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Sequencing of Newborns Does Not Create Negative Psychosocial Effect on Families, Study Finds

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NEW YORK – Researchers studying the psychosocial effect of newborn genomic sequencing on families in the BabySeq project have found that there was no persistent negative psychosocial harm in families who received such sequencing, nor among those who received a monogenic disease risk finding for their infants.

In a paper published on Monday in *JAMA Pediatrics*, researchers at Baylor College of Medicine, the Broad Institute, and elsewhere noted that although newborn sequencing may provide health benefits throughout a person's life, there are concerns that it could also have an unfavorable psychosocial effect on families.

In order to assess those effects on families from the BabySeq Project, the researchers conducted a randomized clinical trial to evaluate the effect of sequencing on the clinical care of newborns. From May 2015 to May 2019, 519 parents of 325 infants at well-baby nurseries and intensive care units completed surveys at enrollment, immediately after disclosure of sequencing results, and at three and 10 months after the disclosure of results.

Newborns were randomized either to a control group, where they receive standard newborn screening and a family history report, or to the sequencing group, where they received the standard screening and family history report plus a report of childhood-onset conditions and highly actionable adult-onset conditions, the researchers said.

The investigators then compared the mean survey responses between groups in three domains of psychosocial impact: parent-child relationship, parents' relationship, and parents' psychological distress. They also compared responses within the sequencing group, between parents of children who received a monogenic disease risk finding and those who did not.

Although mean scores differed for some outcomes at singular time points, the researchers' generalized estimating equations models did not show meaningful differences in parent-child relationship or parents' psychological distress response patterns between study groups over time. Response patterns on one parents' relationship measure differed between groups over time, they said, but the effect decreased over time and no difference was observed on the conflict measure responses over time.

Overall, they added, they found no evidence of persistent negative psychosocial effect in any domain.

"Prior studies suggest that adults don't usually experience negative psychological impact when given genomic information about themselves, but how this impacts parents and the family unit when the information is about their newborns hadn't been previously explored," co-first author Stacey Pereira, an assistant professor at the Center for Medical Ethics and Health Policy at Baylor, said in a statement.

"This study is unique in that it looks, in part, at genetic risk for seemingly healthy babies," added corresponding author Amy McGuire, co-principal investigator of the BabySeq Project and a professor of biomedical ethics at Baylor. "Some are concerned that parents who know that their seemingly healthy child is at risk for disease later in childhood or adulthood will experience more anxiety or alter how they relate to their child. The lack of distress on the family unit is an encouraging sign as we continue to explore the potential risks and benefits, as well as ethical and equity questions related to preventive sequencing of apparently healthy people."

The researchers did note that the study had limitations, including that because few families agreed to hear about the study to begin with, the parents who ultimately enrolled may have had more positive attitudes toward research. Further, they added, although they found no evidence of negative psychosocial impact in this volunteer sample of families, these findings may not be generalizable to a scenario in which newborn sequencing was state mandated.

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