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Satisfied or Not Satisfied: Pain Experiences of Patients with Sickle Cell Disease

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Abstract

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Aims—To examine the relationship between pain and satisfaction in patients with sickle cell disease.

Background—Frequency and severity of unrelieved sickle cell pain are positively associated with mortality. Yet, information is scarce on whether sickle cell patients are satisfied with their pain level.

Design—A cross-sectional, correlational analysis of baseline data from a randomized clinical trial.

Methods—A randomized sample of adult outpatients was recruited between February 2007 - March 2011. Patients completed the PAINReport[®], containing measures of pain, satisfaction and socio-demographics. We analyzed data using Kendall rank correlations, analysis of variance, Tukey-Kramer post hoc tests, Fisher's tests and proportional odds logistic regression.

Results—There were significant correlations between pain outcomes (average pain intensity and composite pain index) and satisfaction with pain level, but average pain intensity more strongly discriminated groups based on satisfaction with pain level. Among pain variables bivariately associated with patient satisfaction with pain level (optimal pain goal, time with tolerable pain and pain expectation), only pain expectation maintained its significant relationship to satisfaction with pain level when average pain intensity was controlled. A smaller percentage of our sickle cell patients reported moderate to severe pain intensity (28%) or high composite pain index (39%) while reporting being satisfied with pain their level than reported in earlier studies using different measures and populations (70–94%).

Conclusion—Satisfaction with pain level was an unambiguous measure of patient satisfaction and a promising indicator of pain that did not show the paradoxical relationship between satisfaction and pain seen with past measures.

Keywords

Sickle cell disease; pain; patient satisfaction; pain intensity; composite pain index; outpatient care; patient perspectives; pain-satisfaction paradox; measurement issues; nursing

INTRODUCTION

Pain, the hallmark symptom of sickle cell disease (SCD), is unpredictable and disabling and underpins a lifelong need for pain care during recurrent acute episodes, as well for persistent chronic pain. The International Association for the Study of Pain (IASP) recommends that acute sickle cell pain be treated immediately (IASP 2007). The IASP, in its declaration of 2010–2011 as a global year of acute pain, also emphasized that optimally treated acute pain leads to better patient satisfaction with care (IASP 2010). In adults with SCD, patients' satisfaction related to their pain has received research attention in only two studies. Patients with SCD cared for at specialized adult SCD centers reported greater satisfaction with care than those at nonspecialized adult SCD centers (Aisiku *et al.* 2007). Of 145 adult outpatients with SCD, 33% were not satisfied with their pain level (Wilkie *et al.* 2010b). In neither study did the authors report the relationship between patient satisfaction and pertinent pain variables, such as optimal pain goal, tolerable pain, pain expectation and past pain treatment effectiveness; nor did the authors report the relationship between patient satisfaction and

self-reported pain outcomes: pain intensity and composite pain index (CPI). It is essential to address this important knowledge gap in patients with SCD because the frequency and severity of unrelieved pain has been associated with mortality (Platt *et al.* 1994) and patients' satisfaction with their pain level could be used as a way to measure the effectiveness and adequacy of pain treatment in this vulnerable population. The purpose of this study was to evaluate the relationship between pain and patient satisfaction with pain level in adults with SCD.

Background

Patient satisfaction is important for ascertaining quality of health care services. The IASP, the American Pain Society and the Agency for Healthcare Research and Quality advocate for assessment of patient satisfaction with pain treatment and offer recommendations about the process (Max 1991, CMS 2002, IASP 2010). Findings from patient satisfaction studies for pain conditions other than SCD (Miaskowski *et al.* 1994, Ward and Gordon 1996, Pellino and Ward 1998, Corizzo *et al.* 2000, Svensson *et al.* 2001, Carrougner *et al.* 2003, Dworkin *et al.* 2011) reveal three important issues: (1) a paradoxical relationship between pain intensity and patient satisfaction--patients report moderate to severe pain intensity yet *also* report being satisfied with their pain management, (Miaskowski *et al.* 1994, Ward and Gordon 1996); (2) broad conceptualization of satisfaction with pain management (Corizzo *et al.* 2000, Svensson *et al.* 2001) or care (Aisiku *et al.* 2007); and (3) measurement of unidimensional pain outcomes such as pain intensity (Miaskowski *et al.* 1994, Ward and Gordon 1996) rather than an indicator of the multidimensional pain experience such as the CPI (Wilkie *et al.* 2010b). The CPI is an alternate score that combines variables collected with the McGill Pain Questionnaire (Melzack 1975) and has demonstrated reliability and validity in cancer and SCD populations (Wilkie *et al.* 2010a, Wilkie *et al.* In review).

Findings from other pain patient populations suggest that patient satisfaction may not be a good indicator of the quality of pain treatment because patients report high or very high satisfaction (70% to 94%) while also reporting moderate to severe pain intensity (Miaskowski *et al.* 1994, Ward and Gordon 1996, Jamison *et al.* 1997, Svensson *et al.* 2001). Due to this paradox, rather than searching for the appropriate outcomes that are associated with the satisfaction construct measured, some pain researchers have advocated for the satisfaction construct to be abandoned (Svensson *et al.* 2001). Perhaps the way previous researchers measured satisfaction did not capture the logically expected relationship between pain intensity and patient satisfaction. It is unknown if this discrepancy also occurs in adults with SCD.

The discrepancy between patients' report of satisfaction and report of moderate to severe pain intensity could be related to the satisfaction measure used. In nearly all of the studies identified, the authors measured satisfaction at a global level: satisfaction with pain treatment (Dworkin *et al.* 2011), satisfaction with pain management (Carrougner *et al.* 2003) and satisfaction with care (Aisiku *et al.* 2007). Despite the value of these measures of satisfaction, the items are too global and less specific. When patients answer these global questions, they take into account several confounding factors, including communication with

clinicians and time to receipt of pain medication, which may not relate to their pain intensity (Miaskowski *et al.* 1994).

A plausible approach to addressing this measurement error in pain research is to use a patient satisfaction questionnaire with several pain outcomes. Patients could be asked to rate their satisfaction with pain level, quality of communication with clinicians, time to receipt of pain medication and pain relief. Perhaps if satisfaction is measured more specifically, the discrepancy between patients' report of satisfaction and pain severity could be decreased, as noted in patients with cancer (Golas *et al.*, unpublished results). This issue has not been addressed in patients with SCD, though validity has been noted of the satisfaction with pain level measure (Jha *et al.* 2010).

Further, previous research indicates that factors such as pain goals (Carrougher *et al.* 2003, Hazard *et al.* 2009), perceived control (Pellino and Ward 1998) and pain expectation (Thomas *et al.* 1998, Svensson *et al.* 2001, Wilkie *et al.* 2013, Tocher 2014) could affect patient report of pain intensity (Carrougher *et al.* 2003) and satisfaction with pain outcomes (Carrougher *et al.* 2003). However, these variables have not been studied simultaneously in one study. In patients with postoperative pain, investigators found that patients' perceived control (the perception that one has control over pain) mediated the relationship between pain intensity and patient satisfaction with pain relief (Pellino & Ward 1998). Also in patients with postoperative pain, pain expectation was an important variable that was associated with pain intensity (Thomas *et al.* 1998, Svensson *et al.* 2001, Tocher 2014) and satisfaction with pain management (Thomas *et al.* 1998, Svensson *et al.* 2001). Patients who preoperatively expected moderate to severe pain and actually experienced such levels of pain still indicated that they were satisfied or highly satisfied with their pain management (Svensson *et al.* 2001). Others reported that the difference between the expected and experienced pain postoperatively was not associated with satisfaction with pain management (Thomas *et al.* 1998). Though these results are conflicting, they still suggest that pain expectation should be researched further to understand its association with satisfaction with pain outcomes.

We postulate that satisfaction with pain level could be associated with factors such as optimal pain goal, time with tolerable pain, pain expectation, past pain treatment effectiveness, self-reported pain intensity and CPI. These factors have not been examined in patients with SCD.

THE STUDY

Aim/s

The aim of this study was to determine the relationships between patient satisfaction with pain level and relevant pain variables in adults with SCD. The pain variables included pain outcomes (pain intensity and CPI) and other pain variables (optimal pain goal, time with tolerable pain, pain expectation and past treatment effectiveness).

Design

This study was a cross-sectional, correlational study. We analyzed baseline data from a randomized clinical trial.

Sample

We recruited patients with SCD who received their care from a university-affiliated sickle cell clinic. Eligibility criteria were: diagnosis of sickle cell disease, receive outpatient and acute SCD care at the university-affiliated sickle cell clinic, report moderate to severe pain (≥ 3 on 0–10 scale) related to the SCD within 12 months before enrollment, emergency department visit or hospitalization for pain within the previous 2 years, speak and read English and age 18 years or older. Exclusion criteria were: legally blind or physically unable to complete study questionnaires. There were 228 consented participants who completed baseline measures between February 2007 and March 2011. The participants' mean (SD) age was 33 (11) years. The majority were African Americans ($n = 223$, 98%), female ($n = 142$, 62%) and had a high school diploma or higher ($n = 209$, 92%). Other demographic information appears in Table 1.

Data Collection

Procedures—During a routine clinic visit or close to hospital discharge, the registered nurses or physicians referred patients to the study by introducing the patients to the trained research specialist. The research specialist screened patients for eligibility, explained the study to them and obtained informed consent. After obtaining signed informed consent, the research specialist obtained baseline measures on pentablet computers at a time and place convenient to the participant, usually the outpatient clinic during a routine visit.

Instruments—We collected all data using the PAINReportIt® (Wilkie *et al.* 2001, Huang *et al.* 2003) software program (Nursing Consult LLC, Seattle, WA). Included in the PAINReportIt® is a computerized version of the McGill Pain Questionnaire (MPQ; Melzack 1975), which is a well-validated multidimensional tool that measures pain location, intensity, quality and pattern. PAINReportIt® was recently validated in a SCD sample from another study (Jha *et al.* 2010). Using pentablet computers with standardized instructions and opportunity to practice, the patient completed the questionnaire items. Patients either touched the screen with a stylus or with a keyboard and mouse as they completed the items. Their data were automatically written to an Access database (Microsoft Corp, Redmond, WA). Patients reported their pain as follows:

1. Patients marked their pain sites on anterior and posterior view of a body outline drawing. The software automatically tabulated the number of different pain sites marked.
2. Patients touched a number to report their current, least and worst pain intensity during the last 24 hours, on a scale of 0 to 10, where 0 is 'no pain' and 10 is 'pain as bad as it could be'. In addition to a score for each scale, we averaged the three scores to create a total pain intensity score that also ranges from 0–10 and has an internal consistency alpha of 0.85 and validity in the SCD population (Jha *et al.* 2010).

3. Patients selected from a 78-word list ranked by severity in 20 groups of verbal descriptors to report their usual SCD pain quality: for example, shooting, burning, cramping and so forth. The 20 groups of verbal descriptors formed five pain quality subscale scores, each called a pain-rating index (PRI). Score ranges are: PRI-sensory 0–42; PRI-affective 0–14; PRI-evaluative 0–5; PRI-miscellaneous 0–17; and PRI-total 0–78. The number of words chosen (NWC) is the sixth pain quality subscale and it ranges 0–20. Each of the 78 words is scored as either selected or not. Normative scores for each of these subscales have been reported (Wilkie *et al.* 1990).
4. Patients chose from nine MPQ pain pattern descriptors that represent constant, intermittent and transient types of pain pattern. Each pattern descriptor is scored as selected or not selected. A total pattern score is created by assigning values to groups of descriptors and summing the values of selected groups (constant = 3, transient = 2, intermittent = 1). The total pattern score ranges 0–6 (Ngamkham *et al.* 2011).
5. The CPI score was computed by converting four scores into proportional scores on a 0-to-100 pain scale and averaging them: (a) the number of pain sites; (b) pain intensity (current, least and worst); (c) PRI-T; and (d) pain pattern. The CPI score ranges from 0–100 and is a single score that summarizes the multidimensional attributes of SCD pain. The reliability alpha for the CPI was found to be 0.71 in a cancer sample (Wilkie *et al.* In review). The CPI is derived from scores with well-known validity and reliability and it was sensitive to an effective educational intervention in a cancer population (Wilkie *et al.* In review) and predictive of acute care use by adults with SCD (Ezenwa *et al.* 2014).
6. Optimal pain goal was measured with a single item. Patients reported their optimal pain goal (pain level you want your pain to be) on a 0–10 scale. This item has been validated in a sample of patients with SCD (Jha *et al.* 2010).
7. Tolerable pain in the past 24 hours was measured with one item that asked patients to indicate how much time in the past 24 hours that their pain was at a tolerable level or lower. Response choices were: 0 = 0–6 hrs; 1 = 7–12 hrs; 2 = 13–18 hrs; 3 = 19–24 hrs. This item is valid in patients with SCD (Jha *et al.* 2010).
8. Past treatment effectiveness was measured with one item. Patients were asked, ‘With past treatment, have you usually had?’ The response options were 0 = good pain relief; 1 = some pain relief; 2 = poor pain relief. This item has been validated in patients with SCD (Jha *et al.* 2010).
9. Pain expectation was measured with a single item that asked the patient to report his/her expectation versus the pain level he/she has now. The response options were ‘worse than expected’, ‘same as expected’ and ‘not as bad as expected’. We validated this item in a sample of people with SCD (Jha *et al.* 2010).
10. Satisfaction with pain level was measured with one single-item question that asked patients their satisfaction with their pain level. This question had no qualifiers, such as now, usual, or within 24 hours. A three-choice response allowed the patient to

indicate ‘yes’, ‘no’, or ‘not sure’. This item is valid in patients with SCD (Jha *et al.* 2010).

11. Questions regarding demographic characteristics also are included in PAINReport[®]. Patients reported their age, gender, ethnicity, marital status, level of education completed and annual family income. We collected these data for the purpose of describing sample characteristics.

Ethical Considerations

The Institutional Review Board of a public university in the Midwest United States approved all data collection for the study.

Data Analysis

The pain data collected with the PAINReport[®] were exported from the Access database to statistical software R (R Development Core Team 2011). Descriptive statistics included means, standard deviations, frequencies, percentages and correlations. ANOVA followed by Tukey-Kramer post hoc test was used to compare satisfaction groups (*satisfied*, *not sure* and *not satisfied*) on average pain intensity and CPI. Fisher’s test was used to examine the association between ordinal pain variables and pain satisfaction. For bivariate analysis between satisfaction with pain level and potential predictors, we also examined the Kendall rank correlation (Kendall’s tau). We used proportional odds logistic regression for a multivariate analysis between satisfaction with pain level and potential predictors, controlling for average pain intensity. We controlled for average pain intensity and not the CPI because our post-hoc analysis indicated that pain intensity more strongly discriminated patients with respect to satisfaction with pain level than the CPI. We set the significance level at an alpha of 0.05.

Validity and Reliability/Rigour

We used measures with good reliability and validity as indicated in the instruments section.

RESULTS

General Description of Satisfaction and Pain Variables

Of the patients enrolled in the study, 228 completed baseline measures. We found that 47.8% ($n = 109$) were satisfied with their pain level; 41.7% ($n = 95$) were not satisfied with their pain level; 9.7% ($n = 22$) answered not sure; and 0.9% ($n = 2$) did not report their satisfaction with their level. The average pain intensity for all subjects was 4.4 (2.9). The mean (SD) of CPI scores was 42.0 (14.1). In Table 2, we present the descriptive statistics for the other pain variables.

Relationship between Pain Outcomes (Pain Intensity, CPI) and Satisfaction with Pain Level

There was a statistically significant relationship between satisfaction with pain level and average pain intensity ($p < 0.001$) and the correlation was moderate ($\tau = -0.48$); there was a statistically significant relationship between satisfaction with pain level and CPI ($p < 0.001$), but the correlation was weak ($\tau = -0.22$).

The mean scores for the pain outcomes by satisfaction group ('satisfied', 'not satisfied', or 'not sure') are reported in Table 2. Comparisons of the three groups on the pain outcomes revealed significant differences among groups on average pain intensity ($F(2, 222) = 49.1, p < 0.001$) and CPI ($F(2, 222) = 10.4, p < 0.001$). Post hoc comparisons indicated that patients not satisfied with their pain levels had significantly higher average pain intensity than those satisfied with their pain level ($p < 0.001$). Patients not satisfied with their pain levels also had significantly higher average pain intensity than those not sure ($p = 0.001$). The difference between patients satisfied with their pain level and those not sure was not statistically significant ($p = 0.17$). Post hoc comparisons also showed that patients not satisfied with their pain level had significantly higher CPI than those satisfied with their pain level ($p < 0.001$). The difference in CPI scores between patients satisfied with their pain level and those not sure was not statistically significant ($p = 0.86$). The difference in CPI scores between patients not satisfied with their pain level and those not sure was also not statistically significant ($p = 0.09$).

Relationship between Other Pain Variables and Satisfaction with Pain Level

Optimal pain goal ($\tau = -0.14, p = 0.02$), time with tolerable pain ($\tau = 0.20, p < 0.001$) and pain expectation ($\tau = 0.26, p < 0.001$) were statistically related to satisfaction with pain level. Past treatment effectiveness ($\tau = 0.086, p < 0.164$) was not significantly related to satisfaction with pain level. In Table 3, we present the correlations among other variables and satisfaction with pain level.

In a multivariate analysis shown in Table 4, we examined the relationship between these significant pain variables and satisfaction with pain level, controlling for average pain intensity. Only pain expectation ($z = 3.158, p = 0.002$) maintained its significant association with satisfaction with pain level.

Patients with Moderate to Severe Pain but Still Satisfied with Pain Level

We examined the percentage of subjects who reported moderate to severe pain intensity or high CPI scores while also reporting being satisfied with their pain level. We found that patients with moderate to severe (4 or higher) pain intensity reported being satisfied with their pain level 28% of the time. Patients with high CPI scores (40 or higher) reported being satisfied with their pain level 39% of the time.

DISCUSSION

In a relatively large sample of adults with SCD who typically reported their pain at a routine clinic visit, we found that there were statistically significant associations between pain outcomes (average pain intensity and CPI) and patients' self-reported satisfaction with pain level. Contrary to our expectation, average pain intensity more strongly discriminated patients in the 'satisfied', 'not satisfied', or 'not sure' groups than did the CPI. We also found statistically significant association between pain variables (optimal pain goal, time with tolerable pain and pain expectation) and satisfaction with pain level. When controlling for average pain intensity, only pain expectation maintained its statistically significant relationship to satisfaction with pain level. Nearly one-third of patients who reported

moderate to severe pain intensity or high CPI also reported satisfaction with their pain level, a percentage much lower than previously reported (Miaskowski *et al.* 1994, Jamison *et al.* 1997, Svensson *et al.* 2001).

The findings of this study support the literature on the association between pain and satisfaction in patients with pain. But this study also reports the association of patient satisfaction with pain level in SCD with pain intensity or CPI. Pain intensity has an important effect on patients' report of satisfaction with pain level using two indicators: (1) there was a medium magnitude of association between pain intensity and satisfaction with pain level; and (2) pain intensity clearly discriminated among satisfaction groups. The fact that patients who were not sure whether they were satisfied with their pain level on average reported pain level between satisfied and dissatisfied patients suggested that an answer of *not sure* can potentially be interpreted as 'Partially Satisfied,' though the difference in average pain intensity between *not sure* and *no* was not statistically significant and additional study is needed. Efforts to understand the reason for patients' uncertainty and what it will take for patients to declare that they are either satisfied or not satisfied with their pain level will be worthwhile.

Though the magnitude of the relationship between CPI and satisfaction with pain level was small, this finding shows a trend in the direction that addresses two important gaps in pain research. Most researchers use pain intensity as a pain outcome (Miaskowski *et al.* 1994, Ward and Gordon 1996, Corizzo *et al.* 2000, Svensson *et al.* 2001, Dworkin *et al.* 2011), though others use satisfaction with pain treatment, pain management, or pain care (Pellino and Ward 1998, Carrougher *et al.* 2003, Aisiku *et al.* 2007). There are two issues with such approaches. First, pain is a multidimensional experience and is more completely measured with multidimensional tools. Second, patient satisfaction with pain level is the most specific measure of patient satisfaction with a pain outcome. Results could be experiment artifacts when measures are less specific indicators of the pain or satisfaction phenomena and could account for inconsistent findings among studies. Efforts to prevent obtaining artifact results in pain research will be valuable.

Our multivariate finding, which showed that pain expectation remained the only pain variable significantly related to satisfaction with pain level when average pain intensity was controlled, suggests that most of the bivariate relationships among the other pain variables (optimal pain goal and time with tolerable pain) and satisfaction with pain level were likely the results of dominant confounding effects of pain level.

Our results examining the association between several pain variables with pain outcomes indicated that pain expectation was significantly related only to pain intensity (Wilkie *et al.* 2013). Similar findings were reported in postoperative patients, where pain expectation was associated with pain intensity experienced (Thomas *et al.* 1998, Svensson *et al.* 2001, Tocher 2014). Thomas and colleagues reported that patients who reported high preoperational pain severity and low expected pain severity were more likely to report worse-than-expected pain experience (Thomas *et al.* 1998). Regarding the current study, the question that remains is why pain expectation and not the other pain variables maintained a significant association with satisfaction with pain level, despite its confounding relationship with pain level. Due to

lack of available research evidence from patients with SCD, this phenomenon is difficult to disentangle in a patient population with lifelong unpredictable and disabling pain.

Available evidence from other pain patient populations regarding how pain expectation and actual pain intensity experienced relate to patient satisfaction with a pain outcome are mixed. A group of investigators reported that the difference between the expected pain and the actual pain that patients experienced in the postoperative period was not related to satisfaction with pain management (Thomas *et al.* 1998). In contrast, Svensson and colleagues (2001) examined the relationship between preoperative pain expectation, the actual pain experienced postoperatively and their relations to satisfaction with pain management. They found that 31% out of the 46% of patients who expected moderate postoperative pain and 40% of the 42% who expected severe postoperative pain reported experiencing the expected pain severity postoperatively, yet 81% of the patients reported being satisfied or highly satisfied with their pain management (Svensson *et al.* 2001). In view of these findings, our results suggest that because patients with SCD expect pain as part of their disease trajectory, a difference between expected pain and actual patient-reported pain intensity possibly determines patient satisfaction with pain level. In future studies, we will focus more attention on the contribution of the discrepancy between pain expectation and experienced pain intensity to patient satisfaction, with pain level as a proxy for the adequacy of sickle cell pain control. Such study will provide evidence to guide pain control strategies for patients with SCD.

Undoubtedly, it is valuable to determine whether patients are satisfied with pain management processes. But questions regarding satisfaction with pain management processes may not capture satisfaction with patient-reported pain outcomes as well as pain intensity or CPI will.

The findings of this study suggest that the discrepant relationship between pain and satisfaction found in previous studies may be minimized by carefully choosing patient satisfaction measures. Investigators have reported that, while many patients report moderate to severe pain intensity, an overwhelming percentage still report being satisfied with pain treatment and this percentage has been as high as 70%, 81%, or 94% (Miaskowski *et al.* 1994, Jamison *et al.* 1997, Svensson *et al.* 2001). In our study, we found that 28% of patients with moderate to severe pain intensity and 39% with moderate to severe CPI also reported being satisfied with their pain level. These numbers are smaller than been previously reported (Miaskowski *et al.* 1994, Ward and Gordon 1996, Svensson *et al.* 2001). The considerably lower paradoxical relationship between average pain intensity or CPI and satisfaction with pain level in our study may be partly due to the fact that we crafted our satisfaction item to focus patients on the pain level *only* as they responded to the satisfaction item.

Due to the paradoxical relationship between pain intensity and satisfaction with pain outcomes reported in pain patient populations other than patients with SCD, some scholars asserted that pattern of pain relief and not pain severity should be used to determine patient satisfaction with a pain outcome (Ward & Gordon 1996). This assertion should be pursued in future studies. However, in our study pain intensity was a strong pain outcome that

differentiated groups based on their satisfaction with pain level; thus, it is still a useful measure to determine patient satisfaction with pain outcome. The discrepancy may be due not only to the pain intensity measure in the prior study, but also the global nature of the satisfaction with the pain outcome measured. Others suggested that patient satisfaction may not be a valid measure to determine quality assurance for pain treatment, implying that patient satisfaction measure should be abandoned (Svensson *et al.* 2001). Our findings highlight the validity of using a specific measure of patient satisfaction as a quality assurance measure. Patients who were satisfied with their pain level also reported better pain outcomes than patients who were not satisfied with their pain level. We measured satisfaction with pain level and not satisfaction with pain treatment, or pain management, or even pain care. The intent was to get patients to focus on their actual pain level when they answered this question. In a previous study reporting what patients with SCD were thinking when they answered the question about satisfaction with pain level, patients considered whether the question referred to their satisfaction with their overall pain level or pain level when in crisis and they thought about the time frame (Jha *et al.* 2010). In another study conducted in patients with cancer, the authors found that patient satisfaction with receiving optimal control for their pain was associated with 'brand loyalty' (intent to return to the institution; Farber *et al.* 1998). Most patients did not report focusing on confounding factors such as whether a nurse or doctor was nice to them or whether they had been waiting long to receive their pain medication or not. However, in a study in patients with postoperative pain where patients considered wait-time to receipt of pain medication, time saved by PCA did not improve patient satisfaction with nursing care (Koh & Thomas, 1994), supporting our assertion that more attention should be given to patient satisfaction with pain level.

Limitations

The study was descriptive, cross-sectional and correlational in nature. We can only infer relationships among variables and cannot claim any causal effects.

CONCLUSION

We reported relationships among pain outcomes, pain variables and satisfaction with pain level in patients with SCD. Though pain intensity more strongly differentiated patients with SCD on satisfaction with pain level, the CPI as a multidimensional pain measure should be studied further.

This study provides evidence regarding the relationship between pain expectation and satisfaction with pain level after controlling pain intensity as a confounding variable. The practice implication is that, if supported by future research in patients with SCD, pain expectation that is met may be a proxy for determining adequacy of control of pain in persons with SCD.

We demonstrated that it is possible to obtain a lower paradoxical relationship between pain outcomes and patient satisfaction with pain level. The research implication is that patient satisfaction as a quality indicator measure may better be captured if measured with a pain outcome more specific and less global. This may reduce the usually high percentage of patients in moderate to severe pain who still report being satisfied with a pain outcome,

therefore minimizing the level of the paradoxical relationship between pain and satisfaction variables.

In the future, prospective, longitudinal and experimental studies should be performed to determine linkages and relationships among pain intensity, CPI and patient satisfaction. Future studies could also focus on explanatory models for the relationships among pain intensity, CPI and satisfaction with pain level, possibly using pain expectation as a mediator.

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SUMMARY STATEMENT

Why is this research or review needed?

- Little information is known about satisfaction with pain, the hallmark symptom of sickle cell disease and the major reason for acute healthcare use, which has been associated with mortality.
- Satisfaction with pain level was an unambiguous measure of patient satisfaction and did not show the paradoxical relationship between satisfaction and pain seen with past measures used.
- Accurately measured and successfully controlled sickle cell pain could lead to a reduced pain-related mortality in this vulnerable population.

What are the key findings?

- Average pain intensity and composite pain index discriminated satisfied, not satisfied and not sure groups, showing the relevance of using both unidimensional and multidimensional measures of pain outcomes in research.
- The strong relationship between pain expectation and satisfaction with pain level when controlling for pain intensity suggests pain expectation's significance to patient satisfaction as a pain control quality assurance measure.
- When patient satisfaction was measured using 'satisfaction with pain level' as opposed to global measures, the percentage reporting high pain level while reporting being satisfied was lower than prior studies.

How should the findings be used to influence policy/practice/research/education?

- Pain researchers should consider adopting patient satisfaction with pain level as a more specific quality assurance measure for pain outcomes.
- Ratings of patients' satisfaction with their pain level should be used to rate adequacy of sickle cell pain treatment by providers.
- Satisfactory control of sickle cell pain should be goal for both providers and healthcare institutions.

Table 1Patients' Sociodemographic Characteristics (*N* = 228)

Variable	Mean (SD) [Min-Max]
Age in years	33.2 (11.1) [18–74]
	Number (%)
Age group (years)	
18–25	73 (32.0%)
26–45	120 (52.6%)
46	35 (15.4%)
Gender	
Female	142 (62.3%)
Male	86 (37.7%)
Race	
Caucasian	3 (1.3%)
African American	223 (97.8%)
Other	2 (0.9%)
Ethnicity	
Non Hispanic	221 (96.9%)
Hispanic	7 (3.1%)
Education	
Up to High school	103 (45.2%)
Beyond High school	106 (46.5%)
Refused/Unknown	19 (8.3%)
Sickle cell type	
SS	164 (71.9%)
SC	41 (18.0%)
Other	23 (10.1%)

Table 2
Descriptive Statistics of Pain Outcomes and Pain Variables by Satisfaction Group (*N* = 228)

Variable	Overall M (SD)	Satisfied (<i>n</i> , %) (109, 47.8) M (SD)	Not sure (<i>n</i> , %) (22, 9.7) M (SD)	Not satisfied (<i>n</i> , %) (95, 41.7) M (SD)	<i>F</i>	<i>p</i>
Optimal pain goal (0–10)	1.0 (2.2)	0.7 (1.9)	2.1 (2.8)	1.1 (2.2)	4.51	.011
Current pain (0–10)	4.2 (3.3)	2.6 (3.0)	3.4 (3.7)	6.3 (2.3)	45.1	<.001
Least pain (0–10)	3.4 (2.9)	2.2 (2.5)	3.2 (3.2)	4.9 (2.6)	27.6	<.001
Worst pain (0–10)	5.6 (3.6)	4.0 (3.5)	5.3 (3.9)	7.6 (2.6)	31.7	<.001
Average pain intensity (0–10)	4.4 (2.9)	2.9 (2.6)	3.9 (2.8)	6.3 (2.1)	49.1	<.001
Composite pain index (0–100)	42.0 (14.1)	38.3 (13.8)	40.0 (16.1)	46.8 (12.2)	10.4	<.001
Pain Expectation						
Worse than expected	24 (11%)	2 (2%)	3 (14%)	18 (20%)		<.001
Same as expected	98 (44%)	43 (41%)	13 (59%)	42 (46%)		
Not as bad as expected	99 (45%)	61 (58%)	6 (27%)	32 (35%)		
Past treatment effectiveness						
Good pain relief	66 (29%)	26 (24%)	7 (33%)	32 (34%)		.609
Some pain relief	107 (48%)	55 (51%)	10 (48%)	42 (45%)		
Poor pain relief	51 (23%)	27 (25%)	4 (19%)	20 (21%)		
Time with tolerable pain in past 24 hours						
0–6 hours	123 (54%)	48 (44%)	12 (55%)	62 (65%)		.076
7–12 hours	41 (18%)	21 (19%)	4 (18%)	16 (17%)		
13–18 hours	12 (5%)	8 (7%)	1 (5%)	3 (3%)		
19–24 hours	51 (22%)	32 (29%)	5 (23%)	14 (15%)		

* Note. The total number satisfaction groups did not add up to 228 because of two missing data.

Table 3Kendall Rank Correlation between Study Variables and Satisfaction with Pain Level ($N = 228$)

Variable	Tau	<i>p</i>
Optimal pain goal (0–10)	–0.144	.018
Time with tolerable in past 24 hours (0 = 0–6 hrs, 1 = 7–12 hrs, 2 = 13–18 hrs, 3 = 19–24 hrs)	0.195	.001
Pain expectation (0 = <i>worse than expected</i> , 1 = <i>same as expected</i> , 2 = <i>not as bad as expected</i>)	0.259	<.001
Past treatment effectiveness (0 = <i>good pain relief</i> , 1 = <i>some pain relief</i> , 2 = <i>poor pain relief</i>)	0.086	.164
Average pain intensity (0–10)	–0.447	<.001
Current pain (0–10)	–0.436	<.001
Worst pain (0–10)	–0.393	<.001
Least pain (0–10)	–0.372	<.001
Composite Pain Index (0–100)	–0.217	<.001

Table 4

Multivariate Analysis of the Relationship between Pain and Patient Satisfaction with Pain Level, Controlling for Average Pain Intensity

	Estimate	Std Err	z	p
Pain intensity	−0.412	0.064	−6.441	<.001
Optimal pain goal	−0.006	0.072	−0.082	.934
Time with tolerable pain	0.081	0.137	0.594	.552
Pain expectation	0.787	0.249	3.158	.002
Past treatment effectiveness	0.189	0.219	0.864	.388