Understanding Chronic Pain in Pediatric Sickle Cell Disease: Insights from a Retrospective Chart Review

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Background:
Sickle cell disease (SCD) is an inherited blood condition characterized by abnormally shaped red blood cells that can obstruct blood flow, often leading to painful vaso-occlusive crises. While the current standard of care utilizes opioid-based strategies to manage acute pain, the development and diagnosis of chronic pain remains poorly understood, particularly in pediatric populations. This study aims to understand the prevalence of chronic pain in pediatric patients with SCD at a single institution.

Methods:
A retrospective chart review was conducted of children with a confirmed diagnosis of SCD who received care at Riley Children's Hospital Sickle Cell Clinic between January 1 and December 31, 2024. Data were extracted from the electronic medical record. This study was approved by Indiana University's Institutional Review Board.

Results:
A total of 441 unique patient charts were reviewed. Twenty-nine were excluded due to being less than 1 year old or not being seen during the study period. Most patients had the Hb SS-genotype (58%) and nearly half (48%) were female. Of the 412 unique patients reviewed, only 16 had an established diagnosis of chronic pain, with an average age of 17 years (SD +/- 2.4).

Fifteen of the 412 patients had 3 or more hospitalizations in a year, 12 of whom did not have a diagnosis of chronic pain. Five had 6 or more opioid prescriptions in 12 months. Similar to the larger cohort, most had Hb SS and about half were female. However, the average age of this cohort was younger (13 years +/- 4.6 years).

Conclusion:
These findings reveal a notable discrepancy between clinical indicators of high pain burden and formal recognition of chronic pain in pediatric patients with SCD, suggesting under-recognition of chronic pain in younger individuals leading to delay in appropriate treatment.