perience pain have not yet developed and the ACOG states that rigorous recent data show that experiencing pain is not possible until the third trimester.[5] This evidence has not stopped politicians from "finding" otherwise and mandating that fetal anesthesia be available (thus closing many clinics that do not have this capacity) or that abortions be outlawed as early as the beginning of the second trimester. Indeed, the U.S. House of Representative has passed H.R. 1797, the "Pain-Capable Unborn Child Protection Act," and more than 40 senators are cosponsoring its companion bill, S. 1670.

It should come as no surprise, then, that Alicia Beltran's arrest and incarceration are consistent with a long history of legislative and judicial misrepresentation of the risks of drug use during pregnancy. Such misrepresentation began in the 1980s and early 1990s, when women were being prosecuted and jailed for "child abuse" (or some variation thereof) if they used cocaine during pregnancy. Without suggesting that cocaine use is safe or that all the effects are known, the 2010 National Institute on Drug Abuse report "Cocaine: Abuse and Addiction" states that the claims that "crack babies" would be born with severe defects or lifelong deficits were a "gross exaggeration." But those claims became the basis for laws such as the one used against Beltran in Wisconsin, where what started with crack cocaine expanded to encompass the state's power to incarcerate a pregnant woman who "habitually lacks self-control" (undefined) with respect to any number of substances, legal and illegal.

Thus was Beltran's liberty taken away, even though medical examination showed that she was drug-free and without symptoms of withdrawal and that her fetus was developing normally. The medical standard of care would call for ongoing monitoring in the course of prenatal care. It would not necessarily require Beltran to return to taking antiaddiction medications, as the state insisted. And it definitely would not call for incarceration in a setting that lacked prenatal care (and, ironically, also lacked capacity to administer the drugs that the state claimed were indicated).

For two decades, legislatures have been encroaching on the realm of medicine. Heedless of medical ethics or evidence-based standards of care, they have been declaring medical "facts," specifying or forbidding medical procedures, and dictating to doctors what they must say to their patients. *Roe v. Wade* was not only about a woman's right to abortion. It was also about the right to her physician's medical judgment and best care, unconstrained by partisan strategies. It is not only women's bodies that are being held hostage to politics; it is also the hearts, minds, and professional pride of their physicians.

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Prenatal Whole-Genome Sequencing — Is the Quest to Know a Fetus's Future Ethical?

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Researchers recently reported sequencing a fetal genome from cell-free fetal DNA in a pregnant woman's blood,[1] heralding the possibility of performing whole-genome sequencing as early as the first trimester of pregnancy. This possibility adds a new level of complexity to decisions about prenatal testing. Current methods such as chorionic-villus sampling and amniocentesis, which must

be performed by physicians, provide information about specific medical conditions. With this advance, expectant parents may eventually obtain genetic information not just about the risk of childhood diseases but also about carrier status for autosomal recessive disorders such as Tay–Sachs disease, the risk of complex adult-onset diseases such as diabetes, the presence of genes causing adult-onset autosomal dominant diseases such as the hereditary breast and ovarian cancer syndrome, and the likelihood of traits such as baldness. Such sequencing could thus blur the boundary between diagnosis and screening for risk of future disease. Parents could learn about the risk of diseases that might never be manifested and about genetic variations of unclear significance.

This innovation raises ethical and policy questions. Should women be offered prenatal whole-genome sequencing? Should parents have access to all their fetus's genetic information? The rationale behind the current genetic screening of children is based on providing direct medical benefit to the child. Newborns are screened for major illnesses that can be avoided by instituting treatment before symptoms appear. A reluctance to provide parents with access to other types of genetic information, including tests for untreatable and adult-onset conditions, has been based on the perception of overriding harms to the child. Common concerns include the psychological burden of information on parents and children, damage to self-esteem, alteration of a family's view of the child, stigmatization, and discrimination. Whole-genome sequencing may further result in unexpected findings such as misattributed paternity, along with findings of unknown clinical significance. The standard approach to interventions without an imminent medical benefit has been cautious, erring on the side of respecting a child's rights not to know and to decide later in life whether to obtain genetic information.

Diagnostic advances, however, have generated discussion about broadening screening criteria. A 2005 report of the American College of Medical Genetics (ACMG) reiterated that therapeutic intervention for the child is the primary justification for screening — but acknowledged that such intervention could be defined more broadly than immediate treatment.[2] The report discussed the example of intellectual disability, for which early intervention can lead to less-severe outcomes. Parents could benefit from results identifying a genetic risk to relatives or future offspring. Societal benefits include progress in biomedical research from data characterizing the incidence and natural history of genetic conditions and the effects of intervention. Early genetic diagnosis could also spare the health care system costly diagnostic quests.

The report received mixed responses, and in 2008, the President's Council on Bioethics recommended a two-tiered approach: mandatory newborn screening should follow classic criteria for the direct medical benefit of the child, and additional genetic findings could be offered to parents who sought them in a research context (providing an opportunity to consider the benefits and risks of disclosure).[3] In 2013, an ACMG–American Academy of Pediatrics policy statement reaffirmed that genetic-screening decisions should be driven by a child's best interest, acknowledging that family benefit as a justification for screening remained controversial.[4]

We would argue that parents who wish to obtain their fetus's genetic information should be permitted to do so after receiving genetic counseling. The ethical foundation for providing this option is a basic right of reproductive choice and parental autonomy; people may choose when, with whom, and how to reproduce, and they have the right to data that may inform these decisions. Parents are free to raise children according to their own beliefs about what is best, free from government interference absent a superseding reason (e.g., abuse) warranting intervention. We grant broad autonomy to parents, even in choices that might not be best for the child, such as decisions not to send children to school after 16 years of age.

The advent of fetal whole-genome sequencing raises concern about potential increases in abortion rates. Although *Roe v. Wade* protects a woman's choice to terminate a pregnancy before viability, abortion remains ethically contentious, with legal limits challenged by state-imposed restrictions on previability abortions. However, currently in the United States, women need not provide any reason for choosing to terminate a pregnancy, so it's difficult to justify restricting abortion in the case of a well-defined reason, such as genetic

disease. Concern about abortion rates does not justify withholding information about genetic markers for future illness. We suggest that fetal whole-genome sequencing be presented as an additional choice. Many parents will probably opt not to obtain this information. Those who seek it can make a compelling argument for their right to receive information that involves the health and well-being of their child or that may guide a decision about pregnancy termination or future reproduction.

Knowledge of risks, even uncertain ones, can reasonably inform reproductive decisions and help parents prepare for a child's future. Many disease risks revealed by whole-genome sequencing will be complex, their manifestation the outcome of an interplay of genes and environment. Learning about an increased risk of a complex disease may motivate families to adopt lifestyle modifications that they might otherwise not make a priority. An increased risk of adult-onset diabetes may spark earlier emphasis on exercise and healthy diet; genetic predisposition to cancer may reinforce the need for cancer screenings. For less-preventable conditions, a positive result may empower parents to learn more; those who seek testing may be more likely to pursue research and experimental options, contribute to advocacy organizations, or galvanize the research community to find a cure. Thus, a fetus's risk of developing an adult-onset disease that is not currently treatable may provide valuable information for parents, children, and society.

Whether these benefits will be realized is uncertain, but earlier fears about the psychosocial burdens of sharing genetic information have proved unfounded. Disclosure of *APOE* (apolipoprotein E) genotyping results to asymptomatic adults, for example, has not been associated with substantial psychological risks.[5] Critics of unfettered access to genetic information fear that increased prenatal choices will cause parents to view children as commodities. Similar concerns were voiced about assisted reproductive technologies that are now widely accepted. As knowledge of genetics expands, so will understanding of what it means to have access to such information. The possibilities of uncertainty and misunderstanding are neither unique to genetics nor grounds for overriding a right to information about one's fetus. Instead of leading to constraints on disclosure, concern about misunderstanding should inspire the development of educational resources to improve comprehension of the complexities and limitations of genetic information.

A practical concern is the shortage of genetic-counseling professionals. The need for accurate information will provide an impetus for increasing the genetics workforce — but may also inspire innovative models of information provision. One such approach may be a Web-based system that can display risk information in various formats to facilitate understanding, allow repeated access to information without added cost, and educate parents about specific risks and benefits before they decide to view particular results.

Whole-genome sequencing has substantial potential for medical and personal utility. We believe that obtaining a fetus's full genetic profile should be the parent's choice. Instead of limiting a child's potential future, knowledge of genetic risks can offer a greater opportunity to inform possibilities for a good life. As sequencing technology becomes integrated into prenatal medicine, we should ensure the availability of genetic counseling to guide patients through complex decision making. It's also critical that we engage in research to capture families' perspectives and experiences as they obtain genetic information. We can remain attentive to emerging challenges while safeguarding parents' freedom to choose, prepare, and be informed about their fetus's risk of disease.

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