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Characteristics and behaviors of mothers who have a child with fetal alcohol syndrome ☆

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ABSTRACT

Fetal alcohol syndrome (FAS) is a leading cause of birth defects and developmental disabilities. The objective of this study was to identify the characteristics and behaviors of mothers of children with FAS in the United States using population-based data from the FAS Surveillance Network (FASSNet). FASSNet used a multiple source methodology that identified FAS cases through passive reporting and active review of records from hospitals, specialty clinics, private physicians, early intervention programs, Medicaid, birth certificates and other vital records, birth defects surveillance programs, and hospital discharge data. The surveillance included children born during January 1, 1995–December 31, 1997. In the four states included in our analysis – Arizona, New York, Alaska, and Colorado – there were 257 confirmed cases and 96 probable cases for a total of 353 FAS cases. Compared to all mothers in the states where surveillance occurred, mothers of children with FAS were significantly more likely to be older, American Indians/Alaska Natives, Black, not Hispanic, unmarried, unemployed, and without prenatal care, to smoke during pregnancy, to have a lower educational level, and to have more live born children. A significant proportion of mothers (9–29%) had another child with suspected alcohol effects. Compared to all US mothers, they were also significantly more likely to be on public assistance, to be on Medicaid at their child's birth, to have received treatment for alcohol abuse, to have confirmed alcoholism, to have used marijuana or cocaine during pregnancy, to have their baby screen positive for alcohol or drugs at birth, to have had an induced abortion, to have had a history of mental illness, to have been involved in binge drinking during pregnancy, and to have drunk heavily (7 days/week) during pregnancy. These findings suggest that it is possible to identify women who are at high risk of having a child with FAS and target these women for interventions.

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1. Introduction

Fetal alcohol syndrome (FAS) is a leading cause of birth defects and developmental disabilities (May and Gossage, 2001). In the United States, an estimated 2000 to 8000 new cases occur each year (May and Gossage, 2001). FAS represents the most severe manifestation of alcohol-related birth defects and developmental disabilities. The number of children with FAS and other fetal alcohol spectrum disorders (FASDs) – predominantly alcohol-related neurodevelopmental disorders (ARNDs) – is estimated to be three times higher than the number of children with FAS alone (Lupton et al., 2004; Sampson et al., 1997). Although prevention of all FASDs should be a public health priority, the need for prevention of the most severe form – FAS – is particularly urgent.

In order to prevent FAS, it is necessary to identify and characterize women who are at risk for having children with FAS. Mothers of children with FAS are difficult to study — most children living in the United States with FAS are not raised by their biological mothers (Astley et al., 2000a; Streissguth et al., 2004). Nevertheless, previous studies have identified a number of characteristics and behaviors of mothers of children with FAS. Some of these risk factors are heavy drinking (including binge drinking), drinking among members of the extended family and social network, more years of drinking, smoking, previous treatment for alcohol and/or drug abuse, older age, high gravidity, lower educational attainment, lower income, lower IQ, sexual and/or physical abuse, and mental illness (Abel, 1982; Astley et al., 2000b; Kvigne et al., 2008, 2003; May et al., 2005, 2007, 2008a; Miller et al., 1995; Viljoen et al., 2002, 2005).

Previous studies have limitations which make them less than ideal for informing FAS prevention strategies in the U.S. Some studies did not have control or comparison groups (Abel, 1982; Astley et al., 2000b), or mothers were identified through clinics rather than through population-based surveillance (Abel, 1982; Astley et al., 2000b; Kvigne

Abbreviations: FAS, fetal alcohol syndrome; FASSNet, Fetal Alcohol Syndrome Surveillance Network; FASDs, fetal alcohol spectrum disorders; ARNDs, alcohol-related neurodevelopmental disorders; AI/AN, American Indians/Alaska Natives; IQ, intelligence quotient.

☆ The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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et al., 2008, 2003). Thus, it is not known whether the mothers studied were representative of all the mothers of children with FAS. Furthermore, previous studies have had relatively small sample sizes – the largest examining mothers of 80 cases – making it more difficult to draw conclusions about some risk factors. Finally, due to differences between international populations, it is not always clear how studies of FAS outside the U.S. (May et al., 2005, 2007, 2008a; Viljoen et al., 2002, 2005) can appropriately inform FAS prevention efforts in the U.S.

The objective of the analysis was to define the characteristics and behaviors of mothers of children with FAS in the United States using population-based surveillance data, and to compare these characteristics and behaviors to those of women of reproductive age in the underlying population. This will facilitate FAS prevention efforts in the United States because it will help identify the women who should be targeted for interventions, the venues where they might be reached, and the issues that need to be addressed in prevention interventions.

2. Methods

2.1. Description of surveillance network

FAS surveillance data were obtained from the CDC-sponsored Fetal Alcohol Syndrome Surveillance Network (FASSNet) (Hymbaugh et al., 2002). FASSNet developed a multiple source surveillance methodology that identified FAS cases through passive reporting and active review of records from sources such as hospitals, specialty clinics, private physicians, early intervention programs, Medicaid, birth certificates and other vital records, birth defects surveillance programs, and hospital discharge data. The surveillance was population-based and for this analysis included children born during January 1, 1995–December 31, 1997. Like many other surveillance systems for birth defects and developmental disabilities, FASSNet relied on existing source records rather than direct examination of children or interviews with parents or other caretakers. For this reason, data on some variables were more complete and reliable (e.g., age, race) while data on other variables were less complete and reliable (e.g., drinking behaviors during pregnancy).

FAS surveillance was done in 5 states. For this analysis, we used data from the four states – Alaska, Arizona, Colorado, and New York – that used a standard multiple-source methodology (Hymbaugh et al., 2002). Wisconsin was excluded from this analysis because it only used birth certificates as a data source for identifying children that might meet the criteria of the FAS case definition. The catchment area for Alaska and Arizona included the entire state; Colorado consisted of six counties in the Denver-Boulder Metropolitan Statistical Area and New York included a nine-county region in Western New York.

2.2. FAS case definition

FAS cases may not have had a clinical diagnosis but were classified as confirmed or probable based on the documentation of surveillance criteria as described in Hymbaugh et al. (2002). Briefly, to be classified as a confirmed FAS case, the child had to meet all three of the following criteria: 1) abnormal facial features consistent with FAS as reported by a physician or two of the following: short palpebral fissures, abnormal philtrum, and thin upper lip; 2) at least one central nervous system (CNS) structural or functional anomaly; and 3) intrauterine or postnatal growth delay. To be classified as a probable FAS case the child had to meet the same facial features criteria and either the CNS or the growth criteria. Documentation of in utero alcohol exposure was not required for confirmed or probable FAS. In analyses of mothers' characteristics and behaviors, we included both confirmed and probable FAS cases.

2.3. Statistical analysis

2.3.1. Comparison data

For the purposes of analysis, we grouped results for different maternal characteristics based on whether we could compare the FASSNet data to state-specific population data from vital records or the census (see Table 1) or whether population data could only be obtained from nationwide surveys not stratified by state (see Table 2). State-specific population data (Table 1) came from birth certificates from the year 1996 or from the 2000 U.S. Census (i.e., for data on employment during pregnancy). Sources for the nationwide survey data are listed in the footnotes to Table 2.

2.3.2. Statistical tests

We calculated the percentages for different maternal characteristics among mothers of FAS cases and mothers from general population state or nationwide data and used 2-sided mid-P exact tests or Chi-square tests as appropriate to assess whether percentages were statistically different. We ran these tests using OpenEpi software (www.openepi.com) and considered a p-value of less than 0.05 to be statistically significant.

2.3.3. Sensitivity analysis

Several variables had a substantial proportion of missing values for the mothers of the FAS cases. This occurred because the FASSNet surveillance was limited to whatever data were available in existing records. For variables where more than 50% of the values were missing, we performed a sensitivity analysis to evaluate the likelihood that the characteristics of the mothers of children with FAS were significantly different from mothers in the general population. This was done by determining what would be the most extreme distribution of results for the missing values of mothers of children with FAS that, when added to the observed values, would still lead to a significant difference compared to the general population (see Table 3). The most extreme distribution we allowed was one in which all the missing values had the same distribution as the values of the general population. So, for example, 81 mothers of FAS cases were on public assistance at birth, 14 were not, and 258 had missing values (Table 3). In the sensitivity analysis for this variable, the most extreme distribution allowable (in this case, the distribution of the general population) added 232 mothers to the group not on public assistance (92% of 258) and 21 mothers to the group on public assistance (8% of 258). After adding these imputed values to the observed values for mothers of children with FAS, we compared mothers of children with FAS to general population mothers and found that the p-value for public assistance was still less than 0.05

3. Results

3.1. Analyses of variables with state-specific comparison data

In each of the four states, compared to the corresponding state population of women who recently gave birth, mothers of children with FAS were more likely to be older, non-Hispanic, unmarried, unemployed, and without prenatal care, to smoke during pregnancy, to have a lower educational level, and to have more live born children. A significant proportion of mothers (9–29%) had another child with suspected alcohol effects (Table 1). In Alaska and Arizona, mothers of children with FAS were much more likely to be American Indians/Alaska Natives (AI/AN) than other racial/ethnic groups represented in the underlying population. In Colorado and New York, mothers of children with FAS were more likely to be black. All associations had a p-value of less than 0.05. One noteworthy finding was that, in Alaska, nearly 1 in 3 mothers of children with FAS had another child with suspected alcohol effects.

Table 1
Comparison of mothers who have a child with FAS and all mothers, stratified by state.

	Alaska (N = 74)			Arizona (N = 118)			Colorado[a] (N = 67)			New York[a] (N = 94)		
Maternal characteristics	FAS Cases[b]	FAS %	State[c] %	FAS Cases[b]	FAS %	State[c] %	FAS Cases[b]	FAS %	State[c] %	FAS Cases[b]	FAS %	State[c] %
Age in years												
12–20	7	10%	16%	5	5%	20%	2	3%	16%	7	9%	13%
21–25	8	12%	28%	7	6%	28%	14	23%	24%	13	16%	21%
26–30	5	7%	26%	32	29%	26%	10	17%	27%	19	23%	29%
31–35	29	43%	20%	34	31%	18%	19	32%	22%	20	25%	26%
36–50	19	28%	10%	31	28%	8%	15	25%	11%	22	27%	11%
Race												
AI/AN	60	86%	24%	62	59%	7%	2	4%	1%	2	2%	0%
Asian or Pacific Islander	0	0%	4%	0	0%	2%	0	0%	3%	0	0%	6%
Black	0	0%	4%	5	5%	3%	8	14%	5%	43	53%	21%
White	10	14%	68%	38	36%	88%	47	82%	92%	36	44%	73%
Ethnicity												
Not Hispanic	74	100%	93%	95	81%	63%	48	72%	78%	93	99%	78%
Hispanic	0	0%	7%	23	19%	37%	19	28%	22%	1	1%	22%
Marital status												
Married	22	30%	68%	11	10%	61%	9	28%	75%	8	10%	60%
Unmarried	52	70%	32%	97	90%	39%	23	72%	25%	73	90%	40%
Employment during pregnancy[d]												
No	8	67%	40%	36	90%	49%	14	67%	39%	65	82%	49%
Yes	4	33%	60%	4	10%	51%	7	33%	61%	14	18%	51%
Prenatal care during pregnancy												
No	5	7%	1%	20	18%	2%	11	24%	1%	10	13%	2%
Yes	66	93%	99%	91	82%	98%	35	76%	99%	69	87%	98%
Smoking during pregnancy												
No	6	8%	80%	33	34%	90%	4	8%	88%	5	6%	95%
Yes	66	92%	20%	64	66%	10%	44	92%	12%	75	94%	5%
Alcohol use during pregnancy												
No	6	8%	96%	0	0%	99%	2	3%	98%	5	6%	99%
Yes	67	92%	4%	111	100%	1%	62	97%	2%	82	94%	1%
Education level												
< High school	25	42%	14%	28	39%	30%	30	56%	19%	39	52%	20%
High school or equivalent	26	43%	43%	32	45%	32%	15	28%	30%	24	32%	34%
Some college	9	15%	43%	11	15%	38%	9	17%	51%	12	16%	46%
Number of live births												
0	8	13%	37%	3	4%	39%	0	0%	43%	10	14%	41%
1	10	16%	30%	11	14%	30%	9	26%	32%	18	25%	32%
2	16	25%	17%	20	25%	18%	8	23%	15%	16	22%	16%
3-4	20	32%	12%	29	36%	11%	11	31%	8%	19	26%	8%
≥ 5	9	14%	4%	18	22%	2%	7	20%	2%	9	13%	3%
Other child with suspected alcohol effects												
No	37	71%	[e]	50	85%	[e]	45	87%	[e]	71	91%	[e]
Yes	15	29%	[e]	9	15%	[e]	7	13%	[e]	7	9%	[e]

Due to rounding not all column percentages add to 100%.
[a] The catchment for FAS surveillance was only part of the state.
[b] Includes confirmed and probable cases; numbers of cases for each variable differ due to missing data. $P<0.05$ for all comparisons between FAS cases and state data.
[c] With the exception of the employment variable, the data source for state percentages is birth certificates from the year 1996 (http://www.cdc.gov/nchs/data_access/vitalstats/vitalstats_births.htm) (Centers for Disease Control and Prevention, 1996).
[d] Data source for employment variable is the 2000 U.S. Census (http://censtats.census.gov/usa/usa.shtml) (U.S.Census and Census by State, 2000), employed female civilian labor force divided by the total female civilian labor force.
[e] No state data available.

3.2. Analyses of variables with national comparison data

Compared to women in national surveys, mothers of children with FAS from the four states combined were more likely to be on public assistance, to be on Medicaid at their child's birth, to have received treatment for alcohol abuse, to have confirmed alcoholism, to have used marijuana or cocaine during pregnancy, and to have their baby screen positive for alcohol or drugs at birth (Table 2). Mothers of children with FAS were more likely to have had an induced abortion, to have had a history of mental illness, to have been involved in binge drinking during pregnancy, and to have drunk heavily (7 days/week) during pregnancy (Table 2). All associations had a p-value of less than 0.05.

3.3. Sensitivity analyses

In the sensitivity analysis (Table 3) we found that despite the high percentage of missing values, the observed significant differences

Table 2
Characteristics of mothers of children with FAS (N = 353).

Maternal characteristics	FAS cases[a]	FAS %	Approximate female U.S. population %
Public assistance at birth			[b]
No	14	15%	92%
Yes	81	85%	8%
Insurance at birth			[c]
Medicaid (current or pending)	165	56%	41%
Other	128	44%	59%
Received treatment for alcohol abuse			[d]
No	10	11%	75%
Yes	77	89%	25%
Confirmed alcoholism			[e]
No	4	8%	94%
Yes	47	92%	6%
Baby screened positive for alcohol			[f]
No	328	93%	>99%
Yes	25	7%	<1%
Baby screened positive for drugs			[f]
No	277	78%	>99%
Yes	76	22%	<1%
Marijuana use during pregnancy			[g]
No	311	89%	97%
Yes	39	11%	3%
Cocaine use during pregnancy			[g]
No	262	75%	>99%
Yes	88	25%	<1%
Number of induced abortions			[h]
0	8	26%	70%
≥1	23	74%	30%
History of mental illness			[i]
No	6	30%	45%
Yes	14	70%	55%
Number of drinks in one sitting during pregnancy			[j]
<4 drinks	16	32%	97%
≥4 drinks	34	68%	3%
Number of days per week drinking during pregnancy			[j]
<7	15	36%	97%
7	27	64%	3%

[a] Includes confirmed and probable cases; numbers of cases for each variable differ due to missing data. P<0.05 for all comparisons.
[b] Mothers who were on Temporary Assistance for Needy Families during 1996, taken from U.S. Census Bureau, Survey of Income and Program Participation, 1996 Panel (O'Hara, 2002).
[c] Medicaid births from 2002, taken from Maternal and Child Health Update: States Increase Eligibility for Children's Health in 2007, National Governors Association, Appendix A. Available at http://www.nga.org/Files/pdf/0811MCHUPDATE.PDF (National Governors Association, 2008)
[d] Among women with an alcohol use disorder, taken from 2001–2002 National Epidemiologic Survey on Alcohol and Related Conditions (Schneier et al., 2010).
[e] Lifetime prevalence of alcohol dependence among women ages 30–44, taken from 2001–2003 National Comorbidity Survey Replication (Kessler et al., 2005).
[f] Newborn drug diagnosis, taken from 1988–1990 National Hospital Discharge Survey (Dicker and Leighton, 1994).
[g] Mothers who used marijuana in the previous 30 days during pregnancy, taken from 2002–2006 National Survey on Drug Use and Health (Muhuri and Gfroerer, 2009).
[h] From National Study on Family Growth (Henshaw, 1998).
[i] Lifetime prevalence of any mental health disorder, including substance abuse, among women ages 30–44, taken from 2001–2003 National Comorbidity Survey Replication (Kessler et al., 2005).
[j] In the previous 30 days during pregnancy, taken from 1999 BRFSS (Alcohol use among women of childbearing age–United States, 2002).

would persist even if the missing values were similar to the values of mothers in the general population. In fact, for the variables employment (in Arizona and New York), public assistance, received treatment for alcohol abuse, confirmed alcoholism, binge drinking, and heavy drinking, the missing values could have been distributed exactly as the general population values and the differences between mothers of children with FAS and general population mothers would still have been statistically significant. Even for the remaining variables, the missing values could have been much closer to the general population values than the observed mothers of children with FAS values and the differences would have remained significant.

4. Discussion

According to population-based surveillance data from four U.S. states, mothers of children with FAS have multiple characteristics that differ substantially from the general population of women of reproductive age overall and during pregnancy in particular. Specifically, they are much more likely to be older, of Black or AI/AN race, not Hispanic, unmarried, unemployed, of lower educational attainment, on Medicaid, on public assistance, and to have severe substance abuse behaviors including daily drinking, binge drinking, smoking, and illegal drug use. In short, the mothers of children with FAS face serious socioeconomic and behavioral challenges especially in the area of substance abuse.

Maternal characteristics identified in this study are similar to those identified in FAS studies that were not population-based (Abel, 1982; Astley et al., 2000b; Kvigne et al., 2008, 2003), suggesting that clinic-based studies may be identifying mothers who are generally representative of all mothers of children with FAS. Maternal characteristics in our study were also similar to those in South Africa (May et al., 2005, 2007, 2008a; Viljoen et al., 2002, 2005), particularly with regards to substance abuse behaviors such as daily drinking and binge drinking.

The primary contribution of this analysis is that it identifies mothers' characteristics of children who were identified through population-based FAS surveillance. This makes it more likely that the sampling of mothers is representative of the entire population of mothers of children with FAS and allows for the use of population-based controls derived from statewide or nationwide population statistics. As a result, we were able to better determine how mothers of children with FAS differed from the underlying population of women of reproductive age or women who just gave birth for variables captured in the FASSNet data set.

One limitation of the study was that certain characteristics were missing from the dataset for many mothers (e.g., employment history, number of induced abortions, history of mental illness). While the results for these characteristics should be considered hypothesis-generating rather than definitive findings, the strength of the associations for most characteristics was great enough to conclude that they are significantly different for mothers of children with FAS compared to other mothers. This was evident in the sensitivity analysis, where despite many missing values for certain variables, the characteristics remained significantly different. The robustness of the differences is attributable to the distributions of the observed values being radically different, in most cases, for the mothers of children with FAS and the general population mothers.

In some cases, associations reported in other studies may not have been reported in this study because the variables were not collected by FASSNet (e.g., maternal history of physical or sexual abuse). Another limitation was that data were only collected from four states rather than the entire United States. Although these states represent a diversity of race/ethnicity and other characteristics, it is not possible to determine whether our results would be substantially different if FASSNet collected surveillance data from the entire United States. A further limitation was that some of the national data sources for the female U.S. population (Table 2, column 4) defined variables somewhat differently (e.g., marijuana use in the previous 30 days during pregnancy vs. marijuana use sometime during pregnancy) and used different data collection methodology compared to FASSNet. In most cases, the differences between FASSNet mothers and the general population were large, but these results should be interpreted cautiously (Table 2). It is possible that FAS cases were more likely to be American Indians or Alaskan Natives because health care providers are more likely to suspect FAS among children in these populations. However, surveillance efforts did not disproportionately target these populations in Arizona or Alaska, so we do not believe ascertainment bias would explain the higher occurrence of FAS cases among American Indians and

Table 3
Sensitivity analysis to determine how the distribution of missing values for mothers of FAS cases may affect observed differences between these mothers and mothers in the state or U.S. population.

Variable	Observed number for FAS cases	Observed percentage for FAS cases	Observed percentage for state or U.S. population	Distribution of missing values for mothers of FAS cases that would still result in a significant ($p<0.05$) difference compared with the state or U.S. population (N = number of missing values)
Alaska employment[a]	Missing = 62			
No	8	67%	40%	47% (N = 29)
Yes	4	33%	60%	53% (N = 33)
Arizona employment[a]	Missing = 78			
No	36	90%	49%	49% (N = 38)
Yes	4	10%	51%	51% (N = 40)
Colorado employment[a]	Missing = 46			
No	14	67%	39%	41% (N = 19)
Yes	7	33%	61%	59% (N = 27)
New York employment[a]	Missing = 15			
No	65	82%	49%	49% (N = 7)
Yes	14	18%	51%	51% (N = 8)
Public assistance[b]	Missing = 258			
No	14	15%	92%	92% (N = 237)
Yes	81	85%	8%	8% (N = 21)
Received treatment for alcohol abuse[b]	Missing = 266			
No	10	11%	75%	75% (N = 200)
Yes	77	89%	25%	25% (N = 66)
Confirmed alcoholism[b]	Missing = 302			
No	4	8%	94%	94% (N = 284)
Yes	47	92%	6%	6% (N = 18)
Number of induced abortions[b]	Missing = 322			
0	8	26%	70%	69% (N = 222)
≥1	23	74%	30%	31% (N = 100)
History of mental illness[b]	Missing = 333			
No	6	30%	45%	41% (N = 135)
Yes	14	70%	55%	59% (N = 198)
Number of drinks in one sitting during pregnancy[b]	Missing = 303			
<4 drinks	16	32%	97%	97% (N = 294)
≥4 drinks	34	68%	3%	3% (N = 9)
Number of days per week drinking during pregnancy[b]	Missing = 311			
<7	15	36%	97%	97% (N = 302)
7	27	64%	3%	3% (N = 9)

[a] From Table 1.
[b] From Table 2.

Alaskan Natives. Finally, because documentation of in utero alcohol exposure was not required in the FAS surveillance case definition, it is possible that some of the children defined as FAS cases were not true cases, but may have been affected by genetic disorders.

Our findings suggest that it is possible to identify women who may be at highest risk of having a child with FAS. Given that, it is possible to target interventions aimed at reducing behaviors that can lead to the birth of a child with FAS. Interventions might have the biggest impact if they are embedded in systems serving women who are older, racial/ethnic minorities, unmarried, unemployed, on Medicaid, or of lower educational level. Nevertheless, the absolute number of FAS cases detected in lower-risk groups was substantial, indicating that all women are at risk and no groups should be ignored in prevention efforts. Screening tools are available for identifying behaviors of risky or dependent drinking, smoking, or drug use in order to detect women at high risk (Barry et al., 2009; Floyd et al., 2008). Venues and agencies that provide public assistance, substance abuse treatment, or abortion services can provide opportunities for risk-identification and intervention. As has been proposed previously (Astley et al., 2000a), women who have had a child with alcohol-related effects may also be targeted for interventions. The observed proportion of mothers of children with FAS who are dependent drinkers (e.g., received treatment for alcohol abuse, confirmed alcoholism) is high enough to suggest that clinical treatment may be necessary for preventing much of FAS. There is some evidence that enhanced case management can benefit women who are at high risk for having children with FAS and can possibly lower rates of FAS (May et al., 2008b). An intensive and comprehensive home visitation intervention also showed promise for reducing alcohol-exposed pregnancies among alcohol and drug-abusing women (Grant et al., 2005).

FAS, however, represents only the tip of the iceberg of adverse effects caused by alcohol during pregnancy. The prevention of other FASDs may require different intervention strategies and programs. Identifying maternal characteristics for children with other FASDs is harder since there is no consensus on diagnostic criteria for the spectrum of disorders. However, it is possible that mothers of children affected by other FASDs may include more women who are not alcohol dependent, but rather are risky drinkers or even moderate drinkers. For these women, selective and indicated prevention interventions, such as Project CHOICES (Floyd et al., 2007), may be the most appropriate for preventing alcohol exposed pregnancies, rather than formal treatment for alcohol dependence (Institute of Medicine, 1996).

Conflict of interest statement

Nothing declared.

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