

Ethics of testing for preterm birth risk weighs uncertain harms and benefits

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Credit: University of California, San Francisco

A new blood test being developed at UC San Francisco may be able to predict a woman's risk for preterm birth with 80 percent accuracy, but knowing such information could also create stress for a woman, which is potentially harmful during pregnancy.

As more powerful blood and genetic testing become available, ethical quandaries like this one are still being sorted out by the medical

community.

For World Prematurity Day this year, UCSF gathered speakers that included Anne Wojcicki, CEO and founder of 23andMe; Barbara Koenig, PhD, director of the UCSF Center for Bioethics; and members of the UCSF Preterm Birth Initiative's Community Advisory Board, Davina Countee and Tanisha Fuller, mothers with experience of [preterm birth](#), to discuss the ethical considerations of preterm birth testing.

Most Women Don't Know Their Risk

For too many women, the first time they hear about preterm birth is the day it happens, said Larry Rand, MD, principal investigator of the California arm of the UCSF Preterm Birth Initiative (PTBi), in opening remarks for the event on Nov. 17 that was organized by PTBi .

One in 10 babies is born prematurely (before 37 weeks), yet most pregnant women are told very little about preterm birth. Despite the scale of the problem, little progress has been made in reducing preterm birth rates. One of the biggest challenges is the difficulty of identifying women at risk, said Rand, but that may be changing.

UCSF researchers are developing a new blood test that can predict a woman's risk for preterm birth with 80 percent accuracy. According to Laura Jelliffe-Pawlowski, PhD, associate professor of epidemiology and biostatistics, who presented the work at the event, the low-cost test can be administered as early as 15 weeks into a pregnancy and not only predicts overall risk, but suggests the specific drivers of that risk, whether it is diabetes, an infection, or the health of the placenta.

"Preterm birth is so hard to address because there are multiple pathways. There's no silver bullet. What we're trying to do is to show a specific pattern of risk so we can get to treatments that are specific," said Jelliffe-

Pawlowski.

The test measures 13 biomarkers in the blood related to placental, lipid, hormone, and immune function, and also considers maternal characteristics such as hypertension, diabetes, obesity, and poverty.

Social and Ethical Questions Around Testing

But the prospect of a test for preterm birth risk, especially one with uncertain accuracy and based on evolving research, raises thorny [ethical questions](#). Even for women at [high risk](#), few interventions are available.

"Interventions now are only for very small slices of the population, and only work for a third of them at best," Rand said. Moreover, a high risk test result might create stress for the mother, and [stress can exacerbate](#) the risk of preterm birth.

In addressing these ethical issues, Koenig noted that while personalized risk prediction is the Holy Grail of precision medicine, it is important to manage the uncertainty inherent in such predictive tools.

The ability to measure risk does not necessarily translate into improved health, especially when no clear interventions are available. Regarding a test for preterm birth risk, she asked, "If we did have really good research that sharing risk information and uncertainty actually leads to worse outcomes, what should we do then? Does the truth-telling element of medicine always take priority?"

She added that an overemphasis on biological testing can remove medicine from its broader social context. "In research, you need to keep both social and biological elements in the analysis," she said. "Genomic analysis by race, for example, is complex and must be carefully done when considering something like preterm birth, a well-known health

disparity in the U.S."

The Power of Knowledge

Countee and Fuller, both of whom are African-American, shared their personal experiences with preterm birth, made more harrowing by the lack of information they received. Both said they would have liked to have known about their risk for preterm birth so they could have prepared themselves and their families.

"Everyone should have the option of knowing," Fuller said. "I didn't get the information that I needed, and I was treated as if I couldn't comprehend it."

Koenig suggested that the takeaway isn't the need for individualized risk testing, but rather that preterm birth is so common that all women should be better educated about its possibilities.

For Jelliffe-Pawlowski, even an imperfect test is a first step toward improving outcomes for preterm birth, both in identifying populations for further research and for individual women at high risk. A woman who is informed of her risk might be more aware of the signs of early labor and more likely to go to the hospital in time for medical interventions to delay labor such as cervical pessary, cervical cerclage and tocolytic administration.

"If we're lucky we might give her a week, but she's got to get to the hospital. For a baby every week is a big deal. We want to give that baby another week if we can," she said.

Provided by University of California, San Francisco

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