Original Article

Perceived Discrimination in Health Care Is Associated With a Greater Burden of Pain in Sickle Cell Disease

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Abstract

Context. Perceived discriminatory experiences in society have been associated with a higher burden of pain among some minority patient populations.

Objectives. To describe the extent to which patients with sickle cell disease (SCD) perceive discrimination from health care providers and to examine the association of these experiences with the burden of chronic SCD pain.

Methods. Cross-sectional analysis of data collected at baseline of a prospective cohort study of SCD patient experiences of care ($n = 291$). Perceived race-based and disease-based discrimination from health care providers were measured using subscales adapted from the Interpersonal Processes of Care Survey. Discrimination scores were examined for their association with patient characteristics and measures of pain burden using descriptive, bivariate, and multivariate analytic techniques.

Results. Respondents reported a greater burden of race-based discrimination from health care providers than has been previously reported by African Americans, and they reported a greater amount of disease-based vs. race-based discrimination. Age and having difficulty persuading providers about pain were the only patient characteristics independently associated with race-based discrimination, whereas older age, greater emergency room utilization, having difficulty persuading providers about pain, daily chronic pain, fewer good days during a week, and a higher severity of pain on their good days were independently associated with greater disease-based discrimination.

Conclusion. Perceived disease-based, but not race-based, discrimination was found to be associated with a greater range of self-reported pain among patients with SCD. If causal, this finding could signal an important new approach to

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mitigating the burden of pain experienced by persons with SCD. J Pain Symptom Manage 2014;48:934–943.

Key Words

Discrimination, patient-provider communication, health care quality, sickle cell disease, chronic pain

Introduction

Racial and ethnic disparities in the burden of pain and quality of pain treatment are a significant public health problem in the U.S.[1] A full understanding of the causes of these disparities is required for their effective mitigation. Racial and ethnic discrimination is hypothesized to play an important role in the development and maintenance of health disparities.[2] Individual perceptions of experiences with racial discrimination have been associated with a number of adverse health behaviors and outcomes, including worse physical and mental health.[3] A growing body of research has begun to explore the impact of racial discrimination as a contributing factor to the higher burden of pain experienced by racial and ethnic minorities. In one study, Edwards[4] found that the lifetime experience of racial discrimination was the strongest predictor of the report of back pain among a sample of African Americans, even after accounting for a number of demographic, physical, and mental health-related factors. Similarly, Burgess et al.[5] found that perceived racial discrimination was associated with greater bodily pain among a sample of older African American men. Although these studies suggest an important potential cause of the high burden of pain typically experienced by African Americans, their design raises questions about generalizability to other African American patient populations. Additionally, both prior studies examined patient experiences of racial discrimination from a wide array of potential sources in society (e.g., school, employment, daily experiences, etc.) but failed to examine discrimination from health care providers. The extent to which perceived discrimination is experienced in health care is an important area of inquiry because it is within this context that health care organizations and health policymakers might exert their greatest level of influence in ameliorating the health effects of discrimination.

The present study seeks to address these two important gaps in our knowledge by examining perceived discrimination in health care among patients with sickle cell disease (SCD). In the U.S., African Americans have the greatest incidence of SCD at one per every 400 African American births.[6] The disease has a significant impact on the health of the affected individual as it is the cause of early mortality and a great degree of morbidity, including frequent episodes of severe acute pain and a high burden of chronic pain.[7,8]

The characteristics of SCD, unfortunately, make it an ideal patient population for the study of the relationship between discrimination and pain. Many health care providers have been shown to possess negative attitudes about SCD patients that serve as significant barriers to the delivery of appropriate pain management in SCD.[9–15] These attitudes contribute to many problems in the interpersonal quality of care delivered to SCD patients.[16–19] Nevertheless, the extent to which SCD patients perceive discrimination from health care providers, and the extent to which this perceived discrimination is independently associated with the burden of SCD pain, is not known. The aims of the present study were twofold: to describe the extent to which patients with SCD perceive discrimination from health care providers and to examine the association between perceived discrimination and the burden of chronic SCD pain.

Methods

Study Design, Subjects, and Setting

Our study was conducted using data collected as part of the Improving Patient Outcomes with Respect and Trust (IMPORT)