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New study finds barriers to pain treatment in children with sickle cell disease

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A new study by researchers from the Medical College of Wisconsin, in Milwaukee, found a substantial variation in hydroxyurea utilization for pain and other sickle cell disease complications in children. Barriers to its use on the part of both providers and patients were also identified. The study led by Amanda M. Brandow, DO, MS, assistant professor of pediatrics at the Medical College and Children's Research Institute at the Children's Hospital of Wisconsin, will be presented at the American Society of Hematology meeting Dec. 7, 2009, in New Orleans.

The study was funded by the National Heart Lung and Blood Institute of the National Institutes of Health. Dr. Brandow is an NIH sickle cell scholar.

Sickle cell disease is often marked by episodes of severe and incapacitating pain called vaso-occlusive painful events, which can sometimes require hospitalization. Hydroxyurea, an oral drug that is most commonly taken once daily, was approved by the U.S. Food and Drug Administration for use in sickle cell disease patients in 1998. While hydroxyurea remains the standard of care for reducing these painful events in adults, little is known about its practice patterns in children.

The researchers surveyed members of the American Society of Pediatric Hematology/Oncology about their practices and patients to evaluate patterns and barriers to hydroxyurea use. Of the 1,128 surveys disseminated, 31 percent (350 surveys) were returned.

To standardize and increase the quality of care for both adults and children with sickle cell disease, the National Heart, Lung, and Blood Institute (NHLBI) provides clinical practice guidelines for the management of this blood disorder. Most of the survey respondents had heard of (87 percent) and read (78 percent) these guidelines, and provider utilization of hydroxyurea correlated with awareness of the NHLBI recommendations.

The survey found that only eight percent of providers had half or most (50 to 90 percent) of their pediatric patients with sickle cell disease on hydroxyurea. Another 54 percent of providers had 10 to 30 percent of pediatric patients on the therapy, and 10 percent of providers had fewer than 10 percent of pediatric patients on hydroxyurea. Although a majority of providers (90 percent) felt that hydroxyurea was effective or very effective for the prevention of pain, some still did not prescribe the drug to eligible children because of apprehension about future reproductive issues (birth defects and infertility in males), despite insufficient evidence to support this concern.

Low patient compliance was cited by 86 percent of providers as another reason they did not prescribe hydroxyurea. Providers reported that children and their families refused hydroxyurea because of a fear of cancer or other possible side effects, concerns that the drug would not work, compliance with required laboratory monitoring, or because they simply did not want to take medication.

The study also found that many providers prescribed hydroxyurea for reasons other than that for which it was intended, despite insufficient evidence of its efficacy for other complications of the disease.

According to Dr. Brandow, "To alleviate this problem, future research in the following areas may help: continued funding of studies to determine the efficacy of hydroxyurea for complications other than pain,

evaluating unconfirmed toxicities of the drug that influence practice, exploring how access to care contributes to noncompliance, and research on methods to promote patient adherence to recommended medical care."

Source: Medical College of Wisconsin (news : web)