Are Children With Sickle Cell Disease (SCD) Receiving Similar Attention In Their Hematology-Oncology Clinics?

Jacqueline C Drummond-Lewis MD, Lynette Tay, PhD Meghan S. Middleton, APRN, Brenda C McClain MD
Department of Anesthesia Yale New Haven Hospital

Introduction: Chronic pain experienced by patients with sickle cell disease (SCD) has been compared to those living with cancer (CA). Both groups experience life threatening disease, impaired quality of life and compromised psychosocial function.[1-3] Treating SCD related pain like CA pain has been a controversial topic in pain management[4-5] Pediatric hematologist-oncologists predominately manage their patient's pain and seek help when the child is requiring increased medical care. This is a report of the practice noted within our institution in the pain management of children with SCD and those with hematogenous and osteogenic CA with similarities regarding severity of illness score (SOI) and chronic pain.

Methods: After institutional approval an independent not blinded review was conducted on the medical record of children with SCD and hematogenous and osteogenic CA who were referred to the Pediatric Pain Clinic. The data was taken from the last hospitalization prior to the referral. The patient's status was based on the ordinal SOI of Horn and Horn[6] with a standardized index modification to evaluate persistent pain. The SOI scores ranged from 7 to 28, high scores represented greater SOI. The time from onset of persistent pain to the time of referral was noted.

Results: A total of 41 medical records were reviewed. Three were deleted due to lost of follow up or death within 30 days of the referral. The mean number of physicians regularly involved in their care at the time of the referral for each group was 2.38 (S.D. = 1.446) for CA and 1.35 (S.D. = 0.745) for SCD ($p = .009$). The duration of pain prior to the referral was 6.062 mo (S.D. = 3.974) for SCD group and 3.736 mo (S.D. = 3.034) for CA group ($p= 0.058$). The modified SOI inter-rater reliability was 0.75. The mean SOI scores in each group was 9.18 for SCD and 9.13 for CA.

Discussion: Despite our small sample size, disparity of pain management of children with SCD and CA was demonstrated. Statistically, significantly fewer physicians were involved in the SCD group. This finding was not dependent on the SOI score. It is unclear whether the discrepancy was due to inherent needs of the disease, physician access, care perspective, or ethnicity. Both groups were cared for by a pediatric hematologist-oncologist, and all received chronic opioids. Pain scores were not significantly different between the groups; however the initial referral was sooner for the CA group. An early and systematic multidisciplinary approach for SCD related pain may improve the quality of life in this population. [7]

Modified Severity of Illness Index

Characteristic	Level 1	Level 2	Level 3	Level 4
Principal Diagnosis	**Asymptomatic**	**Moderate Manifestations**	**Major Manifestations**	**Catastrophic Manifestations**
Complications	None or Very Minor	less important than principal diagnosis	As or more important than principal diagnosis	Catastrophic- death or permanent disability
Interactions	None or Minor	Moderate	Major	Catastrophic
Dependency	Low	Moderate	Major	Extreme
Procedures (Non-O.R.)	Noninvasive diagnostic or Minor Therapeutic	Therapeutic or Invasive Diagnostic	Non-emergency Life Support	Emergency Life Support
Rate of response	Prompt	Moderate Delay	Serious Delay	No Response
response to therapy	Complete- No pain meds needed	Extensive. Resumes analgesic regimen	Incomplete 25% dose increase or addition of analgesic or adjuvants	No Resolution > 25% increase. Poor pain control at discharge

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