

Study shines light on fertility education gaps among adolescent and young adult men with sickle cell disease

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Credit: National Institutes of Health

New research published today in *Blood Advances* indicates that many adolescent and young adult (AYA) men with sickle cell disease (SCD) are unaware of potential SCD-associated fertility issues, highlighting a need for comprehensive fertility education materials for this population.

Researchers found that while most AYA men with SCD want to have genetically related children in the future, few were aware of how their disorder and corresponding treatments might affect their fertility.

SCD is a rare chronic, progressive, life-threatening, inherited [blood disorder](#) that affects more than 100,000 Americans and an estimated 100 million persons worldwide. According to the Centers for Disease Control and Prevention, SCD affects one out of every 365 Black or African American births and one out of every 16,300 Hispanic American births. The condition can cause severe pain, joint and organ damage, and stroke. Advancements in SCD research have prompted the development of groundbreaking therapies, allowing 93% of young people with SCD to live into adulthood, a statistic marking tremendous progress in disease interventions over the last few decades. Existing research suggests that SCD and common treatments, like hydroxyurea, may affect fertility in AYA men with the disorder, leading experts to recommend fertility testing for those with SCD.

"As clinicians, we need to do a better job of integrating discussions regarding SCD-associated fertility concerns with our patients, starting at an early age, and with their caregivers," said Leena Nahata, MD, pediatric endocrinologist and Principal Investigator in The Abigail Wexner Research Institute at Nationwide Children's Hospital.

"Preemptively understanding these risks allows them to make educated decisions about their care and futures."

In collaboration with Dr. Susan Creary, a pediatric hematologist at Nationwide Children's Hospital, Dr. Nahata and colleagues conducted a small pilot study of 20 AYA men between the ages of 14 and 21 with SCD, as well as 15 of their caregivers, from the Comprehensive Sickle Cell Clinic at Nationwide Children's Hospital. All participants completed the Fertility Knowledge and Attitudes Questionnaire, a survey developed by Dr. Nahata and her research team that included questions about

sociodemographic factors, parenthood goals, fertility-related knowledge, and factors influencing interest in fertility testing.

Results highlight that while approximately 85% of surveyed AYAs reported wanting [biological children](#) in the future, most participants and their caregivers responded incorrectly or with uncertainty to the questions. Notably, 35% of AYAs and 47% of their caregivers were unsure how to get a semen sample, and 30% of AYAs and 20% of caregivers did not know its purpose.

These findings underscore a need for accessible fertility education and fertility testing options for AYA men with SCD, specifically focused on how SCD and its associated treatments may affect fertility, as well as information on obtaining fertility tests and explaining the purpose, cost, and the process of the procedure. While these results shine a light on a critical knowledge gap among [young people](#) with SCD, more research must be done to confirm how fertility is affected and how physicians can alleviate this burden. Further, because this was a relatively small study, researchers aim to replicate it in larger populations to validate and expand their findings.

In the future, Dr. Nahata and colleagues strive to advance fertility research for people living with SCD and to develop culturally sensitive and inclusive education materials that promote fertility discussions early on between AYAs and their caregivers.

"I think we need more research on fertility-related outcomes in this population because, in order to fully educate adolescents and [young adults](#) and their parents, we need to first know what to tell them," said Dr. Nahata. "It's also crucial that we develop culturally-tailored educational materials and assess fertility testing barriers, as we know this population already faces barriers to equitable health care."

More information: Leena Nahata et al, Fertility Testing Knowledge and Attitudes in Male Adolescents and Young Adults with SCD and Their Caregivers: A Pilot Study, *Blood Advances* (2022). [DOI: 10.1182/bloodadvances.2022007004](https://doi.org/10.1182/bloodadvances.2022007004)

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