Longitudinal patterns of daily pain in children with sickle cell anaemia

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Daily pain in children with sickle cell anaemia (SCA) has previously been considered rare. Following our recent study introducing the Index of Pain Experience in Sickle Cell Anaemia (IPESCA), this study aims to elucidate longitudinal patterns of daily pain in children using serial IPESCA measurements, along with assessing the feasibility of collecting daily pain experiences through digital and paper-based diaries. We hypothesise that frequent daily pain would be related to higher frequency in older children, that hospital admissions were not an appropriate proxy for pain burden, and that IPESCA measurements would show high variability (e.g., fluctuations) over time. As an exploratory analysis, we hypothesised higher IPESCA are related to poorer executive function.

This sample included children ≤18 years screened for the Prevention of Morbidity in Sickle Cell Anaemia (POMS) trial (n=41). Patients underwent cognitive testing at baseline. IPESCA was calculated from paper pain diaries at baseline, and patients continued tracking pain unprompted using an phone-based app (provided identical information to paper-based diaries) for up to 50 weeks. Children completed age-appropriate Wechsler subtests and Delis-Kaplan Executive Function System (D-KEFS) subtests (i.e., Tower Test) to assess executive function. Caregivers also completed the Behavior Rating Inventory of Executive Function (BRIEF).

Despite receiving only limited reminders, feasibility of daily-pain diary reporting was demonstrated. Thirty-five patients (85%) reported daily pain across the study period. Mean IPESCA over time did not significantly correlate with increasing age. Children with higher mean IPESCA consistently performed worse on memory and executive function tests. Also, hospital admissions for pain did not correlate strongly with daily pain. Our findings indicate that children with SCA have frequent and variable daily pain and are willing to track symptoms for long periods, offering clinicians and opportunity to examine and tailor patient-specific solutions for daily pain.