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Region of Pain and Healthcare Utilization in African American Adults with Sickle Cell Disease (SCD)

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Resumen

La Anemia Falciforme (AF) se refiere a una categoría de enfermedades genéticas en donde la hemoglobina presenta una forma irregular y no lleva el oxígeno suficiente. En este estudio, 99 adultos afroamericanos con AF provenientes de la Clínica de AF del Centro Médico Universitario de la Universidad de Duke, le fueron administrados un cuestionario estandarizado para evaluar información médica y psicosocial. Se encontró que la región del dolor afectó de manera significativa el número de veces que los participantes fueron hospitalizados durante el pasado año F, (2,17)= 5.93, p <.01. Sin embargo, la región de dolor no afectó los resultados psicosociales según fue medido por el SCL-90. Futuros estudios deben examinar el impacto de la región de dolor en adultos afroamericanos con AF como una manera de predecir personas que utilizan frecuentemente los servicios de salud.

Palabras claves: Anemia Falciforme, dolor crónico, región de dolor, utilización servicios de salud.

Abstract

Sickle cell disease (SCD) refers to a category of genetic illnesses in which the hemoglobin has an irregular, sickled shape and does not carry oxygen efficiently. Ninety-six African American adults with SCD from the Duke University Medical Center's Sickle Cell Clinic were administered a standardized questionnaire to evaluate psychosocial and medical information. Region of pain was found to significantly affect the number of times participants were hospitalized in the past year, *F* (2,

17) = 5.93; p = .01. However, region of pain did not significantly affect psychological outcomes as measured by the SCL-90-R. Future studies should examine the impact of region of pain in African American adults with SCD as a way of predicting high utilizers of healthcare services.

Key Words: Sickle Cell Disease, Chronic Pain, Region of Pain, Healthcare Utilization

Sickle cell disease (SCD) is an inherited disease of the blood with symptoms significantly influenced by medical and psychosocial factors (Edwards, Scales, Loughlin, et al., 2005). SCD is most prevalent among populations with African origins, those in the Mediterranean region, Southeast Asia, and the Middle to Far East (Sonati, Costa, 2008). In the United States, SCD occurs once in every 1,000 to 1,400 Hispanic American births and once in every 500 African American births (Marti-Carajal, Conterno, 2006). More than 50,000 African Americans live with SCD in the US and an estimated one in twelve are carriers of the disease (Bloom, 1995). Patients with SCD possess a mutation of the recessive Hemoglobin S gene that under deoxygenation, produces reduced elasticity of the cell membrane and ultimately the sickling of the red blood cell (Tchuenche, 2007). These cells via their shape and poor attachment to oxyhemoglobin are poor transporters of oxygen from the lungs to cells in the body (hypoxia), and poor transporters of carbon dioxide via carbaminohemoglobin, from the body to the lungs where gaseous products of metabolism are expelled. Sickled shaped red blood cells also easily adhere together and to capillary walls, producing vaso-occlusions or blockages that reduce the effectiveness of the circulatory system (Wood, Granger, 2007). Collectively, vaso-occlusion and inadequate oxygen (SCD crisis) deprive tissues and organs of essential components associated with metabolism and normal functioning (Johnson, Carmona-Bayonas, Tick, 2008). These deprivation events also produce wide spread damage throughout the body as well as excruciating episodes of deep organ,

joint, and musculoskeletal pain (Sickle Cell Disease, 2004). In many cases, these processes also produce death.

SCD can also be associated with stroke, leg ulcers, spontaneous abortion, renal insufficiency as well as a range of other physical morbidities and psychological complications (Yale, Nagib, Guthrie, 2000). Jaundice, seizures, hemiplegias, congestive heart failure, osteomyelitis, and bone infarctions are common among adult patients with SCD (Schaeffer, Gil, Burchinal, Kramer, Nash, Orringer, Strayhorn, 1999). Patients may also develop hand-foot syndrome, also known as dactylitis- a condition that causes painful swelling in the hands or feet (Foucan, Ekouevi, Etienne-Julan, Salmi, Diara, 2006).

To date, we have found no studies that explore region of pain in adult patients with SCD as a significant predictor of overall functioning to include healthcare utilization (Brousseau, Owens, Mosso, Panepinto, Steiner, 2010; Raphael, Dietrich, Whitmire, Mahoney, Mueller, Giardino, 2009; Reese, Smith, 1997). We hypothesize that vaso-occlusive complications associated with the upper versus lower extremities (i.e. hands and arms versus legs and feet) may differentially impact healthcare utilization via impairments of activities of daily living that involve the hands versus mobility (legs and feet). Pains and impairment of the arms and hands may produce significantly different functional consequences than pains and impairments of the legs and feet, and ultimately different patterns of psychological distress. Thus, we examined the relationship of upper and lower body pains to healthcare utilization in patients with SCD to answer the research question "is region of pain a relevant consideration in predicting pain and healthcare utilization among patients with SCD?"

Method

Study Design

The current study represents a cross-sectional evaluation of first-year data collected as part of a longitudinal study of the interplay between physiological parameters, psychosocial factors, and pain in patients with SCD. We sought to explore the influence of upper versus

lower body pains on clinical psychological outcomes among patients with SCD.

Participants

Ninety-six consecutive african-american patients (86 female male, 10 male), mean age 36 ± 12.73 (range 18-75), were recruited from the Duke Comprehensive Sickle Cell Center during routine clinic appointments. Patient's mean educational level was 13.53 ± 1.90 years with a median income of $16,000 per year. Participants 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 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 (Mental Retardation, etc.). All Participants were given and signed informed consent, and the study was approved by the Duke Institutional Review Board.

Materials

Longitudinal Exploration of Medical and Psychosocial Factors in Sickle Cell Disease (LEMPFSCD)

The LEMPFSCD is a multidimensional paper and pencil instrument designed specifically for examining this population. The LEMPFSCD is a 700-question tool consisting of pain, demographics, and 8 validated (1- Symptoms Checklist 90-items, Revised, 2- Beck Depression Inventory, 3- Multidimensional Pain Inventory, 4- Short-Form McGill Pain Questionnaire, 5- Menstrual Symptoms Questionnaire, 6- Marlowe Crowne Scale of Social Desirability, 7- Duke Religiosity Scale, 8- John Henryism Scale), content-driven instruments for the assessment of psychiatric, behavioral, and social functioning. As such, it does not have its own psychometric properties (validity and reliability) beyond that associated with each individual scale. For the purpose of the current study the following content areas were examined: demographics, pain region, healthcare utilization, and socially desirable responding.

Pain

The Short Form McGill Pain Questionnaire (SF-MPQ) and a visual analogue scale were used to measure pain severity (Melzack, 1987). 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 visual analogue scale (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 report, we present the results for all four 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 (Grafton, Foster, Wright, 2005). There is a very high correlation between scales of the long and short-forms of the McGill Pain Questionnaire.

Psychopathology

The Symptoms Checklist 90-items, Revised (SCL-90-R; Derogatis, 1977) 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). 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 global severity index (GSI) are exceptionally high and between .96 and .97 (Derogatis, Rickels, Rock, 1976).

Upper and Lower Limb Factors

We analyzed difficulty with moving arms, hands, legs, and feet as representative of upper and lower extremity complications. That is, patients who reported experiencing trouble with movement of their arms and/or hands without assistance during a severe pain episode were categorized as experiencing an upper extremity problem, while those having difficulty with mobility in legs and feet during a severe crisis were characterized as experiencing lower extremity complications. Participants who reported having pain in both upper and lower extremities were categorized as having upper and lower limb pain. We did not analyze participants who had no extremity pain.

Healthcare Utilization

We reviewed the medical records and counted the total number of formal contacts (a clinical note was generated and a billing was produced) each patient generated over the 12 months following evaluation.

Procedures

Study procedures are described in more detail in several previous and recent studies (Edwards, Whitfield, Sudhakar, et al., 2006; Pells, Presnell, Edwards, 2005; Harrison, Edwards, Koenig, 2005). All patients were consented and enrolled individually in the current study during routine visits to the 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 inclusion and exclusion criteria. They were then approached by study personnel about participation. All patients were given a brief verbal overview of the study which included conducting a review of their historical patterns of healthcare utilization from their medical records, and then allowed to read the consent forms. Each subject was allowed to ask questions and gain clarification before signing consent.

Participants 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.

Statistical Analysis

Descriptive statistics were used to describe the sample characteristics. Analysis of Variance (ANOVA) was used to evaluate the differential effects of upper extremity and lower extremity pains on clinical outcomes in patients with SCD. Bonferroni-corrected t-tests were then conducted to define which groups were actually different. We used simple linear regression to analyze the impact of amount of pain to the amount of times the participants needed to contact a health care provider. Variables were examined for violations of normality and outliers via a review of histograms and the majority of the variables were found to have violated this assumption and have outliers. To correct for this, log transformations were performed on the data and the hypotheses were tested using the log transformation.

Results

The study sample consisted of 86 female and 10 men. Patient's mean educational level was 13.53 ± 1.90 years with a median income of $16,000 per year.

Impact of Upper Extremity and Lower Extremity Difficulties on Pain and Clinical Outcomes

ANOVA revealed that region of pain significantly impacted the number of times patients were hospitalized over the past year, F (2, 17) = 5.93; p = .01. Bonferroni-corrected t-test revealed that individuals with upper limb difficulties during pain episodes (M = .23, SE = .78) tended to have fewer hospitalizations over the past year than those who experienced lower limb difficulties during pain episodes (M = .51, SE = .05; t(10) = -3.05, p = .01). Region of pain did not exert a significant influence on any psychological outcomes as measured by the SCL-90-R.

Pain and Healthcare Utilization

Using a series of linear regressions, we analyzed if the number of days in pain per month, the number of days patients had to take extra medication to control their pains, and the number of days patients were disabled by their pains predicted pain intensity, psychological factors, the number of healthcare contacts, or overall physical functioning. The results revealed that number of days in pain over the past month significantly predicted the number of times the participants' contacted their healthcare provider or went to a hospital, [R^2= .48, F(1,17)= 15.37, p = .001]. More specifically, greater numbers of days in pain over the past month was predictive of a greater number of healthcare contacts over the past 12 months.

Conclusion

Based in part on clinical observations that patients with lower body pains appeared to have functional impairments that are different than their counterparts with upper body pains, we compared the two samples in terms of healthcare utilization in adult African Americans with SCD. We note that there was very little SCD specific literature to guide our exploration so our primary hypothesis was a reflection of clinical observations. We found that patients with upper limb pains had fewer hospitalizations than their counterparts with lower limb pains. We explain this finding with functional knowledge from the low back pain literature demonstrating that lower limb pains effects mobility (Clark, Stump, Wolinsky, 1998) and may produce urgency for remedies for pain management and hospitalization that upper body pains may not. Hence, patients with lower body pains may be more inclined to seek medical care at a rate more frequent than their upper body pain counterparts.

We also found that the number of days adult patients with SCD were in pain per month was predictive of their yearly healthcare utilization; patients with greater numbers of days with pain per month also used more healthcare services that year. Although not a surprising finding, it does suggest that the index of pain per month may represent a loose estimate of general pain severity and a general tendency to use

more healthcare-related services to resolve health issues. Whether the index of monthly pain is a reliable estimate of SCD disease severity has yet to be determined. However, future studies should begin to understand the clinical utility of this easy to ascertain measure.

We also found that region of pain was not a significant influence on psychological functioning. African American adult patients with SCD who experience pains that affect mobility (lower body) were no more psychologically distressed than their counterparts whose pains affected grasping and normal upper body activity. We believe this to be an important finding because it suggests in the context of indistinguishable psychological functioning, healthcare utilization is quite directly related to region of pain in the body.

Future studies must begin to explore whether or not region of pain is a simple proxy for ease of mobility and likelihood of physical atrophy. It is possible that atrophy may be an exacerbating factor to influence healthcare utilization in adult patients with SCD.

Limitations

We believe that our modest sample size, which prevented the exploration of relevant covariates, was a limitation to our ability to comprehensively understand the influence of pain in a particular region of the body on all relevant clinical outcomes associated with this population of patients in a single analysis. We also believe that our predominately female sample limits our generalizability to men with SCD. Body image has been found to be a relevant predictor of psychological outcomes among adult men and women with SCD, and upper versus lower body pain may exert differential effects on body image. Hence understanding how region of pain affects men with SCD could be important (Reddy, Edwards, Wood, et al., 2011). Given these limitations to the current study, we believe it to still be important in defining factors that influence pain in the context of known ethnic differences in somatosensory functioning via the central processing of noxious stimuli like pain (Mechlin, Heymen, Edwards, Girdler, 2011). Notably, we do not see limiting our study to a sample of patients with SCD, and not being able to yet generalize or compare to other better

studied populations as a limitation. We believe that there is great value in understanding the influences of region of pain on SCD as a significant addition to the literature in and of itself (Whitfield, Allaire, Belue, Edwards, 2008).

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