Onojobi G, Beach MC, Haywood C Jr. 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. [http://dx.doi.org/10.1177/1359105314539530] [PMID: 24997169]

[54] Walker PM. Sickle Cell Disease: A quality improvement initiative for emergency department providers: University of Nevada. Las Vegas 2013.

[55] P Goddu A, O'Conor KJ, Lanzkron S, *et al.* Do words matter? stigmatizing language and the transmission of bias in the medical record. J Gen Intern Med 2018; 33(5): 685-91. [http://dx.doi.org/10.1007/s11606-017-4289-2] [PMID: 29374357]

[56] Whiteman LN, Haywood C Jr, Lanzkron S, Strouse JJ, Feldman L, Stewart RW. Primary care providers' comfort levels in caring for patients with sickle cell disease. South Med J 2015; 108(9): 531-6. [http://dx.doi.org/10.14423/SMJ.0000000000000331] [PMID: 26332477]

[57] Freiermuth CE, Haywood C Jr, Silva S, *et al.* Attitudes toward patients with sickle cell disease in a multicenter sample of emergency department providers. Adv Emerg Nurs J 2014; 36(4): 335-47. [http://dx.doi.org/10.1097/TME.0000000000000036] [PMID: 25356894]

[58] Haywood C Jr, Lanzkron S, Hughes MT, *et al.* A video-intervention to improve clinician attitudes toward patients with sickle cell disease: The results of a randomized experiment. J Gen Intern Med 2011; 26(5): 518-23. [http://dx.doi.org/10.1007/s11606-010-1605-5] [PMID: 21181560]

[59] Puri Singh A, Haywood C Jr, Beach MC, *et al.* Improving emergency providers' attitudes toward sickle cell patients in pain. J Pain Symptom Manage 2016; 51(3): 628-32.e3. [http://dx.doi.org/10.1016/j.jpainsymman.2015.11.004] [PMID: 26596878]

[60] Jenerette CM, Pierre-Louis BJ, Matthie N, Girardeau Y. Nurses' attitudes toward patients with sickle cell disease: A worksite comparison. Pain Manag Nurs 2015; 16(3): 173-81. [http://dx.doi.org/10.1016/j.pmn.2014.06.007] [PMID: 26025791]

[61] Jenerette CM, Brewer CA, Silva S, Tanabe P. Does attendance at a sickle cell educational conference improve clinician knowledge and attitude toward patients with sickle cell disease? Pain Manag Nurs 2016; 17(3): 226-34. [http://dx.doi.org/10.1016/j.pmn.2016.05.001] [PMID: 27283268]

[62] Jenerette C, Brewer CA, Crandell J, Ataga KI. Preliminary validity and reliability of the sickle cell disease health-related stigma scale. Issues Ment Health Nurs 2012; 33(6): 363-9. [http://dx.doi.org/10.3109/01612840.2012.656823] [PMID: 22646200]

[63] Jenerette CM, Brewer CA, Edwards LJ, Mishel MH, Gil KM. An intervention to decrease stigma in young adults with sickle cell disease. West J Nurs Res 2014; 36(5): 599-619. [http://dx.doi.org/10.1177/0193945913512724] [PMID: 24309381]

[64] Freiermuth CE, Silva S, Cline DM, Tanabe P. Shift in emergency department provider attitudes toward patients with sickle cell disease. Adv Emerg Nurs J 2016; 38(3): 199-212. [http://dx.doi.org/10.1097/TME.0000000000000106] [PMID: 27482992]

[65] Hanik M, Sackett KM, Hartman LL. An educational module to improve healthcare staffs' attitudes toward sickle cell disease patients. J Nurses Prof Dev 2014; 30(5): 231-6. [http://dx.doi.org/10.1097/NND.0000000000000058] [PMID: 25237914]

[66] Ratanawongsa N, Haywood C Jr, Bediako SM, *et al.* Health care provider attitudes toward patients with acute vaso-occlusive crisis due to sickle cell disease: Development of a scale. Patient Educ Couns 2009; 76(2): 272-8. [http://dx.doi.org/10.1016/j.pec.2009.01.007] [PMID: 19233587]

[67] Ezenwa MO, Patil C, Shi K, Molokie RE. Healthcare injustice in patients with sickle cell disease. Int J Hum Rights Healthc 2016; 9(2): 109-19. [http://dx.doi.org/10.1108/IJHRH-07-2014-0015]

[68] Duncan RW, Smith KL, Maguire M, Stader DE III. Alternatives to opioids for pain management in the emergency department decreases opioid usage and maintains patient satisfaction. Am J Emerg Med 2019; 37(1): 38-44. [http://dx.doi.org/10.1016/j.ajem.2018.04.043] [PMID: 29709398]

[69] Masese RV, Bulgin D, Douglas C, Shah N, Tanabe P. Barriers and facilitators to care for individuals with sickle cell disease in central North Carolina: The emergency department providers' perspective. PLoS One 2019; 14(5): e0216414. [http://dx.doi.org/10.1371/journal.pone.0216414] [PMID: 31063506]

[70] Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. PLoS Med 2009; 6(7)e1000097 [http://dx.doi.org/10.1371/journal.pmed.1000097] [PMID: 19621072]

[71] Boynton PM, Greenhalgh T. Selecting, designing, and developing your questionnaire. BMJ 2004; 328(7451): 1312-5. [http://dx.doi.org/10.1136/bmj.328.7451.1312] [PMID: 15166072]

[72] Stuber J, Meyer I, Link B. Stigma, prejudice, discrimination and health. Soc Sci Med 2008; 67(3): 351-7. [http://dx.doi.org/10.1016/j.socscimed.2008.03.023] [PMID: 18440687]

[73] Haywood C Jr, Diener-West M, Strouse J, *et al.* Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease. J Pain Symptom Manage 2014; 48(5): 934-43. [http://dx.doi.org/10.1016/j.jpainsymman.2014.02.002] [PMID: 24742787]

[74] Lattimer L, Haywood C Jr, Lanzkron S, Ratanawongsa N, Bediako SM, Beach MC. Problematic hospital experiences among adult patients with sickle cell disease. J Health Care Poor Underserved 2010; 21(4): 1114-23. [http://dx.doi.org/10.1353/hpu.2010.0940] [PMID: 21099065]

[75] Stanton MV, Jonassaint CR, Bartholomew FB, *et al.* The association of optimism and perceived discrimination with health care utilization in adults with sickle cell disease. J Natl Med Assoc 2010; 102(11): 1056-63. [http://dx.doi.org/10.1016/S0027-9684(15)30733-1] [PMID: 21141295]

[76] Haywood C Jr, Lanzkron S, Bediako S, *et al.* Perceived discrimination, patient trust, and adherence to medical recommendations among persons with sickle cell disease. J Gen Intern Med 2014; 29(12): 1657-62. [http://dx.doi.org/10.1007/s11606-014-2986-7] [PMID: 25205621]

[77] Haywood C Jr, Lanzkron S, Hughes M, Brown R, Saha S, Beach MC. The association of clinician characteristics with their attitudes toward patients with sickle cell disease: Secondary analyses of a randomized controlled trial. J Natl Med Assoc 2015; 107(2): 89-96. [http://dx.doi.org/10.1016/S0027-9684(15)30029-8] [PMID: 27269495]

[78] Whittemore R, Chao A, Jang M, Minges KE, Park C. Methods for knowledge synthesis: An overview. Heart Lung 2014; 43(5): 453-61. [http://dx.doi.org/10.1016/j.hrtlng.2014.05.014] [PMID: 25012634]

[79] Whittemore R, Knafl K. The integrative review: Updated methodology. J Adv Nurs 2005; 52(5): 546-53. [http://dx.doi.org/10.1111/j.1365-2648.2005.03621.x] [PMID: 16268861]

[80] Paez A. Gray literature: An important resource in systematic reviews. J Evid Based Med 2017; 10(3): 233-40. [http://dx.doi.org/10.1111/jebm.12266] [PMID: 28857505]

[81] Leung K, Trevena L, Waters D. Development of an appraisal tool to evaluate strength of an instrument or outcome measure. Nurse Res 2012; 20(2): 13-9. [http://dx.doi.org/10.7748/nr2012.11.20.2.13.c9436] [PMID: 23316533]

[82] Tanabe P, Silva S, Bosworth HB, *et al.* A randomized controlled trial comparing two Vaso-Occlusive Episode (VOE) protocols in sickle cell disease (SCD). Am J Hematol 2018; 93(2): 159-68. [http://dx.doi.org/10.1002/ajh.24948] [PMID: 29047145]

[83] Link BG, Phelan JC. Conceptualizing stigma. Annu Rev Sociol 2001; 27(1): 363-85. [http://dx.doi.org/10.1146/annurev.soc.27.1.363]

[84] Gray AJ. Stigma in psychiatry. J R Soc Med 2002; 95(2): 72-6. [http://dx.doi.org/10.1177/014107680209500205] [PMID: 11823548]

[85] Wakefield E, Jenerette C, Santanelli J, Zempsky W. Face validity of the sickle cell disease health-related stigma scale in youth with sickle cell disease. J Pain 2017; 18(4) [http://dx.doi.org/10.1016/j.jpain.2017.02.158]

[86] Kenny DA, Veldhuijzen W, van der Weijden T, *et al.* Interpersonal perception in the context of doctor–patient relationships: A dyadic analysis of doctor–patient communication. Social Sci Medi 2010; 70(5): 763-8. [http://dx.doi.org/10.1016/j.socscimed.2009.10.065]

[87] Turnbull AE, Hartog CS. Goal-concordant care in the ICU: A conceptual framework for future research. Intensive Care Med 2017; 43(12): 1847-9. [http://dx.doi.org/10.1007/s00134-017-4873-2] [PMID: 28656453]

[88] Roh H, Park KH. A scoping review: Communication between emergency physicians and patients in the emergency department. J Emerg Med 2016; 50(5): 734-43. [http://dx.doi.org/10.1016/j.jemermed.2015.11.002] [PMID: 26818383]

[89] Zill JM, Christalle E, Müller E, Härter M, Dirmaier J, Scholl I. Measurement of physician-patient communication: A systematic review. PLoS One 2014; 9(12)e112637 [http://dx.doi.org/10.1371/journal.pone.0112637] [PMID: 25532118]

[90] Street RL Jr, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns 2009; 74(3): 295-301. [http://dx.doi.org/10.1016/j.pec.2008.11.015] [PMID: 19150199]