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Original Communication

A Pilot Study to Evaluate Awareness of and Attitudes About Prenatal and Neonatal Genetic Testing in Postpartum African American Women

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Abstract

Objective

A pilot study to determine whether prenatal and neonatal sickle cell tests conform to the guidelines established by the American Congress of Obstetricians and Gynecologists and the American Academy of Pediatrics.

Methods

The project was initially structured as a pair of inperson interviews of postpartum women at the University of Chicago, the first collecting medical information and the second surveying the ethical, social, and legal implications (ELSI) of sickle cell trait (SCT). Due to inadequate enrollment, we elected to focus only on the second survey. Descriptive statistics and bivariate analyses were performed.

Results

A convenience sample was established from 205 women who had completed surveys of whom 12 (6%) received no prenatal care. Of the 60 women who completed both surveys, 15 (25%) were unsure of their hemoglobinopathy status. Of the 50 results we could verify, 2 women (4%) incorrectly recalled their hemoglobinopathy status. Of the 193 women who received prenatal care and completed the ELSI survey, 47 knew their hemoglobinopathy status from a previous pregnancy and 1 had sickle cell disease. Of the remaining 145 women, 53 (37%) recalled hemoglobinopathy testing during this pregnancy and 44 (30%) were unsure. Only 56 (39%) recalled being told they could refuse testing. Of the 115 women whose infants had newborn screening done prior to the interview, only 51 (44%) recalled discussions with a pediatric provider.

Conclusion

Despite professional guidelines that stress the importance of education, counseling, and consent for prenatal and neonatal testing, postpartum women do not recall these conversations.

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Keywords

genetics; sickle cell disease; infant health; screening

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