

Natl Black Nurses Assoc. Author manuscript; available in PMC 2013 October 21.

Published in final edited form as:

J Natl Black Nurses Assoc. 2012 December; 23(2): 16–23.

# Voices of Adults Living with Sickle Cell Disease Pain

Maxine A. Adegbola, PhD, RN, CNE, ANEF [Assistant Professor],

University of Texas at Arlington, Arlington, TX

Donelle M. Barnes, PhD, RN, CNE [Associate Professor],

University of Texas at Arlington, Arlington, TX

**Jakki G. Opollo, RN, MSN, MPH [PhD Nursing Student, Graduate Research Assistant]**, Center for Nursing Scholarship & Technology, University of Texas at Arlington College of Nursing, Arlington, TX

Keela Herr, PhD, RN, AGSF, FAAN [Professor & Associate Dean for Faculty],

University of Iowa College of Nursing, Iowa City, IA

Jennifer Gray, PhD, RN [Associate Professor], and

University of Texas at Arlington, Arlington, TX

Ann Marie McCarthy, PhD, RN, FAAN [Professor & Associate Dean for Research]

University of Iowa College of Nursing, Iowa City, IA

#### **Abstract**

The purpose of this qualitative study was to describe the lived experiences of adults with sickle cell disease-related pain. Using a qualitative, phenomenological approach, a purposive sample of 13 African-American adults living with Sickle Cell Disease (SCD) was recruited from a national SCD support group. Participants were asked to describe living with SCD-related pain and their experiences with pain management. Four themes emerged from the data: (1) description of the pain experience, (2) pain scales do not work, (3) managing pain, and (4) managing relationships. Persons living with SCD need comprehensive pain assessment from Health-Care Providers [HCPs], who recognize the impact of pain on their patients' lives. The findings support further research aimed at the assessment and management of SCD-related pain. HCPs are strategically positioned to improve health outcomes for those with SCD pain by listening to patients' unique stories and accurately assessing and effectively intervening to promote pain relief for patients living with SCD-related pain.

Keyword	S
---------	---

sickle cell disease; pain	; phenomenology		

# **Background and Significance**

Sickle Cell Disease (SCD) is an autosomal, recessively-inherited, multi-faceted, chronic blood disease uniquely accompanied by vacillating, chronic, and acute pain attacks that require frequent intervention (Aisiku et al., 2009; Ballas, 2011). This major global health problem affects millions worldwide, especially those with ancestral ties to sub-Saharan Africa (Centers for Disease Control and Prevention [CDC], 2012). In the United States, approximately 100,000 individuals are living with SCD (CDC, 2012).

#### **SCD Defined**

SCD is an umbrella term encompassing several hemoglobin disorders. These hemoglobin disorders occur when an individual is homozygous for hemoglobin S (HbS), or harbors one allele of HbS and another abnormal variant of hemoglobin such as hemoglobin C or  $\beta$ -thalassemia. Individuals who inherited two HbS alleles, one from each parent, will have sickle cell anemia (HbSS). Individuals who inherit HbS and hemoglobin C, one from each parent, will have HbSC. Individuals with HbS and sickle  $\beta$ -thalassemia, one from each parent, will have HbS $\beta$ -thalassemia. There are two forms of HbS $\beta$ -thalassemia, HbS $\beta$ +thalassemia, and HbS $\beta$ 0 thalassemia (CDC, 2010). The HbSS and HbS $\beta$ 0 thalassemia variants manifest as a more severe form of the disease, while HbSC and HbS $\beta$ + thalassemia as a less severe form (Platt & Thorington, 1991). SCD affects the red blood cells causing microvascular occlusion, poorly oxygenated blood supply to tissues, anemia, pain, and multi-system failure.

Pain related to SCD is especially challenging because it is unpredictable and reflects qualities that are both nociceptive and neuropathic. Nociceptive pain refers to tissue damage pain and neuropathic pain refers to pain caused by damage to the peripheral nervous system (Ballas, 2011; Wilkie et al., 2010). SCD pain can be acute (also called crisis), chronic (with unknown etiology or known etiology, e.g., avascular necrosis), or both acute and chronic at the same time. Acute pain combined with chronic pain is also called mixed pain (Ballas, 2011). SCD pain is all encompassing and negatively impacts the patient's quality of life (Booker, Blethyn, Wright, & Greenfield, 2006; Westerdale & Jegede, 2004).

SCD-related impairments are described by Adegbola (2007, 2011a) as biopsychosociospiritual, and these disease-related difficulties affect every dimension of the individual's life. According to Booker and colleagues (2006), individuals have described wide-ranging SCD-related problems including feelings of helplessness, an inability to function in desired or expected roles, fear of early death, loss of virility, frequent priapism (uncontrollable penile erections), social isolation, anger, and non-therapeutic relationships with Health-Care Providers (HCPs).

#### **SCD** and Health-Care Providers

Patients with SCD complain that HCPs are at times insensitive and often do not understand or believe the patient's self-reports of pain (Pack-Mabien & Haynes, 2009). Additionally, some HCPs lack the skills, training, or preparation to accurately assess and manage SCD-related pain (Booker et al., 2006; Pack-Mabien, Labbe, Herbert, & Haynes, 2001). Hence,

individuals with SCD are challenged to explain their pain experience. Patients burdened by HCPs' suspicion and lack of understanding often avoid health-care visits and present to an emergency department only after their pain becomes unbearable or unresponsive to home-initiated interventions (Aisiku et al., 2009; Booker et al., 2006).

HCPs often do not have an objective method for directly assessing the underlying pathophysiologic causes of SCD pain (Todd, Green, Bonham, Haywood, & Ivy, 2006). As with other diseases, they must measure pain from patient's self-reports. To help HCPs assess and manage SCD pain, this study offers insight into the patient's perspective (Adegbola, 2011b; Thomas, 2000).

Prior to the mid 1970s, people with SCD died in their mid-teen or early adulthood years. Scientific advances in treatments, such as the use of Hydroxyurea and prophylactic penicillin, have resulted in longer life spans; 42 years for men and 48 years for women (Platt et al., 1994), and decreasing childhood mortality (Quinn, Rogers, & Buchanan, 2004). This relatively recent change in lifespan may account for the lack of research on SCD pain management in adults (Smith et al., 2008). In addition to the lack of research, there is the lack of a clear definition of chronic pain for individuals with this complex pain syndrome (Taylor, Stotts, Humphreys, Treadwell, & Miaskowski, 2010). Taylor and colleagues (2010), in their review of SCD research studies, discussed many study limitations, the lack of comprehensiveness, and inadequate statistical power.

### SCD: The Experience of Pain

In a landmark study, Smith and colleagues (2008) documented that SCD pain is a daily phenomenon and refuted earlier beliefs that SCD pain occurred only during an acute crisis. Thus, to clarify the complex and multi-faceted ways that pain is experienced, new research must focus on the subjective experiences of pain (Mitchell & MacDonald, 2009). A purely biomedical approach, with its focus on pathophysiology, is inadequate to study both acute and chronic pain and its inherent complexities that persistently affect all areas of people's lives (Thomas, 2000). In addition to a quantitative assessment of SCD pain, a qualitative approach is needed to reveal people's subjective perspective and provide contextual underpinnings for clinical application (Adegbola, 2011b; Greenfield & Jensen, 2010; Thomas, 2000; Thomas & Taylor, 2002).

# Methodology

This study used Heideggerian hermeneutic phenomenology to describe the lived experience of the participant; it seeks to examine and uncover the essential nature and structures of a phenomenon (Dowling, 2004). In this case, the phenomenon was the experience of adults with SCD living with unresolved chronic and acute pain. Because previous researchers assumed that SCD pain was only episodic and acute, or they did not thoroughly or accurately describe SCD chronic pain from the participant's perspective, the Heideggerian approach was selected. To remedy this gap in knowledge, the researchers aimed to advocate for the client's voice in SCD pain description and treatment approaches.

#### **Participant Selection**

A purposive sample of 13 adults (N = 13) diagnosed with SCD, who reported having SCD pain for at least two years, was recruited from a national SCD support group. Participants were eligible if they were at least 18 years old, able to speak English, and could participate in an interview. Consent was obtained and interviews were conducted by telephone, since the support group is national and participants lived far from the researchers.

#### **Institutional Review Board Approval**

Following institutional review board approval (IRB # 2010-0181), informed consent was obtained. All participants were told the purpose of the study, were assured of confidentiality, and were told that data would be reported in aggregate form. A \$25 gift card was offered to participants who provided their mailing address at the end of the interview.

#### **Data Collection**

All interviews were conducted via telephone and each lasted between 30 and 60 minutes. Telephone interviews were conducted because participants did not live in same geographic area as the interviewer [MA]. To elicit data, participants were asked to respond in their own words to the interview questions. Sample questions were, "Tell me about living with sickle cell disease," and "What does chronic pain mean to you?" Pseudonyms were used in transcripts to ensure confidentiality. Interviews were recorded and transcribed verbatim by a trained graduate research assistant. Demographic information, obtained at enrollment, included age, gender, educational level, employment status, and SCD genotype. The openended, semi-structured interview guide allowed the interviewer freedom and flexibility to discover their everyday lived experiences (Morse & Field, 1995). As interviews were transcribed, they were also analyzed, and 13 interviews were completed to assure data saturation (Patton, 2002).

### **Data Analysis**

Although the methodological underpinning of this study was drawn from Heidegger's work, van Manen's (1990) thematic analysis was used to interpret the data and reflect on meanings embedded in the experiences. Data analysis included immersion and iterative organization of the data set into understandable themes, grouped and further synthesized to describe the phenomenon (van Manen, 1997).

The transcripts were read multiple times and themes were jointly identified. Words and phrases germane to the research question were initially identified and were clustered into categories during secondary coding sessions. Interviews in the passage sections were compared and labeled with themes. Themes were grouped into categories to uncover the meaning of living with SCD and chronic pain. This validation process was repeated to uncover a depth of meaning.

Scientific rigor, ethical standards, and quality assurance were maintained throughout the study, with frequent consultations among all authors until consensus was achieved. Peer validation from colleagues outside of the research project who had experience with this

population were solicited and received. Additionally, member checking was used with four participants to verify concordance between the authors' findings and the participants' messages.

#### Results

All of the participants (N = 13) were African-American. There were 3 males and 10 females with an average age of 31 years (range = 21-54 years). Eleven participants had HbSS; one had HbS $\beta^0$  thalassemia; and one had HbSC genotype. At the time of the study, most of the 13 participants were single (n = 9) and had attained some college education (n = 9). In the year before the study, the participants reported between 3 and 10 hospital admissions, unscheduled visits to the emergency department, or had seen a health-care provider. The qualitative analysis led to identification of four themes related to the pain experience: (1) description of the pain experience, (2) pain scales do not work, (3) managing pain, and (4) managing relationships.

#### **Description of the Pain Experience**

Adults with acute pain described their pain as "unbearable," "excruciating," "sharp," "penetrating," "like a hammer, beating and beating," "throbbing," "stabbing," and "squeezing." It is "a pain that I wouldn't wish on my worst enemy." "It's like being hit by a truck and getting run over." "When I get sick I do not want anyone to touch me; I'll be in screaming pain." "The sickle cell pain is what takes you down. You can't move; can't do anything." "The majority of time, my life has been filled with pain." Participants described chronic pain as "constant," "every day," "regular basis," and usually "managed at home."

Participants defined acute pain as an unbearable episode of localized pain that exceeded everyday chronic pain levels and was sometimes accompanied by fever, blurred vision, and other symptoms. Some participants described specific crises or acute pain triggers including stress, cold weather, and dehydration. Compared to throbbing chronic pain, crisis pain was described as stabbing and severe with an intensity of 10 or greater on a 0 to 10-point scale. When home remedies or pain medications failed to provide relief, participants went to the emergency department.

#### Pain Scales Do Not Work

African-American adults with SCD reported that numeric pain rating scales were not useful for rating SCD acute pain, did not reflect the magnitude of pain experienced, and resulted in the prescription of insufficient medications. "The questions they ask are outdated ... the numbers are for children who don't understand pain and can't register it. For adults, it may be quite different." For participants who have lived with chronic pain in the range of 8 to 10, acute pain was "off the charts," that is, it could not be adequately described by existing pain scales. Another participant stated:

"If you are going to use a scale of 0 to 10, then what I've always heard is the worst pain will never be felt. If I tell you it's an eight compared to the worst pain I've ever felt, it's probably a 25 on a scale of pain for an average person, so I think it's deceptive."

Participants desired and expected comprehensive pain assessments beyond a numeric pain scale. HCPs do not ask, but should assess, the location of the pain, its type or quality, and the self-care measures or pain medications that have been taken at home. Participants expressed the desire for a more comprehensive approach when working with adults living with chronic pain and/or having an acute event. One participant explained:

"They (HCPs) should try to investigate all that adults are going through to discover a reason for their particular pain. So to me, you have to identify other parts of their lifestyle to be able to make a good diagnosis and to decide whether they are having chronic pain because something is worn out in your body or because of something that they might be experiencing emotionally."

### **Managing Pain**

Findings from this study indicated, as they grew up living with SCD pain, that participants learned to balance their daily activities, to make decisions about jobs, relationships, and family activities based on their pain levels, and to choose effective medications. For example, they realized that with certain pain triggers, such as cold weather, they had to choose indoor jobs or allow for sick days.

In addition to using pharmacologic agents, the participants used natural approaches to pain management such as heat, massage, or phytochemicals from vegetable and fruit juices. Some looked for alternative therapies due to fear of medication side effects. In reference to the use of Hydroxyurea, one individual reported, "I guess I am just scared of it [Hydroxyurea] being a chemo drug."

At times, adults with SCD described a sense of futility. One participant said, "In my early life, several times I just wanted to die." Others coped with the pain by using a positive attitude, faith in God or spirituality, and a support group. One participant described "faith" as "having a relationship with a higher power, God, that I tap into to help me cope."

#### Managing Relationships

Adults with SCD have had to learn how to manage relationships, both professional and personal, as they dealt with acute and chronic pain. Professional relationships include primary care and emergency care providers, while personal relationships include friends and family.

**Professional relationships**—When they have been in an acute crisis, participants have found it difficult to communicate with emergency department HCPs who were new to SCD or who were not their usual HCP. Rather than using words like "crisis" to sum up their symptoms, they had to expend additional energy to describe their disease and pain, its location and severity, as compared to their communication with a known provider familiar with their disease. This was burdensome because it was taking all the energy they had to cope with the severe, acute pain, and they had none left over for lengthy explanations. Participants also worried about whether HCPs delayed pain medication administration as they considered what to prescribe. Any delay in medication administration lengthened the pain experience. One participant described her frustration during a recent admission: "Your

hematologist might be able to stop by, but you are actually under the care of hospitalists, which I really don't like because I don't think they have enough history to be able to treat me effectively."

Additionally, participants wondered whether their pain levels and symptoms would be believed and taken seriously by HCPs, or if they were simply labeled a "drug addict." Such labeling was hurtful on an emotional level in addition to their physical pain. One participant told her story of hearing HCPs behind the curtain in an emergency department say, "Oh, it's the sick blood who wants her pain medicine again." "They act like they don't understand the [SCD] pain." Not being believed, or being negatively labeled, diminished the patient-provider relationship in these cases. The participants felt further demoralized when they sensed they were viewed as a member of an ethnic minority who was exhibiting the drugseeking behaviors of a drug addict. Any prejudicial label discouraged them from seeking health care, and when multiple labels were assigned, the hurt was compounded.

Labeling and discriminatory remarks, combined with the HCPs' ignorance of treatment, made participants fear they would not get adequate or accurate treatment. For example, an individual feared not receiving enough oxygen when the saturation levels are less than 95% or not being prescribed enough pain medication. These strained the participant-HCP relationship, causing participants to believe they must educate themselves about current SCD treatments so they could request appropriate treatments and seek out specific caring and informed HCPs.

Personal relationships—Some African-American adults with SCD have been called "trait carriers" by others, and have feared that their children would be marginalized with negative labels. Rather than disclose their diagnosis or symptoms, they have sometimes put on a "mask" and pretended to be normal in order to carry out routine activities with friends. One participant said, "I always say I am 'OK' because I don't want people to act like I can't do things. I know how to put on a mask." Telltale signs or symptoms such as corneal jaundice or acute pain, however, sometimes forced them to reveal their disease. One woman with SCD said that she would not initially tell a boyfriend that she has SCD on the first few dates for fear of him being "freaked out" or "upset" when she was in pain. She avoids discussing the disease, or minimizes its impact, in order to carry on with normal relationships.

Putting on a mask has had negative consequences in some situations. For example, adults who hide or minimize pain may cause HCPs to also discount their pain, leading to inadequate or no treatment in the emergency department. One participant stated, "I may not appear to be in as much pain as I'm telling you, but I'm saying, hey look, I got about three more minutes and I'm about to go off in here if you don't hurry up." Another participant explained, "I would really like people to know that chronic pain does not mean that it is not pain, or that I'm so used to it that it does not need to be treated. I'm having pain that must be treated because it's not going anywhere." Adults with SCD have to balance their desire to be treated normally in personal relationships with their need to be clearly understood when they need help or understanding in coping with pain.

## **Discussion**

The findings from this study add to the limited body of knowledge about the lived experiences of adults with SCD pain. Participants described how they lived with unalleviated chronic and acute pain despite current pharmacological options. It is interesting to note that they had difficulty describing their clinical situations and symptoms to unbelieving or unfamiliar HCPs, and they alluded to receiving suboptimal pain management that has been similarly referenced in other studies (Benjamin, Swinson, & Nagel, 2000; Green, Ndao-Brumblay, Nagrant, Baker, & Rothman, 2004; Green et al., 2003).

Similarities between this current data and other SCD studies were observed. For example, SCD pain was unpredictable in its onset and course (Thomas, Hambleton, & Serjeant, 2001). Participants in this study discussed the unplanned and precipitous nature of symptoms, controlling triggers, and maintaining a sense of normalcy. Participants could readily distinguish between chronic pain, acute (crisis) pain, and non-SCD-related pain by drawing on their experiences. They described chronic pain as everyday or constant pain, while crisis pain was localized, intermittent, and usually prompted a need to go to the hospital. In terms of pain management, they depended on historical experience and gut impressions for direction.

A consistently reported complaint was particularly surprising: traditional pain scales were not an effective or realistic way to measure SCD pain. Study participants discussed the inadequacy of traditional 0 to 10 pain scales and noted a difference in pain self-assessment among adults versus children. They explained that children lack a frame of reference for pain, and therefore may need a rigid scale to identify pain intensity. Adults, on the other hand, possessed language skills that enabled them to articulate pain intensity, duration, and quality. Moreover, participants suggested that comprehensive assessment might capture precipitating, compounding, or contributing factors to the pain.

It became apparent that these patients felt uncared for when the pain scale was the only assessment offered; these participants implored HCPs to convey interest, presence, engagement, caring, and attentiveness to each individual's story (Green, 2011). HCPs are encouraged to find new, or revisit the use of, pain scales for SCD, and to explain repeatedly to patients that the use of pain scales was an important gauge of treatment effectiveness.

Often, by the time adults presented to the health-care provider, they had already exhausted all available methods to ameliorate their pain and may become easily irritated by what they perceived as the HCPs' inattentiveness, mistrust, and uncaring behaviors. Provider adherence to specialized protocols, as described by Benjamin and colleagues (1999, 2000), and intervention strategies discussed by Haywood and colleagues (2009), could potentially improve pain management.

Beyond possessing technical and biomedical skills in symptom management, providers must also be attentive to each individual's unique concerns and listen to the individuals' stories (Fox & Chesla, 2008). By listening more, HCPs can help individuals explain their specific challenges and circumstances and expose nuances that may not have been evident initially (Brown, 2012). Such information can help HCPs minimize health disparities and decrease

patients' burden of mental pain (Adegbola, 2011b; Anderson, Green, & Payne, 2009; Green, 2011). Many individuals experienced emotional pain when they perceived that an HCP was inattentive to their needs. Some participants discussed being demoralized by HCPs, which worsened their emotional pain and added to physical suffering. Perceptions of stigma and discrimination described by participants concurred with reports in other studies (Haywood et al., 2009; Jenerette, Brewer, & Leak, 2011).

Some of the reported demoralizing labels such as "sick blood" and "drug seeker" may result from HCP insensitivity and disregard for individuals' self-knowledge of treatments that had worked for them in the past. Increased use of portable prescription cards or compatible electronic records, which document prior pain episodes and effective treatment, are recommended to improve communication among HCPs and to empower SCD patients to remain engaged in their own care. Most individuals with chronic illnesses and longitudinal experiences have an understanding of which interventions or practices are beneficial. HCPs should welcome the individual's input in planning care and should not view the knowledgeable patient as manipulative or conniving.

An electronic portal for obtaining a patient's prior pain management and treatment plan might also minimize the HCPs' skepticism of an individual's self-reported pain and requested treatment. Some of the participants discussed the HCPs' lack of trust, especially when they were unfamiliar with the patient's clinical condition or seemed to lack the skills necessary to assess and manage SCD pain (McHugh & Thoms, 2001; Pack-Mabien et al., 2001). Some patients burdened by these clinical inadequacies and perceived lack of personalized care avoid health-care utilization and visit the emergency department as a last resort (Aisiku et al., 2009; Booker et al., 2006).

Patients have reported dissatisfaction with HCPs' lack of empathy and inadequate management of chronic SCD-related pain, resulting in non-therapeutic patient-HCP relationships (Booker et al., 2006). Other researchers (Anderson et al., 2009; Green et al., 2003; van Ryn & Fu, 2003) have documented that minority patients reported they experienced inappropriate care and perceived less trust and respect from HCPs compared with non-minority patients. The perceived disrespect from HCPs caused increased emotional pain and compounded their physical pain (Anderson et al., 2009; van Ryn & Fu, 2003). Additionally, HCPs outside of comprehensive sickle cell centers may give fragmented care and may be unfamiliar with current management strategies. Emotional and psychological pain can often be addressed by improved culturally appropriate approaches (Brown, 2012), provider presence, and intentional attentiveness (Green, 2011). These skills can be developed through sensitivity training and cultural awareness (Haywood et al., 2009).

Proper management of SCD requires a coordinated, multi-faceted, chronic illness approach that models the updated, multidisciplinary, and specialized disease-specific care provided by comprehensive sickle cell centers and outpatient day hospitals (Benjamin et al., 2000). Adequate pain management and specialized SCD-related services provided by day hospitals or centers reduce the challenges of navigating busy emergency departments, decrease fragmented care, minimize patient suffering, and promote improved health outcomes overall (Brown, 2012). Within such a collaborative model, patients are encouraged to be involved in

their own care. Because SCD is a global health problem (Sickle Cell Disease Association of America, Inc. [SCDAA], 2012; Westerdale & Jegede, 2004; World Health Organization [WHO], 2012), these improved health outcomes can favorably impact global SCD-related care.

# **Implications for Clinical Practice**

To take full advantage of the interpersonal process when assessing and managing pain, HCPs need additional training regarding the importance of trusting and having respect for the individuals in their care (Caird, Camic, & Thomas, 2011; Elander, Lusher, Bevan, & Telfer, 2003). HCPs are also encouraged to develop an understanding of the differences between older and younger patients in coping strategies and the use of the health-care system (Sanders, Labott, Molokie, Shelby, & Desimone, 2010).

Particularly in acute care departments, providers must be trained to do a more rapid yet personalized assessment to be able to alleviate sickle cell pain more quickly. Participants also requested more comprehensive pain assessment with consideration of the accompanying psychosocial factors of living with SCD. Therefore, HCPs should combine an objective numerical pain intensity scale with other more subjective factors including categorical intensity of mild, moderate, and severe; expected level of satisfied pain relief; threshold or tolerance; and aggravating or relieving factors. In summary, the schema to assess and evaluate pain should be more comprehensive, targeted to the population, and tailored to the individual (Brown, 2012).

# Implications for Future Research

Findings from this study suggest that researchers need to develop new pain scales, or modify existing scales, to replace those currently used that assess only one dimension of pain. In addition to assessing pain severity, other related factors, including pain locations, pain quality, behavioral or situational considerations, and associated nuances, should also be determined (Adegbola, 2011b; Green, 2011). For the acute care environment, additional research related to the comprehensive assessment of acute, chronic, and mixed pain is also needed. There is an additional need for future collaborative intra-professional research to focus on objectively measuring pain. This research, and subsequent interventions, could guide progressive care into the future and impact policy.

# **Study Limitations**

This sample reflects proactive, involved individuals who have computer access and who participate in a support network. These findings are limited to information provided by participants who expressed their personal experiences during interviews. Adults were selected from a national SCD support group's electronic database and may not be generalizable to the larger SCD population. Finally, findings from hermeneutic phenomenological studies are often subject to alternative interpretations.

### **Conclusions**

In this study, the participants reported dissatisfaction with pain management and care from HCPs. Individuals often felt demoralized, stigmatized, and uncared for by HCPs who were inattentive to their individual concerns or situations that impacted their pain experience. Participants thought that the numeric pain scale alone did not accurately capture the severity or multi-faceted spectrum of their chronic pain experience, and expressed a desperate need for improved pain management through use of updated assessments. Future research should be attentive to developing or modifying tools that will measure pain in a more precise and comprehensive manner.

Information gained from learning about an individual's pain experiences can support a specific, personalized approach for improving care and can minimize the risk for poor health outcomes. The failure to examine the meaning of one's life is a risk factor for poor health outcomes and disparate care (Krupski et al., 2006).

#### **Clinical Resources**

Sickle Cell Disease Association of America, Inc. (SCDAA). (2012). Retrieved September 15, 2012 from: http://www.sicklecelldisease.org/index.cfm?page=about-scd

The American Pain Society Clinical Practice Guidelines for Management of Acute and Chronic Pain in Sickle Cell Disease. http://www.ampainsoc.org/library/pdf/sicklecell\_guideline02.pdf

Current Guidelines for Sickle Cell Disease Management of Acute Complications. http://www.ebmedicine.net/topics.php?paction=showTopicSeg&topic\_id=209&seg\_id=4261

U.S. Department of Health and Human Services, National Institutes of Health, National Heart Lung and Blood Institute. The management of sickle cell disease. Fourth edition, revised June, 2002. NIH Publication No. 02-2117. (Clinical Guideline). Accessed September 3, 2012, from: http://www.nhlbi.nih.gov/health/prof/blood/sickle/index.htm

# **Acknowledgments**

During this study, Dr. Adegbola was supported by a NINR Postdoctoral Fellowship "Pain and Associated Symptoms: Nurse Research Training" -T32 NR11147 at the University of Iowa College of Nursing. The research project was supported by a grant from Sigma Theta Tau International, Delta Theta chapter. We thank the individuals who participated in this study.

### References

Adegbola, MA. PhD, Doctoral dissertation. The University of Texas at Arlington; 2007. The relationship among spirituality, self-efficacy, and quality of life in adults with sickle cell disease. 2007Proquest, (AAT3289109)

Adegbola MA. Spirituality, self-efficacy and quality of life among adults with sickle cell disease. Southern Online Journal of Nursing Research. 2011a; 11(1):1–16. PMC31377798.

Adegbola MA. Using lived experiences of adults to understand chronic pain: Sickle cell disease, an exemplar. I-Manager Journal on Nursing. 2011b; 1(3):1–12. PMC3398812.

Aisiku IP, Smith WR, McClish DK, Levenson JL, Penberthy LT, Roseff SD, Roberts JD. Comparisons of high versus low emergency department utilizers in sickle cell disease. Annals of Emergency Medicine. 2009; 53(5):587–593. [PubMed: 18926599]

- Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: Causes and consequences of unequal care. Journal of Pain. 2009; 10(12):1187–1204. doi:10.1016/j.jpain.2009.10.002. [PubMed: 19944378]
- Ballas SK. Update on pain management in sickle cell disease. Hemoglobin. 2011; 35(5-6):520–529. [PubMed: 21910604]
- Benjamin, L.; Dampier, C.; Jacox, A.; Odesina, V.; Phoenix, D.; Shapiro, B.; Treadwell, M. Guideline for the management of acute and chronic pain in sickle-cell disease. No.1 ed. American Pain Society; Glenview, Ill: 1999. APS Clinical Guidelines Series
- Benjamin L, Swinson G, Nagel R. Sickle cell anemia day hospital: An approach for the management of uncomplicated painful crises. Blood. 2000; 95(4):1130–1136. [PubMed: 10666181]
- Booker MJ, Blethyn KL, Wright CJ, Greenfield SM. Pain management in sickle cell disease. Chronic Illness. 2006; 2(1):39–50. doi:10.1179/174592006x93860. [PubMed: 17175681]
- Brown M. Managing the acutely ill adult with sickle cell disease. British Journal of Nursing (BJN). 2012; 21(2):90–96.
- Caird H, Camic PM, Thomas V. The lives of adults over 30 living with sickle cell disorder. British Journal of Health Psychology. 2011; 16(3):542–558. doi:10.1348/135910710X529278. [PubMed: 21722275]
- Centers for Disease Control and Prevention. [Retrieved February, 11, 2011] Sickle cell disease data and statistics. 2012. from: http://www.cdc.gov/NCBDDD/sicklecell/data.html
- Dowling M. Hermeneutics: An exploration. Nurse Researcher. 2004; 11(4):30–39. [PubMed: 15227897]
- Elander J, Lusher J, Bevan D, Telfer P. Pain management and symptoms of substance dependence among patients with sickle cell disease. Social Science and Medicine. 2003; 5(9):1683–1696. [PubMed: 12948577]
- Fox S, Chesla C. Living with chronic illness: A phenomenological study of the health effects of the patient-provider relationship. Journal of the American Academy of Nurse Practitioners. 2008; 20(3):109–117. doi:10.1111/j.1745-7599.2007.00295.x. [PubMed: 18336687]
- Green CR. Being present: The role of narrative medicine in reducing the unequal burden of pain. Pain. 2011; 152(5):965–966. doi:10.1016/j.pain.2011.01.041. [PubMed: 21310530]
- Green CR, Anderson KO, Baker TA, Campbell LC, Decker S, Fillingim RB, Vallerand AH. The unequal burden of pain: Confronting racial and ethnic disparities in pain: Erratum. Pain Medicine. 2003; 4(3):277–294. doi:10.1111/j.1526-4637.2005.05018.x. [PubMed: 12974827]
- Green CR, Ndao-Brumblay SK, Nagrant AM, Baker TA, Rothman E. Race, age, and gender influences among clusters of African American and White patients with chronic pain. The Journal of Pain. 2004; 5(3):171–182. doi:10.1016/j.jpain.2004.02.227. [PubMed: 15106130]
- Greenfield BH, Jensen GM. Understanding the lived experiences of patients: Application of a phenomenological approach to ethics. Physical Therapy. 2010; 90(8):1185–1197. doi:10.2522/ptj. 20090348. [PubMed: 20539020]
- Haywood C Jr. Beach MC, Lanzkron S, Strouse JJ, Wilson R, Park H, Segal JB. A systematic review of barriers and interventions to improve appropriate use of therapies for sickle cell disease. Journal of the National Medical Association. 2009; 101(10):1022–1033. [PubMed: 19860302]
- Jenerette CM, Brewer C, Leak AN. Self-care recommendations of middle-aged and older adults with sickle cell disease. Nursing Research and Practice. 2011:1–5. doi:10.1155/2011/270594.
- Krupski TL, Kwan L, Fink A, Sonn G, Maliski S, Litwin MS. Spirituality influences health related quality of life in men with prostate cancer. Psycho-Oncology. 2006; 15(2):121–131. [PubMed: 15880458]
- McHugh G, Thoms G. Living with chronic pain: The patient's perspective. Nursing Standard. 2001; 15(52):33–37.
- Mitchell L, A. MacDonald RA. Qualitative research on pain. Current Opinion in Supportive and Palliative Care. 2009; 3(2):131–135. [PubMed: 19421064]

Morse, JM.; Field, P. Qualitative research methods for health professionals. Sage; Thousand Oaks, CA: 1995.

- Pack-Mabien A, Haynes J. A primary care provider's guide to preventive and acute care management of adults and children with sickle cell disease. Journal of the American Academy of Nurse Practitioners. 2009; 21(5):250–257. doi:10.1111/j.1745-7599.2009.00401.x. [PubMed: 19432908]
- Pack-Mabien A, Labbe E, Herbert D, Haynes J Jr. Nurses' attitudes and practices in sickle cell pain management. Applied Nursing Research. 2001; 14(4):187–192. [PubMed: 11699021]
- Patton, MQ. Qualitative research and evaluation methods. Sage; Thousand Oaks, CA: 2002.
- Platt OS, Thorington BD. Pain in sickle cell disease. New England Journal of Medicine. 1991; 325(1): 11–16. [PubMed: 1710777]
- Platt OS, Brambilla DJ, Rosse WF, Milner PF, Castro O, Steinberg MH, Klug PP. Mortality in sickle cell disease-life expectancy and risk factors for early death. The New England Journal of Medicine. 1994; 330(23):1639–1644. [PubMed: 7993409]
- Quinn CT, Rogers ZR, Buchanan GR. Survival of children with sickle cell disease. Blood. 2004; 103(11):4023–4027. [PubMed: 14764527]
- Sanders KA, Labott SM, Molokie R, Shelby SR, Desimone J. Pain, coping and health care utilization in younger and older adults with sickle cell disease. Journal of Health Psychology. 2010; 15(1): 131–137. doi:10.1177/1359105309345554. [PubMed: 20064892]
- Sickle Cell Disease Association of America, Inc.. About Sickle Cell Disease. 2012. Retrieved from: http://www.sicklecelldisease.org/index.cfm?page=about-scd
- Smith WR, Penberthy LT, Bovbjerg VE, McClish DK, Roberts JD, Dahman B, Roseff SD. Daily assessment of pain in adults with sickle cell disease. Annals of Internal Medicine. 2008; 148(2): 94–101. [PubMed: 18195334]
- Taylor LE, Stotts NA, Humphreys J, Treadwell MJ, Miaskowski C. A review of the literature on the multiple dimensions of chronic pain in adults with sickle cell disease. Journal of Pain and Symptom Management. 2010; 40(3):416–435. [PubMed: 20656451]
- Thomas S, P. A phenomenologic study of chronic pain. Western Journal of Nursing Research. 2000; 22(6):683–705. [PubMed: 11094573]
- Thomas VJ, Hambleton I, Serjeant G. Psychological distress and coping in sickle cell disease: Comparison of British and Jamaican attitudes. Ethnicity & Health. 2001; 6(2):129–136. [PubMed: 11480961]
- Thomas VJ, Taylor LM. The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups. British Journal of Health Psychology. 2002; 7:345–363. [PubMed: 12614505]
- Todd KH, Green C, Bonham VL Jr. Haywood C Jr. Ivy E. Sickle cell disease related pain: Crisis and conflict. Journal of Pain. 2006; 7(7):453–458. [PubMed: 16814684]
- van Manen, M. Researching the lived experience: Human science for an action sensitive pedagogy. SUNY Press; NY: 1990.
- van Manen M. From meaning to method. Qualitative Health Research. 1997; 7(3):345–369.
- van Ryn M, Fu SS. Paved with good intentions: Do public health and human service providers contribute to racial/ethnic disparities in health? American Journal of Public Health. 2003; 93(2): 248–255. [PubMed: 12554578]
- Westerdale N, Jegede T. Managing the problem of pain in adolescents with sickle cell disease. Professional Nurse. 2004; 19(7):402–405.
- Wilkie DJ, Molokie R, Boyd-Seal D, Suarez ML, Kim YO, Zong S, Wang ZJ. Patient-reported outcomes: Descriptors of nociceptive and neuropathic pain and barriers to effective pain management in adult outpatients with sickle cell disease. Journal of the National Medical Association. 2010; 102(1):18–27. [PubMed: 20158132]
- World Health Organization. Sickle cell disease and other haemaglobin disorders fact sheet. 2012. Retrieved from: http://www.who.int/mediacentre/factsheets/fs308/en/index.html