

Commentary

Prenatal genetics in a post-Roe United States

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The Supreme Court removed a federal right to abortion access in June 2022. This returned the legality of abortion to each of the 50 states. This will have a profound impact on the provision of prenatal care in general and prenatal genetic screening and testing.

Prenatal genetic screening and testing—including ultrasound, serum screening, cell-free DNA screening, and diagnostic genetic tests for fetal conditions during pregnancy—has become a routine part of prenatal care in the United States (US). US medical societies, including the American College of Obstetrics and Gynecology, recommend the offer of prenatal genetic screening and/or diagnosis for pregnancies at all risk levels.¹ Although such tests are technically optional, previous research has pointed to the need for more fully informed decision-making processes about what information, if any, families want to receive about their fetus.

Decisions about how much prenatal genetic information to receive, and when, will inevitably take on additional weight now that the US Supreme Court has struck down *Roe v. Wade*. Decided in 1973, *Roe v. Wade* protected abortion access under a constitutional right to privacy. The case held that individual states could not pass laws that unduly restrict access to abortion services.² While *Roe v. Wade* succeeded in protecting access to legal abortion for nearly 50 years, anti-abortion actors have succeeded in passing an increasing number of laws, referred to as targeted regulation of abortion providers (TRAP) laws, that functionally interfere with abortion providers' ability to provide needed care and/or patients' ability to access care.³ Several states implement mandatory waiting periods, unnecessary invasive exams, or excessive licensure for abortion providers, forcing abortion into hospital settings.⁴ Restrictions on the use of public funds to fund abortion services have forced patients to pay for terminations, and any follow-up care, out of their own

pockets.⁵ Because of these and other restrictions, most people in the US do not live within easy traveling distance of an abortion provider, meaning that people in need of abortion care must also pay for transportation, lodging, and childcare. And, as with all state-level legislation, laws can change precipitously when political parties gain or regain control of state legislature.

Thus, in many parts of the US, abortion was already *de facto* inaccessible to many. Nevertheless, the decision that there is no constitutional right to abortion access will have a significant impact. Roughly half of US states have indicated that they will enact bans on abortion if the Supreme Court allows. Others have signaled that they will pass state laws explicitly permitting abortion. In general, historically liberal states are likely to have more permissive laws permitting abortion within the first two trimesters with allowances for maternal health and wellness.⁶ Some historically conservative states, often led by activists on the religious far right,⁷ have already prepared so-called “fetal heartbeat” laws that would criminalize abortion after fetal electrocardiac signals are detected. Some lawmakers have even argued for a conception-based ban that would forbid even Plan B, the so-called “morning after pill” (which is not an abortifacient but interferes with a fertilized egg's implantation into the uterine wall), and would outlaw abortion even in the event of rape or when the pregnant individual's life is in danger. Some states have inserted criminal penalties into these laws, including potentially imprisoning clinicians who perform abortions and allowing citizens to report to law enforcement

women they suspect of having had an abortion.⁸ Women in multiple US states have already faced incarceration and prosecution after experiencing a miscarriage.⁹ If these more extreme measures are permitted to move forward, pregnant individuals, their families, and their health-care providers will be forced to navigate an increasingly complex patchwork of legal risks.

Prenatal genetic screening

The role of prenatal genetics and diagnostics in this new landscape is likely to be fraught. In countries that criminalize abortion, including many Latin American countries, some bioethicists have questioned the ethics of offering prenatal genetic screening, especially when it is offered as an “add on” test that the patient must pay for.¹⁰ If the stated goal of screening for disease is actionability, then, some argue it is problematic or entirely unethical to give a pregnant individual information about a fetus while mandating pregnancy continuation, including information that indicates severe or potentially lethal conditions. Indeed, some prominent conservative activists in the US argue against the offer of any prenatal testing on the basis that it suggests that abortion is an optional course of action in the event of a fetal anomaly.

During the *Roe v. Wade* era, anti-abortion activists frequently attempted to gain a foothold by suggesting laws that do not forbid abortion per se but restrict the reasons for seeking abortion. The two most popular are laws that forbid abortion based on fetal sex or detection of a fetal genetic condition such as Down syndrome. Notably, both may be detected through prenatal genetic



screening as early as 10 weeks gestation. The strategy of such laws is to introduce abortion bans that would theoretically force advocates for abortion access to argue for the abortion of female fetuses or those with a disability. Again, such laws would criminalize providers who provide abortion if they have *reason to believe* that it is being done based on sex or aneuploid status. This deliberately vague language would effectively prevent the return of prenatal genetic information to any pregnant individual who might be willing to consider termination because it is reasonable to assume that any abortion after a positive result from a prenatal genetic screen or diagnostic test could be prosecutable under such laws. Further, many genetic conditions result in higher rates of spontaneous miscarriage, which could put pregnant individuals at risk for prosecution in jurisdictions where such “reason bans” are in place. Parents who may be grieving the loss of a much-desired pregnancy may find themselves defending against accusations of discriminating against future children based on their genetic qualities. Far from reducing bias against those with genetic conditions, such legislation has the likely effect of entrenching perceptions that any genetic condition makes life less worth living. These laws are all relatively new—indeed, most were held up by legal challenges until 2019—so their scope and force are still untested in courts.

Nonetheless, in the many states that are poised to restrict or ban abortion now that the *Roe* decision is struck down, additional hazards await. Even the earliest available prenatal tests—early ultrasounds, or cell-free DNA screening available at 9 to 10 weeks gestation—will not be early enough in many states to allow parents to make informed decisions about pregnancy continuation. One reason to encourage early prenatal care is to provide testing to make sure that both parent and fetus are healthy. But once a pregnancy appears in the medical record, any pregnancy loss could raise suspicion, and perhaps even more so if records indicate positive results from prenatal genetic testing. Some states have indicated they will prosecute even individuals who receive abortion care outside their borders, and the existence of medical records of pregnancy could provide evidence for such prosecution. Thus,

individuals who harbor any uncertainties about continuing their pregnancy will almost certainly be reluctant to seek out early prenatal care, putting their health and the health of the pregnancy at risk.

As with nearly any restrictions on reproductive choices and healthcare, the effects of such laws will fall mainly on those who are already economically, socially, and medically marginalized.¹¹ The impact of TRAP laws has always been felt disproportionately by those of lower socioeconomic status and in particular women of color.¹² The history of racialized medicine in the US has led to a system in which Black women are 3–4 times more likely to experience significant morbidity and/or mortality because of pregnancy than non-Hispanic White women. This disparity holds regardless of other seemingly protective factors such as income and education. There were early hopes that noninvasive prenatal genetics might influence these disparities by allowing for earlier and more accurate risk stratification and the allocation of scarce resources to those at highest risk. Although access to abortion services has been restricted, many safety net providers continue to provide maternal fetal medicine care based on pregnancies identified as high risk via genetic testing. Patients also indicate that knowing fetal sex provides personal and social benefit and aids in pregnancy planning and fetal bonding. In a system in which provision of prenatal genetic information is potentially criminalized, these benefits are lessened if not obviated.

Preimplantation genetic testing

The second area of prenatal genetics that may be impacted, again on a state-by-state basis, is the provision of assisted fertility services, including preimplantation genetic screening and testing (PGT) of embryos to avoid embryos affected by heritable conditions. The technology was originally designed to allow families with a history of severe or lethal genetic conditions to avoid the birth of a child carrying the mutation, often after the birth of an affected child or following multiple miscarriages.¹³ Lethal conditions such as Tay-Sachs and Huntington’s disease have been frequently cited as manifestly ethical applications of the technology. Some families use the technology to identify embryos that are a

human leukocyte antigen (HLA) match for an existing affected child to facilitate inter-sibling transplant. Some clinics have also begun offering aneuploidy testing to all in vitro fertilization (IVF) patients using PGT, although the evidence that this practice improves outcomes is not as compelling. More controversially, private companies are now offering PGT polygenic risk panels that claim to predict risk of multifactorial diseases, including diabetes and autism spectrum disorder. While PGT impacts a relatively small subset of families, for these families its impact can be profound. With the increasing influence of arguments that IVF is fundamentally wrong because embryos are created for instrumental reasons and frequently discarded, the future of PGT is uncertain. While *Roe v. Wade* technically only applied to the medical procedure of terminating an existing pregnancy, many observers are concerned that activists will try to stretch the definition of abortion to the destruction of any embryo, whether *in utero* or not. This outcome can be reasonably anticipated based on countries that have proposed laws that allow IVF procedures only if all resulting embryos are implanted and those, like Poland, that ban IVF altogether.¹⁴

The difference between these other countries and the US, somewhat paradoxically, may be the highly commercialized fertility industry, which has significant lobbying power on both a federal and a state level. Even when the US was hotly debating the permissibility of embryonic stem cell research on the basis that it destroyed embryos that could otherwise become children, the fertility industry was adept at carving out assisted reproduction as a separate, more acceptable venue in which embryos might also be discarded. Even if activists do try to enact laws restricting procedures that rely on genetic testing, including PGT, the fertility industry has signaled that it would resist strongly, as it has resisted efforts toward regulation in the past. In a press release responding to Texas’ bill banning abortion after detection of a fetal heartbeat, the American Society for Reproductive Medicine (ASRM), the lead fertility industry lobbyist, announced that:

In the face of policies that endanger patients’ ability to access needed

reproductive care, ASRM will continue its work to guarantee patients' rights to control their reproductive health choices and providers' ability to provide sound, medically and scientifically based care.¹⁵

These efforts include active litigation challenging laws that restrict reproductive care on the basis that they are a “warning shot from across the bow” to attempts to restrict or ban *in vivo* embryo creation and fertility services. If the industry succeeds in protecting itself from these attempts, while prenatal genetic information becomes more and more circumscribed in the general population, it could have the perverse effect of retaining access to genetic information—including sex, aneuploidy status, and disease state—for the very small number of well-resourced individuals who can access assisted fertility care. While this inequity is not new, because assisted reproductive technology (ART) has always been a source of disparities, it will be exacerbated in a post-Roe world.

Conclusions

Prenatal genetics will undoubtedly see broad impacts from widespread abortion bans in the US, regardless of patients' intentions to continue a pregnancy after receiving genetic results. Even families who do not want to terminate a pregnancy affected by a particular genetic trait may find themselves under increased surveillance and suspicion throughout the pregnancy and beyond. Providers of reproductive healthcare will need to gain familiarity with complex and shifting patchworks of legal restrictions, especially when their patients come from multiple legal jurisdictions. These healthcare providers, even when they only provide genetic services and not any follow-up care, may find themselves in legal, ethical, and professional quandaries. Even genetic test developers and laboratories will likely need to familiarize themselves with relevant laws in designing and returning results from tests. However, pregnant people and their families will surely face

the most legal, practical, medical, and economic hazards—both in seeking genetic information about their pregnancy and in seeking follow-up care considering those results. The prenatal interventions that have leapt forward in the past thirty years may be less available to families in places where pregnancy loss could result in prosecution for providers and patients alike. And, as history has repeatedly shown, these burdens fall heavily on people who are medically and socially marginalized because of racial bias, economic disadvantage, or disability. As prenatal genetics navigates this new legal landscape, it will need to consider not only the future of biomedical technology, but these additional inequities in accessing its promised benefits.

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DECLARATION OF INTERESTS

The authors declare no competing interests.

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