


A Profile on Emergency Department Utilization in Adolescents and Young Adults with Autism Spectrum Disorders

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Published online: 14 November 2016
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Abstract There has been an increase in utilization of the Emergency Department (ED) in individuals with autism spectrum disorder (ASD) which may reflect a deficit of services (Green et al., *Journal of the American Academy of Child and Adolescent Psychiatry* 40(3):325–332, 2001; Gurney et al., *Archives of Pediatric and Adolescent Medicine* 160:825–830, 2006; Leichtman et al., *American Journal of Orthopsychiatry* 72(2):227–235, 2001). The current study examined the rates of ED utilization between 2005 and 2013 in ASD youth 12- to 21-years-old. Adolescents with ASD accessed ED services four times as often as adolescents without ASD. Older adolescents and those living in rural areas showed a significant increase in ED visits over time. Post hoc analysis revealed increased ED utilization for females and behavioral health ED services over time. Better access to and greater understanding of services for adolescents with ASD is a critical need.

Keywords Autism · Adolescence · Emergency department · Service utilization

Introduction

Autism spectrum disorder (ASD) is a chronic, neurodevelopmental disorder that impacts 1 in 68 individuals (Centers for Disease Control and Prevention 2014). Individuals with ASD present with significant impairments in social communication, as well as restrictive, repetitive patterns of behaviors, interests, and activities (American Psychiatric Association 2013). The transition to adolescence is a particularly stressful time for individuals with ASD and their caregivers as social and societal demands increase, physical and sexual maturity advances, and parental emotional stress often peaks (Marcus et al. 1997). A PA Statewide Needs Assessment found that close to half of all caregivers of adolescents with ASD reported an unmet need for services, as well as related unwanted outcomes (e.g., inpatient hospitalization) as they age (Bureau of Autism Services 2011). The existing system significantly underserves this population at a time of high need which contributes to the poor outcomes experienced by many young adults with ASD.

The preliminary finding from this study was also presented as a poster at the 2016 International Meeting for Autism Research, May 11–14, 2015, Baltimore, MD.

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Healthcare Utilization and Cost

As individuals with ASD age, it has been found that physical health service needs are often unmet and that provided services are frequently rated as unsatisfactory (Bureau of Autism Services 2011). Barriers to accessing care were reported to be cost and insurance, availability of providers who will provide healthcare to adolescents and young adults with ASD, as well as lack

of transportation for those living in rural areas (Bureau of Autism Services 2011; Thomas et al. 2007). However, while there is a reported unmet need for services, research in the past decade has concurrently documented higher rates of healthcare utilization in individuals with ASD (Boulet et al. 2009; Croen et al. 2006; Kogan et al. 2008; Warfield and Gulley 2006; Liptak et al. 2006). More specifically, Leonard et al. (2005) found that during inpatient hospitalizations, irrespective of the reason for admission, children with ASD experienced increased contact with health care providers during their hospital stay.

The cost of medical care for children and adolescents with ASD has been found to be approximately three to seven times greater than individuals without ASD (Croen et al. 2006; Peacock et al. 2010; Shimabukuro et al. 2008). This increased cost is likely associated with increased lengths of hospitalizations found for children and adolescents with ASD as compared to individuals without ASD (Kato et al. 2013; Lokhandwala et al. 2012). More concerning is that as children with ASD age into adolescence and adulthood, the cost of healthcare increases (Croen et al. 2006; Leslie and Martin 2007; Newacheck and Kim 2005). This cost has been found to be particularly high for adolescents with ASD between the ages of 15- and 18-years-old and has been posited to result from increased prescription medication use and inpatient hospitalizations (Croen et al. 2006; Shimabukuro et al. 2008). Children and adolescents with ASD and non-psychiatric (e.g., epilepsy) and/or psychiatric comorbidities (e.g., ID, mood disorder) have been found to have higher health care costs (Croen et al. 2006; Peacock et al. 2010). More specifically, it was found that children under 10-years-old had a larger number of non-psychiatric health care costs, while children and adolescents over the age of 10-years-old had a larger number of psychiatric health care costs.

When examining psychiatric comorbidities, the cost remained higher even in comparison to age-matched individuals with similar psychiatric diagnoses without ASD (Croen et al. 2006; Peacock et al. 2010). Many researchers have found that children and adolescents with ASD are at greater risk for psychiatric hospitalization than children with other disorders (Bebbington et al. 2013; Gallaher et al. 2002; Mandell 2008; Saeed et al. 2003). Mandell (2008) found that before reaching 21-years-old approximately 10% of children and adolescents with ASD are admitted to the hospital as a result of a psychiatric crisis (Mandell 2008). More concerning, Mandell (2008) also found that the risk of hospitalization was increasing over time. Although none would argue that there are not cases where hospitalization is justified for children and adolescents with ASD, it is likely that the current rates of healthcare utilization and cost for this population is inflated and may reflect a lack of

lower-level care and services (Green et al. 2001; Leichtman et al. 2001).

Emergency Department (ED) Utilization

There has been a steady increase in utilization of the ED for both non-psychiatric and psychiatric referrals by children and adolescents over time (McCraig and Burt 2005; Mahajan et al. 2009). This trend has also been documented in children and adolescents with ASD and has been found to be increasing at a higher rate when compared to individuals without ASD (Gurney et al. 2006). Deavenport-Saman et al. (2016) found that children and adolescents with ASD had 0.26 more documented visits to the ED when compared to individuals without ASD, and that older children with ASD (i.e., school-age compared to preschool-age) were utilizing the ED more. A recent examination of ED utilization in adults with ASD found a similar trend in high utilization of the ED (Nicoliadis et al. 2013).

Reasons for Referral to ED

Recent research has examined the common presenting issues for children and adolescents with ASD who utilize the ED, including both non-psychiatric and psychiatric concerns. The most common non-psychiatric presenting problems include epilepsy, seizures, and/or neurological symptoms (9–15%) and gastrointestinal disturbances (15%) such as nausea, vomiting, diarrhea, abdominal pain, and constipation (Buie et al. 2010; Cohen-Silver et al. 2014; Coury 2009; Deavenport-Saman et al. 2016; Tuchman et al. 2010; Vohra et al. 2016; Wang et al. 2011). In their sample, Deavenport-Saman et al. (2016) found that 7% of children and adolescents with ASD presented to the ED with upper respiratory infections, 7% presented with viral infections, and 5% presented with otitis media. Previous research has found that children and adolescents with ASD have had an increased relative risk for injury although only 4% of these individuals presented to the ED with unspecified head injuries and 3% presented with dental injuries (Deavenport-Saman et al. 2016; McDermott et al. 2008).

Sills and Bland (2002) found that psychiatric issues were the presenting issue in 1.6% of all ED visits for children and adolescents in general. Since that time, psychiatric-related ED visits have been found to be increasing at a swifter rate than non-psychiatric reasons for referral to the ED (Larkin et al. 2005). Additionally, Kalb et al. (2012) found that ED visits for children and adolescents with ASD were more likely to be related to a psychiatric concern than non-psychiatric concern. In regards to common psychiatric reasons for referral to the ED, Iannuzzi et al. (2015) found that as children with ASD entered elementary school behavioral

issues became a common reason for referral to the ED. However, around the time of entry into middle school, in addition to behavioral issues, mood symptoms, self-injurious behavior, and more significant aggression entered into the top reasons for referral to the ED and remained stable into young adulthood (Iannuzzi et al. 2015). Finally, Wharff et al. (2011) found that children with developmental disabilities, including ASD, were 2.5 times more likely to utilize the ED while waiting for an opening on a psychiatric inpatient facility.

Predictors of ED Utilization

Although there has been substantial research on the medical and psychiatric complexities in children and adolescents with ASD, recent research suggests that the minority of ED visits are warranted for a high level of care. Many researchers have proposed that the increased ED utilization for children and adolescents with ASD may be related to deficits in first line, community-based, outpatient care (Green et al. 2001; Leichtman et al. 2001). Nageswaran et al. (2011) found that parents of children and adolescents with ASD report decreased satisfaction with their children's general health care. Caregivers of children and adolescents with ASD have reported that they have significant trouble accessing their primary care physician (PCP). This barrier is considered to be a factor for the increased ED utilization and higher hospitalization rates for children and adolescents with ASD (Bebbington et al. 2013; Krauss et al. 2003). Gurney et al. (2006) found that caregivers of children and adolescents with ASD reported that they believe their child's PCP does not have a salient role in the care of their child's health. However, the lack of psychiatric evaluations available in outpatient mental health clinics and educational settings was also posited that a key reason for an increase in ED visits by children and adolescents with ASD (Soto et al. 2009).

Caregivers of typically developing children and adolescents who reported that their PCP stresses family centeredness, timeliness, and coordinated care have been found to report decreased numbers of visits to the ED (Brousseau et al. 2009; Piehl et al. 2000; Wang et al. 2005). Similarly, caregivers of children and adolescents with ASD report they are more likely to access the ED for healthcare when they perceived their healthcare providers do not listen to their concerns, display cultural insensitivity, do not supply needed information, and do not involve caregivers in decision making (Lin et al. 2014). Therefore, it is less likely that caregivers of youth with ASD access their PCPs for routine visits that are for minor issues as a result of having less assurance for help with acute, emergent, and/or complex behavioral or health issues (Kogan et al. 2008).

Finally, children in rural areas have been found to have less access to regular and specialty medical and mental health care and therefore may be more likely to present at the ED for mental health care (Cohen and Hesselbart 1993; Slade 2003; Thomas et al. 2007). Approximately half of families of children with ASD living in a rural community reported that they experienced problems with the services they received, most often as a result of lack of availability of well-trained providers (Hutton and Caron 2005). Dew et al. (2013) documented that caregivers of individuals with ASD living outside of metropolitan centers in Australia noted a lack of ASD expertise in healthcare providers in rural and remote areas of the country. Thomas and colleagues found that caregivers of children with ASD who lived in rural communities in the United States reported significantly less access to special summer camps and respite care (Thomas et al. 2007). Another indicator of a paucity of services in rural communities is the documented older mean age of diagnosis of ASD for individuals living in a rural community when compared to those in suburban or urban settings (Mandell et al. 2005). Recent research has begun to examine the efficacy of telehealth remote technology, group-based parent interventions, and training models for PCPs to meet the needs of individuals with ASD and their families in rural settings (Ashburner et al. 2016; Farmer and Reupert 2013; Mazurek et al. 2016; Meadan et al. 2013).

Current Research

There have been several studies since 2009 that have examined ED utilization in a pediatric sample of individuals with ASD (Cohen-Silver et al. 2014; Kalb et al. 2012; Mahajan et al. 2009). The majority of these studies were descriptive in nature outlining the demographic characteristics and common presenting complaints of ED visits in children and adolescents with ASD (Iannuzzi et al. 2015; Kalb et al. 2012; Mahajan et al. 2009; Wu et al. 2015) and in adults with ASD (Vohra et al. 2016). However, more recently have researchers examined predictors and outcomes of children and adolescents with ASD (Cohen-Silver et al. 2014; Deavenport-Saman et al. 2016; Lunskey et al. 2015). For example, a history of physical aggression toward others and no structured daytime activities predicted higher rates of ED utilization in individuals with ASD in a survey of caregivers of individuals between the ages of 12- and 56-years-old (Lunskey et al. 2015). These recent studies have utilized caregiver-report data of 396 adolescents and adults with ASD (Lunskey et al. 2015), small-scale retrospective chart review (N=160; Cohen-Silver et al. 2014), and a small timeframe (3 years) retrospective analysis of ED discharge data (N=1424 children with ASD; Deavenport-Saman et al. 2016).

Hypotheses

The current study intends to examine the rates of ED utilization over 9 years (2005–2013) in youth ages 12- to 21-years-old with ASD. It is hypothesized that (1) adolescents with ASD will have significantly more ED visits as compared to adolescents without ASD; (2) adolescents who are older (over the age of 14-years-old) will have significantly more ED visits as compared to younger adolescents (under the age of 14-years-old); and (3) adolescents living in rural communities will have significantly more ED visits as compared to adolescents living in metropolitan areas.

Methods

Data Source

The MarketScan® Commercial Claims and Encounters database (Truven Health Analytics) consists of reimbursed healthcare claims from a selection of large employers and commercial health plans. Included individuals are covered by private insurance plans across the United States (US), with claims information from more than 130 payers describing the healthcare use and expenditures for more than 50-million employees and family members per year. Ages range from birth to 65 years old when most individuals switch from private insurance to Medicare. Claims for individuals are identified by a unique patient identifier and contain information on inpatient, outpatient and prescription drug service use, as well as patient age, gender, geographic location, and type of health insurance plan. The medical claims contain medical diagnoses coded by the International Classification of Disease: Ninth Revision (ICD-9), whereas

medical procedures are coded by Current Procedural Terminology, 4th edition (CPT-4).

Study Populations

Using the healthcare claims data from MarketScan® between 2005 and 2013, a total of 56,266,305 individuals were identified between the ages 12- to 21-years-old in the current database (see Table 1). In each annual cohort, an ASD sub-cohort of adolescents was constructed of individuals with at least two separate diagnoses of ASD (ICD 9 codes 299.0x and 299.8x) through the entire study period (2005–2013; N=87,683) and a non-ASD sub-cohort of adolescents without ASD diagnosis (N=56,178,622) during the study period.

In each of the annual cohort, adolescents were further categorized into three age brackets: early adolescence (12- to 14-years-old), middle adolescence (15- to 17-years-old) and older adolescence (18- to 21-years-old; see Table 2). Additionally, gender, US census regions (i.e. Northeast, North central, South, and West), type of residence (i.e., urban, rural), and type of health plans were documented (see Table 2). Type of residence was defined as residence within (urban) or outside of (rural) a metropolitan statistical area (msa). A non-zero msa code indicated an urban residence; while a rural residence indicated otherwise (i.e. rural). There were nine types of health plans. PPO and HMO accounted for over 80% of the enrollees in our study cohort while the rest were covered by the other seven types of health plans. Therefore, type of health plan was categories as PPO, HMO or a bundle of the remaining seven health plan types together. A behavioral service related ED visits was identified determined by an ED visit accompanied by a behavioral diagnosis (ICD 9 code 290–319) or behavioral service/consultation (ICD code V11, V40, V61, V62, V79). An ED visit without any behavioral service was considered a non-behavioral ED visit.

Table 1 Annual cohort demographics summary

Cohort	Non-ASD			ASD		
	Population N	Age (years)	Gender (male) %	Population N (%)	Age	Gender (male) %
2005	3,793,254	16.4	50.4	7348 (0.19)	14.9	5800 (78.9)
2006	4,916,450	16.4	50.7	6387 (0.13)	14.2	5113 (80.1)
2007	5,421,997	16.4	50.7	5740 (0.11)	13.8	4649 (80.1)
2008	6,298,873	16.4	50.6	8277 (0.13)	14.1	6603 (79.8)
2009	6,042,184	16.4	50.6	7694 (0.13)	13.8	6126 (79.6)
2010	6,850,506	16.4	50.8	14,207 (0.21)	14.5	11,216 (78.9)
2011	7,988,196	16.5	51.0	14,547 (0.18)	14.3	11,627 (79.9)
2012	8,155,067	16.6	51.0	12,726 (0.16)	14.0	10,149 (79.8)
2013	6,712,095	16.6	51.0	10,757 (0.16)	14.1	8576 (79.7)

Table 2 Summary of demographics of the combined cohort

Characteristics	Proportion of population (%)	Non-ASD (%)	ASD (%)	p value
Age				
12–14	29.60	29.55	63.79	<0.0001
15–17	31.03	31.04	22.22	<0.0001
18–21	39.37	39.41	13.99	<0.0001
Gender				
Male	50.83	50.78	79.68	<0.0001
Region				
Northeast	14.58	14.57	22.04	<0.0001
North Central	24.76	24.76	27.95	<0.0001
South	39.90	39.91	30.52	<0.0001
West	19.25	19.26	18.12	<0.0001
Health plan				
HMO	14.70	14.71	12.75	<0.0001
PPO	63.45	63.45	63.40	<0.0001
Other	21.84	21.84	23.85	<0.0001
Residence				
Urban	82.86	82.85	87.01	<0.0001
Rural	15.70	15.71	11.65	<0.0001

There was variability across individual states as to whether private insurance plans were mandated to cover autism services and interventions over the course of the study period. For instance, of the states with the highest populations, three (TX, OH, and NC) had no autism insurance mandate in place over the duration of the study period. Others in the top 10 most populous states enacted autism insurance reform in 2008 (PA, IL, and FL), 2011 (CA), and 2012 (NY, MI). The only state in the top 10 with autism insurance mandates throughout the entire study period was Georgia, but this was only partial coverage (Bowen 2014). This lack of private insurance coverage for autism would result in undercoding of the diagnosis when private insurance resources were being utilized for payment of delivered health care as documenting ASD could result in denied claims. In states without mandated commercial health insurance coverage, specialized services, such as behavioral health services, where an ASD diagnosis would be more likely to be documented are frequently covered by public health insurance.

Data Analysis

By linking the in-patient and out-patient encounter claims database from 2005 to 2013, the annual utilization of the ED was estimated on an individual patient basis. The number of unique patients who had ED visit(s) among the cohort of adolescent with ASD and those without was

calculated. In particular, the proportion of patients who visited ED among ASD vs. non-ASD adolescent cohorts was determined. Descriptive analyses were used for exploring cohort demographics and the distributions of variables. Univariate association between each factor of interest and the outcome variable was examined using Chi-squared test/Fisher's exact test for categorical variables and *t* test/Wilcoxon rank sum test for continuous variables. Multivariable analysis was performed by logistic regression model. All statistical analyses were performed using SAS version 9.3 software (SAS Institute, Cary, NC). All statistical tests were two-sided, with *p* values less than 0.05 being considered statistically significant.

Results

Despite the fact that there has been a widespread documentation of a steady increase of ASD prevalence since 2000 (Matson et al. 2011), our data did not show any significant increase in ASD prevalence among the target adolescent population. ASD prevalence was found to fluctuate between 0.11 and 0.21% from 2005 to 2013 and was 0.16% during 2013 (Table 1). This range is significantly lower than the CDC prevalence rate range of 0.8–1.5% over the study period (Centers for Disease Control and Prevention 2014). The lower ASD prevalence rates in this sample is most likely reflecting the lack of mandated health insurance coverage as described previously.

Consistent with previous findings in the literature, the majority of the ASD patients in our study cohort were male; the overall ratio was approximately 4:1 male to female. The gender ratio for the entire cohort, which included individuals with and without ASD, was 51:49 male to female. The ASD adolescent population was younger (approximately 14-years-old) than the non-ASD population (approximately 16-years-old) in the annual cohorts. In particular, over 60% of the ASD cohort was just entering the early adolescent group, 22% fell in the middle adolescence group, and only 14% fell in the late adolescence group. In contrast, the three age groups were more evenly represented in the non-ASD population, with early, middle, and late adolescence accounting for 30, 31 and 39% of the non-ASD cohort (Table 2). The South US census region accounted for 40% of the total study population, while Northeast represented the lowest population in the cohort with 15%. PPO was the most used health plan (64%), followed by HMO (15%), while the remainder of the population was insured by the other seven smaller types of health plans. A majority of the study population (83%) lived near a metropolitan area (urban), defined by a non-zero metropolitan statistical area (msa) code; while the remainder of the population (17%) was defined as living in a non-metropolitan area (rural).

We observed a consistent increase in the percentage of ASD patients among all adolescents who visited ED. While the percentage of non-ASD patients who had ED visits remained fairly flat at around 3%, the percentage of ASD cohort patients who had ED visits steadily increased from 3% during 2005 to 16% by 2013, a five-fold increase from 2005 to 2013 equivalent to an annual 20% sequential increase (Fig. 1).

A further breakdown (Fig. 2) by age group showed that, through the study period (2005–2013) a relatively smaller portion (less than 10%) of early adolescents with ASD had documented ED visits per year. However, a much larger proportion (30%) of the middle and late adolescent ASD groups had documented ED visits. In contrast, only 3–4% of all age groups of adolescents without ASD had documented ED visits.

While adolescent males with ASD had more ED visits, which is likely an artifact of the higher ASD prevalence among males, percentage-wise a larger portion females with ASD had ED visits. Adolescent males and females without ASD utilized the ED at near equal frequencies. Furthermore, there was a similar, annual sequential increase of ED visits between male and female adolescents with ASD. Although there was variability over the study period, adolescents with ASD living in rural areas trended towards greater utilization of the ED when compared to adolescents with ASD living in urban areas. This trend was not observed for adolescents without ASD. Among adolescents with ASD who had a documented ED visit, those who had behavioral health service-related ED visits increased from 12% during 2005 to 22% by 2013, compared to an increase from 3 to 6% among adolescents without ASD (Fig. 3).

Multivariable logistic regression showed adolescents with ASD were associated with significant risk of have ED

visit (Adjusted Odds Ratio, aOR=4.775; 95% Confidence Interval, CI=4.678, 4.875; p value <0.0001) after adjusting for the other factors/confounders, such as age group, gender, US census region, geographic location, type of health plans and calendar year (Table 3). All the aforementioned covariates also had statistically significant associations with ED visit, though with more moderate effects.

Discussion

Given the continuing difficulties with the transition from adolescence to adulthood for individuals with ASD, there is increasing interest to better understand the challenges of their teen years (Bureau of Autism Services 2011; Marcus et al. 1997). The primary goal of this study was to examine emergency department (ED) utilization as a preliminary step in exploring the negative health experiences of adolescents with ASD. A large private insurance claims database (MarketScan®) was utilized to compare ED visits for adolescents with and without ASD for the years 2005–2013. It was hypothesized that adolescents with ASD would have significantly more ED visits than adolescents without ASD. Furthermore, adolescents with ASD who were older and living in rural communities were hypothesized to be at increased risk.

The results indicate support of the hypothesis. Over the study period, the percentage of adolescents with ASD who had an ED visit increased from 3.1% in 2005 to 15.8% in 2013 while the percentage of adolescents without ASD with ED visits remained around 3% for the same time period. Adolescents with ASD above the age of 14 accessed the ED at significantly higher rates than those aged 12- to 14-years-old; this discrepancy was not seen

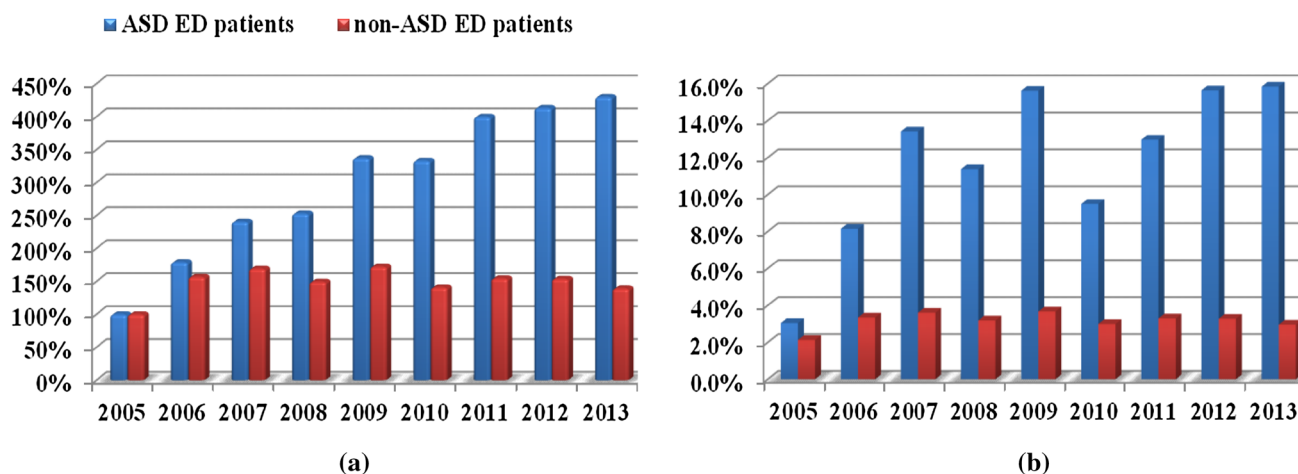


Fig. 1 ED visits among ASD vs. non-ASD adolescent populations. Annual patients with ED patients (a). Annual percentage of patients who had ED visits (b)

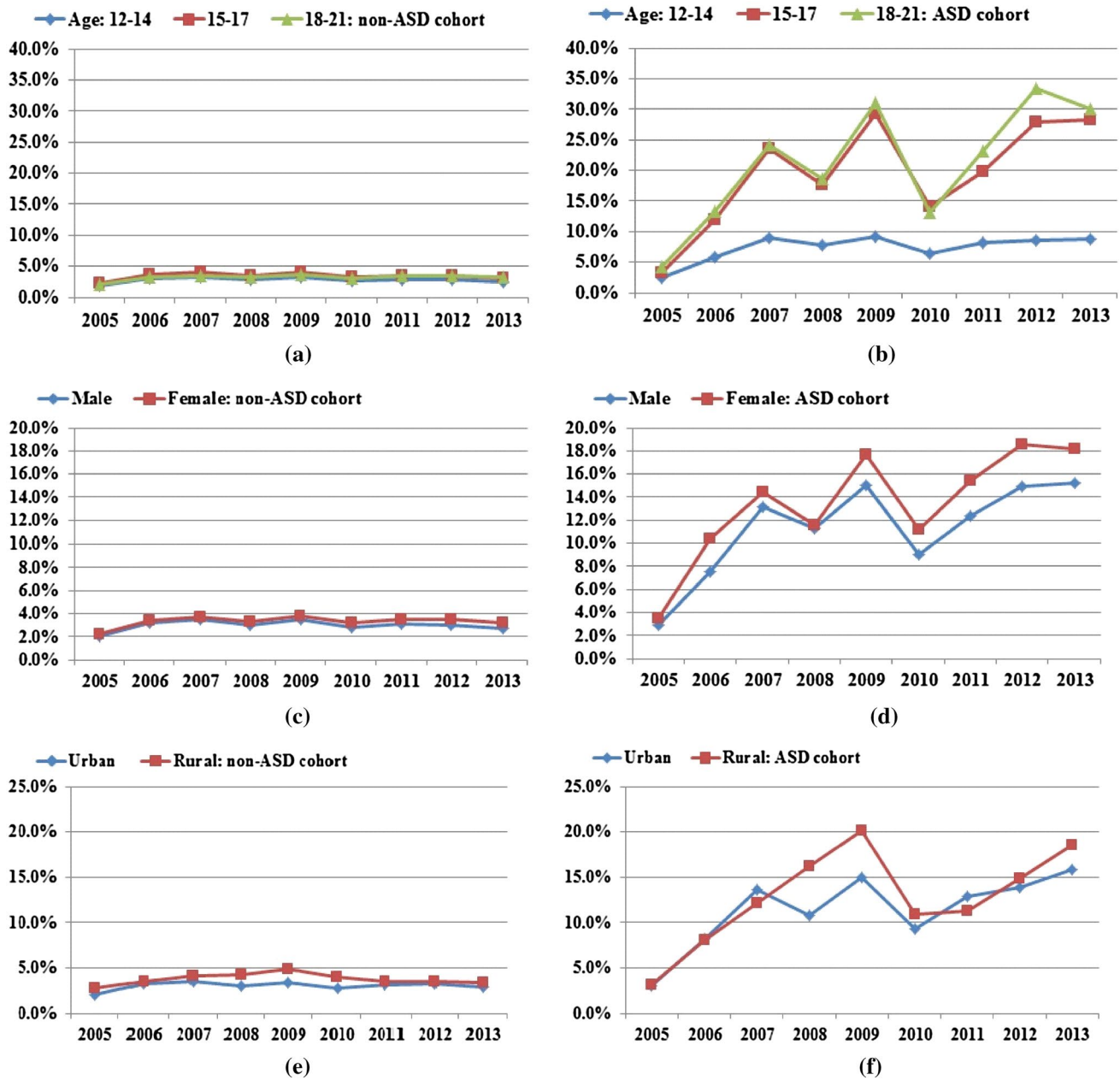


Fig. 2 Proportion of ED patients between ASD and non-ASD sub-populations, breakdown by age groups (a, b); gender (c, d); type of residence, i.e. rural vs. urban (e, f)

in the non-ASD cohort. Individuals with ASD residing in rural areas were slightly more likely to access the ED than individuals with ASD living in urban areas over the entire study period. There was no difference in ED utilization between individuals living in rural as compared to urban areas for the non-ASD cohort. Post hoc analysis revealed increased ED utilization for adolescent ASD females as well as non-ASD females. The proportion of adolescent ED patients who received behavioral health services during their visit increased from 2.6 to 5.9% for the non-ASD

cohort over the study period; the ASD cohort demonstrated a comparable increase from 11.9 to 21.6%. Multivariable logistic regression demonstrated that adolescents with ASD accessed ED services over four times as often as adolescents without ASD after adjusting for confounders such as age, gender, setting, and calendar year.

These results coincide with previous research. Numerous studies have documented high costs of medical care for children and adolescents with ASD (Croen et al. 2006; Peacock et al. 2010; Shimabukuro et al. 2008). More salient

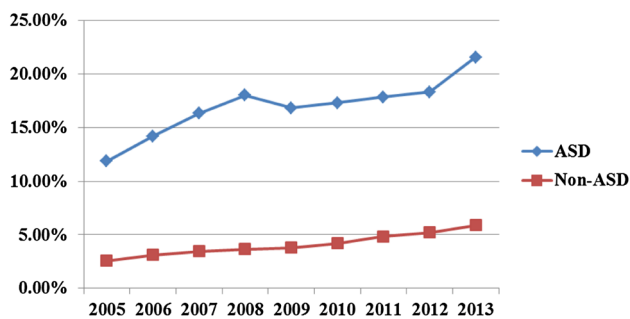


Fig. 3 Proportion of ED patients who received behavioral health service during ED visits

to this line of inquiry is the previous finding that Deavenport-Saman et al. (2016) reported higher ED utilization for children and adolescents with ASD as compared to those without ASD, although they reported the increase as being more modest than this study's findings. This increased utilization encompasses both medical (Cohen-Silver et al. 2014; Deavenport-Saman et al. 2016; Vohra et al. 2016) and psychiatric (Iannuzzi et al. 2015; Kalb et al. 2012; Wharff et al. 2011) referrals. While adolescents in general are presenting with more psychiatric concerns (Sills and Bland 2002), this is particularly true of adolescents with ASD (Kalb et al. 2012). The current study took this line

of research further by examining a large, national database over 9 years. Larger differences in ED utilization between adolescents with and without ASD were discovered. Over the study period, ED utilization for adolescents with ASD demonstrated significant increases while ED utilization for adolescents without ASD demonstrated only a modest increase.

Implications for Research and Practice

The 2015 National Autism Indicators Report found that 60% of youth on the autism spectrum had at least two additional health or mental health conditions with 75% of youth taking at least one prescription medication to treat these conditions (Roux et al. 2015). This report also found a sharp drop off in needed services for youth with ASD between high school and their early 20s such that 26% of young adults on the autism spectrum receive no services and 37% of young adults with ASD are not employed or attending higher education. The National Longitudinal Transition Study—2 published data indicating that 50% of adolescents with ASD behaved in ways at home that resulted in parental disciplinary action and 59% of adolescents with ASD have difficulty controlling their temper when arguing with peers who are not their siblings

Table 3 Multivariable logistic regression to estimate the association among factors/confounder with ED visits

Covariates	ED patient population (%)	Ajusted odds ratio	95% CI	Age	p value
ASD	12.20	4.78	4.68	4.88	<0.0001
Non-ASD	3.20	Reference			
Age					
12–14	2.81	Reference			
15–17	3.49	1.26	1.26	1.27	<0.0001
18–21	3.29	1.19	1.18	1.19	<0.0001
Gender					
Male	3.05	Reference			
Female	3.38	1.12	1.12	1.13	<0.0001
Region					
Northeast	2.71	0.86	0.85	0.86	<0.0001
North Central	3.33	Reference			
South	4.13	1.28	1.28	1.23	<0.0001
West	1.59	0.53	0.52	0.53	<0.0001
Health plan					
HMO	1.35	Reference			
PPO	3.76	2.51	2.49	2.52	<0.0001
Other	2.88	1.94	1.93	1.95	<0.0001
Residence					
Urban	2.57	Reference			
Rural	3.83	1.10	1.10	1.11	<0.0001
Year	–	1.01	1.01	1.01	<0.0001

(Wagner et al. 2005). Increasing needs during adolescence paired with declining services place youth with ASD to be vulnerable to physical and mental health crises.

Previous work has identified several predictors of ED utilization in children and adolescents with ASD. Day and time has been found to predict increased ED utilization in children and adolescents with ASD. Recent research has found that the majority of children and adolescents with ASD present to the ED during weekday, daytime hours (Cohen-Silver et al. 2014). This was increased utilization was found to hold steady in comparison to children and adolescents without ASD's utilization of the ED (Deavenport-Saman et al. 2016). When examining type of insurance and the ability to predict ED utilization, the results have been mixed. Deavenport-Saman et al. (2016) found that children and adolescents with ASD who presented to the ED were more likely to have public insurance (i.e., Medicare managed care or Medicaid fee-for-service) in comparison to typically developing youth. On the other hand, Kalb et al. (2012) found that children and adolescents with ASD who had private insurance had an increased likelihood of an ED visit for psychiatric reasons when compared to children and adolescents without ASD.

Approximately one-fourth of children and adolescents with ASD have been found to make repeated visits to the ED and of this 25%, half of the individuals had been to the ED in the two weeks prior to the current visit (Cohen-Silver et al. 2014). Of the children and adolescents with ASD who present to the ED, almost 20% have been subsequently admitted to the hospital compared to a rate of 10% in children and adolescents without ASD (Cohen-Silver et al. 2014). Deavenport-Saman et al. (2016) found that children and adolescents with ASD were less likely to be admitted to the hospital from the ED if they arrived at the ED during weekday daytime or evening hours, were female, were English-speaking, and who had no insurance. In the same sample, being 6-years-old or older, being non-Hispanic, and traveling a greater distance to the ED led to high admittance rates. Finally, in a sample of adults with ASD, Vohra et al. (2016) found that approximately 33% of ED visits led to a hospital admission while only 10% of adults without ASD were admitted to the hospital after an ED visit.

What is most concerning from our current findings is the consistent sharp increases in ED utilization by adolescents with ASD over the study period particularly as this was not seen in non-ASD youth. In 2005, ASD youth were only slightly more likely to utilize the ED compared to non-ASD youth. In 2013, ASD youth were five times more likely to visit the ED. This increased utilization could only be partially accounted for by increased identified ASD youth; the ASD cohort varied from a low of 5740 (2007) to a high of 14,547 (2011). As this database is comprised of claims from insurance plans of large employers and health plans,

some of the variation over the study period may be due to the financial crisis of 2007 and subsequent recovery. However, the proportion of ASD youth to the total adolescent population in the database remained relatively constant for this time period and the prevalence rate in this sample is below the CDC reported rates throughout the study period. As mentioned previously, many states did not have mandated autism insurance coverage for some or all of the study period which is likely to significantly impact the size of the ASD cohort in this study.

From our analysis, not only are ASD youth utilizing the ED at disproportionate rates, they are accessing the ED for behavioral health concerns at increasing rates outpacing non-ASD youth. By 2013, over 20% of ASD youth were accessing ED services for a readily identified behavioral health concern in the claims data. This appears to be a significant factor as the changes in behavioral health presenting concerns mirror the overall increased ED utilization. Adolescents with ASD who present for emergent psychiatric care appear to have difficulty accessing community based mental health services. Children and adolescents with ASD have been documented as having significant difficulty accessing specialty medical and mental health care when compared with other youth with disabilities (Krauss et al. 2003; Soto et al. 2009). Soto et al. (2009) found that of children and adolescents with ASD who present to the ED, approximately two-thirds current reported that they had ongoing outpatient care, but utilized this infrequently. Cohen-Silver et al. (2014) found that only 44% of ED visits in children and adolescents with ASD were a result of a presenting complaints defined as high acuity and children and adolescents with ASD were 2.6% more likely to have non-urgent ED visits compared to those without ASD. Similarly, Soto et al. (2009) reported in their sample that more than one-third of children and adolescents with ASD referred to the ED could be handled in a “less restrictive environment.” Better access to behavioral health services designed for adolescents with ASD, such as social skills training and specialized care coordination, appears to be a critical need. Greater understanding of service utilization before and after ED visits for youth with ASD is needed to craft more impactful interventions for individuals at risk.

Limitations

Several caveats need to be discussed when interpreting our study results as there are several limitations to this work. First, the claims data were from a sample of private insurers, not including data from Medicare, Medicaid, or the uninsured and thus not representative of the general US population, or of different geographic areas. For example, there are more enrollees from the South and North Central US census regions than Northeast and West regions.

Secondly, there was natural annual fluctuation in the enrollments of MarketScan affiliated health plans, which may affect the sample sizes of our annual study cohorts. Third, we ascertained ASD cases as well as ED visits from the claims records alone without having clinical details, such as clinical event records or visit-specific notes. It is possible that a misdiagnosis occurred due to record entry, coding, and/or other machine or human errors. To minimize diagnostic uncertainty, we ascertain ASD patients with at least two separate diagnoses, of different dates of diagnosis. Given the variation in mandated autism insurance coverage across states over the study period, those identified with ASD may have more severe presentations not representative of the total ASD population. Secondary to the probable undercoding of ASD over the study period, there are undoubtedly individuals with ASD who are in the non-ASD cohort for this study. Additionally, the ASD cohort in this study may represent individuals where a public health insurance source is not available to them which could make them more likely to utilize the ED for health care services. Finally, due to the nature of the retrospective, secondary data analysis, our investigation should be considered as exploratory and certainly need more rigorous, prospective epidemiological study to further confirm. Despite of the aforementioned limitations, we believe our study still present new insight on the profile of ED utilization among ASD adolescents and young adults. Our findings, together with evidence from other sources, may potentially shape to improve healthcare service for the wellbeing of this historically under-served population.

Conclusion

This study found that the number of visits to the ED for adolescents with ASD significantly increased over time in comparison to age-matched typically developing peers. Overall, adolescents with ASD access the ED over four time more often than adolescents without ASD. Middle to late adolescence and residing in rural areas appeared to reflect higher rates of ED utilization in comparison to early adolescence and residing in urban areas. Additional analyses identified higher ED utilization in females with ASD as compared to males with ASD, as well as a significant increase in behavioral health visits in the ED over time. Adolescents with ASD do not appear to be adequately supported through the transition to adulthood as they experience more social and communication difficulties often while dealing with new onset mental health conditions. This may be particularly true for older youth, those residing in rural settings, and for adolescent females with ASD.

Next steps for research related to ED utilization in adolescents and young adults with ASD include examining

databases which contain records for ED utilization in individuals with ASD who have public insurance as this was not included in the current data. The addition of a comparison group such as adolescents with Attention-Deficit/Hyperactivity Disorder (ADHD) in addition to typically developing adolescents may provide information about ED utilization in a separate, but related chronic, behavioral health concern. Additionally, further profiling the characteristics of ASD patients who had ED visits is an important research question. For example, medical records within 12 months before their ED visits can be examined to shed light on predictors to ED visits. Additional variables of question include rates of recidivism, subsequent inpatient hospitalization rates, and length of hospital stays for individuals with ASD as compared to a typically developing cohort. The type of episode of disease or injury with a high-incidence ratio in individuals with ASD as compared to typically developing peers is also of interest. Finally, given the findings in this study related to the increased presence of females with ASD in the ED, there is specific interest in identifying the characteristics of their ED episodes and factors in which they may differ from male adolescents and young adults counterparts.

Acknowledgments This work was supported in part by Penn State University College of Medicine Junior Faculty Development Program Award (Liu), the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1 TR000127 (Kong). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. We also would like to acknowledge the essential support of the Center for Applied Studies in Health Economics (CASHE).

Author Contributions GL contributed to the conception and design of the study, acquisition, analysis and interpretation of data, drafting the manuscript and approving the final version. AMP contributed to the design of the study and interpretation of data, drafting the manuscript and approving the final version, LK contributed to the design of the study and analysis of data, drafting the manuscript and approving the final version. DLL contributed to the analysis of data, drafting the manuscript and approving the final version. MJM contributed toward the conception and design of the study, interpretation of data, drafting the manuscript, and approving the final version.

Compliance with Ethical Standards

Ethical approval For this type of study formal consent is not required.

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