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Pediatricians' Knowledge, Training, and Experience in the Care of Children With Fetal Alcohol Syndrome

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ABSTRACT

OBJECTIVES. Prenatal exposure to alcohol interferes with fetal development and is the leading preventable cause of birth defects and developmental disabilities. The purpose of this study was to identify current knowledge, diagnosis, prevention, and intervention practices related to fetal alcohol syndrome and related conditions by members of the American Academy of Pediatrics.

METHODS. This study was developed collaboratively by the American Academy of Pediatrics and the Centers for Disease Control and Prevention. Questionnaires were mailed to a 3% random sample ($n = 1600$) of American Academy of Pediatrics members in the United States. General pediatricians, pediatric subspecialists, and pediatric residents were included.

RESULTS. Participation rate was 55% ($n = 879$). Respondents almost universally knew the teratology and clinical presentation of fetal alcohol spectrum disorders. However, they were less likely to report comfort with routine pediatric care of these children. Whereas 62% felt prepared to identify and 50% felt prepared to diagnose, only 34% felt prepared to manage and coordinate the treatment of children with fetal alcohol spectrum disorders. Even fewer ($n = 114$ [13%]) reported that they routinely counsel adolescent patients about the risks of drinking and pregnancy.

CONCLUSIONS. The survey confirms that pediatricians are knowledgeable about fetal alcohol syndrome but do not feel adequately trained to integrate the management of this diagnosis or prevention efforts into everyday practice. Furthermore, the respondents were not active in routine anticipatory guidance with adolescents for prevention of alcohol-affected pregnancies. The development, dissemination, and implementation of best practice tools for prevention, diagnosis, and referral of fetal

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Key Words

fetal alcohol syndrome, developmental disabilities, medical home, alcohol

Abbreviations

FAS—fetal alcohol syndrome
 CDC—Centers for Disease Control and Prevention
 IOM—Institute of Medicine
 AAP—American Academy of Pediatrics
 FASD—fetal alcohol spectrum disorders
 ARND—alcohol-related neurodevelopmental disorder
 ARBD—alcohol-related birth defects

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alcohol syndrome that are specific for general and sub-specialist pediatricians are recommended.

INTRAUTERINE EXPOSURE TO alcohol interferes with fetal development and is the leading preventable cause of birth defects and developmental disabilities.¹⁻³ Fetal alcohol syndrome (FAS) first was described in the United States in 1973.^{4,5} Individuals with FAS have 3 hallmark characteristics: central nervous system dysfunction, facial dysmorphism, and growth deficiency.⁶⁻¹⁰ Prenatal alcohol exposure has been associated with cardiac, skeletal, renal, brain, ocular, and auditory anomalies.^{4,5,11} In the past 30 years, it has become clear that the constellation of sequelae represents a spectrum of disorders that range from very mild to very severe.¹²

Despite solid basic science elucidating the pathophysiology of FAS and efforts to raise public awareness of potential fetal damage, ~13% of pregnant US women drink alcohol.^{2,3,13-15} Furthermore, drinking alcohol and sexual activity commonly co-occur during adolescence.¹⁶ The Centers for Disease Control and Prevention (CDC) estimates that FAS is present in 1 per 1000 live births in the United States.¹⁷⁻²⁰ This is equivalent to the incidence of trisomy 21 and 4 times as common as congenital hypothyroidism.^{21,22} Identification of FAS may be more challenging than identifying other congenital conditions because the diagnosis rests on history of maternal drinking, physical examination characteristics, and behavioral symptoms, without any confirmatory laboratory test.²³

There has been extensive work and debate toward the establishment of diagnostic criteria.^{6-8,24-27} The 1996 report by the Institute of Medicine (IOM; published by the National Academy of Sciences; Table 1),⁶ the 2000 American Academy of Pediatrics (AAP) statement,⁷ the 2004 guidelines for diagnosis and referral published by the CDC,²⁴ and the University of Washington diagnostic criteria⁸ all are valuable resources, but lack of uniform terminology increases the challenge for clinicians. To address difficulties in the practical application of existing diagnostic guidelines, Hoyme et al²⁷ proposed and studied revisions to the 1996 IOM diagnostic criteria in 1500 children. The CDC's "Guidelines for Identifying and Referring Persons With Fetal Alcohol Syndrome" adds criteria for documentation of structural, neurologic, and functional central nervous system abnormalities.²⁸

TABLE 1 IOM Diagnostic Categories

FAS
FAS with maternal alcohol exposure
FAS without confirmed maternal alcohol exposure
Partial FAS with confirmed maternal alcohol exposure
Alcohol-related effects
ARBD
ARND

Child health professionals do not always consider prenatal alcohol exposure in the differential diagnosis of behavioral and learning problems.²⁹⁻³⁴ Some clinicians are reluctant to screen for FAS because of time constraints, fear of litigation, lack of available treatment, or fear of stigmatization for mothers and affected children.^{25,35} Even behavioral experts may not consider prenatal alcohol exposure when assessing developmental problems. For example, FAS is not mentioned in the attention-deficit/hyperactivity disorder toolkit developed by the AAP and the National Initiative for Child Health Quality.³⁶ Similarly, FAS was not included in the curriculum for the Developmental/Behavioral Pediatrics Review and Education Program course sponsored by the AAP in 2002 and 2004.

This survey was designed to improve understanding of current knowledge, practices, and educational needs of child health professionals related to fetal alcohol spectrum disorders (FASD). AAP policy on FAS and alcohol-related neurodevelopmental disorder (ARND) states, "Infants and children with a suspected diagnosis of FAS, ARND, or ARBD [alcohol-related birth defects] should be evaluated by a pediatrician who is knowledgeable and competent in the evaluation of neurodevelopmental and psychosocial problems associated with the diagnoses. The need for a skilled evaluation at an early age necessitates referral to a pediatric medical specialist as well as referral to early intervention and education agencies providing services under the provisions of the Individuals With Disabilities Education Act."⁷

METHODS

Instrument

The survey in Fig 1 was developed collaboratively by the AAP, CDC, and representatives from 4 recently established CDC-FAS regional training centers. A team of scientists from these organizations reviewed the scientific literature and existing FAS surveys and developed content areas for the survey. Two practitioner surveys with demonstrated reliability and validity from previous studies were used as models.^{14,34} The survey was sponsored by a cooperative agreement with the National Center on Birth Defects and Developmental Disabilities. An exempt approval by the AAP Investigational Review Board was based on the lack of identifiable information linking human subjects to their responses on the survey. The AAP administered the survey.

Sample

Questionnaires were mailed in April 2003 to a sample of 1600 AAP members generated by applying a random-sample generator to ~48 580 members in the 50 United States. Approximately 80% of US board-certified pediatricians belong to the AAP. General pediatricians, pediatric subspecialists, and pediatric residents were in-

This survey asks for information on your knowledge, attitudes and beliefs about diagnosis, treatment and prevention of Fetal Alcohol Syndrome (FAS) and other prenatal alcohol-related disorders. Please answer the questions by circling the number of the appropriate response or by filling in the blanks.

1. During a typical work week, how many hours per week do you spend in the following professional activities? *If you do not spend any time in a particular activity, please indicate this by entering zero (0) hours in the appropriate space.*

Activity:	Hours:
Direct patient care (self-employed).....	_____
Direct patient care (other than self-employed).....	_____
Administration.....	_____
Academic medicine.....	_____
Research.....	_____
Fellowship training.....	_____
Other.....	_____
TOTAL HOURS/WEEK.....	_____

1a. Are you currently in a pediatric residency training program? Yes No

The following questions are for pediatricians who provide some DIRECT PATIENT CARE. If you do NOT provide direct patient care, please check this box and go to Q# 22

GENERAL KNOWLEDGE

2. What would you estimate the overall prevalence of Fetal Alcohol Syndrome in the United States to be?

- 1 in 10 1 in 100 1 in 1,000 1 in 10,000 1 in 100,000

3. Please check which of the two statements below corresponds most closely with your personal viewpoint. Please pick only ONE box.

- Occasional consumption of alcohol (one drink per day or less) during pregnancy is not harmful to the mother or fetus.
- Pregnant women or women planning to become pregnant should completely abstain from consuming alcohol. **(Skip to Question #4)**



I believe that occasional alcohol consumption (one drink per day or less) is safe during the following trimesters of pregnancy, (check all that apply):

1st trimester 2nd trimester 3rd trimester

4. In your opinion, how many drinks per week would constitute heavy drinking for pregnant women? (Circle your answer)

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14+

5. In your opinion, how many drinks per occasion would constitute binge drinking for pregnant women? (Circle your answer)

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14+

FIGURE 1
FAS survey.

6. Please indicate whether you agree or disagree with the following statements:

	Agree	Disagree	Don't Know
FAS occurs at similar rates in all socioeconomic groups of society	1	2	3
FAS occurs at similar rates among all cultures and ethnic groups	1	2	3

7. Please indicate whether you agree or disagree with the following statements:

	Agree	Disagree	Don't Know
Alcohol's effect on fetal development remains unclear	1	2	3
Prenatal alcohol exposure is a significant risk factor for permanent brain damage	1	2	3
Alcohol withdrawal in a baby at birth is the worst outcome of prenatal alcohol exposure	1	2	3
Young adults with FAS usually achieve successful independence at the expected time (18 to 21 years)	1	2	3
Early diagnosis and ongoing surveillance of FAS may lead to implementation of secondary prevention of disabilities	1	2	3

8. Do you consider any of the following problems to be associated with Fetal Alcohol Syndrome?

	Yes	No	Don't Know
Infantile withdrawal symptoms	1	2	3
Delayed development	1	2	3
Birth defects/malformations	1	2	3
Psychiatric (DSM IV) disorders	1	2	3
Lowered IQ/retardation	1	2	3
Behavioral problems	1	2	3
Low birth weight	1	2	3
Long term emotional disorders	1	2	3
Addictions	1	2	3
Attention deficit hyperactivity disorder	1	2	3

9. Which of the following are included in the facial dysmorphism associated with Fetal Alcohol Syndrome? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Large intercanthal distance | <input type="checkbox"/> Short palpebral fissures |
| <input type="checkbox"/> Full lips | <input type="checkbox"/> Smooth philtrum |
| <input type="checkbox"/> Thin upper lip | <input type="checkbox"/> Flaring nares |
| <input type="checkbox"/> Don't Know/Unsure | |

10. It is easiest to diagnose FAS at what age?

- | | |
|--|--|
| <input type="checkbox"/> Newborn | <input type="checkbox"/> Early Childhood |
| <input type="checkbox"/> Adolescence | <input type="checkbox"/> Adulthood |
| <input type="checkbox"/> Don't Know/Unsure | |

11. Please indicate whether you agree or disagree with the following statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Making a diagnosis of FAS stigmatizes the child and family	1	2	3	4

Please consider your own practice over the past 5 years when answering the following questions.

DIAGNOSIS & TREATMENT

12. Do you provide advice and education on the consequences of alcohol use during pregnancy to your adolescent female patients? (Check ONE box)

- Always/almost always
- Sometimes
- Rarely/never

13. During the past 12 months, how many patients have you... (if none, enter "0")

	Number of patients in past 12 months
suspected as possible FAS?	
recognized as having FAS?	
diagnosed as FAS?	
referred to confirm a diagnosis of FAS?	
provided care for FAS?	

14. Do you make use of a diagnostic schema for FAS in your practice?

- Yes No

If yes, which one of the following do you use?

- Institute of Medicine criteria
- American Academy of Pediatrics criteria
- Seattle 4 digit diagnostic criteria
- Other (please specify) _____

15. Many providers do not make the diagnosis of FAS in their practice. Please indicate which of the following factors may contribute to this situation. (Please select all that apply)

- Lack of time needed to make diagnosis
- Lack of specific training to make the diagnosis
- Belief that making the diagnosis will not make a difference to the individual
- Other (please specify) _____

TRAINING/PERCEIVED COMPETENCE/PERCEIVED NEEDS

16. Do you recall receiving any formal training in the following FAS competencies and if so, indicate where you received this training: (Check all that apply)

	NO	YES			
		Medical School	Post-grad (residency)	CME (received credit)	Other
Ability to recognize the constellation of features associated with FAS and other alcohol-related effects					
Understanding of the basic biomedical mechanisms that result in FAS					
Ability to select valid and reliable assessment instruments to screen for/diagnose FAS and other alcohol-related disorders					

	YES				
	NO	Medical School	Post-grad (residency)	CME (received credit)	Other
Ability to identify risk factors and interventions for secondary FAS disabilities					
Ability to plan and perform clinically relevant treatment and management plans to assist and aid both the patient with FAS and their families					
When appropriate, be able to make a referral for further workup in a child with FAS					
Appreciation and ability to use interdisciplinary team evaluations for individuals with FAS					
Ability to assist clients in accessing local FAS-related resources, including family support					
Utilization of techniques for effectively communicating information to individuals with FAS, their family members, and care providers					
Demonstration of the ability to provide ethical protections to the patient with FAS regarding confidentiality and autonomy					
Ability to educate pregnant women about the effects of alcohol on their babies					
Ability to screen women for risky or hazardous drinking					
Ability to conduct alcohol cessation brief interventions					

17. If you have received any formal training on FAS in any venue (medical school, residency, CME), overall, would you say that training was:

- Poor
 Fair
 Good
 Excellent

18. In general, how prepared do you feel to (Check one box in each row):

	Very Prepared	Somewhat Prepared	Somewhat Unprepared	Very Unprepared
Identify children with possible FAS or other alcohol-related disorders				
Diagnose children with FAS and other alcohol-related disorders				
Manage/coordinate the treatment of children with FAS and other alcohol-related disorders				

19. Please rate how helpful the following kinds of materials or supports would be to you in your clinical practice (Check one box in each row).

	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Concise provider and staff information on prevention, diagnosis, and intervention on FAS and other alcohol-related disorders				

	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Patient education materials on the impact of alcohol use during pregnancy on children				
Clinical guidelines for best practices for diagnosis of FAS and other alcohol-related disorders				
Registry of specialists available for consultation about FAS and other alcohol-related disorders				
Listing of community-based resources for children with FAS				
Materials for office practice including FAS screening and referral checklists and pocket reminders of diagnostic criteria				

20. How helpful would the following mechanisms be to you for receiving training on FAS prevention, diagnosis, and intervention? (Check one box in each row)

	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Regional Conferences (CME)				
Internet-based learning opportunities				
On-site training for myself and colleagues				
Self-study materials (eg, CD-ROM, videos)				

21. Please indicate whether the following types of FAS-related training and educational materials are available in the community where you practice, and whether these resources are helpful, or would be helpful if they became available. (Check all that apply)

	Available	Not	Very Helpful	Somewhat Helpful	Not Very Helpful	Not At All Helpful
Regional Conferences (CME)						
Internet-based learning opportunities						
On-site training for myself and colleagues						
Self-study materials (eg, CD-ROM, Videos)						

BACKGROUND INFORMATION

22. Are you currently in a pediatric residency training program? Yes No

23. What is your gender? Male Female

24. What is your primary employment site? (Please select only one)

- Solo practice / 2 physician practice Community-based health center
- Group practice / Staff model HMO Other (please specify)
- Medical School or parent university
- Hospital or clinic

25. With what racial or cultural group do you identify yourself? Please choose the ONE category below that best describes your ethnicity. This question is optional, but important to the survey.

- White, Non-Hispanic Asian
- Hispanic American Indian/Alaska Native
- African American Native Hawaiian/Pacific Islander

26. What is your age?

27. Years in practice:

28. Do you consider your primary employment location to be: *Circle ONE response*

Urban inner city

Rural

Urban not inner city

Suburban

29. In what area of interest do you spend most of your time?

General pediatrics

Subspecialty area (specify) _____

Thank you. Please return in the enclosed envelope to:

**Attn: Yulee Choe, Manager
Medical Home Screening and Surveillance Program
Division of Children with Special Needs
American Academy of Pediatrics
141 Northwest Point Blvd.
Elk Grove Village, IL 60007-1098**

cluded. A second mailing was sent to participants who did not complete the first questionnaire to improve the response rate.

Statistical Analysis

Data from the survey were double-data entered into Excel for data analysis, including means and frequencies of responses to survey questions. Comparisons between groups of physicians (general pediatricians, subspecialists, and residents) were made using *t* tests for continuous data and Pearson χ^2 tests for categorical data.

RESULTS

Of the 1600 surveys mailed, we received 879, for a total response rate of 55%. Respondents were on average 43 years of age; 52% were female and 75% were white, and they had been in practice a mean of 12 years (all similar to the average membership of the AAP). They represented all US geographic areas (northeast, southeast, midwest, southwest, and northwest). Pediatric subspecialists represented 27% of the respondents compared with 20% of AAP membership ($P < .001$). Pediatric residents composed 13% of the respondents (11% of AAP membership; $P < .001$). Responses from pediatric residents, subspecialists, and general pediatricians differed little. Differences between these groups are noted in results. We report on selected survey responses.

Those surveyed were likely to respond correctly to most general knowledge questions (Table 2). However,

only half accurately estimated the prevalence of FAS (question 2). General pediatricians were more likely than residents or subspecialists to know the estimated birth incidence of FAS ($P < .01$), and occasional drinking was considered safe by 16% of respondents (question 3). Of this group, 19% thought that occasional drinking was safe during the first trimester, 52% during the second trimester, and 98% during the third trimester. Respondents were unlikely to know the accepted definition for heavy drinking (questions 4 and 5).^{*} Pediatricians who had been in practice for ≤ 5 years were more likely to select the correct threshold for binge drinking (4–5 drinks per occasion) compared with those who had been in practice longer ($P < .05$). Most were aware of a poverty–FAS link, but residents were more likely than those in practice to know that FAS rates are increased in disadvantaged economic and cultural/ethnic groups (question 6; $P < .001$).

More than 80% of respondents gave correct responses concerning alcohol's effect on fetal development, prenatal alcohol exposure and brain damage, alcohol withdrawal, and the link between early diagnosis and prevention of secondary disabilities (question 7). Almost all respondents correctly identified FAS-associ-

* At the time of this survey, the CDC, the IOM, and the University of Washington defined heavy drinking as 5 or more drinks per week and binge drinking as 5 or more drinks per occasion. In 2004, The National Institute on Alcoholism and Alcohol Abuse revised the screening definition for "heavy drinking" for women to 4 or more drinks in 1 day and 8 drinks in 1 week.³⁷ The CDC currently uses the following definition of risk drinking: 7 or more drinks per week, 3 or more drinks on multiple occasions, or both.²⁸

TABLE 2 Selected Survey Responses

Survey Question	Correct Response	% Correct Response
General Knowledge		
2	Prevalence 1/1000 live births	53
6	Higher rates with poverty	58
6	Higher rates in minorities, including Native Americans	68
7	Alcohol's effect on fetal development is clear	80
7	Prenatal alcohol risk for permanent brain damage	92
7	Alcohol withdrawal not worst outcome of fetal exposure	86
7	Young adults with FAS do not usually achieve independence at the expected time (18–21 y)	71
7	Early diagnosis and surveillance may lead to secondary prevention of disabilities	86
8	Delayed development	99
8	Birth defects/malformations	96
8	Psychiatric (DSM-IV) disorders	86
8	Lowered IQ/retardation	99
8	Behavioral problems	97
8	Low birth weight	90
8	Long-term emotional problems	82
8	Attention-deficit/hyperactivity disorder	75
10	Easiest developmental period to diagnose FAS is early childhood	57
Clinical experience during past 12 mo		% With ≥1 Patient
13	Suspected possible FAS	42
13	Recognized FAS	20
13	Referred to confirm diagnosis of FAS	18
13	Provided care for a child with FAS	34

DSM-IV indicates *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*.

ated morbidity and facial features (questions 8 and 9). Approximately half (57%) of the respondents correctly perceived early childhood as the optimal period to diagnose FAS, whereas approximately one quarter (28%) perceived the newborn period as the optimal time (question 10).

Alcohol history was not always addressed. More than half (65%) believed that the diagnosis of FAS stigmatizes the child and the family (question 11). Most respondents did not routinely address the consequences of alcohol use during pregnancy with adolescent female patients, and 45% never addressed this topic (question 12).

Actual clinical experience with children with FAS was reported by fewer than half of the respondents (question 13). Very few (13%) respondents reported using standardized criteria for the diagnosis of FAS in their clinical practice (question 14). Only 4 pediatricians reported using the IOM criteria. However, an additional 99 pediatricians, or 85% of those who used any criteria, reported that they used the AAP criteria.⁷ When asked why many providers do not make the diagnosis of FAS in their practice, most (77%) cited lack of training (question 15). Only 29% reported lack of time as a barrier. Few (14%) believed that having a diagnosis does not make a difference to the individual child. (Respondents were allowed to pick >1 answer.)

With respect to training, most (72%) reported attending postgraduate training on the features of FAS, and

70% reported some formal training on indications for referral for additional evaluation (question 16). Only 28% reported any training on selection of valid and reliable assessment instruments for screening or diagnosis of FAS. Approximately half reported training in screening patients for risky drinking, and 69% had received training for education of pregnant women about the adverse prenatal effects of alcohol on the fetus. Only 3% of surveyed pediatricians reported that they had received excellent formal training on the diagnosis and treatment of FAS. Finally, more than half of the respondents reported having had no training in treatment and management, community resources, effective communication, protecting confidentiality, and conducting alcohol cessation interviews. Whereas 62% of respondents reported that they felt prepared to identify possible FAS, somewhat fewer (50%) felt prepared to make the diagnosis (question 18). Even fewer (34%) felt prepared to manage and coordinate treatment of children with FAS. The pediatricians surveyed largely (>85%) endorsed all of the educational methods proposed as potentially helpful (questions 19 and 20).

DISCUSSION

Population-based prevention, secondary prevention, screening, and referral for FAS diagnosis and intervention can be improved by adequate training of pediatricians and other child health professionals. AAP members

who responded to this survey generally were knowledgeable about basic science, clinical signs, symptoms, and epidemiology of FAS. They were less prepared to use diagnostic guidelines, refer for specialty consultation, or coordinate treatment for children with FAS. Pediatricians surveyed infrequently encountered children with FAS. This is not surprising because the combined US rate of FAS, ARND, and ARBD is estimated to be 9 per 1000 live births.³⁸ On the basis of these estimates and an average patient panel of 1500 patients and 50 to 100 newborns per year, a general pediatrician would expect to care for 1 to 2 children with FAS and 9 to 18 children with ARND or ARBD over a practice career. Pediatricians in high-risk practices could expect to care for more children with FASD.^{30,39-45}

Controversy exists about who should make the definitive diagnosis. Pairing early detection and ongoing management by the primary care physician with specialty consultation is a model that holds promise. Although facial features often are distinctive, dysmorphologists are experts on other syndromes that mimic FAS. Neurobehavioral morbidity is most troubling for patients and their families. Unfortunately, neurobehavioral symptoms are less specific, and it is especially difficult to diagnose ARND in nonsyndromal children. Nonetheless, children with identified behavioral and learning problems need intervention regardless of whether they meet diagnostic criteria for FASD. Neurobehavioral specialists can assist with diagnosis and treatment of comorbid mental health disorders. In addition, all 50 states have identified multidisciplinary evaluation clinics for FASD, listed on the National Organization on Fetal Alcohol Syndrome Web site.⁴⁶ The diagnostic evaluation is only the first step in the care of children with FAS. Pediatricians are called on to provide a medical home for these children, coordinate appropriate mental health services, provide consultation to special education programs, and manage medications for attention-deficit/hyperactivity disorder and other comorbid mental health disorders. Furthermore, primary care clinicians (pediatricians, family physicians, and obstetricians) can play an important role in primary prevention of alcohol-exposed pregnancies.

Barriers to diagnosing FAS include inconsistent knowledge, infrequent use of guidelines, beliefs about potential harm caused by the diagnosis, and paucity of intervention. Pediatricians were not uniformly aware of accepted definitions for binge and heavy drinking. Furthermore, several respondents gave examples of their own or their children's exposure to very small amounts of alcohol prenatally with no apparent adverse effects. Although guidelines rarely were used by respondents, the modifications to the IOM diagnostic criteria, proposed by Hoyme et al,²⁷ may increase the use of a diagnostic guideline by both generalists and specialists. A concise standardized approach to assessing alcohol ex-

posure and neurobehavioral symptoms could improve the usefulness of this tool. Although many pediatricians surveyed believed that an FASD diagnosis stigmatizes the child and the family, this is not known. If the diagnosis (rather than the condition) stigmatizes the child and the family, then strategies could be developed to assist families with this secondary burden. Surveyed pediatricians expressed reluctance to concentrate efforts on diagnosing an untreatable condition. Future medical education should include known benefits of early diagnosis and intervention for children with FAS, such as the potential for preventing secondary disabilities.³⁰

Pediatricians provide ongoing care and management for many children with complex medical, behavioral, and mental conditions. However, they do not always perform the definitive diagnostic evaluation for low-prevalence, high-severity conditions. We suggest that pediatricians consider FAS when evaluating microcephaly, intrauterine growth retardation, developmental problems, hyperactivity, behavioral problems, and school failure. FASD or an alcohol-related disorder will provide a unifying diagnosis in a small percentage of these more common conditions. Primary care pediatricians in remote areas and those whose practices include children in foster care, internationally adopted children, children on some Indian reservations, and other communities with high alcohol use may be expert in the diagnosis of FASD. In other practice settings, referral to specialists (geneticists, developmental-behavioral pediatricians, and neurologists) for additional evaluation is recommended. Diagnosis is only the first step for children with FAS and their families. Like other children with complex medical or behavioral disabilities, children with FAS need a pediatric medical home to provide and coordinate care and ensure necessary medical, behavioral, social, and educational services.

Few providers reported counseling adolescent patients about alcohol use and pregnancy. We suspect that it is difficult to identify which adolescent girls are at risk for combined pregnancy and alcohol use. Furthermore, clinicians are called on to provide more public health information than is possible during the limited health care maintenance visit. The list includes prevention of smoking, substance use, unintentional injuries, sexually transmitted diseases, and more. Effective strategies for teaching adolescents and their families about the combined risk of alcohol and pregnancy could be developed for media, schools, or health care systems. Research to determine whether prevention messages should be universally delivered or targeted toward teens with identifiable risk for pregnancy and alcohol use is needed.

Our study has several limitations. Although the 55% response rate is consistent with normative values for physician survey research^{47,48} and respondents generally represented members of the AAP, our findings may not represent all pediatricians. Self-reported attitudes and

practices may be confounded by social desirability bias, such that respondents overestimate their services. It is possible that pediatricians with greater interest in FAS were more likely to complete the survey. Furthermore, pediatricians may not be able to estimate accurately the number of children in their practices with alcohol-related conditions.

CONCLUSIONS

AAP members who responded to this survey were knowledgeable about FAS. However, they reported inadequate training for actual clinical diagnosis, referral, and management. Respondents were unlikely to engage in primary prevention education for FAS with their adolescent patients. Translational research to move from scientific knowledge of teratology and epidemiology to practical tools for the child health professional could result in increased prevention, diagnosis, referral, and intervention for FAS.

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