

Study examines effectiveness of caregiver education about sickle cell trait

April 18, 2018

Despite universal newborn screening that detects the presence of sickle cell trait (SCT), only 16 percent of Americans with SCT know their status. To address this issue, in Ohio, in-person education is offered to caregivers of referred infants with SCT.

“Most people do not know their sickle cell trait status. When a newborn screening result shows that an infant has sickle cell trait, we are there to support the parents with education about SCT and its implications on reproductive health,” says Susan Creary, MD, hematologist at Nationwide Children’s Hospital. “But, to be effective, this education must be appropriate and meet the needs of the parents that we are educating.”

In a study published in *Molecular Genetics & Genomic Medicine*, Dr. Creary and her colleagues investigated the effectiveness of this standardized education at a single institution.

Their results support the idea that many parents of children with SCT have low baseline SCT knowledge, but that their knowledge improves with the 20-minute standardized in-person education. However, the results also suggest that many of these parents have low health literacy and that SCT knowledge may fade over time.

According to the study, only 38 percent of the caregivers had high SCT knowledge scores (>75 percent) before education. However, 90 percent achieved high scores after education. After 6 months, caregivers’ scores were higher than baseline,

but only 73 percent still had high scores.

“Caregivers who did not achieve high knowledge immediately after education – about 10 percent of the cohort – had lower baseline knowledge and health literacy,” says Dr. Creary. “These results suggest that educators may need to provide additional supplemental information about SCT. They also may need to use different education tactics so that all parents are able to understand and remember the education that they received about SCT and can share this knowledge with their children when they are older.”

While prospective studies are needed to determine if these changes result in higher knowledge and retention, the researchers suggest the following changes may improve in-person SCT education and support retention of the information:

- Provide additional education sessions
- Include more visual aids and other learning strategies, such as the teach-back method
- Increase the amount of time spent on the more complicated topics during the education
- Include caregivers when developing new teaching tactics

“We know that in-person education is important for patients and families with low health literacy,” says Dr. Creary. “Previous health education intervention studies show that it is critical for health education to include verbal communication. We cannot rely on a pamphlet or online information to provide caregivers with the knowledge and support that they need to have about SCT.”

Dr. Creary and her team are seeking grant funding to implement and test improvements to caregiver education.

Source:

<https://www.nationwidechildrens.org/>