Original Article

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

Miriam O. Ezenwa, PhD, RN, [*] *Robert E. Molokie, MD,* [†,‡] *Zaijie Jim Wang, PhD,* [ʃ] *Yingwei Yao, PhD,* [*] *Marie L. Suarez, PhD,* [¶] *Brenda Dyal, DNP, FNP-BC,* [*] *Khulud Abudawood, MSN, RN,* [*] *and Diana J. Wilkie, PhD, RN, FAAN* [*]

*From the *Department of Biobehavioral Nursing Science, College of Nursing, University of Florida, Gainesville, Florida; †College of Medicine, College of Pharmacy, and Comprehensive Sickle Cell Center, University of Illinois, Chicago, Illinois; ‡Jesse Brown VA Medical Center, Chicago, Illinois; ʃDepartment of Biopharmaceutical Sciences, Cancer Center and Comprehensive Sickle Cell Center, University of Illinois, Chicago, Illinois; ¶Department of Biobehavioral Health Science (MC 802), University of Illinois at Chicago, College of Nursing, Chicago, Illinois.*

Address correspondence to Diana J. Wilkie, PhD, RN, FAAN, Department of Biobehavioral Nursing Science, College of Nursing, University of Florida, 1225 Center Drive, Room 2203, Gainesville, FL 32610. E-mail: diwilkie@ufl.edu

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Abstract:

Patients with sickle cell disease (SCD) report pain scores that appear greater than those reported in a meta-analysis for patients with cancer, but statistical comparisons of the pain scores from both populations have not been published. The goal of the study described here was to compare pain outcomes reported by outpatients with cancer or SCD.

Descriptive comparative study. Outpatient oncology or sickle cell clinics. The participants were outpatients (N = 415) from three 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). Patients completed the PAIN*Report*It including pain location, quality, pattern, intensity, expectation, satisfaction, and demographic questions. Analyses included the χ^2 test, analysis of variance, and regression. 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. The race-concordant group reported higher worst pain intensity than the SCD ($p < .001$) and race-discordant ($p = .002$) groups. The three groups did not differ significantly on pain expectation ($p = .06$). Regarding satisfaction with pain level, there was a significant difference between the race-concordant and SCD ($p = .006$) groups, but not between the race-discordant and SCD ($p = .12$) groups or between the race-discordant and race-concordant ($p = .49$) groups. Outpatients with SCD reported three 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.

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Outpatients with sickle cell disease (SCD) (Wilkie et al., 2010b) obtained 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 those with 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 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 and those with 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.

Sickle cell disease is an inherited blood disorder affecting about 100,000 Americans, mostly of African descent (National Institutes of Health, National Heart, Lung and Blood Institute, 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 and 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 toward patients with SCD (Labbe, Herbert, & Haynes, 2005), discrimination (Haywood et al., 2014), stigma (Bediako et al., 2014), and health care injustice that patients with SCD report encountering in their pursuit for adequate pain control (Ezenwa, Molokie, Suarez, Yao, & Wilkie, 2015; Ezenwa et al., 2017; 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 pain treatment protocols similar to 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 intravenous and oral controlled-release morphine as opposed to intramuscular meperidine and short-acting oral opioid analgesics. The authors observed a significant reduction in ED visits (67%), number of admissions (44%), total inpatient days (57%), and length of hospital stay (23%) after implementation of the morphine protocol (Brookoff & Polomano, 1992). Lower acute health care utilization in these patients remained at lower levels 1 year after the study (Brookoff & Polomano, 1992). Despite these positive findings, SCD experts contended that SCD pain is different from 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 pain 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 article, we focus on disparities in pain management caused by race and disease. A series of three studies conducted by Todd et al. (1993, 1994, 2000) in emergency departments revealed the suboptimal pain treatment that racial minority patients with isolated long bone fractures received compared with their Caucasian counterparts (Todd, Samaroo, & Hoffman, 1993; Todd, Lee, & Hoffman, 1994; Todd, Deaton, D'Adamo, & Goe, 2000). The pervasiveness of racial

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