

Investigating the Relationship between Children, Depression, and Pain in Black Women with Sickle Cell Disease (SCD)

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Abstract

Medical advances in obstetrics and hematology have encouraged researchers to investigate the reproductive risk in women with Sickle Cell Disease (SCD) attempting motherhood. However, few hematological studies have been completed focused specifically on the reproductive mental health of Black women with SCD. Historically women with SCD have been guided away from childbirth under the premise that they were not emotionally or physically capable of managing children. One question that remains unclear, from the limited research available in this area, is whether the presence of children serves to influence mood and pain in Black women with SCD. The current study examined the effects of the presence of children on self-reported pain and depressive symptoms and the relationship between pain and psychological functioning in African American women with SCD. Self-reported rates of depression, pain intensity, and pain severity were evaluated in 70 African American females with SCD. Results of Analysis of Covariance (ANCOVA) did not find differences in reported mood or pain between women with and without children. The current study serves as an initial observation upon which replication of the current findings and future prospective studies can be conducted. The study may ultimately mature into an area of research that guides reproductive decision-making for women with SCD and their doctors.

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Introduction

The experience of motherhood is differentially defined and experienced as a function of factors such as culture, race, religion, age, and gender. For example, men may view the construct of “motherhood” quite differently than women¹, or post-menopausal women may view the construct differently than women still in their child bearing ages². Nonetheless, within the diversity of the construct of motherhood lies the commonality of an intimate kinship experience for the purpose of facilitating the rearing and maturation of offspring within societal guidelines. There is a multitude of factors that influence how motherhood is manifest, but few studies have ever explored the impact of motherhood on African American women with a genetic disorder such as Sickle Cell Disease (SCD)¹. The process by which women with SCD decide whether to conceive a child or the impact of having a child has yet to be explored.

Prunty and colleagues (2008)¹ defined the motherhood decision in the family planning framework as the choice to forego, start or enlarge a family. Women with illness and diseases have often viewed motherhood as a risky venture due to health-related concerns impacting the physical conditions of baby and mother, fear of the baby inheriting the illness, and risks associated with medications to manage the illness. Women with chronic illnesses are sometimes made to feel irresponsible for their desire to want to experience motherhood³. This could result from the fact that many physicians and providers of care are not very

knowledgeable on the psychosocial processes that promote the desire for motherhood or the consequences of motherhood on clinical outcomes. Research has found that many primary care physicians lack the basic understanding of the principles of genetics ultimately leading to the potential of providing inaccurate information to families regarding their genetic risks³.

SCD is an autosomal recessive blood disorder⁴ with a myriad of symptomatology that collectively affects individuals psychosocially, physically, and psychologically^{5,6,7,8,9,10}. Within the United States on an annual basis, this debilitating blood disorder is responsible for approximately 113,000 hospitalizations and \$488 million dollars in hospitalization costs¹¹. SCD is the most common inherited blood disorder in the United States^{6,11} and disproportionately afflicts individuals originating from the sub-Saharan African region, but also affects individuals of Caribbean, Mediterranean, Hispanic, Native American, East Indian, and Eastern Asian ancestry^{7,9,12,13}. Today, it is estimated that more than 80,000 individuals have SCD in the United States¹⁴.

Pain is not only the most common symptom among patients with SCD, but it serves as the most frequent complication as well as the main presentation for medical care^{7,15,16}. Sickle cell-related pain has been localized as typically occurring in the long bones, the joints, the back, the abdomen, and the chest^{16,17}, however, the pathophysiology of the pain’s duration and frequency is complex in nature and incompletely

(Continued on page 16)

understood^{7,17,18}. There is growing evidence suggesting that the psychological factors surrounding SCD may influence complaints of pain^{5,7,10,19}.

Individuals living with SCD experience an overabundance of life stressors (society's attitudes and perception, discrimination, high cost of health care) that impact their health and quality of life and may result in increased psychological and physical morbidity, and mortality^{8,20}. Although extensive research has been conducted investigating depression in the chronic medical illness population, there is a scarcity of studies investigating the effects of depression among black adults with SCD, especially women. This scarcity is significant because it is noted by researchers that black women appear to be at increased risk for depression²¹. Black women are thought to be disproportionately at risk for depression due to various factors that affect the population and increase the likelihood of a negative life trajectory²². Many of these factors include targeted gender and race related illnesses, low socioeconomic status (which can lead to a number of plausible life circumstances; homelessness, incarceration, exposure to violence, persistent psychological stressors, and poverty), single relationship status, and absence of health care insurance.

The current study examines SCD-related pain severity and intensity as well as depressive symptoms in women with SCD as a function of having or not having children. More specifically, the study posits that, among African American women, those with SCD and children will have higher levels of self-reported pain and

depression compared to women with SCD but without children. The decision to study women with SCD was made for the following reasons: (1) sickle cell affects African Americans at an alarming rate, with one in every 375 African Americans in the United States having SCD⁷; (2) very little has been published in the field of women's health with SCD and depression; and, (3) there is increasing evidence that SCD is an excellent model to study factors that influence African American health.

Method

Design

The current study represents a cross-sectional survey evaluation of first-year data collected as part of a longitudinal study of the interaction among psychosocial, medical, and sociodemographic factors in predicting pain and medical outcomes in patients with SCD. All participants were given and signed informed consent, and the study was approved by the Duke University Institutional Review Board.

Participants

Subjects consisted of 70, ages 18-75, Black female patients with SCD recruited from the Comprehensive Sickle Disease Center at Duke University Medical Center. Individuals were excluded from participation in the study if they were actively in an acute episode of pain or other urgent medical crisis at the time of the clinic visit, had been diagnosed with an eating disorder, or if they were unable to read and comprehend the written instructions for testing. Patients were also excluded from analysis if they had a

significant diagnosis other than SCD (severe mental retardation, etc.).

Measures

Pain intensity.

The Short-Form McGill Pain Questionnaire (SF-MPQ).

The Short-Form McGill Pain Questionnaire and a visual analogue scale (VAS) were used to measure pain intensity²³. The SF-MPQ is structured to assess qualitative and quantitative aspects of pain, including location, intensity, quality, and temporal dimensions. Participants were asked to rate the current intensity of each pain-related adjective by circling "none, mild, moderate, or severe." Participants also rated the items on a 10-point scale. The VAS consists of a 100-mm line with "no pain" written at one end and "worst imaginable pain" written at the opposite end, and was used to assess spontaneous pain. The distance in millimeters from the "no pain" end to the location of the mark gave a measurement of the pain. In the current study, the results were presented for all 4 composite items from the SF-MPQ. Two of the variables were subscales (sensory and affective) of the SF-MPQ. One variable was the VAS. The final variable, the present pain index (PPI), is a single-question summarizing the patient's pain experience. The measure has demonstrated validity and reliability with multiple pain populations. Intraclass correlations, as estimates of reliability, for the sensory, affective, and average pain scores, are 0.96, 0.95, 0.88, and 0.89, respectively.³⁴ There is a very high

correlation between scales of the long and short forms of the McGill Pain Questionnaire.

Depression.

The Symptoms Checklist-90 Items-Revised (SCL-90-R).

The Symptoms Checklist-90 Items-Revised was used to evaluate the magnitude of common psychopathologies, including somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, phobic anxiety, hostility, paranoia, psychosis, General Severity Index (GSI), Positive Symptom Distress Index (PSDI), and the Positive Symptom Total (PST) (Derogatis et al., 1976). Response options range from "0" (not at all) to "4" (extremely). Internal consistency for the subscales ranges from .77 to .90. Cronbach alphas for the GSI are exceptionally high and between .96 and .97.

The Beck Depression Inventory (BDI)

The Beck Depression Inventory was used to measure depression²⁴. The BDI is a 21-item test that measures the presence of and degree of depression in adolescents and adults. The BDI, a commonly used scale for measuring depression in medically-ill populations, has demonstrated high internal consistency, concurrent validity with other measures of depression, and construct validity with psychological, behavioral, and attitudinal variable related to depression.

Procedures

All patients were consented and enrolled individually during routine visits to hematology clinic. Patients were identified by the study hematologist as suitable for participation based upon the patient's ability to read, and their characteristics matched against exclusion criteria. They were then approached by study personnel about participation. All patients were given a brief verbal overview of the study and to inform them that we would be conducting a review of their historical patterns of healthcare utilization from their medical records, and then were allowed to read the consent forms. Each subject was allowed to ask questions and gain clarification before signing consent. Subjects were then provided a copy of the survey, moved to a relatively quiet or isolated portion of the waiting room when possible, and given instructions for completion of the survey by a member of the study team. Additional clarification or instructions were given to patients as requested. Once complete, the survey was collected and an informal debriefing was provided.

Results

Data Analyses

Data from the participants were sorted into two groups- women with children and women without children- to create the primary independent variable for the current study. Thirty-one females did not have biological children (44.3%) whereas 39 females reported biological children (55.7%). Descriptive statistics were used to describe the sample characteristics. A pre-

analysis of simple regressions was conducted in order to identify the influence of demographic variables on dependent variables of interest (pain and depression). Analysis of variance was used to evaluate the differential effects of age and marital status on pain and psychopathology in patients with SCD.

Demographics

Subjects' averaged age was 36.46 ± 14.19 and mean education level exceeded high school graduation (mean education level= 13.60 ± 1.91 ; range 9-17). More than fifty percent of participants were single while only approximately 20% were married (See Table 1 for details of the frequency distribution of relational status). The majority of participants were working full-time (30%) while almost 1 in 5 participants was on disability. Nearly two-thirds of patients (N=42) reported living in a house, a little over one-third (N=23) in an apartment, and approximately 4% reported other living arrangements. Participants reported an average of 2.54 ± 1.30 other occupants lived in their residence.

Table 1: Frequency Distribution of Relational Status

The influence of age was evaluated on each of the dependent variables of interest. Using linear regression modeling, it was found that increased age trended toward significance as a predictor of depression as measured by the SCL-90-R ($p=.09$) and was a significant predictor of pain severity ($p=.02$). Age was not a significant predictor of current pain intensity

($p=ns$). As such and in the context of this finding, subsequent regression analyses were covaried for age.

It was hypothesized that women with SCD who had children would report greater intensity in depression and pain than would women with SCD but without

Variable Label	Frequency	Percentage
Married	16	22.9
Single	36	51.4
Separated	1	1.4
Divorced	10	14.3
Widowed	1	1.4
Living with Significant Other	4	5.7
Missing data	2	2.9
Total	70	100

children. The results of linear regression analysis predicting depression as measured by the SCL-90-R from the number of children and covaried for age revealed that the number of children was not a significant predictor of depression ($p=ns$). Similarly, it was found that the number of children covaried for age was not a significant predictor of current pain intensity ($p=ns$) or pain severity ($p=ns$).

A subsequent regression analysis was performed in order to more closely examine if depression, as characterized in a more traditional psychological and affective manner, would be predicted by the number of children of a woman with SCD. The SCL-90-R measures depression on the more physiological terms whereas the BDI characterizes depression in more psychological terms^{24,25}. Depression as measured by the BDI was not predicted by the number of children a woman has even when covaried for age ($p=ns$).

In order to more closely examine whether pain intensity ratings, as averaged across a week and then a month, were predicted by the number of children a woman had, age was covaried in a linear regression analysis. It was found that the number of children was not a significant predictor of pain averaged across time. Age was not a significant predictor for level of depression or pain intensity.

Discussion

In the United States, SCD primarily affects people of African descent, but has an insidious impact on health around the world affecting large numbers of people in every country on earth²⁶. Women with SCD have higher risk pregnancies and have increased risk for general medical and pregnancy-related complications^{27,28}. As the healthcare industry continues to revolutionize SCD medical care and interventions beginning at birth, the management of pregnancy in women with SCD has become a more common phenomenon²⁶. As the rates of survival among adult women improve within this population, more women with SCD are reaching childbearing age and subsequently facing the challenges associated with fertility and the desire for reproduction. This study was designed to provide some initial evidence for that complicated conversation between providers of care and women with SCD.

The current study did not find the presence of children in Black women associated with their reports of depression or pain. That is to say that there was no

substantive difference between reports of pain and psychopathology in women with and without children. Factors such as age were much more influential than was having children. To our knowledge, this is one of the first studies to examine postpartum reproductive outcomes on physiological and psychological variables in African American women with SCD.

Although contrary to the hypotheses, there is at least some literature to support the current study's findings. Twork and colleagues (2007)²⁹ researched life circumstances, quality of life, and coping behavior in mothers with multiple sclerosis (MS). Although they did not specifically investigate the variable of depression within the population, they did examine the variable of *emotional well-being* of mothers with MS. They concluded that there were no differences between women with MS who had and did not have children.

The limited research devoted to examining the concept of motherhood for women with SCD notes that high value is placed on the role of motherhood in the African American community³⁰. Asgharian and colleagues (2003)³⁰ and Hill (1994)³¹ found that the disease did not affect patients' desires to have children and that they saw their reproductive decision as an assumed part of adult life. Hill (1994)³¹ concluded that motherhood was one of the "few-status-attaining and satisfying options" available to women with SCD that may be economically disadvantaged (para. 43).

Reproductive decisions to procreate may mirror the cultural values and mindset in which a woman is

embedded. Placing such high esteem to motherhood may influence some female patients with SCD to pursue pregnancy in order to gain social status or other intangible gain. In contrast, their doctors may recommend that they not have children for fear that they will stress their physical, social, and economic resources, and may increase the likelihood of pain or negative emotional consequences³². The current study suggests that irrational fears of providers or unsubstantiated exuberance from patients are unreasonable factors on which to base fertility decisions for women with SCD. Despite multiple disparities in reproductive risk factors in African American women, our initial findings do not support denying the option of children for women who have SCD, unless overwhelming medical factors are present. We hope that the current research which does not show differences in depression or pain, is used to initiate dialogue and conversation about issues of fertility and factors that should influence fertility decision-making in Black women with SCD.

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