

Title:

Advances in Reproductive Genetic technology: Expanding toward Global Reproductive Health Equity among populations with Sickle Cell Disease in the United States and Africa

Author:

Shameka Poetry Thomas, PhD^{1,2}

¹Harvard University, School of Public Health; ²National Institutes of Health/National Human Genome Research Institute

Author's Email: shamekathomas@hsph.harvard.edu

Two curative gene-editing therapies for sickle cell disease (SCD) treatment were officially approved by the Food and Drug Administration (FDA) as of December 2023, utilizing CRISPR to modify DNA for SCD. Worldwide approvals for gene-editing not only mark radical scientific innovation for populations living with SCD across the United States (US) and Africa, but also highlight serious bioethical concerns. One important concern is how new reproductive genetic technology (e.g., noninvasive prenatal testing) and gene-editing impacts fertility, pregnancy, and reproductive decision-making among marginalized populations, such as Black American and African women living with SCD. For instance, as gene-editing advances in the US (and clinical trials are being carried out in some parts of sub-Saharan Africa), reproductive health outcomes for those living with SCD is *still* perpetually dismissed and neglected. Another aspect is how noninvasive prenatal testing (NIPT) also is widely becoming routine prenatal care in the US (and across 14 European countries), but also is in the experimental implementation phase to screen for SCD in the fetus. Most clinical trials on NIPT, however, predominately enroll White women in their sample cohorts, which structurally excludes the subsample variance of Black American and African women with genetic conditions. This proposed study draws from two datasets of Black American and African women living with SCD, including: 1) NIPT dataset (N=40) patient cases of women (18-51 years) living with and without SCD in the US context; and 2) Sickle Women and Girls (SWAG) dataset (N=45) patient cases of women and girls (13-25 years) living with SCD in Ghana, West Africa. Results show overlap as to how Black American and African women navigate SCD and prenatal care; perceptions of NIPT for SCD screening in the fetus; the intersection of reproductive health and SCD; and NIPT decision-making processes, relating to fertility concerns in curative gene-therapies for SCD.

As the global landscape of reproductive health is expanding, we must also meet the needs of the global society for populations with genetic conditions. In order to do this, we need a call to action that frames how reproductive health equity and inclusion can be implemented into scientific frameworks, to better improve the integration between reproductive bioethics and reproductive genetic technology among Black American and African women, worldwide.

References:

1. **Thomas, SP, PhD**; Faith Fletcher, PhD, MA; Rachele Willard, BS; Tiara Ranson, BS; and Vence L. Bonham, JD. 2024. "Patient Perceptions on the Advancement of Noninvasive Prenatal Testing for Sickle Cell Disease among Black women in the United States." *American Journal of Bioethics-Empirical Bioethics*.
2. **Thomas, SP, PhD**; Madison Alana Keller, BS; Tiara Ranson, BS; and Rachele Willard, BS. 2023 "Patient Perceptions on Noninvasive Prenatal Testing among Black Women in the United States: A Scoping Review" *BMC Pregnancy and Childbirth*. <https://doi.org/10.1186/s12884-023-05423-w>