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# Research design creates ambiguity related to efficacy of sickle cell, chronic disease specialty clinic

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**ABSTRACT** A clinical appraisal and clinical application of Koch KL, Karafin MS, Simpson P, Field JJ. Intensive management of high-utilizing adults with sickle cell disease lowers admissions. *Am J Hematol.* 2015 Jan;90(3):215-219. doi:[10.1002/ajh.23912](https://doi.org/10.1002/ajh.23912)

**Keywords:** sickle cell, chronic disease, fragmented inpatient care,

## Clinical Context

A twenty year old gentleman with a history of HbSC presented to the emergency department with a pain crisis. He was admitted to internal medicine for management lasting 4 days. Review of his electronic medical record revealed numerous visits to the ED, averaging five to ten per year. Over the course of the admission, he became less adherent to recommendations, like using incentive spirometry, and would not converse with those caring for him. By the time of discharge, he was relieved to finally return to the comfort of his home and family. I felt that the repeated inpatient care, leading to fragmented doctor-patient relationships, negatively impacted the care that we could provide.

## Clinical Question

What alternative healthcare models exist for sickle cell patients that diminish fragmented inpatient care and allow the patient to spend more time at home rather than in the hospital?

## Research Article

Koch KL, Karafin MS, Simpson P, Field JJ. Intensive management of high-utilizing adults with sickle cell disease lowers admissions. *Am J Hematol.* 2015 Jan;90(3):215-219. doi:[10.1002/ajh.23912](https://doi.org/10.1002/ajh.23912)

## Literature Review

Sickle cell disease (SCD) poses the challenge of long term care for a growing number of patients since the average life span of patients with SCD has increased.<sup>1</sup> This literature review focuses on research involving SCD patient interaction with the health care system.

The literature review was initially conducted using Google Scholar, with general topical search terms related to multispecialty clinics for care of patients with SCD. The most relevant article was by Grosse et al.,<sup>2</sup> who noted that there is no consistent national network

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of specialty clinics for patients with SCD. Using the “see related” function in Google scholar, the papers by Aisiku,<sup>3</sup> which dealt with patient satisfaction, and Raphael,<sup>4</sup> who compared day hospitalization versus inpatient care for children with SCD, were reviewed. Raphael found a reduction in hospitalization days in the pediatric population. This same paper was then located in PubMed and the see related function was again used to locate relevant papers. A retrospective study in 2015 by Lanzkron, et al. evaluating the Sickle Cell Infusion Center (SCIC) for SCD treatment at Johns Hopkins Hospital focused on three areas to evaluate the impact of the dedicated SCD center on the patient care, emergency department visits, and the community. The study evaluated the first few years of operation of the center from February 2008 to December 2011. SCD patients could present directly to the SCIC, or SCD patients who presented to the ED could be transferred to the SCIC for treatment, which resulted in lower costs per patient, fewer hospital admissions and reduced 30 day readmissions due to SCD.<sup>5</sup> Subsequent PubMed search terms included sickle cell disease management; sickle cell disease specialty clinic; and sickle cell disease high utilizing adults, intensive management. This search resulted in the paper chosen for this critical appraisal, which had the advantage of reporting both pre- and post-implementation data.

## Critical Appraisal

The article written by Koch, et al. (SORT Level of Evidence: 3) is a study of adults with SCD admitted to the Medical College of Wisconsin (MCW) in Milwaukee.<sup>6</sup> The authors described this as a retrospective cohort study, but it could better be described as a before-and-after comparison, typical of quality improvement projects, because a cohort design requires two groups with different exposures and a primary outcome. This limits the generalizability of this data: the authors identify three groups of patients using past utilization patterns, but the patients all originate from a single group being cared for at MCW. By defining the groups with risk stratification, the confounding and bias is a property inherent in how the groups are constructed, and may not be related to the intervention at all. The behavior of “super utilizers” could be affected by social support, financial situation, transportation problems, severity of disease, drug seeking behavior, or other unidentified variables. The authors accounted for none of these. Additionally, because of a lack of blinding, implementation bias is a significant concern in this paper. One strength of this before-and-after study was that the authors had a full year of data prior to program implementation followed by a full year of data after patient entry into the program.

For the entire group of patients, there was not a statistically significant reduction in rate of ED/hospital admissions per patient year. The moderate increase utilization in the low and moderate utilizers (which accounted for 85% of patients) may explain this, because it offset the decreased utilization of the 17 patients labeled super utilizers. Because the patient in the clinical scenario would have been classified as a moderate utilizer and not a super utilizer, he may not have benefitted from a program like the authors describe.

## Clinical Application

The patient, the doctor, and health care system act together in a way that mutually impact each other. Caring for patients with chronic medical conditions presents a unique set of challenges including long term follow-up care. It will be important to keep an open mind to new ways of structuring care models of the health system, like having specialized treatment clinics for SCD patients, to provide more efficient and higher quality care. It is important to consider the organization of our medical system and pursue innovation in order to improve the quality of patient care and wisely manage resources.

Lessons learned include:

- 1.) Building a trusting relationship with the patient may be as important as having a dedicated multi-specialty clinic for patients with SCD.
- 2.) Super-utilizing SCD patients may have special needs that should be assessed on an individual basis.
- 3.) A thorough critical appraisal of scholarly work is extremely important.

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