

STRONG CHILDREN'S RESEARCH CENTER

Summer Research Scholar

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ABSTRACT

Title: *Quality of Inpatient Care for Sickle Cell Disease (SCD): A Scoping Review of Patient, Caregiver, and Provider Perspectives*

Background: Sickle cell disease (SCD) is a genetic red blood cell disorder that leads to frequent hospitalizations. Currently, there are no explicit guidelines on how to provide quality care for people with SCD in inpatient settings. Our overall objective is to identify potential inpatient SCD care quality indicators by completing a scoping review of inpatient SCD care literature using the Donabedian model (structure, process, and outcome). This study focused on identifying qualitative research addressing inpatient SCD care with a focus on patient, caregiver, and healthcare team perspectives.

Methods: Peer-reviewed articles were identified using controlled vocabulary and text words for "qualitative studies" and "sickle cell disease" in PubMed, Embase, CINAHL, Scopus, World Health Organization, PsycINFO, and Web of Science databases through May 2023. A team of reviewers then screened articles for inclusion using a collaborative online software designed for conducting literature reviews. Inclusion criteria were (1) studies with a qualitative research approach, and (2) research that addressed inpatient SCD care in the study setting, participants, or results. Articles were dual screened, and discrepancies were resolved by clinical faculty and staff. Themes and illustrative quotes were extracted, and will be categorized into structural, process, or outcome measures as outlined within the Donabedian model of quality.

Results: 9,913 studies were identified in the database search and screened. 48 full-text articles were included in the scoping review. Research was conducted predominantly in the United States (52%) and United Kingdom (23%), with remaining studies from Africa, Asia, and the Americas. 32 articles (67%) involved adult patients and 19 studies (40%) involved pediatric patients. Across all studies, 38 patients, 14 caregivers, and 18 healthcare providers were represented.

Conclusion: A scoping review was conducted to identify patient, caregiver, and healthcare team perspectives of inpatient SCD care. Future steps will include categorization using the Donabedian model and thematic analysis.