Moderate Chronic Pain, Weight and Dietary Intake in African-American Adult Patients with Sickle Cell Disease

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In this exploratory study, we evaluated weight status and dietary intake patterns during painful episodes in adult patients with SCD. Specifically, we explored the relation between pain severity and body mass index (BMI), and we tested the hypothesis that dietary intake would be reduced and dietary content altered during periods of increased pain. We conducted an analysis of survey data from 62 patients involved in a longitudinal evaluation of the relationship of medical and psychosocial factors to pain. Nearly half of patients with SCD were overweight, and 20% were obese. BMI was positively related to interference associated with pain. Although BMI was not statistically associated with reported pain severity, >40% of patients reported that they perceived their pain to be affected by their weight. Less than 20% of patients reported that they perceived that their weight affected their pain. Regarding dietary patterns, the majority of patients reported eating less during episodes of pain and significantly decreasing their intake of fats and proteins. We conclude that there is a need to better understand the relation among weight, dietary patterns and pain in patients with SCD in order to provide patients with accurate education and effective treatment recommendations for managing their disease and reducing current and future risks of lifestyle and disease-related morbidities.

Key words: sickle cell disease ■ nutrition ■ dietary intake ■ body mass index ■ chronic pain

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INTRODUCTION

Sickle cell disease (SCD) is an inherited blood disorder that diminishes the capacity of red blood cells to carry oxygen. One in 375 African Americans in the United States has SCD. SCD also affects individuals of Hispanic, Native American, East Indian, Greek, Italian and Eastern Asian ancestry.[1-2] The characteristic marker of this disease involves the sickling of blood cells, which occurs when deoxygenated hemoglobin molecules distort the normal shape of red blood cells. These cells can constrict blood flow, causing disruptions in the supply of oxygen to tissues and organs and inhibiting the elimination of carbon dioxide. This vasoocclusive process results in tissue and organ damage as well as other SCD-related complications. Specifically, sustained vasoocclusion can produce systems-level damage and other medical complications, including but not limited to delayed growth and sexual maturation, generally poor health, acute and chronic pulmonary dysfunction, stroke, aseptic necrosis of the hip and/or shoulders, sickle cell retinopathy, dermal ulcers, cognitive impairments secondary to chronic hypoxia and early-onset cerebral vascular events (CVEs),[3] severe and debilitating pain and low body weight.

Given these complications, patients with SCD have historically experienced extended periods of hospitalization, high healthcare utilization rates, frequent emergency room visits, early exposure to narcotics, and psychosocial dysfunctions. They also experience impaired quality of life (QOL) to include reduced physical activity and early mortality.[3-6] Stan-

dard treatments for SCD-related complications have included pharmacologic and psychotherapeutic management of painful crises and efforts to increase caloric intake and weight gain to counterbalance the effects of poor nutrition and low body weight.

Until recently, patients with SCD typically only lived into their 30s. Today, we have progressed such that patients with SCD are living longer and with less disease-related morbidities due, in part, to drugs like hydroxyurea. An antimetabolite, hydroxyurea was approved in 1967 as an anticancer drug and was used in the treatment of a variety of hematological diseases, such as clonal myeloproliferative disorders (MPDs) and malignant solid tumors.[7-9] As one of the best indices of recent pharmacologic, medical and psychosocial progress, Platt et al.,[10] in a sample of 3,764 patients with SCD, reported a median age at death of 42 years for males and 48 years for females with sickle cell anemia, and 60 years for males and 68 years for females with hemoglobin SC disease. Although a significant relative improvement, these mortality rates remain nearly 30 years below nondiseased controls (70 and 75, respectively).[10]

This relative increase in longevity, possibly representative of better-managed disease-related morbidities, better nutrition and less frequent pain crises, has yielded an expected increase in weight and general physical functioning as well as decreased disability. However, increased longevity has also yielded a sudden need to understand, manage and reduce unanticipated morbidities of lifestyle—such as essential hypertension, diabetes and obesity—diseases that are common to aging cohorts of African Americans.[11]

Regarding caloric intake and eating patterns, the historical thinking among many treating clinicians has been that caloric intake is reduced among patients with SCD during painful crises, and this reduction is balanced by weight gains that are the result of better pain management. More specifically, reduced pain results in reduced disability and ultimately an increased probability of activity and better nutrition. However, little, if any, research has been done to determine the accuracy of these clinical assumptions for patients with SCD.

A small body of literature suggests an association between increased stress levels and reductions in macronutrient intake.[12,13] Similarly, a limited number of studies have indicated that reduced stress levels (pain can be considered a specific type of stressor) are associated with improved dietary choices and nutritional status. One study found that men vary the distribution and content of meals they ingest during the day based on the type of work stress they experience and perceived job control.[11] None of these models, however, has been explored in samples of patients with SCD.

Other studies have reported a relationship between increased stress and eating; some individuals increase their food intake in response to heightened stress levels.[14,15] Although commonly thought to be unique to individuals who eat emotionally or with diagnosed eating disorders, this pattern of increased dietary intake in response to stress has been documented in nonclinical samples.[16] Because the topic of changes in dietary intake has not been examined in patients with SCD, it is difficult to estimate with certainty whether they increase or decrease their dietary intake in response to pain as a stressor.

Dietary intake can significantly influence body weight. To date, few studies with patients who have SCD have examined the frequency with which they present as underweight and normal weight, and even fewer studies, overweight and obese. This may be indicative of an assumption that patients with SCD are underweight or normal weight at best as a function of their poor nutritional and disease status.

In other chronic pain populations, investigations of weight status and the impact of weight on pain have increased. For example, there is an established positive relationship between osteoarthritis and weight regardless of the location of the affected joint (i.e., knee, hip, hand, neck).[17] This association may exist, in particular among arthritis patients, because pain contributes to inactivity and a fear of movement secondary to pain (kinesiophobia), which may result in weight gain.[18] In addition, being overweight has been shown to be an important predictor of painful conditions, such as lower back pain.[19] Emerging evidence suggests that the association between persistent pain and overweight status may be mediated by inflammatory and endocrine processes and not simply biomechanical factors.[17] Given these findings and their implications regarding effective management of pain, as well as the lack of specific data about adult patients with SCD and weight, it is important to determine whether overweight status is associated with increased pain in patients with SCD. Although it is possible that SCD-related pain is similar to other types of pain in this regard, it is also possible that increased pain is associated with decreased weight in patients with SCD if caloric intake is substantially decreased during painful episodes.

In general, the dietary patterns of individuals with chronic medical illnesses, including chronic pain, have not frequently been studied. To date and to our knowledge, few studies, if any, have evaluated the effects of weight on reports of pain and the presence of pain on dietary intake in adult patients with SCD. When these relationships have been explored, dietary factors associated with SCD have only been investigated in the context of developmental delays in children and adolescents (e.g., delayed growth and sexual maturation).[20] These studies typically yield recommendations for improvements in the nutritional status

of children with SCD, but few recommendations exist for the management of adult macronutrient intake. Consequently, the sequelae of better physical functioning and increased weight on patterns of overweight and obesity in SCD are not well understood. In order to develop appropriate recommendations and adequately educate patients about management of their disease, it is crucial to begin to understand the effects of chronic pain on patterns of eating and weight in adult patients with SCD.

The current exploratory study evaluated the general frequency with which patients who have SCD are underweight, normal weight, overweight or obese. To date and to our knowledge, we are the first to examine the association between patients' weight and reported pain levels, as well as the reported interference of pain in the lives of adult patients with SCD. We retrospectively evaluated patients' reports of their patterns of dietary intake during pain episodes and the perceived relation of their body weight to pain. We tested a hypothesis that dietary intake would be reduced and dietary content would be altered by chronic pain. We believe this study to be the first to explore dietary intake in the context of pain in patients with SCD, and one of few studies to document and consider the relation between weight and pain in SCD.

METHODS AND PROCEDURES

Study Design/Subjects

The current study used a survey design and medical records review to evaluate the effects of weight and BMI on pain and pain on dietary intake in patients with SCD. The study represents a cross-sectional analysis of first-year data collected as part of a larger, five-year, longitudinal survey and medical records evaluation of the relationship of medical and psychosocial factors to pain in patients with SCD. We sought to document patterns of weight as a function of height [body mass index (BMI)], the association of BMI to pain and pain-related indices, and an evaluation of changes in patterns of eating as a function of the presence of pain.

One-hundred-seventy-five consecutive patients receiving routine follow-up care were approached from the Duke Comprehensive Sickle Cell Center. Of the 175 patients approached, 140 patients provided consent for participation in the current study. Of patients who gave consent, 62 completed testing, 40 partially completed testing, 37 had not begun testing by the time of analysis, and one patient completed testing but had significant and relevant portions of the questionnaire unanswered. Twenty-nine male and 33 female subjects completed the consent and assessment process during the first 12 months of enrollment. Individuals who declined participation generally indicated: 1) time constraints, 2) already participating in another research study, or 3) not interested in participating in scientific research. Only completed datasets were used in the current analysis. All subjects signed informed consents and the study was approved by the Duke institutional review board. Patients were not provided monetary compensation for their participation in the study.

Subjects were excluded from participation if they were actively in an acute episode of pain or other urgent medical crisis at the time of clinic visit, had a diagnosed eating disorder, or if they were unable to read and comprehend the written instructions for testing. Patients were also excluded if they had a known physical diagnosis other than SCD (pulmonary hypertension, etc.).

Pain

The Multidimensional Pain Inventory (MPI-2) is a short form of the West Haven–Yale Multidimensional Pain Inventory (WHYMPI).[21] The MPI-2 assesses self-reported levels of pain and the extent to which pain interferes with normal daily activities. It also assesses support and engagement in daily activities. The MPI has demonstrated adequate psychometric properties. Specifically, internal reliability coefficients range from 0.70–0.90 and test-retest reliabilities over a two-week period range from 0.62 to 0.91.[21]

Diet/Nutritional Intake

Participants responded to several questions developed for the purpose of this investigation that were designed to assess eating and nutritional patterns in the context of pain in general, and during painful episodes in particular. General dietary/nutritional questions assessed whether participants believe that their pain affects their weight (i.e., "Does your pain affect your weight?") and whether their weight affects their pain (i.e., "Does your weight affect your pain?"). They were also asked whether they follow a special diet. With regard to dietary patterns associated with painful episodes, the level of pain required to influence or change participants' eating habits was assessed as well as the direction of change (i.e., eat more, eat less or eating habits not affected by pain levels). Participants were asked specifically whether they eat more, less or experience no change in their consumption of several macronutrients (i.e., fats, sugar, protein, salt). To our knowledge, the diet/nutrition questions posed in this study have not been used in previous studies; thus, specific psychometric properties of these questions have not been assessed.

Longitudinal Exploration of Medical and Psychosocial Factors in Sickle Cell Disease

The Longitudinal Exploration of Medical and Psychosocial Factors in Sickle Cell Disease

(LEMPFSCD), designed specifically for examining this population, was administered to each participant during routine clinic visits. The LEMPFSCD is a 700-question tool consisting of pain, demographic, and eight validated, content-driven instruments for the assessment of psychiatric, behavioral and social functioning. For the purpose of the current study, the following measures and question sets were examined: demographics (including BMI), pain, dietary intake and psychological distress. Participants completed the LEMPFSCD while waiting for and then after their normally scheduled appointments. Average completion time was approximately three hours.

STATISTICAL ANALYSIS

Descriptive statistics were used to describe the sample characteristics. Pearson r correlation coefficients were used to evaluate the relationship of BMI to pain severity and interference from pain. Chi-square was used to evaluate reported changes in dietary intake of macronutrients like proteins, fats and sugars. Lastly, Analysis of Variance (ANOVA) was used to evaluate the differential effects of weight status (overweight and obese versus normal weight) on pain and changes in dietary intake in patients with SCD. P values <0.05 were used to establish statistical significance for analyses which included Pearson correlations, Chi-square and ANOVA.

RESULTS

Mean BMI (weight in kg/height in m^2) for the sample was 25.93 ± 6.84, with no significant differences observed between men and women. Underweight (n=4; BMI <19), normal (n=27; BMI=19–24.9), overweight (n=17; BMI=25–29.9) and obese (n=14; BMI >30) patients did not differ in age or education. Income across the past year did not influence BMI or pain severity, $F(4,52)=0.821$, p=ns and $F(4,50)=1.00$, p=ns, respectively. Mean education for the sample was 13.37 ± 1.87 (range=9–18 years) and mean age of the sample was 37.12 ± 11.67 years (range=18–70 years). See Table 1 for a presentation of weight status as a function of gender and mean education as a function of weight status. Mean reported pain severity was 34.98 ± 14.19 as measured by the MPI (range=0–100). Only 13% (n=8) of patients reported following a special diet and 45% (n=28) were taking hydroxyurea at the time of evaluation as per a review of medical records.

In comparison to data reported from the Behavioral Risks Factor Surveillance System (North Carolina State Center for Health Statistics; SCHS, 2003), the percentage of SCD patients who were obese in our sample is similar to that of the general population (22% SCD and 24% NC). The percentage of patients with SCD who were overweight is lower than the population in the state (27% SCD, 36% NC), and the percentage of patients who were normal weight is slightly higher (44% SCD, 41% NC). Approximately 7% of our sample of patients with SCD were underweight. A comparison with N.C. statistics was not conducted because this data was not reported in the Behavioral Risks Factor Surveillance System. Given the relatively small number of individuals who were underweight in our sample, analyses using weight status were limited to comparisons of obese, overweight and normal weight.

Weight status (overweight and obese versus normal weight) exerted a significant effect on pain interference, $F(1,60)=4.12$ $p<0.05$). This effect remained significant even after controlling for age, $F(1,59)=4.37$, $p<0.05$). Using correlational analyses, BMI was not found to be associated with reported pain severity (r=0.09, p=ns) but was significantly associated with the level of interference in daily activities associated with pain (r=0.25, p=0.05).

In response to the direct questions, "Does your pain affect your weight" and "Does your weight affect your pain," >40% of patients reported that their pain affected their weight. Less than 20%, however, reported that their weight affected their pain. Chi-squared analyses revealed no significant differences in the frequency of affirmative and negative responses related to weight affecting pain (χ^2= 1.33, ns). However, participants were significantly more likely to report that their weight does not affect their pain ($\chi^2=34.13$, $p<0.001$).

When asked at what level of pain (ranging 0–10) patients' eating patterns were influenced or changed, patients reported that moderate pain levels (M=5.66, SD=2.54) resulted in altered eating patterns. Eighty-seven percent of patients reported that they "eat less" during episodes of pain, 13% reported "no change" in their consumption of food, and no patients indicated that they increased food consumption during episodes

Table 1. Weight status by gender; mean education level by weight status

	Underweight	Normal Weight	Overweight	Obese
Males	2	12	9	6
Females	2	15	8	8
Years of education (mean ± SD)	13.08 ± 2.39	13.56 ± 1.80	13.35 ± 1.66	13.08 ± 2.39

Underweight: BMI <19, normal weight: BMI <25, overweight: BMI 25–29, obese: BMI>30

of pain (Figure 1). During pain episodes, a significant frequency of patients indicated that they were likely to decrease their intake of fats (χ^2=10.55, p<0.01) and proteins (χ^2=4.43, p<0.01) but not their intake of foods containing sugar or salt (Figure 2, Table 2).

DISCUSSION

In the current study, we found that almost one-half of adult patients (average age of 37 years) with SCD can be categorized as overweight, and >20% can be categorized as obese. To our knowledge, this is the first study to document a trend towards overweight and obesity in a mature sample of patients with SCD. Obesity is an important outcome for consideration in this population, particularly as they age, because it is associated with increased risk of morbidities of lifestyle, including essential hypertension, type-2 diabetes, prostate and breast cancers, dementia, depression, increased disability and reduced quality of life as well as higher incidence of mortality.[22,23]

Traditionally, poor health and early death have insulated patients with SCD from many of the morbidities of lifestyle that are prevalent in other populations of aging African Americans. Since the recent introduction of hydroxyurea into the management of SCD and the increased utilization of a range of psychosocial and behavioral strategies,[3,24] a significant percentage of patients are living healthier and longer lives. However, as the average BMI of this population has increased, adult patients with SCD may be at greater risk for development of morbidities of lifestyle than once believed.

We hypothesized that increased weight would be related to reports of increased pain and interference associated with pain. As predicted, BMI was moderately positively associated with self-reported *interference* associated with pain. In contrast, when analyzed separately, weight status as a categorical descriptor (overweight and obese versus normal weight) and BMI as a continuous variable were not related to reported pain severity. Consistent with this finding, when asked directly if their weight affected their pain, <20% of patients reported that their weight exerted significant effects on their pain. Although we did not find a statistically significant relationship between pain severity and weight, we were at a loss to explain that >40% of patients believed that their pain affected their weight.

Independent of patient's perception, our statistical finding indicating the lack of a relation between weight and pain severity is consistent with previous studies conducted with other chronic pain populations. Several studies have found that degree of overweight is not directly related to pain severity ratings. For example, Marcus[22] found, in a sample of 372 patients with chronic pain that were divided into three categories (normal weight, overweight and obese), that pain severity and days per week with pain were not affected by weight category. However, similar to the current study, functional ability was inversely related to weight. Thus, it appears that degree of overweight is more closely associated with functional disability due to pain than with pain severity.

The finding in the present study that 40% of SCD patients believed that their pain affected their weight is interesting, particularly when contrasted with the result that <20% believe that the inverse is true (i.e., that their weight affected their pain). It is possible that patients are not aware of the association, or do not believe, that their weight exerts a significant impact on their pain levels. This would not be surprising among SCD patients, given that little attention has been paid to issues of overweight in SCD. In contrast, a larger percentage of patients, though still not the majority, believe that their pain affects their weight. Although the current study did not further assess the nature of this belief, it is possible that some patients with SCD believe that their weight has been negatively impacted by the decreased levels of activity that

Figure 1. Changes in dietary intake in response to pain episode

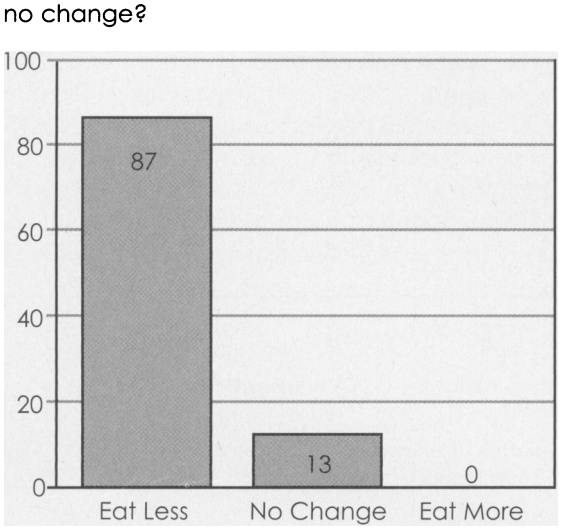


Table 2. Frequencies and Chi-squares for changes in macronutrient intake during pain episodes

	Eat Less	Eat More	No Change	χ^2(2)	p
Fat	23	8	9	10.55	0.005
Sugar	20	10	11	4.44	0.11
Protein	22	4	13	12.46	0.002
Salt	20	9	13	4.43	0.11

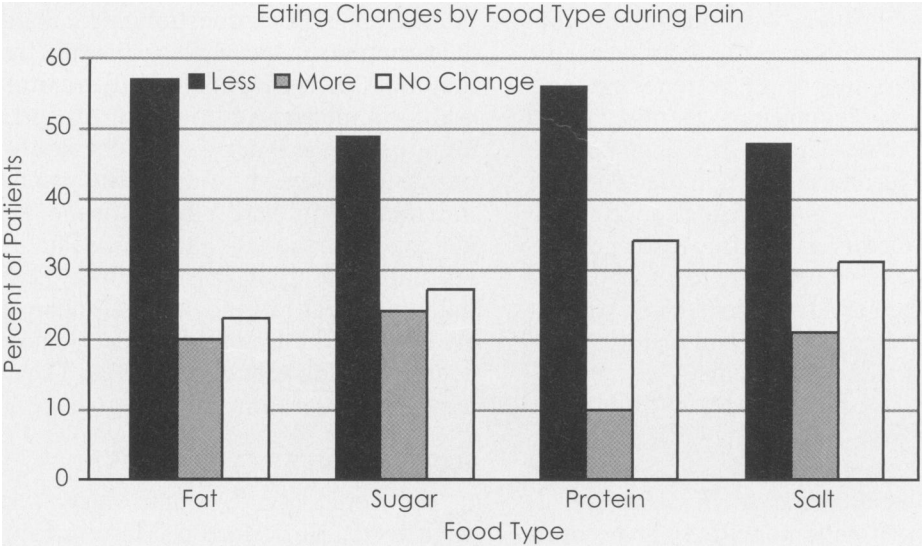
occur when pain is present. These preliminary findings suggest that patients with SCD may be misinformed or unaware of the relation between their weight and pain. Furthermore, endorsement of the belief that pain should prevent one from engaging in physical activity may lead to the adoption of maladaptive strategies for coping with painful episodes.

We also evaluated data on changes in eating patterns in patients with SCD during pain episodes to suggest a possible mechanism through which patients may associate their weight and experiences of pain. Nearly 90% of the patients evaluated indicated that they reduce their caloric intake during episodes of pain associated with SCD. Of special significance is that moderate pain (an average rating of 5 on a 10-point scale)—not just severe pain—produced changes in patterns of dietary intake. Also notable is that no patients reported that their caloric intake increased during these painful episodes. In addition to reducing total caloric intake, patients reported that they were more likely to decrease the amount of fat and proteins that they ingested during episodes of pain, yet they did not report noticeable or significant changes in their intake of foods containing sugars or salts.

It is important to begin to understand changes in dietary intake during episodes of pain and the impact that these changes may have on risks for other diseases. Opportunities for malnourishment and/or the development of nutritional deficiencies may uniquely exist in patients with SCD. In the case of other diseases where pain may exist for shorter periods of time and in a more predictable manner, and where alterations of dietary intake are proportionately short, risk of malnourishment and nutritional deficiencies is low. However, in SCD, where pain episodes can last for months and are not always managed with hospitalization, there may be an increased risk of negative consequences due to prolonged changes in dietary intake (e.g., inadequate nutrient consumption). This issue is particularly concerning given our finding that moderate pain levels may be sufficient in substantially altering the pattern of dietary intake among patients with SCD.

In general, our findings indicate that patients with SCD may be at risk for additional health problems and disease-related morbidities both when they are functioning well and without pain and when they are experiencing painful episodes. Specifically, these preliminary results suggest that almost 50% of patients may be at risk of becoming overweight or obese. Given patients' reports, it is not likely that this risk is due to overeating during pain episodes but possibly due to better clinical management of the disease. In fact, when compared to general N.C. statistics, the weight categorization of our sample approximated that of the state, although the rates of overweight (BMI=25–29.9) remain lower in the SCD sample. During painful episodes, patients may be at increased risk of acute malnourishment across extended periods of pain, even when the pain is at moderate severity. Although somewhat paradoxical, it is generally accepted that adequate nutritional intake is necessary for weight loss, as metabolic processes slow when food intake is significantly reduced. As such, patients with SCD who consistently decrease their food intake during persistent painful episodes may ultimately impact their metabolic processes, possibly resulting in difficulties maintaining a healthy weight. It is important, conse-

Figure 2. Changes in dietary intake of specific macronutrients in response to pain



quently, to remain cognizant of the nourishment status of patients with SCD as a standard of practice during all phases of management.

Limitations

The cross-sectional design and modest sample size associated with the current study may present as a limitation to the generalizability of the current findings. Although we recognize that the lack of underweight patients in the current study may distinguish this sample from other clinics around the country, we believe, however, that the current study is an important first step in a series of needed studies to describe the epidemiology of overweight and obesity, better characterize the subsequent risk for morbidities associated with lifestyle, and understand the relationship of increased weight to experiences of pain in patients with SCD. Another factor limiting the generalizability of our findings is our utilization of a convenience sample in this study rather than randomly surveying a representative sample of patients with SCD.

The exploratory questions used to assess dietary habits under the influence of pain could represent another limitation of the current study. Specifically, the items used to assess dietary changes and the perceived effects of weight on pain (and pain on weight) were developed for the purpose of this study and have not been utilized in previous research. Thus, the psychometric properties of these items are unknown. Although the use of retrospective self-report data is widespread and justifiable in this exploratory study, this method of assessment is limited by reporting biases and errors in recall.

Future studies must begin to explore the effects of weight and eating habits on chronic pain and disability in samples of patients large enough to allow for the simultaneous exploration of mediational effects and relevant covariates towards a more ecologically valid model of health in this population. For example, we must begin to understand the impact of eating habits and weight on reports of pain in the context of how deviant reports of pain and pathology are from other African-American populations with pain. We further must begin to understand the relationship between observed and reported ratings of changes in dietary intake in obese and non-obese patients. We lastly must begin to understand if the models established in African-American populations generalize to other minority and majority populations with chronic illness and pain.

CONCLUSIONS

Extending the previous literature, we believe that the current study is the first to demonstrate: 1) approximately 50% of patients with SCD are overweight and approximately 25% are obese; 2) there is a significant reduction in caloric intake and a significant alteration in the patterns of macronutrient intake as the result of moderate pain in patients with SCD; and 3) similar to other chronic pain populations, weight appears to exert a greater impact on functional disability associated with pain in patients with SCD than pain severity. These new findings suggest at least two critical insights for the clinical management of this population. First, we must more aggressively identify and manage issues of overweight and obesity, particularly as patients with SCD age or are exposed to longer periods without pain episodes. Assisting patients to achieve and maintain a healthy balance between low weight and overweight/obesity may prove to be one of the more effective interventions towards the reduction of risk for morbidities of lifestyle. This may require the reconceptualization of patients with SCD who have historically been insulated through poor health and early death as being at risk for morbidities of lifestyle.

Secondly, clinicians and researchers may need to be more attentive to the nutritional status of patients with SCD during painful episodes. The current study suggests that patients may alter what and how much they eat while experiencing moderate-to-severe pain. Above and beyond our normal evaluations and treatment, patients may benefit from nutritional and dietary consultation before, during and after extended periods of painful crises.

Although the results of the current study must be considered in the context of its limitations, preliminary findings suggest areas for future research. Specifically, more systematic investigations of the impact of weight on pain and of pain on weight in SCD, and of the dietary patterns of patients with SCD both during and outside of painful episodes, are warranted. Such research could make use of previously validated questionnaires regarding food intake (e.g., Block questionnaire, Food Frequency Questionnaire), as well as prospective reporting methods, including daily self-monitoring of pain and food intake. Additionally, prospective assessment of physical activity levels would likely contribute to the topic of weight, eating and pain in SCD in a meaningful way. Finally, further assessment of weight-, nutritional- and pain-related beliefs and attitudes among SCD is necessary, given that attitudes, expectations and beliefs about health and pain are often predictive of individuals' tendency to adopt adaptive health-related behaviors. The current study moves us closer towards these goals.

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