

Our research over the last 8 years suggests that most sickle cell pain is managed at home by older children and adolescents, and by families of infants and young children. In this grant proposal, we will continue to expand our knowledge of the incidence of vaso-occlusive and other pain and its characteristics in infants and young children with SCD using parental daily reports. Child self-report will be included as these children reach school-age, an age group not previously studied. Daily parent-report formats will utilize daily email using 2-way pagers and staff initiated bi-weekly telephone interviews for parents of infants, followed by electronic daily diaries using PDAs for parents of young children. These novel data collection approaches have considerable advantages compared with our previous use of paper diaries, and will expand family participation in these and similar studies.

We will also examine as our second Aim, in conjunction with Project II, the relationship between the incidence and/or frequency of sickle pain in these infants and young children and various hematologic and biologic parameters. The focus of this investigation will expand beyond the relationship between pain incidence, fetal hemoglobin, erythrocyte-endothelial cell adhesion, and coagulation activation examined in our previous studies, to include measures of WBC, platelet, and endothelial cell activation, and will use additional novel statistical methodology in collaboration with the Statistics and Data Management Center.

Based on information from parent report and our clinical experience, for our third project Aim, we will develop, implement, evaluate, and disseminate a parent-mediated home pain management protocol for the management of sickle pain in infants and young children. These management protocols and their associated educational materials will address some of the pain management issues identified in our previous studies, including inadequate dosing and frequency of analgesics, and inadequate assessment and re-assessment of pain. The availability of reliable communication between family and the healthcare team and programmable PDAs will provide a unique opportunity to implement and evaluate such a program. This focus on parents' continues our Center's support for young families started with our HRSA-funded Grandparent support program, while the education effort will coordinate with those of the clinical and patient services cores. Examining the dynamics influencing effective and ineffective pain self-management skills will provide information for increasing competence in these children that will provide preliminary information that could be used to develop future interventions for our longitudinal cohort when it reaches mid-childhood.