

PARENT-REPORTED BARRIERS TO ADHERENCE FOR CHILDREN WITH SICKLE CELL DISEASE

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Children with sickle cell disease (SCD) have complex regimens, which may include pain management medications, fluid hydration, monitoring of fevers, antibiotics, transfusions, chelating agents, hydroxurea, and exercise. Poor adherence to the treatment regimen can have significant health-related outcomes, including hospitalizations, ED visits, and missed days at school. Previous research has suggested adherence rates of 88-96% for hydroxurea and 12-69% for oral prophylactic penicillin. Although adherence to medications has been documented in the literature, few studies have examined barriers to good disease management in SCD. The purpose of the current study was to examine parent-reported barriers to several components of the SCD treatment regimen, as well as successful strategies attempted by families to improve adherence.

Participants included 59 children with SCD, ranging from 6-18 years, and their parents. Mean age of the sample was 13.0 years and 46% were male. Parents completed a demographics form, a self-reported measure of adherence and barriers to adherence, and information regarding health care utilization (e.g. hospitalizations, ED visits). Medical chart reviews were also conducted to complete a Prescribed Treatment Plan for each patient.

Results indicated that 75% of parents utilized OTC pain medications at the onset of their child's mild pain symptoms. In addition, 86% of parents identified other pain management strategies, including hot baths/showers, heating pads, sleeping, distraction, and relaxation. The primary barriers noted for pain medications included difficulty swallowing pills, forgetting or losing medications, disliking taste/side effects, and feeling as if their child is taking too many medications. Parents reported that the most successful strategy to address these barriers was parental reminders (39%). Regarding oral antibiotics, approximately 47% of children were prescribed an antibiotic. Primary barriers for antibiotics included difficulty swallowing pills and forgetting to take them. Similarly, parents reported that the most successful strategy to address these barriers were parental reminders (61%). For fluid hydration, results indicated that children were drinking an average of 8.0 (SD = 3.9) glasses of fluids daily, with 5.5 (SD=3.4) glasses being water. The primary barrier for adequate fluid hydration was forgetting and successful strategies to increase fluid hydration included parental reminders (24%), just "doing it" (9%), using different flavored beverages (9%), and "knowing it will help" (9%).

Overall, results suggest that parents of children with SCD identify several barriers to effective disease management (e.g. forgetting, difficulty swallowing pills, disliking taste/side effects). Parents reported using various strategies to improve adherence and approximately 50% indicated that parental reminders have been an effective method to increase their child's adherence. Data from the current study suggests that health care teams need to discuss these issues and share successful strategies with patients and parents in order to provide interventions that directly meet families' needs.