WHAT HUMAN SERVICE PROFESSIONALS KNOW AND WANT TO KNOW ABOUT FETAL ALCOHOL SYNDROME

Linda Caley[1], Charles Syms[2], Luther Robinson[3], Julie Cederbaum[4], Madelyn Henry[5], Nancy Shipkey[5]

School of Nursing, University at Buffalo[1], School of Social Work, University at Buffalo[2], School of Medicine and Biomedical Sciences, University at Buffalo[3], School of Social Policy & Practice, University of Pennsylvania[4], School of Nursing, University at Buffalo[5], USA

ABSTRACT

Background

Although human service professionals are critical to prevention of primary and secondary disabilities among those who are or could be affected by prenatal exposure to alcohol surprisingly little information is available on their knowledge, attitudes, or beliefs about this problem. This article presents the results from a statewide survey (2005) undertaken in the United States to gain such information.

Objective

The purpose of the study was to: a) measure the knowledge, attitudes, and beliefs about Fetal Alcohol Syndrome (FAS) of professionals working in the fields of child welfare/child protective services, foster care, and Medicaid enrollment, and b) use that knowledge to inform educational and training resources to help them with their work.

Methods

A purposive sample of human service professionals in 42 counties completed a self-administered survey patterned after similar FAS surveys for other professionals.

Results

The results were based on answers from 1,168 human service professional respondents that showed that they were knowledgeable about primary prevention. However, it also revealed that they had lesser knowledge of epidemiology, how to recognize children with FAS, and methods to work with them. The fact that 90% of the respondents reported they did not care for children with FAS - is an important finding.

Conclusions

Although these findings suggest that human service professionals are knowledgeable about primary prevention, they lack additional education and assertive assessment protocols. These resources are needed to help them work with families and children who are already affected by exposure to alcohol in utero.

Key Words: *Fetal alcohol syndrome, community health services, child welfare, social work, community outreach, preventive health services*

Human service professionals are critical to prevention of primary and secondary disabilities among those who are or could be affected by prenatal exposure to alcohol, one of the most vulnerable of populations. Professionals working with children and adolescents are particularly likely to be involved with this population. Surprisingly, little information is available however on the knowledge, attitudes, or beliefs of those human service professionals working with this population.

Given the widespread prevalence of Fetal Alcohol Spectrum Disorder (FASD), the tremendous needs of affected children and families, and the critical importance of human service professionals to the well-being of this

population, it is imperative that we know more about their practice in this area. This article presents the results from a statewide survey (2005) undertaken in the United States to gain such information.

BACKGROUND

Many children identified as alcohol affected are of minority or low socioeconomic status, live in highly stressed families, and lack access to appropriate, necessary resources. As the Institute of Medicine reported,[1] children affected by prenatal alcohol exposure often come to the attention of protective service agencies and they frequently enter foster care and may be placed for adoption.[1-3] May et al.[4] and Streissguth et al.,[5] identified that 73-80% of children with full-blown Fetal Alcohol Syndrome (FAS) are in foster or adoptive placement. Children affected by alcohol in utero are also at higher risk for behavioral and psychological problems and are more likely to be involved with the juvenile justice system.[2,6]

In their study of children with FAS or Fetal Alcohol Effects (FAE) Streissguth[2] found that 43% of children of school age have a disrupted school experience (defined as suspension, expulsion, or dropping out). Of those age 12 years of age and over, 60% had trouble with the law, and/or confinement (inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime). In addition, in this age group alcohol/drug problems were experienced by 30% and inappropriate sexual behavior was reported in 45%. Overall, 94% of persons had mental health problems.

OBJECTIVES

The purpose of this study was to: a) measure the knowledge, attitudes, and beliefs about FAS of professionals working in the fields of child welfare/child protective services, foster care, and Medicaid enrollment, and b) use that knowledge to inform educational and training resources to help them with their work. In this article we report results of respondents who identified themselves as social workers or case workers in the child welfare or social services departments in their counties in New York State.

METHODS

This descriptive study used a modified Dillman survey methodology[7] - multiple contacts with prospective respondents were made to maximize the response rate.

Human Subject Protection

Human subject approval was obtained from University at Buffalo Behavioral Sciences IRB to conduct the study and permission sought from the Commissioner of Social Services in each county to survey their staff. To assure confidentiality, plain individual sealable manila envelopes for the completed surveys were provided for all respondents. Participation in the survey was voluntary.

Sample

A purposive sample of child welfare/child protective services, foster care, and Medicaid enrollment staff and supervisors in counties outside of New York City were surveyed over a five month period.

Instrument

The self-administered survey incorporated questions from similar surveys[8-10] and was pilot tested with staff at the Center for Development of Human Services (CDHS) and students at the University at Buffalo, The State University of New York. The final survey consisted of demographic questions and 15 questions specific to knowledge, attitudes, and beliefs about FAS. In addition, open-ended questions asked how many clients workers had suspected, recognized, referred, or provided care and what additional information they need to better serve clients affected by prenatal alcohol exposure.

While the study was being developed, the consensus statement on the use and meaning of the term FASD was released in the United States; however, the decision was made to focus strictly on FAS as our collaborators did not feel the term FASD would be recognized.

Survey Distribution and Return

Personal phone calls were made to the contact person identified by each commissioner as responsible for distribution and collection of the survey, alerting them to the arrival of the

instrument. Follow-up letters were sent to each contact person after the surveys had been mailed and personal phone calls were made to the contact person after the return date for the surveys had passed. Boxes sent to the contact person contained surveys in self-sealing manila envelopes for distribution to participants. Those who completed the survey placed the questionnaire in the manila envelope and sealed it.

Data Analysis

One-way frequencies (for categorical variables) and descriptive statistics (for continuous variables) were conducted for each variable. Tests of significance were calculated to determine if answers differed by gender, age, ethnicity, and length of time in position, however there were no significant differences in any findings based on these variables.

RESULTS

Of the 57 New York State commissioners contacted, 42 (74%) agreed to allow their staff to participate; 8 commissioners (14%) declined; 7 (13%) commissioners did not respond. A total of 2,868 surveys were sent to 42 counties for distribution. Of these, 1,902 (66%) were returned. A number of respondents chose to mail completed surveys directly to the principal investigator with notes about their interest in the subject or questions regarding personal experiences with FAS. Table 1 shows the demographic breakdown of the 1168 (62%) respondents who were case workers or social workers.

The majority of the respondents self-identified as white, non-Hispanic (91%) and female (82%). The age of respondents ranged from 21–69 years (mean age 40 years). Respondents, other than those who identified themselves as social workers, listed 60 different positions or combination of position titles. Designation regarding status as a case worker was made in consultation with collaborators from the Center for Development of Human Services.

TABLE 1 Demographics of Respondents

	Frequency (%)
Gender (n^1 = 1162)	
Female	960 (82)
Male	206 (18)
Age (n^1 = 1007)	
20-29	191 (19.1)
30-39	322 (32.2)
40-49	265 (26.5)
50-59	201 (20.1)
60-69	28 (2.8)
Race (n^1 = 1143)	
White non-Hispanic	1041 (91.1)
African – American	54 (4.7)
Hispanic	32 (2.8)
Asian	8 (0.7)
American Indian/ Alaska Native	2 (0.2)
Native Hawaiian/ Pacific Islander	3 (0.3)
Other	3 (0.3)
Years in Job Position Title (n^1 = 1128)	
1 year or less	125 (11.1)
>1-5 years	461 (40.8)
>5-10 years	237 (21.0)
>10-15 years	127 (11.3)
>15-20 years	97 (8.6)
>20-25 years	24 (2.1)
>25 years	30 (2.7)

[1]Numbers do not add up to 1168 due to missing data on this question

Prevention

Currently there is no known "safe" level of alcohol use for women during pregnancy and women are advised to completely abstain from alcohol during pregnancy, which the majority of respondents knew. A substantial number of respondents (90%) believed that pregnant women or women planning to become pregnant should abstain from consuming alcohol; 10% believed women should have one drink or less during their pregnancy. Further, respondents were asked if they believed FAS was preventable; 89% believed it was.

Epidemiology

Respondents varied considerably in their knowledge of the epidemiology of FAS including prevalence rates and socioeconomic risk factors as shown in Table 2. Prevalence rates for FAS differ according to the type of method used to identify them; however 1 per 1,000 births is currently accepted as the prevalence rate in the general U.S. population.[1,11] Responding to a 5-item response question asking them to identify the prevalence rate of FAS in the U.S., 39.6 % of respondents chose the prevalence rate of 1 per 1,000. The majority thought it was either more prevalent (40.6 %) or rarer (19.7%).

TABLE 2 Respondents' Knowledge and Belief about FAS Epidemiology

FAS Prevalence Rates (n = 1140)	**Frequency (%)**
1 in 10	102 (8.9)
1 in 100	361 (31.7)
1 in 1000	452 (39.6)
1 in 10,000	186 (16.3)
1 in 100,000	39 (3.4)
FAS Occurs in Similar Rates in All SES Groups (n =1159)	
Agree	521 (45.0)
Disagree	460 (39.7)
Don't Know	178 (15.3)

The reported rates for alcohol use during pregnancy have been associated with high poverty, low income, and low education; however FAS can and does occur in all races and across all socioeconomic status (SES) levels.[1,11] With regard to socioeconomic status as a risk factor, respondents were split in their answers to the question, "FAS occurs at similar rates in all socioeconomic groups of society". Forty-five percent agreed with this statement, 39.7 % percent disagreed, and 15.3 % stated they did not know if FAS occurs at similar rates in all socioeconomic groups of society.

Recognition of FAS

One important way that human services professionals might identify children who have been exposed to alcohol in utero is recognition of the physical features associated with FAS. The current guidelines state, on the basis of racial norms (i.e., those appropriate for a person's race), a person must exhibit all three of the following characteristic facial features: 1) smooth philtrum (University of Washington Lip-Philtrum Guide rank 4 or 5); 2) thin upper lip (vermillion border) (University of Washington Lip-Philtrum Guide rank 4 or 5); and 3) small palpebral fissures (<10th percentile).[12]

However, among this sample, few respondents were able to correctly identify these. Only 209 (18.2%) identified short palpebral fissures, 328 (28.5%) smooth philtrum, and 420 (36.5%) thin upper lip. Importantly, 46.7 % of the participants indicated that they either did not know or were unsure of which facial features were associated with FAS. Further, respondents' inserted unsolicited comments in which they noted that they did not know the terms provided.

Experience with Clients Affected by FAS

This survey asked respondents to indicate how many clients in the last 12 months they had suspected, recognized, referred to confirm, or provided care with regard to FAS. Table 3 shows their responses to this question. The majority of respondents reported that, in the past 12 months, they had not suspected a client of having FAS (56%), recognized a client as having FAS (80%), referred a client to confirm FAS (87%), or had not cared for any children with FAS (90%).

TABLE 3 Respondents' Reporting, Suspecting, Recognizing, Referring or Providing Care for Clients with FAS

During the last 12 months how many clients have you:	Percent Responding Yes					
	Number of Clients					
	0	1	2	3	4	Range
Suspected as possible FAS?	56%	17%	12%	6%	3%	0-50 Clients
Recognized as having FAS?	80%	11%	5%	2%	<1%	0-15 Clients
Referred to confirm a diagnosis of FAS?	87%	9%	2%	<1%	<1%	0-15 Clients
Provided care for with FAS?	90%	6%	2%	1%	<1%	0-30 Clients

Educational Needs

The survey asked whether respondents had received any formal training in seven important areas related to helping to prevent secondary disabilities in children already affected by FAS. As shown in Table 4, the majority of respondents reported not having received formal training concerning FAS.

The top three areas for which respondents reported receiving some training were: a) effects of fetal alcohol exposure on the developing fetus (48.9%); b) recognizing features associated with FAS and other alcohol-related effects (43%); and c) identifying risk factors associated with fetal alcohol exposure (40.8%).

The survey also asked respondents to identify how prepared they felt to: a) identify children with possible FAS or other alcohol-related disorders; and b) manage/coordinate the treatment of children with FAS and other alcohol-related disorders. Table 5 shows their responses. Over 70% reported feeling unprepared to identify children with FAS and over 85% reported feeling unprepared to manage/coordinate treatment of these children.

TABLE 4 Type of Formal Training for FAS

TOPICS	Reported Receiving Training	
	Yes N[1] (%)	No N (%)
Recognizing features associated with FAS and other alcohol-related effects	496 (43.0)	657 (57.0)
Effects of fetal alcohol exposure on the developing fetus	565 (48.9)	591 (51.1)
Methods to screen children suspected of having prenatal alcohol exposure	120 (10.4)	1036 (89.6)
Identifying risk factors associated with fetal alcohol exposure	473 (40.8)	685 (59.2)
Interventions to prevent secondary FAS disabilities	139 (12.0)	1015 (88.0)
Making referrals for children suspected of having prenatal alcohol exposure	199 (17.2)	956 (82,8)
Assisting clients in assessing local FAS-related resources	133 (11.5)	1021 (88.5)

[1] Numbers do not add up to 1168 due to missing data on this question

TABLE 5 Type of Preparation by Different Levels of Preparedness

In general, how prepared do you feel to:	Very Prepared	Somewhat Prepared	Somewhat Unprepared	Very Unprepared
	N[1] (%)	N (%)	N (%)	N (%)
Identify children with possible FAS or other alcohol-related disorders?	18 (1.6)	321 (27.7)	401 (34.6)	420 (36.2)
Manage/ coordinate the treatment of children with FAS and other alcohol-related disorders?	14 (1.2)	157 (13.6)	385 (33.2)	602 (52.0)

[1]Numbers do not add up to 1168 due to missing data on this question

Strengths and Limitations

There are a number of strengths to the study. The sample represented workers from 74% of the counties in New York State outside of New York City. Further, because of the scarcity of information in this area, these results provide important initial insights on where to best target educational and training programs. However, the survey findings must be viewed in relation to several study limitations. Because random sampling was not employed, the results of this study have limited generalizability. As such, the findings are not generalizable to all social workers and case workers. Studies of human service personnel in other geographic areas are needed to supplement these findings.

CONCLUSIONS

Recommendations

The findings from this study raise important public policy issues. Human services professionals, in particular social workers and case workers, are found in a wide variety of practice settings; as such these professionals are well positioned to reduce new cases of FAS or, when necessary, intervene with individuals and families affected by FAS. This study provides critical information that can act as a template to assist in the enhancement of required information and skill sets.

On the positive side, while this study was being conducted both the United States and Canadian governments undertook major public policy initiatives to bring the problem of fetal alcohol spectrum disorder to the public's attention[13,14] and the message on prevention was being heard. The participants in this study had particular strengths in knowing that FAS is preventable and that pregnant women should abstain from alcohol use during pregnancy.

Early diagnosis and access to appropriate interventions and resources is critical to preventing the birth of affected children in the future; as well as obtaining appropriate intervention, counseling and treatment for the mother, previously undiagnosed siblings, and secondary disabilities.[2,15] Unfortunately, participants in this study were less knowledgeable about the epidemiology of FAS and the facial dysmorphia associated with FAS. This may contribute to the fact that few participants reported suspecting, recognizing, referring, or providing care for a child with FAS. Both the Canadian and United States governments have continued to make educational materials available. These include guidelines for diagnosis[12,15] and free online courses ranging from understanding the causes of FASD to working with children already affected.[16] These resources can be useful in aiding the human service professionals to identify those at risk. Additional studies are needed to document and measure how the curriculum and other materials on this subject are reaching front line human service professionals.

Human service professionals have to address multiple issues in the families they work with. To help keep the needs of children with FASD in the forefront, assertive assessment protocols need to be implemented. Given the large percent of children with FASD in the foster care, adoption, juvenile justice and mental health systems, professionals in these systems need to have a high index of suspicion that a child with behavioral or mental health problems has secondary disabilities resulting from in utero alcohol exposure. While the use of a uniform FASD screening technique is important, the likelihood that children with FASD

will be identified and referred would be increased if institutions or organizations have one or more individuals with the knowledge of best resources for diagnosis and treatment in their community, who is responsible for systematically following up the child.

Reviews and statistics of how many children were screened, appropriately identified with FASD, and received treatment by individual agencies should be reported on a regular basis. Techniques similar to those used in the pharmaceutical industry, such as FASD detail representatives, could provide ongoing reminders of the need to screen for FASD.

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Corresponding Author:
lcaley@buffalo.edu

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