

LETTERS—CONCISE RESEARCH REPORTS

Improving Care for Patients with Sickle Cell Disease: a Qualitative Study of Hospitalized Sickle Cell Patients

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INTRODUCTION

Sickle cell disease (SCD) is a hereditary blood disorder that affects approximately 100,000 Americans.¹ Acute pain episodes, or vaso-occlusive crises, account for approximately 70% of acute care visits for patients with SCD.¹ Patients with SCD face unique obstacles to care, including difficulty communicating the severity of their pain and fear of being labeled as a “drug addict.”² The combined annual cost of Emergency Department visits, Urgent Care visits, and hospitalizations for SCD has reached over \$2.4 billion annually.³ In an effort to improve care for SCD patients who have required frequent readmission, we interviewed hospitalized SCD patients and asked for input on how our health system can better meet the needs of our SCD population.

METHODS

Adult SCD patients admitted to the inpatient medicine services at the University of Colorado Hospital between March 2017 and May 2018 were identified and approached for consent. Interviews were conducted by a professional research assistant (RA), digitally recorded, and transcribed verbatim. The interview script included questions regarding experiences with disease management, perceptions of quality of care, access to care (insurance, PCP, specialists, medications), and psychosocial factors affecting hospital experience and follow-up care (finances, living environment, behavioral health). Two team members independently analyzed the transcripts using a general mixed inductive/deductive approach to theme analysis supported by ATLAS.ti software. Following independent coding, differences between reviewers were resolved through group discussion (all four team members) and codes were developed through team-based iterative analysis. This study was IRB approved.

Preliminary findings were presented (abstract and poster) at the Rocky Mountain Hospital Medicine Symposium on October 16, 2016, and the Society of General Internal Medicine national conference on April 12, 2018.

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RESULTS

Twelve hospitalized patients with SCD were invited to participate in semi-structured interviews; seven consented and completed the interview. Those who declined participation included one patient with an imminent discharge and four patients who were unavailable when the RA reached them on at least 2 occasions. Interviews varied from 7.5 to 54 min (average length 16.5 min). Some patients provided extensive narrative explanations, while others provided brief answers and declined to expand their answer even with additional probing questions. All interviews contained valuable information and were included in data analysis.

Identified themes included (1) the importance of patient/provider relationships, (2) the challenges of readmission, (3) the relevance of psychosocial factors, and (4) healthcare system factors (Table 1). Patients highlighted a desire for clinicians to convey understanding of the patient’s history and their individualized treatment plans, as well as best practices in SCD. One patient stated, “[If] you’re going to try to help a sickle cell patient, you gotta know what’s going on with sickle cell.” When readmitted, patients often stated that they had not felt ready for discharge during their previous hospital stays due to inadequate pain control. Many patients expressed mistrust for their inpatient team. One patient reported, “They pre-judge you. They think you’re only there to get medicine and then they tell you you’re not in much pain... [I] feel neglected and pushed around, passed around – that’s a bad way to feel when you’re sick.” Some patients spoke about depression and social isolation related to their frequent admissions and uncontrolled symptoms, and their need for additional social support both within and outside of the hospital. One patient stated, “I’m depressed a lot of the time when I come in here... I know when I leave with sickle cell, with this disease, it’s not the end of the battle. It’s not even close.” Most patients reported that they did not have an established relationship with a PCP and relied on their hematologist for all of their medical needs as most felt their hematologist knew them better.

DISCUSSION

Findings from our interviews suggest a number of interventions that could improve outcomes for patients with SCD, including (1) enhanced communication between patients and

Table 1 Themes and Representative Quotes from Qualitative Interviews with Patients with Sickle Cell Disease

Themes	Quotes
Patient/provider relationship	<p>“Sometimes they do not really want to listen... on some occasions I’m running into those (doctors) who like, ‘I do not care what you are talking about, you ain’t going to school for this, I did.’”</p> <p>“They judge and they [kind] of pass me around to other doctors, and it feels bad to the point where I’ve actually left the hospital.”</p>
Readmissions	<p>“I felt half way ready but...hours and hours before my discharge, my body just showed me signs that, yeah, I wasn’t ready...”</p> <p>“I was discharged a little too early. I was still in a lot of pain so when I got home and was taking my meds and they wasn’t helping. I could not move so I’m still sitting there like I am here.”</p>
Psychosocial factors	<p>“It hurts me cause it makes me go in pain and I have certain feelings too...nobody give a care how I feel. Nobody cares.”</p> <p>“As a doctor, you gotta see a lot. You see some unfortunate things. It’s gotta be tough but from the other side, it’s tough going through what I’m going through as well so, you gotta have some compassion.”</p>
Healthcare system factors	<p>“Well they [PCP] hold everything together. You gotta have a good one cause they know about the sickle cell, like they really know about it but at the same time you know about everything else too so they pretty much hold me together like glue.”</p> <p>“Just like with any disease, you gotta have those who are passionate about it. Like you got people out here who really want to cure cancer, like they really believe they can. That’s awesome because one day they might...You gotta have somebody that wants to rid the world of sickle cell in the right way.”</p>

inpatient providers that includes discussion of previous treatments and an individualized care plan that incorporates patient feedback into pain management plans; (2) interdisciplinary

bedside rounds involving the hematologist, social worker, and pain service when applicable; and (3) developing coordinated care plan with a PCP and outpatient specialists. Care-coordination programs for “high need, high cost” patients such as patients with SCD can decrease acute care visits and the cost of care.⁴ Based upon our interviews, efforts to improve care coordination at the time of discharge for patients with SCD in a way that explicitly address plans for care in future admissions should be a priority.

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Compliance with Ethical Standards:

Conflict of Interest: The authors declare that they do not have a conflict of interest.

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