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Coping with Pain in the Face of Healthcare Injustice in Patients with Sickle Cell Disease

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Abstract

To evaluate the pain coping strategies of patients with sickle cell disease (SCD) who experience healthcare injustice from either physicians or nurses during medical visits for pain management. It is unknown how patients' coping with pain relates to their experiences of healthcare injustice from physicians or nurses. This descriptive comparative study included adult outpatients with SCD who completed the *PAINReportIt*®, Healthcare Justice Questionnaire®, and Coping Strategies Questionnaire-SCD. Data were analyzed using independent *t* tests. Frequent coping strategies of patients who experienced *healthcare justice* from physicians were praying-hoping and from nurses were praying-hoping, calming self-statements, diverting attention, and increasing behavioral activity. In contrast, frequent coping strategies of patients who experienced *healthcare injustice* from physicians were catastrophizing and isolation and from nurses were isolation. Patients who experienced *healthcare justice* used different sets of pain coping strategies than those who experienced *healthcare injustice* during medical visits for pain management.

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Compliance with Ethical Standards

Conflict of interest We have no potential conflicts of interest with respect to the research, authorship, and/or publication of this article interest except Drs. Molokie and Wilkie received a grant from Pfizer for an unrelated study and Dr. Wilkie is Chairman and Founder of eNURSING llc.

Ethical Approval The Institutional Review Board of an urban public university in Illinois approved the study prior to commencement. Each patient signed a written informed consent form. The study complied with ethical standards regarding research involving human subjects.

Research Involving Human Participants and/or Animals "This article does not contain any studies with animals performed by any of the authors." This article involves studies conducted with human participants. As stated above, the research protocol was approved by the Institutional Review Board of an urban public university in Illinois.

Informed Consent "Informed consent was obtained from all individual participants included in the study."

Keywords

Sickle cell disease; Healthcare injustice; Pain coping strategies; Model of perceived unfairness

Introduction

Healthcare injustice, defined as the perception of unfairness of the treatment that one experiences from healthcare providers considered important in their care [1], is associated with adverse psychological and physiological consequences in patients with sickle cell disease (SCD) [1]. Yet, little is known about the pain coping strategies of patients with SCD who report that they experience healthcare injustice when they seek help for pain management. Pain is a major complication of SCD and the most common reason patients are admitted to the hospital [2–4]. In 2005 and 2006 [2], patients with SCD visited the emergency department 109,344 times to receive treatment for pain. The annual healthcare cost for patients with SCD is \$2.4 billion [5]. A recent study found that 40 % of patients with SCD were readmitted within 30 days of discharge [2], likely indicating that their pain was inadequately treated during the initial visit. The frequent use of acute healthcare services by patients with SCD [2, 3], combined with the negative attitude of healthcare providers towards patients' chronic use of opioids for pain control [6–8], provide myriad opportunities for patients with SCD to experience healthcare injustice during medical visits.

Recent research supports this assertion and shows that patients with SCD experience healthcare injustice from both physicians and nurses during medical visits for pain management [9]. However, to date, there are lack of studies that explain how patients' coping with pain relates to their experiences of healthcare injustice, which may increase their stress and pain [1]. Thus, the purpose of this study was to evaluate the pain coping strategies of patients with SCD who experience healthcare injustice when they seek help for pain management.

Background

Pain Coping Strategies in Patients with Sickle Cell Disease—Coping is defined as strategies that people use to moderate the harmful effects of life stressors on their psychological well-being [10] or on their physical health [11]. Research evidence suggests that patients with SCD use a variety of strategies to cope with SCD pain [11, 12], including praying-hoping, resting, taking fluids, and isolation, and less frequently reinterpreting or ignoring pain sensations. Collectively, these findings indicate that SCD patients may cope with pain using different strategies. There are no research evidence on the pain coping strategies of patients with SCD who reported experiencing healthcare injustice in the management of their pain. The experience of healthcare injustice might resurrect memories of past perceived unfair treatments, and could influence their behavior [13].

Understanding the pain coping strategies of patients with SCD who experience healthcare injustice is pertinent for at least two reasons. First, in the US, the majority of patients with SCD are of African descent, a group that experiences a disproportionate share of social, economic, and healthcare inequalities because of overt/covert institutionalized racism [14].

Second, because SCD is a condition that requires continual pain management, many healthcare professionals may inappropriately label patients with SCD as “drug seekers” or “drug addicts” [9] and as a result, fail to optimally manage their pain. In this study, we aim to provide insight on this topic by examining the potential associations between healthcare injustice and types of pain coping strategies used by patients with SCD.

Theoretical/Conceptual Framework

This research was guided by the model of perceived unfairness (MPU). The MPU postulates that the perception of unfairness (e.g., healthcare injustice, a psychological stressor) initiates stress responses, which may subsequently affect health outcomes adversely [15], or increase certain behaviors, such as avoidance [16] and social isolation [13, 17]. Therefore, we evaluated the pain coping strategies of patients with SCD who experienced healthcare injustice from physicians or nurses to ascertain the pain coping strategies they endorsed.

Methods

Design

This study was a cross-sectional comparative study. We recruited patients from a university-affiliated, minority-serving, outpatient Comprehensive Sickle Cell Clinic located in Illinois.

Participants

Our sample included 52 outpatient adults with SCD. Inclusion criteria were: (a) diagnosis of SCD; (b) use of opioids for pain crisis; (c) ability to speak and read English; and (d) age 18 years or older. Exclusion criteria were: (a) legally blind or (b) physically unable to complete study questionnaires. The sample's mean age was 34 ± 11 years (ranged from 20–70 years). The majority were African-Americans ($n = 48$, 92 %) and female ($n = 41$, 79 %). Forty-eight patients (92 %) completed high school or higher education. Other details about patients' socio-demographic information are presented in Table 1.

Data Collection

Procedures—Patients who attended their scheduled clinic visits and the final data collection point for a longitudinal study completed the PAINReportIt® tool [18, 19], a computerized version of the McGill Pain Questionnaire (MPQ) [20]. Patients were also invited to complete three additional paper-based questionnaires regarding their pain treatment. All eligible patients expressed interest in completing the additional questionnaires and provided informed consent prior to study participation. Patients who did not attend their scheduled clinic visits, but who were admitted to the hospital for pain treatment, were also approached to determine their interest in completing the three additional questionnaires. The 52 patients in this pilot study completed the questionnaires at the following locations: (1) Sickle Cell Clinic ($n = 39$, 75 %); (2) inpatient units just prior to discharge from hospitalization related to vaso-occlusive crisis ($n = 9$, 17 %); and (3) home (patients took the questionnaires home for completion and returned them via mail or in-person at the next clinic visit, which was a week later; $n = 4$, 8 %).

Measures

Healthcare Justice Questionnaire: The Healthcare Justice Questionnaire[®] (HJQ), adapted from organizational justice questionnaire [21], is a 20-item scale that measures unfairness in healthcare treatment in four domains: procedural justice; distributive justice; interpersonal justice; and informational justice [1, 9]. Because of our previous adaptive work and the context specificity of healthcare justice, two versions of the HJQ were created: one for interactions with physicians and another for interactions with nurses. The two versions differed only by context because physicians and nurses play different roles in pain management for patients with SCD. Patients completed both versions. Response options were 1 (*to a small extent*) to 5 (*to a large extent*). The HJQ ratings were scored separately for physicians and nurses. An overall healthcare justice score was calculated via a mean of the 20 items for each version. Lower scores on HJQ signify *healthcare injustice* while higher scores signify *healthcare justice*. The Cronbach's reliability alphas of HJQ ranged from 0.85 to 0.93 [1].

Coping Strategies Questionnaire-Sickle Cell Disease (CSQ-SCD): The CSQ-SCD is an 80-item questionnaire that measures the various ways patients with SCD cope with pain [11]. The first part of the CSQ-SCD has three major categories that contain 13 subscales; there are 6 items in each scale for a total of 78 items measured on a 7-point Likert scale (ranges 0–6): 8 cognitive subscales (Diverting Attention, Reinterpreting Pain Sensations, Calming Self-Statements, Ignoring Pain Sensations, Praying-Hoping, Catastrophizing, Fear Self-Statements, and Anger Self-Statements); 2 behavioral sub-scales (Increasing Behavioral Activity and Isolation); and 3 physiological subscales (Taking Fluids, Resting, and Heat/Cold Massage). Response options were 0 (*never do that*) to 6 (*always do that*). Patients' responses indicated how often they used each pain coping strategy when they had pain. An overall pain coping strategies score for each subscale was computed by taking the mean of respective subscale items. Higher scores indicated higher frequency of use of pain coping strategies. In addition, the CSQ-SCD had one effectiveness ratings category with two 1-item subscales (ranging from 0–6). The first subscale, control over pain (1-item subscale), asked patients how much control they had over pain on an average day, with response choices being 0 (*no control*) to 6 (*complete control*). The second subscale, ability to decrease pain (1-item subscale), asked patients how much they were able to decrease pain on an average day. Response options were 0 (*can't decrease it at all*) to 6 (*can decrease it completely*). Higher scores on effectiveness ratings subscales indicated good sickle cell pain control. The CSQ-SCD 13 subscales have demonstrated good reliabilities that ranged from $\alpha = 0.69$ to 0.91 [11]. In this sample, the alpha reliabilities ranged from 0.54 to 0.89.

Socio-demographic Characteristics: Socio-demographic data including age, gender, race/ethnicity, marital status, level of education, and annual family income were collected using PAINReport[®] [18, 19]. These data were collected for the purpose of describing the sample characteristics.

Analysis

Healthcare justice and *healthcare injustice* groups were created using a median score of 3.5 as a cut-off. Patients who scored below 3.5 formed the *healthcare injustice* group while

patients who scored above 3.5 comprised the *healthcare justice* group. Descriptive statistics such as means, standard deviations, frequencies, and percentages, were computed. Data were analyzed using independent *t* tests. Statistical significance was set at an alpha of 0.05.

Ethical Review

The Institutional Review Board of an urban public university in Illinois approved the study prior to commencement. Each patient signed a written informed consent form.

Results

Descriptive Statistics of Study Variables

The HJQ-physicians total score ranged from 1 to 5, and the mean (SD) was 3.68 (.79). The HJQ-nurses total score ranged from 1 to 5 and the mean (SD) was 3.52 (.86). Table 2 presents the mean (SD) and Cronbach's alphas of the 13 CSQ-SCD subscales, as well as the mean (SD) of the effectiveness ratings.

Comparison of Justice and Injustice Groups on Pain Coping Strategies

As shown in Table 3, our comparative analysis results showed that patients who reported *healthcare justice* from physicians trended toward using heat/cold massage and used praying-hoping significantly more frequently than patients who reported *healthcare injustice* from physicians, who often used catastrophizing and isolation, and trended toward using fear self-statement and anger self-statement to cope with pain. The *healthcare justice* and *healthcare injustice* groups did not differ significantly on effectiveness ratings for control over pain and ability to decrease pain.

The results of our comparative analysis for the HJQ-nurses are presented in Table 3. Results show that patients who reported *healthcare justice* from nurses were significantly more likely to use praying-hoping, diverting attention, calming self-statements, and increasing behavioral activity; and trended toward using ignoring pain sensations than patients who reported *healthcare injustice* from nurses, who were more likely to use isolation, and trended toward using catastrophizing and fear self-statement. For the effectiveness ratings, patients who reported *healthcare justice* from nurses were more likely to report that they could control ($p = .038$) and a trend to decrease ($p = .093$) their pain than patients who experienced *healthcare injustice* from nurses.

Discussion

To our knowledge, we are the first to reveal significant differences in pain coping strategies used by patients with SCD who experienced either *healthcare justice* or *health-care injustice* from physicians or nurses. Compared to patients who experienced *healthcare justice* from physicians or nurses, patients who reported *healthcare injustice* from physicians or nurses used pain coping strategies that have been associated with negative health outcomes [17, 22–25].

Our findings suggest that patients with SCD who reported either *healthcare justice* or *healthcare injustice* endorsed different sets of pain coping strategies. Patients reporting

healthcare justice from physicians used praying-hoping while patients reporting *healthcare justice* from nurses used praying-hoping, diverting attention, calming self-statements, and increasing behavioral activity significantly more than patients reporting *healthcare injustice* from the respective provider groups. These pain coping strategies have been associated with positive pain outcomes. For instance, praying-hoping was related to decreased pain intensity in patients with chronic low back pain [26]. In a sample of patients with SCD, previous investigators who did not measure healthcare injustice, found that patients with SCD used praying-hoping strategy [11, 12]. Praying-hoping could be a culturally-endorsed pain coping strategy for patients with SCD, majority of whom are African Americans. Historically, African Americans cope with stress-evoking situations and circumstances using religion- or spiritual-centered coping strategies [27, 28].

Further, diverting attention, calming self-statements, and increasing behavioral activity could be promoted for many patients with SCD because these strategies have also been linked to positive pain outcomes. Diverting attention was associated with reduced current pain intensity in adult orthopedic patients who had total hip or knee arthroplasty [29]. In male children and adolescents with SCD, increased behavioral distraction was related to decreased worst pain intensity [30]. Other researchers reported that African Americans students compared to Caucasians students most frequently used diverting attention, coping self-statements, and increasing behavioral activity to cope with episodic pain [31], suggesting their potential relevance as pain coping strategies for patients with SCD.

We also found that patients reporting *healthcare injustice* from physicians used catastrophizing and isolation while patients reporting *healthcare injustice* from nurses used isolation significantly more than those reporting *healthcare justice* from physicians or nurses. In patients with cancer, catastrophizing was related to increased pain levels and psychological distress [22–25]. Low endorsement of catastrophizing was significantly related to reduced pain intensity, psychosocial, and physical impairments in patients with low back pain [26]. The reason that patients in the *healthcare injustice* group endorse catastrophizing pain coping strategy than patients reporting *healthcare justice* is unclear. But, catastrophizing has been associated with perceived injustice in a Canadian sample of patients with whiplash injury [32]. It is possible that patients with SCD who reported healthcare injustice may use catastrophizing to cope with pain as a consequence of historically-entrenched learned behavior for coping with systemic stressors [27, 28]. In a healthy sample of college students, investigators found that African American students frequently used catastrophizing to cope with pain [31]. Literature review evidence regarding the adverse mental and physical health consequences of perception of injustice suggested that perceived injustice and catastrophizing may share emotional distress as the pathway by which they negatively affect pain outcomes [33]. Untangling the relationship between healthcare injustice and catastrophizing will be useful for dissuading patients with SCD who experience healthcare injustice from endorsing it as a pain coping strategy.

Isolation was another pain coping strategy that patients with SCD who experienced *healthcare injustice* significantly endorsed than those who reported experiencing *healthcare justice*. Other investigators who did not measure healthcare injustice found that patients with SCD used isolation as a pain coping strategy [11, 12]. We cannot compare current findings

with that of others due to the differences in the study measures. But, we wondered whether patients who report experiencing healthcare injustice from physicians or nurses coped using isolation to avoid, as much as possible, the emotional distress associated with such experience. The theory of self-preservation, which postulates that reasonable individuals would avoid circumstances that may threaten their health and well-being, supports this notion [34]. Further, research in an animal model shows that chronically-stressed adult mice had demethylation in their hypothalamic gene that codes for corticotrophin releasing factor, which predicted stress-induced social isolation [17]. While no such study has been reported in patients with SCD, future studies should consider evaluating perceived healthcare injustice as a potential epigenetically-based factor prompting lasting modification in gene expressions that are linked to behavioral changes such as coping in isolation [13].

Further, we found that *healthcare justice* or *healthcare injustice* physician or nurses groups were equally as likely to use resting and taking fluids. These strategies are promoted for patients with SCD to mitigate vaso-occlusive pain crisis [12]. The *healthcare justice* or *healthcare injustice* physician or nurses groups did not differ significantly on using heat/cold massage. Evidence about heat/cold massage as a non-drug pain coping strategy is conflicting because patients with SCD use this strategy [35, 36] despite the fact that extreme heat or cold temperatures have been associated with vaso-occlusive pain crisis [37, 38]. It is unclear from available evidence what effective role of heat/cold massage is among patients with SCD and additional study is warranted.

Research efforts to address the coping strategies of patients with SCD who report experiencing healthcare either justice or injustice in their pain control ought to evaluate their coping styles. One coping style to consider is repression. Repressive coping style is defined as an individual's propensity to constrain the experience and the expression of negative feelings or unpleasant cognitions in order to avert one's positive self-image from being threatened [39]. Evidence suggests that repressive coping style are particularly associated with endorsement of specific pain coping strategies. In order to reduce the emotional effects of a threatening stimulus, persons endorsing repressive coping style have tendencies to rely on two particular strategies: (1) they intentionally do not pay attention to it [40, 41]; and (2) they engage in active behavioral or cognitive activities to evoke a positive mood or divert attention from a negative mood [42]. It appears that SCD patients who reported experiencing *healthcare justice* used repressive coping style by endorsing praying-hoping, diverting attention, calming self-statements, and increasing behavioral activity compared to patients who reported *healthcare injustice*. As shown in cancer patients, those patients who used a repressive coping style reported significantly lower scores on catastrophizing than patients who did not use repressive coping style [43]. Patients with cancer endorsing repressive coping style were significantly more likely to also report lower scores on MPQ such as decreased levels of current pain quality on the sensory component of MPQ, affective component, and total MPQ scores than patients not endorsing repressive coping style [43]. Understanding patients' coping style increases the likelihood of developing future patient-centered interventions that coach patients on how to cope with pain even in the face of healthcare injustice experience.

Limitations

Due to the exploratory nature of the study, we could not ascertain the mechanism through which healthcare injustice influenced pain coping strategies in patients with SCD. In addition, we could not assert that the experience of healthcare injustice caused patients to prefer certain pain coping strategies. We will address these limitations in a future qualitative or mixed-methods study.

Conclusion

We found that patients with SCD who perceive *healthcare justice* from physicians or nurses use different pain coping strategies than patients who perceive *healthcare injustice* from physicians or nurses. Future prospective findings could inform interventions that reduce healthcare injustice and encourage patients with SCD to use pain coping strategies that are associated with positive health outcomes.

New Contribution to the Literature

We are the first to report on the significant differences in pain coping strategies used by patients with SCD who reported experiencing either *healthcare justice* or *health-care injustice* from physicians or nurses. These novel findings provide preliminary evidence for future studies on this topic.

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Table 1

Socio-demographic characteristics of patients (N = 52)

Variable	Number (%)
Race/ethnicity	
African American	48 (92)
Hispanic	1 (2)
Other	3 (6)
Gender	
Female	41 (79)
Male	11 (21)
Age group	
18–25	13 (25)
26–45	31 (60)
46	8 (15)
Education	
High school	48 (92)
Unknown	4 (8)
Sickle cell genotype	
SS	42 (81)
SC	6 (12)
Other	4 (8)

SS = hemoglobin SS, SC = hemoglobin SC

Table 2Descriptive statistics for the Coping Strategies Questionnaire-Sickle Cell Disease ($N = 52$)

Major scale categories	Subscales	Mean (SD)	Cronbach's alpha
Cognitive strategies	Diverting attention	2.9 (1.7)	0.85
	Reinterpreting pain sensations	1.4 (1.5)	0.84
	Calming self-statements	3.9 (1.6)	0.86
	Ignoring pain sensations	2.2 (1.5)	0.81
	Praying and hoping	4.3 (0.9)	0.54
	Catastrophizing	2.9 (1.5)	0.80
	Fear self-statements	3.2 (1.5)	0.81
	Anger self-statements	3.0 (1.2)	0.68
Behavioral strategies	Increasing behavioral activity	2.9 (1.4)	0.74
	Isolation	3.2 (1.7)	0.89
Physiological strategies	Taking fluids	4.3 (1.5)	0.86
	Resting	4.5 (1.0)	0.70
	Heat/cold massage	3.8 (1.2)	0.62
Effectiveness ratings	Control over pain	3.8 (1.2)	–
	Ability to decrease pain	3.5 (1.1)	–

Table 3Comparison of justice and injustice groups on pain coping strategies ($N = 52$)

	Coping strategies	Injustice (Doctor, <3.5)	Justice (Doctor, 3.5)	<i>p</i>
Cognitive strategies	Diverting attention	2.7 (1.7)	2.9 (1.7)	.655
	Reinterpreting pain sensations	1.6 (1.5)	1.3 (1.4)	.452
	Calming self-statements	3.7 (1.6)	4.1 (1.6)	.351
	Ignoring pain sensations	2.5 (1.5)	2.1 (1.5)	.381
	Praying and hoping	4.0 (0.9)	4.5 (0.9)	.046
	Catastrophizing	3.5 (1.1)	2.5 (1.5)	.016
	Fear self-statements	3.7 (1.4)	2.9 (1.6)	.073
	Anger self-statements	3.4 (1.0)	2.7 (1.3)	.053
Behavioral strategies	Increasing behavioral activities	2.6 (1.2)	3.1 (1.4)	.275
	Isolation	3.9 (1.5)	2.8 (1.8)	.028
Physiological strategies	Taking fluids	4.0 (1.4)	4.4 (1.6)	.317
	Resting	4.3 (1.0)	4.6 (1.0)	.317
	Heat/cold massage	3.4 (1.2)	4.0 (1.1)	.069
Effectiveness ratings	Control over pain	3.8 (1.2)	3.8 (1.2)	.851
	Ability to decrease pain	3.3 (1.3)	3.6 (0.9)	.317
	Coping subscale	Injustice (Nurse, <3.5)	Justice (Nurse, 3.5)	<i>p</i>
Cognitive strategies	Diverting attention	2.2 (1.8)	3.4 (1.4)	.014
	Reinterpreting pain sensations	1.1 (1.5)	1.6 (1.4)	.242
	Calming self-statements	3.3 (1.6)	4.5 (1.4)	.005
	Ignoring pain sensations	1.8 (1.6)	2.5 (1.3)	.095
	Praying and hoping	3.9 (1.0)	4.7 (0.7)	.001
	Catastrophizing	3.2 (1.5)	2.6 (1.4)	.093
	Fear self-statements	3.7 (1.5)	2.9 (1.5)	.059
	Anger self-statements	3.3 (1.0)	2.7 (1.4)	.132
Behavioral strategies	Increasing behavioral activity	2.4 (1.4)	3.3 (1.3)	.028
	Isolation	3.8 (1.6)	2.7 (1.7)	.028
Physiological strategies	Taking fluids	4.0 (1.5)	4.5 (1.5)	.272
	Resting	4.5 (1.0)	4.5 (1.0)	.826
	Heat/cold massage	3.5 (1.0)	4.0 (1.3)	.168
Effectiveness ratings	Control over pain	3.4 (1.3)	4.1 (1.0)	.038
	Ability to decrease pain	3.2 (1.2)	3.7 (1.0)	.093