Restrictions on Abortion Affect Genetic Counseling Practice: Genetic Counselors in Abortion Unfriendly States Reflect on Current and Impending Challenges

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RESTRICTIONS ON ABORTION AFFECT GENETIC COUNSELING PRACTICE:
GENETIC COUNSELORS IN ABORTION UNFRIENDLY STATES REFLECT ON
CURRENT AND IMPENDING CHALLENGES

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ABSTRACT

Genetic counselors (GCs) play an important role in providing and coordinating care for patients considering abortion care secondary to fetal anomaly and/or genetic diagnosis. Restrictive legislation affecting abortion access in the United States has increased in recent years. Only a few studies have analyzed the effects of restrictive legislation on GCs. This study aimed to understand how prenatal GCs’ practice is impacted by restrictive legislation and how GCs are preparing for more restrictive legislation. Thirty-four qualitative interviews were conducted with GCs practicing in Texas, as well as states categorized as “leans hostile,” “hostile,” and “very hostile” by the Guttmacher Institute. Our findings revealed that prenatal GCs adapted patient discussions, witnessed timing affect access to abortion, and noted excess stress related to legislation and patient coaching. Many participants shared that their institutions were more of a barrier than a resource regarding abortion care. Collectively, the traditional role of the prenatal GC has been altered in response to restrictive legislation. GCs are conflicted on how prenatal testing will be utilized if abortion legislation becomes more restrictive. In Texas, the uncertainty of the “aiding and abetting” language of Senate Bill Eight has impacted the way GCs are able to counsel their patients. Overwhelmingly, participants shared that resources providing updated information on legislation would be helpful to GCs, and resources funding abortion care would be helpful for patients. Further restrictive legislation may irreversibly change how reproductive medicine and prenatal genetic counseling are practiced, resulting in further reproductive inequities across the US.
INTRODUCTION

Prenatal GCs provide care for pregnant patients and may play a critical role in healthcare coordination in the event that a patient receives a diagnosis of a fetal anomaly or other threat to the health and wellbeing of the future child. The American College of Obstetrics and Gynecology (ACOG) recommends that every pregnant patient be offered the option of prenatal genetic screening or diagnostic testing regardless of their age or a priori risk for chromosomal abnormalities. Professional guidelines highlight the role prenatal GCs have in helping patients negotiate the decision-making process before and after prenatal diagnosis. The National Society of Genetic Counselors (NSGC) “supports the right of all individuals and couples to make reproductive choices. These include using information from genetic counseling and/or testing to decide whether to pursue a pregnancy, to utilize assisted reproductive technologies, to prepare for the birth and future needs of their offspring, to make an adoption plan, or to end a pregnancy. NSGC firmly believes that reproductive decisions should be made in the context of unbiased and comprehensive information, free from discrimination or coercion” (NSGC, 2018).

State laws on abortion have the potential to impede or complicate a GC’s ability to fulfill these professional and ethical obligations to their patients. Many GC conversations related to abortion care occur at later gestational ages, defined here as 20+ weeks gestation, as detailed fetal anatomic surveys and prenatal diagnostic procedures such as amniocentesis are not available until the second trimester of pregnancy (KFF, 2019). The timing of fetal diagnosis is relevant because many abortion restrictions are based on gestational age or fetal development (Graziani et al., 2018). For these reasons and others, state abortion law has been shown to impact the role of the GC (Cooney et al., 2017; Graziani et al., 2018).
In 1973, *Roe v. Wade* affirmed a constitutional right to abortion by establishing a trimester system whereby abortion within the first trimester could not be regulated by state laws, abortion in the second trimester could be regulated by the state in the interest of fetal life, and abortion in the third trimester could be outlawed by individual states. In 1992, *Planned Parenthood v. Casey* abandoned the trimester framework, drawing a line instead at “viability,” which was ambiguously defined. In *Casey*, the Court also created the “undue burden” standard, asserting that placing an undue burden on the pregnant person pre-viability was illegal, introducing an opening for certain types of restrictions to be passed pre-viability. In 2021, the most active year for abortion restrictions since the 1973 *Roe v. Wade* decision, 108 bills passed restricting abortion in 19 different states, largely among Southern and Midwestern states (Nash, 2021). Many of the restrictions that have been passed exacerbate barriers that disproportionately affect individuals of lower socioeconomic status (Ostrach & Cheyney, 2014). Bills restricting abortion have taken a variety of forms (Guttmacher Institute, 2022), including restrictions on insurance coverage and public funding; bans limiting abortion by gestational age or fetal development; restrictions mandating waiting periods and counseling requirements; method bans prohibiting certain types of abortion procedures; restrictions requiring parental consent, notification, or judicial approval; reason bans restricting abortion if requested based on the fetus’s sex, race, or prenatal diagnosis; so-called “born-alive laws” requiring medical care for a fetus born in the rare instance of an unsuccessful abortion; targeted restriction of abortion provider (TRAP) laws placing medically unnecessary requirements on clinics and providers; and trigger laws enacting restrictions in the event that *Roe v. Wade* is overturned. Other states have passed legislation intended to proactively protect abortion access, such as allocating travel funds and making abortion procedures cheaper. Connecticut and California are even considering bills
that would protect abortion providers in the state from potential lawsuits filed by officials in states where abortion is illegal (Vestal, 2022). Protection efforts have been increasing in recognition of the sheer proportion of individuals now traveling out of state to obtain access to abortion care (Spitzer & Ellmann, 2021).

Two of the many abortion restrictions passed into law in 2021 are notable for their actual or potential impact on patient care. One is the Texas Senate Bill 8 (SB8), which restricts abortion access to approximately six weeks gestational age. The law was designed to avoid challenges in the courts and does not deputize any agent of the state to enforce it, but instead permits anyone who does not work for the state to file a lawsuit against anyone who performs an abortion or “aids and abets the performance or an inducement of an abortion” (Millhiser, 2021). This bill took effect on September 1, 2021, and despite legal challenges such as the Department of Justice suing the state of Texas over the constitutionality of the bill, has remained in place (The United States Department of Justice, 2021). SB8 has already drastically limited access to abortion throughout the state of Texas, causing patients and providers to look out of state for abortion care options (Nash, 2021). In the first month after SB8 was enacted, there was a 60% decrease in Texas abortions. Neighboring states strained to accommodate the surplus, resulting in a backlog of appointments that further delayed this time-sensitive medical care (Weber, 2022). Less than three weeks later, legislation was signed that restricts the ability of Texas residents to purchase or sell mifepristone and misoprostol, the medications used for medical abortions which are available between seven and eleven weeks gestation, further restricting access to care in the state (Klibanoff, 2021; Planned Parenthood, 2022). Upon enactment of TX SB8, many abortion advocates expressed concern that other states would use a similar model to restrict access. Indeed, these fears were realized in March 2022 when Idaho passed a bill banning abortion after
six weeks gestation. While Idaho’s law does not have the “aiding and abetting” verbiage included in SB8, and therefore has fewer implications for genetic counseling, it still forces genetic counseling patients to travel out of state to obtain an abortion (Luthra, 2022). At the time of this writing, 11 SB8 “copycat” bills have been proposed in different states, and the Guttmacher Institute has predicted that as many as 14 states may introduce legislation similar to SB8 (Durkee, 2022).

A second law in the news in 2021 was Mississippi’s 2018 Gestational Age Act, which restricts all abortion in the state after 15 weeks gestation. Jackson Women’s Health Organization, Mississippi’s last abortion clinic, challenged the constitutionality of the Gestational Age Act, and it was deemed unconstitutional by the U.S. District Court for the Southern District of Mississippi and the U.S. Court of Appeals for the Fifth Circuit on December 13, 2019. Mississippi then filed a petition urging the Supreme Court of the United States (SCOTUS) to uphold the Gestational Age Act on June 15, 2020. SCOTUS agreed to hear the case, and many court watchers believe that the mere act of agreeing to hear the case shows that the conservative SCOTUS justices (namely, Justices Clarence Thomas, Samuel Alito, Neil Gorsuch, Amy Coney Barret, Brett Kavanaugh, and John Roberts) are open to overturning both Roe and Casey (Rovner, 2021). Dobbs v. Jackson Women’s Health Organization was challenged by the Center for Reproductive Rights and was heard by the SCOTUS justices on December 1, 2021 (CAC, 2022). With liberal SCOTUS justices limited to Justices Elena Kagan, Ketanji Brown Jackson, and Sonia Sotomeyer, the Supreme Court now has a 6-3 conservative majority that many expect will allow the Gestational Age Act to remain in place despite stare decisis from Roe and Casey, thus abandoning the viability standard and allowing states to restrict abortion prior to viability. Furthermore, the Mississippi solicitor has explicitly argued for the justices to overturn both Roe
and Casey (Rovner, 2021). If Roe is overturned, 12 states (Arkansas, Idaho, Kentucky, Louisiana, Mississippi, Missouri, North Dakota, Oklahoma, South Dakota, Tennessee, Texas, and Utah) currently have trigger laws in place that would immediately come into effect, restricting or banning access to abortion. There are 4 additional states (Arizona, Michigan, Wisconsin, and West Virginia) that have pre-Roe abortion bans on the books that would, once again, become enforceable (Parks, 2021). According to the Guttmacher Institute, as of October 2021, a total of 21 states have laws or constitutional amendments already in place to ban abortion if Roe were overturned or fundamentally weakened (Nash, 2021).

Previous studies have examined the impact of abortion restrictions on GCs, genetic counseling practice, and their patients. Woltanski et al. (2009) examined how the views of female GCs on abortion compare to those of women in the general population, concluding that GCs are significantly more likely to agree that abortion should be a reproductive option. Graziani et al. (2018) focused on the familiarity of prenatal GCs with abortion legislation, exploring the experiences of GCs when working with patients needing abortion care occurring after 24 weeks gestation. The authors concluded that GCs believe that it is part of their role to discuss abortion care in these circumstances, however, one-third of them reported little to no understanding of the procedures used in late abortion and three-fourths reported that they had little to no understanding of federal abortion law (Graziani et al., 2018).

Cooney et al. (2017) surveyed GCs to assess the effects of restrictive legislation on prenatal practice. They conducted a mixed-methods study and found that GCs in the US, on average, did not feel that abortion restrictions affected their practice. However, the majority were concerned about their ability to be effective patient advocates if certain restrictions were put in place. GCs in the South and Midwest regions were significantly more likely than other GCs to
say that changes in abortion law had affected practice and that difficulties in arranging abortions affected how and when genetic counseling services were offered (Cooney et al., 2017).

A qualitative study in 2019 by Koenig et al. also investigated the views of prenatal GCs on abortion restrictions and genetic counseling practice. They concluded that GCs and their patients were affected by decreasing access to abortion. Additionally, these restrictions were identified as placing a financial and emotional burden on prenatal patients. As a result, some GCs reported becoming more involved with reproductive rights advocacy initiatives in their states (Koenig et al., 2019). Most recently, Jayaraman et al. (2021) examined those issues identified by Koenig et al. (2019) in a larger cohort and concluded that prenatal GCs and their patients are being impacted by restrictive abortion legislation, particularly legislation centered around gestational age limits. This study also concluded that GCs find these restrictions created significant financial and emotional burden on their patients amplifying the impact of reduced access. Collectively, these studies demonstrate the manner in which legislation affects the amount of time patients have to make reproductive decisions after prenatal diagnosis, and how this creates a serious effect on the practice of prenatal genetic counseling (Jayaraman et al., 2021).

As we navigate the rapidly changing landscape of access to abortion in the US, it is necessary to update assessments of its impact on prenatal genetic counseling practice and to understand the evolving needs and concerns of prenatal GCs in states where access to abortion care has or likely will be drastically reduced following the upcoming decision in Dobbs v. Jackson Women’s Health Organization.
What is known about this topic:

Previous genetic counseling studies centered on abortion have focused predominantly on general understanding of abortion restrictions, the role of the GC in abortion-centered discussions, the impact of abortion laws on direct practice, and the implications of access for patients.

What this paper adds to the topic:

This study explores the impact of evolving abortion legislation on the practice of genetic counseling within predominantly abortion-hostile states, and how GCs and their institutions are preparing for tightening restrictions that will alter the future of prenatal diagnosis and reproductive medicine.

METHODOLOGY

Participants

All practicing board-certified and board-eligible prenatal GCs who practice in a state categorized by the Guttmacher Institute as “leans hostile,” “hostile,” or “very hostile” to abortion were invited to participate in the study. Most participants were members of the National Society of Genetic Counselors (NSGC), although membership in NSGC was not a requirement for inclusion. Participants were identified by direct recruitment from the NSGC directory or by snowball sampling. This study was approved by the Sarah Lawrence College Institutional Review Board (IRB) in July of 2021.
Interview Guide

The semi-structured interview guide (see Appendix) was created to cover key points while allowing the interviewer to explore alternative themes as they arose. It was drafted by the principal investigators with input from the research team and piloted with two prenatal GCs not included in the study. The interview guide incorporated the main goals of understanding 1) how prenatal genetic counseling practice may be impacted by restrictions on abortion access, and 2) how individuals may be preparing for future restrictions if Roe v. Wade is overturned. The interview guide aimed to direct conversation in three areas: 1) effects on genetic counseling practice, 2) potential plans in the event of the overturning of Roe, and 3) future implications on reproductive medicine. Within these categories, we also inquired about personal feelings, useful resources, and institutional impacts on practice.

Procedures

Board-certified and board-eligible GCs self-identifying as practicing within a prenatal/reproductive specialty were eligible for participation in our study if they lived in a state that had legislation limiting access to abortion. Eligible states included: Alabama, Arizona, Arkansas, Florida, Georgia, Idaho, Indiana, Kansas, Kentucky, Louisiana, Mississippi, Missouri, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, and Utah. With the exception of Texas (TX), states were grouped by their level of hostility toward abortion as per a categorization system provided by the Guttmacher Institute: Leans Hostile (LH), Hostile (HO), Very Hostile (VH). In the early stages of our study’s development, TX passed SB8, a law that radically altered the availability of abortion. Though classified as hostile based on its pre-SB8 legislation, TX now permits individuals to seek civil
penalties for any abortion performed after the potential detection of fetal heartbeat, effectively limiting abortion to the first 6 weeks of pregnancy. Since over 90% of abortions take place later than 6 weeks, at the time of this writing, TX is the most difficult state in the US in which to obtain abortion care. Because the abortion landscape in TX was unlike any other state during the duration of our study, we elected to place TX in a category of its own. One GC we contacted worked for a telehealth company, and due to their practice in multiple states, this GC was coded as Telehealth (TH).

All VH states were included in the study, in addition to all HO states that have trigger laws that will prohibit all abortion if the federal statute Roe v. Wade is overturned. In addition, we included HO states that have a large GC population such as Alabama, Arizona, Kentucky, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, Tennessee, and Utah. LH states that have large populations of GCs such as Florida, Georgia, Idaho, and Kansas were included in order to access the whole spectrum of hostility toward abortion. For the purposes of anonymity, a GC’s home state will be identified only by category and not by name, with the exception of Texas, where the number of practicing prenatal GCs was adequate to provide functional anonymity.

A total of 180 prenatal GCs were emailed asking for their participation in the study and encouraged to disseminate our recruitment email to colleagues that might be interested. Ultimately, 34 semi-structured video interviews were conducted by the authors, with each co-author leading 17 interviews. Informed consent documentation was collected prior to the interview over email. The interviews were recorded over Zoom, and transcripts were provided by the Zoom transcription service. The interviews were de-identified and participants were identified only by the categorization of their home state. Each participant received a $10 gift card
in appreciation of their participation. This is the first qualitative study to focus specifically on the impact of restrictive legislation in states with legislation hostile to abortion.

Data Analysis

Transcripts were corrected for errors after the interviews were completed. This process included removing timestamps and the name of the participant. The two principal investigators agreed on 5 interviews to review separately, with each selecting initial codes to describe the data. We used a process of thematic analysis, which involves searching across a data set to find repeated patterns of meaning (Braun & Clarke, 2006). This analytic process was iterative as themes were refined with more data. Interviews were chosen that represented the sample in its entirety with one transcript each selected from TX, HO, LH, and VH states. Coding was done via descriptive analysis. Once initial themes were uncovered and agreed upon by the principal investigators, each coded the same 7 interviews independently until inter-rater reliability was met using the software Dedoose. Inter-Rater reliability was met when the kappa coefficient surpassed 85% agreement. The principal investigators then coded the rest of the interviews independently and thematic saturation was met when no new codes emerged from the data. Each theme was demarcated into categories for analysis.

RESULTS

Seven broad themes arose from the data. They described (a) How Abortion Restrictions have Affected the Practice of Genetic Counseling; (b) How Institutional factors are impacting practice; (c) Role of the Genetic Counselor in Hostile States; (d) Implications of the Potential Reversal of Roe v. Wade Protections; (e) Potential Implications of Abortion Restrictions on
Reproductive Medicine; (f) How SB8 is Affecting Genetic Counseling Practice; and (g) Resources for the Genetic Counselor and the Patient.

How Abortion Restrictions have Affected the Practice of Genetic Counseling

The prenatal GCs in our study discussed the impact that abortion restrictions have had on their pre-test counseling setting, the changes in practice they have adopted or considered because of time pressures created by legal changes, the increased stress on prenatal GCs practicing in states with abortion restrictions, and barriers that exacerbated the impact of abortion restrictions.

Most participants, regardless of how their state was categorized, felt that their pre-test and post-test counseling had changed overall. Many participants shared that addressing the difficulty of accessing abortion was imperative to disclose during pre-test counseling as a form of anticipatory guidance. Several participants in hostile states shared that reason bans have impacted what they share with patients. Some participants discussed this information with patients in a pretest setting prior to a fetal diagnosis as the patient’s ability to obtain a termination could depend on what they communicated to an abortion provider. As a result, many participants mentioned that there was an added level of responsibility and pressure put on the patient in these situations. All of the participant’s shared that they are still offering prenatal testing, but what patients are able to do with that information depends on state law. Many participants indicated that discussing legislation and clarifying nuances of the laws has become part of their regular practice. Participants discussed how abortion stigma complicated counseling since patients in these states often expressed opposition to abortion until faced with a prenatal diagnosis.
Our counseling is just unique in that we have to counsel a little bit more in-depth about the various laws and how that affects the options that they are able to move forward with. So I think compared to other prenatal counselors, our -- probably our discussion revolving around termination of pregnancy just probably looks different since we're discussing a little bit more of legal issues that determines where they can go. -HO15

Really difficult to discuss with a patient in a certain allotment of time when you're trying to do it with an interpreter and, you know, talk about all of these other important things that they should know. Like, this shouldn't have to be something that we are taking away from time spent on other conversations to talk about the legal system, whenever we're conducting a health care appointment. Like that's just ridiculous but it's where we're at yeah. -HO13

I think it's important to share... that we do see so many patients in this region who are deeply religious who may have previously advocated for shutting down abortion clinics, who, you know, walk in saying termination is absolutely off the table, we would never do it, and then they have a prenatal diagnosis. Particularly if it's something that is lethal and you see this shift in them that it's almost like a protective instinct comes out in a different way than they expected. And this is just a very common occurrence here. But something that so many people who have this strong stance against abortion care could never see until they're in that situation. -HO16

Some participants shared that addressing termination and having difficult and uncomfortable conversations about abortion availability earlier than they would have wished was essential given the time-sensitive nature of abortion care. In many states, patients have limited
access to abortion after visualizing an anomaly on a 20-week anatomy scan. In some practices, performing anatomy scans at 18 weeks has allowed for more flexibility; one participant even proposed moving anatomy scans to 16 weeks gestational age.

_The idea of maybe the first time I meet someone bringing up the idea of like termination isn't my favorite part of the conversation. But getting a feel for that super early if I'm meeting you at 12 weeks and it looks like this kid maybe has a lethal skeletal dysplasia and we're talking about the need for like maybe six to eight weeks of testing, I need to know if we need to like do that now, or if we can like wait and see and you're happy to do that later and it isn't a big deal, so I think it accelerates conversations that makes them very concrete. And it brings up for me, I think a lot of stuff that patients aren't necessarily in the headspace for yet. And so I think that that's the biggest thing is it definitely accelerates conversations._ -LH1

_We've had times where we've had a patient who we've kind of pushed our usual 20-week anatomy scans. We're pushing closer to that 18-week point if we know that we need as much time as possible for decisions to be made._ -HO6

Advising patients on what they could share with an abortion provider was a common theme among states that had reason bans. Several GCs shared how this “coaching” through the abortion process took an emotional toll on them. Most GCs in this study were aware of their state-specific legislation and mentioned that being aware of legislation both enacted and pending was required for maintaining a high level of care. However, several participants felt it was exceedingly difficult to stay up to date due to the sheer volume of legislation being proposed.
One participant shared that a patient was initially unable to receive an abortion because she was not up-to-date on a recently passed reason ban in their state.

The House here passed a bill that prohibited termination of pregnancy, based on gender, a disability, or genetic condition, genetic status, and I didn't know about it. I feel like a bad genetic counselor, but nobody said anything about it and I didn't realize it was a thing until about September. -VH2

It's almost like you don't know what to pay attention to until it happens because they're just going to keep throwing garbage at the wall and seeing what sticks. -HO4

Never before did we have to talk about how to have conversations when they called abortion clinics. -HO6

It's a constant state of misunderstanding, there are a lot of discussions that I have that are uncomfortable, such as telling patients that if they are seeking an abortion related to the diagnosis of Down syndrome, that it is still legal yet they have to be incredibly careful not to disclose their intentions or else that provider would not be able to help them in that. It feels, like, we have to lie to be able to get the services that our patients need. So it's uncomfortable, yeah. -HO2
So you are able to kind of advise your patients as to what they’re, what they can say when they, if they decide that they want to terminate, so I don't like saying that. That feels kind of icky like it almost feels like we're coaching them through these scenarios. -HO13

Participants described a variety of intertwined barriers to abortion access that ultimately played a role in deterring patients from obtaining abortion care, including state-specific restrictions such as reason bans, gestational-age bans, and waiting periods; traveling out of state; and the socioeconomic status of a patient. GCs generally agreed that traveling out of state was the best option for patients that presented late to care or past their state’s restriction window. However, all participants conferred that the solution of traveling out of state was not feasible for patients without the financial and other logistical means. A shared sentiment among participants in all degrees of abortion hostility was socioeconomic status as a prominent barrier to abortion access.

I definitely have seen that families have to make different decisions or have to make “less informed” decisions again like gut check versus having the actual chromosomes in your hands because of the socio-economic pressures that exist there. I've had families that have had to carry because of it, so it's not even necessarily that we were out of time, it's that they literally couldn't afford it. And I've had families who have again had to make those accelerated decisions without necessarily all of the information because they didn't want to risk having to go out of state and having to pay, you know X number of dollars over and make the travel plans and all of that in response, so I definitely think that it probably does disproportionately affect those of lower socioeconomic status. -LH1
How Institutional Factors are Impacting Practice

Many GCs described their institution’s response to systemic changes or regulations related to abortion. While some received guidance and support, most participants viewed their institution more as a barrier than a resource. Participants described examples of institutional support, including shared resources, plans for institution-wide conversations, and plans to protect employees. Legal guidance was described as useful by some participants for interpreting the boundaries of their practice, while others said it provided minimal assistance. Institutions were faulted for inconsistency and a lack of planning or communication. Conversations with colleagues were considered the most useful source of information, particularly among participants that worked in a team of GCs.

*I don't know about in the wider institution if people have given it as much thought. I think just in general people probably don't give it much thought unless it happens to affect them personally which is probably why this legislation is going to, a lot of it passes, but yeah but I know that like MFM and OBs feel a lot of concern over the direction that these laws are going.* -HO14

*We got an email from a provider who also works at one of the clinics, providing the guidance that they had gotten from their legal team, and then it also actually led us to restructure the way that we do our in-hospital terminations for fetal indications.* -HO4

*I mean it's definitely been a topic that's talked about in Maternal Fetal Medicine, which is my department. You know I'm not privy to some of those discussions happening outside of, you know,
my particular unit, kind of in the larger division and departmental areas, but I know it's it's a concern and I've been involved in part of those discussions, but I don't have the full picture.

-HO14

**Role of the Genetic Counselor in Hostile States**

The role of the GC normally falls within the scope of practice of providing resources, information, and emotional support for a patient. With the passage of increasingly restrictive abortion legislation, GCs have had to adapt and assume responsibilities that may not be considered traditional within the field. Participants shared that self-education on policy and legal jargon, awareness, and comfort in coordinating abortion care, and advocacy efforts were all necessary to move the field forward. Many participants discussed that understanding how to maintain the same quality of care for patients, despite revolving laws, was a challenge. Most of these GCs self-educated on how to interpret legal jargon and policy that could inevitably affect their practice. Some participants in states with state-mandated scripts and waiting periods discussed needing to adapt how they coordinate care in order to aid their patients in receiving abortion care. Other participants in those states felt that dealing with scripts and waiting periods was not within their scope of practice. Several participants mentioned that educating other healthcare professionals on the current laws was a new addition to their role. This varied depending on the status of awareness the physician/healthcare professional had initially, but was noted by a few participants.

*I think it's going to require genetic counselors and other health care providers to be a little more savvy when it comes to understanding legal jargon and the law and how government works, you
know, you learn all of that in school, as you grow up, but it, you know, unless you really go into that field it doesn't hit you in the day to day. -HO15

We have to inform ourselves and figure out how we can still provide services to our patients because it's not their fault if this is happening. It's still our job to do what we can for them. -VH1

It's really the genetic counselors that do a lot of the abortion related like coordination and care, and so I think some of our other providers - our OBs or MFM - are not necessarily in the know or understandably to some degree, given all the other Covid-related things going on, were not as on top of the legislation that was moving forward with abortion. -TX8

When you're not able to provide a patient with all of their options - and as a genetic counselor it's our job to make sure that they are informed about all of the choices that they have -and if we're not able to do that, it sort of feels like we're not able to do our our role in our job equally and fairly to everybody. -HO15

Advocacy outside of the GC role was discussed by a variety of participants. Some participants felt that they were unable to be advocates in their personal life for fear that there would be downstream repercussions to their patients. This was a more prevalent theme among Texas participants and those in Very Hostile states. One participant shared an anecdote of a colleague facing institutional issues after posting publicly on reproductive rights. Another GC felt that they wanted to take action in some way to advocate for patients, but without systemic change, felt that efforts were futile.
Participants were involved in a variety of advocacy roles including volunteering at abortion clinics, collaborating with local Planned Parenthood clinics, involvement in special interest groups, and professional network task forces. Advocacy through research efforts was also mentioned by a participant. One participant who volunteered as an abortion clinic escort felt that it allowed for her to provide more honest anticipatory guidance about the process. Genetic counseling state licensure efforts were also brought up in a few interviews and some GCs discussed how restrictive legislation has potential impacts on their advocacy for state licensure.

Just being able to be more thorough and kind of proactive, anticipatory in guiding them on what to expect, yeah. And then, you know, I'll tell them too hey I'll be there Saturday, you know, for your consent visit or for your procedure - you'll, you will see me, so I think that helps them sometimes as well, feel more there - hey, hey, there's a familiar face here. -VH4

Historically, a perceived connection between genetic counseling and termination, I think, has impeded legislators in Texas from feeling like this is an important issue and I think that that's become less important, which isn't great, as you know, we've been able to appreciate that genetic counseling is much larger than that and to take the focus off of that. -TX1

Implications to the Potential Reversal of Roe v. Wade Protections

Due to the potential implications of the Supreme Court decision on Dobbs v. Jackson Women’s Health, we asked the participants about expectations and plans for future changes. Overwhelmingly, the participants expressed concern and fear for what might happen if the protections of Roe v. Wade were overturned. Participants were concerned for their patients and
themselves. Some anticipated worse health outcomes and unsafe abortions. Some participants said that they would have a difficult time continuing to practice within prenatal genetics or would consider moving to another state. One participant predicted that more GCs would become involved in advocacy efforts.

Only one participant (VH1) replied that providers in their state had proactively prepared to increase access. Their patients would have reasonable access to a Planned Parenthood clinic that had moved across the border to a state which is less hostile to abortion. Another participant mentioned their institution had discussed moving clinics, but there were no official plans in place. Of the remaining participants, most reported no institutional efforts to prepare for changes in practice.

Many participants were aware of trigger laws that would make abortion illegal, requiring all patients desiring abortion care to travel out of state. Participants from Texas and other states where this is already commonplace noted that their patients would be forced to travel even further if Roe was overturned, increasing health care disparities.

_I am fearful for so many reasons. If this, you know, if Roe v. Wade gets overturned, for all the reasons, but also how much harder it will be to practice here, how much harder it will be to just be from this area._ -VH2

_We have not had a conversation about it. Everybody is worried about it, but there is not an institutional like “What would we do if this actually happened?” We talk about if Roe v. Wade was overturned, but more on a lunchroom chit-chat level than any kind of, like, you know, like,
an anxiety level, like, this is happening, but nothing that's official or actionable is what I would say. -HO5

Absolutely not so, you know, as I've kind of alluded to, with me, being the only prenatal genetic counselor here in a Catholic organization, you know, a lot of it is just, you know, day by day, fly by the seat of our pants, for better or for worse. Obviously, at that point, you know, we're going to have to get patients connected with more out-of-state options which we are fairly well versed and being able to do that. -HO13

There's just never going to be equitable access to people who can't travel, can't provide, find childcare, can't, you know, can't take time off of their job to travel, like, it doesn't matter how much funding you provide, that's not going to protect people's jobs and livelihood and so you just can't replace equitable access in somebody's home community with with that. So I really think we're all sort of dreading what may happen if they reverse the protections that we've been afforded by Roe v. Wade. -HO10

Texas isn't the best state to ask that because I think we're almost living in a state where Roe v. Wade has already been overturned. -TX8

Potential Implications of Abortion Restrictions on Reproductive Medicine

Participants were asked how they see their practice changing due to restrictive legislation that is either already in effect or may soon be passed. They were also asked to comment on if they see the role of prenatal diagnosis changing due to hostile legislation. All participants agreed
that there will still be a role for prenatal diagnosis when it comes to planning, preparation, and management for the family, newborn, and delivery. However, multiple participants did question whether this role will remain important if restrictive legislation continues to be passed.

Participants differed on the potential impact on prenatal testing. Some saw non-invasive prenatal screening (NIPS) becoming more common because patients might not want to risk the complications of diagnostic procedures if they would be unable to access abortion care. One participant thought chorionic villus sampling (CVS) would disappear entirely; another suggested that it would be more utilized because it can be used earlier in pregnancy than amniocentesis. Still, other participants questioned whether patients would wait long enough to even receive results from any diagnostic genetic testing, potentially leading to abortions that would not have occurred otherwise.

Participants in VH states and Texas noted existing changes to reproductive medicine in their states. One participant observed that they have noticed an increase in preconception testing such as carrier screening and pre-implantation genetic testing with in-vitro fertilization (IVF), and other participants expected to see an increase in IVF and preconception testing in the future.

*That's the whole point of, you know, offering testing. For people to be informed of their choices, and if you take away choices, what's the point in being informed?* -VH3

*I've even had preconception patients that have said, you know, we're really struggling considering the IVF route because of the law. And so you know I think patients are really thinking about, kind of, what the consequences would be, and what their situation might be in the future.* -TX2
I already see CVS dying. I mean it died here, but I see the advent of all this noninvasive screening and I see that going away. And I think we will see an increased burden on our healthcare system in terms of children with complex health conditions being born that, here they are, but I don't think other states are prepared for this. -VH2

I'm guessing some patients will just be like “You know what, I'm just going to like opt out of all this.” Not even do the prenatal testing, just terminate a pregnancy, even though it might be a healthy pregnancy because there's this chance it could be an unhealthy pregnancy. -TX10

Participants also expressed concerns that less prenatal testing will increase the number of children born with genetic conditions. One participant suggested that the focus of prenatal testing would shift to conditions with fetal therapy options where a diagnosis could lead to a potential treatment.

Many participants also worried about the health of pregnant individuals unable to attain abortions when they are medically indicated, despite the fact that laws (to date) generally have exceptions for the life and health of the pregnant person. Participants explained that it can be exceedingly difficult to prove that abortion is necessary for the health of the pregnant person, and even when they are able to prove a need, it remains difficult to obtain this care in a timely manner. Participants were also concerned that these restrictions would increase health disparities among pregnant patients.
I worry about maternal health, morbidity, and mortality. I already practice in one of the top five states for the worst of that. You think about some of these conditions, hydrops, you can have maternal mirror syndrome, you can have impacts of health and, yes, maybe that would be a permissive reason for an abortion, but when it takes you four hours to get anywhere you’re just going to die already. -VH2

They're just going to increase the health disparities because there's going to be doctors that put their neck out there for affluent people that can make the case like this is what I need, and this is what I want, and they're going to say yeah you're right, and then for the underserved populations that can’t advocate for themselves, their case isn’t going to be heard. -TX5

The Impact of SB8 on Genetic Counseling

All 11 prenatal GCs from Texas said that SB8 has affected them and their practice; however, not all participants felt the same level of impact, and there was considerable confusion about what was permissible. All eleven indicated that their patients who seek abortion care now have to travel out of state. Participants were concerned about documentation in writing or the possibility that phone calls could be recorded, or that recordings by interpretive services could be used against them. Some of the participants received guidance from their institution’s legal teams about what they can and cannot say or document within the medical record, but feelings of uncertainty remained. Legal guidance on practice and documentation varied. For example, some participants were allowed to provide their patients with resources in how to find out-of-state options for abortion or resources that could aid them in finding funds for abortions, and others were not.
Initially, someone who is not in genetic counseling might say, “Oh this doesn't really impact you because you're not providing.” But the language of aiding and abetting, you know, that implicates counseling, and, of course, we're not going to counsel our patients about an option that's not available legally. -TX1

It's very unclear, so that really puts a divide between the providers and the patients, because even when they ask us, like, I’m kind of scared to give them information which is not great, because they're in like a very stressful situation to begin with if they're considering this. -TX3

You know, documentation, because if something is subpoenaed, you know what, what are we allowed to have in the medical records, or what's the safest thing, and I mean it was just stuff like it's better to talk over the phone than to put something in writing in an email, and, you know, just things like that, that you normally wouldn't think about when you're communicating with patients per se. -TX4

The participants had mixed responses when discussing specific ways in which the law has affected how they counsel. A few participants expressed that the legislation has not affected what they say to patients, only their ability to coordinate care. However, more participants indicated that they now discuss the laws more thoroughly with patients, though they need to be very deliberate with their word choices in order not to be seen as “aiding and abetting.” The participants also discussed clarifying in advance their patients’ motivations for testing in order to provide anticipatory guidance for those who might seek an abortion, legally or otherwise. To
this end, some counselors said that SB8 caused them to pivot to a more psychosocial style of counseling, but one participant said she does less psychosocial counseling now, fearing that discussing abortion even in the abstract would be against the law.

So our pretest counseling has changed slightly to make sure that patients are going into testing, knowing the challenges they may face, if they want to terminate a pregnancy. -TX5

It's just going to be, you know, more counseling about the dangers of unsafe abortion practices. Trying to explain to patients, like, understanding you might be desperate, but just really emphasizing how dangerous that can be. -TX9

Multiple participants noted that it was stressful to be a prenatal GC in Texas under SB8; one even suggested that it might be better to move out of state, although that counselor also expressed concern about the need for prenatal genetic counseling to remain in Texas.

I’ve had people scream at me during a consult ‘abortion is murder’. There are absolutely people out there who will pursue this if they know that you were involved in any shape or way, and I think what everyone is afraid of is it snowballing, you know, it's successful and then another person sees it and it's, just like the lawsuits keep coming. -TX9

I do think there is definitely a need for reproductive counselors in states like Texas or other conservative states just because that's really where meaning comes from having those
conversations with patients to make sure they feel supported make sure they can still access care so they can still have those discussions, regardless of what state laws are or are not. -TX8

SB8 was also discussed in 10 of 23 interviews with participants not practicing in Texas. Participants expressed concern that similar legislation could be passed in their state. Our single participant who practiced in a telehealth setting reported being impacted by SB8. The implications for telehealth providers remain particularly unclear. One participant from a VH state felt conflicted about SB8 being put into effect because it could have the positive potential to prepare GCs for pending restrictive legislation.

I ended up joining the Texas State Genetic Counseling society just in desperate need of trying to keep up with any kind of updates. Because we know when we still have a lot of questions about what it means and how it impacts what we're allowed to say to patients with a lot of internal conversations about, you know, like, we want to carefully follow the law, but we also want to make sure that we are doing our due diligence as genetic counselors. Our job is to provide comprehensive information to patients that is pertinent to their particular situation and to have it, a law that says you're allowed to say certain things that is a necessary part of what the patient may need for their own care. Really, really hard to be put in that situation. We've struggled to navigate how to do it. -TH1

I had posted on my list-serv about my troubles and my challenges and I felt that they were ignored because I practice in this, you know, less populated area and nobody thinks of us, or you know, and, and I was a little bitter about it, I was like yeah, this is a problem and I, I'm glad it
took a larger state with a larger quantity of genetic counselors for y'all to realize this, but I get bitter sometimes because I’m like there's others of us who are dealing with this and have been dealing with it. Of course, I'm glad it's finally gotten everyone's attention. -VH2

Resources for the Genetic Counselor and the Patient

The participants were asked what resources would be of assistance for GCs as well as useful for the patients seeking abortion care. Participants mentioned more support and guidance from professional organizations on handling abortions in restrictive states would be helpful for GCs. Specifically, participants mentioned the need for concise and updated information on regulations in other states. Many participants shared that socioeconomic status was a significant barrier to abortion care and that a consolidated resource towards which to direct patients in need of financial help would be most impactful.

DISCUSSION

This study provides new insights into how GCs and their patients are being affected by abortion restrictions in states defined as “very hostile,” “hostile,” or “leans hostile” to abortion. Although in earlier studies, GCs did not report changes to workplace attitudes or patient care as a result of legal restrictions on abortion (Cooney et al, 2017), the current study suggests many prenatal counselors are presently seeing an impact on their practice. Several of the GCs described a need to warn patients of state regulations because of their potential impact on decisions about prenatal testing or carrier screening. Notably, participants mentioned the need to introduce the subject of abortion care in the pre-test setting, in order to make clear to patients what option would be off the table. This change impacts the structure of a pre-test consultation,
and our study suggests that the need to provide anticipatory guidance can negatively impact provider-patient rapport.

Specific abortion restrictions including SB8, SB8 copycat laws, and ‘reason bans’ are having an effect on how GCs speak to their patients. Our participants described difficult conversations, concerns about being sued, and the need to “coach” patients on how to discuss their decision to pursue abortion with an abortion provider, given that revealing prenatal diagnostic information might make the procedure illegal. The potential societal implications of coaching a patient to lie or selectively conceal information from health care providers have not been adequately explored.

Other abortion restrictions limit the procedure based on gestational age or fetal development, and as a result, participants noted that they were under pressure to provide potentially diagnostic information earlier. Some prenatal GCs said they had begun offering fetal anatomy sonograms at 16-18 weeks, although some, but not all, studies show that anatomy scans prior to 18 weeks are more likely to result in undiagnosed anomalies (Elamaran et al. 2017, Waller et al. 2009; Monteagudo et al. 2003, Timor-Tritsch et al. 2009).

Prenatal GCs in Texas were uniquely able to speak to the challenges associated with limited access to abortion, since the passing of TX SB8 in September 2021 made most abortions illegal in the state, and included civil penalties that restricted their ability to discuss abortion with patients. Participants expressed uncertainty regarding how to proceed under SB8, and were appreciative of institutional guidance and protection where it was offered. At least one of the participants who did not receive institutional guidance reported that they have ceased to discuss abortion with patients, a step at odds with the ethical practice of genetic counseling as defined by the NSGC (NSGC, 2018). Overall, communicative institutions were seen as useful in states
outside of Texas as well, with participants sharing that the direction provided from their institutions clarified counseling implications of legislation changes. GCs also raised the fear of being recorded via phone or having emails shared. Restrictions on practice that impact telehealth counseling would disproportionately affect patients for whom work, disability, or location is an obstacle to receiving services in person, or individuals who require interpretation services (Rhoades & Rakes, 2020).

Texas GCs also shared how the restrictive abortion legislation has affected them personally. Overwhelmingly, they were frustrated and exhausted. One participant was considering moving in order to practice genetic counseling in a different state. Studies have documented the impact of burnout on the profession of genetic counseling (Caleshu et al., 2021); our participants’ responses suggest that SB8 and other restrictions on abortion access may exacerbate issues of burnout in this population. Despite the attention that SB8 received nationally, few GCs in other states seemed prepared for the potential impact of similar laws. At the time of her interview, one participant revealed that she did not believe Roe would be overturned and was relatively calm about the current situation in her state. After hearing from a colleague about incoming legislation in her region, she reached back out to us to explain that although her initial level of concern only days prior was low, it was now “extremely high.”

Participants had several suggestions regarding what resources they would like to see made available, especially given the likelihood of further restrictions on abortion in the near future. Many of the participants shared that the addition of interpreting legal wording and legislation would be a helpful discipline in which to be trained. One participant shared that not understanding how to read the law enacted in her state and decipher what it meant for her practice created a deficit in patient care, raising the question of whether GCs should be routinely
trained in interpreting legal jargon. Additionally, participants mentioned the need for a condensed and frequently-updated resource to gather what abortion restrictions have been enacted in which states. As the future of many states’ abortion restrictions is unknown, a resource listing places to physically send patients would be beneficial in practice. Similar to other studies that focus on barriers to abortion, socioeconomic factors are the largest deterrents for pregnant patients seeking abortion care (Ostrach, 2014). A centralized location to access financial resources for patients needing funds for abortion-related expenses was proposed as a helpful resource by almost all of the participants.

All of the participants continued to perceive the utility of prenatal genetic testing, even when abortion is not an option for a patient legally, practically, or personally, but some suggested that the role of the prenatal GC could be diminished in states with restrictive abortion legislation. As one participant noted (LH1), “we could get answers for you, but you can't terminate, some families may literally say maybe I don't want to know at that point.” Some participants foresaw a pivot to preconception counseling, and several noted an increase in preconception testing to allow the potential use of IVF. Participants disagreed about how restrictions on abortion would impact the use of diagnostic testing, which fell sharply after the introduction of NIPS. Some prenatal GCs expressed concern that prenatal diagnosis may disappear entirely if abortion care is not an option; others thought that use of CVS might increase since it can be performed earlier than amniocentesis.

**STUDY LIMITATIONS**

This study had several limitations. There is likely self-selection bias because participants chose to be in the study; therefore, the study may not represent all prenatal GCs or all points of
view within the field. Additionally, with a sample of 34 participants, broad generalizations cannot be made. Furthermore, we did not have participants from all VH, HO, or LH states as per the Guttmacher Institute classifications. In addition, due to the evolving nature of abortion restrictions, our participants’ experience represents only a snapshot in time, and admittedly within a particularly tenuous era of abortion access in the United States.

**PRACTICE IMPLICATIONS**

This study highlights the importance of GCs securing up-to-date information on legislation affecting access to abortion in all states. Clear institutional guidance may aid GCs in understanding how new state and federal laws can affect one’s clinical practice as well as institutional and personal liability. Creating resources that help GCs stay abreast of changing legislation should be considered, and the National Society of Genetic Counselors (NSGC) may wish to partner with organizations such as the Guttmacher Institute, the National Network of Abortion Funds (NNAF), WeTestify, Who Not When, SisterSong, and many others in order to broadly disseminate up-to-date abortion access information amongst healthcare providers. Given that new laws create or are expected to create restrictions on the basis of gestational age or fetal development, future studies should examine the implications of performing anatomy sonograms earlier in gestation. Institutions should also consider proactive steps to avoid burnout and retain the genetic counseling workforce, particularly as it pertains to prenatal GCs confronting dissonance created by the distinct possibility of a post-*Roe* America and a professional obligation to counsel and advocate for all reproductive options.
RESEARCH RECOMMENDATIONS

Further research should examine the impact on genetic counseling practice as laws continue to evolve. Potentially, a larger study that would involve GCs in all 50 states could compare not only hostile states but also more middle-ground states and even states that have protective abortion legislation. We were able to interview one GC that worked in a telehealth setting; however, further research on the implications of restrictive legislation on telehealth providers is warranted.

CONCLUSION

This study draws on 34 qualitative interviews of prenatal GCs working in states where abortion access is restricted and may be further restricted about the impact these restrictions have had on their practice. GCs participating in our study report that they are having to adapt their practice as a result of new laws governing abortion, both in the content and the scope of what they are discussing with their patients. This study also identified that SB8 places a heavy burden on prenatal GCs in Texas with respect to their professional practice and emotional wellbeing, raising concerns as other states take steps to enact similar legislation. This study also discovered that few GCs seem prepared for the potential reversal of the Constitutional protections provided by Roe v. Wade. Additionally, prenatal GCs in these spaces indicate that they would benefit from state-specific information related to abortion law, and information on travel funding for patients for whom money is an obstacle to access. As abortion access continues to dwindle, there may be a need to reevaluate the role prenatal GCs have in an abortion-restricted state. Institutions should provide clear guidelines to their prenatal GCs in order for them to practice within the ethical framework of genetic counseling.
REFERENCES


Klibanoff, E. (2021, December 2). Medical abortions after seven weeks are now a felony in Texas. The Texas Tribune. Retrieved from https://www.texastribune.org/2021/12/02/Texas-ban-medical-abortion/


APPENDIX

Appendix 1: Interview Guide

1. Introduction
   a. Hi, my name is Grace/Sofia! Thank you so much for agreeing to speak with me and consenting to this study. As you know, abortion legislation is rapidly evolving and this is becoming a more pertinent topic to understand as it applies to prenatal genetic counseling. Many different types of regulative bans such as reason bans have become larger issues as our country deals with a court case that may effectively eliminate *Roe v Wade*. Our goal for today is to speak to you about your experience with this restrictive legislation and to understand how your practice may change depending on abortion restrictions. We are particularly interested in understanding how the evolution of these laws are impacting reproductive genetic counseling both in the ability to offer prenatal testing, and in the propensity of the genetic counselor to offer it.

2. Affect on Practice and Institution
   Abortion laws are changing rapidly in many states...
   a. What has the situation been like for you?
      i. Have you changed what you discuss in pretest counseling?
      ii. Are you seeing any changes in terms of what pregnant patients are offered by genetic counselors or doctors?
      iii. Do patients ask questions about what is available to them?
      iv. Is this a subject of discussion or concern in your institution?
   b. Is this affecting your ability to provide prenatal counseling and testing?
   c. If there is a positive result after prenatal testing, how is this affecting your practice?
      i. In a situation with a positive result, do you see changes in your ability to offer services?
   d. Have you seen patients affected by this legislation?
      i. Have certain patient populations been affected more than others?

3. Concerns about future
   a. For yourself and among other genetic counselors, are you seeing or anticipating any changes in practice?
   b. Is there a sense of what would happen if *Roe v. Wade* were to be overturned?
   c. Are there any plans in place for potential changes related to abortion restrictions or reason bans?
4. **Personal feeling**
   a. How are you feeling about all of this?
   b. Are the attitudes in the institution or genetic counselors changing?
      i. Are pregnant patients being treated differently?

5. **Types of Resources**
   a. What types of resources for either you (the GC) or the patient would be helpful moving forward?
   b. What services are you able to offer a patient who needs to travel out of state for a termination? Is it adequate?

6. **Wrap-up**
   a. In your opinion, how do you see these legislative changes reshaping the practice of reproductive medicine?
      i. If women lose the right to choose in your state, what role will there be for prenatal diagnosis?
   b. Is there anything else regarding this topic that you would like to share with me today?