

OBSTETRICS

Prenatally diagnosed fetal conditions in the age of fetal care: does who counsels matter?

Stephen D. Brown, MD; Jeffrey L. Ecker, MD; Johanna R. M. Ward, MSc; Elkan F. Halpern, PhD; Sadath A. Sayeed, MD, JD; Terry L. Buchmiller, MD; Christine Mitchell, RN, MS, MTS; Karen Donelan, EdM, ScD

OBJECTIVE: We sought to characterize practices and attitudes of maternal-fetal medicine (MFM) and fetal care pediatric (FCP) specialists regarding fetal abnormalities.

STUDY DESIGN: This was a self-administered survey of 434 MFMs and FCPs (response rate: MFM 60.9%; FCP 54.2%).

RESULTS: For Down syndrome (DS), congenital diaphragmatic hernia (CDH), spina bifida: MFMs were more likely than FCPs to support termination (DS 52% vs 35%, $P < .001$; CDH 49% vs 36%, $P < .001$; spina bifida 54% vs 35%, $P < .001$), and consider offering termination options as highly important (DS 90% vs 70%, $P < .001$; CDH 88% vs

69%, $P < .001$; spina bifida 88% vs 70%, $P < .001$). For DS only, MFMs were less likely than FCPs to think that pediatric specialist consultation should be offered *prior* to a decision regarding termination (54% vs 75%, $P < .001$). MFMs reported higher termination rates among patients only for DS (DS 51% vs 21%, $P < .001$).

CONCLUSION: MFM and FCP specialists' counseling attitudes differ for fetal abnormalities.

Key words: congenital abnormalities, fetal, physician attitudes, pregnancy management, prenatal diagnosis

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The clinical management of women with pregnancies complicated by congenital fetal conditions in the United States has become increasingly multidisciplinary. Traditionally, obstetricians or maternal-fetal medicine (MFM) specialists have managed these pregnancies in affiliation with general hospitals or women's and

★ EDITORS' CHOICE ★

infants' hospitals. Now, other models of prenatal care have emerged nationally within "fetal care" or "fetal treatment" centers in children's hospitals and/or under the leadership of pediatric specialists, with or without MFM collaboration.^{1,2}

These changes in clinical practice environments raise issues of whether pregnant patients will receive different information or clinical options depending on their locus of care. Differences have been demonstrated in attitudes and counseling among prenatal health care providers from different disciplines, including pe-

From the Departments of Radiology (Dr Brown) and Surgery (Dr Buchmiller); the Division of Newborn Medicine, Department of Medicine (Dr Sayeed); the Advanced Fetal Care Center (Dr Buchmiller); and the Office of Ethics (Ms Mitchell), Children's Hospital Boston; the Maternal-Fetal Medicine Division, Department of Obstetrics and Gynecology, (Dr Ecker), Mongan Institute for Health Policy (Dr Donelan), and the Institute for Technology Assessment (Dr Halpern), Massachusetts General Hospital; the Department of Health Policy and Management, Harvard School of Public Health (Ms Ward); and the Division of Medical Ethics, Department of Global Health and Social Medicine, Harvard Medical School (Dr Sayeed and Ms Mitchell), Boston, MA. Additional contributors are listed in the Acknowledgments.

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Reprints: Stephen D. Brown, MD, Department of Radiology, Children's Hospital Boston, 300 Longwood Ave., Boston, MA 02115. Stephen.brown@childrens.harvard.edu.

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diatric and obstetric specialists outside the United States.³⁻⁸ However, no analysis has yet characterized the practices of these new fetal care pediatric (FCP) centers, or assessed how their provision of prenatal health care differs from that of MFM practices.

The purpose of this study was to characterize the practices of FCP and MFM specialists in the United States, and to determine whether these specialists' counseling attitudes and clinical recommendations differ when fetal abnormalities are diagnosed. We explored these questions using a survey completed in 2010 of pediatric and MFM specialists working within fetal care and fetal treatment centers in the United States, and their surrounding geographic regions. This analysis characterizes physician practice, and compares experiences and perspectives about prenatal counseling when congenital fetal conditions are diagnosed.

MATERIALS AND METHODS

The research team designed the survey with fieldwork conducted through self-administered mail survey and telephone reminders by Harris Interactive during the period Nov. 13, 2009, through Feb. 5, 2010. The study protocol, and instrument and recruitment materials were approved by the Children's Hospital Boston Clinical Investigation Committee.

Sample and list development

We used the American Medical Association (AMA) Masterfile to select a national sample of MFM specialists drawn in proportion to their representation in the same states in which we identified fetal care centers. We identified 454 MFM specialists (designated as either primary or secondary specialty) in 21 states (matched to fetal care center distribution by last 3 ZIP code digits). The masterfile did not indicate whether MFM specialists practiced in fetal care centers—this information was collected in our survey.

No available source (including the AMA Masterfile) provided a comprehensive listing of physicians practicing in pediatric specialties in fetal care or fetal treatment centers. Therefore, we developed a comprehensive listing using a 2-stage process.

First, we identified all fetal care, fetal therapy, and fetal treatment centers from national listings of related research centers, professional organizations, and children's hospitals, and Internet searches using the terms "fetal care," "fetal treatment," "fetal therapy," and "fetal surgery."⁹⁻¹¹ We searched those centers' institutional websites and physician directories to identify pediatric subspecialists who provided fetal diagnostic or treatment services in the centers. Centers were variably composed. Specialties included urology, nephrology, cardiology, neurology, neurosurgery, genetics, orthopedics, surgery, radiology/imaging, anesthesiology, neonatology, and perinatology. We confirmed contact information through Internet searches and telephone calls to the centers, and verified physician contact information with the AMA Masterfile. The resultant file included 416 FCPs in 21 states: Arizona, California, Connecticut, Florida, Illinois, Kansas, Maryland, Massachusetts, Michigan, Minnesota, Missouri, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Washington, and Wisconsin.

Survey instrument development

We developed the instrument using existing literature on professionals' knowledge, attitudes, and self-reported behaviors toward disabilities, intrauterine interventions, conscientious objection, prenatal diagnosis, and pregnancy termination.^{3,4,7,8,12-20} We conducted key informant telephone interviews with 8 MFM and FCP specialists in different regions nationally to assess relevant survey domains. Items assessing attitudes about pregnancy termination for congenital fetal conditions were adapted from health care provider surveys about prenatal diagnosis and termination for various conditions.^{3,4,6-8,20} Hypothetical scenarios about intrauterine interventions were generalized from an MFM survey about maternal-fetal surgery.¹⁷ Questions regarding the provision of information about prenatally diagnosed conditions were based on scenarios and scales from a survey of health care trainees' attitudes toward disabilities.¹⁸ A draft of the instrument was reviewed by a panel of external experts in survey research, physician professionalism, bioethics, obstetrics, and pediatric developmental medicine. A final draft questionnaire was pretested with 10 physi-

cians from the target eligible group to assess comprehension, completion time, and recruitment methods, and was also subject to internal timing and quality checks by Harris Interactive. The final survey instrument was 8 pages long, and included 49 questions incorporating 106 items. Self-administration time in pretests was approximately 20 minutes.

Data collection

Questionnaire packets were mailed in November 2009 using US Postal Service priority mail to 870 physicians. Initial packets contained the questionnaire, a cover letter explaining the survey, a postage-paid return envelope, and a \$70 honorarium. Two additional postal contacts were made, with follow-up calls to persistent nonresponders to determine eligibility and encourage response.

Response rates were calculated by dividing the number of completed surveys returned by the total mailed items less individuals who reported they no longer practiced, were not in practice relevant to the survey, or for whom a correct address—and therefore, study eligibility—could not be determined.

Statistical analysis

MFM specialist data were weighted by state (limited to select ZIP codes matching the FCP physician ZIP codes), age, and sex relative to the US population of physicians with a secondary or primary specialty of MFM.

Data analyses were completed using SPSS version 18 (SPSS Inc, Chicago, IL). Bivariate analyses to assess response differences between MFMs and FCPs were conducted using χ^2 tests for categorical variables and *t* tests for continuous variables. All statistical tests were 2-sided. We used multivariate logistic regression to determine if MFM/FCP differences persisted for our key dependent variables (pregnancy termination rates; appropriate timing of pediatric specialty referrals; and provision of information about pregnancy termination) when controlling for physician personal and professional characteristics, including sex, age, personal or family history of disability, race/ethnicity, gross income, support for pregnancy termination, academic medical center affiliation,

fetal care treatment center affiliation and management, ownership of employment, onsite availability of first- or second-trimester termination, and number of patients with each provided diagnosis. Standard measures of religion, religiosity, political party, and political ideology were included in the survey, but the size of the sampled groups limited our ability to include these variables in regression models. This limitation seemed less important when, as discussed below, we did not detect differences between groups for these measures.

RESULTS

Physician and practice characteristics

In all, 242 MFM and 192 FCP specialists completed the survey, yielding response rates of 60.9% and 54.2%, respectively. Table 1 shows physician characteristics. Compared to MFMs, FCPs were younger, more likely male, and more likely to work within nonprofit and/or academic centers.

MFM and FCP respondents did not differ significantly regarding political affiliation (MFM: 36% Democrat, 19% Republican, 31% independent vs 44%, 15%, 27%, respectively, for FCPs), religious affiliation (MFM: 22% Roman Catholic, 19% Jewish, 31% other Christian vs 26%, 18%, and 25%, respectively, for FCP), religiosity (strength of religious influence in daily work life; MFM 42% very/somewhat strong vs FCP 39%), or political ideology (MFM: 42% liberal, 21% conservative vs 45% and 21%, respectively, for FCPs). As differences between MFM and FCP groups were not seen for these variables and given that sample size limited the number of variables we could use for modeling, these variables were not included in our regression equations. We focused our analysis on the personal and professional characteristics shown in Tables 1 and 2.

Table 2 shows several aspects of respondents' clinical activities. In all, 90% of FCPs and 50% of MFMs reported fetal care or treatment center affiliation. Among respondents with a fetal care center affiliation, FCPs were significantly

more likely than MFMs to practice in a center primarily managed by a pediatric surgeon. MFMs were more likely to practice in a center primarily managed by an MFM specialist. Among physicians with a fetal care center affiliation, FCPs were significantly more likely to practice within a children's hospital, while MFMs were more likely to practice in a general hospital/medical center.

Virtually all MFMs surveyed provide counseling personally to women about pregnancies with suspected or confirmed fetal abnormalities. In all, 90% of FCPs either provide their own counseling and/or practice in centers where colleagues provide counseling. Among FCP respondents, 5% said they neither provide nor refer patients for these services, but they do provide patient care in these centers.

Significantly more MFMs practice in sites where first- and second-trimester pregnancy termination is available. Of MFM respondents, 20% provide these services to patients, whereas 1% of FCPs reported they perform terminations (not shown). In all, 45% of FCPs, compared to 4% of MFMs, reported that they neither provide nor refer patients for pregnancy termination (data not shown).

Table 2 also shows maternal-fetal interventions available on site. Specialists differ significantly for all but percutaneous image-guided intrauterine fetal procedures.

Table 3 reports bivariate results regarding respondents' clinical experiences and professional attitudes in treating pregnant patients in the setting of fetal Down syndrome (DS), congenital diaphragmatic hernia (CDH), and spina bifida. A greater proportion of MFMs see patients for each condition. Among physicians who do see these patients, the average number of patients in a typical year is similar between FCPs and MFMs for DS and spina bifida, but FCPs see more CDH cases.

Respondents were asked to estimate the pregnancy termination rates among their patients for each aforementioned fetal diagnosis. In bivariate analyses, MFMs reported a >2 times higher pregnancy termination rate among patients carrying a fetus with DS and significantly

higher rates for CDH and spina bifida. The MFM:FCP odds ratio for higher rates of termination for DS was 2.670, (95% confidence interval, 1.183–6.023; $P = .02$). Despite our samples' sex difference, sex was not significant in predicting pregnancy termination rates for DS (male:female odds ratio, 0.622; 95% confidence interval, 0.302–1.284; $P = .2$). Specialty was not a significant predictor of higher termination rates in multivariate models for CDH and spina bifida.

Professional attitudes

As shown in Table 3, respondents were asked how strongly they would support or oppose—in their role as a health professional providing consultation to a married couple—a couple's decision to terminate a 19-week pregnancy with diagnosed fetal DS, CDH, or spina bifida. MFMs were more likely than FCPs to somewhat or strongly support a decision to terminate the pregnancy for all 3 conditions. This question served as an independent variable for our multivariate models.

We asked about respondents' attitudes regarding the appropriateness and timing of patient consultations by pediatric specialists with relevant expertise for each fetal condition (Table 3). FCPs were significantly more likely than MFMs to report that pediatric-specialist consultation with the pregnant woman should take place *prior* to the decision to continue or terminate a pregnancy with DS. This finding persisted in regression analysis (not shown).

Respondents were asked their attitudes about the importance (1 = low importance, 5 = high importance) of offering certain information when a married couple seeks guidance on whether to continue a pregnancy in the setting of DS, CDH, and spina bifida. Although >90% of MFMs and FCPs responded that offering information on the clinical characteristics of the conditions is of high importance (data not shown), MFMs were significantly more likely than FCPs to respond for each condition that offering options for pregnancy ter-

TABLE 1
Physician characteristics

Characteristics	FCP (%), n = 192	MFM (%), n = 242	P value	MFM in fetal care center (%), n = 124	MFM not in fetal care center (%), n = 113	P value
Sex^a						
Male	65	55		57	55	
Female	31	43	.02	43	44	.83
No answer	5	2		0	2	
Age, y^a						
Mean	49.8	52.0	.02	53.2	51.0	.10
Median	49	53		54.0	52.0	
Ethnicity/race^b						
White, non-Hispanic/Latino	73	74		73	79	
Black, non-Hispanic/Latino	2	3		3	3	
Hispanic/Latino (white or black)	3	3		1	4	
Asian or Pacific Islander	14	8	.14	8	9	.03
Other	2	5		9	1	
Refused	3	5		5	3	
No answer	4	2		2	1	
Gross annual income						
<\$100,000	3	5		7	3	
\$100,000-199,999	17	11		13	9	
\$200,000-299,999	26	25		25	27	
\$300,000-399,999	16	23	.14	26	21	.29
\$400,000-499,999	18	15		14	16	
≥\$500,000	11	13		10	16	
No answer	9	9		4	10	
Employment^{a,b}						
Self-employed	0	10	< .001	4	16	.004
Employed by physician practice	25	29	.39	24	35	.07
Employed by hospital	46	32	.002	36	30	.36
Employed by contract corporation	9	6	.14	9	3	.03
Other	18	24	.17	29	18	.04
Ownership of employment^{a,b}						
For profit	8	23	< .001	22	26	.45
Not for profit	81	60	< .001	68	53	.04
Religious order or organization	8	5	.29	7	4	.47
Physician owners	1	14	< .001	8	21	.004
Work setting/AMC affiliation^{a,b}						
Hospital, within AMC	75	46	< .001	55	40	.02
Hospital, affiliated with AMC	11	14	.59	12	17	.19

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(continued)

TABLE 1
Physician characteristics (continued)

Characteristics	FCP (%), n = 192	MFM (%), n = 242	P value	MFM in fetal care center (%), n = 124	MFM not in fetal care center (%), n = 113	P value
Hospital, not affiliated with AMC	1	7	.004	5	8	.27
Ambulatory, within AMC	4	8	.12	9	8	.35
Ambulatory, affiliated with AMC	3	5	.29	6	5	.37
Ambulatory, not affiliated with AMC	2	12	< .001	7	17	.02
Other	3	8	.03	9	8	.35
Type of practice ^{a,b}						
Solo	0	8		7	9	
Single specialty group with <10 doctors	24	34		20	50	
Single specialty group with ≥10 doctors	28	19	< .001	31	7	< .001
Multispecialty group with <10 doctors	1	4		2	5	
Multispecialty group with ≥10 doctors	43	33		29	29	
No answer	5	2		0	0	
Specialty						
Surgical	23	—	—	—	—	—
Pediatric	52					
Other	8					
No answer	17					
Disability						
Yes	1	3		97	96	
No	95	96	.13	3	4	.44
No answer	4	1		0	0	
Family member with disability						
Yes	27	25		27	25	
No	68	74	.57	73	75	.74
No answer	5	1		0	0	

Missing answers are excluded from analysis. Proportions may not total 100 due to rounding and multiple response. AMC, academic medical center; FCP, fetal care pediatric; MFM, maternal-fetal medicine.

^a Significant difference ($P < .05$) between FCP and MFM specialists (using χ^2 tests for categorical and t tests for continuous variables); ^b Significant difference ($P < .05$) between MFMs affiliated and not affiliated with fetal care centers.

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mination at different stages of pregnancy is of high importance (Table 3). Logistic regression models (not shown) confirm that these differences persist between MFMs and FCPs for all 3 conditions.

We also assessed attitudes about intrauterine fetal interventions by asking physicians to respond to clinical vignettes in which a couple has decided to continue their pregnancy (Table 4). The vignettes involve a 19-week fetus with a nonlethal condition that will likely need ≥1 major postnatal surgeries. The ex-

pected outcome with postnatal surgery is severe intellectual and/or physical disability. Respondents were asked to review 2 hypothetical prenatal procedures to treat the condition and provide recommendations. One was an open intrauterine procedure with obstetrical and perinatal risks commonly associated with intrauterine spina bifida repair.¹⁷ The second was a minimally invasive procedure with uncommon risks. For each procedure, there were 2 possible postnatal expected outcomes: high prob-

ability of moderate or mild disability. FCPs and MFMs did not differ regarding the likelihood of making recommendations for or against either procedure, regardless of expected outcome.

COMMENT

This study characterized the practices of FCP specialists and MFM specialists and evaluated whether their counseling and recommendations differed for fetal abnormalities. We found significant differ-

TABLE 2
Clinical activities at place of work

Activities	FCP (%), n = 192	MFm (%), n = 242	P value	MFm in fetal care center (%), n = 124	MFm not in fetal care center (%), n = 113	P value
Affiliation with fetal care or treatment center ^a						
No	6	48		0		
Yes	90	50	< .001	100	N/A	N/A
No answer	4	2		0		
Center managed mainly by . . . (fetal care affiliates only)						
Pediatricians	17	16	.71	16		
Pediatric surgical specialists ^a	45	14	< .001	14		
MFm specialists ^a	62	82	< .001	82		
Other	9	8	.60	8		
Location (fetal care affiliates only)						
General hospital/medical center ^a	37	58	.001	58		
Women's/women and infants' hospital	21	22	.75	23		
Children's hospital ^a	48	18	< .001	18		
Free-standing clinic or outpatient facility ^a	1	8	.005	8		
Multisite	6	8	.41	8		
Counseling provided about pregnancies where fetus has suspected or confirmed abnormality						
On site ^a	90	99	< .001	99	100	.33
Off site	5	7	.03	8	7	.86
Neither provide nor refer ^a	5	0	< .001	0	0	N/A
Interventions available on site						
Pregnancy termination, 1st trimester ^a	30	51	< .001	52	50	.56
Pregnancy termination, ≥2nd trimester ^a	27	53	< .001	54	52	.33
Percutaneous fetal blood transfusions ^{a,b}	47	70	< .001	79	62	.009
Percutaneous image-guided (nonlaparoscopic) intrauterine fetal procedures other than blood transfusions ^b	54	51	.12	63	40	.001
Laparoscopic intrauterine fetal surgery ^{a,b}	45	16	< .001	26	6	< .001
Open uterine fetal surgery ^{a,b}	36	6	< .001	11	1	.001
Cesarean section for fetal or maternal benefit ^a	60	89	< .001	93	85	.08
Delivery by EXIT ^{a,b}	66	48	< .001	61	37	.001

Missing answers are excluded from analysis. Proportions may not total 100 due to rounding and multiple response.

EXIT, ex utero intrapartum treatment; FCP, fetal care pediatric; MFm, maternal-fetal medicine; N/A, not applicable.

^a Significant difference ($P < .05$) between FCP and MFm specialists (using χ^2 tests for categorical and t tests for continuous variables); ^b Significant difference ($P < .05$) between MFms affiliated and not affiliated with fetal care centers.

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ences between MFms and FCPs in their clinical practices and many of their prenatal counseling attitudes. For each congenital condition studied, FCPs and MFms differed significantly regarding their support for pregnancy termination, and the importance they ascribed to provision of information about termina-

tion. However, MFms and FCPs differed only for DS in their attitudes regarding whether FCP consultation should be offered before patients decide about pregnancy termination, and only for DS in their reported termination rates among their patients. FCPs and MFms did not make different recommendations re-

garding intrauterine interventions. Further, they did not report different proportions of patients who choose prenatal interventions for CDH or spina bifida.

Published data are scant regarding practices within pediatric-based fetal care centers, and how obstetric and pediatric pro-

TABLE 3

Clinical experiences and professional attitudes regarding fetal conditions

Variable	Down syndrome			CDH			Spina bifida		
	FCP (%), n = 192	MFM (%), n = 242	P value	FCP (%), n = 192	MFM (%), n = 242	P value	FCP (%), n = 192	MFM (%), n = 242	P value
See patients pregnant with fetus with diagnosis in given year ^{a-c}									
Yes	67	93		64	88		60	92	
No	24	2	< .001	25	7	< .001	28	3	< .001
No answer	9	5		11	5		12	5	
Mean no. of patients with fetus with diagnosis in typical year of practice (of those who see patients with diagnosis) ^b	9.61	11.49	.10	9.56	5.43	.001	7.46	6.59	.31
Patient outcomes (mean percentage of patients/y) ^{a-c}									
Terminate pregnancy	21	51	< .001 ^d	17	28	< .001	29	42	< .001
Have intrauterine fetal treatment (other than termination)	1.14	.63	.511	11.77	11.43	.916	8.01	6.48	.458
Pediatric consult for pregnant women should take place. . . ^a									
Prior to decision to terminate	76	54		82	80		82	77	
Only if pregnancy continues	10	17		9	12		8	15	
Only after delivery	4	6	< .001 ^d	1	0	.55	1	1	.13
No consult necessary	2	16		0	1		0	1	
No answer	8	7		8	7		8	7	
Importance of providing information for options for pregnancy termination at different stages of pregnancy ^{a-c}									
More important (4-5 on 5-point scale)	70	90	< .001 ^d	69	88	< .001 ^d	70	88	< .001 ^d
Less important (≤3 on 5-point scale)	23	8		23	9		23	9	
No answer	7	2		8	2		7	2	
Support of patient decision to terminate pregnancy (in role as health professional) ^{a-c}									
Support	35	52		36	49		35	54	
Neutral	46	43	< .001	39	46	< .001	38	42	< .001
Oppose	10	2		12	3		12	3	
No answer	9	3		13	2		14	2	

Missing answers are excluded from analysis. Proportions may not total 100 due to rounding. CDH, congenital diaphragmatic hernia; FCP, fetal care pediatric; MFM, maternal-fetal medicine.

^a Significant difference ($P < .05$) between FCP and MFM specialists for Down syndrome (using χ^2 tests for categorical and t tests for continuous variables); ^b Significant difference ($P < .05$) between FCP and MFM specialists for CDH (using χ^2 tests for categorical and t tests for continuous variables); ^c Significant difference ($P < .05$) between FCP and MFM specialists for spina bifida (using χ^2 tests for categorical and t tests for continuous variables); ^d Variables that remained significant in multivariate modeling as described in text. Multivariate analyses are not presented in this table. Termination rates, timing of pediatric consultation, and provision of information about termination were key outcome variables in multivariate modeling. Numbers of patients seen and patients/y, and support for patient decision were independent variables.

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viders' attitudes and recommendations may differ regarding fetal conditions.^{1,3,4,6} In an age when both open intrauterine surgery and pregnancy termination are options when certain fetal conditions are di-

agnosed, empirical analysis of the scope and impact of any provider differences is crucial. To our knowledge, this is the first study to compare the prenatal clinical practices and attitudes of FCP and MFM

specialists. Prenatal diagnosis and intervention continue to evolve rapidly, and these data provide an important baseline about practice organization and clinical practice.

TABLE 4
Intervention scenarios

Would or would not recommend procedure 1 in given scenario, %	Definitely would recommend, %	Probably would recommend, %	Probably would not recommend, %	Definitely would not recommend, %	No answer, %	<i>P</i> value
Neonate has high probability of moderate intellectual and/or physical disability						
FCP	12	27	45	8	8	.77
MFM	9	30	45	8	9	
Neonate has high probability of mild intellectual and/or physical disability						
FCP	13	45	30	5	7	.89
MFM	11	49	28	5	6	
Would or would not recommend procedure 2 in given scenario, %						
Neonate has high probability of moderate intellectual and/or physical disability						
FCP	22	37	32	3	6	.69
MFM	24	33	32	5	7	
Neonate has high probability of mild intellectual and/or physical disability						
FCP	32	51	11	1	5	.72
MFM	27	53	13	1	6	

Scenario given: Assume you are meeting a couple (married, both age 26 y). Woman is pregnant with 19-week fetus with nonlethal condition that will likely need ≥ 1 major postnatal surgeries. Condition commonly results in severe intellectual and/or physical disability. Couple has decided to continue pregnancy. Please review following hypothetical procedures and outcomes and provide your likely recommendations. Assuming this procedure is available and mortality for fetus or neonate is low, how strongly would you recommend this procedure in setting of outcomes noted?

Procedure 1: Prenatal open intrauterine surgical procedure has been developed to repair condition. Common surgery related obstetrical risks include: oligohydramnios, premature rupture of membranes, preterm uterine contractions, premature delivery, and pulmonary edema. After procedure, patients are typically hospitalized for 1-2 wk until delivery. Less common complications include uterine rupture, placental abruption, maternal small bowel obstruction, maternal blood transfusion, pregnancy loss, and need for cesarean sections for future pregnancies.

Procedure 2: Prenatal, minimally invasive procedure has been developed to repair condition. Procedure-related obstetrical risks include uncommon (approximately 3%) risks of intrauterine infection, maternal septicemia, and pregnancy loss.

Proportions may not total 100 due to rounding.

FCP, fetal care pediatric; MFM, maternal-fetal medicine.

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Our study has some limitations. First, our FCP listing, while current at the time of the survey, may have excluded some physicians in this evolving field. Our slightly lower FCP response rate may have resulted from imprecision in identifying the relevant physicians. Our sample sizes limited our multivariate analyses, especially regarding geography, heterogeneous FCP composition, and the complexities of physicians' personal, religious, and political attitudes. Still, many of the FCP/MFM differences, especially for DS, persisted in our regression models. Selection and response biases are concerns in surveys such as ours. To address such possible biases, we used weighting to correct for nonresponse

bias by specialty group and geography. Survey length can also affect responses, although the 20-minute administration time was relatively standard for such questionnaires. We recognize that self-reports of physician practice and attitudes may not reflect actual practice. In addition, many questions we used regarding clinical care, while carefully developed and tested, contained language that could be interpreted differently by different providers. We asked, for example, about support for patient choices, yet while the word "support" was undefined, its use is common in scales of physician attitudes. We have no reason to believe FCPs and MFMs would interpret the language differently. Because we did

not include a question about abortion apart from the context of fetal abnormalities, we cannot separate attitudes regarding these conditions from beliefs about abortion, per se. It is possible that attitudes and practices reported by MFMs in the 21 states sampled here may not represent those of MFMs in states without fetal care centers. Finally, because our study did not examine screening, but rather, referral once a prenatal diagnosis was made, we could not address any differences between specialties with regard to screening for congenital conditions.

A few studies performed outside the United States have specifically compared obstetric and pediatric clinical special-

ists' attitudes regarding congenital fetal conditions.^{3,4,6} Unlike these studies, the present survey of exclusively US practitioners confirmed that most respondents cared for women with these pregnancies, and it controlled for important differences in personal demographic and practice characteristics. Further, we compared obstetric and pediatric practitioners' attitudes in an era when many more major pediatric centers house prenatal diagnosis and treatment services, and we compared practitioners' attitudes specifically regarding emerging intrauterine interventions.

Numerous authors posit that differences in attitudes and counseling among prenatal health care providers may relate to divergent personal values, professional interests, clinical experiences, interpretation of the "facts" of the clinical situation, approaches to dealing with medical uncertainty, and different experiences with evolving tools for prenatal diagnosis and therapy.^{3-6,14,21-26} Some note that, due to the circumstances of their respective practices, pediatric and obstetric specialists may hold divergent views of their obligations to pregnant women and fetuses, adopt different attitudes in weighing maternal risk for fetal benefit, hold contrasting perceptions of life with disabilities, or possess differing concerns for the physical, psychological, and social well-being of pregnant women.^{1,4,5,21,23,26}

The different degree to which FCPs and MFMs would support a patient's decision for pregnancy termination for all 3 congenital conditions aligns with these general hypotheses. The higher importance that MFMs attribute to provision of information about termination also comports with hypotheses about potentially divergent ethical and clinical sensitivities between obstetric and pediatric-based specialists. At issue is whether such differences affect patient decisions in light of long-standing concerns regarding providers' influence over obstetrical and neonatal outcomes in general,^{5,25,27-39} and, more specifically, over patients' decisions regarding pregnancy termination for fetal abnormalities.³

Our data suggest that, for spina bifida and CDH, strong differences in clinical practices and in provider attitudes about

abortion are not necessarily associated with differences in patient outcome, or in specific recommendations about important aspects of management, such as the timing of prenatal consultation with a pediatric specialist or the appropriateness of intrauterine interventions. These results are consistent with recent findings by Harris et al⁴⁰ that many obstetricians remain willing to help patients receive services that the physicians find personally morally objectionable. Our data would imply that many pediatric-based fetal care specialists may be similarly disposed.

We cannot explain why, after multivariate analysis, our reported termination rates differed between specialties for DS. The role of provider differences in practice and attitudes around DS cannot be excluded. Disability rights advocates have long asserted that obstetricians embed their counseling with negative or poorly informed messages about DS and skew their counseling toward termination.⁴¹⁻⁴⁵ Similar claims about spina bifida, however, are not supported by our results.^{46,47} Alternately, FCPs' counseling could underemphasize the challenges of DS, although pediatric specialists themselves may hold stereotypical misunderstandings about perceived quality of life for children with chronic health conditions.⁴⁸⁻⁵⁰ Many pediatric subspecialists who provide prenatal counseling may not perceive it as their role to discuss termination, but it is unclear why this would disproportionately affect DS counseling. However, given our finding that a considerable percentage of FCPs neither provide nor refer patients for pregnancy termination, nor think that offering information about termination is of high importance, the question remains of whether patients who obtain FCP counseling are receiving all information germane to their decision.

Patient preferences may also have contributed to the reported outcome differences for DS. Patients who obtain FCP counseling for DS may be fundamentally less inclined toward pregnancy termination. We know of no empirical data regarding a priori preferences about pregnancy termination among patients who do and do not seek or receive referrals for FCP counseling. Anecdotal reports sug-

gest that many patients who seek counseling for spina bifida in some FCP centers are determined to continue their pregnancies.⁴⁷ Our data belie any association with termination rates for spina bifida. Additionally, patients and providers alike may view predominantly surgical and nonsurgical conditions differently. Attitudes and understanding may differ for conditions or disabilities perceived as predominantly physical rather than intellectual. Regardless, our study provides compelling data to warrant further research regarding providers' influence over patients' decisions about pregnancy termination for DS and other congenital conditions. Further analyses must assess whether specialists' provision of information prenatally is concordant with outcomes and quality of life.^{51,52}

The different termination rates for DS demonstrated here could also be influenced by patient referral patterns and the logistics of caring for pregnant women. Typically, fetal conditions are diagnosed initially by obstetricians, and often by MFMs. Patients who are immediately certain regarding termination might not then opt for a pediatrics referral. Diagnosis and referral does not characteristically occur in the opposite direction (ie, from pediatric specialist to MFM). Further research is needed to ascertain how often pregnant patients with various diagnoses self-refer to fetal care centers, are referred by their primary obstetrics providers, or are referred by an MFM whom they have seen first, and how such paths affect pregnancy outcomes.

Finally, despite similar responses between physician groups regarding intrauterine interventions, intragroup data suggest that physician recommendations will remain highly variable regarding such procedures. Despite recently demonstrated benefits to intrauterine surgery,⁵³ our data suggest that establishing efficacy for intrauterine procedures will not necessarily create uniformity in the related prenatal counseling recommendations, or agreement about how benefits and risks should be weighed. Further research is critical to understand how counseling balances information and

recommendations about intrauterine interventions.

Overall, our results suggest that prenatal counseling about congenital fetal conditions varies considerably between and within MFM and pediatric-based fetal care practices in the United States. Significant differences in attitudes and practices exist around pregnancy termination and the general counseling process. For some fetal conditions, such as spina bifida and CDH, our study suggests that such provider differences may not matter for pregnancy outcomes. For other conditions, such as DS, however, our study supports concerns that prenatal decisions and outcomes may sometimes reflect provider attitudes. Outcome differences may be confounded by patient self-selection and natural referral patterns. Further elucidation of these professional and patient-related factors is essential as a new structure for counseling prospective parents evolves toward increasing involvement of pediatric-based specialists and centers. ■

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