

Original Article

Sickle Cell Disease Patients With and Without Extremely High Hospital Use: Pain, Opioids, and Coping

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Abstract

Context. Patients with sickle cell disease (SCD) and extremely high hospital use (EHHU) encounter significant challenges in pain management because of opioid medication use for pain and providers' concerns about addiction.

Objectives. To characterize engagement with the health care system surrounding opioid pain management among SCD patients with EHHU by comparing their experiences with low-hospital-using (LHU) patients and their medical providers' perspectives.

Methods. One-on-one, semistructured qualitative interviews with patients and medical providers were audiotaped and transcribed. Participants were eight SCD patients with EHHU; matched by age, gender, and hemoglobinopathy type with eight SCD patients with low hospital use; and five providers identified by patients with EHHU as important to their care. A multidisciplinary team conducted chart review, created narrative summaries from the interviews, and used qualitative software to code transcripts based on themes.

Results. High-hospital-using patients and LHU patients had similar descriptions of their experience of pain and pain management with opioids. Patients and medical providers shared concerns about addiction. LHU patients described themselves as allies using specific interpersonal and symptom-related strategies, whereas high-hospital-using patients took a defensive and reactive stance toward their providers, who were similarly defensive about their care.

Conclusion. The prescription of opioid medications for SCD pain management exacerbates issues of distrust in the patient-provider relationship. Such issues dominate patient care in patients with EHHU. Patients with EHHU and providers may learn from the proactive nature of LHU patients' engagement with the health care system as further research and interventions are designed for EHHU. *J Pain Symptom Manage* 2015;49:539–547. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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Key Words

Doctor-patient relationship, sickle cell disease, opioids, pharmaceutical care, hematology, addictive behavior, pain

Introduction

Pain in sickle cell disease (SCD) is ubiquitous and heterogeneous. Its management is frequently inadequate and controversial because of the addictive potential associated with opioid analgesics. Such controversy is concentrated in a small population of SCD patients who account for the majority of inpatient hospital stays,^{1,2} a population we call patients with extremely high hospital use (EHHU), pejoratively labeled in hospital settings as “sicklers,”³ and “frequent flyers.”⁴

Barriers to effective pain management in SCD include sociocultural factors affecting pain assessment and concerns regarding addiction and pseudoaddiction.⁵ Administration of opioid analgesics has been a mainstay for acute crises in SCD,⁶ but patients with SCD in an emergency department encountered longer delays for initial analgesic administration than patients with similar pain presentations.⁷ Providers only may see “the tip of the iceberg”⁸ of SCD pain and underestimate its severity because of the frequency; patients with SCD report variety in pain⁹ and on more than 50% of days.¹⁰ As patients with SCD age, acute episodic pain^{11,12} may develop into a multidimensional chronic pain syndrome punctuated by acute episodes,^{13,14} distinguishing SCD from many other conditions associated with chronic pain.¹⁵

Evidence of the association between incidence of addiction and prescription of opioid pain management for SCD patients, especially patients with EHHU, is scant.^{16–18} Despite little evidence, fears of addiction among prescribing providers are common, and patients feel stigmatized as drug seeking when presenting with pain.¹⁹ Among physicians surveyed on SCD pain management, 53% of Emergency Department physicians believed that more than 20% of SCD patients are addicted to opioids compared with 23% of hematologists.²⁰ At home, patients combine remedies with pain medications and in hospital settings act as advocates for their care.²¹ Patients’ assertiveness might earn them the label “difficult”²² for

displaying behaviors associated with addiction and pseudoaddiction, such as obtaining analgesic prescriptions from multiple sources, having disputes with hospital staff, and self-discharging from the hospital.^{16,23,24}

In our previous qualitative work, EHHU was linked to a history of hospitalization and opioid use from a young age, which perpetuated missed social, educational, and vocational milestones.²⁵ Quantitative comparisons of EHHU and low-hospital-using (LHU) patients have found that the groups had similar coping strategies, social support, and personalities, as well as lifetime history of SCD-related complications,²⁶ but qualitative differences between these groups with respect to negotiating opioid pain management with providers are not well understood. This study characterizes challenges among patients with EHHU by comparing their experiences with those of LHU patients and perspectives of their medical providers.

Methods

This was a qualitative study of patients with EHHU, their medical providers, and patients with LHU. All patients provided informed consent. The research protocol was approved by Yale University School of Medicine Institutional Review Board, New Haven, CT.

Participants

Participants comprised 21 individuals: eight SCD patients with EHHU; matched by age, gender, and hemoglobinopathy type with eight SCD patients with LHU; and five providers who were individually identified by each EHHU patient as their most important provider. All patient-participants self-identified as African American. EHHU was defined by the threshold of 100 hospital days/year over each year. Patients were purposively identified through the Yale-New Haven Hospital Resource Information Management System from January 1, 2008, to December 31, 2010 and chart review further compared patients’ clinical histories. Participants were approached by telephone or in person. Providers

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