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Exploring the Feasibility of Using Electronic Health Records in the Surveillance of Fetal Alcohol Syndrome

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Abstract

Background—Explore the use of electronic health records (EHRs) in fetal alcohol syndrome (FAS) surveillance systems.

Methods—Using EHRs we identified diagnoses and anthropometric measurements related to the FAS criteria developed by the Fetal Alcohol Syndrome Surveillance Network (FASSNet) among children aged 0 to 12 years.

Results—There were 143,393 distinct children aged between 0 and 12 years enrolled in Kaiser Permanente, Georgia, during the study period. Based on diagnoses and anthropometric measurements, 20,101 children met at least one criterion of interest, and when grouped into combinations of different criteria there were 2285 who met GROWTH+CNS criteria, 76 children who met GROWTH+FACE criteria, 107 children who met CNS+FACE criteria, and 93 children who met GROWTH+CNS+FACE criteria. The prevalence of FAS as defined by FASSNet is 1.92 per 1000 children. We linked 17,084 (85.0%) children to their mothers in the health plan; only 3% of mothers of children in the GROWTH+CNS+ FACE group had an indication of alcohol or drugs use, but they had the highest rate of depression (39%).

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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.

Additional Supporting Information may be found in the online version of this article.

Conclusion—Data of utility in identification of FAS are readily available in EHRs and may serve as a basis for intervention with at-risk children and in planning of future FAS surveillance programs.

Keywords

electronic health records; fetal alcohol syndrome; surveillance

Introduction

Prenatal alcohol exposure is the leading preventable cause of birth defects and developmental disabilities (American Academy of Pediatrics. Committee on Substance Abuse and Committee on Children With Disabilities, 2000). The diverse constellation of structural, developmental, and behavioral abnormalities that results from prenatal alcohol exposure is referred to as Fetal Alcohol Spectrum Disorders (FASD), the most severe of which is Fetal Alcohol Syndrome (FAS) (Barr and Streissguth, 2001; Ebrahim et al., 1998; Centers for Disease Control and Prevention, 2002).

The diagnosis of FAS rests on the demonstration of characteristic facial features, prenatal and/or postnatal growth deficiency, structural or functional abnormalities of the central nervous system (CNS), and a history of prenatal alcohol exposure. Therefore, the most effective diagnostic regime involves multidisciplinary assessment. Because of this diagnostic approach, the identification of appropriate data sources for surveillance is challenging. Given the many challenges of FAS surveillance, it has been suggested that the majority of children with FAS remain undetected; thus, current prevalence estimates are likely to be underestimates (May et al., 2009).

Previous FAS surveillance systems have varied considerably in their methods. Passive surveillance systems collect data from registries or existing records (e.g., birth certificates, birth defect registries, and registries of children with developmental disabilities) and use the available information to ascertain FAS cases. Although this approach is relatively inexpensive, the lack of consistent and complete data and difficulty obtaining relevant longitudinal information from different disciplines are major disadvantages. Active case ascertainment methods include in-school studies and aggressive searches for children with FAS in selected populations or catchment areas (May and Gossage, 2001). While active case ascertainment methods are ideal for identifying children with FAS and have generated the highest prevalence estimates, they involve interdisciplinary interactions and are expensive, time consuming, and labor intensive (May et al., 2009).

Recent evidence-based studies have shown that early, targeted intervention can improve the lives of children with FAS (Peadon et al., 2009). Educational and learning strategies were evaluated in seven studies and suggest that virtual reality training, cognitive control therapy, language and literacy therapy, mathematics intervention, and rehearsal training for memory may be beneficial strategies. Three studies suggested that social skills training may improve social skills and behavior at home and Attention Process Training may improve attention. Pharmacological interventions, evaluated in two studies, showed some benefit from stimulant medications. Important lessons emerged from some of these studies that may

explain success, such as parent education and training, teaching children specific skills they would usually learn by observation or abstraction, and integration into existing systems (Bertrand, 2009). With improved methods to identify suspect children, these evidence-based interventions can be used to improve the long-term outcomes of children with FAS.

Electronic health records (EHRs) have been used recently to create new surveillance systems for chronic kidney disease (Navaneethan et al., 2011), diabetes (Harris et al., 2010), melanomas (Eide et al., 2011), and urinary tract infections (Landers et al., 2010). Others have compared surveillance based on EHRs with traditional surveillance systems for acute hepatitis B (Klompas et al., 2008), acute lung injury (Herasevich et al., 2009), agriculture-based injuries (Earle-Richardson et al., 2011), incidence of Chlamydia infection (Suijkerbuijk et al., 2011), and surgical site infections (Inacio et al., 2011). In contrast, the literature on use of EHRs for birth defects is sparse. Bukowinski and colleagues (Bukowinski et al., 2008) extracted data on hemangiomas and 21 birth defects from EHRs and used the data to investigate associations. The current status of EHR systems in centers for adult congenital heart disease has been evaluated recently (Weiss et al., 2011), including the level of interest in a uniform system on a national basis toward research and other applications.

The goal of the current investigation was to assess the feasibility of developing an FAS surveillance system using EHRs available in an integrated health care system. The first objective was to search for and extract pertinent data elements from the EHRs database that would provide relevant FAS case definition information. The second objective was to analyze these data to assess the availability of particular data elements.

Methods

Data Source and Study Population

Kaiser Permanente, Georgia (KPGA), is an integrated health care system that provides comprehensive medical care services to approximately 240,000 members in the metropolitan Atlanta area (approximately 1.4 million distinct members since 1995). KPGA uses a comprehensive medical record system to record all member interactions within the KPGA health care system, resulting in extensive health record data including: enrollment history, pharmacy dispensing, primary care and specialist encounters, laboratory tests and results, emergency department visits, and hospital admissions and discharges. As of mid-2005 all KPGA medical office primary care and specialty visits are documented and accessible in an EHR.

Fetal Alcohol Syndrome Criteria

For the purpose of assessing the availability of information within EHRs that could be used in the surveillance of FAS, we identified elements related to the FAS surveillance criteria developed by the Fetal Alcohol Syndrome Surveillance Network (FASSNet), a network of states which were funded by the Centers for Disease Control and Prevention to establish or enhance population-based surveillance of fetal alcohol syndrome (Hymbaugh et al., 2002). These criteria are based on the three following themes:

1. Facial features (henceforth known as FACE): short palpebral fissures, thin narrow upper lip, and smooth philtrum.
2. CNS: (a) structural: head circumference below the 10th centile for age and sex; (b) functional: developmental delay, attention-deficit/hyperactivity disorder, and intellectual disability.
3. Restricted growth (GROWTH): birth weight or length for gestational age and sex and/or postnatal weight or height for age and sex below the 10th centile.

For this study, we used a computerized searching method to identify children having any of these criteria and combinations of these criteria. FACE was considered positive even when only one of the facial features was present.

Steps to Identify Potential Children With Fas

Step 1—We first identified children enrolled in KPGA at least once (regardless of length of enrollment) between January 1, 2006, and September 30, 2012. This cohort was then used in all further steps.

Step 2—By using the International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) as shown in Table 1, and/or anthropometric measurements as explained further, we identified children aged 0 to 12 at the time of the encounter, with information related to any of the FAS criteria. For each anthropometric measurement we used national centiles (Centers for Disease Control and Prevention, 2010) for a cutoff of <10th centile (for age and sex) as an indication of restricted growth.

Step 3—Children with at least one of the criteria identified in Step 2 were selected for the final cohort and grouped into mutually exclusive combinations of FACE only, GROWTH only, CNS only, GROWTH+CNS, CNS+FACE, GROWTH+FACE, and GROWTH+CNS +FACE, where the child required only one of the criteria to be assigned to a particular group. For example, a child in the GROWTH+CNS had at least one GROWTH criterion and at least one CNS criterion, but no FACE criterion. Based on these groups, we examined various characteristics of the children including the age at which the criteria were met, race and ethnicity, and their usage of care by a specialty physician or clinic.

Step 4—For the children identified in Step 3, physician progress notes were extracted from EHRs in the form of unstructured text and facial features were searched using text string searches for common terms/phrases developed as part of the FASSNet abstractor guidelines (see Supp. Table A1, which is available online). We performed text string searches for terms related to facial features by “process of elimination,” where we first searched for broad terms and then narrowed the records down through several iterations of refinement by manually looking through the text and eliminating phrases that did not relate to the criteria of interest.

Step 5—Using a unique family subscriber identifier, we linked the children identified in Step 3 to their mothers' records within the health plan database and searched for any indication of tobacco use, alcohol use, drug use, mental diagnoses, or antidepressant use.

Because not all of the children identified in Step 3 were born in the KPGA system, we decided not to limit the search for these conditions to the pregnancy period, but instead searched for them at anytime within the mother's EHR. Any indication of maternal alcohol use was identified in two ways: (1) by means of ICD-9-CM codes suggesting alcohol use (Table 1); or (2) the physician recorded information about alcohol use in the EHR. The EHR has a field labeled “alcohol use (yes/no)” with an accompanying field “alcohol comment.” If a mother's record had at least one “yes” indicated in the field “alcohol use (yes/no),” this was considered a “yes” even if other EHRs for the mother indicated “no.” A similar method was used for the tobacco use field. Due to the inconsistency in the “alcohol use (yes/no)” field, we also searched the “alcohol comment” field for any indication of at least daily alcohol use. When examining the distinct values in this comment field we found most comments were short with minimal complexity. Therefore, we did not perform complex text string searches on the alcohol comment field (unlike the unstructured text of the physician progress notes when identifying facial features), but rather observed and categorized the comments manually.

Statistical Analyses

To assess differences in race, gender, and age across the case-status groups, we used the chi-square test of independence and analysis of variance. We stratified the analyses by those who met only one criterion, and those who met a combination of criteria, and conducted the comparisons among the case-status groups within these two larger groups. When examining race we collapsed “American Indian,” “Hispanic,” “Asian/Pacific Islander,” and “Other” into the category of “Other” due to low numbers.

Results

There were 143,393 distinct children aged between 0 and 12 years (i.e., < 13 years) enrolled in KPGA at least once between January 1, 2006, and September 30, 2012. From the children's EHRs, we extracted information on anthropometric measurements and diagnoses or characteristics of interest. For anthropometric measurements, we extracted 19,648 birth weight readings, 14,795 birth length readings, 547,423 postnatal height readings (available for 87,093 children), 840,193 postnatal weight readings (available for 92,210 children), and 205,568 birth and postnatal head circumference readings (available for 37,617 children up to the age of 3 years). When we searched for the diagnoses of interest, there were a total of 600,708 records extracted belonging to 14,570 distinct children and, on average, each child had nine distinct encounter dates (range = 1–673) and two distinct ICD-9-CM codes (range = 1–16).

As shown in Table 2, 20,101 children met at least one criterion of interest. Among these, 8616 met at least one of the GROWTH criteria, 13,437 met at least one of the CNS criteria, and 702 met at least one of the FACE criteria. Within the GROWTH criteria, the most common subcriterion was an indication of “slow fetal growth” (ICD-9-CM 764.x) (n = 2919) followed by low postnatal weight (n = 2859); within the CNS criteria, the most common sub-criterion was small postnatal head circumference (n = 840) for structural anomalies, and attention-deficit/hyperactivity disorder (n = 7211) for functional anomalies;

within the FACE criteria, the most common subcriterion was anomalies of skull and face bones (*n* = 679).

When grouping the children into mutually exclusive groups based on combinations of different criteria, 2285 distinct children met both the GROWTH+CNS criteria, 76 children met both the GROWTH+FACE criteria, 107 children met both the CNS+FACE criteria, and 93 distinct children met the GROWTH+CNS+FACE criteria. Ninety-one of these had a FACE diagnosis of ICD-9-CM 756.0 ("Anomalies of skull and face bones"). In addition, we identified 12 children who had a 760.71 ICD-9-CM code ("Alcohol-Fetal alcohol syndrome") indicating prenatal alcohol exposure. However, only nine of them were among the children selected in the main cohort for having at least one FAS criterion (4 = CNS only, 5 = CNS+GROWTH). The other three children met no criteria and were excluded from further analyses. We also searched for diagnoses of DiGeorge (ICD-9-CM 279.11) and Velocardiofacial (ICD-9-CM 758.32) syndromes among all 20,101 children and a total of 13 had at least one of these conditions, with only two of these children belonging to the GROWTH+CNS+-FACE group. These syndromes were not present among children in the CNS+FACE or GROWTH+FACE groups.

Table 3 shows selected characteristics of the distinct children who met only one FAS criterion or a combination of FAS criteria. The GROWTH+CNS+FACE group had a higher percentage of whites (46%) compared with blacks (22%), while there were more blacks in the GROWTH+-FACE and FACE only groups. The distributions by sex also differed among the single criterion groups, but not among the combination groups. Among the groups that met a single criterion, those in the CNS only group were older when they met this criterion than the groups who met the growth or face only criteria. Consistent with this result, when we compared children with a combination of criteria, those that included the CNS criterion in the combination were older regardless of the combination of criteria they had met.

Of children in the main cohort, 18,867 (94%) had physician progress notes available, with a total of 931,401 progress notes. These notes were available in all children in the GROWTH +CNS+FACE group and in at least 92% of the children in each of the other groups. Overall, 37% of the children had 1 to 20 distinct notes available, 20% had 21 to 40 notes, 13% had 41 to 60 notes, and the remainder had over 60 notes available. When searching for terms/ phrases related to facial features within the progress notes (Table A1), there were only five children with common phrases related to eye abnormalities (esotropia = 4, strabismus = 1), but none of these children had an indication of abnormal facial features by means of ICD-9-CM. In fact, four of them were in the CNS only group and one in the GROWTH+CNS group. We did not find any records with text related to thin narrow upper lip, smooth philtrum, flattened face, or related anomalies of the nose.

Table 4 shows the characteristics of the mothers we linked to the children in the main cohort. We successfully linked 17,084 (85.0%) of the children to their mothers with the GROWTH+CNS+FACE group having the highest percentage of linked mothers (94.6%). Of those not linked, there were 112 children with no family subscriber identifier and 2947 enrolled under a male subscriber with no female in the family. There were 27 children that had two females listed as the main subscriber and spouse, domestic partner, or spousal

equivalent; therefore, there was no way of assigning either one as the mother. For these combinations, we searched both females' EHRs for alcohol use and other conditions. Based on distinct numbers, there were 496 (2.9%) children with a mother that had an indication of alcohol use ("daily" use from a physician comment or a diagnosis). For mental diagnoses, depression was highest in each of the groups when compared with other mental diagnoses. Overall, the GROWTH+CNS+FACE and CNS ONLY groups had the highest rate of smoking, alcohol, depression, and antidepressant use when compared across the groups.

When counting the number of children who had at least one visit to a physician/facility listed as "specialist care" in the EHR database, the children in the GROWTH+CNS+FACE group had the highest percentage in all selected specialist care categories, except for behavioral health, which was highest among the CNS only group (Fig. 1). Among children in the GROWTH+CNS+FACE group, the highest percentage of children visiting a specialist care physician/facility was for neurology (64%) and ophthalmology (57%).

For the FASSNet surveillance project, children were considered to meet the case status for FAS when they met criteria for CNS+FACE or GROWTH+FACE ("probable" case status) or for GROWTH+CNS+FACE ("confirmed" case status). Using the 143,393 children once enrolled in KPGA between January 1, 2006, and September 30, 2012, as a denominator, the prevalence of FAS as defined by FASSNet case status is 1.92 per 1000 children (or 1.91 per 1000 if we exclude the two children with DiGeorge and Velocardiofacial syndrome).

Discussion

To our knowledge, this is the first study that has explored the use of EHRs in an integrated healthcare system as a method of identifying children with possible FAS. Our study shows how the extensive information available within the EHRs might eventually be extracted and used for FAS surveillance. For example, we were able to identify over 20,000 children having at least one finding of interest from over 600,000 records extracted. Among these, 93 had at least one finding in all three of the areas of interest (i.e., GROWTH, CNS, and FACE), whereas 2468 had anomalies in only two areas (GROWTH+CNS, GROWTH +FACE, or CNS+FACE). When searching physician progress notes for facial features, we failed to identify any information pertaining to thin narrow upper lip or smooth philtrum, but found five notes related to eye abnormalities. This could be due to one or more of the following factors: (1) our text search approach was not sensitive enough to detect the phrases of interest; (2) these features are uncommon and, therefore, few positive hits would be expected; and (3) these anomalies are more often recorded by trained physicians such as dysmorphologists, while the majority of encounters for the children in our cohort were with general pediatricians.

While the purpose of this pilot project was not to develop a prevalence estimate for FAS, it is worthwhile to compare our estimate to previously reported estimates. Of the 143,393 children enrolled between January 1, 2006, and September 30, 2012, 276 met the FASSNet surveillance case criteria for FAS, resulting in a FAS prevalence of 1.92 per 1000 children. This prevalence estimate is within the range of reported FAS birth prevalence in the U.S. general population using varying surveillance methods (Cordero et al., 1994; May and

Gossage, 2001; May et al., 2009). Prevalence for FAS in the reported studies ranged from 0.1 per 1000 births in metropolitan Atlanta (1981–89) to 2.0 per 1000 births in North Dakota (1991–94). The KPGA prevalence is a little higher than those reported for FASSNet, which, for birth years 1995 to 1999, ranged between 0.30 and 1.50 per 1000 births among four surveillance sites (CDC, 2002; Meaney and Miller, 2003). It is of interest to note that in FASSNet, the criteria for facial features was a diagnosis of abnormal facial features reported by qualified examiners or at least two of the facial features of a thin narrow upper lip, short palpebral fissures, or smooth philtrum, whereas in our study, the majority of children with FACE were ascertained by means of a nonspecific ICD-9-CM code.

It is logical to assume that manual abstraction and review of these EHR records is probably the most accurate method for identifying facial features related to FAS. However, to implement surveillance on a large population using this method would be time consuming and expensive. For this reason, searching the physician progress notes is preferable and should be further developed using natural language processing (NLP). Multiple studies have used NLP to examine various outcomes in physician progress notes within EHRs (Love et al., 2011; Murff et al., 2011; Hou et al., 2012) and the literature on this subject continues to grow. To improve the success of NLP for FAS, education of family practitioners and pediatricians as well as neurologists, ophthalmologists, and other specialists would be necessary to improve recognition and documentation of FAS facial features.

A potential problem with EHR-based FAS surveillance using computerized searching methods across large databases is the misclassification of children with other developmental disabilities or congenital anomalies as FAS (i.e., false-positives). However, with further development of robust methods, this misclassification would likely be minimal compared with the numerous advantages of applying an automated computerized searching method across large populations to identify children potentially with FAS who would benefit by evidence-based interventions at an earlier age. Because the facial features of FAS have been reported to be present in several other syndromes including, but not limited to, DiGeorge, Velocardiofacial; using ICD-9-CM codes, we searched for these syndromes and among the 276 children with probable FAS only two children were identified, both with DiGeorge and Velocardiofacial syndrome. This does not negate the possibility that other children in the group with potential FAS may have this or other as yet undiagnosed syndromes.

When examining maternal alcohol use during pregnancy and other maternal factors, we faced three main challenges. First, linking the mother to the child within health plan data may not be totally accurate when based solely on a family subscriber identifier, because we cannot be certain that we have identified the biologic mother as there were only 5473 (27%) of the children in our final cohort actually born within the Kaiser Permanente health care system. Therefore, the individual may be a legal guardian or adoptive parent, albeit these numbers would be small. Second, it is not possible to understand if the maternal alcohol use occurred during pregnancy of the identified child. Third, it is not possible to determine the reliability of information pertaining to alcohol use, particularly when self-reported by the patient to the physician. This circumstance, however, applies to all surveillance systems investigating alcohol use. In our study, we identified only a small number of women with alcohol and/or drug use, and it is interesting that the patterns for alcohol and drug use were

similar across the mutually exclusive groups of children, which may provide validation on the accuracy of this information. It is well known that mothers underreport alcohol during pregnancy (Morrow-Tlucak et al., 1989; Strandberg-Larsen et al., 2006; Bhuvaneswar et al., 2007), thus limiting the use of this information in the surveillance of FAS. Another approach to overcoming the limitations of self-reported maternal alcohol use is to identify mental health conditions that may be associated with alcohol use. Despite the low number of mothers of children in the GROWTH+CNS+FACE group having any indication of alcohol or drug use, it was interesting to find that these mothers had the highest rate of depression and antidepressant use compared with all other groups. The link between alcohol use and depression is well established (Dixit and Crum, 2000; Littlejohn, 2005; Leis et al., 2012; Vythilingum et al., 2012). The stigma associated with alcohol use during pregnancy is likely to result in underreporting, which would not be the case for depression during pregnancy. Our findings beg the question of whether maternal depression could serve as a proxy for alcohol use during pregnancy. It is important to note, however, that the higher rate of depression may be associated with the challenges of caring for a child with FAS or mental/social disabilities.

One of the problems of tracking potential FAS cases in any healthcare records system is the lack of a gold standard for identification of FAS, such as an ICD-9 code specific to FAS that could be applied in the search or a laboratory test that identifies individuals with the condition. This problem also limits our ability to evaluate easily the individuals identified with potential FAS through EHR records with respect to a diagnostic code or positive lab test. This limitation creates the need for another method of evaluating the individuals we identified, such as independent abstraction of the hard copy medical records. It was not possible to conduct medical record abstractions in the current study, but this will be required for future investigations. This situation may improve with implementation of the ICD-10 coding system which does include a code specific for FAS with facial dysmorphology.

The surveillance of FAS is further complicated by the fact that the various diagnostic criteria are not all evident simultaneously either at birth or in childhood and, consequently, surveillance of children with potential FAS requires continuous follow up. If not evident at birth, growth restriction is usually evident within the first few years of life, and given that height and weight are measured at each physician encounter, restricted growth could be identified reasonably early using EHRs. On the other hand, facial features, and particularly functional CNS disabilities, may require a longer time period to become more evident or be diagnosed. This was demonstrated in these data when we found that children that met CNS criterion, whether singly or in combination with other criteria were older when they met any of the criteria, suggesting the influence of school-age testing for CNS involvement. For this reason, a major advantage of using EHRs for FAS surveillance is not only the ability to take a snap-shot in time of all the information required to capture potential FAS cases, but also to follow children over time and capture the criteria in a timely manner as they evolve. Using an automated computer searching method on updated data would allow the surveillance of FAS to be extremely timely with children being captured as early as the information in the administrative data is updated (which is usually daily). Furthermore, computer searching methods such as ours could improve outcomes for children and mothers by incorporating

built-in EHR communication to alert providers. An integrated healthcare system such as Kaiser Permanente could serve as a model on how to use EHRs to improve health outcomes.

Conclusions

Our research shows that there is much information available within EHRs that can be accessed to enhance current surveillance of FAS. However, these methods may not overcome obstacles such as the reticence of physicians to make the diagnosis of FAS, because of the social stigma it may imply, or the deficiencies in clinical recognition of minor anomalies that serve as clues for its diagnosis. Nevertheless, this approach may help identify some children at risk who would benefit from evidence-based interventions which are now becoming available. The use of EHRs and automated data extraction processes in the surveillance of FAS has yet to be explored thoroughly and warrants further attention as the use of these methods allows for low cost and less labor intensive procedures, as well as up-to-date data extractions and the longitudinal follow-up of children with FAS.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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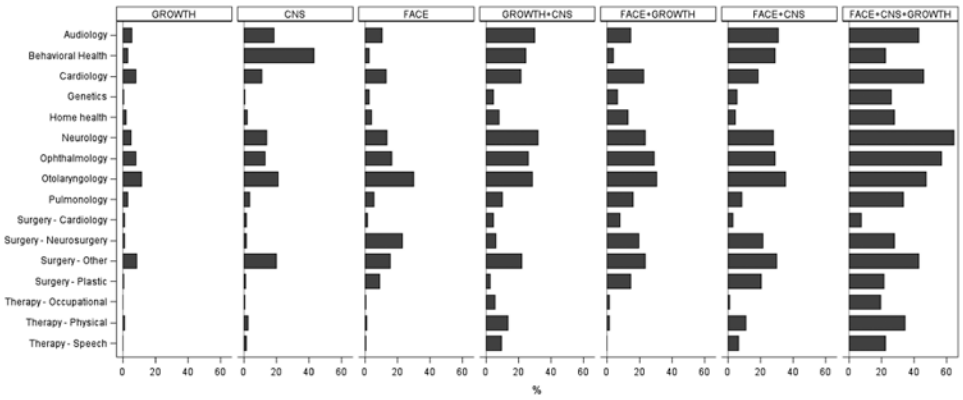

Figure 1.

Percentage of children in each distinct group who had at least one visit to each specialty care.

Table 1

ICD-9-CM[a] Codes and Anthropometric Measurements Used for Potentially Identifying Children with Fetal Alcohol Syndrome (FAS)

Criteria	ICD-9-CM CODE/anthropometric measurement
FACE	
Anomalies of the skull and face bones	756.0
Other specified congenital anomalies of eyelid	743.63
Anomalies of the nose	748.1
Major anomalies of the jaw size	524.0
CNS[b]	
Small head circ. (birth, postnatal)	< 10th % ile for gender and age
Microcephaly	742.1
Congenital reduction of brain	742.2
Developmental delay	
Motor skills disorders	315.4,315.8,315.5
Communication disorders	315.31,315.32,315.35,315.39,307.0,307.9
Learning disorders	315.00,315.01, 315.02, 315.1, 315.2, 315.9
Pervasive develop. Disorders	299.00,299.8
Attention deficit disorder of childhood	314.0,314.00,314.01,314.9
Conduct disorders	312.8,312.81,313.81,312.9
Intellectual disability	
Mental retardation	317,318.0,318.1,318.2,319
GROWTH	
Slow fetal growth and fetal malnutrition	764
Light-for-dates infant w/o mention of fetal malnutrition	764.0,764.00 – 09,764.1,764.10 – 19
Fetal malnutrition without mention of light-for-dates	764.2,764.20 – 29
Fetal growth retardation unspecified	764.9
Lack of physical level in childhood	783.4,783.40,783.41,783.42
Small birth weight	< 10th % ile for gender and age
Small postnatal weight	< 10th % ile for gender and age
Small birth length	< 10th % ile for gender and age
Small height	< 10th % ile for gender and age
FAS	
Alcohol affecting fetus or newborn via placenta or breast milk	760.71
Maternal alcohol use	
Alcohol induced mental disorders	291.0–5, 291.8,291.81,291.82,291.89,291.9
Alcohol dependence syndrome	303,303.0,303.00–03, 303.9,303.90–93,
Nondependent alcohol abuse	305.0,305.00,305.01–03

Criteria	ICD-9-CM CODE/anthropometric measurement
Alcoholic polyneuropathy	357.5
Alcoholic cardiomyopathy	425.5
Alcoholic gastritis	535.3,535.30,535.31
Alcoholic fatty liver	571.0–3
Excessive blood level of alcohol	790.3
Toxic effect of ethyl alcohol	980.0–2, 980.8,980.9
Personal history of alcoholism	V11.3
Alcoholism in family	V61.41
Screening for alcoholism	V79.1
Maternal drug use	
Amphetamines	304.4, 304.40–43, 305.7, 305.7–73
Cannabis	304.3,304.30–33, 305.2, 305.20–23
Cocaine	304.2, 304.20–23, 305.6, 306.60–63, 970.81
Drug dependence	292.0, 292.84, 304.80–81/83/90/91,305.72, 305.90–93, 648.30/31/33, 779.5
Maternal mental conditions	
ADHD[c]	314.0,314.00,314.01,314.9
Adjustment disorder	309.0,309.24,309.28,309.3,309.4,309.89,309.9
Anxiety	293.84,300.00,300.02,300.09,300.4,306.1
Bipolar	295.70, 296.00/03,296.4/40–46, 296.5/50–56, 296.6/60–66,296.7,296.80,296.89, V17.0
Depression	296.2/20–26,296.3/30–36,298.0,300.4,311,648.42,648.44,V11.8

[a] ICD-9-CM, The International Classification of Diseases, Ninth Revision, Clinical Modification.

[b] CNS, central nervous system.

[c] Attention Deficit Hyperactivity Disorder.

Table 2

Number of Children with Specific Fetal Alcohol Syndrome (FAS) Criteria Identified via ICD-9-CM[a] Codes and Anthropometric Measurements

Total enrolled at least once (0–12 years of age)	Any *n*	Distinct[b] *n*	Mutually exclusive groups		
GROWTH related criteria		8616	Growth only n = 6162 (30.6%)	Growth + CNS n = 2285 (11.4%)	Growth + CNS + Face n + 93 (0.5%)
Birth weight< 10thcentile	1945				
Birth length < 10thcentile	1498				
Postnatal weight <10thcentile	2859				
Postnatal height < 10thcentile	2181				
Indication of slow fetal growth (ICD-9-CM)	2919				
Central nervous system (CNS) related criteria		13437	CNS only n = 10952 (54.5%)		
(structural)		1427			
Birth head circumference< 10thcentile	427				
Postnatal head circumference< 10thcentile	840				
Microcephaly (ICD-9-CM)	214				
(functional)		12257			
Developmental delay	6433				
Attention deficit hyperactivity disorder	7211				
Intellectual disability	35				
FACE related criteria (ICD-9-CM)		702	Face only n = 426 (2.1%)	Growth + Face n576 (0.4%) CNS + Face n + 107 (0.5%)	
Anomalies of the skull and face bones	679				
Other specified congenital anomalies of eyelid	6				
Anomalies of the nose	21				
Major anomalies of the jaw size	0				
Total distinct children per group			n = 17540	n = 2468	n = 93
Total distinct children overall			n = 20101		

[a] ICD-9-CM, The International Classification of Diseases, Ninth Revision, Clinical Modification.

[b] May exhibit criteria from more than one category.

Table 3

Characteristics of the Distinct Children with at Least One of the Fetal Alcohol Syndrome (FAS) Related Criteria (n = 20,101) [a]

Single criterion				Combinations of criteria			
Total	**GROWTH only 6162**	**CNS only 10952**	**FACE only 426**	**GROWTH + FACE 76**	**CNS + FACE 107**	**GROWTH + CNS 2285**	**GROWTH + CNS + FACE 93**
RACE, n (%)							
White	1356 (22.0)	2925 (26.7)	119 (27.9)	17 (22.4)	34 (31.8)	604 (26.4)	43 (46.2)
Black	1870 (30.3)	2727 (24.9)	166 (38.9)	32 (42.1)	38 (35.5)	651 (28.5)	21 (22.6)
Other	773 (12.5)	667 (6.1)	36 (8.4)	3 (4.0)	12 (11.2)	233 (10.2)	11 (11.8)
Unknown	2163 (35.1)	4633 (42.3)	105 (24.6)	24 (31.6)	23 (21.5)	797 (34.9)	18 (19.3)
p value		<0.0001				<0.0001	
SEX, n (%)							
Male	47.31	68.43	62.21	53.95	66.36	61.79	59.14
Female	52.69	31.57	37.79	46.05	33.64	38.21	40.86
p value		<0.0001				0.3651	
AGE AT CRITERIA, years – mean (min, max)							
GROWTH	2.6 (0,12.8)	-		1.1 (0,9.7)	-	2.7 (0,12.8)	1.3 (0, 9.7)[c]
CNS		6.3 (0,12.9)		-	3.5 (0,12.1)	2.9 (0,12.8)	1.5 (1,10.1)[c]
FACE		-	1.3 (0,12.9)	1.1 (0,10.3)	1.8 (0,12.7)	-	1.6 (0,9.8)[NS]
p value		<0.0001					
CURRENT AGE[b], years – mean (min=0, max=19.0 for all)							
	6.0	11.2	6.3	5.9	8.0	7.3	6.1
p value		<0.0001			<0.005		

[a] All seven categories are mutually exclusive.

[b] Current age as of September 30, 2012.

NS, not significant (*p* value 0.089),

[c] <0.0001; comparing mean age for each combination of criteria across the three mutually exclusive groups.

Table 4

Characteristics of Mothers with Records Linked to Child's Records (These Numbers Are Presented at the Child Level)

	TOTAL	GROWTH only	CNS only	FACE only	GROWTH + FACE	CNS + FACE	GROWTH + CNS	GROWTH + CNS + FACE
Children linked to the mother, n	17,084	5044	9399	390	66	98	1999	88
%	85.0	81.8	85.8	91.5	86.8	91.6	87.5	94.6
Maternal age (at child's DOB), %								
<=20	4.5	3.7	6.4	1.5	1.5	0.0	2.2	0.0
21 – 25	17.1	17.7	18.0	10.0	12.1	17.3	12.7	9.2
26 – 30	30.4	31.6	29.9	34.6	34.8	25.5	29.1	34.5
31 – 35	28.6	28.4	27.7	33.8	28.8	35.7	31.8	25.3
36+	19.1	18.7	18.0	20.0	22.7	21.4	24.2	31.0
Indication of tobacco use[a], n (%)								
Yes	1604	416 (8.2)	973 (10.3)	33 (8.5)	6 (9.1)	4 (4.1)	163 (8.1)	9 (10.2)
No	12982	3991 (79.1)	6886 (73.3)	318 (81.5)	56 (84.8)	87 (88.8)	1574 (78.7)	70 (79.5)
Former smoker	892	225 (4.5)	534 (5.7)	15 (3.8)	1 (1.5)	5 (5.1)	107 (5.3)	5 (5.7)
Missing	1606	412 (8.2)	1006 (10.7)	24 (6.1)	3 (4.5)	2 (2.0)	155 (7.7)	4 (4.5)
Indication of alcohol use[a], n (%)								
Information on alcohol available in EHR								
Yes (flag for alcohol use)	7366	1930 (38.3)	4325 (46.0)	171 (43.8)	26 (39.4)	49 (50.0)	831 (41.6)	34 (38.6)
No (flag for alcohol use)	7531	2522 (50.0)	3752 (39.9)	181 (46.4)	34 (51.5)	45 (45.9)	954 (47.7)	43 (48.7)
Missing	2187	592 (11.7)	1322 (14.1)	38 (9.7)	6 (9.1)	4 (4.1)	214 (10.7)	11 (12.5)
Physician comment indicating “daily”use	121	27 (0.5)	79 (0.8)	2 (0.5)	1 (1.5)	0	11 (0.5)	1 (1.1)

	TOTAL	GROWTH only	CNS only	FACE only	GROWTH + FACE	CNS + FACE	GROWTH + CNS	GROWTH + CNS + FACE
Alcohol related ICD-9-CM								
Any diagnosis below (distinct number)					393			
Alcohol induced mental disorders	2	1 (0.0)	1 (0.0)	0	0	0	0	0
Alcohol dependence syndrome	144	29 (0.6)	95 (1.0)	2 (0.5)	0	1 (1.0)	17 (0.8)	0
Nondependent alcohol abuse	161	35 (0.7)	104 (1.1)	2 (0.5)	0	1 (1.0)	19 (0.9)	0
Other alcohol related[b]	178	31 (0.6)	127 (1.3)	0	1 (1.5)	0	17 (0.8)	2 (2.3)
Alcohol use-"daily" or ICD-9-CM (distinct)	496 (2.9)	95 (1.9)	340 (3.6)	4 (1.0)	2 (3.0)	1 (1.0)	51 (2.5)	3 (3.4)
Indication of drug use (ICD-9-CM), n (%)								
Amphetamines	23	3 (0.0)	19 (0.2)	0	0	0	1 (0.0)	0
Cannabis	69	19 (0.4)	42 (0.4)	0	1 (1.5)	1 (1.0)	5 (0.3)	1 (1.1)
Cocaine	49	14 (0.3)	28 (0.3)	0	0	0	7 (0.4)	0
Drug dependence	72	19 (0.4)	40 (0.4)	1 (0.3)	0	1 (1.0)	11 (0.6)	0
Any drug condition (distinct)	178 (1.0)	44 (0.9)	105 (1.1)	1 (0.3)	1 (1.5)	2 (2.0)	24 (1.2)	1 (1.1)
Indication of mental related diagnoses (ICD-9-CM), n (%)								
ADHD[c]	569	75 (1.5)	424 (4.5)	5 (1.3)	0	5 (5.1)	56 (2.8)	4 (4.5)
Adjustment disorder	1085	248 (4.9)	641 (6.8)	23 (5.9)	1 (1.5)	6 (6.2)	154 (7.7)	12 (13.6)
Anxiety	3522	730 (14.5)	2260 (24.0)	65 (16.6)	12 (18.2)	23 (23.4)	413 (20.6)	19 (21.6)
Bipolar	485	82 (1.6)	340 (3.6)	5 (1.3)	1 (1.5)	0	55 (2.7)	2 (2.3)
Depression	4253	869 (17.2)	2732 (29.1)	81 (20.7)	15 (22.7)	25 (25.5)	497 (24.8)	34 (38.6)
Any mental condition (distinct)	6143 (35.9)	1299 (25.7)	3879 (41.2)	126 (32.3)	20 (30.3)	37 (37.7)	722 (36.1)	42 (47.7)

	TOTAL	GROWTH only	CNS only	FACE only	GROWTH + FACE	CNS + FACE	GROWTH + CNS	GROWTH + CNS + FACE
Antidepressant use[d], n (%)								
Yes	5892	1175 (23.3)	3858 (41.0)	108 (27.7)	21 (31.8)	32 (32.6)	659 (32.97)	39 (44.3)
No	3869	3869 (76.7)	5541 (58.9)	282 (72.3)	45 (68.2)	66 (67.3)	1340 (67.0)	49 (55.7)

[a] Indication of tobacco/alcohol use is for “anytime” and not necessarily “during pregnancy” because not all women had a pregnancy within Kaiser Permanente, Georgia.

[b] Other alcohol related, alcoholic cardiomyopathy, alcoholic gastritis, alcoholic fatty liver, excessive blood level of alcohol, toxic effect of ethyl alcohol, personal history of alcoholism, alcoholism in family, screening for alcoholism.

[c] ADHD, attention-deficit / hyperactivity disorder.

[d] Antidepressants: The majority searched for were (1) selective serotonin reuptake inhibitors, (2) tricyclic antidepressants, and (3) mono amine oxidase inhibitors.

NOTE: There were no indications for ICD-9-CM codes for alcoholic polyneuropathy.

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