

2014

# How Patients' Self-Disclosure about Sickle Cell Pain Episodes to Significant Others Relates to Living with Sickle Cell Disease

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## Repository Citation

Derlega, Valerian J.; Janda, Louis H.; Miranda, Jeannie; Chen, Ian A.; Goodman, B. Mitchell III; and Smith, Wally, "How Patients' Self-Disclosure about Sickle Cell Pain Episodes to Significant Others Relates to Living with Sickle Cell Disease" (2014). *Psychology Faculty Publications*. 61.

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## Original Publication Citation

Derlega, V. J., Janda, L. H., Miranda, J., Chen, I. A., Goodman, B. M., & Smith, W. (2014). How patients' self-disclosure about sickle cell pain episodes to significant others relates to living with sickle cell disease. *Pain Medicine, 15*(9), 1496-1507. doi:10.1111/pme.12535

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## PRIMARY CARE & HEALTH SERVICES SECTION

### Original Research Article

# How Patients' Self-Disclosure about Sickle Cell Pain Episodes to Significant Others Relates to Living with Sickle Cell Disease

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Disclosure: There were no funds from external sources used in conducting the research.

### Abstract

**Objectives.** This cross-sectional study examines to whom and how fully sickle cell disease (SCD) patients talk to others about sickle cell pain, how helpful it is to talk with others about these pain episodes, and the association between talking to others about sickle cell pain episodes and patients' psychological adjustment and coping strategies in managing the disease.

**Methods.** A convenience sample of 73 African American patients with SCD (30 men and 43 women), were recruited from two SCD clinics at the time of routine medical visits. Most participants had been diagnosed with hemoglobin SS, and they reported an average number of 8.61 pain episodes in the previous 12 months. Participants were asked to whom, how fully, and how helpful it was to talk to significant others about SCD pain episodes experi-

enced in the last 12 months. Patients also completed measures of their psychological adjustment as well as how they would manage a future sickle cell pain episode. Self-report ratings were made on Likert-type scales.

**Results.** Based on paired samples *t*-tests, participants talked significantly more fully about their thoughts and feelings concerning pain episodes to God and to their primary medical providers than to either their parents, siblings, or an intimate partner/close friend. Bivariate correlations indicated that amount and helpfulness of talking about pain episodes to God and to parents were significantly associated with better psychological adjustment on selected measures. Also, bivariate correlations indicated that helpfulness in talking with siblings, intimate partner/close friend, and primary medical providers was positively related with willingness to go to a physician in the event of a future pain episode.

**Conclusions.** The results document to whom and how helpful it is to talk with others about SCD pain episodes and how SCD disclosure is related to strategies for managing this disease.

**Key Words.** Sickle Cell Disease; Talking with Others about SCD; SCD Self-Disclosure; Psychological Adjustment; Pain Management

### Introduction

Sickle cell disease (SCD) is a serious genetic disorder found in people whose ancestors originated in Africa, Mediterranean Europe, Asia, the Pacific Islands, or the Middle East. It is estimated that about 1,000 babies are born each year in the United States with SCD, and currently, there are approximately 89,000 people in the United States with this disease. Although different racial and ethnic groups are affected by SCD, African Americans represent the largest number of individuals with SCD in the

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United States [1,2]. The disorder is characterized by easily deformed red blood cells that hemolyze (i.e., breakdown) quickly, causing anemia and blocking of small blood vessels (termed vascular occlusion). Vascular occlusion and subsequent inflammation, in turn, can lead to different sequelae, including gallbladder, liver, and kidney dysfunction along with heart failure, lung disease, and characteristic bone changes [3–5]. Some patients have an acute exacerbation of the disease characterized by bone pain and fatigue several times per year, but many have pain episodes as often as every day [6].

Modern advances have extended life expectancy for patients with SCD. For instance, in the most frequent type of SCD, hemoglobin SS (HbSS) or sickle cell anemia patients can expect to live to 42–48 years. Patients with the second most frequent type of SCD, hemoglobin SC (HbSC), may live to 60–80 years. These life expectancies are a marked improvement compared with the 1960s and 1970s when life expectancy was just 14 years [7–11]. The improvement in life expectancies for SCD patients, however, comes at a cost to many disease sufferers. SCD patients who survive into adulthood may experience significant organ damage and suffer from multiple chronic diseases [9]. The financial cost incurred for medical care of SCD patients who survive into adulthood is also enormous. In 2009, the estimated discounted lifetime health care costs for a patient with SCD reaching age 45 were \$460,151 [12].

Despite an increase in life expectancy associated with improvements in medical treatments, psychological and social factors play an important role in SCD patients' quality of life as well as in how well they cope with this disease [13]. For instance, a study of 308 SCD patients from Richmond and Hampton Roads, Virginia, found that their health-related quality of life was similarly low to hemodialysis patients on emotional and physical problems interfering with everyday life activities and social functioning [14]. Also, research indicates psychological states, such as stress and depression, are associated with more frequent pain episodes and more severe symptoms [15–17]. Coping strategies are related to self-care activities such as taking in fluids, resting, and seeking assistance for pain episodes [18]. Religion and spirituality (e.g., church attendance, prayer, and Bible study) are also related to SCD patients' appraisal of pain [19,20].

There are numerous studies focusing on family functioning and peer relationships in coping with chronic pain related to, for instance, daily headaches, fibromyalgia, and cancer pain [21–23]. However, there is limited research on the role of interpersonal and communication factors affecting living with SCD [24,25]. Nevertheless, consistent with the stress buffering hypothesis [26], social factors are expected to promote positive mental and health outcomes for SCD patients by influencing reactions to disease-related symptoms (such as whether or not to seek medical help in response to a SCD-related pain episode) and how well patients take care of themselves. We assume that social interactions and communications with significant others

(such as talking with others about sickle cell pain episodes) may provide social support and assist individuals to manage and to live a better quality of life with this disease. In our view, "who" SCD patients talk to about SCD as well as the helpfulness of these interactions may influence patients' psychological adjustment and how they meet SCD-related challenges such as intermittent exposure to sickle cell pain episodes.

Many studies that have found an association between self-disclosure about stressors and health outcomes focus on what is termed expressive self-disclosure. In the research paradigm for expressive self-disclosure, individuals are asked to write about their feelings about a stressful experience in their personal lives, for instance, being exposed to traumatic events or dealing with a life-threatening illness. A meta-analysis of 146 studies conducted by Frattaroli [27] found that expressive disclosure had an *r* effect size of 0.075 overall across outcome measures reflecting both physical and psychological functioning. Effects of expressive disclosure were stronger for measures of psychological adjustment and reported health than for measures of health behaviors (such as medication adherence).

Although expressive disclosure is associated with positive health outcomes, it does not provide evidence about the *social benefits* of self-disclosure based on, say, talking with significant others about major health problems. Talking with others about health problems may provide useful information about how to cope with the disease and/or it may facilitate obtaining tangible support. Talking to others about one's health problems may also provide emotional support, assuming that the disclosure recipient reacts with acceptance and understanding that, in turn, increases self-worth and confidence to cope with medical problems [28–30].

There is extensive research as to whether HIV-positive patients disclose to others about their HIV positive status as well as the physical and/or psychological health consequences of HIV disclosure [31,32]. However, this literature may have limited implications for SCD. With the latter disease, significant others (such as parents, siblings, and friends) are likely to know about SCD patients' disease status because it is a life-long disease that involves intermittent experiences with pain episodes, medical complications, and hospital stays. Nonetheless, SCD patients must make decisions about whether or not to talk with these others about their medical problems, such as their experiences with sickle cell pain episodes, and talking to significant others about such issues may be perceived as more or less helpful, and that in turn may affect how SCD patients cope with this disease. Based on these considerations, we decided to focus in this preliminary study on SCD patients' decisions about to whom and how fully they talk with others about experiences with sickle cell pain, how helpful it was to talk with others about these pain episodes, and the association between talking to others about sickle cell pain episodes and patients' psychological adjustment and coping strategies in managing the disease.

**Research Question 1: To Whom and How Fully Do SCD Patients Talk about Recent Experiences with Sickle Cell Pain and How Helpful Is It to Talk about These Pain-Related Events?**

We were interested in learning the degree to which SCD patients talked with significant others (including mother, father, brother, sister, intimate partner, physician, nurse, or religious figure such as a minister or priest, and God). Religion and spiritually based behaviors (including praying and talking directly with God) have a major place for many African Americans who are dealing with health-related problems [19,20,33–36]. God was included as a “disclosure target” for our African American participants, given that religion and spirituality may play an important role in coping with health problems, including SCD, for this group of patients.

**Research Question 2: How Is Talking to Others about Sickle Cell Pain Related to Psychological Adjustment for SCD Patients?**

Although some controversy exists [24], previous research suggests that SCD patients may be at increased risk for psychological problems [10,37–40]. For instance, the occurrence of painful and unpredictable pain episodes and intermittent hospitalizations associated with SCD may lead to a sense of hopelessness and loss of control in living with the disease. Also, the use of pain medications (including opioids) and frequent visits to emergency rooms and/or hospitals expose SCD patients to being stereotyped as a “drug addict” that, in turn, may cause them to feel self-conscious at being stigmatized [24,40].

Self-disclosure about SCD-related issues (including the occurrence of pain episodes) may assist SCD patients to gain information about their illness and to provide insight about coping with health problems, including lowering depression and stigma self-consciousness about being an SCD patient. Also, talking with others about SCD-related pain episodes may increase self-efficacy in dealing with the disease and with pain episodes when they occur. For instance, it has been found that SCD patients who are socially isolated are more likely to experience a negative affect [41]. There is also research [42] suggesting that patients who find benefits associated with living with a disease (such as being more accepting of things, bringing family members closer together) report greater psychological adjustment.

**Research Question 3: How Is Talking to Others about Sickle Cell Pain Associated with Managing a Future Sickle Pain Episode?**

It has been reported that socially isolated SCD patients are less likely to utilize medical services [41]. Given that socially isolated SCD patients might be less likely to self-disclose, we wanted to consider how self-disclosure about SCD-related pain episodes was related to

willingness to seek medical help with a sickle cell pain episode. In addition, talking with significant others may provide insight into how to manage SCD pain episodes as well as who to count on when needing assistance. Hence, self-disclosure might be related to the use of different methods to cope with sickle cell pain in the future (e.g., getting help from friends as well as seeking medical assistance).

## Methods

### Participants

A convenience sample of 73 African American SCD patients (30 men and 43 women) participated in this cross-sectional survey. The sample size was determined by the availability of participants for this preliminary study. Most participants had been diagnosed with HbSS, and a smaller number were diagnosed with HbSC and sickle beta thalassemia. Participants were recruited for a questionnaire study focusing on the social and personal effects of living with SCD. Participants were asked to describe with whom they talked about their experiences with sickle cell pain, how they felt psychologically living with SCD, and how they coped with pain episodes. Participants were recruited from among patients at two SCD clinics: Eastern Virginia Medical School (Norfolk, Virginia) and Virginia Commonwealth University/Medical College of Virginia (Richmond, Virginia), from June 2008 through December 2008. The research was approved by the Institutional Review Boards of Old Dominion University, Eastern Virginia Medical School, and Virginia Commonwealth University/Medical College of Virginia. See Tables 1 and 2 for background information about our participants, including details about their demographic characteristics and SCD pain-related experiences in the last 12 months. Three patients declined to participate because they had time constraints. No one refused to participate because of the nature of the study.

### Procedure

Participants were recruited at two SCD clinics for a study on “Social Issues in Living with Sickle Cell Disease.” Prospective participants were asked to complete a questionnaire focusing on to whom they talked, about pain-related issues in dealing with SCD (e.g., family, friends, health care providers), and whether it was helpful to talk with these others about “pain-related thoughts and feelings.” One of the investigators (a psychologist who was unaffiliated with the SCD clinics) conducted the recruitment, and he also presented the instructions for completing the questionnaire to all the participants. If SCD patients consented to participate, then they proceeded to a private location in the health care facility to complete the paper-and-pencil questionnaires following a routine appointment with their medical health care provider. To insure anonymity, participants did not identify themselves by name on the questionnaire. Each person received \$5.00 as reimbursement for their participation.

**Table 1** Demographics

Variable	N (%)
Gender	
Men	30 (41.1)
Women	43 (58.9)
Age	
18–27	21 (28.8)
28–37	23 (31.5)
38–47	21 (28.8)
48–57	6 (8.2)
58–69	2 (2.7)
Race (ethnicity)	
African American	73 (100)
Education level	
High school or less	25 (34.2)
At least some college	48 (65.8)
Total annual household income	
Less than \$30,000	46 (64.8)
Over \$30,001	25 (35.2)
Marital status	
Married	26 (35.6)
Intimate partner	25 (34.2)
Single, widowed, or divorced	22 (30.1)
SCD diagnosis	
Sickle cell anemia	50 (69.4)
Sickle cell hgb (HbSC)	13 (18.1)
Sickle beta thalassemia	8 (11.1)
Don't know	1 (1.4)
SCD pain management	
Heat application	45 (61.6)
Rest and stop activity	44 (60.3)
Opioids	64 (87.7)
Nonopioids	25 (34.2)
No medications	1 (1.4)
I did not have pain	1 (1.4)

Reports of physical complications and SCD pain management were based on events in the previous 12 months. The percentages reported in Table 1 are based on the total number of participants (N = 73), except for the demographic information about household income (N = 71), SCD diagnosis (N = 72), and work status (N = 67) where there were some missing data that was not included in the percentage computation.

HbSC = hemoglobin SC; SCD = sickle cell disease.

### Questionnaire Measures

#### Demographic Information and Pain Experiences

Participants first provided demographic information (e.g., age, gender, income, specific SCD diagnosis), and then, they completed an adapted version of Gil's [43] Structured Pain Interview. Participants filled out a paper-and-pencil questionnaire that included questions on number, duration, and intensity of pain episodes; ways of coping with sickle cell pain; and frequency of visits to an emergency room, hospital, and/or physician for pain.

**Table 2** Means and standard deviations of pain experiences in the previous 12 months

Variable	N	M	SD	Range
Number of pain episodes	67	8.61	11.42	0–60
Duration of pain episodes (days)	65	6.16	6.51	0–42
Intensity of pain episodes (from 0 indicating “no pain” to 10 indicating “as bad as it can be”)	70	7.64	2.21	0–10
Number of ER visits due to pain episodes	71	2.38	3.11	0–15
Number of hospitalizations due to pain episodes	72	1.72	2.20	0–11
Duration of hospital stays due to pain episodes (days)	61	5.31	4.23	0–15
Number of physician visits due to pain episodes	71	6.28	7.91	0–52

“N” refers to the number of participants who answered each question. We should note that women, compared with men, reported more pain episodes (means of 10.00 vs 6.56,  $P < 0.05$ ) and fewer visits to a physician due to pain episodes (means of 4.42 vs 9.14,  $P < 0.05$ ). There were no differences between men and women on the other measures in this table. ER = emergency room; SD = standard deviation.

#### Talking to Others about Sickle Cell Pain

Participants were asked to identify to whom they had talked when they experienced sickle cell pain episodes in the last 12 months. Participants were provided with a list of significant others, including mother, father, close friend, intimate partner, primary care physician, and God. Participants answered “yes” or “no” if they talked to each “other” about the pain episodes. Participants were asked to restrict their responses to others who were alive or who had a role in their life (e.g., a coworker if the participant were employed or a minister if the person was involved in a religious organization). Then, participants rated how fully they had talked to each of these persons and how helpful it was to talk to each of them about what happened during the sickle cell episode(s). Ratings were made on a 5-point scale, ranging from 1 (*least*) to 5 (*most*).

Several measures were included to assess depressive symptoms, SCD-related stigma, benefit finding in living with SCD, and pain efficacy dealing with sickle cell pain episodes. These measures are described below.

#### Centers for Epidemiological Studies-Depression Scale

The measure of depressive symptoms experienced during the previous week was based on responses to an 11-item version of the Centers for Epidemiological Studies-Depression Scale (CES-D) [44]. Sample items included, “I felt hopeful about the future,” “I felt my life had been a



failure,” and “I felt sad.” Ratings were made on a 4-point scale, from 1 (*rarely or none of the time*) to 4 (*most of the time*). Scores across individual items were averaged with higher scores indicating a greater number of depressive symptoms experienced in the last 7 days. Cronbach’s alpha was 0.86.

#### Stigma Consciousness Questionnaire

Self-consciousness about being stigmatized or stereotyped, based on the SCD diagnosis, was measured using an adapted nine-item version of Pinel’s Stigma Consciousness Questionnaire [45]. Sample items included, “When interacting with someone who doesn’t have sickle cell disease, I feel like they interpret all my behaviors in terms of the fact that I have sickle cell,” and “Most people have a lot more negative thoughts than they actually express about sickle cell disease.” Ratings were made on a 7-point scale, ranging from 0 (*strongly disagree*) to 6 (*strongly agree*), and items were averaged so that higher scores reflected higher stigma consciousness associated with SCD. Cronbach’s alpha was 0.73 for our sample.

#### Benefits Finding Questionnaire

A modified, 17-item version of Antoni et al.’s [42] Benefits Finding Questionnaire assessed patients’ perceptions of benefits associated with the SCD diagnosis. Sample statements included, “Having sickle cell has led me to be more accepting of things,” “Having sickle cell has shown me that all people need to be loved,” and “Having sickle cell has brought my family closer together.” Responses were made on a 5-point scale, ranging from 1 (*not at all*) to 5 (*extremely*) with higher scores indicating the perception that more benefits accrued from living with SCD. Cronbach’s alpha for our participants was 0.93.

#### Pain Self-Efficacy Questionnaire

The 10-item Pain Self-Efficacy Questionnaire [46] assessed participants’ confidence to engage in various activities (e.g., enjoy things, cope without medication, live a normal lifestyle, socialize with friends and family) despite sickle cell pain. Ratings were made on a 7-point scale, ranging from 0 (*not at all confident*) to 6 (*completely confident*), with higher scores indicating higher pain self-efficacy. Sample items included, “I can still accomplish most of my goals in life despite the pain” and “I can do some form of work despite the pain (“work” includes housework, paid and unpaid work). Cronbach’s alpha for the pain self-efficacy scale was 0.91.

#### How Participants Anticipate Managing Sickle Cell Pain

Six different methods of coping with a future pain episode were listed. These methods included the following: “I would go to a doctor,” “I would go to a hospital or to an emergency room,” “I would take non-narcotic pain medication,” “I would take narcotic pain medications,” “I would try to get help from family or friends,” and “I would try to

hold off doing something hoping the pain goes away or improves.” Ratings were made for each statement on a 4-point scale, ranging from 1 (*I would not do this at all*) to 4 (*I would do this a lot*).

#### Statistical Analysis

Means and standard deviations were calculated for most of the items in the survey. Pearson product–moment correlations were calculated between the amount of talking with others about sickle cell pain episodes and the endorsement of pain management techniques in dealing with a pain episode in the future and between the helpfulness of talking with others about sickle cell pain episodes and the endorsement of pain management techniques in dealing with a pain episode in the future. Also, *t*-tests for independent samples were used to compare men with women with respect to their experiences with pain and the strategies they used to cope with it, while *t*-tests for paired samples were calculated to determine if there were differences in the extent to which patients talk to various others and the degree to which such communications were helpful. All statistical analyses were performed using SPSS Version 20.0 (SPSS Inc., Chicago, IL, USA).

To simplify the statistical analyses, we combined the data for several categories of “others.” We combined the ratings for mother and father to create a “parent” category on the amount and helpfulness of disclosure. Similarly, ratings for brother and sister were combined into a “sibling” category, primary physician and primary nurse were combined into “primary medical providers” category, and intimate partner and close friend were combined into an “intimate partner/close friend” category. We also limited these analyses on amount and helpfulness of disclosure to categories of “others” for whom we had a substantial number of observations, that is, parents, siblings, intimate partner/close friend, primary medical providers, and God.

## Results

### Characteristics of Participants

The demographic characteristics of the participants are summarized in Table 1. Our sample was quite similar to that of the PiSCES Project (Pain in Sickle Cell Epidemiology Study) with respect to age (mean of 35.12 for our sample; 34.15 for the PiSCES sample), somewhat more likely to have at least some college (65.8% for our sample; 49.1% for the PiSCES sample), and somewhat more likely to be married (35.6% for our sample; 23.9% for the PiSCES sample) [10,47].

Our participants may have experienced fewer pain episodes than those in the PiSCES sample. In this survey, participants reported an average of 8.61 episodes over the previous 12 months, whereas the PiSCES participants reported an average of 8.87 episodes over the previous 6 months [47]. The greater number of pain episodes

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reported by the PiSCES participants, after adjusting for time, may be a consequence of the difference in the specifics of the question. We asked participants to recall the number of pain episodes they had experienced over the previous 12 months, while McClish et al. [47] had participants complete daily diaries for up to 6 months. The results regarding pain episodes and the attempts to deal with them can be found in Table 2.

### *Research Question 1: To Whom and How Fully Do SCD Patients Talk to Others about Recent Experiences with Sickle Cell Pain and How Helpful Is It to Talk About These Pain-Related Events?*

Table 3 summarizes data describing who in participants' social networks knew about their SCD diagnosis. Generally speaking, most or all people in participants' social network knew about their diagnosis. On the other hand, Table 3 documents considerable variability in who the participants talked to about pain episodes that happened in the previous 12 months. There was a high percentage of patients who talked about SCD pain episodes to their primary physician, God, mother, intimate partner, close friend, primary nurse, counselor/psychologist, and employer/supervisor. For these categories of others, the percentage of participants who talked about their pain episodes ranged from 72.3% to 91.7%. Fewer patients, ranging from 23.4% to 54.3%, talked about their pain episodes to father, brother, casual friend, minister/clergy, dentist, and coworker. There was an intermediate

percentage of participants who talked about SCD pain episodes to their sister (63.2%).

Because the age of the participant might influence to whom they talked (younger participants may be more likely to have living parents), we examined the relationship between age and how fully participants talked with the various categories of others. The only significant correlations were between age and amount of disclosure and helpfulness of disclosure about pain episodes within the previous 12 months with primary medical providers ( $r = 0.30$ ,  $P < 0.05$ ;  $r = 0.38$ ,  $P < 0.01$ , respectively).

Next, we examined how fully participants self-disclosed to others about sickle cell pain episodes and the helpfulness of such talks that occurred in the last 12 months. We looked for differences among categories of people to whom participants disclosed or the degree to which it was helpful to talk to them. The results of these analyses can be found in Table 4. Participants talked more fully about their thoughts and feelings about pain episodes to God and to their primary medical providers than to either their parents, siblings, or their intimate partner/close friends. There was no difference in the level of self-disclosure to God vs primary medical providers about the sickle cell pain episodes. Also, there was no difference in the level of self-disclosure about pain episodes among parents, siblings, and intimate partners/close friends. The same pattern of results was found when we compared participants' ratings of helpfulness

**Table 3** Number and percentage of participants' social network members who knew about their SCD diagnosis and to whom they talked about sickle cell episode(s) during the previous 12 months

Variable	Number and Percentage of Particular Others in Participants' Networks Who Knew about Their SCD Diagnosis		Number and Percentage of Participants Who Talked to a Particular Other about Pain Episode(s)	
	N	%	N	%
Mother	65/65	100	55/65	84.6
Father	45/46	97.8	25/46	54.3
Brother	55/55	100	30/55	54.5
Sister	56/57	98.2	36/57	63.2
Intimate partner	61/62	98.4	51/62	82.3
Close friend	68/69	98.6	52/69	75.4
Casual friend	52/63	82.5	24/63	38.1
Primary physician	72/72	100	66/72	91.7
Primary nurse	65/65	100	47/65	72.3
Dentist	41/47	87.2	11/47	23.4
Employer/supervisor at work	23/23	100	20/23	87.0
Coworker	23/23	100	11/23	47.8
Counselor/psychologist	9/9	100	7/9	77.8
Minister/clergy	49/61	80.3	21/61	34.4
God	—	—	63/70	90.0

The denominator term in the N column represents the total number of participants who reported having a particular other in their social network.

SCD = sickle cell disease; — = We did not ask participants if God knew about their illness.



**Table 4** Means and standard deviations for amount and helpfulness of talking to particular others

Variable	M and SD (N)	Variable	M and SD (N)
Amount of disclosure to:		Helpfulness of disclosure	
Parents	3.49 <sub>a</sub> (1.29) (57)	Parents	3.22 <sub>a</sub> (1.46) (57)
Siblings	3.35 <sub>a</sub> (1.40) (49)	Siblings	3.32 <sub>a</sub> (1.45) (49)
Intimate partner/close friend	3.84 <sub>a</sub> (1.18) (64)	Intimate partner/close friend	3.48 <sub>a</sub> (1.36) (63)
Primary medical providers	4.39 <sub>b</sub> (.77) (64)	Primary medical providers	4.41 <sub>b</sub> (.81) (64)
God	4.64 <sub>b</sub> (.92) (59)	God	4.57 <sub>b</sub> (.96) (58)

The *P* value for the paired samples *t*-tests ( $P = 0.005$ ) in each column was based on a Bonferroni correction (0.05 divided by 10 comparisons). Means that do not share a common subscript in a column are significantly different from one another. The *N* in parentheses represents the number of observations for each measure. The ratings were made on a 5-point scale with 1 labeled as "least" and 5 labeled as "most."

SD = standard deviation.

of talking to various others about sickle cell pain episodes. It was significantly more helpful for participants to talk with God and/or primary medical providers than to parents, siblings, and intimate partner/close friends.

#### *Research Question 2: How Is Talking to Others about Sickle Cell Pain Related to Psychological Adjustment for SCD Patients?*

We examined the relationship between level of, and helpfulness, of self-disclosure to parents, siblings, intimate partner/close friends, primary medical providers, and God with depressive symptoms, stigma consciousness, benefit finding, and pain self-efficacy. Our expectation that amount of self-disclosure would be associated with positive psychological consequences was generally confirmed. Amount and helpfulness of talking with God about pain episodes were negatively related to frequency of depressive symptoms ( $r_s = -0.41$ ,  $P < 0.01$ , and  $-0.54$ ,  $P < 0.01$ , respectively). Also, amount and helpfulness of talking with God were positively related to pain self-efficacy ( $r_s = 0.28$ ,  $P < 0.05$ , and  $0.32$ ,  $P < 0.05$ , respectively). Thus, amount and helpfulness of talking with God were related to lower frequency of depressive symptoms and to higher confidence in managing life's activities despite sickle cell pain. We also found that amount and helpfulness of talking with parents about pain episodes were associated with lower SCD-related stigma self-consciousness ( $r_s = -0.34$ ,  $P < 0.05$ , and  $-0.29$ ,  $P < 0.05$ , respectively). Participants who talked more fully about their SCD pain episodes to parents were less self-conscious about being stigmatized or stereotyped by SCD. Finally, helpfulness in talking to siblings ( $r = 0.31$ ,  $P < 0.05$ ) as well as to intimate partner/close friends ( $r = 0.35$ ,  $P < 0.01$ ) about pain episodes was positively associated with finding benefits in living with SCD. Higher helpfulness in talking to siblings and to intimate partner/close friend about sickle cell pain episodes was associated with endorsing more benefits associated with a SCD diagnosis.

#### *Research Question 3: How Is Talking to Others about Sickle Cell Pain Associated with Managing a Future Sickle Pain Episode?*

Tables 5 and 6 present the bivariate correlations between the amount and helpfulness in talking about pain episodes to significant others and participants' anticipated responses to sickle cell pain episodes that might happen in the future. Our predictions were generally supported. Amount and helpfulness of talking with parents were positively related with getting help from family and friends in response to a pain episode. Importantly, amount of talking about pain episodes to siblings, intimate partner/close friend, primary medical providers, and to God was also associated with going to a doctor in the event of a future pain episode. We also found that helpfulness in talking with siblings, intimate partner/close friend, and primary medical providers was related with willingness to go to a doctor if a pain episode were to occur. Finally, helpfulness in talking with an intimate partner/close friend about previous pain episodes was related to willingness to take opioids to manage SCD pain in the future.

#### **Discussion**

The present study provided descriptive data about to whom SCD patients talk about recent sickle cell pain episodes, how fully they talk to others about these pain episodes, and how helpful it was to talk about these pain events to various others. The research also allowed us to examine the relationships between how fully and how helpful it was to talk with others about sickle cell pain episodes and participants' psychological adjustment and anticipated coping with sickle cell pain in the future.

In discussing the results, we should first mention that despite the fact that most people in patients' social networks had knowledge of their SCD diagnosis, there was a considerable diversity in "who" participants talked to about their sickle cell pain episodes. Most patients identified their primary physician, God, mother, intimate partner, close friend, primary care nurse, counselor/

**Table 5** Bivariate correlations between the amount of talking with others about sickle cell pain episodes and the endorsement of pain management techniques in dealing with a pain episode in the future

Variable	Amount of Talking to Various Others				
	Parents	Siblings	Intimate Partner/ Close Friend	Primary Medical Providers	God
I would					
Go to doctor	0.19 (57)	0.41** (49)	0.35** (64)	0.33** (64)	0.26* (59)
Hospital or ER	0.16 (57)	0.24 (49)	0.33** (64)	0.17 (64)	0.05 (59)
Nonopioids	0.19 (57)	0.20 (49)	-0.02 (63)	0.01 (64)	-0.10 (58)
Take opioids	-0.03 (57)	-0.05 (49)	0.16 (64)	-0.08 (64)	-0.09 (59)
Get help from family or friends	0.30* (57)	0.13 (49)	0.12 (64)	0.07 (64)	0.15 (59)
Hold off doing something	0.02 (57)	0.12 (49)	0.07 (64)	0.06 (64)	-0.04 (59)

\* $P < 0.05$ ; \*\* $P < 0.01$ .

The number in parentheses represents the number of observations in computing each bivariate correlation.

ER = emergency room.

psychologist, and employer/supervisor at work as someone with whom they talked about a sickle cell pain episode that they experienced in the last 12 months. Participants were less likely to talk about a sickle cell pain episode with a father, brother, casual friend, minister/clergy, a coworker, or a dentist. On the other hand, patients reported talking more fully and that it was more helpful to talk with God and/or a primary medical provider (i.e., a physician or nurse) about sickle cell pain episodes in contrast to their parents, siblings, and/or an intimate partner/close friend. These results document the possible range of significant others (including God) with whom individuals talk about sickle cell pain. However, the results also indicate that SCD patients make a distinction among various others in terms of how fully and how helpful it may be to talk about sickle cell pain episodes when these pain events occur.

The results were modest, albeit suggestive, about the associations between amount and helpfulness in talking to particular others about sickle cell pain episodes and participants' psychologist adjustment. Participants were less self-conscious about being stigmatized by SCD if they talked more fully to their parents about sickle cell pain and if they perceived that talking to them had been helpful. There was no other association between the amount and helpfulness of talking about sickle cell pain episodes to any others in predicting SCD-related stigma. These results suggest the possible role of open and supportive talk between children with SCD and their parents in combating concerns about being the target of SCD-related stereotypes. Interestingly, helpfulness of talk with siblings and intimate partners/close friend was positively associated with finding benefits with SCD disease. It may be that the responsiveness and support provided by siblings, intimate

**Table 6** Bivariate correlations between the helpfulness of talking with others about sickle cell pain episodes and the endorsement of pain management techniques in dealing with a pain episode in the future

Variable	Helpfulness of Disclosure to Various Others				
	Parents	Siblings	Intimate Partner/ Close Friend	Primary medical providers	God
I would					
Go to doctor	0.09 (57)	0.31* (49)	0.31* (63)	0.26* (64)	0.11 (58)
Hospital or ER	0.12 (57)	0.21 (49)	0.37** (63)	0.16 (64)	-0.02 (58)
Nonopioids	0.24 (57)	0.33* (49)	0.06 (62)	-0.04 (64)	-0.17 (57)
Take opioids	0.11 (57)	0.04 (49)	0.32** (63)	-0.12 (20)	0.03 (58)
Get help from family or friends	0.40** (57)	0.27 (49)	0.19 (63)	0.17 (64)	0.19 (58)
Hold off doing something	-0.09 (57)	-0.04 (49)	0.00 (63)	0.03 (64)	-0.07 (58)

\* $P < 0.05$ ; \*\* $P < 0.01$ .

The number in parentheses represents the number of observations in computing each bivariate correlation.

ER = emergency room.

partners, and close friends shine a positive light on the possibilities for personal growth and a high quality of life despite the challenges and adversity that SCD patients confront living with this disease.

Religious and spiritual activities (e.g., attendance at religious services, prayer, reading the Bible and religious books) assume an important role in the lives of African Americans [48]. Hence, it is not surprising that the amount and helpfulness of talking to God were associated with lower depression and higher pain self-efficacy. When SCD patients talk fully to God about their experiences with pain and when this talk is perceived to be helpful, patients may feel more empowered and “in control” [20].

We should also note the positive association between amount of talking with siblings, intimate partners/close friend, primary medical providers (i.e., physicians and nurses), and to God and participants’ willingness to contact a physician in the event of a future pain episode. A similar pattern was found between helpfulness in talking about recent pain episodes to siblings, intimate partner/close friend, and primary medical providers and going to a doctor in case of a future pain episode. Although the results are cross sectional, they suggest that how fully one talked and the helpfulness in talking with others about what happened during recent pain episodes may either alleviate patients’ concerns about contacting a physician in the event of a future sickle cell pain episode and/or it may strengthen patients resolve to problem solve (by contacting a physician) in the event of a possible medical emergency.

We must be cautious about the clinical implications of the results because of its correlational nature. Nevertheless, the results indicate that SCD disclosure is, for many patients, a frequently used and helpful behavior in coping with pain episodes. On the other hand, there are some participants who decided not to talk about their thoughts and feelings about SCD pain episodes to others or who did not find SCD disclosure to be helpful. It might be useful for SCD patients (particularly those who perceive that there are barriers in talking with members of their social network about SCD) to consider participating in a support group with other SCD patients. Illness support groups provide participants with the opportunity to tell and hear stories about how group members are coping with their health problems [49]. These groups provide mutual support for patients and, potentially (in the case of SCD patients), may give them a better understanding of how to cope with SCD pain episodes as well as how to live with this disease generally. We noted in the introduction that writing about stressful experiences (i.e., expressive self-disclosure) has beneficial effects for mental and physical health [24]. A few studies even indicate that expressive writing concerning health problems affects how well someone copes with these issues (including positive changes in how people feel about their illness) among cancer patients and in self-reports of lower pain intensity among chronic pelvic pain patients [50–52]. In the absence of someone to talk to about sickle cell-related issues, SCD patients might be encouraged (perhaps with

monitoring and feedback from a health professional) to write about their deepest thoughts and feelings about SCD. Expressive writing about SCD might be useful in changing how SCD patients think about their illness and possibly improve their skills and self-efficacy in coping with SCD-related health problems.

We should note several limitations of the research. First, the data are cross sectional. We cannot infer cause and effect conclusions based on our results. It would be important to conduct prospective research examining how previous experiences in talking with various others about sickle cell pain might predict future reports about SCD patients’ psychological adjustment and how these patients are coping with the disease. Second, we have a relatively small sample of SCD patients in our study. It would be important to replicate the research with a larger number of participants to increase statistical power.

Despite these limitations, our results suggest important avenues for future research in examining how SCD patients cope with this disease and the nature of self-disclosures they make. In particular, our participants report that they talk relatively fully with their primary medical providers and with God and that such self-disclosures are particularly helpful. Interestingly, the amount and helpfulness in talking with parents about sickle cell pain episodes may play a unique role in reducing patients’ self-consciousness about being the target of SCD-related stigma, and amount and helpfulness in talking about pain episodes to God may empower patients so that they experience fewer depressive symptoms. Thus, our findings suggest how talking with “significant others” (parents, God, intimate partner/close friend as well as medical care providers) about sickle cell pain episodes may influence SCD patients’ quality of life.

We have not focused in this research on how participants might have differed in the types of SCD disclosure about pain episodes. For instance, we don’t know how often SCD disclosure was used to express frustration about a pain episode as opposed to, say, using SCD disclosure to gain others’ assistance in planning how to cope with future pain episodes. Future research should examine the reasons generated for SCD disclosure to significant others as well as how the content of SCD disclosure might be more or less beneficial in coping with pain episodes. It would also be of interest to note what types of responses to SCD disclosures are perceived as helpful or unhelpful.

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