Physicians' Perception of Sickle-cell Disease Pain

Fátima Lucchesi, Ph.D., Maria Stella Figueiredo, M.D., Erika B. Mastandrea, M.Sc., James L. Levenson, M.D., Wally R. Smith, M.D., Alessandro F. Jacinto, M.D., Vanessa de A. Citero, M.D.

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Abstract: The aim of this study was to evaluate the physician's perception of pain experienced by patients with sickle-cell disease (SCD). Pain experiences reported by patients were compared with physicians' perception of the patient's pain, and the treatment decision-making process was evaluated. Fifty-two patient–physician pairs were assessed. Before the clinic visit, the patients completed a 3-item on pain experienced 24 h prior to the visit and the PHQ-9. After the patient visit, the physicians completed a questionnaire assessing their perception of the patient's pain and a questionnaire on the factors taken into consideration when evaluating the patient's pain experience. The physicians rated the patients' pain as more intense than did the patients themselves; and there was agreement between pain intensity measurements ($p < 0.05$). The physicians' perception was influenced by the pain intensity reported by the patient, results of blood count at the time of the patient visit, and medication availability in the public health services. However, these factors were not predictive of the patient's pain intensity perceived by the physician. Patients' depressive symptoms were not predictive factor of the physicians' perception. Biochemical, genetic and symptomatic characteristics of SCD influenced the physicians' perception of the patient's pain experience, while psychosocial aspects did not.

Keywords: Sickle-cell ■ Pain perception ■ Physician–patient relations ■ Attitude of health personnel

Author affiliations: Fátima Lucchesi, Escola Paulista de Medicina, Universidade Federal de São Paulo, Brazil; Maria Stella Figueiredo, Escola Paulista de Medicina, Universidade Federal de São Paulo, Brazil; Erika B. Mastandrea, Escola Paulista de Medicina, Universidade Federal de São Paulo, Brazil; James L. Levenson, Virginia Commonwealth University, Richmond, VA, USA; Wally R. Smith, Virginia Commonwealth University, Richmond, VA, USA; Alessandro F. Jacinto, Universidade Estadual Paulista Julio de Mesquita Filho, Brazil; Vanessa de A. Citero, Escola Paulista de Medicina, Universidade Federal de São Paulo, Brazil

Correspondence: Vanessa de A. Cítero, M.D., Escola Paulista de Medicina, Universidade Federal de São Paulo, Department of Psychiatry, Rua Borges Lagoa 570, 1° andar, Vila Clementino, CEP 04038-030 São Paulo, SP, Brazil. Tel./fax: +55 11 5576 4990., email: vcitero@uol.com.br

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INTRODUCTION

Sickle-cell disease (SCD) is a hereditary chronic disease caused by a genetic mutation that forms the abnormal hemoglobin S (HbS). SCD has a high prevalence in the Brazilian population, especially among individuals of African descent.[1,2] The onset of symptoms, which are usually severe and painful, may appear at 6 months of age, and the clinical evolution of the disease is characterized by high morbidity and mortality.[3] The median survival of patients with SCD has increased from 20 years in 1970 to 40 or 50 years nowadays.[4] The biopsychosocial development[5] and quality of life of patients with SCD and their families may be significantly compromised by the disease.[6,7] In adulthood, psychosocial dysfunctions are caused by the interaction of the effects of the disease and the socio-cultural context in which individuals of African descent live, especially stigmatization and lack of employment.[8]

The clinical manifestations of SCD are heterogeneous among patients living in different locations and are influenced by age, gender, gene expression, and environmental factors.[9] From a clinical point of view, SCD is a chronic disease characterized by exacerbations and remissions, ultimately resulting in organ failure and premature death. The recurrence of acute crises in association with chronic pain creates a unique pain syndrome.[10] SCD may lead to low self-esteem, anxiety, depression, social isolation, decreased ability to perform activities of daily living, because the painful crises affect how patients perceive themselves in relation to others.[11,12]

The patient's self-report of pain is essential for physicians to make treatment decisions. Self-reported pain in SCD patients provides a reliable measure of pain experience.[13] The assessment of the patient's pain by the physician is also based on subjective observations and little is known about how much the physician takes into account the patient's opinion regarding pain intensity, the patients' history and attitude toward the disease, and whether these factors influence the analgesic therapy prescribed by the physician.

Several studies[12,14–19] have reported that the pain intensity described by SCD patients tends to be influenced by psychosocial factors; however, the importance given to these factors by physicians is yet to be well understood. In Brazil, where the present study was conducted, physicians are encouraged to let the patient participate on the decision regarding their treatment, in an attempt to entice the patient to become more involved in their medical care.

The aim of the present study was to assess the physician's perception of the pain experienced by the SCD patient. The pain reported by the patient was compared with the physician's perception of the patient's pain, and the treatment decision-making process was evaluated. Factors addressed by the physicians during the clinic visit and the influence of epidemiological, clinical and psychosocial factors on the physician's perception of the pain experienced by patients were also investigated. Our hypothesis was that the physician rates the patient's pain as more severe than the patient himself, especially when the patient has depressive symptoms (impairing quality of life), increased number of clinical complications (suggesting poor clinical outcome), a severe genotype of SCD (negatively impacting the clinical course of the disease), or when the physician performs poorly in assessing the patient's pain during the clinic visit.

METHODS

This cross-sectional study is part of the Brazilian version of the Pain in Sickle-Cell Epidemiology Study[4] (PiSCES), which proposes the etiological assessment of biopsychosocial factors involved in SCD. Data collected in Brazil, describing the perception of pain as reported by SCD patients and perceived their physicians, were evaluated. This study was conducted from November 2009 to April 2010.

The study was approved by the Research Ethics Committee of the *Escola Paulista de Medicina, Universidade Federal de São Paulo*, Brazil, approval number 0050/08. Written informed consent was obtained from all physicians and patients prior to their inclusion in the study.

The initial sample was composed of 54 physician−patient pairs. A physician−patient pair was formed when a patient who met inclusion criteria was seen for the first time by a given physician in a clinic visit.

The physicians were either second-year residents in internal medicine, residents in hematology with prior specialization in internal medicine or hematologists with postgraduate degree in the specialty, all from the Hematology Outpatient Clinic at the university.

Patients with SCD aged 16 years or older not cognitively impaired were included in the study. Cognitive status was assessed using the Mini Mental State Examination[20] adapted to take into account the education level of the Brazilian population.[21] Patients with pain caused by any condition other than SCD were excluded from the study. The final sample size was 52 physician−patient pairs because two patients met exclusion criteria.

All patients completed a 3-item questionnaire assessing pain experienced 24 h prior to the clinic visit. The instrument was developed by the PiSCES group,[4] and translated and adapted for the Brazilian population. In this questionnaire, pain intensity (how badly it hurts), level of distress (how upset the patient feels because of pain), and interference (how much pain disrupts activities of daily living) are rated on a 10-point Likert-type scale ranging from 0 (none) to 9 (extremely).

The patients also completed a questionnaire assessing socio-demographic (gender, marital status, education level, age, and income) and clinical characteristics (SCD genotype, clinical complications and previous admissions due to SCD) and the cross-culturally validated Brazilian-Portuguese version of the Patient Health Questionnaire (PHQ-9)[22,23] to determine the presence of depressive symptoms. The PHQ-9 is a reliable screening instrument widely used in primary health care.

Immediately after the patient visit, another investigator who was blinded to the patient's responses, asked the physician to complete the same instrument assessing the pain experienced by the patient, and a questionnaire on the factors considered by the physician when evaluating the patient's pain experience, including the type and level of difficulty faced when evaluating a patient with pain and SCD, and interfering factors that influenced the choice of treatment.

The physicians also completed a socio-demographic questionnaire (gender, marital status, education level, age, and time since graduation), and a questionnaire on the physician performance during the clinic visit in assessing the patient's pain.[24] The latter instrument, which had been translated and adapted into Brazilian-Portuguese, addresses the beliefs of physicians in the management of chronic nonmalignant pain and factors considered by physicians when assessing patients with pain, thus measuring the physicians' performance during the clinic visit. The instrument has 26 items with responses coded either no (0) or yes (1), with the sum of positive responses yielding the total score for attitudes and beliefs considered in the treatment decision. There is no cutoff score determining a good or poor physician performance during the patient visit, but the instrument provides a qualitative assessment that helps physicians to gauge their own performance.

The frequency of physicians' answers was reported in Tables 1 and 2. To compare the pain measures between patients and physicians it was applied the Mann−Whitney *U* Test. The intraclass correlation coefficient (ICC) and 95% confidence intervals (CI) were used to measure the agreement between physicians and patients on the level of the pain experienced by the patients (reported in Table 3).

The study hypothesis was tested using a multiple logistic regression model to assess whether the physician's