New tool helps young adults with sickle cell disease in the transition to adult care

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Child and adolescent hematologists at Boston Medical Center (BMC) have developed a tool to gauge how ready young adults with sickle cell disease are for a transition into adult care. In a new article for the *Journal of Pediatric Hematology/Oncology*, Amy Sobota, MD, MPH, and her collaborators have shown that a questionnaire geared to the needs of young adults with sickle cell disease can pinpoint areas of need before the patient goes into an adult clinic.

BMC's sickle cell disease transition clinic, which is unique in Boston, was established in 2008 and serves approximately 45 patients.

Sickle cell disease is a hemoglobin disorder, the molecule in red blood cells that carries oxygen to the tissues. Due to a genetic mutation, sickle cell patients make red blood cells that are shaped like a crescent or "sickle." These patients are often anemic and can get bouts of extreme pain when sickled red blood cells become caught in small vessels of the body. Sickle cell disease traditionally has had a high mortality rate; however, children with sickle cell disease are now living longer, healthier lives thanks to early diagnosis and effective treatment.

These welcome changes have given new importance to the young patient's point of transition into adult care.

Previous studies have shown that patients with SCD who are transitioning from pediatric to adult care have more admissions and emergency department visits. "We saw that these patients had specific

needs, and that is why we started the transition clinic at BMC," said Sobota, who is an attending in pediatric hematology/oncology at BMC and an assistant professor of pediatrics at Boston University School of Medicine.

To determine the tool's efficacy, the researchers looked at the answers provided by 33 patients between the ages of 18 and 22 who completed the assessment. A majority, 97 percent, of the respondents said they could explain sickle cell disease to another person and that they understood "how they got" the genetic disease, and 94 percent understood that sickle cell disease might be passed on to their children.

All of the patients said that they planned to attend college or obtain post-high-school training, but only 70 percent knew where to find information about job training and opportunities. Sixty four percent of transitioning patients said they understood the various types of health insurance available to them, but only 13 percent had drawn up a portable medical history form that they could give to adult healthcare providers. Encouragingly, 97 percent of young sickle cell patients claimed a good social support system.

Finally, patients were asked about their ability to manage independent living and 73 percent of the patients had some job experience, full- or part-time. Although all of the patients were 18 and over, only 79 percent said they were already going to doctor's appointments on their own. However, few mentioned that they had anxiety about transitioning to adult care.

"Our study indicates that this assessment tool – the only one of its kind – provides important information to physicians of patients with sickle cell disease who are transitioning from pediatric to adult care," said Sobota. "Caregivers can use this information from patients in order to effectively tailor and guide their treatment and education through this transition."

More information: BMC hematologists have put together a comprehensive guidebook for young adults with sickle cell disease that addresses many of their personal concerns and gaps in knowledge, available at goo.gl/ZtWC0r

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