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Differences in Sensory Pain, Expectation, and Satisfaction Reported by Outpatients with Cancer or Sickle Cell Disease

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Abstract

Background—Patients with sickle cell disease (SCD) report pain scores that appeared greater than those reported in a meta-analysis for patients with cancer, but statistical comparison of pain scores from both populations has not been published.

Aims—To compare pain outcomes reported by outpatients with cancer or SCD.

Design—Descriptive comparative study.

Setting—Outpatient oncology or sickle cell clinics.

Subjects—Outpatients (N=415) from 3 studies: (1) 106 patients with SCD, 93% African-American (referent group), (2) 140 patients with cancer, 90% Caucasian (race-discordant); (3) 169 patients with cancer, 20% Caucasian, 65% African-American (race-concordant).

Methods—Patients completed PAINReportIt including pain location, quality, pattern, intensity, expectation, satisfaction, and demographic questions. Analyses included Chi-square, ANOVA, and regression.

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Results—Outpatients with SCD reported more pain location sites than the race-discordant ($p<.001$) and race-concordant ($p<.001$) cancer groups; higher pain quality than the race-discordant ($p<.001$) and race-concordant ($p<.001$) groups; and greater pain pattern scores than the race-discordant ($p<.001$) and race-concordant ($p<.001$) groups. Race-concordant group reported higher worst pain intensity than SCD ($p<.001$) and race-discordant ($p=.002$) group. The three groups did not differ significantly on pain expectation ($p=.06$). Regarding satisfaction with pain level, there was a significant difference between race-concordant and SCD ($p=.006$), but not between race-discordant and SCD ($p=.12$) or race-discordant and race-concordant ($p=.49$) groups.

Conclusions—Outpatients with SCD reported three out of four sensory pain parameters that were greater than those reported by outpatients with cancer. A better understanding of these differences is pertinent to improving pain outcomes.

Keywords

Cancer pain; sickle cell pain; satisfaction; expectation; pain treatment; PAINReport

Introduction

Outpatients with sickle cell disease (SCD) (Wilkie, Molokie, et al., 2010) reported McGill Pain Questionnaire scores greater than literature-based normative scores for patients with cancer (Wilkie, Savedra, Holzemer, Tesler, & Paul, 1990), but statistical comparison of pain scores of adult outpatients with SCD and cancer was not possible because standard deviations were unavailable for the normative scores. Normative scores, one of the psychometric properties of an instrument, are the typical (usual) values obtained when the instrument is used in a specific population at a defined period in time that can be used as a reference for comparison with other populations or time points. Two decades ago, experts suggested that SCD pain treatment protocols should be modeled after protocols developed for cancer pain treatment (Ballas, Rubin, & Gabuzda, 1992; Brookoff & Polomano, 1992; Portenoy, 1992; Smith, 1992). Subsequent debate occurred among sickle cell investigators about how to quantify and treat SCD pain (Ballas et al., 1992; Brookoff & Polomano, 1992; Portenoy, 1992; Smith, 1992). However, studies in which investigators compared pain in patients with cancer or SCD have not been reported. The purpose of this study was to compare multidimensional pain outcomes reported by adult outpatients living with cancer or SCD. This information will be helpful for planning future research of appropriate pain treatment protocols for different pain populations.

SCD is an inherited blood disorder affecting about 100,000 Americans, mostly of African descent (US Department of Health and Human Services, 2009). Pain, the hallmark symptom of SCD, is intractable and disabling, adversely affecting patients' and their families' productivity and quality of life. Pain is also the key reason for the approximately 197,333 annual emergency department (ED) visits by patients with SCD between 1999–2007 with 11% encounters attributed to chest pain and 67% of the visits credited to other or unspecified pain (Yusuf, Atrash, Grosse, Parker, & Grant, 2010). Sickle cell pain is inadequately managed and associated with lack of provider knowledge (Whiteman et al., 2015), negative attitude of providers towards patients with SCD (Labbe, Herbert, & Haynes, 2005), discrimination (Haywood et al., 2014), stigma (Bediako et al., 2014), and healthcare

injustice that patients with SCD report encountering in their pursuit for adequate pain control (Ezenwa, Molokie, Suarez, Yao, & Wilkie, 2015; Ezenwa, Yao, Molokie, et al., 2016; Zempsky, 2009), lack of objective clinical findings of pain (Ballas, 2005), and concerns about addiction and “pseudo-addiction” (Wright & Adeosum, 2009). Consequently, providers often misinterpret patients’ needs for opioids as an aberrant drug-seeking behavior (Martin & Moore, 1997).

Others suggest that sickle cell pain is poorly controlled because the usual pain treatment protocol used in this population is inconsistent with the frequent, severe, complex, and lifelong nature of sickle cell pain (Brookoff & Polomano, 1992). To improve pain control in patients with SCD, a group of researchers suggested that SCD should be treated with similar pain treatment protocols as those used in the cancer population (Brookoff & Polomano, 1992). For example, Brookoff and Polomano (1992) in a longitudinal study of 50 SCD patients prone to use of the ED and inpatient care for pain control examined the effects of implementing a cancer pain treatment model in patients with SCD. This model included using intravenous and oral controlled-release morphine as opposed to intramuscular Meperidine and short-acting oral opioid analgesics. The authors found a significant reduction in ED visits (67%); number of admissions (44%); total inpatient days (57%), and length of hospital stay (23%) after the implementation of the morphine protocol (Brookoff & Polomano, 1992). Lower acute healthcare utilization in these patients remained at lower levels one year following the study (Brookoff & Polomano, 1992). Despite these positive findings, SCD experts contended that SCD is different than cancer pain requiring SCD pain protocols rather than cancer pain protocols (Ballas et al., 1992; Brookoff & Polomano, 1992; Portenoy, 1992; Smith, 1992). However, studies have not been conducted to compare the characteristics of cancer and SCD pain. Observational studies focused on comparison of the sensory nature of sickle cell pain and cancer pain would add additional evidence to inform the design of trials for SCD pain treatment protocols based on cancer pain management concepts and provide a relative frame of reference for SCD so that providers may better understand and thereby improve management of SCD pain.

There is a variety of disparities in pain management in the United States (Bernabei et al., 1998; Green, Baker, Smith, & Sato, 2003; Meghani, Byun, & Gallagher, 2012; Vallerand, Hasenau, Templin, & Collins-Bohler, 2005). For the purposes of this paper, we focus on disparities in pain management due to race and disease. A series of three studies conducted by Todd and colleagues in emergency departments showed the suboptimal pain treatment that racial minority patients with isolated long bone fractures received compared to their Caucasian counterparts (Todd, Deaton, D’Adamo, & Goe, 2000; Todd, Lee, & Hoffman, 1994; Todd, Samaroo, & Hoffman, 1993). The pervasiveness of racial disparities in pain management in the United States was brought to fore in a comprehensive literature review (Ezenwa, Ameringer, Ward, & Serlin, 2006) and a systematic review (Cintron & Morrison, 2006). Based on analysis of the studies reviewed, Ezenwa and colleagues (2006) reported that although the magnitude of the reported racial and ethnic disparities was overall small, minority patients continued to suffer with pain when there are available pain treatment modalities to alleviate their pain (Ezenwa et al., 2006). Findings from Cintron and colleagues (2006) systematic review indicated that healthcare providers underestimated the pain severity, were less likely to record pain scores reported by minorities and were less

likely to give opioid analgesics to minority patients compared to non-minority patients (Cintron & Morrison, 2006). Reasons for the racial disparities in pain management was a gap that Ezenwa and Fleming addressed and found that perceived discrimination was one of the explanatory factors (Ezenwa & Fleming, 2012) and another group of researchers found that perception of control over pain could explain the disparities they found in patients with cancer (Vallerand et al., 2005).

While pain management researchers have made strides in understanding racial disparities in pain management, completely absent from the pain management literature is research evidence regarding disparities in pain management with a focus on contrasting disease conditions such as SCD, cancer, or other pain patient populations in a single study. The source or trajectory of pain may differ by disease condition. Understanding any disparities in pain management between disease groups could provide insights about strategies that were advantageous for optimal pain management.

The aim of this study was to determine whether outpatients with SCD report: (1) more severe sensory pain (location, intensity, quality, and pattern), (2) worse pain relative to their expectation, and (3) greater dissatisfaction with their pain level than outpatients with cancer. A sample of outpatients with SCD, which is predominantly African American, will serve as our referent group. Access to a predominately Caucasian (race discordant) cancer outpatient sample, a predominately African American (race concordant) cancer outpatient sample, and a SCD outpatient sample, along with observations from one prior study, prompted our comparisons of race discordant or race concordant cancer groups to a SCD group. Since African Americans are a known pain disparities group (Bernabei et al., 1998; Green et al., 2003; Meghani et al., 2012; Vallerand et al., 2005), we expected that the cancer-race discordant group would have less pain than the cancer-race concordant group and the SCD group and that the cancer-race concordant and SCD group would have similar pain.

Methods

Design

This study was a comparative secondary analysis study. The Institutional Review Boards of the participating institutions approved this study.

Setting

The primary research studies were conducted in two university-affiliated outpatient oncology clinics in the Northwest and Midwest and one university-affiliated outpatient sickle cell clinic in the Midwest. The Midwest clinics were part of a large minority-serving institution.

Subjects

Subject eligibility and exclusion criteria appear in Table 1. Included in this study were 415 outpatients from 3 studies: (1) 106 patients with SCD, 93% African American (referent group), mean age 34.2 ± 11.2 year, (2) 140 patients with cancer, 90% Caucasian (race discordant), mean age 50.7 ± 12.7 year; and (3) 169 patients with cancer, 20% Caucasian,

65% African American (race concordant), mean age 54.1 ± 13.1 year. The samples differed by age ($p < .001$) with the SCD sample being 20 years younger than either of the cancer samples. Subjects' sociodemographic information is shown in Table 2.

Procedures

Patients were recruited during an outpatient clinic visit. The registered nurses or physicians referred the patients to the study and introduced the patients to the trained researcher. The researcher screened patients for eligibility, explained the study to them, and obtained informed consent. After informed consent, patients completed the study questionnaires using a pentablet computer.

Instruments

1. McGill Pain Questionnaire (MPQ) was part of PAINReport[®], a computerized measure of pain location, intensity, quality, and pattern. Patients:
 - a. marked their pain sites on anterior and posterior views of a body outline drawing;
 - b. reported 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";
 - c. selected from a 78-word list ranked by severity in 20 groups to report their usual pain quality, for example, shooting, burning, cramping, and so forth. Each of the 78 words is scored as selected or not. Calculated from the 20 groups of verbal descriptors, the pain-rating index total (PRI-T) ranges from 0–78. Normative scores for the PRI-T have been reported (Wilkie et al., 1990); and
 - d. chose from 9 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 from 0 to 6, with higher scores representing more complex pain pattern. Construct validity of the pain pattern score is supported by significant differences in pain location, intensity and quality scores by pain pattern (Ngamkham, Holden, & Wilkie, 2011).
2. Pain expectation was measured by PAINReport[®] with a single item that asks the patient to report their current pain level relative to their expectation. The response options were worse than expected, same as expected, and not as bad as expected. The validity of this measure has been reported in both patients with sickle cell disease and cancer (Jha et al., 2010).
3. Satisfaction with pain level was measured by PAINReport[®]. One single-item question asks the patients their satisfaction with their pain level. This question has no qualifiers, such as now, usual, or within 24-hours, but it follows the pain

now, least and worst pain in the past 24 hour items. A three-choice response allows the patient to indicate yes, no, or not sure. This item has been found to be valid in both sickle cell disease and cancer samples (Ezenwa, Molokie, Wang, Suarez, et al., 2016; Golas, Park, & Wilkie, 2016; Jha et al., 2010).

4. Questions regarding demographic characteristics also are included in PAINReport®. Patients reported their age, gender, ethnicity, marital status, level of education, annual family income, prior use of computers, and current access to computers. We collected these data for the purpose of describing sample characteristics.

Statistical Analysis

We analyzed data using R, a free software environment used for statistical analyses and creating graphics (R Core Team, 2014). Descriptive statistics (means, SD, frequencies, percentages) were computed for demographic variables and the pain outcome measures. Chi-square, Fisher's tests and ANOVA were used to compare groups on demographic variables. To compare the three groups on continuous pain measures, we utilized ANOVA. For group comparison of ordinal pain variables (i.e., pain expectation and satisfaction with pain level), we performed, for each outcome measure, likelihood ratio tests of two nested ordinal regression models, one without the group predictor versus one with. Tukey's post hoc test was used for multiple pairwise comparisons if the omnibus tests showed significant difference between study settings.

Results

General Description of Study Variables

The descriptive statistics for the study's demographic variables are reported in Table 2. Table 3 presents descriptive statistics for the pain variables.

Number of Pain Sites

The number of pain sites by study sample appear in Table 3 and Figure 1. The two cancer samples did not differ significantly ($p=.12$) with an average of 2.3 (2.0) sites for (race discordant and 1.9 (1.4) sites for race concordant. The SCD sample reported 3.5 (2.1) sites on average, which was significantly higher than either of the two cancer samples ($p<.001$ for both).

Worst Pain Intensity

The mean scores for the worst pain intensity in the past 24 hours by study sample appear in Table 3 and Figure 2. There was a statistically significant difference between the three samples. The race concordant cancer sample reported a mean worst pain intensity of 6.6 (2.7), significantly higher than either the race discordant cancer sample (mean=5.5, SD=2.0, $p=.002$) or the SCD sample (mean=5.0, SD=3.3, $p<.001$). The difference between the race discordant cancer sample and the SCD sample was not statistically significant.

Pain Quality

The mean pain rating index scores (PRI-T) by study sample appear in Table 3 and Figure 3. The race concordant cancer sample reported PRI-T scores similar to those of the race discordant cancer sample ($p=.92$), with averages of 25.6 (15.5) and 26.2 (12.5), respectively. The average PRI-T score of the SCD sample was 34.5 (17.0), significantly higher than either of the cancer samples ($p<.001$ for both).

Pain Pattern

The mean scores for the pain pattern by study sample appear in Table 3 and Figure 4. The two cancer samples reported similar mean pain patterns scores, 2.5 (1.6) for race discordant and 2.7 (1.9) for race concordant, with $p=.52$. The SCD sample reported significantly higher pain pattern scores, with an average of 3.8 (1.7) and $p<.001$ when compared to either of the cancer samples.

Expectation about Pain

The distribution of responses to the expectations about pain item by study sample appear in Table 3 and Figure 5. The comparison of the three samples shows that the differences among the groups on expectation about pain were marginally significant ($p=.048$). Posthoc comparison shows that the race discordant group reports significantly worst outcome than the SCD sample ($p=.038$). The differences between the race concordant cancer group and the other two groups were not statistically significant.

Satisfaction with Pain Level

The distribution of responses to the satisfaction with pain level item by study sample appear in Table 3 and Figure 6. The comparison of the three samples shows a statistically significant differences among the samples, $p=.008$. The pairwise comparison shows the race concordant cancer group to be more dissatisfied than SCD ($p=.006$), but nonsignificant difference between race discordant and SCD ($p=.13$) or race discordant and race concordant cancer groups ($p=.44$).

Discussion

The results of the first statistical comparison between outpatients with cancer and SCD on sensory pain, pain expectation, and satisfaction with pain level show that compared to the two samples of outpatients with cancer, outpatients with SCD at a regularly scheduled clinic visit reported significantly greater number of pain location sites, higher pain quality, and higher pattern scores. However, outpatients with cancer who are predominantly African Americans reported greater worst pain intensity in the previous 24 hours than the outpatients with cancer who are predominantly Caucasians or outpatients with SCD. Regarding expectation about pain, the SCD sample reported a better outcome than the race discordant sample ($p=.038$). Outpatients with SCD reported greater satisfaction with their pain level than the outpatients with cancer who are predominantly African Americans but did not differ from outpatients with cancer who are predominantly Caucasians on satisfaction with pain level.

Findings from this analysis suggest that race was a potential factor for worst pain in the cancer samples as the race concordant group reported significantly higher pain than the race discordant group. These findings are consistent with the findings within the disparities literature that African Americans with cancer are more likely to report greater pain intensity than Caucasians with cancer (Green et al., 2003; Stephenson, Dalton, Carlson, Youngblood, & Bailey, 2009; Vallerand et al., 2005). Inconsistent with the pain literature is the fact that patients with SCD reported pain intensity lower than that reported by the race concordant cancer sample. Given that both groups are comprised of majority African Americans, one would expect that both groups would report greater worst pain intensity than the race discordant cancer group comprised of predominantly Caucasian patients. Other factors such as the stage of disease or the fact that patients with cancer could have preexisting chronic pain may explain this finding.

Findings also suggest that disease was a potential factor for pain location sites, pain quality, pain pattern, expectation, and satisfaction with pain level, as there was significant difference between the SCD group and one or both of the cancer samples but not between the two cancer groups. These findings underscore the disparities between SCD and cancer as disease types. Traditionally, patients with cancer pain have garnered sympathy for their pain from not only their healthcare providers but from the public. Much of the public support is related to the media campaign mounted by cancer organizations, foundations, and friends and families of cancer survivors about the monstrous nature of cancer pain. As a result, colossal funds have flooded toward the treatment of cancer and pain associated with it. In comparison, patients with SCD have not received such support from their healthcare providers, the public, or the media. The SCD community has not been as effective as the cancer community in mounting media campaigns and successfully recruiting celebrities who can champion their cause about the destructive nature of sickle cell pain. The lack of research funding for SCD pain has slowed the progress related to pain care for these patients. For example, SCD was discovered over 100 years ago but pain researchers are still unraveling the nuances of sickle cell pain including its neuropathic component, which was discovered using both sickle cell knock-out mice (He et al., 2016) and in humans using the quantitative sensory testing (Campbell et al., 2016; Ezenwa, Molokie, Wang, Yao, et al., 2016). These emerging findings may require a paradigm shift in pain management of sickle cell pain as was possible in cancer pain management but they need to be confirmed as more research findings become available.

Although the SCD group reported larger number of pain sites, pain quality scores, and pain pattern scores than both cancer groups, the SCD group was more satisfied with the pain level than the race concordant cancer groups. The finding regarding satisfaction is not surprising because the SCD group over their lifetime had likely experienced more intense pain during *sickle cell crisis* than they reported during the outpatient visit.

The finding that the SCD group was more likely to report pain not as bad as expected than the race discordant group suggests that the SCD group would expect more severe pain as their condition changed. For patients with SCD, the findings regarding their expectation of pain may relate to the more intense crisis pain the patients with SCD had experienced throughout their lives. At a routine outpatient clinic visit, patients may expect their pain to

be less than their crisis pain, which is usually managed at an acute care center, emergency department, or inpatient unit (Benjamin, Swinson, & Nagel, 2000; Wilkie, Johnson, Mack, Labotka, & Molokie, 2010).

If institutional expertise in caring for minority patients was instrumental for better pain care as we speculated, one would expect that outpatients with cancer who are predominantly African Americans would also report less pain intensity, as did outpatients with SCD since both groups were cared for in the same minority serving institution. Our findings suggest the contrary. Instead, the outpatients with cancer who are predominantly African Americans reported higher worst pain intensity than outpatients with cancer who are predominantly Caucasians and the outpatients with SCD. Two factors could be at play. First, cancer is known to be a disease of old age (White et al., 2014). It is plausible that patients with cancer who are predominantly African Americans diagnosed with cancer at older age may not have similar level of relationship, as did outpatients with SCD usually diagnosed at birth, necessary to form bonds and mutual trust that foster improved pain care as we saw in the case of outpatients with SCD (Molokie et al., in press 2017). Second, it is possible that our findings support the current research evidence on the existence of historical and contemporary racial disparities in pain treatment of patients with cancer (Bernabei et al., 1998; Ezenwa et al., 2006). Researchers could decipher our assertions in future studies of direct comparison between patients with SCD or cancer from the same minority serving institution in the same study.

It is worth noting that all patient groups, race discordant, race concordant, and SCD, were able to provide pain scores using a valid pain measure, *PAINReport*, a computerized version of McGill Pain Questionnaire. Patients' ability to reliably self-report their pain will help mitigate decades of racial disparities in pain assessment and its management where African Americans fare worse, especially when healthcare providers were in charge of reporting pain of minority patients. For example, evidence from a systematic review shows that providers are more likely to underreport pain of minority patients and are also more likely not to document the pain of minority patients compared to Whites (Cintron & Morrison, 2006). That the African Americans in this study easily used the computerized pain measure is contrary to popular belief that the digital divide would likely prevent them from using the technology. The Pew report shows that the likelihood of African Americans and Hispanics to own smart phones and to use the smart phones to access their health information on the internet is higher than that of their Caucasian counterparts (Fox & Duggan, 2012). Further, the African Americans who own cell phones are more likely than Caucasians to utilize their cell phones for the purpose of tracking their health outcomes via text messages and downloaded applications (Fox & Duggan, 2012). To extrapolate this finding to patients with SCD who are mostly African Americans, it's very probable that the use of modern technology will be extremely instrumental in assessing and subsequently managing sickle cell pain as has been supported by our research (Ezenwa, Yao, Engeland, et al., 2016; Jha et al., 2010) and that of others (McClellan et al., 2009; Shah, Jonassaint, & De Castro, 2014). Perhaps, part of the effort in modeling SCD pain treatment protocol after that of cancer would include leveraging computer technology to track patients' pain and encouraging patients to promptly manage pain at its onset and to visit a Day Hospital or

Acute Care Center before the pain becomes unbearable and difficult to manage at home (Molokie et al., in press 2017).

Despite our novel and interesting findings, some limitations detracted from the findings. All three samples were convenient samples, and it is unclear how representative they are of the patients served in the three settings within the two geographically distant institutions. The analyses reported here do not take into consideration analgesics or other factors such as stage of disease or preexisting chronic pain in patients with cancer that could have influenced the reported pain. Finally, there are other types of disparities such as age and gender disparities, which may be operating within the three samples. We did not focus on age and gender disparities in pain management because they were outside the scope of the current study but we will evaluate them in future research.

Our study findings have both research and practice implications. With respect to research, clearly, number of pain location sites, pain quality, and pattern are important sensory pain parameters that contribute to pain experience for patients with SCD. Pain researchers ought to evaluate these pain components in other pain patient populations including cancer patients in order to have a comprehensive understanding of pain experience other than pain intensity as is the status quo. Regarding practice implications for our findings, the fact that cancer patients who are predominantly African American reported worst pain intensity that is greater than their counterparts who are predominantly Caucasians indicate that racial disparities in pain management is still a major issue in the United States. Educational interventions for healthcare providers that focus on empathy and human dignity could incentivize them to assess correctly and optimally treat pain in minority patients without bias in order to ameliorate racial disparities in pain management.

Conclusions

In conclusion, we found that outpatients with SCD reported a greater number of pain location sites and higher pain quality and pattern scores than outpatients with cancer but reported less worst pain intensity in the previous 24 hours than race-concordant patients with cancer. Outpatients with SCD also reported that they were less dissatisfied with their pain level at the time of a clinic visit than race-concordant patients with cancer. These findings may relate to the more intense and recurrent crisis pain that the patients with SCD had experienced throughout their lives. Although SCD crisis pain is known to be severe, our findings are suggestive that outpatients with SCD also report pain that is moderate to severe. In outpatients with SCD, three of the four pain parameters were greater than those reported by cancer outpatients, including a predominately African American sample of patients with cancer. These findings will be helpful for planning future research of appropriate pain treatment protocols for different pain populations.

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Mean Number Pain Sites

Figure 1.

Comparison of study samples on number of pain sites $F(2,411) = 26.0, p < 0.001$.

CaC = Caucasian patients with cancer (race discordant); CAAA = African American patients with cancer (race concordant; SCD = sickle cell disease (race referent).

Figure 2.

Comparison of study samples on worst pain intensity. $F(2,411) = 12.8, p < 0.001$

CaC = Caucasian patients with cancer (race discordant); CaAA = African American patients with cancer (race concordant); SCD = sickle cell disease (race referent).

Figure 3.

Comparison of study samples on pain quality. $F(2,412) = 13.1, p < .001$

CaC = Caucasian patients with cancer (race discordant); CaAA = African American patients with cancer (race concordant; SCD = sickle cell disease (race referent).

Mean Pain Pattern Score

Figure 4.

Comparison of study samples on pain pattern. $F(2,411) = 19.3, p < .001$

CaC = Caucasian patients with cancer (race discordant); CaAA = African American patients with cancer (race concordant; SCD = sickle cell disease (race referent).

Figure 5.

Comparison of study samples on expectation about pain (N=415)

CaC = Caucasian patients with cancer (race discordant); CaAA = African American patients with cancer (race concordant); SCD = sickle cell disease (race referent).

Figure 6.

Comparison of study samples on satisfaction with pain level (N=415)

CaC = Caucasian patients with cancer (race discordant); CAAA = African American patients with cancer (race concordant; SCD = sickle cell disease (race referent).

Table 1**Study Features, Sample Eligibility and Exclusion Criteria**

Study name (N)	Study Cancer (race discordant, n = 140)	Study Cancer (race concordant, n = 169)	Study SCD (referent, n = 106)
Funding source	1R01CA81918	2R01CA81918	R01HL078536
Data collection dates	1999–2002	2003–2010	2003–2013
Study site and setting	Seattle, WA outpatient oncology	Chicago, IL outpatient oncology	Chicago, IL outpatient adult sickle cell clinic
Study design	4-week RCT, pre- and post-test measurements	4-week RCT, pre- and post-test measurements	3-mo RCT pre- and post-test measurements
Sample eligibility criteria	Cancer, pain or fatigue in past week, spoke/read English, ≥ 18 years of age *	Cancer, reported pain level ≥ 3/10 in past week, spoke/read English, age ≥ 18 years	SCD, pain ≥ 3/10 in past 12 months; SCD-related ED visit or hospitalization in past two years; speak/read English, age ≥ 18 years
Sample exclusion criteria	Surgery < two months, physically or mentally unable to complete procedures	Surgery < two months, physically or mentally unable to complete procedures	Legally blind and/or physically unable to complete procedures

Note. Race concordant = African American patients with cancer; Race discordant = Caucasian patients with cancer, ED = emergency department; RCT = randomized controlled Trial; SCD = sickle cell disease (race referent).

* Selected all patients with pain of ≥ 3/10 to make the pain eligibility for this sample comparable to the other two samples (race concordant and SCD).

Table 2**Subjects' Sociodemographic Variables by Study Samples**

Variable	Category	Race discordant (N=140)	Race concordant (N=169)	SCD (N=106)	P
Sex	Male	52 (37%)	75 (44%)	38 (36%)	.275
	Female	88 (63%)	94 (56%)	68 (64%)	
Education	Up to high school	42 (30%)	75 (44%)	38 (36%)	<.001
	Some college or more	86 (61%)	57 (34%)	64 (60%)	
	Unknown	12 (9%)	37 (22%)	4 (4%)	
Race/Ethnicity	White	126 (90%)	33 (20%)	1 (1%)	<.001
	African American	4 (3%)	110 (65%)	99 (93%)	
	Hispanic	1 (1%)	19 (11%)	5 (5%)	
	Other/Unknown	9 (6%)	7 (4%)	1 (1%)	
Age	40+	117 (84%)	135 (80%)	35 (33%)	<.001
	<40	23 (16%)	21 (12%)	71 (67%)	
	Unknown	0 (0%)	13 (8%)	0 (0%)	
	Mean (SD)	50.7 (12.7)	54.1 (13.1)	34.2 (11.2)	

Note. Race concordant = African American patients with cancer; Race discordant = Caucasian patients with cancer, ED = emergency department; RCT = randomized controlled trial; SCD = sickle cell disease (race referent).

Table 3

Study Pain Variables Categorized by Study Samples

Variable	Race discordant (N=140) Mean (SD)	Race concordant (N=169) Mean (SD)	SCD (N=106) Mean (SD)	P
Number of pain sites	2.3 (2.0)	1.9 (1.4)	3.5 (2.1)	<.001
Pain quality	26.2 (12.5)	25.6 (15.5)	34.5 (17.0)	<.001
Pain pattern	2.5 (1.6)	2.7 (1.9)	3.8 (1.7)	<.001
Pain now	3.5 (2.2)	4.9 (3.0)	3.5 (3.2)	<.001
Least pain in last 24 hours	2.8 (2.1)	3.7 (2.8)	3.2 (2.8)	.017
Worst pain in last 24 hours	5.5 (2.0)	6.6 (2.7)	5.0 (3.3)	<.001
	%	%	%	
Pain expectation				.049
Worse than expected	10%	20%	8%	
Same as expected	66%	40%	51%	
Not as bad as expected	24%	40%	41%	
Satisfaction with pain level				.008
No	49%	58%	40%	
Not sure	16%	11%	10%	
Yes	35%	32%	50%	

Race concordant = African American patients with cancer; Race discordant = Caucasian patients with cancer; SCD = sickle cell disease (race referent); SD = standard deviation.