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Administratively Reported Fetal Alcohol Spectrum Disorders in Commercially- and Medicaid-Insured Samples of Children in the United States, 2015 – 2021

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Abstract

Background: Fetal alcohol spectrum disorders (FASDs) are lifelong conditions that can occur in a person with prenatal alcohol exposure. Although studies using intensive, in-person assessments of children in selected communities have found higher estimates of children with FASDs than studies of healthcare claims data, claims-based studies provide more current information about individuals with recognized FASDs from diverse populations. We estimated the proportion of children with administratively reported FASDs in two large healthcare claims databases.

Methods: We analyzed MerativeTM MarketScan[®] commercial and Medicaid claims databases, that include nationwide data from employer-sponsored health plans and from Medicaid programs in 8–10 states, respectively. For each database, we estimated the proportion of children aged 0–17 with administratively reported FASDs, identified by one inpatient or two outpatient codes for prenatal alcohol exposure or fetal alcohol syndrome during the entire seven-year period from 2015–2021 and during each year.

Results: During 2015–2021, 1.2 per 10,000 commercially-insured and 6.1 per 10,000 Medicaid-insured children had an administratively reported FASD; estimates varied by sex, geography, and

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other available demographics. Among commercially-insured children, 0.5 per 10,000 in 2015 and 0.6 per 10,000 children in 2021 had an administratively reported FASD; among Medicaid-insured, 1.2 per 10,000 in 2015 and 2.1 per 10,000 children in 2021 had an administratively reported FASD.

Conclusions: Although an underestimate of the true population of children with FASDs, patterns in administratively reported FASDs by demographics were consistent with previous studies. Healthcare claims studies can provide timely, ongoing, information about children with recognized FASDs to complement in-persons studies.

Keywords

Fetal alcohol spectrum disorders; Healthcare claims; Commercial insurance; Medicaid insurance; Public health surveillance

1. Introduction

Fetal alcohol spectrum disorders (FASDs) are a group of overlapping diagnoses, including fetal alcohol syndrome (FAS), that can occur in a person with prenatal alcohol exposure. Individuals with FASDs might have a combination of developmental, behavioral, learning-related, or physical problems. People with FASDs might require lifelong care (Turchi et al., 2018).

Public health surveillance of children with FASDs is important for understanding the magnitude and scope of these disorders in the population and planning support needs; however, estimates of children with FASDs vary depending on the study population and methods used. Studies using in-depth, in-person assessments of first-graders in selected communities in the United States (U.S.) from 2010–2016 found the prevalence of FASDs ranged from 11.3–71.4 per 1,000 children (May et al., 2018; May et al., 2021). These in-person studies identified children with and without previously recognized FASDs but are time- and resource-intensive to conduct. Studies using administrative databases, such as healthcare claims, to assess the proportion of children with administratively reported FASDs have found lower estimates than in-person studies. For example, a healthcare claims study found the proportion of children younger than 17 years of age with FAS (the most involved diagnosis under the FASD umbrella) in eight unidentified states in 2005 was 1.6 per 10,000 Medicaid-enrolled children (Amendah, Grosse and Bertrand, 2011).

Despite lower estimates than in-person studies, healthcare claims might be an important source for public health surveillance of FASDs, as these studies efficiently use existing data, can provide annual estimates, and might provide more current information than other sources about individuals with recognized and reported FASDs from diverse populations; such studies can help assess the magnitude of children with recognized FASDs and inform healthcare and other service needs. Recent studies of administratively reported FASDs have not been published, therefore we analyzed two large healthcare claims databases to assess the overall proportion of children with administratively reported FASDs during 2015–2021 and the yearly proportion of children with administratively reported FASDs from 2015–2021.

2. Materials and methods

2.1 Data source and sample

The Merative™ MarketScan® Commercial Database includes person-level, deidentified healthcare claims from a nationwide convenience sample of employer-sponsored insurance plans; more than 250 self-insured employers and other health plans contribute data, with more than 69 million enrollees from 2015–2021. The Multi-State Medicaid Database includes claims from Medicaid programs (including the Children's Health Insurance Program) in 8–10 deidentified states, with more than 21 million enrollees from 2015–2021. Both samples were restricted to plans with complete reporting of mental health and substance use services, which might be utilized for an FASD diagnosis; the commercial database also was restricted to employer-submitted claims. To assess the overall proportion of children with administratively reported FASDs during 2015–2021, our sample included children aged 0–17 years (as of the start or end of their enrollment, and the start or end of the 2015–2021 study period) with 365 or more days of enrollment anytime during 2015–2021; to assess yearly proportions, we created yearly samples that included children aged 0–17 years during a calendar year who were enrolled during the entire year.

2.2 Case definition

Administratively reported FASDs were identified by FASD-related International Classification of Diseases (ICD) diagnosis codes for prenatal alcohol exposure (ICD-9 760.71 or ICD-10 P04.3) or FAS (ICD-10 Q86.0); including both prenatal alcohol exposure and FAS codes might better capture the full range of FASDs and is consistent with previous literature (Amendah, Grosse and Bertrand, 2011; Senturias, Ali and West, 2022). To meet our primary case definition, an FASD-related code had to appear on one or more inpatient claims or two or more outpatient claims seven or more days apart. Because there is no established case definition for administratively reported FASDs in healthcare claims databases (O'Donnell et al., 2022), we conducted sensitivity analyses that vary the number of claims required to meet a case definition; specifically, we examined a more liberal definition requiring an FASD-related code on one or more claims, regardless of setting, and a more conservative definition requiring an FASD-related code on two or more claims seven or more days apart, regardless of setting.

2.3 Analysis

We estimated the overall proportion of children who met our FASD case definition any time during 2015–2021 among those with 365 or more days of enrollment any time during 2015–2021. Estimates are presented separately for commercially- and Medicaid-insured populations, overall and by available demographics (sex, Census Division, and rurality for commercially-insured, as well as by sex and race/ethnicity for Medicaid-insured). For both samples, we examined the age at which the case definition was met. We also estimated the yearly proportion of children who met the FASD case definition in each year during 2015–2021 among those with continuous enrollment during that calendar year.

MarketScan data were accessed using Treatment Pathways 4.0, a web-based platform. Statistical significance testing was not performed owing to the descriptive nature of this

study and the large database size, which might result in significant p-values that are not meaningful.

3. Results

Among 6,424,256 commercially-insured children aged 0–17 years during 2015–2021, 1.2 per 10,000 children had an administratively reported FASD; 1.4 per 10,000 male children and 1.1 per 10,000 female children had an administratively reported FASD (Table). By Census Division, the proportion of children with an administratively reported FASD ranged from 0.8 per 10,000 in the South Atlantic to 2.3 per 10,000 in the West North Central. The proportion of children with an administratively reported FASD among children in rural and non-rural areas was 1.5 and 1.2 per 10,000, respectively. Among children with an administratively reported FASD, 23.2% met the case definition at ages 0–5 years, 49.2% at 6–11 years, and 27.6% at 12–17 years (data not shown). Results of our sensitivity analyses found 1.9 and 1.1 per 10,000 children had an administratively reported FASD using a more liberal and more conservative case definition, respectively (data not shown).

Among 5,696,305 Medicaid-insured children aged 0–17 years during 2015–2021, 6.1 per 10,000 enrollees had an administratively reported FASD; 6.8 per 10,000 male children and 5.4 per 10,000 female children had an administratively reported FASD (Table). By race/ethnicity, the proportion of children with an administratively reported FASD ranged from 1.6 per 10,000 among Hispanic children to 7.3 per 10,000 among non-Hispanic white children. Among children with an administratively reported FASD, 55.3% met the case definition at ages 0–5 years, 31.1% at 6–11 years, and 13.5% at 12–17 years (data not shown). Results of our sensitivity analyses found 8.8 and 4.3 per 10,000 children had an administratively reported FASD using a more liberal and more conservative case definition, respectively (data not shown).

Among commercially insured children continuously enrolled in the calendar year, the proportion with an administratively reported FASD was 0.5 per 10,000 in 2015 and 0.6 per 10,000 in 2021 (Figure). Among Medicaid-insured children continuously enrolled in the calendar year, the proportion with an administratively reported FASD was 1.2 per 10,000 in 2015 and 2.1 per 10,000 in 2021.

4. Discussion

We found the overall proportion of children with administratively reported FASDs during 2015–2021 was 1.2 per 10,000 for commercially-insured and 6.1 per 10,000 for Medicaid-insured children. Our estimates from the Medicaid-insured sample are higher than a previous study of MarketScan Medicaid data assessing FAS during 2003–2005 (Amendah, Grosse and Bertrand, 2011). In contrast, both commercially-insured and Medicaid-insured estimates are much lower than population-based prevalence estimates of all FASDs in selected communities using in-person assessments (May et al., 2018; May et al., 2021). However, the patterns in administratively reported FASDs by characteristics observed in this study are consistent with previous studies. Specifically, reports have found a higher prevalence of children with FASDs in foster, child welfare, or other childcare systems (which might

provide Medicaid eligibility) than in general populations (Lange et al., 2013), a slightly higher prevalence of FASDs among male than female children (Fox et al., 2015; May et al., 2021), and variability in FASD prevalence by geography (Fox et al., 2015; May et al., 2018). Studies also have reported FASDs are more likely to be recognized once children enter school (Moberg et al., 2014), which is consistent with our finding that 49.2% of commercially-insured children who met the FASD case definition met the case definition during ages 6–11 years.

Among commercially-insured children, the yearly proportion with an administratively reported FASD was 0.5 per 10,000 in 2015 and 0.6 per 10,000 in 2021 and, among Medicaid-insured children, was 1.2 per 10,000 in 2015 and 2.1 per 10,000 in 2021. Examining administratively reported FASDs in each calendar year facilitates comparisons over time, but yearly estimates are lower than the overall 2015–2021 estimates because pooling multiple years of data might identify children with less frequent FASD-related healthcare encounters, as observed with other conditions (Grosse, Green and Reeves, 2020). It is unclear why administratively reported FASDs by year appeared to vary among Medicaid-insured but not commercially-insured children. Changes over time might reflect changes in the true prevalence, changes in diagnostic criteria or assessment, coding, reporting practices (including transitioning from ICD-9 to ICD-10), or changes in the database composition. Notably, alcohol consumption during pregnancy increased slightly from 9.2% in 2011 to 11.3% in 2018 (Denny et al., 2020), underscoring the need for public health surveillance to monitor FASDs among children.

Previous studies using in-person assessments (May et al., 2018; May et al., 2021) that identified children with previously recognized and unrecognized FASDs might better approximate the true population of children with FASDs. Administrative studies might underestimate the true prevalence of FASDs, in part, because of underdiagnosis of FASDs in the general population. Indeed, one study found 80% of youth with an FASD in a child welfare agency had not been previously diagnosed (Chasnoff, Wells and King, 2015). Identifying children exposed prenatally to alcohol and, therefore, at risk for an FASD facilitates accurate diagnosis, treatment, and care. However, information about alcohol consumption during pregnancy might not be available to pediatric providers and providers have reported feeling uncomfortable diagnosing FASDs or referring children for diagnostic services (Smith et al., 2017). The American Academy of Pediatrics (AAP) recommends that pediatric providers screen all children for prenatal alcohol exposure and document results should FASD-related characteristics emerge later (American Academy of Pediatrics, 2017), and provides resources to support FASD screening, assessment, and diagnosis (American Academy of Pediatrics, 2023).

Although findings from this study underestimate true prevalence of children with FASDs, healthcare claims data might be an important data source for future public health surveillance activities as these data can provide ongoing information about children with recognized and reported FASDs. Such data sources can provide a minimum prevalence estimate that complements those from in-person studies; and such information can be used to understand the characteristics of children with recognized and reported FASDs and inform healthcare and support service needs for families caring for a child with an FASD.

However, efforts are needed to improve the utility of administrative data. For example, coding and documenting FASDs might be challenging due to a limited number of applicable codes, and algorithms to identify children with FASDs in administrative records have not been standardized or evaluated against a gold standard (O'Donnell et al., 2022). The AAP provides resources for coding FASDs (American Academy of Pediatrics, 2021) and the U.S. Centers for Disease Control and Prevention is working with clinical and public health partners to understand FASD-related information in administrative and clinical data sources to inform future public health surveillance (Centers for Disease Control and Prevention, 2023).

Our findings are subject to limitations. First, the administratively reported prevalence of FASDs likely underestimates the true prevalence due to underdiagnosis, as described. Second, case finding algorithms for FASDs have not been validated (O'Donnell et al., 2022), and some children with a diagnostic code for prenatal alcohol exposure might not meet criteria for an FASD diagnosis. Third, the commercial claims database is a convenience sample and is not representative of all children covered by employer-sponsored health plans. Finally, the Medicaid database includes programs in 8–10 deidentified states, which change over time and might result in discrepancies between the race/ethnicity distribution observed in this study and national Medicaid populations (Centers for Medicare & Medicaid Services, 2023).

Although studies of healthcare claims data likely underestimate true prevalence of children with FASDs, they can provide a more current, minimum estimate of children with recognized and reported FASDs to complement estimates from in-person studies, which might be useful for evaluating trends and planning for healthcare and support service needs. However, efforts are needed to improve identification of children with FASDs in administrative databases to enhance the utility of these data for public health surveillance.

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Nothing declared.

Disclaimer

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

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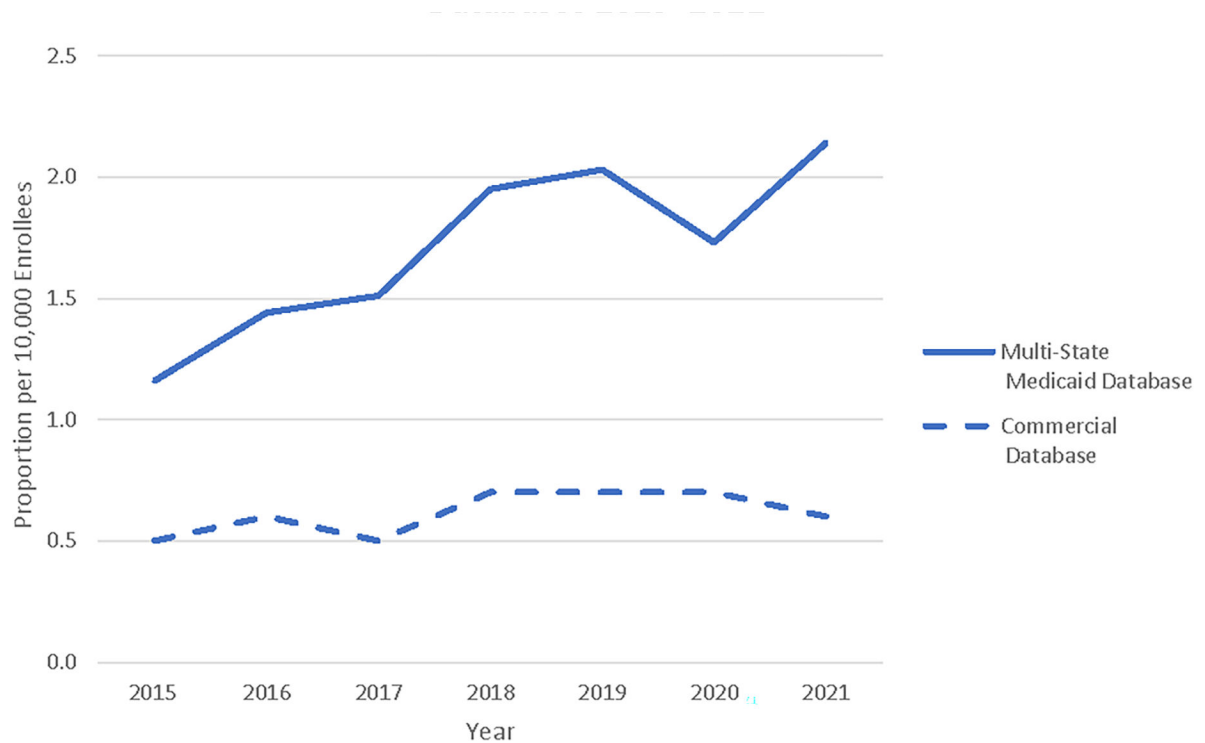


Figure: Administratively Reported Fetal Alcohol Spectrum Disorders¹ among Children Aged 0–17 Years, by Calendar Year² — MarketScan Commercial and Multi-State Medicaid Databases 2015–2021

¹Children with fetal alcohol spectrum disorders (FASDs) were identified by one of the following FASD-related International Classification of Diseases diagnosis codes on one or more inpatient claims or two or more outpatient claims 7 days apart anytime during a calendar year: ICD-9 760.71 (noxious influences affecting fetus or newborn via placenta or breast milk, alcohol), ICD-10 P04.3 (newborn (suspected to be) affected by maternal use of alcohol), and ICD-10 Q86.0 (fetal alcohol syndrome (dysmorphic)). ICD-9 code sets were replaced by ICD-10 code sets in October 2015.

Administratively Reported Fetal Alcohol Spectrum Disorders among Children Aged 0–17 Years¹ — MarketScan Commercial and Multistate Medicaid Database, United States, 2015–2021

Table:

	Commercial Database			Multi-State Medicaid Database		
	All Children	Children with an Administratively Reported FASD ²	Proportion (per 10,000)	All Children	Children with an Administratively Reported FASD ²	Proportion (per 10,000)
	No.	No.		No.	No.	
Overall	6,424,256	794	1.2	5,696,305	3,479	6.1
Sex						
Female	3,143,411	350	1.1	2,748,588	1,474	5.4
Male	3,280,845	444	1.4	2,947,717	2,005	6.8
Census Bureau Divisions³						
New England	259,649	24	0.9	-- ⁴	--	--
Middle Atlantic	768,340	67	0.9	--	--	--
East North Central	1,097,259	205	1.9	--	--	--
West North Central	443,653	102	2.3	--	--	--
South Atlantic	1,309,200	107	0.8	--	--	--
East South Central	479,859	55	1.1	--	--	--
West South Central	848,274	96	1.1	--	--	--
Mountain	443,787	49	1.1	--	--	--
Pacific	731,988	86	1.2	--	--	--
Unknown/Missing	42,247	3	0.7	--	--	--
Rurality³						
Non-rural	5,708,457	693	1.2	--	--	--
Rural	676,562	99	1.5	--	--	--
Unknown/Missing	39,237	2	0.5	--	--	--
Race/Ethnicity⁵						
Hispanic	-- ⁴	--	--	485,262	77	1.6
Non-Hispanic Black	--	--	--	1,693,590	924	5.5
Non-Hispanic Other	--	--	--	246,954	134	5.4
Non-Hispanic White	--	--	--	2,606,359	1,904	7.3

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Multi-State Medicaid Database					
Commercial Database			Multi-State Medicaid Database		
All Children		Children with an Administratively Reported FASD ²	All Children		Children with an Administratively Reported FASD ²
No.	No.	Proportion (per 10,000)	No.	No.	Proportion (per 10,000)
--	--	--	664,140	440	6.6
Missing					

Abbreviation: FASD= Fetal Alcohol Spectrum Disorder

¹ Children were enrolled for 365 or more days at any time during the study period.

² Children with FASDs were identified by one of the following FASD-related International Classification of Diseases diagnosis codes on one or more inpatient claims or two or more outpatient claims days apart anytime during the 2015–2021 study period: ICD-9 760.71 (noxious influences affecting fetus or newborn via placenta or breast milk, alcohol), ICD-10 P04.3 (newborn (suspected to be) affected by maternal use of alcohol), and ICD-10 Q86.0 (fetal alcohol syndrome (dysmorphic)). ICD-9 code sets were replaced by ICD-10 code sets in October 2015.

³ Geography and rurality information reflects location at the time of enrollment. More information about Census Bureau Divisions can be found at: https://www.census.gov/programs-surveys/economic-census/guidance-geographies/levels.html#par_textimage_34.

⁴ Census division and rurality were only available for the Commercial database, and Race/Ethnicity was only available for Multi-State Medicaid database

⁵ Non-Hispanic other category includes American Indian and Alaska Native, Asian or Pacific Islander, and multiracial enrollees.