Sleep Quality, Pain and Self-Efficacy among Community-Dwelling Adults with Sickle Cell Disease

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Abstract

The aim of this paper was to report the findings of a study examining relationships among sleep, pain, self-efficacy, and demographic attributes of community-dwelling adults with sickle cell disease (SCD). Sleep difficulty has been self-reported among adults with chronic pain. Past studies have demonstrated that chronic pain results in sleep difficulties and other complications that threaten effective functioning. Community-dwelling adults with SCD are living longer and need to be evaluated for sleep quality, pain, and self-efficacy. Little is known about whether adults with SCD-related pain have disturbances in sleep and self-efficacy, and if these disturbances are affected by age and/or gender. The purpose of this descriptive, correlational study was to examine the relationships among sleep, pain, self-efficacy, and demographic attributes among community-dwelling adults with SCD, and who use support services of state SCD Associations in the United States. For this secondary data analysis, the study was conducted from June, 2014 to December, 2014 and used a descriptive correlational design to analyze data from a primary study of a convenience sample of 90 subjects with SCD, who were 18 years of age and older. Linear regression was used to compute the relationship between dependent and independent variables. All measures were self-reported. It was found that gender did not significantly affect reports of sleep, pain, or self-efficacy. Self-efficacy accounted for direct relationships with sleep and inverse relationships with pain. Some individuals (16.7%) reported sleeping very well, however, the majority (83.3%) was not sleeping very well, and a greater number of individuals (93.3%) reported having some pain. Among adults with chronic SCD pain, self-efficacy is important in maintaining a stable quality of health. Future assessments, interventions, and research should include comprehensive sleep and pain evaluations, and measures to improve self-efficacy and sleep quality, as well as measures to decrease pain among community-dwelling adults with SCD.

Key Words: adults, community-dwelling, pain, self-efficacy, sleep quality, sickle cell disease

Introduction

Quality sleep is essential for healthy living; hence impaired sleep quality potentially impairs health and may aggravate pathology associated with other conditions. Impaired sleep quality among community-dwelling adults with chronic pain is often reported (Abernethy, 2008; Green, Ndao-Brumblay, & Hart-Johnson, 2009; Leff et al., 2008; Warms, Marshall, Hoffman, & Tyler, 2005), and there is evidence of bi-directionality, in that sleep disruption leads to increased pain, and increased pain severity leads to sleep disruption (Abernethy, 2008; Affleck, Urrows, Tennen, Higgins, & Abeles, 1996; Brand, Gerber, Pühse, & Holsboer-Trachsler, 2010; Pieh, Popp, Geisler, & Hajak, 2011).

Brand and colleagues (2010) found that sleep, pain, quality of life, and depressive symptoms are interrelated. That is, disrupted sleep perpetuates chronic pain resulting in physiological and psychological complications such as cognitive changes, brain atrophy, and increased mortality and morbidity (Tennant, 2009; Torrance, Elliott, Lee, & Smith, 2010; Tracey & Bushnell, 2009). Evidence from both animal and human studies has demonstrated that chronic pain results in irreversible brain atrophy, sensory, emotive, and cognitive neurogeneration that threatens self-efficacy and functioning (Tennant, 2009; Torrance et al., 2010). Based on the altered brain physiology and neurochemistry, chronic pain is a disease (Tennant, 2009; Tracey & Bushnell, 2009).

Background and Significance

Chronic pain, a disease (Tennant, 2009; Tracey & Bushnell, 2009), and its sequel symptoms are likely to affect health and quality of life generally among adults, and specifically among adults who are ethnic minorities (Goodin et al., 2011). Emerging structural brain studies are showing that individuals who develop chronic pain may have some structural or genetic predisposition to developing pain (Mansour et al., 2013). Such predisposition may help to support theories of neuroplastic changes induced by earlier painful vaso-occlusive events that some individuals with chronic sickle cell disease [SCD] pain experience. As these individuals age they tend to report more pain that is believed to be a transition to a chronic stage (Hollins et al., 2012).

Sickle cell disease [SCD] is an umbrella term for genetic hemoglobin disorders that are accompanied by the characteristic acute, chronic, and vasoocclusive pain. In general, the chronic pain, sometimes called recurrent acute pain, affects all areas of the individual’s life, is challenging for healthcare providers to manage, and can negatively transform the individual’s life into pathologies that include depres-
sion and coping difficulties (Ballas, Gupta, & Adams-Graves, 2012). Hence, adults with SCD and chronic (or recurrent acute) pain need to be afforded better assessment, management, and treatment outcomes that can possibly minimize or obliterate accompanying complications.

It is known that sleep and pain disturbances affect diverse populations and minorities (Green et al., 2009). African-American individuals with chronic pain are more burdened with decreased health, and report more sleep disturbances accompanying chronic pain when compared with similar non-Hispanic Whites (Green & Hart-Johnson, 2010; Green et al., 2009). Additionally, African-Americans receive inadequate chronic pain assessment, insufficient and poor quality pain care, and fewer referrals to pain specialists (Green & Hart-Johnson, 2010).

Sleep and pain studies related to gender differences have resulted in mixed reports (Hollins et al., 2012; McClish et al., 2006; Zhang et al., 2012). Zhang and colleagues (2012) found that females had more sleep problems and more pain than did males. In other studies there have been reports that females have more pain (Hollins et al., 2012; Zhang et al., 2012), while McClish and colleagues (2006) reported that among individuals with SCD-related pain, males and females have the same reports concerning pain.

There is limited research among adults with SCD in the area of sleep quality and pain. Even fewer pain and sleep studies that focused on SCD have involved participants who are children and adolescents (Daniel, Grant, Kothare, Dampier, & Barakat, 2010; Goldstein et al., 2011; Graves & Jacob, 2014; Long, Krishnamurthy, & Palermo, 2008; Palermo & Kiska, 2005; Valrie, Gil, Redding-Lallinger, & Daeschner, 2007a; Valrie, Gil, Redding-Lallinger, & Daeschner, 2007b; Valrie, Bromberg, Palermo, & Schanberg, 2013). In one study that included adult SCD participants, the researchers found increased age to be associated with increased pain ratings. However, age-related changes in pain ratings were not found among healthy non-SCD controls (Hollins et al., 2012). Wallen and colleagues (2014) found that more than 70% of adults with SCD who were involved in a clinical trial reported sleep disturbance, and 21% reported depression (Wallen et al., 2014). In another study involving adult participants with SCD, age was also found to be associated with pain ratings with older participants reporting increased pain (Smith & Scherer, 2010). It remains unclear if adults with SCD-related pain and sleep disturbances are affected by age and gender.

Self-efficacy is concerned with a person’s belief about his or her personal capabilities to cope and overcome specific challenges (Bandura, 1977; Bandura, 1982). In general, self-efficacy predicts specific behaviors, and also results in specific behaviors (Bandura, 1977; Bandura, 1982).

In the case of sickle cell disease management, self-efficacy is the belief in one’s ability to execute required tasks pertaining to day-to-day disease management (Adegbola, 2011, 2007). Previous studies of self-efficacy among adults with SCD have revealed that those who reported lower levels of self-efficacy have increased pain and more physical and psychological SCD-related symptoms than individuals who reported higher levels of self-efficacy (Edwards, Telfair, Cecil, & Lenoci, 2000; Edwards, Telfair, Cecil, & Lenoci, 2001; Lenoci, Telfair, Cecil, & Edwards, 2002). Additionally, individuals with SCD and with increased self-efficacy reported an increased quality of life (Adegbola, 2011). Self-efficacy is a predictor of positive health outcomes such as decreased pain and decreased illness burden (Adegbola, 2011; Edwards et al., 2000; Edwards et al., 2001; Lenoci et al., 2002), but the combined relationships among sleep, pain, and self-efficacy have not been explored in adults with SCD.

**Purpose of the Study**

From the review of the literature of adults with SCD, little is known about the experiences of adults regarding sleep quality, pain severity, and self-efficacy. Additionally, it remains unclear if adults with SCD-related pain who are community-dwelling have sleep disturbances that are affected by their age and gender. Thus, this study aimed to examine the relationships and explain possible variances among sleep quality, pain severity, SCD-related self-efficacy, and demographic characteristics (gender, age) among community-dwelling adults with sickle cell disease.

It was hypothesized that among community-dwelling adults with SCD: (1) sleep quality is positively related to disease-specific sickle cell disease self-efficacy, (2) pain severity is inversely related to sickle cell disease self-efficacy, (3) pain severity and sleep quality are inversely related, (4) gender does not significantly influence pain severity, and (5) age significantly influences pain severity, sleep quality, and self-efficacy.

**Methodology**

**Design, Sample and Setting**

This study used a descriptive correlational design to collect data from a convenience sample of 90 adults (N = 90) with SCD. This study is a secondary analysis and was conducted between June, 2014 and December, 2014. The primary study’s aim examined the relationships among quality of life, self-efficacy, and spirituality.

Participants were contacted through state affiliate chapters of the national Sickle Cell Disease Association of America (SCDAA). Initially, staff at a local SCDAA chapter in the southwest United States was contacted directly, and later, through a SCDAA representative, other state chapter directors were contacted. The state directors of local SCDAA chapters contacted their constituents and informed them of the study. The state chapters of the SCDAA offered support groups for adults and had access to adult individuals with SCD who used the non-medical support resources offered by the chapters. The study was available electronically through SurveyMonkey Inc. (SurveyMonkey Inc.), a web-based platform, as well as via paper and pencil copies with U.S. postage paid return mail. SCDAA state directors disseminated the mailed out copies. Participants who consented...
anonymously completed the self-reported U.S. postage paid mailed out or electronically accessed surveys.

Institutional Review Board Approval

Community-dwelling participants with SCD, who were 18 years of age and older and able to read and write English, were invited to participate in the primary study after Institutional Review Board (IRB) approval. Likewise, for the secondary analysis, IRB approval (2014-0017) was granted.

Instrumentation

The testing instrument was a self-report questionnaire. It included items designed to elicit demographic information and information on sleep quality, pain, and SCD-specific self-efficacy.

The Functional Assessment of Cancer Therapy-General [FACT-G] (Cella, McCain, Peterman, Mo, & Wolen, 1996) was used to elicit this information as well as the Sickle Cell Self-Efficacy Scale (SCSES) (Edwards et al., 2001). The FACT-G was used with other chronic illnesses and with SCD. The conceptual basis, psychometrics, and specifics related to use with the SCD population have been previously discussed (Adegbola, 2006; Adegbola, 2011). For this study, to measure sleep quality and pain, a single item (for each) on the FACT-G was used. The validity of these two items has been demonstrated within the context of the QOL instrument, FACT-G. The single item for sleep was worded “I am sleeping well.” For the measurement of pain, the single item was worded “I have pain.” The response choices for both were: not at all (0), a little bit (1), somewhat (2), quite a bit (3), and very much (4). Higher scores indicated higher sleep quality or perceived pain quality.

The Sickle Cell Self-Efficacy Scale [SCSES] (Edwards et al., 2001), a 9-item Likert-type disease specific questionnaire was used in other SCD-related studies (Adegbola, 2011; Clay & Telfair, 2007; Edwards et al., 2000). This measurement identified the individual’s ability to function and to manage day-to-day SCD symptoms. For each item the response options were: (1) not at all sure, (2) not sure, (3) neither, (4) sure, and (5) very sure. Responses for the 9 items were totaled, with higher scores indicative of higher self-efficacy and possible scores of 9 to 45. The internal consistency for the SCSES has been reported as 0.89 (Edwards et al., 2000).

Data Analysis

Statistical analyses were calculated using Statistical Package for Social Sciences [SPSS], version 21 (IBM SPSS Statistics for Windows, 2012). To characterize the sample, descriptive statistics were computed to describe self-efficacy, pain, and sleep. Higher scores indicated higher sleep quality and higher scores indicated perceived pain quality. With SCD self-efficacy, higher scores indicated higher self-efficacy and the ability to handle day-to-day SCD-related symptoms.

The response rate was 36%. Two hundred questionnaires were mailed out in paper and pencil format and 73 were returned via U.S. mail. Additionally, 18 completed questionnaires were returned via electronic format. There was total of 91 returned questionnaires, but one was discarded because the participant reported having sickle cell trait and not SCD. The 90 questionnaires used for the analysis had few missing data that were handled by dictates of the instruments being used.

Cronbach’s α was computed for the SCSES. Percentages were computed for the categorical variable gender. Cronbach’s correlation computed relationships between sleep and self-efficacy. Correlations were computed on the following variables: gender/sleep, gender/pain, age/sleep, age/pain, and pain/sleep. There was no statistical significance among these variables.

Linear regression was computed for the outcome variables. In this regression, the outcome variables sleep and pain contained numeric codes for the subjects’ status and included five levels each. The 5-level outcome variable, pain, was coded as 0, 1, 2, 3, 4, in which 0 is not at all, 1 is a little bit, 2 is somewhat, 3 is quite a bit, and 4 is very much. Sleep was coded as 0, 1, 2, 3, 4, in which 0 was not at all, 1 was a little bit, 2 was somewhat, 3 was quite a bit, and 4 was very much. The 5-level predictor variable, self-efficacy, was coded as 1, 2, 3, 4, 5, with the representative values in which 1 was not at all sure, 2 was not sure, 3 was neither, 4 was sure, and 5 was very sure. The responses were totaled to give a self-efficacy score. The predictor variable gender was coded 1 male and 0 female.

Results

Demographics

Ninety community-dwelling adults (N = 90) with SCD returned completed questionnaires as presented in Table 1. Most participants were female (74%). The age range was 18 to 67 years of age with a mean of 39.5 years (SD 11.9). Most of the participants (53.3%) were single and half of the participants (50%) reported having some college education. Most participants (67.7%) reported earning less than $35,000 per year. The genotype frequencies revealed that most of the participants, 53.4% (47) have HbS S and 30.7% (27) reported HbSC. Of the HbSS participants, 34 (51.5%) were female and there were 13 males (59%). For those with HbSC, 19 (29%) were female and 8 (36%) were male (See Table 1).

Sleep and Pain

Table 2 outlines the description of the pain and sleep data from the case processing summaries. Of this SCD population, most adults (93.3%) reported having some pain within the last 7 days, while less than 17% (16.7%) admitted to sleeping well within the past 7 days. Hence, 83.3% reported not sleeping well. Gender did not reflect differences in pain reports. From this population of 67 women, 39 (58.2%) compared to 13 of 23 men (56.5%) reported having much pain. For this population, based on the SCSES scores, the mean self-efficacy was 30.23, SD 8.12. The Cronbach’s alpha (α) for SCSES was 0.87.
Table 1. Demographic Characteristics of Community-Dwelling Adults with Sickle Cell Disease (N = 90)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total participants</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>90 (100%)</td>
<td>67 (74%)</td>
<td>23 (26%)</td>
</tr>
<tr>
<td>Single</td>
<td>51.6%</td>
<td>34 (50.7%)</td>
<td>14 (60.9%)</td>
</tr>
<tr>
<td>Married</td>
<td>23.7%</td>
<td>16 (23.9%)</td>
<td>6 (26.1%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>16.1%</td>
<td>14 (20.9%)</td>
<td>1 (4.3%)</td>
</tr>
<tr>
<td>Separated</td>
<td>1.1%</td>
<td>1 (1.5%)</td>
<td>1 (4.3%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>2.2%</td>
<td>1 (1.5%)</td>
<td>1 (4.3%)</td>
</tr>
<tr>
<td>Other</td>
<td>2.2%</td>
<td>1 (1.5%)</td>
<td>1 (4.3%)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>6.5%</td>
<td>3 (4.5%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>15.1%</td>
<td>11 (16.4%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Some college</td>
<td>48.4%</td>
<td>36 (53.7%)</td>
<td>9 (39.1%)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>19.4%</td>
<td>12 (17.9%)</td>
<td>6 (26.1%)</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>7.5%</td>
<td>5 (7.5%)</td>
<td>2 (8.7%)</td>
</tr>
</tbody>
</table>

The means and standard deviations of self-efficacy were relatively similar for men and women.

Hypothesis Testing

Hypothesis 1: Sleep quality is positively related to disease-specific self-efficacy. There was a direct, positive relationship between sleep and self-efficacy, \( r = .508, \) at 0.01 level. Hypothesis was supported.

Hypothesis 2: Pain severity is inversely related to sickle cell disease self-efficacy. There was an inverse relationship between sleep and pain, \( r = -.341 \) at 0.01 level. Hypothesis was supported.

Hypothesis 3: Pain severity and sleep quality are inversely related. Pain and sleep are inversely related, \( r = -.401 \) at 0.01 level. Hypothesis was supported.

Hypothesis 4: Gender does not significantly influence pain severity. A linear regression analysis evaluated the prediction. The \( f \) test of the ANOVA reflected, \( F (1, 89) = .287, p = .59 \) and the \( t \) test associated with the independent variable was \( t (89) = -.535, p = .59 \). Hypothesis was supported.

Hypothesis 5: Age significantly influences pain severity, sleep quality, and self-efficacy. Linear regression demonstrated no significance, \( F (1, 86) = 1, p = .396 \). Hypothesis was rejected.

Discussion

This study attempted to identify trends in the explanatory variables: pain, sleep, self-efficacy, age, and gender. The major findings are that gender and age are not significantly related to either sleep or pain. Self-efficacy performance was similar for both males and females. The findings were in line with the expectations that: sleep quality is positively related to SCD-specific self-efficacy, pain is inversely related to SCD self-efficacy, and pain and sleep are inversely related. The hypotheses were supported by the analyses. Findings confirm the expectation that self-efficacy is important for handling SCD-related symptoms.

Previous research has found that higher levels of self-efficacy are associated with and predictive of decline in pain and physical symptoms (Clay & Telfair, 2007; Edwards et al., 2001). Additionally, research supports the notion that the disease-specific SCS E S instrument is psychologically sound and can be used as a screening tool for adults (Edwards et al., 2001) and adolescents (Clay & Telfair, 2007) who may be at risk for negative psychological and physical outcomes as a result of having SCD. The findings of the present study highlight the importance of self-efficacy in dealing with a chronic illness, SCD, and its sequel complications such as pain. For adults with SCD, self-efficacy can mediate illness outcomes, and such knowledge can help practitioners and patients become attentive to areas of living and self-care management that are specific for this population. Self-care management interventions based on self-efficacy can be tailored to meet clients’ needs for improved health outcomes and improved quality of life.

In this study, gender and age were not significant for pain severity reports or sleep quality. In earlier outpatient chronic pain and SCD-related studies, gender was not a significant predictor of rating pain (Call-Schmidt & Richardson, 2003; McClish et al., 2006). Hollis and colleagues (2012) found that females reported increased pain more than did males. However, the report of the increased female pain included all females in the study and not just those with SCD (Hollins et al., 2012). Additionally, Hollis and colleagues (2012) reported that pain intensity was related to increasing age. In this study, gender and age did not significantly affect pain. The small sample size may have contributed to this study’s outcome.

The results of this study apply especially to patients with chronic illnesses such as sickle cell disease, chronic...
pain, and its sequel complications. The findings provide further evidence that there are strong relationships between sleep quality and self-efficacy among community-dwelling adults with SCD. Self-efficacy impacts self-reported symptoms and may serve as a predictor of disease burden (Clay & Telfair, 2007). Health-care providers need to focus on encouraging or facilitating self-efficacy with future interventions.

**Implications for Clinicians**

Clinicians need to assess and evaluate sleep quality and wellness in individuals with chronic pain and assist the patient in instituting sleep hygiene and self-care measures that will improve self-efficacy and quality of life, and decrease pain (Call-Schmidt & Richardson, 2003). Clinicians should assess for the risk of sleep disturbances among those with chronic pain (Graves & Jacob, 2014; Green et al., 2009), and should ask specific questions when interacting with patients with chronic pain who may also be community-dwelling and possibly not under continuous care of a health-care provider. Clinicians should ask if sleep is interrupted by pain or pain disrupts sleep. Additionally, periodic objective measures can be unobtrusively used with portable devices to objectively measure sleep-related problems.

Additionally, clinicians should assist in preventing or identifying cognitive changes related to complications of chronic pain as previously described (Tennant, 2009; Torrance et al., 2010). There is concern about the effects of bi-directional pain causing decreased sleep and decreased sleep causing increased pain (Edwards, Almeida, Klick, Haythornthwaite, & Smith, 2008). The reports of recurrent acute pain and chronic pain may reflect heightened negative pain response, which possibly is influenced by earlier painful vaso-occlusive episodes and neuroplastic changes (Hollins et al., 2012). It is known that neurocognitive changes related to recurrent and chronic pain disallow patients with SCD from detecting small increases in pain that may signal the onset of an episode, and may disallow individuals from being able to take appropriate steps to abate the event (Vichinsky et al., 2010). Clinicians can teach and empower patients and providers to be attentive to patients’ sometimes subtle symptoms and not delay treatment.

**Limitations of the Study**

There were limitations to this study that make it necessary to interpret the study findings with caution. The study used a convenience sample and the findings may not be generalizable to all. However, the sample looked similar to other national samples of individuals with SCD in terms of distribution of gender, genotype, and educational levels. Further, this cross-sectional study did not allow for measurement of variables over time, limiting cause and effect conclusions. The sample size of 90 was small and may have prevented better revelation of data. Finally, there may have been an element of bias in recalling events over the past 7 days. Individuals’ reports may differ over time as they recalibrate perceptions.

**Implications for Future Studies**

Future studies should include the use of objective measurement for sleep quality, for example, by using a portable device that registers cardiopulmonary coupling recordings of breathing and heart rate patterns. This objective measurement, akin to the objective measurement of temperature with a thermometer, can be used as a screening device for community-dwelling adults. Additionally, future research should include a comprehensive sleep assessment of different components of sleep. Studies can include a variety of sleep aspects, such as: sleep quality, duration and architecture, difficulty falling asleep, staying asleep, early awakening, interrupted sleep, and supplementation of sleep through napping (Call-Schmidt & Richardson, 2003). In this study, the measurement of sleep was limited to a 0-5 scale of “I am sleeping well.” As described previously, the self-report to this single item did not give information of various architectural assessments of sleep such as falling asleep easily or awakening from sleep. Further research can also include examination of specific psychosocial variables such as catastrophizing and the impact on pain and sleep (McHugh, Casey, & Lawlor, 2011), especially among individuals who have developed confidence in self-care management (Caird, Camic, & Thomas, 2011).

The findings of this study provide further evidence that there are strong relationships between sleep quality and self-efficacy among community-dwelling adults with SCD. Self-efficacy impacts self-reported symptoms and may serve as a predictor of disease burden (Clay & Telfair, 2007). Health-care providers need to focus on encouraging or facilitating self-efficacy in future interventions. Regarding chronic pain care, the Institute of Medicine report, Relieving Pain in America (2011), posed excellent discussions regarding the need to have a palliative focus and improve clinical and self-management approaches that enhance self-efficacy of individuals with pain and help to maintain a balanced quality of life (Institute of Medicine [IOM], 2011).

**Conclusions**

Overall, this study is an important first step for exploring the relationship between sleep, pain, and self-efficacy among community-dwelling adults with sickle cell disease. The knowledge gained from this study is beneficial to clients, clinicians, and stakeholders in helping adults with SCD self-manage and cope with chronic pain. Increased self-management skills, coping, and self-efficacy will lead to improved quality of life. Additionally, there should be more focus on sleep health among those with chronic pain, and the evaluation of sleep quality needs to be comprehensive.

Despite limitations, this study found strong and medium correlation among sleep and self-efficacy, and self-efficacy and pain. The results give support for includ-
ing sleep assessment in health evaluations and interventions that focus on improving self-efficacy for individuals with chronic pain. Future studies should include more detailed sleep assessment of adults with SCD and evaluate the bi-directional effects of pain-sleep-pain.

References


SurveyMonkey Inc. Palo Alto, California, USA.


