Significance

In this review of patients presenting with lethal fetal anomalies, we found that there is a significant time lapse between referral and consultation between patients who choose to terminate and those who continue their pregnancies. Patients traveled an average of 50 miles one-way for care.

Introduction

As of May 2019, 33 states have passed laws restricting or limiting abortion services, including “trigger laws” that make abortion illegal in the event that Roe v. Wade is overturned. In addition, nine states have passed extreme abortion laws, including making abortion illegal as early as 6 weeks of gestation. In 2019, Missouri passed a law restricting
abortion after 8 weeks of gestation and criminalizing physicians for providing abortion care. This law is currently enjoined and therefore is not in effect. The early gestational age limit of the Missouri law and other states laws are problematic, in part, because major anatomic and genetic abnormalities cannot be diagnosed until later in pregnancy, effectively removing the option of termination of pregnancy in cases of severe or lethal fetal abnormalities. As the risk for abortion-related complications increases with gestational age, the addition of barriers that delay access to abortion have the potential to increase maternal risk. Over the last 10 years, technology has been developed to screen for genetic abnormalities, such as Trisomy 21 or Down Syndrome, as early as 10–11 weeks gestation, however, there is no way to diagnose fetal structural abnormalities at such early gestational ages. In states with gestational age bans that precede the gestational ages at which fetal abnormalities can be reliably diagnosed, patients with severe or lethal fetal anomalies often require referral to another state for abortion care, adding further barriers and delay in care.

Legislative restrictions have led to closure of all but one abortion clinic in Missouri, located in St. Louis, in the past decade. Currently, there is a single abortion clinic that provides induced abortions in the state of Missouri. Patients in Missouri experience barriers to access to abortion including: (i) a large rural population often requiring large distances to travel for access to care, (ii) a 72-hour mandatory waiting period between obtaining consent and performing the procedure often requiring two trips to the St. Louis area, and (iii) “same physician consent”, requiring that the same physician who consents the patient must be the one to perform the abortion, adding logistical and scheduling complexities often delaying the procedure beyond the minimum 72 h waiting period.

The Saint Louis region provides a unique opportunity to examine geographic barriers to abortion care because St. Louis is located directly at the border of two states: Missouri, with restrictive abortion legislation and the currently enjoined 8-week abortion ban and Illinois, with legislation protecting access to abortion. Thus, patients in Missouri often travel to neighboring states, including Illinois, to seek abortion care, which would likely increase if the currently enjoined law was enacted. The objective of this study was to compare distance to care and referral to evaluation time in patients with severe and lethal fetal anomalies continuing versus terminating their pregnancy among patients seen at the Washington University in St. Louis (WUSTL) Fetal Care Center (FCC). In addition, we aim to estimate the impact of the Missouri gestational age abortion ban on distance to termination care in this patient population.

Methods

This is a retrospective cohort study of patients seen at the WUSTL FCC with a severe or lethal fetal anomaly between July 1st, 2018 and June 30th, 2019. The primary outcome was distance and referral to evaluation to the WUSTL FCC between those who chose to continue their pregnancy and those who chose to terminate. Additionally, we performed geographic modeling travel distances based on three possible situations of abortion access in our region: (1) present situation with continued access to abortion services in the St. Louis area near the WUSTL FCC, (2) requirement to travel to an abortion clinic adjacent to St. Louis in Illinois (but still in the greater St. Louis region, approximately 18 miles from WUSTL FCC) that only provides surgical abortions (dilation and curettage, D&C, or dilation and evacuation, D&E) up to 24 weeks gestation, and lastly (3) requirement to travel to a full-spectrum abortion facility to viability (both surgical abortions and induction abortions) in Chicago, Illinois, approximately 300 miles from WUSTL FCC. The distinction between surgical and induction abortions is important given these diagnoses are at later gestational ages (beyond 18 weeks) and they are desired pregnancies, many patients desire to view the fetus which is not possible with surgical abortions. The secondary outcome was to determine the travel distance to abortion care in those patients who chose to terminate with severe and lethal anomalies. This study was approved by the Institutional Review Board at Washington University in St. Louis (WUSTL) prior to initiation (ID# 20,190,914).

The WUSTL FCC sees approximately 500 patients annually who have suspected fetal anomalies or genetic disorders. The WUSTL FCC provides multidisciplinary collaboration with Maternal Fetal Medicine (MFM), Newborn Medicine, Pediatric Subspecialists, Pediatric Palliative Care, Genetics, and Family Planning. The FCC patient database was utilized to identify eligible patients. Electronic medical records were reviewed to verify the fetal diagnosis in the database. Patients were included in this analysis if they had a diagnosis of a severe or lethal fetal anomaly defined as: hypoplastic heart syndrome, severe congenital diaphragmatic hernia (defined as a observed lung to head ratio (LHR) < 1, and/or liver present in the chest), osteogenesis imperfecta (type I, type IIA/IIB), thanatophoric dysplasia, achondrogenesis, other severe skeletal dysplasias (defined by femur-to-abdominal circumference ratio < 0.16 or chest circumference < 1 percentile), bilateral renal agenesis, Potter sequence, anencephaly or acrania, encephalole, lissencephaly, severe hydrocephalus (defined as lateral ventricles > 15 mm) or hydranencephaly, alobar holoprosencephaly, severe complex cardiac defect (as defined by the MFM or pediatric cardiologist) with the plan for comfort.
care at the time of delivery due to the severity of lesion, severe aneuploidies (such as Trisomy 13 (T13), Trisomy 18 (T18), or Turner’s Syndrome (45X) with cystic hygroma or hydrops) confirmed on invasive testing, and other rarer or multi-system anomalies (such as sironomelia, body stalk anomalies, multiple major anomalies, severe early-onset hydrops)\textsuperscript{13–15}. All diagnoses were the final diagnoses obtained from prenatal consultation at WUSTL FCC, which includes specialized fetal anatomic survey, genetic testing (non-invasive and invasive), genetic counseling, consultation with maternal fetal medicine specialists, and other ancillary imaging if indicated (MRI, fetal echo, etc.).

Once patients were identified, we extracted data regarding maternal demographic and medical comorbidities (maternal age at diagnosis, race, ethnicity, insurance status, obstetric history, medical co-morbidities including BMI, pre-existing diabetes/A1c, chronic hypertension), final diagnosis if postnatal evaluation completed, referral time frame (from outside provider to WUSTL FCC evaluation), and pregnancy outcome (termination or delivery and complications thereof) from the electronic medical record. For geographic analysis on referral distances and time to obtain care at WUSTL FCC, we obtained the following data: maternal home address at time of referral, location of referring provider, rural/urban status, gestational age at time of referral, gestational age at first FCC visit, number of prenatal visits at the FCC, and geographic distance required for travel from the patient’s home to the FCC (one-way). Delivery outcomes collected were gestational age at delivery or termination, type of labor (induction versus spontaneous), mode of delivery, and indication for cesarean section if performed. If pregnancy termination was not performed at our institution, this information was based on nurse phone follow up documented in the chart. Lastly, neonatal outcomes collected included whether a prenatal palliative consult was provided, birth weight, birth gender, Apgars (1, 5, 10 min), neonatal death after delivery, and if the neonate was discharged alive. Data collected was collected and managed in a secure, Research Electronic Data Capture (REDCap) tool hosted at WUSTL\textsuperscript{16, 17}.

Statistical analysis was conducted using STATA (College Station, TX) \textsuperscript{18}. Demographics, distance and referral timing were compared between patients who continued their pregnancy and those who underwent termination. In addition, distance to termination care was calculated for each patient who chose to terminate and estimated if the 8-week ban were to go into effect. The comparisons were performed utilizing Fisher’s exact, chi-squared, and Mann-Whitney Test as appropriate for categorical and continuous variables. No a priori sample size calculation was performed as we used a fixed sample size. Geocoding analysis, a process by which a physical address is translated into geographic coordinates on the Earth’s surface, was used to model the three geographic situations of abortion access availability (St. Louis proper, greater St. Louis region but located in Illinois, and Chicago). Geocoding and mapping was performed using Arcgis Desktop 10.6 (Redlands, CA, USA) \textsuperscript{19}. Patient residential locations were plotted, and then concentric 50-mile radii were overlayed to illustrate distance to each facility. Straight-line distances in miles from patient residence locations to each facility were calculated using the great circle formula\textsuperscript{20}.

### Results

From July 2018 to June 2019, 463 patients were seen in WUSTL FCC and 13% (60/463) were diagnosed with severe or lethal fetal anomalies comprising the study population for this analysis. Of these, 21 (35%) patients underwent an abortion and 39 (65%) patients continued the pregnancy to delivery. The most common severe or lethal fetal diagnosis was aneuploidy (31.7%), followed by severe neurological defects (25.0%) (Table 1). There were no significant differences in baseline characteristics between those who continued pregnancy versus those who underwent termination of pregnancy including race, insurance status, or rural/urban status (Table 2).

For our primary outcomes, patients who underwent pregnancy termination were referred to WUSTL FCC at a significantly earlier gestational age (median 19 weeks [IQR 17, 20 weeks]) compared to those who continued the pregnancy (20 weeks [IQR 18, 24 weeks]), \( p=0.04 \), Table 3. There was a statistically significant difference between the median latency time (days from referral to evaluation at WUSTL FCC) between patients who underwent an induced abortion and those who continued the pregnancy (8 days [IQR 4,13 days] v. 14 days [IQR 9, 22 days], \( p<0.01 \)). The average referral time for all-comers is 7 days typically. Distance of travel to WUSTL FCC was considered both dichotomously (less than or greater than 50 miles) and continuously and neither was statistically different in patients who underwent

| Table 1 | Fetal anomalies noted within the cohort |
|---|---|
| Anomaly | N | % |
| Severe cardiac defect | 11 | 18.3 |
| Congenital Diaphragmatic Hernia | 4 | 6.7 |
| Renal agenesis, urinary tract outlet obstruction | 7 | 11.7 |
| Major neurological anomaly* | 15 | 25.0 |
| Aneuploidy | 19 | 31.7 |
| Other* | 14 | 23.3 |

*anencephaly, acrania, holoprosencephaly, lissencephaly, encephalocele
+ body stalk anomalies, multiple major anomalies, hydrops, sirenomelia

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Table 2  Demographic data of the patient population

| Demographic                        | Termination, (n/%) | Continuation of pregnancy, (n/%) | p-value |
|------------------------------------|-------------------|---------------------------------|---------|
| Maternal age (mean, SD)            | 30, 6.3           | 27, 4.7                         | 0.71    |
| n = 21                             |                   | n = 39                          |         |
| Maternal Chronic hypertension      | 2 (10.5)          | 4 (11.1)                        | 1.0     |
| Maternal Pre-existing Diabetes     | 0                 | 2 (5.4)                         | 0.54    |
| Maternal Obesity (BMI > 30)        | 9 (42.9)          | 20 (52.6)                       | 0.60    |
| Non-Hispanic White                 | 16 (80)           | 24 (66.7)                       | 0.42    |
| Non-Hispanic Black with Latina     | 3 (15.0)          | 11 (30.6)                       |         |
| Latina                             | 1 (5.0)           | 1 (2.8)                         |         |
| Medicaid                           | 7 (35.0)          | 20 (54.1)                       | 0.23    |
| Commercial                         | 13 (65.0)         | 15 (40.5)                       |         |
| VA/Military                        | 0                 | 2 (5.4)                         |         |
| Nulliparity                        | 13 (61.9)         | 30 (79.0)                       | 0.22    |
| Urban status                       | 11 (55.0)         | 17 (47.2)                       | 0.16    |
| Suburban status                    | 16 (80)           | 30 (79.0)                       |         |
| Rural status                       | 0                 | 5 (13.9)                        |         |

Table 3  Distance and referral timing differences in patients who underwent pregnancy termination and those who delivered

| Termination (n = 21) | Delivery (n = 39) | P-value |
|----------------------|-------------------|---------|
| Gestational age at referral, weeks | 19 [17, 20] | 20 [18, 24] | 0.04 |
| Gestational age of first FCC visit, weeks | 20 [18, 21] | 24 [21, 27] | <0.01 |
| Latency between time of referral to time of evaluation at FCC, days | 8 [4, 13] | 14 [9, 22] | <0.01 |
| Distance to FCC from patient home, miles | 54.2 [18.8, 113.1] | 56.4 [9.4, 92.9] | 0.37 |
| Distance to FCC from patient home, miles, n(%) ≤ 50 miles | 9 (42.9) | 18 (46.2) | 0.8 |
| Distance to FCC from patient home, miles, n(%) < 50 miles | 12 (57.1) | 21 (53.9) | |
| Gestational age at outcome (termination, IUFD, delivery), weeks | 22 [21, 22] | 35 [33, 37] | <0.01 |
| Visits to FCC | 1 [1] | 2 [1, 3] | <0.01 |

The median gestational age when patients underwent an abortion was 22 weeks [IQR 21, 22 weeks], Table 3. Approximately half of the patient population underwent pregnancy termination at our academic hospital and the other half underwent pregnancy termination at an outside abortion clinic (49% versus 51% respectively). There was no difference in gestational age at time of pregnancy termination between sites (p = 0.29). Patients who underwent an abortion traveled a median of 118 miles [IQR 61, 211 miles] one-way to the abortion site. If the Missouri gestational age law were to go into effect, patients would be traveling a median distance of 292 miles [IQR 264, 342 miles], one-way in order to obtain an induction termination or any pregnancy termination at gestational age > 24 weeks (data not presented in a table).

The geocoding maps provide a visual depiction of the possible change in travel distance for these patients if they were to seek termination care at present and in the event the injunction of the 8-week ban were lifted. Geocoding analysis modeled three different travel distance situations for termination care: First, distance traveled from the patient’s home to WUSTL FCC near the St. Louis outpatient termination clinic (Fig. 1), distance traveled from the patient’s home to an abortion clinic in Illinois (still in the greater St. Louis region) which only provides surgical procedures such as dilation and evacuation (D&E) (Fig. 2), and distance traveled from the patient’s home to a medical center in Chicago that would provide full spectrum abortion care through later gestational age terminations, surgical procedures, and induction terminations (Fig. 3).
the gestational age limit is viability, or 24 weeks in most cases. Thus it is noteworthy that the median gestational age at which FCC evaluation occurred in patients who continued their pregnancy was often already beyond the gestational age at which termination of pregnancy is an option under current Missouri and Illinois laws. It is unknown what proportion of this group would have pursued pregnancy termination had this option been available to them. Nor is it clear what confers this difference, as the median scheduling time is 7 days from referral to evaluation. Prior studies suggest that there are high rate of support in both the general population and the Maternal-Fetal medicine community for termination for lethal anomalies. Despite this support, the Missouri legislation passed a law that would eliminate the option of abortion for severe and lethal anomalies. The fact that many patients were already seen beyond the current gestational age limit for Missouri may have contributed to why these patients chose to continue their pregnancy. It is possible that referring providers delayed referral to WUSTL FCC due to ongoing work-up in their own practice. Additionally, implicit biases and assumptions regarding patient willingness to pursue termination may have led to a lack of urgency for referral. While these reasons for delay in referral is unclear, this is an area for future research to determine how to best support and educate referring physicians in abortion restrictive states.

The distance of travel from the patient’s home to WUSTL FCC evaluation did not differ between those who chose to terminate versus continue a pregnancy. A median of 50 miles one-way travel was required for patients to have fetal evaluation and many patients traveled over 90 miles one-way for evaluation. However, if the Missouri gestational age ban were to go into effect, the median distance traveled by patients seeking terminations would increase by almost an additional 200 miles one way. Despite having the right to safe, legal abortion since Roe v. Wade in 1973, nearly 40 million patients in the United States of reproductive age live in states that are hostile to abortion rights today. The state of Missouri represents one of these access deserts. It is estimated that 17% of patients in the United States seeking abortions must travel more than 50 miles in order to obtain an abortion and 12% of patients in the Midwest traveled 50–100 miles to obtain abortion services. Our findings confirm this, as patients with severe or lethal anomalies traveled a median distance of >100 miles one way for their pregnancy termination. Given the current 72-hour mandatory waiting period in Missouri, patients may have significant travel requirements for counseling and consent prior to their procedure. Illinois has taken steps to protect abortion rights by signing the Reproductive Health Act into law declaring reproductive health care (abortion, contraception, sterilization, pregnancy, maternity care) a fundamental right.

**Discussion**

We identified 60 patients in a 1-year time span who were diagnosed with lethal or severe fetal anomalies in Missouri. Of these patients, more than a third pursued termination of pregnancy, the other two-thirds of patients continued the pregnancy. It is important to note that <1% of abortions in the US occur beyond 20 weeks gestation and the reasons for these abortions are typically due to anomalies, maternal life endangerment, or significant delay in access to care. The implications of the Missouri abortion ban for patients with severe and lethal anomalies are burdensome and in many cases, will lead to a complete lack of access to care. Patients who underwent pregnancy termination were seen significantly earlier at WUSTL FCC in pregnancy compared to patients who continued the pregnancy. Patients who had a longer latency between referral and confirmation of diagnosis at our referral center were more likely to continue pregnancy. However, distance to the WUSTL FCC did not confer a difference in continuation versus termination of pregnancy.

In Missouri, the current law prevents abortion services at gestational age beyond 22 weeks and in adjacent Illinois the gestational age limit is viability, or 24 weeks in most cases. Thus it is noteworthy that the median gestational age at which FCC evaluation occurred in patients who continued their pregnancy was often already beyond the gestational age at which termination of pregnancy is an option under current Missouri and Illinois laws. It is unknown what proportion of this group would have pursued pregnancy termination had this option been available to them. Nor is it clear what confers this difference, as the median scheduling time is 7 days from referral to evaluation. Prior studies suggest that there are high rate of support in both the general population and the Maternal-Fetal medicine community for termination for lethal anomalies. Despite this support, the Missouri legislation passed a law that would eliminate the option of abortion for severe and lethal anomalies. The fact that many patients were already seen beyond the current gestational age limit for Missouri may have contributed to why these patients chose to continue their pregnancy. It is possible that referring providers delayed referral to WUSTL FCC due to ongoing work-up in their own practice. Additionally, implicit biases and assumptions regarding patient willingness to pursue termination may have led to a lack of urgency for referral. While these reason for delay in referral is unclear, this is an area for future research to determine how to best support and educate referring physicians in abortion restrictive states.

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Fig. 3 Distance to Full Spectrum Abortion Clinic in Chicago - This map represents distances from patient homes to a university program in Chicago that provides full spectrum abortion care in Chicago, IL. Each black dot represents a patient location. The map is color coded by radius of distance from the primary location.
right, and prohibiting the state from interfering with reproductive health decisions. The geocoding maps illustrate this change in distance most starkly in Fig. 3 demonstrating distance to a center in Chicago where a patient could obtain full-spectrum abortion care, including surgical and induction terminations. Legislative efforts to restrict abortion do not increase safety and quality of the procedure, nor are these regulations founded on evidence to support their implementation.54. Rather, as demonstrated by our study, the restrictions create greater distances to travel and potential further delays in care.

The strengths of this study include analysis of a population with confirmed severe or lethal fetal anomalies who would be completely excluded from abortion care access by bans in the first trimester. Additionally, detailed geographic data and gestational age at evaluation allowed for a nuanced analysis of the burdens of obtaining abortion care for this population. The juxtaposition of Missouri and Illinois with their differing abortion legislation allowed an important geocoding analysis, which is likely generalizable to other states in the Midwest with adjacent states with differing abortion legislation. This study is not without limitations. First, the sample size of 60 patients limited statistical analyses to make robust conclusions on rare outcomes. Second, our cohort was not racially or ethnically diverse. The majority of patients in both groups were noted to be Non-Hispanic white. Lastly, our study focused on those with severe and lethal anomalies, which is a particularly unique and rare subset of patients seeking abortion and pregnancy care that would not be generalizable to the population as a whole. Additionally, we were unable to assess whether patients who continued their pregnancies would have sought pregnancy termination if they had been seen earlier. It is possible that the interval between referral and consultation was longer because patients expressed a strong interest in continuing the pregnancy with their primary obstetricians. These diagnoses are complex, and it is possible that the patients who continued their pregnancies had multiple ultrasounds at their primary obstetrician’s office prior to referral, which would have delayed their referral. Regardless, the interval from referral to consultation remains important to consider because the decision to pursue pregnancy termination may be altered by prognosis obtained at the time of formal fetal care consultation.

While abortion, specifically second-trimester abortion, is a safe medical procedure, with a <1% complication rate, increasing gestational age does increase the risk of the procedure.5, 24. While the current Missouri law is temporarily enjoined by court order and not in effect, the legislation threatens to put undue burden on patients seeking abortion needing to travel significant distances and eliminates the option of pregnancy termination for lethal fetal anomalies and genetic disorders, which cannot be diagnosed until well after 8 weeks of gestation. Recent trends in gestational age at time of surgical abortion for fetal aneuploidy suggest that median age (12-14wks) has decreased over recent years due to earlier diagnosis.6, 7, 30. However, timing of abortion has not changed for patients undergoing surgical abortion for structural abnormalities at 20 weeks or more.7. In summary, this analysis demonstrates that patients with severe or lethal fetal anomalies are often evaluated at later gestational ages, which may preclude their access to abortion services. Additionally, the patients in Missouri travel significant distances both for access to quaternary care for complex fetal anomalies, as well as, for access to abortion services. If the currently enjoined law is enacted the legislation would eliminate the option of termination of pregnancy for patients with severe or lethal fetal anomalies and increase the burden of travel twofold. Improvements in access to care for this patient population would include legislation that protects pregnancy termination in situations where diagnosis cannot be made until later in pregnancy and efforts to improve ease of evaluation by maternal, fetal, and pediatric subspecialists.

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Declarations

Conflict of Interest The other authors do not have any potential conflicts of interest to report.

Ethics This study was approved by the Institutional Review Board at Washington University in St. Louis (WUSTL) prior to initiation (ID# 20,190,914).

Previous presentations This data was presented in a Scientific Forum at the Annual Society for Maternal Fetal Medicine Meeting in January 2021, that was held virtually due to the COVID-19 pandemic.

Consent to Participate Given the retrospective nature of this chart review, consent was not deemed necessary by the Institutional Review Board at WUSTL.

Consent to Publish All authors consent to publication of the data and results presented in this manuscript. All authors contributed significantly to data collection, analysis, and manuscript preparation.

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