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Patient-Reported Outcomes: Descriptors of Nociceptive and Neuropathic Pain and Barriers to Effective Pain Management in Adult Outpatients with Sickle Cell Disease

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Abstract

Despite frequent episodes of severe recurrent pain in sickle cell disease (SCD), sensory pain in outpatient adults with SCD lacks sufficient characterization. Furthermore, pivotal barriers may interfere with these patients' adherence to prescribed analgesic therapies, but have not been studied systematically. We describe sensory pain characteristics, barriers, and analgesic use reported by adults with SCD during routine clinic visits. Patients (N=145, 67% female, 94% African American) completed measures on a pen-tablet computer. Patients reported an average of 3.6±2.3 pain sites; mean current pain intensity (3.3±3.2), least (3.0±2.7) and worst (4.9±3.5) pain intensity in 24 hr on a 0-10 scale; multiple neuropathic (4.5±3.4, 8.3% selected none) and nociceptive (6.8±4.0) pain descriptors; and continuous pain pattern (59%). Their mean pain barriers score was 2.2±0.9, and 33% were dissatisfied with their pain levels. Only 14% reported taking at least one adjuvant drug, 82% were taking nonopioids, 85% step 2 opioids, and 65% step 3 opioids. Patients reported using, on average, 4.9±2.7 analgesics. Their pain barriers scores are similar to or greater than people with cancer. Importantly, their pain may be both nociceptive and neuropathic, contrary to common expectations that SCD pain is only nociceptive. Few patients, however, took drugs effective for neuropathic pain.

Keywords

Sickle cell pain; pain measurement; patient-related barriers; neuropathic and nociceptive pain

Introduction

Despite a lifetime with frequent episodes of severe recurrent vaso-occlusive pain in sickle cell disease (SCD) that often requires prolonged hospitalizations, the sensory pain experience in adult outpatients with SCD lacks sufficient characterization. Furthermore, pivotal patient-related barriers¹⁻⁵ such as fear of addiction or tolerance to opioid analgesics may interfere with patients' adherence to prescribed analgesic therapies, but have not been studied systematically in SCD. Clinicians require sufficient information about the sensory pain experience (location, intensity, quality, and pattern) to prescribe analgesics appropriate for the pain etiology. For optimal pain relief, patients then must overcome barriers that prevent them from adhering to the analgesic prescriptions. Our study purpose was to describe the sensory pain characteristics, barriers and analgesic use reported by adult outpatients with SCD.

Pain is insidious for those with sickle cell disease, affecting all aspects of life. A nationwide epidemiological survey data indicated that annually only 39% of patients with SCD have no pain episodes that require hospitalization, 55% have 1 to 2 painful episodes, 5% have 3 to 10 episodes, and 1% have more than 10 episodes that require hospitalization.⁶ Risk for mortality in adults with SCD increases for patients with increased rates of painful episodes.⁶ In some patients with SCD, on autopsy the cause of death has been attributed to pain crisis,⁷ and others died during a pain crisis without clinical evidence of organ failure.⁸ Despite knowledge of the frequency of pain episodes and their effects on all aspects of life, including stress and mood,⁹ less is known about the sensory characteristics of the pain.

We identified only three studies with small numbers of children and no studies of adults in which investigators simultaneously measured the location, intensity, quality and pattern of SCD pain.¹⁰⁻¹² Also, no investigators have measured patient-related pain barriers in SCD. The specific aim of our study was to describe sensory pain (location, intensity, quality and pattern), patient-related pain barriers, and the analgesics used by adult outpatients with SCD.

Methods

Design

As part of a randomized clinical trial (R01 HL078536), we conducted a descriptive analysis of baseline data. The Institutional Review Board at the University of Illinois at Chicago (UIC) approved the study.

Sample

We recruited consecutive patients from the UIC outpatient sickle cell clinic who met the following eligibility criteria: (a) at least 18 years old; (b) diagnosed with SCD; (c) receiving ongoing care at the sickle cell clinic; (d) a history of SCD-related pain (> 3 on 0-10 scale) within the past 12 months; (e) have an SCD-related emergency department (ED) visit or hospitalization within the past two years; and (f) speak and read English. Persons legally blind and/or physically unable to complete the computerized questionnaire were excluded from participation. We received referrals for 210 patients, but 31 were not eligible (17, 8% of referrals, who were unable to read English or were cognitively impaired, usually secondary to strokes), and 34 declined participation, usually because they were not interested.

The sample available for analysis included 145 participants (69% of referrals) who were attending a routine outpatient clinic visit, predominantly African American (94%), women (67%), and educated beyond high school (48%). Among the 104 SCD patients who completed the computer accessibility items, computer use ranged from never used a

computer (15.4%) to daily use (50%), with 16.3% indicating weekly use and 14.4% indicating monthly use. Table I lists other demographic characteristics of the sample.

Procedures

During routine clinic visits, registered nurses and physicians in the sickle cell clinic referred and introduced patients to the trained research specialist. The research specialist explained the study purpose and procedures and obtained written informed consent. The research specialist then introduced the data collection computer program to patients, allowed them to practice, and gave them privacy to complete it, but was available to answer any of their questions.

Instruments

We used *PAINReportIt*® to measure the patients' sensory pain experiences. *PAINReportIt*®¹³⁻¹⁵ (Nursing Consult LLC, Seattle WA; 801-414-0627) is a software program that presents a computerized extension of the McGill Pain Questionnaire (MPQ)¹⁶ (©1970 Ron Melzack), a multidimensional tool that measures pain location, intensity, quality and pattern that has been validated in a different sample of patients with sickle cell disease.¹⁷ Using a pen-tablet computer (Acer, Taipei, Taiwan) (Figure 1) with standardized practice before beginning the questionnaire items and instructions presented on each screen, patients reported their sensory pain by touching the screen with a stylus or using the keyboard (virtual or standard), with their data automatically written to an Access® database. The validity and reliability of the MPQ are well-documented with more than 30 years of research. Researchers have demonstrated equivalence of *PAINReportIt*® to the MPQ.¹³ Specifically, we adhered to the following steps: (1) Patients marked the location of all their pain sites on an anatomical drawing. We tabulated the number of pain sites each patient marked. (2) Patients recalled their current, least, and worst pain a number from 0 (no pain) to 10 (pain as bad as it could be) and used the same scale to report their worst toothache, headache and stomachache. (3) Patients selected from 78 verbal descriptors ranked in 20 groups by intensity to report the quality of their SCD pain. We used Melzack's¹⁶ original scoring system to derive subscale scores. The 20 groups of verbal descriptors represented four domains: (A) the pain rating index-sensory (PRI-S), which included 42 words; (B) pain rating index-affective (PRI-A), which included 14 words; (C) pain rating index-evaluative (PRI-E), which included five words; and (D) pain rating index-miscellaneous (PRI-M), which included 17 words. The sum of the four PRI scores created the pain rating index-total (PRI-T) score. To examine the quality of SCD pain without the influence of intensity, we counted the number of words chosen (NWC) to describe their pain. We also tabulated the number of nociceptive and neuropathic words^{18, 19} selected, based on extensive literature that has differentiated pain syndromes with the MPQ pain quality descriptors.^{16, 20-29} (4) Patients selected from nine pain pattern descriptors. We assigned a numerical value to each pain pattern (3 points for constant, continuous, or steady, 2 points for brief, momentary or transient, and 1 point for intermittent, periodic, or rhythmic).³⁰ We summed the values to create a total pain pattern score, with possible scores ranging from 0 (no pain pattern descriptors selected) to 6 (a descriptor selected from each type of pain pattern). (5) We calculated a composite pain index (CPI) score by converting the following scores to z scores and summing them: number of pain sites, pain intensity (current, least, and worst), PRI-T, and pain pattern.³⁰ The possible CPI score ranged from 50 to 340 and provided a single score that represented the multidimensional pain experience. The CPI has been sensitive to effects of a multimedia intervention focused on cancer patient-related pain barriers. The mean scores of the control group were 202 ± 30 pre and 204 ± 31 post intervention, and the mean scores of the experimental group were 198 ± 29 pre and 196 ± 26 post intervention.³⁰ (6) Patients selected from lists of analgesics those drugs that they used to control their pain. Analgesic categories included nonopioid drugs (e.g., acetaminophen, non-steroidal anti-

inflammatory drugs [NSAIDs]), adjuvant drugs (e.g., membrane-stabilizing drugs, antidepressants), and opioids (e.g., hydrocodone, morphine, hydromorphone). We tabulated the number of medications used per patient by drug category. (7) Patients reported their personal characteristics such as age, race, ethnicity, and education.

We used a 13-item Barriers Questionnaire (BQ-13) to measure SCD patients' beliefs about pain and pain management. The BQ-13 is an abbreviated version of Ward's^{4, 31} 27-item BQ, measured on a 5-point Likert scale (0 = do not agree; 5 = agree very much). In our previous research,³² patients with cancer complained about the redundant items comprising the BQ-27. We therefore reduced the items and retained one item from each of the eight domains and each of the five items referring to side effects of pain medications, thereby producing the BQ-13, which also retained adequate internal consistency.^{14, 33} In the current SCD sample, the BQ-13 also demonstrated adequate internal consistency, with a Cronbach's alpha of .75.

To measure feasibility and acceptability of PAINReportt plus analgesic lists and the BQ-13 (referred to collectively as PAINReportt-Plus-ABQ) in the SCD population, the patients completed a 13-item Computer Acceptability Scale (CAS) that ranged from 0 (lowest acceptability) to 13 (highest acceptability) and reported their history of using computers.¹⁴ The program automatically calculated the time required to complete PAINReportt-Plus-ABQ sections (Table I).

Analysis

We exported data from the Access® tables to SPSS 17 for data analysis. We conducted descriptive analyses, Pearson's correlations, and Student's *t* tests to examine relationships between variables.

Results

Univariate Results

Cause of pain—Nearly half of the SCD patients reported that their pain was caused by their disease (*n* = 57, 40%), but it is not clear from their responses if they considered the pain to be crisis pain. The other patients reported that their pain was caused by the weather (*n* = 27, 18%), activity (*n* = 7, 5%), stress (*n* = 6, 4%), other causes (*n* = 15, 10%), or unknown causes (*n* = 33, 23%).

Location—SCD patients reported experiencing pain in multiple locations, which ranged from 0 to 10 sites (mean 3.6 ± 2.3). The upper back (63%) and left arm (61%) were the most common body areas marked as painful. The other areas included head (14%), right arm (35%), chest (26%), abdomen (26%), lower back (12%), left leg (34%) and right leg (43%).

Intensity—Only 51 of the 145 patients reported that they were experiencing no pain (0/10) while they were completing PAINReportt-Plus-ABQ at the clinic visit. Seventeen percent of the sample reported mild pain (1-3/10), 27% reported moderate pain (4-6/10), and 19% reported severe pain (7-10/10). Half (52%) of the patients were satisfied with their pain level, 33% were not satisfied, and 11% were not sure if they were satisfied. Table II presents the descriptive statistics for other pain intensity results.

Quality—SCD patients' PRI-T scores ranged from 0 to 73, with a mean score of 32.5 ± 16.4 . The mean NWC was 10.6 ± 4.8 , and on average they selected 4.5 ± 3.4 neuropathic descriptors. Only 8.3% of the sample selected no neuropathic descriptors. Table II presents descriptive findings for the pain quality scores, and Table III presents the frequency of

patients' selection of sensory (nociceptive or neuropathic), affective, and evaluative descriptors.

Pattern—Eighty percent of the SCD patients described their pain pattern as constant, continuous, or steady. Additionally, 53% of the patients reported their pain pattern was intermittent, periodic, or rhythmic, and 43% described their pain as momentary, transient or brief. The mean total pain pattern score was 3.8 ± 1.7 (Table II).

Composite pain index—The CPI scores for SCD patients ranged from 141 to 297. The mean CPI score was 200.8 ± 25.9 (Table II).

Analgesics—SCD patients reported using a variety of analgesics to control their pain (Table IV). The total number of analgesics used per patient ranged from 1 to 15, with the mean number being 4.9 ± 2.7 . Step 2 opioids, according to the opioid classification for mild to moderate pain,³⁴ were the most frequently reported analgesics, with 85% of 145 responding patients reporting use. Adjuvant drugs were the least-used group of analgesics, with 14% of the patients reporting use of a least one adjuvant drug. Only 19% of the sample took no doses of their analgesics during the last 24 hours before they completed PAINReport-Plus-ABQ. Table IV presents other descriptive findings for the patient-reported analgesics.

Pain barriers—Table V presents the mean and SD for each of the BQ-13 items, as well as subscales and total scale scores. SCD patients reported that nausea and constipation were the most troublesome side effects of pain medications; 83% indicated that nausea was a distressing side effect, and 80% indicated that constipation was an upsetting side effect. SCD patients themselves were also concerned about the potential for addiction to pain medications, with 85% of the patients indicating a belief that people are easily addicted to pain medications.

Acceptability—The scores from 104 participants who completed the CAS to date ranged from 3 to 13. The mean CAS score was 11.3 ± 1.3 .

Bivariate Results—Table VI presents correlations among the sensory pain variables. Few of the sensory pain scores differed by gender, age group, or if patients were satisfied or not with their pain level. The average current pain score differed for women (3.9 ± 3.3) and men (2.2 ± 4.0) ($t(141) = 3.00, p < .01$). We found similar findings for least pain (women 3.5 ± 2.8 ; men 2.0 ± 2.3 ; $t(141) = 3.25, p < .001$); worst pain (women 5.3 ± 3.4 ; men 3.9 ± 3.5 ; $t(141) = 2.31, p < .05$); and worst headache (women 8.3 ± 2.3 ; men 7.3 ± 2.9 ; $t(139) = 2.12, p < .05$). The average scores for the worst toothache differed by age group (18-25 yr 6.0 ± 3.6 , 26-35 yr 7.4 ± 3.3 , > 36 yr 8.3 ± 2.6 , $F(2,138) = 6.37, p < .01$), but not for the worst stomachache (18-25 yr 7.9 ± 2.5 , 26-35 yr 7.6 ± 2.4 , > 36 yr 7.5 ± 2.5 , $F(2,138) = .29, p = .75$). Patients who were not satisfied with their pain levels reported higher mean current pain scores than patients who were satisfied (not satisfied 4.7 ± 2.9 , satisfied 2.2 ± 3.0 , $t(137) = 4.91, p < .001$). We noted similar findings for the mean worst pain score (not satisfied 6.2 ± 3.0 , satisfied 3.7 ± 3.4 , $t(137) = 4.61, p < .001$). Those not satisfied also reported higher BQ-8 scores than patients who were satisfied (not satisfied 2.3 ± 1.0 , satisfied $2.1 \pm .9$, $t(135) = 1.08, p = .281$). There was a trend for patients not satisfied to also report higher BQ-13 scores (not satisfied 2.3 ± 1.1 , satisfied 2.1 ± 0.7 , $t(135) = 1.0, p = .32$).

Discussion

Our findings are the first to document simultaneously the pain location, intensity, quality, and pattern of adults with SCD during a routine outpatient clinic visit and to include their analgesic use and patient-related barriers to effective pain management. These patients with SCD reported intense sensory pain that for most was continuous and in several sites. They selected verbal descriptors that have been associated with both nociceptive (related to tissue injury) and neuropathic pain, contrary to common expectations that their pain is only nociceptive.³⁵ They also reported scores on a scale that measures patient-related barriers to effective pain management that are similar to or greater than people with cancer.³¹

A striking finding is that patients with SCD selected verbal pain quality descriptors that have been associated with or predictive of neuropathic pain in other pain populations.^{16, 20, 24, 25, 28, 29, 36} Neuropathic pain is defined as pain arising as a direct consequence of a lesion or disease affecting the somatosensory system.³⁷ Persistent, inadequately relieved pain or pain enhanced by stress may result in enabled N-methyl-D-aspartate (NMDA) receptors in the spinal cord, which produces altered signal processing within the central nervous system.³⁸ This type of neuropathic pain differs from the typical neuropathic pain that has been reported in adults with sickle cell disease.³⁹

Rarely have investigators reported the verbal descriptors from the MPQ,^{40, 41} and only recently have investigators created subscale scores by counting the number of nociceptive and neuropathic descriptors selected by patients, an adaptation from the NWC subscale.^{18, 19, 22} Because the verbal descriptors are useful for diagnosing neuropathic pain,²⁹ our identification of the potential for patients to have neuropathic pain is important. Since experts recommend that analgesic therapies are tailored to the type of neuropathic pain in cancer populations,⁴² this approach could be useful for patients with SCD. Our findings, however, provide insufficient evidence to support the conclusion that the pain of SCD has neuropathic components. Additional studies are needed to validate the subjective report of neuropathic pain, with sensory testing of the pain site for better evidence of allodynia and hyperalgesia, which would be diagnostic for neuropathic pain. In further studies of pain in SCD, investigators also can test the effectiveness of adjuvant analgesics that are recommended for continuous dysesthesia or for intermittent or transient dysesthesia in patients who report pain with selected neuropathic descriptors.

Another compelling finding in this study is the severity of the pain reported by adults with SCD during a routine outpatient clinic visit. It is well known that patients with SCD report severe pain associated with vasoocclusive “crisis” pain. Recently, Smith and colleagues⁴³ reported that daily pain in 232 older adolescents and adults with SCD was mild on pain days (3.5 ± 0.4 SE) and moderately intense on crisis days (6.2 ± 0.2 SE), but they used a 0-9 scale. Our findings with a 0 to 10 scale are similar for scores for current pain and worst pain in the last 24 hours. Our finding regarding an average of 3.5 pain sites is consistent with the average number of pain sites reported in the PiSCES study of 260 older adolescent and adult outpatients with SCD⁴⁴ but less than the average of 8 sites reported by 40 hospitalized children.¹² However, the PRI scores presented in Figure II show that SCD pain that is more severe than cancer pain or the pain of labor during childbirth.⁴⁵ Other investigators^{40, 41} who have used the MPQ in patients with SCD have not reported all the PRI scores. Gil and colleagues⁴⁰ reported a PRI-T score of 15.4 ± 7.8 in a sample of 31 adults with SCD, about half of whom were experiencing pain on the study day, whereas two-thirds of our sample were experiencing pain when they completed PAINReport® and their PRI-total score was much higher: 32.5 ± 16.4 . The minimum education level in our sample was completed high school, which is similar to the educational backgrounds in the PiSCES study,⁴³ but in Gil et al.’s⁴⁰ sample the minimum education level was 9th grade. These or other differences may

explain differences in the PRI-T scores found in the two studies. It is unknown how the PRI scores from this sample relate to those from other SCD samples since those scores were not published. Nor is it known how the persistent, mild to moderate pain on average, with more-intense recurrent episodes of “crisis” pain, may affect report of sensory, affective, and evaluative components of the pain experience in cross-sectional studies or over time in longitudinal studies. Importantly, the correlations among the PRI scores are consistent with findings from other studies,^{16, 46} which lends validity to our findings.

Our findings from use of the patient-related barriers scale reveal that SCD patients hold beliefs about pain medications that may hinder effective pain control. In other chronic pain conditions, those who had similar results on these scales unnecessarily experienced pain because of erroneous beliefs about the addictive nature of pain medications and the inability to cope with medication side effects.^{4, 312} Our mean BQ scores are similar to Ward’s and Gatewood’s⁴ findings in their study of patient-related barriers in persons with and without cancer pain. For the items representing the 8 pain management domains, the mean scores from our sample were lower for one subscale, similar for one, and higher for six domains than those of two other studies of cancer patients.^{4, 31} In particular, the mean scores for SCD patients’ beliefs about addiction were nearly as high as those for cancer patients: 2.7 ± 1.8 , as compared to 2.9 ± 1.1 , respectively. Interventions that specifically address SCD patients’ concerns about addiction may improve pain control. Interventions also directed to overcome patient-related barriers have been effective in cancer patients^{47, 48} and logically could benefit patients with SCD pain. Our team is engaged in a randomized clinical trial to overcome the patient-related barriers in SCD using the tailored, multimedia computer intervention, PAINUCope® (Nursing Consult LLC, Seattle, WA). Given the advances in reducing the digital divide in minority communities⁴⁹⁻⁵¹ and our deliberate design of the computer screens to accommodate people with low health literacy and disease impairments, it is not surprising that the average CAS score indicated exceptionally high acceptability of the pen-tablet-based pain measurement tool. We found similar findings in the general public and people with cancer.¹⁵ We therefore expect continued success in use of the innovative pen-tablet-based tools to measure pain experienced by people with SCD in outpatient, emergency, acute care center, and hospital settings, where our study is also being conducted, and to provide the tailored, multimedia education to address patient-related barriers to SCD pain management.

In summary, we present novel findings about the sensory pain characteristics and patient-related barriers reported by adult outpatients with SCD. Their barriers are greater than outpatients living with cancer. Their sensory pain is likely to involve both nociceptive and neuropathic mechanisms, but this possibility requires additional study with sensory testing for allodynia and hyperalgesia and trials with adjuvant drugs. Their pain is severe and continuous, persisting beyond the typical painful episodes commonly associated with ED visits and hospitalizations. Their sensory, affective, evaluative and miscellaneous pain dimension scores are higher than published normative scores for cancer pain and the pain of childbirth. Additional research is needed to address patient-related barriers and to improve control of SCD pain.

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Figure 1.
PAINReportt® displayed on an Acer pen-tablet computer
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Figure II.
Mean Pain Rating Index (PRI) scores: Outpatient sickle cell pain, outpatient cancer pain, labor pain, and pain in general.⁴⁵

Table I

Demographic characteristics (N = 145) and amount of time required to complete the *PAINReportIt®*-Plus-ABQ program

Variable	Category	Number (%)	Mean (SD)	Min-Max
Gender	Male	48 (33.1%)		
	Female	97 (66.9%)		
Age in years	Male		33.5 (10.8)	
	Female		34.2 (11.9)	
	Total		34.0 (11.5)	18-74
Age Group	18-25 years old	43 (29.7%)		
	26-35 years old	42 (29.0%)		
	36 years old	60 (41.4%)		
Race/Ethnicity	Caucasian	2 (1.4%)		
	African American	136 (93.8%)		
	Hispanic	4 (2.8%)		
	More than one race	3 (2.1%)		
Education	Completed high school	60 (41.4%)		
	Some or graduated college	70 (48.3%)		
	Missing	15 (10.3%)		
Sickle Cell Type	SβTH	9 (6.2%)		
	SβTH ⁺	4 (2.8%)		
	SαTH	1 (0.7%)		
	SC	19 (13.1%)		
	SS	109 (75.2%)		
	Missing	3 (2.1%)		
Minutes required to complete each section of the <i>PAINReportIt®</i> -Plus-ABQ tool	Demographic Data	103	12.0 (8.3)	0.1 - 54.8
	McGill Pain Questionnaire	140	21.4 (11.3)	0.1 - 57.5
	Medications	136	13.4 (8.7)	2.0 - 56.3
	Barriers Questionnaire	136	3.6 (2.9)	0.1 - 29.4
	Computer Acceptability Scale	115	4.3 (3.8)	1.1 - 37.3
	Total for all five components	90	54.9 (21.5)	21.7 - 139.2

Table II

Descriptive statistics for the pain measures (N = 145)

Variable	Category	Number (%)	Mean (SD)	Min-Max
Number of Pain Sites			3.6 (2.3)	1-13
Pain Intensity (0-10 possible)	Current pain		3.3 (3.2)	0-10
	Worst pain in last 24 hr		4.9 (3.5)	0-10
	Least pain in last 24 hr		3.0 (2.7)	0-10
	Worst ever headache		8.0 (2.6)	0-10
	Worst ever stomachache		7.7 (2.5)	0-10
	Worst ever toothache		7.4 (3.2)	0-10
Pain Goal (0-10 possible)	Optimal goal for pain level		.98 (2.3)	0-10
	Tolerable pain level		3.3 (2.2)	0-10
Pain Expectation	Worse than expected	9 (6.1%)		
	Same as expected	66 (44.9%)		
	Not bad as expected	63 (42.9%)		
	No answer	9 (6.1%)		
Number of Hours in Last 24 that Pain was Less than Tolerable Level	0-6 hours	74 (51.0%)		
	7-12 hours	23 (15.9%)		
	13-18 hours	10 (6.9%)		
	19-24 hours	34 (23.4%)		
	No answer	4 (2.8%)		
Pain Rating Index (PRI)	PRI-S: Sensory (0-42 possible)		18.3 (8.5)	0-38
	PRI-A: Affective (0-14 possible)		4.7 (3.8)	0-14
	PRI-E: Evaluative (0-5 possible)		3.5 (1.9)	0-5
	PRI-M: Miscellaneous (0-17 possible)		6.2 (4.7)	0-17
	PRI-T: Total (0-78 possible)		32.5 (16.4)	0-73
Pain Words	Number of words chosen (0-20 possible)		10.6 (4.8)	0-20
	Number of nociceptive words (0-28 possible)		6.8 (4.0)	0-20
	Number of neuropathic words (0-26 possible)		4.5 (3.4)	0-14
Pain Pattern	Total pattern score (0-6 possible)	116 (80%)	3.8 (1.8)	0-6
	Constant group	77 (53.1%)		
	Intermittent group	62 (42.8%)		
	Transient group			
Composite Pain Index	(50 -340 possible)		200.8 (25.9)	141-297

Table III

Frequency of pain quality descriptors selected by 145 outpatients with sickle cell disease.

Neuropathic descriptors	Number (%)	Nociceptive descriptors	Number (%)	Other descriptors	Number (%)
Aching	98 (67.6%)	Beating	32 (22.1%)	Fearful	23 (15.9%)
Boring	4 (2.8%)	Cramping	51 (35.2%)	Frightening	28 (19.3%)
Burning	15 (10.3%)	Crushing	33 (22.8%)	Terrifying	23 (15.9%)
Cold	23 (15.9%)	Cutting	19 (13.1%)	Grueling	24 (16.6%)
Cool	5 (3.4%)	Dull	28 (19.3%)	Punishing	46 (31.7%)
Drawing	3 (2.1%)	Gnawing	14 (9.7%)	Cruel	26 (17.9%)
Drilling	21 (14.5%)	Heavy	47 (32.4%)	Vicious	24 (16.6%)
Flashing	12 (8.3%)	Hurting	83 (57.2%)	Killing	36 (24.8%)
Flickering	11 (7.6%)	Lacerating	1 (.7%)	Tiring	59 (40.7%)
Freezing	8 (5.5%)	Piercing	35 (24.1%)	Exhausting	74 (51.0%)
Hot	25 (17.2%)	Pinching	22 (15.2%)	Wretched	15 (10.3%)
Itchy	22 (15.2%)	Pounding	70 (48.3%)	Blinding	11 (7.6%)
Jumping	25 (17.2%)	Pressing	47 (32.4%)	Sickening	62 (42.8%)
Lancinating	2 (1.4%)	Pulling	30 (20.7%)	Suffocating	15 (10.3%)
Numb	26 (17.9%)	Pulsing	44 (30.3%)	Annoying	79 (54.5%)
Penetrating	42 (29%)	Rasping	2 (1.4%)	Troublesome	35 (24.1%)
Pricking	10 (6.9%)	Sharp	110 (75.9%)	Miserable	73 (50.3%)
Quivering	6 (4.1%)	Sore	60 (41.4%)	Intense	66 (45.5%)
Radiating	19 (13.1%)	Splitting	18 (12.4%)	Unbearable	76 (52.4%)
Scalding	1 (.7%)	Squeezing	23 (15.9%)	Nagging	47 (32.4%)
Searing	6 (4.1%)	Taut	5 (3.4%)	Nauseating	27 (18.6%)
Shooting	69 (47.6%)	Tearing	22 (15.2%)	Agonizing	44 (30.3%)
Smarting	3 (2.1%)	Tender	48 (33.1%)	Dreadful	34 (23.4%)
Spreading	36 (24.8%)	Throbbing	111 (76.6%)	Torturing	44 (30.3%)
Stabbing	61 (42.1%)	Tugging	15 (10.3%)		
Stinging	26 (17.9%)	Wrenching	20 (13.8%)		
Tight	39 (26.9%)				
Tingling	28 (19.3%)				

Table IV

Analgesics reported by subjects as being used for pain control and number of patients using at least one dose of each medication in the 24-hour prior to completing PAINReport®-Plus-ABQ (N = 145)

Drug Type	Number of Patients (%)	Mean (SD)	Min-Max	Number of Patients (%) with 24-Hour Dose > 0
Step 1 Nonopioid	119 (82%)	1.8 (1.1)	0-5	
<u>Commonly used nonopioid</u>				
Acetaminophen	105 (72%)			57 (39%)
Ibuprofen	83 (57%)			53 (37%)
Ketorolac	20 (14%)			8 (6%)
Naproxen	18 (12%)			9 (6%)
Acetylsalicylic acid	9 (6%)			4 (3%)
Adjuvant Drugs	20 (14%)	.17 (.5)	0-3	
<u>Commonly used adjuvants</u>				
Amitriptyline	6 (4%)			4 (3%)
Hydroxyzine	4 (3%)			3 (2%)
Phenytoin	2 (1%)			1 (1%)
Sumatriptan	2 (1%)			1 (1%)
Lidocaine	3 (2%)			1 (1%)
All Opioids	131 (90%)	2.8 (2.1)	0-11	
Step 2 opioid	123 (85%)	1.5 (1.1)	0-5	
<u>Commonly used Step 2 opioid</u>				
Codeine w/acetaminophen	96 (66%)			50 (35%)
Hydrocodone	67 (46%)			45 (31%)
Meperidine	17 (12%)			8 (6%)
Codeine	23 (16%)			13 (9%)
Tramadol	15 (10%)			8 (6%)
Step 3 opioid	94 (65%)	1.3 (1.5)	0-8	
<u>Commonly used Step 3 opioid</u>				
Morphine sulfate-injection	41 (28%)			22 (15%)
Morphine sulfate-immediate release	35 (24%)			22 (15%)
Morphine sulfate-sustained release	23 (16%)			12 (8%)
Oxycodone-controlled release	21 (15%)			13 (9%)
Hydromorphone	30 (21%)			15 (10%)

Table V

Descriptive statistics for Barrier Questionnaire items and scales for the current sickle cell sample (N = 145) and three previously reported samples

Variable	Domain	Mean (SD)			
		Sickle Cell N=145	With Cancer N=270 ⁺	With Cancer N=53 ⁺⁺	Without Cancer N=40 ⁺⁺⁺
Pain Management Subscale (BQ-8 items)	1. Having pain means that the disease is getting worse. 2. I do not like having shots. 3. Pain medicine cannot really control pain. 4. People get addicted to pain medicine easily. 5. It is important to be strong by not talking about pain. 6. It is more important for the doctor to focus on curing illness than to put time into controlling pain. 7. If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse. 8. It is easier to put up with pain than with the side effects that come from pain medicine.	2.2 (1.9) 2.9 (1.9) 1.8 (1.8) 2.7 (1.8) 1.6 (1.7) 2.1 (1.9) 2.6 (1.9) 1.5 (1.6)	2.1 (1.5) 1.7 (1.4) 1.0 (1.0) 2.2 (1.4) 1.1 (1.1) 1.3 (1.3) 1.5 (1.3) 2.0 (1.1)	2.2 (1.6) 2.3 (1.5) 1.0 (1.0) 2.5 (1.4) 1.0 (1.2) 1.3 (1.3) 1.7 (1.4) 2.1 (1.0)	2.0 (1.4) 2.0 (1.4) 1.4 (1.1) 2.9 (1.1) 1.4 (1.2) 1.5 (1.1) 1.6 (1.3) 2.4 (.9)
Side Effects Subscale (BQ-5 items)	1. Drowsiness from pain medicine is really a bother. 2. Confusion from pain medicine is really a bother. 3. Nausea from pain medicine is really distressing. 4. Pain medicine often makes you say or do embarrassing things. 5. Constipation from pain medicine is really upsetting.	2.2 (1.6) 2.5 (1.9) 3.2 (1.9) 1.0 (1.4) 2.7 (1.8)			
BQ-8 subscale [*]		2.2 (1.0)			
BQ-5 subscale ^{**}		2.3 (1.3)			
BQ-13 scale ^{***}		2.2 (0.9)			

^{*} Cronbach's alpha for internal consistency reliability: 0.63

^{**} 0.77

^{***} 0.75

⁺ (Ward *et al.*, 1993)

⁺⁺ (Ward and Gatwood, 1994)

⁺⁺⁺ (Ward and Gatwood, 1994)

Table VI

Correlations among sensory pain variables (N = 145)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Pain now													
2. Pain worst	.53 [#]												
3. Toothache	.22 ⁺	.12											
4. Stomachache	.10	.16	.20 [*]										
5. Headache	.25 ⁺	.23 ⁺	.22 ⁺	.53 [#]									
6. PRIS	.06	.10	.07	.27 [#]	.22 [*]								
7. PRIA	.06	.14	.06	.18 [*]	.16	.70 [#]							
8. PRIE	-.04	-.01	.06	.93	.17	.46 [#]	.46 [#]						
9. PRIM	.10	.16	.09	.24 ⁺	.23 ⁺	.72 [#]	.67 [#]	.51 [#]					
10. PRIT	.07	.13	.08	.26 ⁺	.23 ⁺	.94 [#]	.84 [#]	.61 [#]	.87 [#]				
11. NWC	.08	.09	.09	.27 [#]	.21 [*]	.90 [#]	.80 [#]	.54 [#]	.82 [#]	.95 [#]			
12. Nociceptive	.08	.11	.09	.27 [#]	.25 ⁺	.84 [#]	.66 [#]	.44 [#]	.69 [#]	.84 [#]	.76 [#]		
13. Neuropathic	.10	.12	.03	.25 ⁺	.18 [*]	.84 [#]	.59 [#]	.40 [#]	.73 [#]	.83 [#]	.83 [#]	.72 [#]	
14. Pattern	.09	.08	.14	.27 [#]	.12	.55 [#]	.42 [#]	.37 [#]	.48 [#]	.56 [#]	.63 [#]	.44 [#]	.54 [#]

* $p < .05$

+ $p < .01$

$p < .001$

⁶ Pain Rating Index-Sensory

⁷ Pain Rating Index-Affective

⁸ Pain Rating Index-Evaluative

⁹ Pain Rating Index-Miscellaneous

¹⁰ Pain Rating Index-Total

- I1* Number of Words Chosen
- I2* Number of Nociceptive Words
- I3* Number of Neuropathic Words