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Methods for Surveillance of Fetal Alcohol Syndrome: The Fetal Alcohol Syndrome Surveillance Network II (FASSNetII) – Arizona, Colorado, New York, 2009 - 2014

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Abstract

Surveillance of fetal alcohol syndrome (FAS) is important for monitoring the effects of prenatal alcohol exposure and describing the public health burden of this preventable disorder. Building on the infrastructure of the Fetal Alcohol Syndrome Surveillance Network (FASSNet, 1997-2002), in 2009 the Centers for Disease Control and Prevention awarded five-year cooperative agreements to three states, Arizona, Colorado, and New York, to conduct population-based surveillance of FAS. The Fetal Alcohol Syndrome Surveillance Network II (FASSNetII, 2009-2014) developed a surveillance case definition based on three clinical criteria: characteristic facial features, central nervous system abnormalities, and growth deficiency. FASSNetII modified the FASSNet methods

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in three important ways: 1) estimation of a period prevalence rather than birth prevalence; 2) surveillance of FAS among school-age children (ages 7-9 years) to better document the central nervous system abnormalities that are not apparent at birth or during infancy; and 3) implementation of an expert clinical review of abstracted data for probable and confirmed cases classified through a computerized algorithm. FASSNetII abstracted data from multiple sources including birth records, medical records from child development centers or other specialty clinics, and administrative databases such as hospital discharge and Medicaid. One challenge of FASSNetII was its limited access to non-medical records. Therefore, the FAS prevalence that could be estimated was that of the population identified through an encounter with the healthcare system. Clinical and public health programs that identify children affected by FAS provide critical information for targeting preventive, medical and educational services in this vulnerable population.

Keywords

Birth defects; clinical review; developmental disabilities; fetal alcohol syndrome; population-based surveillance

INTRODUCTION

Prenatal exposure to alcohol causes a range of abnormal clinical outcomes referred to as fetal alcohol spectrum disorders (FASDs); the most involved manifestation of which is fetal alcohol syndrome (FAS). Diagnostic features of FAS include facial dysmorphology, central nervous system (CNS) abnormalities, and growth deficiency (Jones et al., 1973). Individuals with FAS have physical and cognitive disabilities requiring costly, lifelong care. A recent report revealed that the average annual medical expenditure for children with FAS is nine times greater than for children without FAS (Amendah et al., 2011). Identifying children with FAS and providing appropriate interventions are key steps toward monitoring the impact and burden of this condition and improving the quality of life for these individuals and their families (Olson and Montague, 2011).

Public health surveillance of FAS presents unique challenges compared to other birth defects and developmental disabilities. In particular, because both physical and neurodevelopmental issues are included in the diagnostic criteria, multiple data sources are usually required to satisfy the case definition. Also, alcohol use during pregnancy might not be documented in records. In situations of maternal addiction, children affected by prenatal alcohol exposure might not reside with their birth mother complicating record finding. Finally, although some physical features of FAS are present at birth or in infancy, many of the CNS abnormalities associated with FAS do not manifest until the late preschool or early school years.

Despite these challenges, efforts to quantify the number of children with FAS continue. Reported prevalence of FAS worldwide ranges from 0.1 to 120 per 1,000 children (May et al., 2009) depending on the study population. Within the United States the prevalence of FAS, as reported by the Centers for Disease Control and Prevention (CDC), ranges from 0.1 to 1.5 cases per 1,000 births (CDC, 1993; CDC, 1995; CDC, 1997; CDC, 2002). May et al.

(2009) reported a range of 2 to 7 per 1,000 cases in various racial and socioeconomic populations in the United States. The variation in prevalence is likely the result of differences in case definition and ascertainment methods, but could also reflect regional differences in the prevalence of prenatal alcohol exposure.

In 1997, the CDC awarded five-year cooperative agreements to Alaska, Arizona, Colorado, New York, and Wisconsin, to establish or enhance population-based surveillance of FAS among infants and young children. These states became known as the Fetal Alcohol Syndrome Surveillance Network (FASSNet). FASSNet developed a multiple-source methodology for conducting surveillance of FAS through review of medical and clinical records (Hymbaugh et al., 2002) and in collaboration with CDC developed a surveillance case definition based on the diagnostic criteria presented in the 1996 Institute of Medicine report on FAS (IOM, 1996).

Building on the infrastructure of FASSNet, in 2009 CDC awarded five-year cooperative agreements to Arizona, Colorado, and New York, referred to as the Fetal Alcohol Syndrome Surveillance Network II (FASSNetII), to conduct population-based surveillance of FAS in children ages seven to nine years. The older age cohort was selected to detect CNS abnormalities that are not apparent at birth or during infancy. In addition, a clinical review component was developed and implemented as part of the surveillance methodology. In this manuscript we describe the methodology used by FASSNetII.

METHODS

Population

The FASSNetII study population included children ages seven, eight, and nine years (birth years 2001, 2002 and 2003) who resided within the catchment areas of the three sites, Arizona, Colorado, and New York, in the year 2010. Arizona ascertained cases statewide, whereas Colorado selected a seven county area (metropolitan Denver: Adams, Arapaho, Boulder, Broomfield, Denver, Douglas, and Jefferson counties) and New York selected nine western counties (Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Monroe, Niagara, Orleans, Wyoming). Since residency can be difficult to determine for children with FAS because of frequent placement in foster care or being under the supervision of Child Protective Services, a residency criteria protocol was implemented. Generally, if a child's address within the catchment area for the study year could not be confirmed, but an address within the catchment area was identified for the year prior to the study year (2009) and the year after the study year (2011) then residency during 2010 was assumed to be within the catchment area.

Data Sources and Case-finding Procedures

FASSNetII used a standardized methodology that relied on both passive reporting of cases and active review of records from a variety of sources. In New York, FAS is a reportable condition by legislation and in Colorado, by board of health regulations. Reporting of FAS is not mandated in Arizona.

To identify potential cases of FAS, sites used their state birth defects monitoring program, which included access to vital records, hospital discharge data, and selected administrative data sets. In addition, other surveillance systems (e.g., autism and other developmental disabilities) were used to identify children who might have FAS. Additional sources included Medicaid and health maintenance organization databases, as well as data from the juvenile justice system. Genetic, developmental and specialty clinics were contacted and asked to identify children evaluated for suspected or confirmed FAS, alcohol-related neurodevelopmental disorders (ARND) or prenatal alcohol exposure. Private physicians also were contacted to request reports of children with FAS, but no children with FAS were identified from this source.

Computer queries of International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes were used at several sources to identify children who might have FAS. The ICD-9-CM code 760.71 (alcohol affecting fetus or newborn via placenta or breast milk) was the code most often used, either alone or in combination with other codes such as ICD-9-CM codes 315 (specific delays in development), 317 (intellectual disability – mild), 318 (intellectual disability – other specified), 742 (other congenital anomalies of the nervous system), 764 (slow fetal growth and fetal malnutrition), 765 (disorders relating to short gestation and low birth weight) and 783 (symptoms concerning nutrition metabolism and development).

Once identified, records of children suspected of having FAS were screened to determine if they met the age and residency requirements before records were requested or data were abstracted. All possible data sources were pursued until the surveillance case definition was met or sources were exhausted.

Surveillance Case Definition

The surveillance case definition for FASSNetII (Table 1) used the same general criteria as FASSNet (Hymbaugh et al., 2002). These criteria were operationalized from the recommendations of the 1996 Institute of Medicine report on FAS (IOM, 1996) and included prenatal or postnatal growth deficiency, CNS abnormalities, and characteristic facial features. Since prenatal alcohol exposure is necessary to cause FAS, maternal alcohol use was included in the surveillance case definition and abstracted when available, but due to difficulty in obtaining documentation of this information, it was not required to meet the surveillance case definition.

Growth Deficiency—Growth deficiency was defined as weight, height/length, or weight for height/length at or below the 10^{th} centile at any time from birth to the most recently abstracted record based on standard growth curves for intrauterine and postnatal growth (Kuczmarski et al., 2002; Alexander et al., 1996; Lubchenco et al., 1966). Postnatal measures were corrected for gestational age up to 24 months if the recorded gestational age was <37 weeks. Birth measures were corrected for gestational age if the recorded gestational age at birth was <40 weeks.

CNS Abnormalities—CNS abnormalities included small head circumference and/or CNS dysfunction diagnosed by a qualified examiner. Small head circumference was defined as a

measurement at or below the 10th centile at any time from birth to the most recently abstracted record and was assessed from standard curves of head circumference (Rollins et al., 2010; Lubchenco et al., 1966).

Qualifying criteria for CNS dysfunction included (1) a diagnosis of developmental delay if recorded in the medical record by a qualifying examiner or based on standardized testing results more than one standard deviation below the mean in at least two of the following developmental domains: language, cognitive/intellectual, adaptive functioning, social/emotional/behavioral, executive functioning, memory, attention, academic motor and global/general; (2) a standardized measure of intelligence falling at or greater than two standard deviations below the mean or a diagnosis of intellectual disability recorded in the medical record by a qualified examiner; and/or (3) a diagnosis of attention deficit disorder or attention deficit hyperactivity disorder (ADHD) recorded in the medical record by a qualified examiner. A qualified examiner was defined as an examiner with the appropriate license or degree and deemed qualified in the field of interest.

Facial Features—Short palpebral fissures, abnormally smooth philtrum, and thin upper lip are the most discriminating facial features of FAS. The case definition criterion for these facial anomalies was met through either (1) a qualitative statement from a qualified examiner that the child had facial features consistent with a diagnosis of FAS, or (2) documentation by a qualified examiner of at least two of the three characteristic facial features of FAS (i.e., short palpebral fissures, smooth philtrum and thin upper lip). The short palpebral fissure criterion was met by either a qualitative statement from a qualified examiner or by an objective measure recorded in the medical record that was compared to a standard used for palpebral fissure length (Thomas et al., 1987). Likewise, the lip and philtrum criteria were met by either a qualitative statement or by documentation of a level four or five lip/philtrum appearance according to the criteria developed by Astley and Clarren (1995).

Case Classification

Documentation of the specific features characteristic of FAS formed the basis of case classification as confirmed, probable, or not FAS. An individual was considered positive for one of these features if a qualified examiner documented the feature in any of the abstracted records. Confirmed FAS was defined as documentation of facial features, CNS abnormalities and growth deficiency; probable FAS was defined as documentation of facial features and either CNS abnormalities or growth deficiency (Table 1). In FASSNet, case classification was done by a computer-generated algorithm, while in FASSNetII case classification was accomplished by the computer-generated algorithm as well as a clinical review of abstracted data for a subset of potential cases.

Case Classification by Computer Algorithm—A computer-generated algorithm examined all characteristic features of FAS across all abstracted records and used those features to assign case status. The algorithm employed the most inclusive criteria for confirmed and probable FAS, since it recognized a feature to be present if it had ever been documented as present, regardless of whether that feature was documented as not present by

another qualified examiner in another record. The algorithm did not distinguish between qualified examiners who might have different levels of expertise to judge the phenotypic facial features, so observations of a pediatrician, developmental pediatrician and a clinical geneticist or dysmorphologist each carried equal weight. The algorithm also did not distinguish between examiners such as developmental pediatricians, family practitioners, or pediatricians who have different levels of expertise to judge developmental disability. In addition, documentation of a characteristic feature of FAS at any age was acceptable.

Case Classification by Clinical Review—To conduct case classification in more depth than was possible through an algorithm-based process alone, FASSNetII established a Clinical Review Committee (CRC). The CRC consisted of two dysmorphologists and a clinical psychologist that reviewed all cases classified as confirmed or probable by the algorithm.

Prior to cases being reviewed by the CRC, designated individuals at each surveillance site performed quality checks for completeness and accuracy of the abstracted information. This process also provided quality control of the computerized algorithm. Within each site, local review was conducted on records that the computer algorithm had classified as either probable or confirmed. Sites also reviewed other cases that had confirmation of only one facial feature or that were classified by the algorithm as probable, but lacked confirmation of CNS to assure possible cases were not missed.

A pooled database of de-identified cases from all surveillance sites identified from local review as eligible for clinical review was created and distributed to all CRC members for review. Each member independently reviewed and evaluated the abstracted information for each child. The clinician assigned a case status, based on the available information, and this assignment was recorded in the surveillance database. A report containing case status assigned by each clinician was distributed to all sites.

If all three CRC members agreed on case status, the case underwent no additional review. If there was disagreement among the three CRC members, the case was reviewed during a conference call of the CRC. After discussion of each case, if CRC members were able to agree on a case status, that status was assigned. Occasionally, the CRC reached a conclusion that additional information was needed in order to arrive at consensus. In these cases an effort was made to ascertain additional information, and the case was reviewed again by the CRC during the next month's conference call. If CRC members disagreed about case status and no more information was available, the case status assignment defaulted to the lowest level of certainty. For example, if there was disagreement between categorizing the case as confirmed or probable, the case would be assigned to the probable category.

Final Case Categorization—Every child suspected of having FAS was screened for inclusion in FASSNetII and was classified into one of six categories. The first three categories included those who did not meet the inclusion criteria: children who did not have a birth year in 2001-2003; children who died prior to 2010; and children who did not meet the residency requirement. Category four included children who did not meet the case definition by algorithm and for which all sources of data for abstraction were exhausted.

Categories five and six were for cases that met the case definition. Category five included any child that was considered a confirmed or probable case by the computer algorithm, but was determined to be "not a FAS case" by the CRC. Category six included confirmed and probable cases that met the case definition by both the computer algorithm and the CRC.

Data Quality

Several measures were employed to maintain data quality and the consistency of data collection among sites. Data managers regularly reviewed the abstracted data for completeness and accuracy. The database application used for data collection at all sites was programmed with automated consistency and range check for selected variables.

Standard data abstraction procedures and an abstraction manual were developed with representation from all sites and CDC. During the first year of the project, abstractors participated in 12 hours of training. To facilitate reliability across sites, abstractors met monthly via conference call to review de-identified records and discuss issues encountered by the abstractors. Issues not addressed in the abstractors' manual were resolved by consensus of the Principal Investigators and/or study clinicians. In addition, during years two and three of the project two quality-control exercises were completed to assess inter-abstractor agreement on key data elements relevant to the case definition. Adjustments were made to the protocol when discrepancies were found, and additional training was provided to promote consistency in future data abstractions.

DISCUSSION

Surveillance of FAS is an important public health activity that will bring attention to the burden of this preventable life-long disability. Compared to other methodologies such as clinic-based studies, records-based systems like FASSNetII are less expensive (May et al., 2009) and have the potential for long-term sustainability. In addition, the methodology used by FASSNetII can be integrated with existing birth defects or developmental disabilities monitoring programs and allows access to additional data to identify potential risk factors for both mother and child outcomes.

FASSNetII modified the surveillance methodology of FASSNet in three important ways: 1) estimation of a period prevalence rather than birth prevalence to address a highly mobile target population; 2) identification of school-age children to better document the CNS abnormalities that are not apparent at birth or during infancy; and 3) implementation of a clinical review of abstracted data of probable and confirmed cases to review and classify cases in more depth than is possible through a computerized, algorithm-based process.

One strength of FASSNetII was its use of multiple data sources to gather the diagnostic information needed to meet the surveillance case definition. Multiple sources were particularly important since children with FAS are often evaluated by a multidisciplinary team of experts (e.g., geneticist, developmental psychologist) or even a series of specialists. Further, some aspects of the case definition manifest for different children at a variety of developmental stages. For example, growth deficiencies and facial features are typically

apparent at birth or during infancy, but some CNS functional abnormalities do not emerge until later in the preschool or school age years.

A second strength of FASSNetII was that it provided an estimate of the period prevalence for school-age children rather than birth prevalence. A period prevalence is more useful for predicting the service needs of children with FAS since many functional disabilities emerge later in development, and adopted children could be included in the prevalence estimate. It allows for migration of families in and out of the catchment area as well as the capture of children in foster, adoptive or other out of home care situations. In addition, surveillance of FAS in older children provided an opportunity to better identify and describe a greater range of CNS abnormalities associated with FAS.

A final strength of FASSNetII was the inclusion of a clinical review component into the surveillance system. This provided an opportunity to assess aspects of previous public health surveillance efforts for FAS, especially FASSNet, which was exclusively a records-based system. Use of a clinical review component has proven effective in surveillance programs for other conditions such as autism spectrum disorders (Rice et al., 2007) and Duchenne and Becker muscular dystrophy (Miller et al., 2006) and could have important implications for future FAS surveillance efforts.

Public health surveillance for FAS has several inherent challenges which created limitations for FASSNetII. First, FASSNetII was limited in its ability to assess and ensure the completeness of case ascertainment. Its quality assurance and control procedures helped to ensure that the abstractions of a given case were as complete as possible, yet there were no procedures in place to ensure that every child with FAS was captured by the surveillance system, nor any gold standard against which the surveillance system could be measured. Second, FASSNetII was limited by its data sources. It largely relied on medical records data, which could be incomplete. This is evidenced by a recent study by Hansen et al. (2014) that used electronic health records and the FASSNet case definition to examine prevalence of children with features of FAS in a managed healthcare group and found documentation of the characteristic facial features of FAS lacking. Third, FASSNetII did not implement a standardized clinical evaluation for every child suspected with FAS; it relied on documentation provided by a wide array of community providers, with variable training and experience in the assessment of the condition. Fourth, because children with FAS can be disproportionately in the foster care system and/or living with adoptive families, it was challenging to identify these children and to obtain some types of information, especially prenatal alcohol exposure, biological parent's demographic information, and/or the child's legal address in 2010 to ensure that the criterion for residency was met. Finally, FASSNetII relied on data sources that were primarily from inpatient healthcare facilities. The sites were not able to consistently access outpatient records, behavioral health records, or school records. Therefore, the FAS prevalence calculable through FASSNetII data is that of the population identified through an encounter with the healthcare system. It represents the subpopulation of children with access to specialty care such as genetics or multi-disciplinary developmental clinics. The proportion of children with FAS who do not interact with the healthcare system in the United States is not known.

FAS surveillance is an important public health activity for monitoring the effects of prenatal alcohol exposure as well as describing the public health burden of this disorder. Although records-based systems such as FASSNetII generate lower estimates of FAS prevalence than clinic-based studies and active in-school systems (May et al., 2009), its multiple-source methodology represents an important component of a sustainable surveillance system for FAS. Coordinated public health activities that emphasize the importance of identifying and diagnosing children with FAS or any of the FASDs to clinical care providers will help harmonize efforts across these different approaches.

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Table 1

Fetal Alcohol Syndrome Surveillance Network II (FASSNetII) Case Definition

	PHENOTYPE POSITIVE		
DIAGNOSTIC CATEGORY	**FACE**	**CENTRAL NERVOUS SYSTEM (CNS)**	**GROWTH**
Confirmed FAS Phenotype With or Without Documentation* of In utero Alcohol Exposure	Abnormal facial features consistent with FAS as reported by a physician **Or** Two of the following: • Short palpebral fissures • abnormal philtrum • thin upper lip	At least one structural or functional anomaly **STRUCTURAL** Head circumference ≤ 10th centile at birth or any age **Or** **FUNCTIONAL** Standardized measure of functioning in at least 2 of 9 domains ≥1 standard deviations below the mean or diagnosis of developmental delay by a qualified examiner **Or** Standardized measure of IQ ≥ 2 standard deviations below the mean on a standardized test or diagnosis of intellectual disability by a qualified examiner **Or** ADD or ADHD diagnosed by a qualified evaluator	Growth delay indicated in at least one of the following: **INTRAUTERINE** Weight or height corrected for gestational age ≤ 10th centile **Or** **POST NATAL** Weight or height ≤ 10th centile for age **Or** Weight for height ≤ 10th centile
Probable FAS Phenotype With or Without Documentation* of In utero Alcohol Exposure	**Required** Same as Confirmed	Must meet **either** CNS or GROWTH criteria as outlined in the CONFIRMED phe	
Suspect	All children referred into the surveillance system.		

FAS – fetal alcohol syndrome; IQ – intelligence quotient; ADD – attention deficit disorder; ADHD – attention deficit hyperactivity disorder

*Documentation in any abstracted record of maternal alcohol use during the index pregnancy.