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Health care provider attitudes toward patients with acute vaso-occlusive crisis due to sickle cell disease: Development of a scale⋆

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Abstract

Objective—Patients with sickle cell disease (SCD) often perceive negative provider attitudes, which may affect the quality of patient–provider communication and care during vaso-occlusive crises (VOCs). This study investigated the validity and reliability of a scale to measure provider attitudes toward patients with acute VOC.

Methods—Using a cohort of adults with VOC (September 2006 to June 2007), we administered a 10-item provider questionnaire within 72 h of patient encounters. After factor analysis, we created a 7-item Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS); higher scores indicate more positive attitudes. We assessed internal consistency and evidence of construct validity, exploring bivariate relationships between provider or patient characteristics and the PASS score using multilevel modeling.

Results—We collected 121 surveys from 84 health care providers for 47 patients. Patients averaged 30.3 years in age, and 60% were women. Among providers, 79% were nurses, and 70% worked in inpatient settings. PASS scores averaged 24.1 (S.D. 6.7), ranged 7–35, and had high internal consistency (Cronbach's alpha = 0.91). As hypothesized, inpatient vs. emergency department providers ($\Delta = 4.65$, $p < 0.001$) and nurses vs. other providers ($\Delta = 0.95$, $p < 0.001$) had higher PASS scores. Higher patient educational attainment (Δ per year $= 2.74$, $p < 0.001$) and employment ($\Delta = 5.62$, $p = 0.001$) were associated with higher PASS scores. More frequent hospitalizations (Δ per episode $= -0.52$, $p < 0.001$) and prior disputes with staff ($\Delta = -7.53$, $p = 0.002$) were associated with lower PASS scores.

Conclusion—Our findings provide preliminary evidence for the reliability and construct validity of the PASS score in measuring provider attitudes toward patients with VOC.

Practice implications—Future studies should examine the validity of PASS in other cohorts of patients with SCD and their providers. With further evidence, PASS may prove useful for

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⋆I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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investigating the impact of provider attitudes on the quality of communication and care provided to these patients.

Keywords

Validity and reliability; Instrument development; Patient–provider relationship; Pain management; Sickle cell disease

1. Introduction

Persons with sickle cell disease (SCD) are vulnerable to suboptimal health care during vaso-occlusive crises (VOCs). In small qualitative studies, patients with SCD have consistently provided compelling personal stories about their own negative experiences during hospital treatment for pain, including inadequate analgesia, conflicts with staff, and lack of respect from providers [1–3].

Evidence suggests that variations in the quality of pain management are multifactorial, related to “behaviors of providers, patients, and health care organizations” [4]. The 2005 American Pain Society Quality Improvement Guidelines called for interventions toward five objectives: (1) recognizing and treating pain promptly, (2) involving patients in the pain management plan, (3) improving treatment patterns, (4) reassessing and adjusting the pain management plan as needed, and (5) monitoring processes and outcomes of pain management [4]. Thus, evidence-based guidelines place patient–provider communication and shared decision-making as central to the quality of pain management care.

Health care providers’ attitudes toward patients may be one contributing factor to the quality of communication and care that patients receive [5–8]. In one study in the primary care setting, physicians with higher respect for particular patients demonstrated more positive communication behaviors in encounters with those patients [9]. However, less is known about the relationship between provider attitudes, the quality of patient–provider communication, and the quality of care for patients with VOC. In one national survey of physicians at NIH-funded comprehensive sickle cell centers, 40% of physicians believed that SCD patients are often undermedicated for pain, with concerns of drug abuse ranked as a top barrier to optimal management [10]. Other studies suggest that health professionals overestimate the prevalence of addiction among patients with SCD [11].

To understand how provider attitudes affect the quality of communication and care for patients with pain, investigators need tools to measure accurately and reliably the variations in provider attitudes. This may be particularly challenging because providers may be reluctant to acknowledge their own negative attitudes toward patients. To our knowledge, no studies have examined the validity or reliability of tools to measure attitudes toward patients with SCD-related pain. The purpose of our study was to develop a scale, assess its reliability and validity, and determine how patient and provider-level characteristics correlate with positive attitudes toward patients with VOC.

2. Methods

2.1. Study design

We developed an instrument to measure providers’ attitudes toward patients with SCD-related VOC, and then tested its reliability and validity in a cohort study of healthcare providers. We conducted a cohort study of adult patients with VOC and their health care providers at a mid-Atlantic, urban academic medical center, from September 2006 to June 2007. Eligible patients were adults age 18 or older with any sickle cell hemoglobinopathy

(Hb SS, Hb SC, Hb S/alpha-thalassemia, or Hb S/beta-thalassemia) who presented for VOC during the study period. Eligible providers included nurses, nurse practitioners, physician assistants, or physicians providing direct emergency department (ED) or inpatient care to enrolled patients.

An institutional review board of the Johns Hopkins Medical Institutions reviewed and approved the study procedures. All participating patients and providers gave informed consent.

We developed an instrument in the following steps:

1. Item generation to maximize content validity.
2. Data collection with healthcare provider questionnaires in an acute care setting.
3. Item variability and descriptive statistics in the study sample.
4. Factor analysis and subscale exploration to determine dimensionality.
5. Calculation of internal consistency.
6. Investigation of construct validity.

For brevity, we have called this instrument the Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS).

We developed scale items to represent the construct of the positive provider attitudes toward patients with SCD-related VOC. To maximize content validity of this instrument, we conducted a literature review about attitudes toward sickle cell patients [1–3,5,9–26]. We also solicited input from investigators with experience and expertise in the treatment of patients with SCD pain from the provider perspective (Sophie Lanzkron, Neda Ratanawongsa, Neil Powe, Mary Catherine Beach), in the experience of treatment for sickle cell disease pain from the patient perspective (Carlton Haywood, Jr.), in the measurement of patient experience of care (Neil Powe, Mary Catherine Beach), and in bioethics (Carlton Haywood, Jr., Mary Catherine Beach). This team identified potential aspects of attitudes toward a patient with pain from VOC, including positive regard for a patient (respect, liking, glad to have entered medicine) [5,7,9], feelings of affiliation with a patient (able to imagine being friends with patient, empathy) [26,27], and frustration with a patient [28,29].

In addition, we identified several potential beliefs about a patient's behaviors (perceptions of patient's likelihood of exaggerating pain, manipulating providers, abusing drugs, and being noncompliant) [26] that providers have associated with less favorable attitudes toward patients with SCD [4,10,12,14,30]. We theorized that the association between provider attitudes and these behavioral attributions could result from two mechanisms. First, providers' perceptions of patient behaviors may lead them to feel more negatively toward patients; for example, providers may perceive patients who rate their pain as "13 out of 10" as exaggerating their pain, which causes them to feel negatively toward those patients. Second, providers' negative attitudes toward patients may predispose them toward interpreting patient behaviors' in a negative light; for example, providers who feel negatively toward a patient may interpret a patient's statements as manipulative. With either mechanism, we deemed these beliefs about a patient's behavior as potential manifestations of providers' attitudes toward patients with SCD-related pain.

Based on this process, we developed 10 items comprising a providers' attitude toward patients with VOC, phrased in positively and negatively worded statements (Table 2). In total, we included 7 items from previously validated instruments [5,9,26] and created 3 new items. We chose wording for items and response options to minimize social desirability bias, such as by reverse-coding some items and offering specific anchors for Likert responses. Response options involved 5-point Likert scales: much more than average to much less than average, strongly agree to strongly disagree, or extremely likely to not at all likely. Higher scores on each item indicated more positive attitudes.

2.2. Data collection with patients and healthcare providers in an acute care setting

Eligible patients were recruited from the adult sickle cell and hematology outpatient clinics, the emergency department, the inpatient units, or within 5 days after a discharge from the hospital. If a patient agreed to be in the study, baseline data were collected by patient interview and medical record abstraction.

The baseline patient interview collected demographic characteristics (e.g., age, gender, educational attainment, employment and employment status). The baseline patient interview was conducted by a trained interviewer and took approximately 15 min to complete. Patients were paid $10 for completion of the baseline interview.

Baseline medical record abstraction by a trained research assistant included clinical characteristics (type of hemoglobinopathy, previous complications of SCD, current medications and comorbidities), healthcare utilization, and documentation of disputes with staff.

When a previously enrolled patient presented to the acute care setting – up to a maximum of three times – we recruited healthcare providers who were substantively involved in that patient’s care. We recruited nurses, nurse practitioners, physician assistants, resident physicians, and attending physicians because all play a role in assessing pain and titrating the administered amount of pain medications to patients with VOC in our hospital setting. We sought up to four providers per patient per setting (ED or inpatient); for example, a patient who presented to the ED and was later admitted to the hospital could have up to eight providers surveyed for the study. The number of providers eligible for recruitment depended on how many different providers cared for patients during their stays in each setting. Providers completed a confidential written questionnaire within 72 h of their interactions with an enrolled patient which assessed their attitudes toward that particular patient using the newly developed instrument and collected basic demographic information. We chose 72 h to allow sufficient time to recruit providers to complete questionnaires while minimizing potential difficulties with recall.

The primary independent variables collected for this study included:

- Provider characteristics: setting (inpatient vs. ED) gender, role (nurse vs. physician or physician assistant), and race (African-American vs. other).
- Patient sociodemographic characteristics: patient-reported educational attainment (some high school, high school or GED degree, some college, college, or graduate school), income (less than or greater than $10,000), and employment status.
- Markers of sickle cell disease severity: chart-documented history of avascular necrosis, chart-documented history of acute chest syndrome, and patient-reported number of inpatient overnight hospitalizations.
- Markers of patient behaviors of particular concern to providers: chart-documented disputes about pain medications, chart-documented narcotics dependence, chart-documented prior discharges against medical advice, and positive toxicology screening tests during the current episode.

2.3. Item variability and descriptive statistics in the study sample

We first explored the responses to each item on the PASS. *A priori*, we decided to eliminate any item with >5% missing data or with a significant ‘floor’ or ‘ceiling’ effect defined as >95% of responses in the most positive or negative category.

We calculated means and standard deviations for each item to assess their variability. We also described provider attitudes by dichotomizing responses to individual items in the scale, calculating proportions of survey responses indicating negative attitudes.

2.4. Factor analysis and subscale exploration to determine dimensionality

Although we theorized that the items would capture a unifying construct of positive provider attitudes toward patients with VOC, we used exploratory factor analysis to determine if the scale captured more than one dimension of provider attitudes. We conducted exploratory principal components analyses and scree plots, retaining factors with Eigenvalues greater than 1. We also compared Akaike Information Criterion (AIC) values for different analyses. We then conducted factor analysis using maximum likelihood estimation and varimax rotation to examine factor pattern loadings and uniqueness values.

We anticipated that the factor analysis may reveal multiple dimensions because of the three different types of response options, rather than being attributable to underlying latent factors. We conducted bivariate analyses to compare how each potential subscale related to prespecified independent variables.

2.5. Internal consistency

We calculated Cronbach’s alpha to determine the internal consistency of the 7-item PASS score, as well as corrected item–total correlations. Although these measurements are often categorized as a type of reliability, these measures of internal structure are also classified as evidence of validity under the modern classification system [31].

2.6. Construct validity

We then investigated the construct validity of the PASS score. We hypothesized that particular provider and patient factors with a strong theoretical relationship from our literature review would be significantly associated with variations in the PASS score. We hypothesized that inpatient [2], nursing, female [5], and African-American providers [32] would have more positive attitudes toward SCD patients with VOC. We also hypothesized that providers would have more positive attitudes toward patients with higher socioeconomic status [26] and less positive attitudes toward patients with more severe sickle cell disease [5,33] and documented behaviors of possible concern to providers [28,29]. With the continuous PASS score as the primary outcome, we investigated how PASS scores varied with the patient and provider factors listed above in bivariate analyses.

Because we had repeated measurements for some providers and some patients, we used multilevel modeling with crossed random effects to account for clustering by provider and patient [34]. To account for multiple comparisons, we adjusted our significant level to $p \leq 0.003$. In the results below, the beta coefficient from the regression model is symbolized as *delta* (Δ), which represents the PASS score difference between groups or change per unit measurement associated with the predictor variables. We performed all statistical analyses using STATA Intercooled version 10.0 (Stata Statistical Software: Release 10.0, Stata Corporation, College Station, TX, 2007).

3. Results

3.1. Participant characteristics

We collected 121 questionnaires from 84 health care providers about 47 patients presenting for 78 episodes of VOC. Among those approached for recruitment, patient response rate was 121/124 (98%) and provider response rate was 149/205 (73%).

Table 1 presents the participant characteristics. Patients averaged 30.3 years in age, 60% were women. Forty-three percent had at least some college education, and 26% were employed. Seventy percent had SS hemoglobinopathy, 77% had a history of acute chest syndrome, 23% had a history of avascular necrosis, and 13% had been hospitalized ≥10 times within the last year. Just over one half of patients (53%) had one VOC episode of care during the study period, while the rest had more than one episode during the study period.

Among the 84 providers, 79% of providers were nurses, and 70% worked in inpatient settings. They averaged 34.1 years in age, 70% were women, and 26% were African-American. Providers completed between 1 and 5 surveys for the study.

3.2. Provider attitudes: item variability and descriptive statistics in the study sample

No item had >5% missing data or significant ceiling or floor effects: thus all items were initially retained in the scale. Table 2 presents the means and standard deviations for each item, as well as the corrected item–total correlations for the 10 preliminary items (Table 2).

Among the 121 provider–patient interactions, 12–13% of surveys indicated below average liking, empathy, and respect for their patients, and 17% of providers felt frustrated in caring for the patient. In two-thirds of encounters, providers felt the patient was at least a little likely to exaggerate discomfort, fail to comply with medical advice, abuse drugs, or manipulate providers.

3.3. Factor analysis and subscale exploration to determine dimensionality

Exploratory principal components analyses and scree plots suggested two latent dimensions, with two Eigenvalues above 1 (5.64 and 1.19). Based on these results and a lower AIC for the 2-factor solution, we chose to retain two factors for initial analyses.

Table 3 presents factor pattern loadings and uniqueness values for the initial 10-item factor analysis. Two factors emerged: a “positive regard” factor comprised of 3 items – liking, empathy, and respect – and a “beliefs about patients” factor comprised of 4 items – perceptions of patient’s pain exaggeration, non-compliance, drug abuse, and manipulation. The remaining three items had high uniqueness values.

We hypothesized that the factor analysis results may be attributable to the different response options for those two sets of items. To test this, we conducted bivariate analyses to compare how the two PASS subscales related to prespecified variables. We found comparable coefficients and *p*-values for the relationships between the independent variables and the “positive regard” and “beliefs about patient” subscales (results not shown), suggesting that the two factors likely resulted from different response options rather than true dimensionality. For subsequent analyses, we combined the two subscales into a single 7-item scale.

We eliminated the remaining 3 items for the following reasons: their high uniqueness values on factor analysis, low corrected item–total correlations, and negligible impact on the overall scale’s internal consistency (10-item Cronbach’s alpha = 0.910 vs. 7-item Cronbach’s alpha = 0.907). Table 3 shows factor loadings for the final 7-item PASS scale.

3.4. The 7-item PASS and internal consistency reliability

We calculated the PASS score for each provider survey, summing all 7 items. On this scale, the possible range is 5–35, with higher PASS scores indicating more positive attitudes.

The mean PASS score was 24.1 (S.D. 6.7), the median score was 25, and scores extended nearly across the scale's full range (7–35), representing the variability in attitudinal scores.

The internal consistency of the PASS was high (Cronbach's alpha = 0.907). Corrected item–total correlations were 0.59–0.81 (Table 2).

3.5. Construct validity: bivariate associations between patient and provider characteristics and the PASS score

As hypothesized, inpatient compared to ED providers ($\Delta = 4.65$, 95% CI 2.14–7.16, $p < 0.001$) and nurses compared to other providers ($\Delta = 0.95$, 0.51–1.39, $p < 0.001$) had higher PASS scores (Table 4). Female providers had higher PASS scores than male providers ($\Delta = 3.88$, 95% CI 0.64–7.12, $p = 0.02$), but this did not meet our corrected level of statistical significance.

Among patient characteristics, higher patient educational attainment (Δ per year = 2.74, 95% CI 1.53–3.96, $p < 0.001$) and employment ($\Delta = 5.62$, 95% CI 2.39–8.84, $p = 0.001$) were significantly associated with higher PASS scores. Three markers of SCD severity were associated with lower PASS scores: prior avascular necrosis ($\Delta = -3.89$, 95% CI −7.38 to −0.40, $p = 0.03$), prior acute chest syndrome ($\Delta = -3.94$, 95% CI −7.65 to −0.27, $p = 0.04$), and increasing frequency of hospitalization within the last year (Δ per episode = −0.52, −0.79 to −0.24, $p < 0.001$), although only the latter met the corrected level of statistical significance. Of the potentially concerning behaviors, patients with histories of discharges against medical advice ($\Delta = -4.93$, 95% CI −9.50 to −0.35, $p = 0.04$), narcotics dependence ($\Delta = -5.33$, 95% CI −9.33 to −1.33, $p = 0.01$), and positive toxicology screening for illicit drug use during the current episode ($\Delta = -4.30$, 95% CI −8.46 to −0.14, $p = 0.04$) tended toward lower PASS scores. Prior disputes with staff ($\Delta = -7.53$, 95% CI −12.36 to −2.70, $p = 0.002$) was significantly associated with lower PASS scores.

4. Discussion and conclusion

4.1. Discussion

In this cohort study, we found preliminary evidence for the validity and reliability of a questionnaire for measuring health care provider attitudes toward SCD patients with VOC. Providers reported a range of attitudes toward patients, with a moderate proportion of negative attitudes on individual items and summary scores representing the full possible spectrum of the scale. The high Cronbach's alpha provides support for both reliability and internal structure validity for PASS in this application [31].

This study also provides evidence of the construct validity of the PASS score based on its relationships with patient and provider factors that prior literature has cited as being related to provider attitudes toward patents. Just as the PASS scores were associated with educational attainment and employment status, van Ryn and Burke [26] found that physicians' feelings of affiliation toward patients were significantly associated with socioeconomic status.

Our finding that markers of higher SCD severity are associated with lower PASS scores is also consistent with some existing literature. Hall et al. [5,33] found that providers liked patients more if patients were in better health. Powars et al. [35] found that avascular necrosis and acute chest syndrome are associated with an increased likelihood of developing further complications and mortality. However, interpretation of these findings is complicated by the potential for avascular necrosis to cause chronic pain requiring opioid use, which can heighten providers' concerns for narcotics dependence [14]. Similarly, providers may consider number of hospitalizations less as a marker of SCD severity than as an indicator of inappropriate utilization, which has been associated with physician frustration in other studies [36,37].

Chart-documented narcotics dependence, positive toxicology screening for illicit substances, and discharges against medical advice did not reach our conservative level of statistical significance for an association with provider attitudes. Although the literature suggests that providers actually overestimate the risk of narcotics addiction and drug abuse among sickle cell patients [16,22,30], studies of provider frustration suggest that their attitudes may be negatively influenced by these perceptions [28,29,38]. Discharges against medical advice may represent suboptimal patient–provider communication or conflict during hospitalization, leading both to provider frustration and to poorer clinical outcomes for patients [39–41]. Although it is possible that these factors are not associated with provider attitudes toward patients with VOC, our study may have been underpowered to detect these relationships.

In considering the relationship between patient behaviors and provider attitudes, one should consider that some behaviors deemed concerning by providers may be appropriate patient responses to their circumstances. Elander et al. [30] describes how several “concern-raising behaviors” – such as disputes with staff about analgesia or self-titration of opioid therapies – may actually represent patients' responses to undertreatment of their pain or pseudoaddiction. Thus, our analysis is not intended to ascribe value judgments to these behaviors, but rather to highlight potential relationships between providers' perceptions of these behaviors and their attitudes toward patients with SCD-related pain. Indeed, providers' awareness of their negative attitudes toward patients may yield diagnostic clues to how their own stressors or the environment may be adversely affecting their behaviors toward patients [42].

Our findings are also consistent with studies demonstrating that provider factors relate to their attitudes toward patients. In Hall et al. [5] female providers liked patients more than their male counterparts. Levinson et al. [29] found that practice setting was significantly associated with provider frustration toward patients. Shapiro et al. [21] found that hematologists were less concerned than ED providers for drug addiction in SCD patients, and Murray and May [2] found that patients felt that inpatient providers were more understanding compared with general practitioners or ED providers. These findings may result from differences in training, systems factors of time or patient continuity in the ED setting, or experiences with other patient populations with concerning pain behavior that then influence ED providers attitudes toward SCD patients.

Our findings also reveal that a moderate proportion of providers in the acute setting have negative attitudes toward patients with SCD-related pain, especially in their concern that patients may be exaggerating discomfort or manipulate them. Future studies are needed to investigate the relationship between the PASS score and a variety of outcomes in sickle cell disease care, including the quality of communication with patients, the quality of pain management, length of stay, rates of readmission, and patient satisfaction. Studies in other settings have found that provider attitudes may affect the quality of provider communication [9] and predict patient satisfaction and patient continuity with a provider [5]. Future research can help determine whether there is a threshold effect for positive provider attitudes or whether such attitudes have a dose–response relationship with clinical outcomes in VOC care.

As part of quality improvement interventions for SCD care, provider education to improve provider attitudes is critical. The PASS score may be helpful to determine which providers need targeted education and to measure the effectiveness of these interventions. In addition to imparting knowledge about the evidence basis for SCD management [22], this education should promote improved basic communication skills, advanced communication skills for encounters which providers find challenging, and training to promote self-awareness when they begin to feel negative reactions to patients [13,42–44]. In addition, providers need cultural competency training, recognizing the ways that race, ethnicity, and culture may affect their attitudes and communication behaviors with people with SCD [13,45,46].

The limitations of this study should be considered. First, our scale development process involved one person with sickle cell disease rather than diverse patient perspectives; however, our literature review did include studies that explored patients' perspectives. Second, our sample size was insufficient to allow for split-sample reliability testing. Repeated psychometric testing on the PASS should be conducted in a separate study sample. Third, the sample size may have limited our power to detect relationships between certain variables and the PASS score. Although certain results did not meet our conservative level of significance, the direction of our findings was as hypothesized in all cases. Fourth, our provider questionnaire may have benefited from the inclusion of measures of social desirability bias, which may have affected our analyses [47]. However, our findings indicate that providers are willing to report more negative attitudes in confidential, anonymously collected surveys. Fifth, we were unable to compare characteristics between responders and non-responders, and provider response bias may have led to over- or underestimation of provider attitudes or the relationship between these attitudes and other variables. Fifth, our sample was limited to a single institution and had a high proportion of inpatient nurses who were not specifically dedicated to the care of sickle cell patients. We might expect more positive attitudes from providers who have chosen to focus on sickle cell care, and thus the PASS may perform differently in other populations and settings. Finally, our study was not designed to determine whether statistically significant differences in the PASS score are clinically meaningful.

4.2. Conclusion

In conclusion, our findings provide preliminary evidence for construct validity of the PASS score in measuring provider attitudes toward SCD patients with VOC. PASS scores indicated variable provider attitudes, which differed significantly based on particular patient and provider characteristics.

4.3. Practice implications

Future studies should examine the validity of PASS in other cohorts of patients with SCD and their providers. With further evidence, PASS may prove useful for investigating the impact of provider attitudes on the quality of communication and care provided to these patients.

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References

1. Alleyne J, Thomas VJ. The management of sickle cell crisis pain as experienced by patients and their carers. J Adv Nurs. 1994; 19:725–32. [PubMed: 8021394]

2. Murray N, May A. Painful crises in sickle cell disease—patients' perspectives. Br Med J. 1988; 297:452–4. [PubMed: 3139140]
3. Maxwell K, Streetly A, Bevan D. Experiences of hospital care and treatment seeking for pain from sickle cell disease: qualitative study. Br Med J. 1999; 318:1585–90. [PubMed: 10364116]
4. Gordon DB, Dahl JL, Miaskowski C, McCarberg B, Todd KH, Paice JA, et al. American Pain Society recommendations for improving the quality of acute and cancer pain management: American Pain Society Quality of Care Task Force. Arch Intern Med. 2005; 165:1574–80. [PubMed: 16043674]
5. Hall JA, Horgan TG, Stein TS, Roter DL. Liking in the physician–patient relationship. Patient Educ Couns. 2002; 48:69–77. [PubMed: 12220752]
6. Hall JA, Roter DL, Katz NR. Meta-analysis of correlates of provider behavior in medical encounters. Med Care. 1988; 26:657–75. [PubMed: 3292851]
7. Gerbert B. Perceived likeability and competence of simulated patients: influence on physicians' management plans. Soc Sci Med. 1984; 18:1053–9. [PubMed: 6463673]
8. Stewart MA. Effective physician–patient communication and health outcomes: a review. CMAJ. 1995; 152:1423–33. [PubMed: 7728691]
9. Beach MC, Roter DL, Wang NY, Duggan PS, Cooper LA. Are physicians' attitudes of respect accurately perceived by patients and associated with more positive communication behaviors? Patient Educ Couns. 2006; 62:347–54. [PubMed: 16859867]
10. Labbe E, Herbert D, Haynes J. Physicians' attitude and practices in sickle cell disease pain management. J Palliat Care. 2005; 21:246–51. [PubMed: 16483093]
11. Pack-Mabien A, Labbe E, Herbert D, Haynes J Jr. Nurses' attitudes and practices in sickle cell pain management. Appl Nurs Res. 2001; 14:187–92. [PubMed: 11699021]
12. Elander J, Marczewska M, Amos R, Thomas A, Tangayi S. Factors affecting hospital staff judgments about sickle cell disease pain. J Behav Med. 2006; 29:203–14. [PubMed: 16496211]
13. Thomas VJ, Cohn T. Communication skills and cultural awareness courses for healthcare professionals who care for patients with sickle cell disease. J Adv Nurs. 2006; 53:480–8. [PubMed: 16448491]
14. Upshur CC, Luckmann RS, Savageau JA. Primary care provider concerns about management of chronic pain in community clinic populations. J Gen Intern Med. 2006; 21:652–5. [PubMed: 16808752]
15. Khattab AD, Rawlings B, Ali IS. Haemoglobinopathies and healthcare provision for ethnic minorities. Br J Nurs. 2005; 14:824–7. [PubMed: 16116410]
16. Elander J, Lusher J, Bevan D, Telfer P. Pain management and symptoms of substance dependence among patients with sickle cell disease. Soc Sci Med. 2003; 57:1683–96. [PubMed: 12948577]
17. Johnson L. Sickle cell disease patients and patient-controlled analgesia. Br J Nurs. 2003; 12:144–53. [PubMed: 12610369]
18. Thomas VJ, Taylor LM. The psychosocial experience of people with sickle cell disease and its impact on quality of life: qualitative findings from focus groups. Br J Health Psychol. 2002; 7:345–63. [PubMed: 12614505]
19. Gorman K. Sickle cell disease. Do you doubt your patient's pain? Am J Nurs. 1999; 99:38–44. [quiz 44]. [PubMed: 10091567]
20. Sutton M, Atweh GF, Cashman TD, Davis WT. Resolving conflicts: misconceptions and myths in the care of the patient with sickle cell disease. Mt Sinai J Med. 1999; 66:282–5. [PubMed: 10477486]
21. Shapiro BS, Benjamin LJ, Payne R, Heidrich G. Sickle cell-related pain: perceptions of medical practitioners. J Pain Symptom Manage. 1997; 14:168–74. [PubMed: 9291703]
22. Elander J, Midence K. A review of evidence about factors affecting quality of pain management in sickle cell disease. Clin J Pain. 1996; 12:180–93. [PubMed: 8866159]
23. Waldrop RD, Mandry C. Health professional perceptions of opioid dependence among patients with pain. Am J Emerg Med. 1995; 13:529–31. [PubMed: 7662056]

24. Armstrong FD, Pegelow CH, Gonzalez JC, Martinez A. Impact of children's sickle cell history on nurse and physician ratings of pain and medication decisions. J Pediatr Psychol. 1992; 17:651–64. [PubMed: 1359048]
25. Dames-Fincher G. A patient's perspective on sickle cell disease treatment. J Natl Med Assoc. 1992; 84:739–41. [PubMed: 1404470]
26. van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. Soc Sci Med. 2000; 50:813–28. [PubMed: 10695979]
27. Larson EB, Yao X. Clinical empathy as emotional labor in the patient–physician relationship. J Am Med Assoc. 2005; 293:1100–6.
28. Hahn SR, Thompson KS, Wills TA, Stern V, Budner NS. The difficult doctor–patient relationship: somatization, personality and psychopathology. J Clin Epidemiol. 1994; 47:647–57. [PubMed: 7722577]
29. Levinson W, Stiles WB, Inui TS, Engle R. Physician frustration in communicating with patients. Med Care. 1993; 31:285–95. [PubMed: 8464246]
30. Elander J, Lusher J, Bevan D, Telfer P, Burton B. Understanding the causes of problematic pain management in sickle cell disease: evidence that pseudoad-diction plays a more important role than genuine analgesic dependence. J Pain Symptom Manage. 2004; 27:156–69. [PubMed: 15157040]
31. American Psychological Association, American Educational Research Association, National Council on Measurement in Education. Standards for educational and psychological testing. Washington, DC: American Educational Research Association; 1999. Standards for educational & psychological tests.
32. Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR. Patient-centered communication, ratings of care, and concordance of patient and physician race. Ann Intern Med. 2003; 139:907–15. [PubMed: 14644893]
33. Hall JA, Epstein AM, DeCiantis ML, McNeil BJ. Physicians' liking for their patients: more evidence for the role of affect in medical care. Health Psychol. 1993; 12:140–6. [PubMed: 8500441]
34. Rabe-Hesketh, S.; Skrondal, A. Multilevel and longitudinal modeling using Stata. College Station, TX: Stata Press; 2005.
35. Powars DR, Chan LS, Hiti A, Ramicone E, Johnson C. Outcome of sickle cell anemia: a 4-decade observational study of 1056 patients. Medicine (Baltimore). 2005; 84:363–76. [PubMed: 16267411]
36. Hahn SR, Kroenke K, Spitzer RL, Brody D, Williams JB, Linzer M, et al. The difficult patient: prevalence, psychopathology, and functional impairment. J Gen Intern Med. 1996; 11:1–8. [PubMed: 8691281]
37. Lin EH, Katon W, Von Korff M, Bush T, Lipscomb P, Russo J, et al. Frustrating patients: physician and patient perspectives among distressed high users of medical services. J Gen Intern Med. 1991; 6:241–6. [PubMed: 2066830]
38. Wasan AD, Wootton J, Jamison RN. Dealing with difficult patients in your pain practice. Reg Anesth Pain Med. 2005; 30:184–92. [PubMed: 15765460]
39. Windish DM, Ratanawongsa N. Providers' perceptions of relationships and professional roles when caring for patients who leave the hospital against medical advice. J Gen Intern Med. 2008
40. Ibrahim SA, Kwoh CK, Krishnan E. Factors associated with patients who leave acute-care hospitals against medical advice. Am J Public Health. 2007; 97:2204–8. [PubMed: 17971552]
41. Fiscella K, Meldrum S, Barnett S. Hospital discharge against advice after myocardial infarction: deaths and readmissions. Am J Med. 2007; 120:1047–53. [PubMed: 18060925]
42. Levinson W. Frustrating patients: using our feelings as diagnostic clues. J Gen Intern Med. 1991; 6:259–60. [PubMed: 2066833]
43. Vanderford ML, Stein T, Sheeler R, Skochelak S. Communication challenges for experienced clinicians: topics for an advanced communication curriculum. Health Commun. 2001; 13:261–84. [PubMed: 11550851]
44. Epstein RM. Mindful practice. J Am Med Assoc. 1999; 282:833–9.

45. Cooper LA, Beach MC, Johnson RL, Inui TS. Delving below the surface. Understanding how race and ethnicity influence relationships in health care. J Gen Intern Med. 2006; 21:S21–7. [PubMed: 16405705]

46. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient–physician communication during medical visits. Am J Public Health. 2004; 94:2084–90. [PubMed: 15569958]

47. Loo R, Thorpe K. Confirmatory factor analyses of the full and short versions of the Marlowe–Crowne Social Desirability Scale. J Soc Psychol. 2000; 140:628–35. [PubMed: 11059209]

Table 1

Characteristics of 47 patients and 84 health care providers in a cohort study of provider attitudes toward patients with sickle cell disease and acute vaso-occlusive crisis.

Patient characteristic	
Mean age, years (±S.D.)	30.3 (7.8)
Women, *n* (%)	28 (59.6)
Educational attainment, *n* (%)	
Less than high school	6 (12.8)
High school diploma or GED	21 (44.7)
At least some college	20 (42.6)
Employed, *n* (%)	12 (25.5)
Currently receiving disability, *n* (%)	33 (70.2)
Household income >$10,000, *n* (%)	28 (62.2)
Hemoglobinopathy, *n* (%)	
SS	32 (69.6)
SC	9 (19.6)
S-beta(0) thalassemia	4 (8.7)
S-beta(+) thalassemia	1 (2.2)
Prior acute chest syndrome, *n* (%)	36 (76.6)
Prior avascular necrosis, *n* (%)	11 (23.4)
Current hydroxyurea therapy, *n* (%)	17 (36.2)
Prior hospitalizations, *n* (%)	
0–2	21 (44.7)
3–5	14 (29.8)
6–9	6 (12.8)
≥10	6 (12.8)
Median	3
Range	0–19
Acute care episodes in current study, *n* (%)	
1	25 (53.2)
2	13 (27.7)
3	9 (19.2)
Provider characteristic	
Mean age, years (±S.D.)	34.1 (10.1)
Women, *n* (%)	70 (83.3)
Race/ethnicity, *n* (%)	
White	48 (57.1)
African-American	22 (26.2)
Asian, Hawaiian, Pacific Islander	8 (9.5)
Hispanic	2 (1.2)
Other	4 (4.8)
Provider setting, *n* (%)	

Patient characteristic	
Inpatient	25 (29.8)
Emergency department	58 (70.2)
Provider type, *n* (%)	
Nurse	66 (78.6)
Nurse practitioner	0 (0.0)
Physician assistant	5 (5.9)
Physician	13 (15.5)
Number of surveys in study, range	1–5

Table 2

10 Items[*] comprising a preliminary Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS), from a cohort study of provider attitudes toward patients with sickle cell disease and acute vaso-occlusive crisis (n = 121 surveys).

	% of surveys	% of surveys	% of surveys	% of surveys	% of surveys	Mean	S.D.	Corrected item–total correlations 10-item/7-item
Not every patient is regarded the same. Compared to the average patient…	Much less than average	Less than average	Average	More than average	Much more than average			
1. How much do you like this patient?[a] (liking means warmth and enthusiasm for seeing)	3.3%	9.1%	43.0%	34.7%	9.9%	3.39	0.91	0.73/0.70
2. How much empathy do you have for this patient?	1.7%	10.7%	37.2%	40.5%	9.9%	3.46	0.88	0.59/0.59
3. How much respect do you have for this patient?[b]	2.5%	10.7%	46.3%	24.8%	15.7%	3.40	0.96	0.75/0.74
Thinking about this patient, please indicate whether you tend to agree or disagree with the following statement.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree			
4. This patient was frustrating to take care of.	4.1%	13.2%	11.6%	39.7%	31.4%	3.81	1.14	0.60/NA[c]
5. This patient is one of those people who makes me feel glad I went into medicine.	5.8%	24.0%	42.2%	17.4%	10.7%	2.97	1.04	0.60/NA[c]
6. This patient is the kind of person I could see myself being friends with[d].	5.0%	12.4%	33.9%	31.4%	17.4%	2.56	1.07	0.54/NA[c]
In your opinion, how likely is this patient to…	Not at all likely	A little likely	Some-what likely	Very likely	Extremely likely			
7. … over-report (exaggerate) discomfort?[d]	33.9%	15.7%	20.7%	19.0%	10.7%	3.43	1.40	0.79/0.80
8. … fail to comply with medical advice?[d]	24.0%	26.5%	20.7%	15.7%	13.2%	3.32	1.35	0.74/0.74
9. … abuse drugs, including alcohol?[d]	33.1%	31.4%	16.5%	9.1%	9.9%	3.69	1.29	0.66/0.67
10. … try to manipulate you or other providers?[d]	34.7%	16.5%	19.8%	14.1%	14.9%	3.42	1.46	0.80/0.81

[*] All items are scored on a five-point Likert scale. Items 1–4 are scored from 1 to 5, and items 5–10 are reverse scored.

[a] Ref. [5].

[b] Ref. [9].

[c] NA = not applicable. These items were not included in the 7-item scale.

[d] Ref. [26].

Table 3

Factor loadings for 10-item/7-item factor analyses for the Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS), from a cohort study of provider attitudes toward patients with sickle cell disease and acute vaso-occlusive crisis (n = 121 surveys).

Item	**10-Item factor analysis**			**7-Item factor analysis**		
	“Positive regard” loadings	**“Beliefs about patient” loadings**	**Uniqueness**	**“Positive regard” loadings**	**“Beliefs about patient” loadings**	**Uniqueness**
Liking	0.86	0.31	0.17	0.84	0.31	0.19
Empathy	0.73	0.23	0.41	0.84	0.23	0.40
Respect	0.78	0.38	0.25	0.79	0.37	0.23
Frustration	0.44	0.45	0.60			
Makes me glad I went into medicine	0.48	0.37	0.63			
Could see myself being friends with	0.32	0.43	0.71			
Over-report (exaggerate) discomfort	0.32	0.84	0.18	0.32	0.84	0.18
Fail to comply with medical advice	0.29	0.78	0.31	0.30	0.77	0.31
Abuse drugs	0.22	0.74	0.41	0.23	0.73	0.41
Try to manipulate providers	0.29	0.90	0.11	0.29	0.90	0.11

Table 4

Associations between particular provider/patient characteristics hypothesized to vary with the Positive Provider Attitudes toward Sickle Cell Patients Scale (PASS) in a cohort study of provider attitudes toward patients with sickle cell disease and acute vaso-occlusive crisis.

Patient or provider characteristic	Mean for primary group	Mean for reference	Difference in positive attitude score	95% confidence interval	*p*-Value
Provider					
Inpatient provider vs. emergency department	21.71	17.06	4.65	2.14 to 7.16	<0.001[a]
Nurse vs. physician or physician assistant	20.18	19.23	0.95	0.51 to 1.39	<0.001[a]
Woman vs. man	25.23	21.35	3.88	0.64 to 7.12	0.02
African-American race vs. other categories	26.03	24.17	1.86	−0.94 to 4.65	0.19
Patient					
Increasing levels of educational attainment		17.67	2.74[b]	1.53 to 3.96	<0.001[a]
Household income >$10,000 vs. ≤$10,000	23.02	20.39	2.63	−0.56 to 5.81	0.11
Employed vs. unemployed	23.28	17.66	5.62	2.39 to 8.84	0.001[a]
History vs. no history of avascular necrosis	21.62	25.51	−3.89	−7.38 to −0.40	0.03
History vs. no history of acute chest syndrome	23.82	27.76	−3.94	−7.65 to −0.27	0.04
Increasing number of hospitalizations within last year		27.14	−0.52[c]	−0.79 to −0.24	<0.001[a]
Chart-documented discharge against medical advice vs. none within last year	20.25	25.18	−4.93	−9.50 to −0.35	0.04
Chart-documented disputes with staff about pain/analgesia vs. none within last year	17.76	25.29	−7.53	−12.36 to −2.70	0.002[a]
Chart-documented narcotics dependence vs. none within last year	20.11	25.44	−5.33	−9.33 to −1.33	0.01
Positive vs. negative toxicology test during current episode	20.91	25.21	−4.30	−8.46 to −0.14	0.04

[a] Meets level of significance $p \leq 0.003$.

[b] Change in score with each additional year of education.

[c] Change in score with each additional hospitalization.