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Late termination of pregnancy for lethal fetal anomalies: a national survey of maternal–fetal medicine specialists☆,☆☆,★,★★

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Abstract

Objective: The objective was to ascertain the practices and opinions of US maternal–fetal medicine specialists regarding termination of pregnancy as a management option following late diagnosis of lethal fetal anomalies.

Study design: We conducted a cross-sectional mail survey of all US members of the Society of Maternal Fetal Medicine to ascertain how they manage pregnancies diagnosed with lethal fetal anomalies after 24 weeks of gestation. We analyzed the proportion of respondents that discuss termination of pregnancy as a management option, barriers to offering or accessing late termination services, and respondents' opinions about what anomalies are lethal and when pregnancy termination should be permitted.

Results: The response rate was 41% (869/2119). Nearly all (93%) respondents discuss delivery near term or when complications arise, while 75% discuss the option of termination of pregnancy soon after the diagnosis of lethal fetal anomalies. Only 52% of the physicians indicated that their patients could obtain termination of pregnancy after 24 weeks at their affiliated medical centers or through providers within 50 miles. Real or perceived legal restrictions represented the most common reason for lack of local services. The proportion of respondents that felt strongly or very strongly that termination of pregnancy should be allowed was 76% for lethal anomalies and 58% for anomalies likely to result in significant long-term impairment.

Conclusion: Although limited by a modest response rate, our study found that physicians do not consistently discuss immediate termination of pregnancy as an option following late diagnosis of lethal fetal anomalies, and they face numerous barriers to providing these services.

Implications: This national survey supports the need for improved services for pregnant women who desire later termination of pregnancy following diagnosis of serious fetal anomalies. Helpful efforts might include educating physicians about the laws and regulations governing late termination of pregnancy, forging more consistent standards of care, and improving collaboration between MFM specialists and family planning providers to enhance access to care.

Keywords: Fetal anomalies; Abortion; Termination of pregnancy; Pregnancy complications; Society of Maternal Fetal Medicine

1. Introduction

Major congenital anomalies occur in approximately 3% of live births in the United States and represent the leading cause of infant mortality [1]. Although fetal chromosomal abnormalities are amenable to early detection through modern prenatal testing, structural malformations and certain genetic conditions often are diagnosed later in pregnancy [2–5].

Studies worldwide indicate that a sizable proportion of women with pregnancies affected by serious fetal anomalies choose to terminate, with rates varying by the type and

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severity of the disorder [6–16]. In a large US single-institution study, 77% of pregnant women diagnosed with lethal fetal anomalies before 24 weeks elected termination [9]. Data indicate that, even in the late second or third trimester, a majority of women would elect to interrupt pregnancies affected by severe or lethal fetal anomalies [7,10,17].

Offering the option of late termination of pregnancy (TOP) to women whose fetuses have lethal anomalies accords with sound ethical principles [18,19] and federal law. Although states vary in their regulation of later abortion care, the US Supreme Court repeatedly has reaffirmed the Constitution's core protection: while a state may, if it chooses, ban TOP where the fetus is viable (as long as the ban includes exceptions to protect the woman's life and health), a state cannot ban TOP where the fetus is not viable [20,21]. Under the Constitution, viability is the point at which the fetus has a reasonable likelihood of sustained survival with or without artificial support, as determined in each case by the physician's medical judgment; a state cannot define viability in terms of a specific number of weeks of gestation [22]. Therefore, the federal Constitution explicitly guarantees a woman and her doctor the right to decide to end a pregnancy, without regard to gestational age, if the fetus has a lethal anomaly. In violation of this constitutional standard, some states ban TOP after a certain number of weeks. Absent a court challenge resulting in an order blocking enforcement, those laws are in effect.

Maternal–fetal medicine specialists provide care for women with complicated pregnancies, yet little is known about their attitudes and practices regarding TOP as a management option following late diagnosis of lethal fetal anomalies. We surveyed all US members of the Society of Maternal Fetal Medicine (SMFM) to ascertain their current practices and to identify barriers that they may face in providing late TOP services or referrals for patients.

2. Materials and methods

In 2011, we conducted an anonymous cross-sectional mail survey of all US members of the SMFM. We identified the cohort through the society's membership list, which provided members' names and postal addresses; SMFM did not permit disclosure of email addresses. We mailed a paper survey to each US member with a cover letter asking the recipient to return the completed survey in a self-addressed stamped envelope. Four weeks later, we remailed the survey to the entire cohort with instructions to complete the questionnaire only if the recipient had not responded to the initial mailing. We did not offer incentives because they would have compromised the anonymity of the survey. The Institutional Review Board of the Mount Sinai School of Medicine designated the survey as exempt from human protection regulations.

The research team developed the survey by consensus and piloted it among eight MFM specialists. Consisting of 19 questions, the survey addressed demographics, clinical practices, institutional policies, and opinions and attitudes regarding TOP for lethal fetal anomalies. We asked about the management options that the physicians or their staff discuss with women who present with lethal fetal anomalies after 24 weeks (including TOP soon after the diagnosis, delivery near term or when spontaneous labor ensues or if maternal compromise arises). We inquired about the availability of late TOP services at the physicians' affiliated medical centers or through referral and barriers to access.

To explore opinions about the lethality of specific fetal conditions, we asked the specialists to indicate whether they considered each of the following fetal anomalies to be lethal: anencephaly, renal agenesis, trisomy 18, trisomy 13, severe hydrocephalus and polycystic kidneys. Although no universally accepted definition or "set" of lethal anomalies exists, all of these conditions have been cited in lists of lethal malformations in the literature [23]. Attitudes about management of lethal fetal anomalies were assessed by asking the specialists to rank their agreement with six statements using a 5-point Likert scale (1=strongly agree, 5=strongly disagree).

Physicians indicating that their medical centers did not offer late TOP services for lethal anomalies were asked to cite the reasons why from a close-ended list of responses, one of which stated that "…state law prohibits TOP at or after 24 weeks LMP." To determine the proportion of physicians incorrectly citing state prohibitions as a reason, a legal consultant performed an analysis of state laws governing late TOP at the time of the survey.

Our primary outcome was the proportion of MFM specialists that discussed TOP as a management option for women with lethal fetal anomalies diagnosed after 24 weeks of gestation. We hypothesized that the physicians would be less likely to discuss TOP than delivery near term or when spontaneous labor or complications ensue. Secondary outcomes included barriers to offering or accessing late TOP services and the physicians' opinions about what anomalies are lethal and when TOP should be permitted.

A two-sample χ^2 test (and a two-sample Wilcoxon rank sum test) was used to compare distributions of categorical (and continuous) demographic variables of our survey respondents with those of SMFM members. The latter data were obtained from two sources: the results of a 2008 SMFM membership survey published in the medical literature [24] (for age, gender and type of practice) and 2013 data on practice location obtained directly from the SMFM. We used univariable and multivariable (adjusting for physician age; gender; location of MFM training; location of practice; years in MFM practice and agreeing with the opinion statement, "Termination of a pregnancy affected by a lethal anomaly should be allowed under all circumstances") log-binomial regression models to estimate prevalence ratios (PRs) and corresponding 95% confidence intervals (CIs) comparing the