

## Children with sickle cell disease receiving inadequate care

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A new study finds that youth populations with sickle cell disease (SCD) are receiving inadequate healthcare, and thus may fail to benefit from scientific advances. The study, published in *Pediatric Blood & Cancer*, finds that the patients, mostly African Americans, often lack insurance or access to specialized sickle cell centers for treatment.

SCD, a blood disease characterized by abnormally shaped red blood cells, affects close to 100,000 persons in the United States alone. The disease is a chronic medical condition, which causes frequent episodes of pain and may lead to serious infections as well as stroke.

According to one of the study authors, Jean Raphael, of the Baylor College of Medicine, significant percentages of children with SCD fail to see a specialist even once per year and that only 10 percent of cases are followed by hematologists. Additionally, the number of hematologists and other health care providers dedicated to care of these patients may be insufficient to provide adequate care.

"This topic has significant relevance to healthcare quality and delivery to children with chronic conditions," says Raphael. "Rising healthcare costs in the U.S. due to chronic diseases demand more from the healthcare system for better long-term survival."

An accompanying editorial by Dr. Jane Hankins of St. Jude Children's Research Hospital notes that in a country where advances in care and research for SCD are praised as among the best in the world, children

with this condition continue to receive inadequate health care and consequently fail to fully benefit from substantial progress in scientific research.

"As with any chronic pediatric condition, management of SCD requires more frequent and more substantial use of medical resources, but managed care organizations and pediatricians do not receive compensation rates reflective of the high cost of caring for these children," says Hankins.

"The combination of a disease that combines progressive organ damage, poverty, racial inequalities, disease stigmatization, uninsured or unstably insured children and poorly compensated health care professionals results in a precarious situation. It is important to draw attention to problems in health care delivery as this information may help spur changes that will result in increased effort and resources."

Source: Wiley

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