

Clinical Article

Trends in Fetal Alcohol Syndrome

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Abstract

A sixteen-fold decreased incidence of fetal alcohol syndrome (ICM-9-CM code 760.71) was reported in the period 1985-1996 at the Albert Einstein College of Medicine affiliated hospitals. This result contrasts with the six-fold increased incidence in the period of 1979-1993 reported by the Birth Defects Monitoring Program of the US Department of Health and Human Services. Factors which may have contributed to the contrasting rates of incidence are discussed such as race, maternal age, socio-economic status, drug use, abortion rates, and educational background. *Int Pediatr.* 2003;18(2):114-118.

Key words: alcohol consumption, congenital disorder, fetal alcohol syndrome, maternal alcohol

Introduction

Fetal alcohol syndrome is a multisystem disorder that arises from maternal alcohol consumption, occurring in approximately 0.97/1000 live births.¹ In 1973, Jones et al delineated this disorder in the offspring of chronic alcoholic mothers.² The syndrome consists of prenatal and postnatal growth deficiency, deficient intellectual and social performance, and a pattern of minor structural abnormalities of the cranio-facies as well as limbs and heart.

Based on information from the national Birth Defects Monitoring Program (BDMP), the US Department of Health and Human Services reported on the trend of FAS from 1979-1993. The report showed a six-fold increase in the incidence of FAS during this period.³ The information from the BDMP was obtained through hospital discharge data of newborns in nonfederal, short-term stay hospitals. Cases of FAS were identified using the hospital

discharge code 760.71 which is defined as "noxious influences affecting fetus via placenta or breast milk, specifically alcohol; includes fetal alcohol syndrome," ICD-9, 1994 (International Classification of Diseases, Ninth Revision Clinical Modification).⁴

Although the data gathered using this discharge code are not specific for fetal alcohol syndrome, it is the current standard means by which the incidence of FAS is calculated. There are currently studies in progress to assess better means of acquiring such information in an accurate and timely way without infringing upon patient confidentiality. One recent study assessed birth certificates as a source for FAS incidence, but found only 11% sensitivity.⁵

One of the above authors - a clinical geneticist asked to consult in neonatal intensive care units and well baby nurseries - has observed that the area served by the Albert Einstein College of Medicine (including but not exclusive to the Bronx) has seen a trend in FAS not at all similar to reported data. In contrast to a six-fold increase in the incidence of FAS, the author has noted a significant decrease in the incidence of FAS. The purpose of this study is to test this observation.

Methods

In order to quantify the author's observation, data were gathered from five of the Albert Einstein College of Medicine affiliated hospitals including Jacobi Medical Center, Weiler Hospital, Bronx Lebanon Hospital, North Central Bronx Hospital, as well as Long Island Jewish Hospital. All data gathered were anonymous with respect to patient identifiable information. Data were gathered from the years in which these hospitals computerized their discharge data; not all hospitals began computerizing their data the same year. Professionally-trained coders were responsible for the coding in the discharge department of each hospital. No charts were reviewed to test the accuracy of the diagnosis.

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The total number of reports of code 760.71 was divided by the number of live births in that hospital in that year and then multiplied by 1000 in order to calculate the incidence of FAS per 1000 live births per year.

Results

The data collected from each hospital are presented in Fig 1 and Table 1. The combined incidence of FAS throughout the five hospitals was also calculated per 1000 live births per year and can be seen in Fig 2. The total number of births recorded from each hospital and for each year varied greatly because of the size of the hospital, institutional changes in the obstetrics programs and because coding of nursery discharges from two hospitals did not begin until after 1985. The coding for NCB was incomplete during the first year of coding. The total number of births recorded over the 12 year period from Weiler was 41,623, Jacobi 31,461, Bronx-Lebanon 11,708, NCB 32,461, and LIJ 50,973. The total number of births in the study was 168,226.

Discussion

Both Figures 1 and 2 show that in contrast to the six-fold increase seen nation-wide by the US

Department of Health and Human Services, in the five hospitals surveyed, the trend in FAS incidence reached its highest point in 1989 (1.18/1000) and has since decreased to a low of 0.07/1000 in 1996 (a sixteen-fold decrease). Our data from 1993 (0.58/1000), the last year reported on by the US Department of Health and Human Services, are somewhat consistent with the published data (0.67/1000). The reporting from our hospitals also agrees with the prevalence of 0.2/1000 in 1994 reported by New York State (New York State Department of Health Congenital Malformations Registry Annual Report, 1998). However, our data from 1995 show an incidence of only 0.17/1000 as compared to the report of 0.97/1000 by Abel.¹

Many factors must be considered when discussing the incidence of fetal alcohol syndrome. These include maternal age, socio-economic status, race, drug use, the rate of abortion, educational background, as well as factors affecting data reporting. We will discuss some of these issues.

The patient population served by the Albert Einstein College of Medicine is diverse. It includes patients with private insurance as well as those on Medicaid. It includes a large percentage of patients of lower socio-economic status who are underserved, with a very high prevalence of alcoholism, drug addictions, and HIV related illnesses. Minority patients,

Table 1 - Data of FAS and number of live births per year in each hospital

	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996
HOSPITAL												
Weiler												
760.1	2	2	0	2	0	1	1	0	1	1	0	0
total	3118	3075	3384	3471	3703	3611	3563	3617	3513	3631	3881	3056
Jacobi												
760.1		5	7	4	8	6	3	2	2	1	0	0
total		2788	2943	3148	3301	3230	2991	2948	2985	2899	2394	1834
Bronx-Leb.												
760.1									7	3	2	1
total									3241	3214	3048	2205
NCB												
760.1	0	0	5	6	7	5	2	2	0	1	1	0
total	239	2785	2986	3273	3571	3394	3432	3446	3261	3153	3105	2802
LIJ												
760.1	1	3	0	3	2	1	10	4	0	0	0	0
total	3723	4037	4065	4272	4058	4098	4156	4280	4196	4331	5231	4526

Data of FAS (code 760.71) and number of live births (total) per year in each of five of the Albert Einstein College of Medicine affiliated hospitals in NY; Weiler, Jacobi, Bronx Lebanon (Bronx Leb.), North Central Bronx (NCB), Long Island Jewish (LIJ).

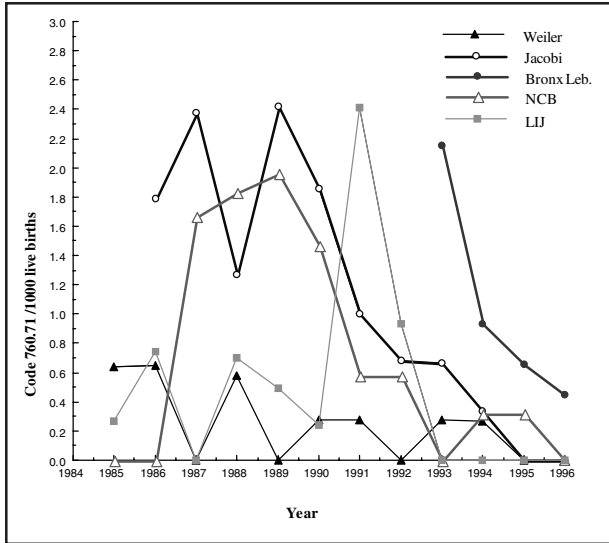


Fig 1 - Incidence of FAS (code 760.71) per 1000 live births per year in each of five of the Albert Einstein College of Medicine affiliated hospitals in NY; Weiler, Jacobi, Bronx Lebanon (Bronx Leb.), North Central Bronx (NCB), Long Island Jewish (LIJ).

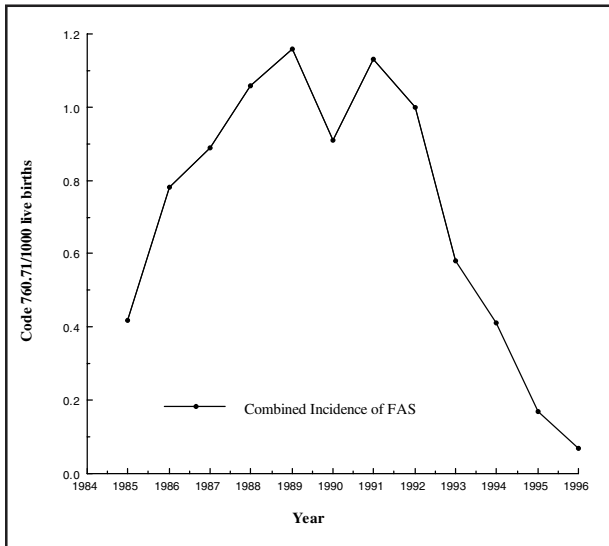


Fig 2 - Combined incidence of FAS (code 760.71) per 1000 live births per year in five of the Albert Einstein College of Medicine affiliated hospitals in NY.

African Americans and Hispanics, represent the majority of patients.

The population also includes a large number of pregnant teenagers.⁶ This is relevant because it may be

harder for these women, some as young as 10 years of age to acquire alcohol. The high percentage of babies born to women under 21 in this community may significantly contribute to the decreasing and/or lower incidence of FAS reported. In one study by Day and Richardson that characterized heavy drinkers, it was found that such women are more often Caucasian, of higher education, higher income, and work full time.⁷ This description does not apply to many of the people in the community served by the Einstein hospitals. Another study showed that binge drinking and heavy drinking were highest among the white teenage group, a group not heavily represented in this area.⁸

Another factor that may influence the incidence of FAS is the high rate of abortions performed in this area. New York State as a whole has one of the highest abortion rates. As of 1992, NY ranked second, behind only Washington DC, in the number of abortions per 1000 live births (US Bureau of the Census, 1996).⁹ Those women who conceive unwanted pregnancies and might continue to drink throughout their pregnancy, may also be women who choose to have abortions, thereby decreasing the incidence of children born with FAS.

It is possible that those women who drink also use drugs such as cocaine and heroine and/or may be malnourished-both which may lead to early spontaneous abortions. These habits may also contribute to preterm delivery and a high rate of perinatal mortality, further decreasing the incidence of FAS. It is also possible that when a newborn is affected by a condition more obvious than FAS, such as drug withdrawal or a positive toxicology screen, the discharge diagnosis may reflect this problem while overlooking FAS.

One hypothesis considered by the authors is that the incidence of FAS is being replaced by an increased incidence of cocaine embryopathy-congenital defects attributed to maternal cocaine abuse. This hypothesis was hard to support upon examination. There are not yet computerized hospital records available with that information due to the lack of a discharge code for cocaine embryopathy. The data that were available included the incidence of cocaine found in newborn urine (code 760.75). The data only extended back five years and do not show a significant trend in either an upward or downward direction. The data collected on the discharge diagnosis of general drug withdrawal

in the newborn population (779.5) actually show a slightly downward trend from 1985-1996. These data do not help us explain the decreasing incidence of FAS in this population.

A recent questionnaire study of 67 clinic patients in the north-east Bronx (Hoffman, unpublished data) found that almost 90% of the women surveyed knew that maternal alcohol use can cause mental retardation. Almost 97% of the women surveyed also knew that no alcohol should be used during pregnancy. Of these women, 60% reported that they had learned about maternal alcohol use from health care professionals.¹⁰

It is possible that due to the high level of awareness concerning drug and alcohol abuse in the Bronx, the doctors of the Albert Einstein College of Medicine may be more likely to discuss issues concerning alcohol and drug use during pregnancy. Discussing these issues may create a more highly educated group of pregnant women who are less likely to drink during pregnancy.

The accuracy and frequency of reporting of FAS by physicians is probably the most important factor in determining prevalence. The clinical identification of FAS is the major problem contributing to its under-recognition and reporting despite the fact that approximately 15% of pregnant women report drinking.¹¹ Stoler et al observed that only one of seven infants with possible alcohol related effects was properly identified.¹² One study does point out that due to racial differences, certain classic features of FAS such as a thin upper lip may be overlooked by physicians in black infants.¹³ However, we have no reason to believe that reporting of FAS by physicians at our institutions and subsequent discharge coding is anymore or less accurate than the data reported in other surveys.

One of us (Alan Shanske, MD) has had a long experience as a clinical geneticist and has observed a real decrease in patients with FAS attending our genetics clinics. Fully 2.1% of patients registered in our center in 1985 were identified as having FAS. There have been no new patients registered between 1993 and 2000. It is unlikely that the physicians in the Albert Einstein system are less attuned to the features of FAS than other physicians throughout the country. In fact, due to the problems of alcohol and drug abuse in this community, it is probable that the physicians here may be more likely to recognize the disorder. The accuracy of reporting by our hospitals is supported by the

prevalence in New York State reported in the Congenital Malformations Registry Annual Report for 1994 of 0.2/1000.¹⁴ A comparison was made in the New York State registry of FAS prevalence in other birth defects registries: The Metropolitan Atlanta Congenital Defects Program (MACDP) reported a prevalence of 0.23/1000 for the years 1985-1993 and the California Birth Defects Monitoring Program (CBDMP) reported a prevalence of 0.15/1000 for the years 1983-1989. All three registries are well aware of the problems of underreporting and of following up cases.

The discharge code itself is another factor affecting the incidence of FAS reported. Code 760.71 (ICD-9, 1994) is not specific for FAS, and may thereby inflate the incidence of FAS reported. Discharge coding may also include false positives due to the lack of changing the coding status upon follow-up examination which may rule out FAS. In addition, the people who officially code FAS change throughout the years, causing inconsistencies in coding. This is a problem that exists throughout the US and is therefore not specific to this population.

There may be several factors contributing to the decreasing and lower incidence of FAS in the communities served by the Albert Einstein College of Medicine including socio-economic status, race, maternal age, drug abuse, and high abortion rates. Although we see this decreasing trend and low incidence of FAS, it is important to continue to maintain our efforts of prevention and early diagnosis of FAS.

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