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Accessibility of Pregnancy Termination: A Pilot Study of Genetic Counselors and Abortion Providers Throughout the United States

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Abstract

Recent literature suggests that availability and accessibility of pregnancy termination services affects patient care and decision-making. Because of this, there is a need to evaluate the impact of new legislation on accessibility. This study evaluated the accessibility of pregnancy termination throughout the United States by surveying prenatal genetic counselors and abortion providers. 116 responses from currently practicing prenatal genetic counselors and 30 responses from abortion providers within the United States were used in data analysis. Accessibility of pregnancy termination was assessed using the variables of cost, time, and distance. The degree of legislative impact was estimated using Guttmacher Institute's *Policy Trends in the States 2017*, which categorizes states into four regions: supportive, middle-ground, hostile, and extremely hostile, based on the number of abortion restrictions enacted. Overall, the findings show some evidence indicating that access to abortion is more limited in states with increased legislation. Genetic counselors in hostile states were more likely to refer patients to outside providers at every evaluated gestational age range than counselors in supportive states, with 89.9% of counselors referring to providers greater than 4 hours away for referrals over 24 weeks gestation compared to 56.5% in supportive states. Counselors in hostile states were also more likely to report factors such as insurance coverage, out of pocket costs, wait times, travel, and the availability of appointments as having an impact on patients' decisions to terminate a pregnancy than counselors in supportive states.

Key Words: Abortion, pregnancy termination, accessibility, genetic counseling

Introduction

Current Legislation in the United States

Since the 1973 ruling of the landmark case *Roe v. Wade*, abortion legislation within the United States has continued to evolve. There have been many attempts to restrict abortion via state law and these have been variously upheld and dismissed at the federal level (“Abortion :: Fourteenth Amendment,” n.d.)(Pergament & Ilijic, 2014). One influential case brought to the Supreme Court in 1992 was *Planned Parenthood of Southeastern Pennsylvania v. Casey*. While upholding *Roe v. Wade* and the constitutional right to abortion, *Casey* weakened the restriction standards by permitting state regulations that did not place an “undue burden” on women seeking abortions before the point of viability. Since *Casey*’s enactment in 1992, legislation restricting abortion access has increased, with 288 state-level restrictions enacted between 2011-2015 alone (Cooney, Hercher, & Bajaj, 2017). These laws generally fall within the following categories:

- 1) **Mandatory counseling:** 35 states across the United States require that a woman receive counseling before an abortion is performed in order to be fully consented (“Counseling and Waiting Periods for Abortion,” 2017). Depending on the state, this counseling may include information on fetal development, potential health effects/risks, adoption services, descriptions of the procedure itself, or discussion of fetal pain. Although many scripts contain accurate information intended to inform and educate patients, some contain false, exaggerated or misleading information (“Counseling and Waiting Periods for Abortion,” 2017)(Berglas et al., 2017)(M. Medoff, 2015).
- 2) **Mandatory waiting periods:** 27 states require a specified delay (usually 24-72 hours) between consenting for abortion and the procedure (“Counseling and Waiting Periods for Abortion,” 2017). In addition to potentially increasing patient stress (Cooney et al., 2017), mandatory waiting periods force patients to make multiple visits to the clinic, increasing the procedure’s overall cost and provider fees by an average of 19% (M. Medoff, 2015).
- 3) **Mandatory ultrasounds:** While only 14 states require information about ultrasound be provided to women seeking an abortion, 26 states have ultrasound regulations for abortion providers, and four require a patient to view and listen to the description of the ultrasound image by abortion providers before a termination (“Requirements for Ultrasound,” 2017). In the first trimester, ultrasounds are

usually not routine or medically necessary for abortions, making them frequently an unnecessary and expensive step in the termination process (M. Medoff, 2015)(“Requirements for Ultrasound,” 2017).

- 4) Mandatory consent for minors: Under *Roe v. Wade*, minors (women less than 18 years old) have the right to terminate a pregnancy. However, 37 states require some form of parental/guardian involvement or consent, which in some cases may be waived by a court or under specific circumstances (M. Medoff, 2015)(“Parental Involvement in Minors’ Abortions,” 2017).
- 5) Restriction before viability: Although viability is largely accepted to be 24 weeks gestation and outlined as such under *Roe v. Wade*, 17 states have challenged that standard by enacting legislation that prohibits abortion past 20 weeks gestation on the belief that fetuses can feel pain at that time (Cooney et al., 2017)(“State Policies on Later Abortions,” 2017).
- 6) Targeted Regulation of Abortion Providers (TRAP): TRAP laws refer to any piece of legislation that specifically places regulations or requirements on facilities where abortions are performed. Holding these facilities to a much higher standard than other comparable surgery centers by requiring admitting privileges for doctors and/or expensive modification of the physical space, TRAP legislations have led to closure of abortion clinics and reduced abortion access, especially in rural areas of the U.S.; in 2014, it was estimated that 90% of all counties did not have an abortion clinic (Cooney et al., 2017)(M. Medoff, 2015)(“Targeted Regulation of Abortion Providers (TRAP) Laws,” 2017). In June of 2016, the United States Supreme Court ruled that TRAP legislation in Texas created an undue burden for women seeking services under *Casey*, which may decrease and possibly reverse the spread of TRAP laws across the U.S (Cooney et al., 2017).
- 7) Restrictions on procedures: In addition to the 2003 Federal Partial Birth Abortion Act, which restricted the ability to terminate a fetus that was partially removed from the vaginal cavity, states have enacted legislation banning certain abortion procedures (Weitz, 2009). In 2016, four states introduced legislation banning dilation and evacuation (D&E) procedures, which account for approximately 95% of second-trimester abortions methodology (“Bans On Specific Abortion Methods After 1st Trimester,” 2017), despite the fact that D&E is the preferred methodology for a majority of providers due to the lower risk

of complications, decreased hospitalization time, and lower cost relative to other second trimester procedures (Kerns, Swanson, Pena, Wu, & Shaffer, 2012) (Bryant, Grimes, Garrett, & Stuart, 2011).

While supporters of these laws describe them as check-points and safeguards within the system that help provide safe procedures and fully consented/informed patients, opponents argue that the legislation is an attempt to revoke reproductive rights and access to abortion as medical care (Pergament & Ilijic, 2014)(Berglas et al., 2017)(Rebouche & Rothenberg, 2012). In a 2009 study, Medoff argued that state restrictions on abortion providers are reducing the number of available providers, thereby limiting access to abortion (M. H. Medoff, 2009). The group found that between 2011 and 2014, there was a 6% decline in the number of abortion clinics available throughout the United States, with the most dramatic decreases seen in the Midwest (22% decline) and the South (13% decline). Consistent with that, these regions also experienced the most significant restrictions enacted during this time frame (Jones & Jerman, 2017).

Role of Pregnancy Termination in Genetics

Prenatal genetic testing is used to detect changes in fetal chromosomes and/or genes (Malpas, 2017). With the expansion of prenatal genetic testing options and improved predictive value, the American College of Medical Genetics and Genomics has recommended that all pregnant women be offered genetic screening and diagnostic testing (Kathy Beal, 2016). In a 2013 study, it was estimated that 72% of pregnancies between 2011 and 2012 underwent some form of genetic screening for aneuploidy (Palomaki, Knight, Ashwood, Best, & Haddow, 2013); with the implementation of non-invasive prenatal screening using cell-free fetal DNA since 2012, that number may be even higher today. While individuals choose to undergo prenatal genetic testing do so for their own reasons, one of several purposes of prenatal genetic testing is to allow for the option of termination of an affected pregnancy (Pergament & Ilijic, 2014).

In a statement on access to reproductive options after a prenatal diagnosis in 2013, the American College of Medical Genetics supported the use of prenatal genetic testing to allow for the option of termination, by stating: “The practice of medical genetics is predicated on the principle of providing patients with accurate information on the genetic disorder or congenital anomaly that affects them, a family member, or an unborn fetus... the ACMG believes strongly that a balanced discussion of options, including termination of pregnancy,

should be available (Board, 2013).” This belief is also shared by majority of the American public; in 2007, polls suggested that 74% of Americans believe abortion should be an available option for women if a fetal genetic disorder or malformation is prenatally detected (Rebouche & Rothenberg, 2012)(Woltanski, Cragun, Myers, & Cragun, 2009)(Ackerman & Mcdermott, 2012)(Hercher, 2017).

While prenatal genetic testing serves purposes unique for each individual that uses it, abortion and prenatal genetic testing inevitably intersect, adding to the complex relationship between healthcare and politics in the United States(Pergament & Ilijic, 2014)(Rebouche & Rothenberg, 2012). Recent abortion legislation on the state level targeting prenatal genetic testing is evidence of this intersection. In 2013, North Dakota passed House Bill No. 1305, becoming the first state to prohibit abortions if the fetus was found to have a genetic abnormality (“Abortion Bans in Cases of Sex or Race Selection or Genetic Anomaly,” 2017)(Koppelman, 2013)(King, 2012). The American College of Medical Genetics has come out in opposition to legislation like the North Dakota bill stating: “Access to safe and legal termination of pregnancy for genetic disorders or congenital anomalies that may be diagnosed prenatally is a critically important option for some pregnant couples, and the ACMG strongly opposes legislation that places limits on this access (Board, 2013).” As of May 2017, Indiana and Louisiana have passed laws similar to North Dakota House Bill 1305, although both have been blocked by the courts pending resolution of legal challenges. Three other states require counseling on perinatal hospice services if an abortion is sought due to a lethal fetal abnormality (“Abortion Bans in Cases of Sex or Race Selection or Genetic Anomaly,” 2017).

Impact of Changing Policies and Legislation on Genetic Counseling

According to the National Society of Genetic Counselors, genetic counselors are healthcare professionals who specialize in both medical genetics and counseling to provide risk assessments and supportive counseling, educate patients, interpret genetic testing, and serve as patient advocates (“About Genetic Counslors,” 2017). In 2014, the National Society of Genetic Counselors (NSGC) issued this statement on reproductive freedom: “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...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 (“Reproductive Freedom Position Statement,” 2014).”

Caitlin Cooney et al. in the recent (2017) paper *Genetic Counselors’ Perception of the Effect on Practice of Laws Restricting Abortion* proposed that abortion legislation could impact genetic counselors in three ways: “By prohibiting abortion prior to viability, by placing restrictions on clinics that affect their ability to offer services, and by mandating counseling and waiting periods that interfere with timely access to abortion procedures (Cooney et al., 2017).” Study results suggest that such legislation can have a direct impact on genetic counseling patients who choose to terminate, including increased costs and travel times, and may limit their ability to have an abortion (Cooney et al., 2017). By prohibiting abortion prior to viability (24 weeks gestation is the widely accepted date) and mandating counseling/waiting periods, regulations may also limit options for patients by the time prenatal test results return (Rebouche & Rothenberg, 2012). Additionally, Caitlin Cooney states that “decreased access to abortion may force (genetic) counselors to adopt a more directive manner in response to a reduced time frame for decision making (Cooney et al., 2017).” These consequences not only prevent counselors from carrying out their jobs appropriately, but also could pressure patients into making a decision that may not be the right decision for the future of the family.

States like Missouri and Oklahoma have already introduced (but not passed) abortion legislation that specifically targets genetic counselors (Genetic diagnostic and counseling services to be established--outreachcenters, duties--referral for abortion, procedure, requirements., 1985)(Licensure, accreditation, certification not contingent upon acceptance of abortion as treatment option, 2006). In Missouri, Statute 191.320 of House Bill 612, states that medical genetic providers and genetic counselors “shall not include referral for abortion unless abortions are certified in writing by a physician that, in his professional judgment, the life of the mother would be endangered (Genetic diagnostic and counseling services to be established--outreachcenters, duties--referral for abortion, procedure, requirements., 1985).” These laws exemplify the conflict between professional genetic counseling organizations, like The National Society of Genetic Counselors, and law makers. As Midwestern and Southern states respectively, the Missouri and Oklahoma laws also illustrate the regional differences seen across the United States as identified by Caitlin Cooney et al. who found that “a larger

percentage of (genetic) counselors in the South and Midwest regions have experienced more changes that have affected patients, colleagues, and their counseling style (Cooney et al., 2017).”

Conclusion

Pregnancy termination is the subject of considerable debate in the United States. Recent literature suggests that availability and accessibility of pregnancy termination services affects patient care and decision-making. Because of this, there is a need to evaluate the impact of new legislation on accessibility of pregnancy termination throughout the United States.

Purpose

The purpose of this study is to evaluate the accessibility of pregnancy termination throughout the United States by region, as compared with the level of restrictive legislation. Accessibility of pregnancy termination was assessed using the variables of time, distance and cost. The degree of legislative impact was estimated using Guttmacher Institute’s *Policy Trends in the States 2017*, which categorizes states into four regions: supportive, middle-ground, hostile, and extremely hostile, based on the number of abortion restrictions enacted (Nash, Benson Gold, Mohammed, Ansari-Thomas, & Cappello, 2018).

Methodology

Participants

This study evaluated the accessibility of pregnancy termination throughout the United States by surveying prenatal genetic counselors and abortion providers.

An online survey for genetic counselors was distributed through the National Society of Genetic Counselors’ listserv. The initial email was sent to 3,586 genetic counselors, and a reminder email was sent to 3,692 genetic counselors. Genetic counselors who currently practice in a prenatal setting within the United States were eligible to participate. All participants were members of the National Society of Genetic Counselors. A total of 116 responses were used in data analysis.

Several abortion providers within each state were contacted with the goal of obtaining three providers to participate in the survey. Of note: a small number of states do not have three practicing abortion providers. In states with more than three providers, the goal was to select those providers that offered the late term abortions and to select for diverse locations. Selection began by utilizing resources for medical professionals regarding pregnancy termination to create a list of providers known to offer late term abortions specifically for fetal anomalies and/or genetic conditions. Other providers were found based on online searches for abortion providers on a state-by-state basis. The researchers utilized online search engines using the search term “abortion providers in [insert state of interest]”. In analyzing search results, the researchers looked at provider’s websites to assess the gestational age limit of that facility. Facilities with the latest gestational age limits were given preference for participation. If there were more than three providers with similar gestational age limits within the state, the researchers gave preference to soliciting facilities in diverse locations throughout the state. In total, 126 abortion providers were identified, 30 of which agreed to participate in the survey and whose responses were used in data analysis.

Instrumentation

An online survey created through SurveyMonkey.com was designed to assess prenatal genetic counselors’ perspectives on accessibility of pregnancy termination. The survey contained 23 questions relating to counselor and patient demographics, assessments of accessibility variables (time, distance and cost), and open-ended questions aimed to elicit genetic counselors’ concerns regarding accessibility for their patients.

A structured interview was designed to assess the patient population and services available within abortion facilities. These questions were asked during a phone or email interview with providers. The interviews consisted of a series of 14 questions relating to provider and patient demographics, assessments of the accessibility variables of time, distance and cost, and services available specifically for terminations due to a genetic anomaly. An online survey through SurveyMonkey.com, only accessible to the researchers, was created to store the data from these interviews.

This study was IRB approved by the IRB committee at Sarah Lawrence College (Appendix A). A copy of both surveys is available in Appendix B.

Procedures

The survey for genetic counselors was distributed via email through the National Society of Genetic Counselors' listserv on January 17, 2018. A reminder email was sent on January 31, 2018. The content of these emails is available in Appendix C. Consent was obtained via a consent form on the initial page of the survey (Appendix D). Participants were able to skip any questions and withdraw from the survey at any time. No IP addresses, names, contact information, or other personally identifiable information was collected. Upon submission of a survey, the participant's responses were uploaded and stored by SurveyMonkey.com.

Abortion facilities were initially contacted via contact information available on their websites. Initial contact involved a recruitment script that was either emailed, copied into the form on their website, or read aloud on the phone. The recruitment script is available in Appendix E. After the initial contact, interviews were conducted via phone or email after a consent script was read, depending on the providers' preference. A copy of this consent script is available in Appendix F. The interviewee was provided contact information for the researchers and the IRB committee members. Participants were able to skip any questions and withdraw from the interview at any time. In order for information to remain anonymous, the interview answers were entered into a survey on SurveyMonkey.com only accessible by the researchers. Data collection from abortion providers was completed between December 15, 2017 and February 5, 2018.

Data Analysis

For data analysis, participants were categorized into groups based on the Guttmacher Institute's state hostility classification system as defined in *Policy Trends in the States 2017* (Nash et al., 2018). States were classified as (1) supportive, (2) middle-ground, (3) hostile, and (4) extremely hostile based on the number of restrictions in legislation affecting access of abortion. According to the Guttmacher Institute:

“States are categorized based on how many of 10 major types of abortion restrictions they have enacted: Requiring parental involvement before a minor's abortion; mandating medically inaccurate or misleading pre-abortion counseling; requiring a waiting period after abortion counseling at a clinic, thus necessitating two trips to the facility; mandating a non-medically indicated ultrasound before an abortion; banning Medicaid funding of abortion except in cases of life endangerment, rape or incest; restricting abortion coverage in private health plans; imposing medically inappropriate restrictions on

medication abortion; requiring onerous and unnecessary regulations on abortion facilities; imposing an unconstitutional ban on abortion before viability or limits on abortion after viability; and enacting a preemptive ban on abortion if Roe v. Wade is overturned. A state is considered supportive of abortion rights if it has no more than one of these restrictions, a middle-ground state if it has 2–3, a hostile state if it has 4–5 and an extremely hostile state if it has 6–10.”

In an effort to determine accessibility of pregnancy termination in relation to legislation, participant data was categorized into these defined regions of hostility:

1. Supportive: CA, CT, HI, ME, MD, MT, NJ, NM, NY, OR, VT, WA
2. Middle-ground: AK, CO, DE, IL, MA, MN, NV, NH, WY
3. Hostile: GA, ID, IA, PA, RI, WV
4. Extremely Hostile: AL, AZ, AR, FL, IN, KS, KY, LA, MI, MS, MO, NE, NC, ND, OH, OK, SC, SD, TN, TX, UT, VA, WI

For the purposes of this study, similar regions of hostility (for example, extremely hostile and hostile) as well as other similar data categories were sometimes combined due to small sample size for purposes of statistical analyses.

Results

Demographics

The initial email containing the genetic counselor online survey was sent to 3,586 genetic counselors via the NSGC listserv; 980 individuals opened the email (28.2%), and 112 individuals opened the survey link (3.1%). The reminder email was sent to 3,692 genetic counselors; 1,005 individuals opened the email (27.9%), and 85 opened the survey link (2.3%). The survey had a total of 135 respondents. Due to a glitch in the online survey, the first 48 respondents were only able to complete the first five questions relating to demographics. These responses were not used in data analysis; however, individuals who attempted the survey were encouraged to re-submit their responses. This was by direct email for respondents who personally reached out to the researchers about the glitch as well as in the reminder email through the genetic counselor listserv (Appendix C). Additionally, 17 responses were excluded as they were from respondents who do not practice

prenatally. Since the goal of this study was to evaluate accessibility throughout the United States in relation to United States legislation, 2 responses from Canadian counselors were also excluded. In total, 116 responses were used in the data analysis.

Of the 116 total respondents, 3 counselors identified as male (2.59%), 113 identified as female (97.41%), and 0 individuals identified as “other”. Of the participants, 53 genetic counselors practiced in academic medical centers (45.69%), 20 counselors worked within a private practice (17.24%), 19 counselors worked in public or community hospitals (16.38%), 11 practiced in private hospitals (9.48%), 7 worked in catholic hospitals (6.03%), and 6 respondents stated they worked in alternative settings (5.17%). A majority of the respondents had less than 10 years of experience with the following break-down: 31 respondents with less than 2 years (26.72%), 27 people with 2-5 years (23.28%), 29 respondents with 6-10 years (25%), 18 respondents with 11-20 years (15.52%), and 11 respondents with more than 20 years (9.48%).

Genetic Counselor Demographics		n(%)
Gender	Female	113 (97.41%)
	Male	3 (2.59%)
	Other	0 (0%)
State hostility	Extremely hostile	45 (39.5%)
	Hostile	9 (7.9%)
	Middle-ground	11 (9.6%)
	Supportive	49 (43.0%)
Work Setting	Academic medical center	53 (45.69%)
	Private practice	20 (17.24%)
	Public/community hospital	19 (16.38%)
	Private hospital	11 (9.48%)
	Catholic hospital	7 (6.03%)
	Other	6 (5.17%)
Years of practice	<2 years	31 (26.72%)
	2-5 years	27 (23.28%)
	6-10 years	29 (25%)
	11-20 years	18 (15.52%)
	>20 years	11 (9.48%)

The states where respondents practice were categorized into groups based on The Guttmacher

Institute’s analysis of hostility to abortion: supportive (49 respondents; 43%), middle-ground (11 respondents;

9.6%), hostile (9 respondents; 7.9%), and extremely hostile (45 respondents; 39.5%). Two respondents who practice in Washington, D.C. identified themselves as “other” in state demographics. Washington D.C. is not included in the Guttmacher Institute’s hostility map, therefore, data collected from those surveys were not used for portions of the analysis that relied on hostility ratings. Responses to the open-ended questions, however, were evaluated.

A semi-structured interview was constructed with the goal of surveying 126 abortion providers throughout the United States as selected by the researchers. Time limitations and facility willingness to participate provided a total of 30 responses successfully completed (23.8% of anticipated participants). These responses were also separated into the 4 categories of hostility to abortion based on the state in which the facility operated: supportive (12 participants; 40%), middle-ground (4 participants; 13.3%), hostile (4 participants; 13.3%), and extremely hostile (10 participants; 33.3%).

Hostility Classification	Genetic Counselor Participants	Abortion Provider Participants
Supportive	49 (43%)	12 (40%)
Middle-Ground	11 (9.6%)	4 (13.3%)
Hostile	9 (7.9%)	4 (13.3%)
Extremely Hostile	45 (39.5%)	10 (33.3%)

Genetic Counselor Survey:

Genetic counselors were asked how quickly a termination could be arranged for patients seeking a termination at different gestational ages: before the end of the first trimester (<12+6 weeks), between 13-17+6 weeks, between 18-19+6 weeks, between 20-23+6 weeks, and over 24 weeks. In examining the data of a state’s hostility/support for abortion by wait times, there were no statistically significant statistical differences. Over all, wait times were not significantly different as a function of a state’s hostility/support for abortion.

There were, however, statistically significant differences in where genetic counselors refer women for termination services across a variety of gestational age categories in states characterized by hostility/support for abortion. For patients seeking to terminate before the end of the first trimester, 29.2% (14) of counselors in extremely hostile and hostile states, 75% (6) of those in middle-ground states, and 81% (34) of those in

supportive states referred to abortion services within their institution, with the remainder in each case referring to local free-standing abortion providers (Chi-square=25.68(df=2), $p<0.001$).

For abortion service referrals between 13 and 17+6 weeks gestation, 35% (14) of counselors in extremely hostile/hostile states, 75% (6) of those in middle-ground states, and 77.5% (34) of those in supportive states referred to services within their institution, with the remainder in each case referring to local free-standing abortion providers (Chi-square=15.88(df=2), $p<0.001$).

For abortion service referrals between 18 and 19+6 weeks gestation, 40% (14) of counselors in extremely hostile and hostile states, 71.4% (5) of those in middle-ground states, and 75% (30) of those in supportive states referred to abortion services within their institution, with the remainder in each case referring to local free-standing abortion providers (Chi-square=9.94(df=2), $p<0.01$).

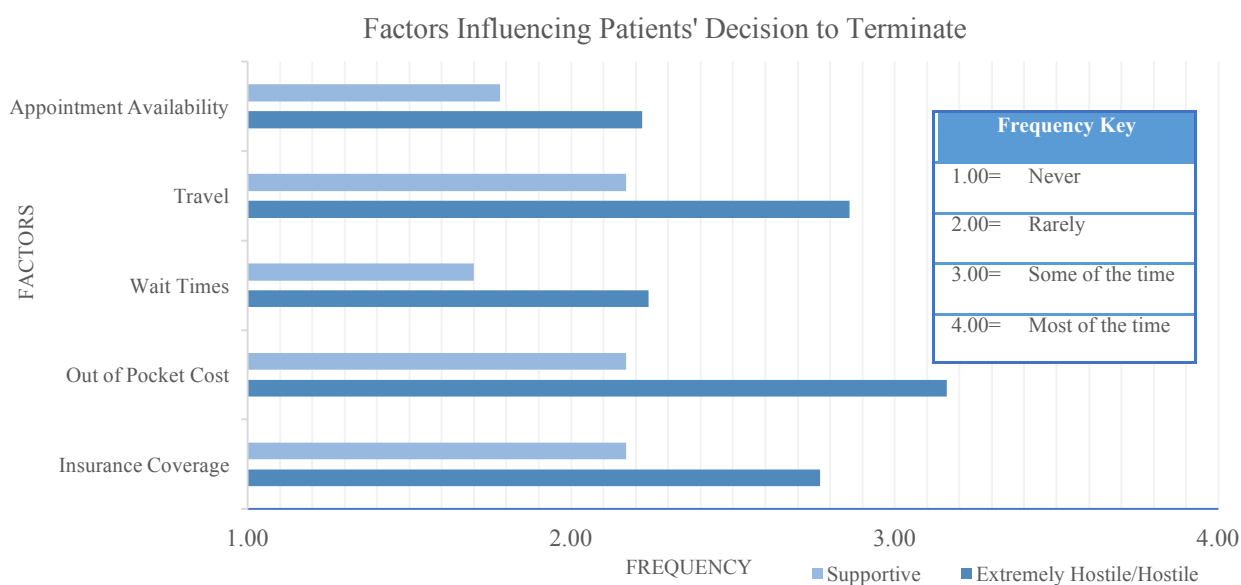
For abortion service referrals between 20 and 23+6 weeks gestation, 9.1% (4) of counselors in extremely hostile/hostile states, 66.7% (4) of counselors in middle-ground states, and 73.7% (28) of counselors in supportive states referred to services within their institution. In middle-ground and supportive states the remainder reported referring to local free-standing abortion providers, while only 27.3% (12) of counselors in extremely hostile/hostile states reported referring to local free-standing providers, with 63.6% (28) reporting no local referrals. The use of out of town providers in this gestational age range was the most significant difference in referrals between respondents from middle-ground or supportive states and those from states that are extremely hostile/hostile (Chi-square=47.22 (df=4), $p<0.001$).

For patients seeking to terminate after 24 weeks gestation, 89.9% (44) of counselors in extremely hostile/hostile states and 90% (9) of counselors in middle-ground states referred to out of town providers greater than 4 hours away, while 56.5% (26) of those in supportive states referred to providers more than 4 hours away (Chi-square=15.39 (df=2), $p<0.001$). For the 43.5% (20) of counselors in supportive states who were *not* using out of town providers greater than 4 hours away, 40% (8) had services available within their institution, 20% (4) referred to other local hospitals, 20% (4) referred to local free-standing providers, 10% (2) referred to an out of town provider less than 2 hours away, and 10% (2) referred to an out of town provider between 2 and 4 hours away.

Gestational Age of Referral	Location of Referral	n	Extremely Hostile/Hostile	Middle-Ground	Supportive	Method	P-value
Referral for 12+6 weeks	Available in my institution	54	29.2% (14)	75.0% (6)	81.0% (34)	Chi-Square 25.68 (df=2)	P<0.001
	Local free-standing abortion provider	44	70.8% (34)	25%(2)	19.0% (8)		
Referral for 13 – 17+6 weeks	Available in my institution	51	35% (14)	75% (6)	77.5%(31)	Chi-Square 15.88 (def=2)	P<0.001
	Local free-standing abortion provider	37	65.0%(26)	25.0%(2)	22.5%(9)		
Referral for 18- 19+6 weeks	Available in my institution	49	40%(14)	71.4%(5)	75%(30)	Chi-Square 9.94 (df=2)	P<0.01
	Local free-standing abortion provider	33	60%(21)	25%(2)	25%(10)		
Referral for 20- 23+6 weeks	Available in my institution	36	9.1% (4)	66.7% (4)	73.7% (28)	Chi-Square 47.22 (df=4)	P<0.001
	Local free-standing abortion provider	23	27.3% (12)	33.3% (2)	23.7% (9)		
	Out of Town Provider	29	63.6% (28)	0%(0)	2.6% (1)		
Referral >24 weeks	Out of town provider <4 hours away	79	10.2%(5)	10.0% (1)	43.5% (20)	Chi-Square 15.39 (df=2)	P<0.001
	Out of town provider >4 hours away	26	89.8% (44)	90.0% (9)	56.5% (26)		

A series of question using rating scales were asked about issues that might restrict the choice to terminate a pregnancy. These items were analyzed by extremely hostile/hostile versus middle-ground versus supportive states in a one-way ANOVA. Tukey's post hoc analysis indicated that the differences were always between two categories, extremely hostile/hostile versus supportive states. Given this analysis and the small number of respondents from middle-ground states (10), a t-test was used to determine the differences between

extremely hostile/hostile and supportive states. In each instance, genetic counselors in extremely hostile/hostile states reported factors such as insurance coverage, out of pocket costs, wait times, travel, and the availability of appointments as having a greater influence in a patient's decision to terminate than those in supportive states. This difference was statistically significant.



Factors Influencing Patient Decision to Terminate	Hostility Rating	Mean	Standard Deviation	Mean Difference	t	P-value
Insurance Coverage	Hostile State	2.77	0.72	.60	4.21	P<0.001
	Supportive States	2.17	0.68			
Out of Pocket Costs	Hostile State	3.16	0.71	0.99	7.19	P<0.001
	Supportive States	2.17	0.64			
Wait times	Hostile States	2.24	0.77	0.54	3.86	P<0.001
	Supportive States	1.70	0.59			
Travel	Hostile States	2.86	0.80	0.93	6.22	P<0.001

	Supportive States	2.17	0.68			
Appointment availability	Hostile States	2.22	0.74			
	Supportive States	1.78	0.68	0.44	2.93	P<0.01

Factor key: 4= most of the time, 3= some of the time, 2= rarely, 1= never

Abortion Provider Interview:

In analysis of the abortion provider data in regards to the facility’s gestational age limit as a function of hostility-support ratings, the extremely hostile states had the lowest average limit at 18 weeks, the hostile states had an average of 22+1 weeks, the middle-ground states had an average of 22+6 weeks, and the supportive states had an average of 22+4 weeks. Comparing the two largest categories of extremely hostile (n=10) and supportive (n=12), there was a statistically significant difference (t (20) = 2.71, p<.05), as the supportive states had a gestational age limit that was 4.6 weeks higher than the extremely hostile states (approximately 4 weeks and 4 days).

Only 7 facilities reported exceptions to the gestational age limit in the case of a genetic anomaly; 6 of the 7 (85.7%) were in supportive states. Comparing extremely hostile and supportive states, no extremely hostile states had exceptions to the gestational age limit in the case of an anomaly, while 50% (6) of the supportive states had an exception. This difference was statistically significant (Fisher’s Exact p<.05).

Abortion facilities were asked how close the nearest center was for a referral if a patient exceeded their facility’s gestational age limit. Only 20% (2) in extremely hostile states were able to refer to a local facility or a facility less than 2 hours away, while 54.5% (6) of facilities in supportive states referred to these closer facilities. However, this difference was not statistically significant (Fisher’s Exact p = .18).

There were no significant differences in wait times for patients based on hostility of the state where the facility was located. However, when asked how long the state’s mandatory waiting period was, no facilities in 12 supportive states (100%) had a mandatory period, while all 10 of the facilities (100%) in extremely hostile states had waiting periods ranging from 24 to 72 hours. The difference was statistically significant (Fisher’s Exact p<.001).

Medication-based terminations were offered in 93.3% (28) of facilities, D&C procedures were offered in 90% (27), and D&E procedures were offered in 73.3% (22) facilities. There were no statistical differences in availability of these procedures in categories of hostility/support. However, only 5 facilities offered induction of labor and 4 of the 5 facilities (80%) were in supportive states. No extremely hostile states provided induction of labor. However, the difference between supportive and extremely hostile states was not statistically significant (Fisher's exact $p=0.09$).

There were no differences in how many visits were required for a medical termination by type of state. Extremely hostile states had a mean number of 1.8 visits, supportive states had a mean number of 1.91, hostile states had a mean of 1.75, and middle-ground states had a mean of 1.67 visits. Additionally, there were no differences in the average costs of a medication-based abortion. The average cost in supportive states was \$683, in extremely hostile states it was \$607, in middle-ground states it was \$692, and in hostile states the average cost was \$493.

The average number of visits for a D&C abortion in extremely hostile states was 1.78 and in supportive states 1.27. This difference was statistically significant ($t(18)=1.99$, $p<0.05$, for a one-tailed test).

There were not differences in the number of visits required for a D&E abortion by type of state. However, there were differences in the cost of a D&E abortion ($t(11)=2.94$, $p<0.05$). In extremely hostile states the average cost was \$1,591, and in supportive states the average cost was \$3,957.

While 91.7% (11) of facilities in supportive states accepted Medicaid, 50% (5) of facilities in extremely hostile state did, a statistically significant difference in the acceptance of Medicaid by type of state (Chi-square=4.77 (df=1), $p<0.05$). In terms of accepting other insurance, there were no statistical differences: 80% (8) of extremely hostile states, 100% (4) of hostile states, 75% (3) of middle ground states, and 100% (12) of supportive states accepted insurance. As far as the availability of financial assistance, again, there was no statistically significant difference. 100% (10) of extremely hostile, 100% (4) of hostile states, 75% (3) of middle-ground states, and 83.3% (10) of supportive states provided financial assistance.

There was no statistically significant difference in the reported average distance patients had to travel to clinics among facilities factored by categories of hostility/support. On average, 59.26% (16) of providers

described the majority of their patients as traveling from out of town and less than 2 hours away, 25.93% (7) described them as local or in town, 11.11% (3) described their patients as traveling over 4 hours, and 3.7% (1) described their patients as traveling between 2-4 hours for care.

Comparing Genetic Counselors and Abortion Providers:

Genetic counselors' responses to the questions regarding how quickly a termination could be arranged were compared to providers' responses. On an index where 1=1-2 days, 2=2-4 days, 3=5-7 days, and 4=more than one week, the only statistical difference was for patients choosing to terminate a pregnancy over 24 weeks gestation. Providers reported a shorter time to arrange the procedure with a mean score of 1.86 (around 2 days), while counselors reported a mean score of 2.81 (around 5-7 days) ($t(68)= 2.78, p<0.01$). Other gestational time intervals, after the first trimester, 13-17+6 weeks, 18-19+6 weeks, and 20-23+6 weeks, did not indicate significant differences between counselor and provider responses.

Discussion

Finding 1: Accessibility in Terms of Time

Abortion providers in extremely hostile states were found to have more mandatory waiting periods and earlier gestational age limits, and required more appointments on average for a D&C procedure, restricting availability and increasing the time necessary to obtain an abortion. These factors are likely to contribute to a decrease in accessibility. While responses from genetic counselors did not indicate any significant differences in the time needed to arrange terminations between states when classified by their hostility to abortion, genetic counselors in hostile states were more likely than those in supportive states to indicate that wait times and availability of appointments had an impact on patients' decisions about whether or not to terminate a pregnancy. In addition, in their free responses, several genetic counselors referenced time constraints negatively affecting abortion accessibility for patients due to restrictive legislation and increased regulations. In particular, counselors in hostile states often provided examples stressing time pressure and its impact on clinical care. As one counselor noted:

"[Our state] has a limitation now of 22 0/7 weeks gestation, making 21 6/7 weeks gestation the last day in the state to perform the procedure. Typically, anatomy scans aren't performed until 20-ish weeks. If a

patient can be referred to us and have amnio ASAP, we still may not have results back in time to aid the patient in their decision before the state legal limit has passed, forcing them to travel 4+ hours to a different state for an abortion.”

Statistically significant differences in reports from genetic counselors and abortion providers in the time required to schedule a termination after 24 weeks gestation should be researched further. Genetic counselors reported needing longer periods of time to organize an appointment, which may indicate there are underreported barriers for patients choosing to terminate due to a fetal anomaly.

Finding 2: Accessibility in Terms of Cost

According to the genetic counselors surveyed, both insurance coverage and out-of-pocket costs were more likely to influence a patient’s decision to terminate in hostile states than supportive states. Our survey of providers did not suggest that costs were higher for procedures in hostile states, so this may suggest that more of the cost is borne by the patient, which can be a barrier in terms of accessibility for abortion services. This counselor’s description demonstrates the complex relationship between state legislation and financial accessibility:

“In the state of Wisconsin, only lethal diagnoses (ex: trisomy 18, 13, large cystic hygromas) can be performed in the hospital. All other diagnoses, including severe diagnoses, must be performed at a clinic not associated with a hospital. In these cases, insurance does not cover it.”

The responses of the genetic counselors were mirrored by those of abortion providers as hostile states were less likely to accept Medicaid. In terms of the costs of procedures, our study identified no differences across states as categorized by hostility to abortion with the exception of costs for dilation and evacuation (D&E), the most commonly procedure used in second trimester abortions, which was more expensive in supportive states. This price difference could be due to the fact that supportive states are more likely to perform D&E procedures at a later gestational age, which typically leads to a more expensive procedure. Other variables,

such as differences in cost of living, could also be influencing this cost difference. This difference warrants further study.

Finding 3: Accessibility in Terms of Distance

Genetic counselors in hostile states indicated travel as having a larger influence in their patients' decisions about whether or not to terminate a pregnancy than those in supportive states. Additionally, for each gestational age range evaluated, genetic counselors in hostile states were more likely to refer patients to outside providers rather than within their institution. As the gestational age increased, extremely hostile/hostile states and middle-ground states were more likely to refer to outside providers greater than 4 hours away while 43.5% of counselors in supportive states were able to use services closer to home. Pressures associated with the need for patients to travel for services was a theme expressed by a number of genetic counselors in response to open-ended questions:

“I try to gauge early on if they might consider termination. 9 times out of 10 this would require significant travel for them, and I want them to be aware of this. Many patients are not aware that there isn't a local, legal way for them to end a pregnancy if they wish.”

“It's disgraceful that local abortions are only available until 15 weeks, 5 days. From 16.0-21.6, they have to drive to Atlanta, GA, which is 4-5 hours away from many patients. “

These findings are not surprising given that the majority of abortion providers in hostile states were unable to make any exceptions to their gestational age limits in the cases of fetal anomaly. Providers that were willing or able to offer a termination later in pregnancy in these circumstances were more likely to be found in supportive states. Although there was not a statistical difference in the average reported distance patients traveled between states, overall, our findings suggest a negative relationship between state hostility and abortion accessibility in terms of distance.

Additional findings:

Genetic counselors were asked to share their thoughts at the end of the survey on how abortion

legislation has impacted their practice in ways that the previous questions may not have addressed. Several counselors stated that restrictions have led to a more directive form of counseling when patients are considering terminating a pregnancy. One counselor reports:

“I’ve had to be more urgent about a decision to terminate. If they receive a terrible diagnosis at 20 weeks, they may only have a day or two to decide before we are past the consent window.”

These findings are consistent with Cooney’s findings from 2017, which showed that counselors were concerned about being forced to be more directive in discussions regarding termination or prenatal testing (Cooney et al., 2017). Additionally, some counselors felt that changes in legislation have impacted the choices they can offer patients:

“I am extremely cautious in my working, making sure to emphasize that there are a lot of factors that go into the process, and I can never guarantee termination as an option for them.”

Other counselors report adjusting when they offer certain tests to patients, due to changes in gestational age limits within their state:

“Several years ago, the legal limit for termination in our state was changed to be earlier. We now encourage individuals to pursue screening (both MSS, cfDNA, and ultrasounds) at the earlier side of the window if appropriate (i.e. anatomy ultrasound at 18 weeks rather than 20 weeks) if maternal factors allow.”

This is consistent with Cooney’s study, which reported that some counselors and physicians were bringing patients in earlier for their anatomy scans due to timing concerns and recent changes in legislation regarding gestational age limits (Cooney et al., 2017).

Limitations

Study limitations included ascertainment biases for both the survey of genetic counselors and the structured interviews of abortion providers. The selection method of providers began with gathering information

from resources provided to medical communities, which involves an inherent bias. These clinics may not accurately represent the availability and accessibility of abortion across the US and may have also skewed patient population data. Of the providers contacted, many were hesitant to participate or unwilling to respond to emails and/or phone calls, and willingness to participate may reflect a fundamental difference that might have influenced our results. Additionally, both data sets from abortion providers and genetic counselors were self-reported and therefore may not be an accurate representation of the population.

Another limitation of the study was the small sample size of providers, which fell short of the initial goal of three providers per state. For this reason, many states are not represented and others are represented inadequately. Many clinics cited concerns about safety before being willing to participate.

There were also several limitations related to the survey measurements and questions, including the measurements we used to gather data on cost. A number of providers noted that different procedures have varying costs depending on how far along the patient is in their pregnancy, rather than the procedure type itself. For the purposes of this study, cost was reported as the highest number in a given range. The same limitation existed with regard to the number of appointments required. Often, the number of appointments was determined by gestational age rather than procedure. Some clinics did or did not include follow up appointments in the number of visits required. There appeared to be some inconsistency in how the question was interpreted. Furthermore, many clinics, in an attempt to reduce inconvenience to patients, would recommend that follow up be performed by other facilities. As with cost, if the number of appointments was given in a range, the response was reported as the highest number for the purposes of this study. For future studies, we recommend that investigators design survey questions that account for these scenarios as to better assess the difference in time and cost between clinics.

Technical challenges with the online genetic counselor survey lead to the first 48 participants incorrectly being sent to the end of the survey after completing only the first five demographic questions. These responses were disregarded. The affected counselors were able to retake the survey once the glitch was corrected, but some participants were lost despite follow up emails.

Additionally, this study did not define the term “genetic anomaly” for participants and therefore did not differentiate between general prenatal anomalies and lethal anomalies. It’s recommended that future studies

distinguish between lethal and non-lethal anomalies, as this is a key determinant to when a procedure can legally be performed in some states.

Conclusion

The purpose of this pilot study was to evaluate the accessibility of pregnancy termination throughout the United States, to measure the possible impact of restrictive legislation on patient care and decision-making. Overall, the findings show some evidence indicating that access to abortion is more limited in states with increased legislation. Genetic counselors in hostile states were more likely to refer patients to outside providers at every evaluated gestational age range than counselors in supportive states, with 89.9% of counselors referring to providers greater than 4 hours away for referrals over 24 weeks gestation compared to 56.5% in supportive states. Counselors in hostile states were also more likely to report factors such as insurance coverage, out of pocket costs, wait times, travel, and the availability of appointments as having an impact on patients' decisions to terminate a pregnancy than counselors in supportive states. Additionally, abortion providers in hostile states were found to have more mandatory waiting periods and earlier gestational age limits, and required on average more procedure-related appointments. Per this study's results, state legislation limiting abortion affects patient care; however, further, more comprehensive research is needed.

Conflict of Interest:

Lauren Facchini declares that she has no conflict of interest.

Brianne Dingmann declares that she has no conflict of interest.

Kaitlyn Brown declares that she has no conflict of interest.

Laura Hercher declares that she has no conflict of interest.

Caitlin Cooney declares that she has no conflict of interest.

Komal Bajaj declares that she has no conflict of interest.

Human studies and informed consent statement:

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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Appendix A:

IRB Approval Letter

SARAH · LAWRENCE · COLLEGE

INSTITUTIONAL REVIEW BOARD
1 Mead Way, Bronxville
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December 12, 2017

Brianne Dingmann, Kaitlyn Brown, and Lauren Facchini
Human Genetics Program
Sarah Lawrence College
1 Mead Way, Bronxville
NY 10708

Dear Brianne, Kaitlyn, and Lauren,

I have reviewed your proposal, "Nationwide accessibility of pregnancy termination: A comprehensive survey of genetic counselors and abortion providers throughout the United States," and approve it for expedited review because your planned research poses minimal risk to your participants. In making this determination, the IRB has followed the requirements of the Common Rule using expedited review procedures. This approval is limited to the activities described in your approved protocol narrative, and applies only to work in the settings specified in your protocol.

Sincerely,



Elizabeth Johnston, D.Phil.,
Co-chair, Sarah Lawrence IRB Review Board, SLC (FWA) #00009775

Appendix B:

Genetic Counselor Survey:

1. Is prenatal genetic counseling currently part of your role as a genetic counselor? (yes/no)

*If you have answered “no” to this question, your future responses will not be used in data collection. You may end the survey now.
2. What state do you practice in? (Dropdown options)
3. How many years have you been a practicing genetic counselor?
 - a. <2 years
 - b. 2-5 years
 - c. 5-10 years
 - d. 10-20 years
 - e. 20+ years
4. With which do you identify? (Male/Female/Other)
5. Which of the following best describes your primary work setting?
 - a. Public or community hospital
 - b. Academic medical center
 - c. Private hospital
 - d. Catholic hospital
 - e. Hospital with a religious affiliation other than Catholic (please specify)
 - f. Private practice
 - g. Industry
 - h. Other
6. If a patient chooses to terminate a pregnancy prior to the end of the first trimester (<12+6 weeks), where would you typically refer them?
 - a. services are available within my institution
 - b. other local hospital
 - c. local, free-standing abortion provider

- d. out of town provider <2 hours away
 - e. out of town provider 2-4 hours away
 - f. out of town provider >4 hours away
7. If a patient chooses to terminate a pregnancy prior to the end of the first trimester (<12+6 weeks), how quickly can this be arranged?
- a. 1-2 days
 - b. 3-4 days
 - c. 5-7 days
 - d. more than a week
8. If a patient chooses to terminate a pregnancy between 13-17+6 weeks, where would you typically refer them?
- a. services are available within my institution
 - b. other local hospital
 - c. local, free-standing abortion provider
 - d. out of town provider <2 hours away
 - e. out of town provider 2-4 hours away
 - f. out of town provider >4 hours away
9. If a patient chooses to terminate a pregnancy between 13-17+6 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 2-4 days
 - c. 5-7 days
 - d. more than a week
10. If a patient chooses to terminate a pregnancy between 18-19+6 weeks, where would you typically refer them?
- a. services are available within my institution
 - b. other local hospital

- c. local, free-standing abortion provider
 - d. out of town provider <2 hours away
 - e. out of town provider 2-4 hours away
 - f. out of town provider >4 hours away
11. If a patient chooses to terminate a pregnancy between 18-19+6 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 2-4 days
 - c. 5-7 days
 - d. more than a week
12. If a patient chooses to terminate a pregnancy between 20-23+6 weeks, where would you typically refer them?
- a. services are available within my institution
 - b. other local hospital
 - c. local, free-standing abortion provider
 - d. out of town provider <2 hours away
 - e. out of town provider 2-4 hours away
 - f. out of town provider >4 hours away
13. If a patient chooses to terminate a pregnancy between 20-23+6 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 2-4 days
 - c. 5-7 days
 - d. more than a week
14. If a patient chooses to terminate a pregnancy over 24 weeks, where would you typically refer them?
- a. services are available within my institution
 - b. other local hospital

- c. local, free-standing abortion provider
 - d. out of town provider <2 hours away
 - e. out of town provider 2-4 hours away
 - f. out of town provider >4 hours away
15. If a patient chooses to terminate a pregnancy over 24 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 2-4 days
 - c. 5-7 days
 - d. more than a week
16. How often is insurance coverage a factor in patient's choice of whether or not to terminate a pregnancy?
- a. Most of the time
 - b. Some of the time
 - c. Rarely
 - d. Never
17. How often are out of pocket costs a factor in patient's choice of whether or not to terminate a pregnancy?
- a. Most of the time
 - b. Some of the time
 - c. Rarely
 - d. Never
18. How often are wait times a factor in patient's choice of whether or not to terminate a pregnancy?
- a. Most of the time
 - b. Some of the time
 - c. Rarely
 - d. Never
19. How often is travel a factor in patient's choice of whether or not to terminate a pregnancy?
- a. Most of the time

- b. Some of the time
 - c. Rarely
 - d. Never
20. How often is availability of appointments a factor in patient's choice of whether or not to terminate a pregnancy?
- a. Most of the time
 - b. Some of the time
 - c. Rarely
 - d. Never
21. How have changes in abortion legislation in your state affected the way you counsel? (I.e. Non-directive, mandated medical misinformation).
22. What are your concerns regarding access of abortion for your patients?
23. In your experience, what are the major barriers your patients experience when seeking an abortion?

Abortion Provider Interview Questions:

1. What is your facility's gestational age limit for abortion?
2. Does your facility have exceptions to the gestational age limit in the case of genetic anomaly?
 - a. Yes (how late?)
 - b. No
3. If a patient exceeds your gestational age limit, how close is the nearest center you can refer out to?
 - a. Local, in town
 - b. Out of town <2 hours
 - c. 2-4 hours away
 - d. >4 hours away
4. If a patient chooses to terminate a pregnancy prior to the end of the first trimester (<12+6 weeks), how quickly can this be arranged?
 - a. 1-2 days

- b. 3-4 days
 - c. 5-7 days
 - d. more than a week
5. If a patient chooses to terminate a pregnancy between 13-17+6 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 3-4 days
 - c. 5-7 days
 - d. more than a week
6. If a patient chooses to terminate a pregnancy between 18-19+6 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 3-4 days
 - c. 5-7 days
 - d. more than a week
7. If a patient chooses to terminate a pregnancy between 20-23+6 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 3-4 days
 - c. 5-7 days
 - d. more than a week
8. If a patient chooses to terminate a pregnancy over 24 weeks, how quickly can this be arranged?
- a. 1-2 days
 - b. 3-4 days
 - c. 5-7 days
 - d. more than a week
9. How long is your state's mandatory waiting period?

- a. My state doesn't have a mandatory waiting period
- b. 24 hours
- c. 48 hours
- d. 72 hours
- e. >72 hours

10. What type of procedures do you offer, how many visits are required, and how much does each one cost on average? (Check all that apply and fill-in boxes)

- a. Medication
- b. D&C
- c. D&E
- d. Induction of labor

11. Do you accept Medicaid?

- a. Yes
- b. No

12. Do you accept insurance?

- a. Yes
- b. No

13. Do you offer financial assistance to patients?

- a. Yes
- b. No

14. On average, how far do patients travel to your clinic?

- a. Local, in town
- b. Out of town <2 hours
- c. 2-4 hours away
- d. >4 hours away

15. What services do you offer for patients undergoing a genetic abortion? (Check all that apply)

- a. Pictures

- b. Viewing of the fetus
- c. Cord banking
- d. POC testing
- e. Other: (fill in)

Appendix C:

Initial Email to Genetic Counselors through NSGC

Dear Genetic Counselor,

Our names are Lauren Facchini, Kaitlyn Brown, and Bri Dingmann, and we are second year genetic counseling students at Sarah Lawrence College. Our graduate thesis looks at the accessibility of pregnancy terminations, specifically for genetic counseling patients, given the recent legislative changes throughout the United States.

You are invited to participate in a research study evaluating the overall accessibility of pregnancy termination services for your patients.* This study involves completion of an anonymous survey that will take approximately 10 minutes of your time. This study is part of a capstone project and is open to all genetic counselors that practice prenatally.

Your responses are greatly appreciated so that we may accurately identify the overall accessibility of these services for our patients.

If you wish to participate in this study, please follow the link below. Consent will be indicated by clicking on a button after reading the consent script at the beginning of the survey.

<https://www.surveymonkey.com/r/GQY7WS5>

If you have questions or concerns, please contact any of us or our advisor, Laura Hercher.

lfacchini@gm.sl.c.edu

kbrown2@gm.sl.c.edu

bdingmann@gm.sl.c.edu

lhercher@aol.com

Thank you for your valued time and consideration,
Lauren Facchini, Kaitlyn Brown, and Bri Dingmann
Genetic Counseling Graduate Students
Sarah Lawrence College

*We recognize that you may have received survey requests to provide data on a similar topic and understand your time is valuable. In the spirit of collaboration, we have reached out to those working on similar projects to ensure our thesis will provide novel information. We urge you to consider participating in our data collection as we hope to be able to substantiate previous work and provide a baseline of quantitative data from both genetic counselors and abortion providers.

Reminder Email to Genetic Counselors through NSGC

Dear Genetic Counselor,

We need your help!

Our names are Lauren Facchini, Kaitlyn Brown, and Bri Dingmann, and we are second year genetic counseling students at Sarah Lawrence College. Our graduate thesis looks at the accessibility of pregnancy terminations, specifically for genetic counseling patients, given the recent legislative changes throughout the United States.

PLEASE NOTE: due to a Survey Monkey glitch, many of the people who attempted to take our survey after our initial email were unable to complete more than the first few questions. If you did not complete the survey you will be able to take it again now, and we hope that you will!

You are invited to participate in a research study evaluating the overall accessibility of pregnancy termination services for your patients.* This anonymous survey will take approximately 10 minutes of your time. This study is part of a capstone project and is open to all genetic counselors that practice prenatally.

Your responses are greatly appreciated so that we may accurately identify the overall accessibility of these services for our patients.

If you wish to participate in this study, please follow the link below. Consent will be indicated by clicking on a button after reading the consent script at the beginning of the survey.
<https://www.surveymonkey.com/r/GQY7WS5>

If you have questions or concerns, please contact any of us or our advisor, Laura Hercher.
lfacchini@gm.sl.c.edu
kbrown2@gm.sl.c.edu
bdingmann@gm.sl.c.edu
lhercher@aol.com

Appendix D:

Genetic Counselor Survey Consent

Accessibility of pregnancy termination - Genetic Counselors

Summary and Consent

Thank you for participating in our survey. Your feedback is important.

Increases in abortion legislation have led to a number of restrictions on providers and facilities across the nation. The goal of this study is to evaluate the impact of new legislation on the accessibility of pregnancy termination throughout the United States through surveying both prenatal genetic counselors and abortion providers in each state.

We invite all prenatal genetic counselors to participate in this anonymous survey about the logistics regarding accessibility of pregnancy termination services.

This survey will take approximately 10 minutes of your time. Participation is completely voluntary. Participants can discontinue the survey at any time or chose not to answer questions without justification. Participants will not be compensated.

All responses will be kept anonymous, confidential, and are not anticipated to compromise the privacy or safety of the participants. We recognize that certain states within the US may have a limited number of practicing prenatal genetic counselors. Therefore, it is our duty to warn that those counselors may be at an increased risk of identification despite anonymous data collection.

If there are questions or concerns, you may contact the researchers, Lauren Facchini (lfacchini@gm.sl.c.edu), Kaitlyn Brown (kbrown2@gm.sl.c.edu), and Bri Dingmann (bdingmann@gm.sl.c.edu), and/or the faculty advisor, Laura Hercher (lhercher@aol.com).

If you have questions about your rights as a research participant, please contact the IRB co-chairs Elizabeth Johnston (914)-323-6672 and Claire Davis (914)395-2605 or irb@sarahlawrence.edu.

By clicking next, you are consenting to participate in this research. We truly value and appreciate your time and knowledge!

10%

Next

Appendix E:

Abortion Provider Recruitment Script

Hello,

My name is _____ and I am a second year graduate student studying Genetic Counseling at Sarah Lawrence College. My colleagues, _____ and _____, and I are investigating patient accessibility in obtaining therapeutic abortions in the US for our thesis project.

We are reaching out to you and your facility because you have been identified as a trusted abortion provider and we would like to set up a time to speak with you further about the patient population and services offered at your facility. Our ultimate goal is to provide baseline metrics of accessibility through evaluating time, distance and cost surrounding pregnancy termination that can be measured throughout time to reflect the impact of continually changing legislation proposed across the United States.

The work you do is not only vital to genetic counseling patients but to the whole of women's health and we appreciate your participation in our research. Responses elicited in the phone call may be used in data collection that will be made available to the genetic counseling community, with the hopes of publication. We understand that your privacy and safety is of great concern and do not anticipate that the information provided by the phone call will compromise that privacy and safety. If there are specific concerns that would impact your willingness to speak with us about these issues, please let us know so that we may find a way to address those concerns.

We understand that your schedule is extremely busy and would like to schedule a time that is mutually convenient for a brief phone call. Please provide us with the appropriate contact's information (name, phone number, email address) and a time that works best.

Thank you for your time and the work that you do,

Kaitlyn Brown, Lauren Facchini, and Bri Dingmann

Program of Human Genetics

Sarah Lawrence College

Appendix F:

Consent Script for Abortion Provider Interview

Hello,

My name is _____ and I am a second-year graduate student studying Genetic Counseling at Sarah Lawrence College. My colleagues, _____ and _____, and I are investigating patient accessibility in obtaining therapeutic abortions in the US for our thesis project.

We are reaching out to you and your facility because you have been identified as a trusted abortion provider and we would like to speak with you about your patient populations' experience with obtaining services offered at your facility. Our ultimate goal is to provide baseline metrics of accessibility through evaluating time, distance and cost surrounding pregnancy termination that can be measured throughout time to reflect the impact of continually changing legislation proposed across the United States.

The work you do is not only vital to genetic counseling patients but to the whole of women's health and we appreciate your participation in our research. Responses elicited in the phone call may be used in data collection that will be made available to the genetic counseling community, with the hopes of publication. We understand that your privacy and safety is of great concern and do not anticipate that the information provided by the phone call will compromise that privacy and safety. If there are specific concerns that would impact your willingness to speak with us about these issues, please let us know so that we may find a way to address those concerns.

This phone interview will take approximately 10-15 minutes of your time, and you can choose to discontinue at any time. Your participation in this research is completely voluntary. Participants will not be compensated. If you have questions or concerns about this study after completion, you may reach me at this number/email:

_____. By continuing, you are confirming that you have consented to participate in this study.