

Table 4: Evidence Supporting the Importance of Appropriate Hematology Care and Satisfaction with Care for Children with Sickle Cell Disease

Type of evidence	Key findings	Level of evidence (USPSTF ranking*)	Citation(s)
Clinical guidelines	General pediatricians often serve as the main providers of care for children with SCD, with hematologists functioning as consultants. This arrangement developed because all children need to see pediatricians for developmental checks and immunizations. A system has evolved where general pediatricians are the main contact and hematologists provide advice about SCD-related interventions.	III	National Heart Lung and Blood Institute. The Management of Sickle Cell Disease. National Institutes of Health. Bethesda, MD, 2002.
Clinical guidelines	<p>Satisfaction data are useful because they provide a personal viewpoint that cannot be found by abstracting administrative data or even by observing care. Satisfaction data that are creditably obtained will accurately reflect the personal and psychological realities of caring for children with special needs.</p> <p>Satisfaction data are important for children with special health care needs because there are not many other identified indices of outcome. Satisfaction can be measured at the individual level (the quality of the interaction); provider network or plan level (satisfaction with receipt of services); or community level (effectiveness of addressing health needs of an entire population).</p> <p>There are four dimensions of care pertaining to parental satisfaction: 1) developmentally appropriate care (acknowledges the complex interaction between development and health status); 2) family-centered care (recognizes the pivotal role of family in care and is sensitive to cultural background and inclusion regarding decision-making); 3) technical competence (emphasizes provider expertise in care of children with special needs, including risk assessment and good judgment); 4) interpersonal competence (applies technical skills in the context of human relationships; includes kindness and respect and effective communications).</p>	III	Ireys HT, Perry JJ. Development and evaluation of a satisfaction scale for parents of children with special health care needs. Pediatrics 1999; 104(5):1182-1191.

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Clinical guidelines	<p>Patient satisfaction is mix of perceived need, expectations, and experience of care. Satisfaction represents a comparison between a patient's perception of the performance of the health care provided and what the patient wanted or expected.</p> <p>Core satisfaction issues that apply to children include being treated with dignity, effective communications with providers, getting needed care, getting care quickly, and confidentiality.</p>	III	Darby C. Patient/parent assessment of the quality of care. <i>Ambul Pediatr</i> 2002; 2(4 Suppl): 345-348.

Note: USPSTF criteria for assessing evidence at the individual study level are as follows: I) Properly powered and conducted randomized controlled trial (RCT); well-conducted systematic review or meta-analysis of homogeneous RCTs. II) Well-designed cohort or case-control analytic study. III) Opinions of respected authorities, based on clinical experience; descriptive studies or case reports; reports of expert committees.