

ORIGINAL ARTICLE

Late termination of pregnancy for lethal fetal anomalies: a national survey of abortion providers training and experience

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ABSTRACT

Introduction: Profound fetal anomalies are sometimes diagnosed in the late second and third trimester among women in the United States leading them to seek termination services. Guidelines and protocols to inform management are lacking in the scientific literature.

Methods: A national survey of United States Fellowship in Family Planning graduates and faculty was conducted in 2014 to assess their self-identified fund of knowledge and training regarding provision of late second and third trimester terminations. Information regarding demographics, patient encounters, and education were analyzed for trends and associations.

Results: The response rate was 46%; 245 persons were queried with 112 responses. The majority of respondents learned about or wanted to learn about late termination during their training. Twenty nine percent of respondents reported a good knowledge foundation regarding the technical aspects and protocols of third trimester terminations, and 19% provide this service. Among physicians who provide the service: they were more likely to have met a woman who was unable to access a third trimester termination, expressed a desire to learn and engaged in patient care during Fellowship, trained on the West Coast, and identified as a faculty member at a Fellowship in Family Planning programs ($p < 0.01$).

Discussion: Among nationally surveyed abortion providers and educators, the majority of respondents endorsed some exposure to late termination. However, knowledge, access, and experience with procedures were regionally limited. Patient care experience during training is associated with ongoing provision of third trimester procedures. Expanded patient care opportunities during training may enable better dissemination of safe practices, increased access, and standardization of care.

KEYWORDS

Abortion, fetal demise, lethal anomaly, dilation and evacuation, termination, third trimester, late term induction, medical abortion

INTRODUCTION

Birth defects are the leading cause of infant mortality in the United States, followed by prematurity (Mathews & MacDorman, 2012). Anencephaly, renal agenesis, Trisomy 13 and 18 occur in approximately one of four-to-eight thousand births (Parker et al., 2010). However, pregnancy outcomes and prevalence data are limited due to variable and inconsistent state reporting. Improvements in antenatal testing technology and fidelity have resulted in more information becoming available to pregnant women. However, due to delays in access or referral many women will not receive definitive diagnostic testing for anomalies until the late second or third trimester. Women with anomalous pregnancies request termination at a range of gestational ages (Hern, 2014).

Third trimester termination is sought out in unique situations (Bosma, van der Wal, & Hosman-Benjaminse, 1997; Marret et al., 1999; Vial, Boithias, Audibert, Frydman, & Dehan, 2002), and is considered ethically justified in the context of lethal fetal anomaly (Chervenak, Farley, Walters, Hobbins, & Mahoney, 1984; Chervenak & McCullough, 1990, 1996). Due to stigma, inflammatory perceptions or political restrictions, information regarding management and referral for third trimester termination in the United States is not widely available (Grimes & Stuart, 2010; Kandel & Merrick, 2003; Strong, 2003). Concordantly, the practices and procedures involved are not published as nationally recognized evidence based guidelines or protocols (Borgatta & Kapp, 2011; Hern, Zen, Ferguson, Hart, & Haseman, 1993; Perritt, Burke, & Edelman, 2013). The peer review literature on the subject is limited to international case series and reports, or extrapolation of second trimester abortion practices (Bosma et al., 1997; Chervenak et al., 1984; Chervenak & McCullough, 1990, 1996; Grimes & Stuart, 2010; Hern, 2014; Marret et al., 1999; Parker et al., 2010; Vial et al., 2002). In the absence of specific guidelines, several institutions apply protocols intended for labor induction of a viable fetus to the management of profound fetal anomalies or fetal demise. The diagnosis, counseling, management or referral of patients in need of a third trimester termination can be challenging and warrants further investigation and guidance (Garel & Kaminski, 2002).

Provision of these services may be limited by provider scope of knowledge, ethics, and preferences (Savulescu, 2001; Steinauer & Sufrin, 2014; Strong, 2003). Furthermore, it is unknown how many United States physicians participate in the care of women who need a third trimester termination. The aim of this pilot survey was to assess if members of the Fellowship in Family Planning community express a good fund of knowledge regarding third trimester termination or report providing this service.

METHODOLOGY

Study design: A cross-sectional national survey of Fellowship in Family Planning graduates, faculty, and affiliates was conducted in 2014 to assess self-defined fund of knowledge regarding provision of third trimester termination. Information collected included: provision of third trimester termination, abortion education and training, Fellowship training, academic affiliation, and scope of practice. Survey participants were asked if their program or standard patient practice utilized or drew upon expert opinion and evidence-based guidelines, potentially from other aspects of obstetrics and abortion care, such as the management of fetal demise. Participants who were able to identify protocols and practices that were based in existing labor and abortion guidelines were considered to have a good fund of knowledge about third trimester abortion, and self-reported a good fund of knowledge. Respondents also described their desire to learn about and how they learned about third trimester termination, their ability to refer, and management practices (pharmacologic or technical). Albert Einstein College of Medicine Institutional Review Board approval was obtained. A sample of convenience without any *a priori* power analysis was utilized.

Study population: The Fellowship in Family Planning (Fellowship) is a postdoctoral training program that hones skills in the provision of contraceptive technologies and abortion (Landy & Darney, 2011; Steinauer, Dehlendorf, Grumbach, Landy, & Darney, 2012). Knowledge of and experience with third trimester termination are not part of the requirements for graduation (Landy & Darney, 2011). However, graduates and

faculty of the Fellowship are recognized as experts in abortion care and are often identified as collaborative subspecialists by other women's health providers and their patients. For this reason, a survey of their practices and fund of knowledge was a unique opportunity to characterize the practices and perception of United States abortion leaders, educators, and providers regarding an extremely challenging and ethically charged practice: third trimester termination. Participants were recruited via a voluntary email listserv that the Fellowship administration maintains to connect graduates, faculty and affiliates in the United States and Canada.

Study procedures & methods: Invitations to complete the survey were individually, electronically distributed to all members of Fellowship email listserv. Non-responders were sent a second survey invitation 4 months later. Research Electronic Database Capture (REDCap) was used to administer questions and compile data in an online portal. Identifying information was removed, data points were checked for accuracy and validity, responses were coded, and output was analyzed using Stata, 12.1 statistical software (StataCorp, College Station, Texas). Among participants who identified as providing third trimester terminations or who possessed a good fund of knowledge trends and associations were analyzed using two-sided Chi-square, Fisher's exact and Mann-Whitney tests. Associations were considered statistically significant for tests resulting in a p value less than 0.05 or a confidence interval that did not include one. Descriptive statistics were also compiled.

RESULTS

245 persons were queried with 112 responses, a response rate of 46%. Twenty nine percent reported a good knowledge foundation regarding the technical aspects and protocols for third trimester terminations, and 19% provide this service. The majority of participants were female (92%, 103/112) physicians (100%, 112/112) who currently provide abortion care (98%, 110/112) and graduated from a Fellowship in Family Planning (96%, 108/112) (Table 1). Participants learned about abortion during residency (84%, 94/112), direct mentorship (71%, 79/112), workshops (15%, 17/112), Fellowship (22%, 25/112), medical school (4%, 5/112) and were self-taught (2/112). Participants graduated from 24 different Fellowship programs, with 29% (30/103) attending programs on the West Coast and 44% (45/103) attending programs on the East Coast (Table 2). The median birth year was 1977 and the majority of participants were born after 1973 (69%, 76/110), the year of the United States Supreme Court *Roe v Wade* decision. The median year of enrollment in Fellowship was 2010.

Most respondents identified as academic faculty at teaching hospitals (88%, 99/112), and 53% (59/112) of respondents work in settings without a Fellowship in Family Planning program. Thirty participants work at a private clinic, 12 engage in contract work, and one respondent is employed by a non-governmental organization.

The majority of respondents have encountered a woman seeking a third trimester termination (71%, 80/112), felt confident that they could immediately refer a woman (61%, 68/112), and have encountered a woman who was unable to access a third trimester termination (63%, 71/112).

Among participants who attended a Fellowship, 64% (69/108) expressed a desire to learn about third trimester terminations, citing lecture (80%, 86/108), discussion (73%, 79/108) and patient care (68%, 73/108) as appropriate learning modalities. Forty six percent (49/107) formally learned about third trimester termination during Fellowship, through lectures and conference workshops (Table 3). The most common means by which participants learned about third trimester terminations was discussion with peers (35%, 39/112) or providing patient care (31%, 35/112). Twenty nine percent (31/108) reported a good knowledge foundation regarding the technical aspects and protocols of third trimester terminations, and 19% (21/109) provide this service. Respondents who reported a good fund of knowledge or who reported providing third trimester terminations were more likely to have learned about third trimester termination and participated in patient care during Fellowship when compared to persons who not provide care ($p < 0.01$). Additionally, persons who provided third trimester terminations were more likely to have encountered a woman who was unable to access a third trimester termination in the past ($p < 0.01$), graduated from a West Coast Fellowship program ($p < 0.01$),

consider direct patient care as the appropriate means for fellows to learn about third trimester termination ($p < 0.01$), and currently work as academic faculty on the West Coast ($p < 0.01$). Gender ($p = 0.27$), year of birth ($p = 0.17$), year of Fellowship enrollment ($p = 0.37$) and discussion with peers about third trimester abortions ($p = 0.2$) were not correlated with a good fund of knowledge or the provision of third trimester terminations among respondents.

Among physicians who provide third trimester terminations a gestational limit of 26 weeks was identified by 1 respondent. Others did not identify a gestational limit. Respondents who reported a good fund of knowledge versus those who identify as providing third trimester terminations were more likely to have met a woman who was seeking a third trimester termination ($p = 0.09$ vs. < 0.01), expressed a desire to learn about this during Fellowship ($p = 0.07$ vs. < 0.01), and identify as academic faculty ($p = 0.5$ vs. 0.12) at a Fellowship program ($p = 0.31$ vs. < 0.01).

DISCUSSION

Termination of pregnancy in the third trimester is executed in a limited number of clinical settings and scenarios. Third trimester abortion is an exceptionally rare procedure, likely accessed by a few hundred women each year in the United States. However, the majority of obstetrician gynecologists will care for a woman diagnosed with a profound fetal anomaly in the third trimester. It was expected that a minority of abortion providers would identify a good understanding and fund of knowledge about the protocols and technical aspects involved with third trimester termination care. However, among Fellowship in Family Planning graduates and affiliates almost a third of the sample endorsed a good knowledge foundation and a fifth identified as providing this service. Demographics and education experience suggest that knowledge, access and experience with third trimester procedures is regionally concentrated on the West Coast. Direct patient care experience while training demonstrated a compelling association with providing ongoing third trimester termination services.

A survey of Society of Maternal Fetal Medicine (MFM) members noted that the majority of respondents believe termination of pregnancy should be allowed for profound anomalies, yet only 75% discuss this option with patients at the time of diagnosis and only half would be able to refer patient for this care (Jacobs et al., 2015). A survey of current MFM fellows noted that the majority of fellows expressed a desire to learn about termination services during their training and the majority of Fellowship directors incorporated training opportunities in dilation and evacuation (Rosenstein, Turk, Caughey, Steinauer, & Kerns, 2014). Expanded patient care opportunities during training may enable better dissemination of safe practices, increased access, and standardization of care.

The findings of our survey suggest that some of the needs for effective communication, referral and education are being met through peer discussions. It was interesting to find that this scope of knowledge and skills are prevalent among recent graduates of the Fellowship in Family Planning across the country. Additionally, the majority of participants felt confident that they could refer a woman for care and stated that they had learned something about third trimester termination in the past. It is compelling that a majority of respondents who identify as providing third trimester terminations are also academic faculty. There is the potential that more trainees will be involved in the care, which may in turn facilitate increased awareness, knowledge and access.

A limitation of this pilot investigation was the response rate. The sample may not be representative of the national abortion provider fund of knowledge due to sampling methodology, whereby voluntary members of the Fellowship listserv were contacted and were under no obligation to respond. It may be that other physicians in United States, such as Maternal Fetal Medicine doctors, surgeons, family medicine physicians, or general obstetrician/gynecologists, provide this care for compelling reasons but they were not captured by this survey. There was no compensation or incentive offered for participation in the survey. Participants who have an interest in the topic or provide this care may have been more likely to respond, which would have resulted in

an overestimate of the samples' experience with third trimester termination. Participants may have an inaccurate perception of their fund of knowledge and respondents may define third trimester termination differently. If all non-responders are considered as lacking a good fund of knowledge then those who affirm a good fund of knowledge is closer to 13% (31/246). Similarly, the number of participants who provide third trimester termination, when non-responders are considered to omit this scope of practice, would be approximately 9% (21/246).

Respondents were asked to describe the procedures or pharmacologic interventions involved with this care however no information was submitted. There are no current protocols and a dearth of materials that detail these practices in the peer reviewed literature. More information is needed on the utilization of medications such as mifepristone, cervical preparation, and intra-operative techniques that may reduce complications and improve outcomes among women receiving a third trimester termination. These techniques may expedite evacuation of the uterus, reducing risk of infection, hemorrhage, time spent in a high acuity labor and delivery setting, and potentially avoiding the need for hysterotomy and other surgical morbidities.

The need for protocols and best practices with regard to management of profound fetal anomalies and intrauterine fetal demise in the third trimester represents a significant gap in knowledge related to the care of the complex obstetric patient. This survey notes some knowledge gaps are being filled by informal learning and peer to peer sharing, but knowledge and skills are still lagging even amongst abortion subspecialists and providers who are exposed to some formal training. Potential interventions for addressing these gaps have been suggested and increasing research focused on the care of women with late diagnoses of profound fetal anomalies is strongly recommended.

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Table 1: Characteristics of survey participants

	Female	Male	Total responses
Gender	103	9	112
	Yes	No	
Currently provide abortions	110	2	112
Current academic faculty	99	13	112
Current Family Planning Fellowship faculty	53	59	112
Born < 1973 (Roe v Wade)	34	76	110
Fellowship graduate	108	4	112
Began Fellowship > 2010	50	56	106
Employed in the United States	108	4	112

Table 2: Geographic training and current practice among participants

	West Coast	East Coast	Other	
Fellowship training	30	45	28	103
Current faculty practice	32	45	28	108
Family Planning Fellowship faculty*	20	20	6	46

*Among physicians who provide third trimester termination care they were more likely to have Fellowship training on the West Coast, and identified as a current faculty member at a Family Planning Fellowship program ($p < 0.01$).

Table 3: Exposure to third trimester termination among Family Planning Fellowship Graduates

	Yes	No	
Encountered a woman seeking*	80	32	112
Encountered a woman unable to access	71	41	112
Can refer	68	44	112
Interest in learning*	69	37	108
Learned in Fellowship	49	58	107
Patient care in Fellowship	35	77	112
Good technical knowledge	31	77	108
Currently provides care*	21	88	109

*Among physicians who provide: they were more likely to have met a woman seeking a third trimester termination, expressed a desire to learn, and identified as a faculty at a Family Planning Fellowship program, when compared to physician who reported a good fund of knowledge ($p < 0.01$).