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ORIGINAL PAPER

Risk Factors for Emergency Department Utilization Among Adolescents with Autism Spectrum Disorder

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Abstract

This study reaffirms our previous work documenting a higher number of Emergency Department (ED) visits by adolescent females with Autism Spectrum Disorder (ASD) as compared to adolescent males with ASD, as well as significantly more ED visits by older adolescents than younger adolescents with ASD. Combined externalizing and internalizing psychiatric co-morbidities as well as internalizing conditions alone predict a higher number of ED visits in this study. Illness severity as demonstrated by patterns of visits to primary care physicians and psychiatric referrals prior to ED visits and the prescription of two or more classes of psychotropic medications also predict higher number of ED visits. Finally, as expected, previous ED visits predict future ED visits. The identification of these factors may prove helpful in determining adequacy of current supports and resources for teens with ASD navigating the challenges of adolescence.

Keywords Autism · Adolescence · Risk factors · Emergency Department · Service utilization

Researchers have found a steady increase in Emergency Department (ED) visits by children and adolescents with Autism Spectrum Disorder (ASD) in the 2000's for both non-psychiatric and psychiatric referrals (Mahajan et al. 2009; McCaid and Burt 2005). This trend has also been documented more recently (Kalb et al. 2018; Liu et al. 2017) for adolescents and young adults with ASD who had higher documented ED visits compared to their same-age peers without ASD. More specifically, Liu et al. (2017) reported that adolescents with ASD between the ages of 12- and 21-years-old visited the ED over four times more often than adolescents without ASD. In light of rising healthcare costs for individuals with ASD (Boulet et al. 2009; Croen et al. 2006; Kogan et al. 2008; Liptak et al. 2006; Warfield and Gulley 2006), there is a need for a more thorough investigation into determining profiles of adolescents with ASD who are at a high risk of having an ED visit. This is particularly salient given the increase in prevalence rates recently published by the Centers for Disease Control (CDC) from the 2014 surveillance year which documented 1 in 59 children have ASD (Baio et al. 2018), as well as individuals with ASD being an aging population.

Mental Health Comorbidities

Characteristics associated with ASD such as behavioral inflexibility, stereotypies, self-injurious behaviors (SIB), sensory hypo- and hypersensitivities, and deficits in social communication contribute to significant emotional dysregulation for individuals with ASD (Samson et al. 2014). As such, the majority of individuals with ASD have comorbid mental health diagnoses (Gordon-Lipkin et al. 2018; Gotham et al. 2015; Matson and Nebel-Schwalm 2007; Mattila et al. 2010), including *internalizing* (e.g., anxiety, depression) and *externalizing* (e.g., disruptive behavior, conduct problems) disorders. It has been posited that the increase in complexity of illness presentation from primarily disruptive behavior (e.g., aggression) to a combined presentation of more significant symptoms which may or may not include SIB paired with a paucity of services has resulted in increased the number of ED visits for adolescents with ASD (Iannuzzi et al. 2015; Liu et al. 2017). In fact, Kalb et al. (2012)

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found that these more complex, acute comorbidities were associated with increased risk for ED visits and subsequent hospitalization.

Intellectual Disability (ID) Comorbidity

Individuals with ASD can be diagnosed as with or without a comorbid ID (Association 2013). ID is diagnosed as comorbid with ASD if the individual presents with cognitive and adaptive skill deficits at or more than two standard deviations below the mean as compared to same-age, typically developing peers. As with individuals with ASD alone, individuals with ASD and ID can also present with co-occurring internalizing and externalizing behaviors which likely significantly impact an individual's daily functioning and quality of life (Matson and Shoemaker 2009). In particular, IQ is negatively correlated with severity of ASD and challenging behaviors which persist over time as individuals age; therefore, individuals with ASD and ID likely have a higher risk of behaviors which may lead to increased ED visits compared to individuals with ASD without ID (Murphy et al. 2005; O'Brien and Pearson 2004).

Medication Management

Polypharmacy is generally defined as medications prescribed to individuals that are simultaneously filled across two or more classes of medications (Spencer et al. 2013). Given that the majority of children and adolescents with ASD present with mental health comorbidities, it is not uncommon for medical professionals to practice polypharmacy, even though the majority of this practice is "off-label." Jobski et al. (2017) completed a systematic literature review examining prevalence rates of pharmacological treatments of comorbid psychopathology in children and adolescents with ASD. Antipsychotics were the most frequently prescribed, followed by medications for symptoms of Attention-Deficit/Hyperactivity Disorder (ADHD), and finally, antidepressants (Jobski et al. 2017). Esbensen et al. (2009) demonstrated that for antipsychotics and antidepressants higher prevalence rates were correlated with age and that individuals were likely to continue to be prescribed medication over time.

The prescription of psychotropic medications, particularly multiple medications, may be indicative of poor medication management (e.g., prescription of antipsychotics when not indicated) or a treatment indicative of the complex impairment(s) of the aging individual with ASD. However, at this time to the authors' knowledge, there is no information as to the associations of dosage of treatment services (e.g., extent of potential polypharmacy, frequency of contacts with the prescriber) or type of prescriber [primary care provider (PCP) (e.g., pediatrician, family physician) vs. specialist (psychiatrist, developmental pediatrician, neurologist)] with frequency of emergencies resulting in ED visits.

Access to Healthcare Providers

It is safe to assume that if adolescents with ASD had better access to outpatient mental health services to support these mental health complexities, lower rates of ED visits for this population would be observed. This deficit in services has been well documented (Green et al. 2001; Krauss et al. 2003; Leichtman et al. 2001). Approximately two-thirds of children and adolescents with ASD have regular, ongoing outpatient management of their healthcare through their PCPs. However, visits to PCPs have been found to be infrequent and difficult to access (Bebbington et al. 2013; Krauss et al. 2003; Nageswaran et al. 2011). Even when PCPs were available, Lin et al. (2014) documented high ED visits by children and adolescents with ASD in situations when caregivers of these individuals reported that they felt that their PCPs did not listen to their concerns, supply needed information, and/or involve caregivers in decision making.

Beyond care by PCPs, many adolescents with ASD would benefit from accessing medical specialists such as psychiatrists. As individuals with ASD age, the use of non-pharmacological treatments [e.g., Applied Behavior Analysis (ABA), outpatient therapy] decreases and psychiatric service visits for medication management increases (Cidav et al. 2012). However, there is a paucity of these providers for the aging ASD population. For example, Mire et al. (2014) found the number of outpatient specialty service visits for individuals with ASD peaks during preschool. Additionally, a 2011 Needs Assessment of individuals with ASD living in Pennsylvania documented a significant unmet need for medication management (PA Bureau of Autism Services 2012). The 5% to 15% of adults with ASD reported unmet needs for medication management likely reflects the discharge of adolescents with ASD from pediatric services when they turn 18-years-old (PA Bureau of Autism Services 2012).

Specific Aim and Hypotheses

The aim of the current study was to identify risk factors of ED visits of adolescents with ASD. The literature indicates that the risk factors for ED visits in adolescents with ASD include presence of mental health and/or ID comorbidities, prescription of psychotropic medications from two or more categories of drug classes (i.e., polypharmacy), being in a transition period (i.e., the transition into high school during early adolescence and out of high school during late adolescence), and no contact with a psychiatrist in the 6 months prior to the ED visit. It is specifically hypothesized that that having a comorbid internalizing mental health diagnosis, prescriptive polypharmacy, and being in a transition period will be associated with a higher risk of ED visits. Additionally, it is hypothesized that contact with a psychiatrist in the 6 months prior to the ED visit will be associated with a lower risk of ED visits and contact with a PCP will not be protective.

Methods

Design

A longitudinal, national claims database consisting of a retrospective cohort was utilized to examine demographic and medical profiles in association with frequency of visits to the ED.

Data Source and Study Cohort

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 (Hansen 2017). Included individuals are covered by private insurance plans across the United States (US). However, since MarketScan® is based on a convenience sample, it does not represent the US general population. Nevertheless, the large database contains 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 64-years-old, the latter age being 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).

From the healthcare claims data from MarketScan® during 2005–2014, individuals with ASD were defined as those with at least two separate diagnoses of ASD (ICD-9 codes 299.0× and 299.8×) through the entire study period. While it is estimated that ASD is estimated to affect about 1 million Americans under 21-years-old, the 2005–2014 MarketScan® database contains over 200,000 ASD patients under 21-years-old. Among those ASD patients, only individuals with a minimum of two full consecutive calendar years of enrollment in the MarketScan® and who were 12- to 21-years-old during their second full year of enrollment were included in the database. The study cohort, after applying all inclusion/exclusion criteria contained 63,886 eligible subjects.

Measures

The ED visits were summarized at the individual level on a yearly basis. First, identification year was defined as a full calendar year when an individual was enrolled in the whole year and aged within the 12- to 21-years-old bracket, provided an individual also enrolled through the full calendar year during the previous year. The status of ED visits of an individual was then defined based upon if a patient had visited ED or not during an identification year. Risk factors were defined within a certain time window prior to the ED visit. For example, prior visits to PCPs/specialists were assessed within 6 months of an ED visit; prescriptions of psychotropic medications were assessed within 3 months of an ED visit. An index date of ED visit for an identification year was defined as the first ED visit date during that year. For an identification year without ED visit, the index date is set to be July 1st of that year.

The risk factors reflecting health status and healthcare services include presence of a comorbid mental health diagnosis, number of *different* categories of psychotropic medications during the 3 months prior to the index date, and documented visits to a PCP and/or a psychiatrist in the 6 months prior to the index date. Type of comorbid mental health diagnosis was defined as *internalizing* [e.g., major depressive disorder (296.xx), depressive disorder (311.xx), anxiety disorders (300.xx)], *externalizing* [e.g., attention-deficit/hyperactivity disorder (ADHD; 314.xx); oppositional defiant disorder (ODD; 313.81); disruptive behavior disorder (DBD; 312.9); psychotic disorder: 298.9], *both*, or *neither*. ID was defined by the ICD-9 codes: 317, 318.0–2 and 319. Psychotropic medications were categorized as: (1) antidepressants; (2) mood stabilizers/anticonvulsants; (3) antipsychotics; (4) anxiolytics; (5) stimulants; (6) non-stimulant ADHD medications [norepinephrine reuptake inhibitor (atomoxetine), central alpha agonists]. Individuals with ASD were considered as visiting a PCP (provider specialty code: 204, 206, 240, 260, 400, 825, 845) or a psychiatrist (365, 458, 824) if this visit was billed within the 6 months prior to the index date.

Demographic characteristics include gender, age, type of health plan, type of residence (rural, urban), US census regions (northeast, north central, south, west). Nine types of health plans were recorded in the data. *Health maintenance organization* (HMO), of which a PCP serves as a gatekeeper for any referral to any other specialists, and *preferred provider organization* (PPO), of which a PCP referral is not required, account for over 80% of the enrollees in the study cohort. Therefore, type of health plan was defined as PPO, HMO or other. Urban residence was defined by a non-zero metropolitan statistical area (MSA) code and rural was defined as residence outside an urban MSA.

Data Analysis

ED visit was defined on a yearly basis for each individual. To examine the risk factors of frequency of ED visits, descriptive analyses were conducted to examine the annual rates of ED visit (i.e., proportions of ASD patients who had ED visits during a calendar year) stratified by demographics and risk factors of interest. Next, longitudinal analyses were performed using a first-order Markov transition model to account for the correlations of repeated measures over years within the individual subjects. The status of ED visit in the previous year was considered as a predictor in the model to incorporate the within-subject correlations. Specifically, a multivariable logistic regression model was fitted with ED visit at current year as the outcome variable. Age at current year was considered as a time-varying variable and grouped into three brackets: 12- to 14-years-old (early), 15- to 17-years-old (middle), and 18- to 21-years-old (late) adolescence stages to evaluate the longitudinal change of ED visits within the individuals throughout adolescence. The main factors of interest in the model are gender, age bracket at current year, gender by age interaction, status of ED visit (yes/no) during the previous year, mental health comorbidity, PCP/psychiatrist visit and psychotropic medications prior to the ED index date. Other covariates adjusted in the model were age at cohort entry, calendar year at cohort entry, US census region, type of residence (urban/rural), and health insurance plan. A secondary analysis was performed to determine the effects of risk factors on recurrent ED visit in a calendar year given there was an ED visit in the previous year. Odds ratios and 95% confidence intervals were calculated for the logistic regression models. All analyses were performed using SAS version 9.4 software (SAS Institute, Cary, NC). All tests were two-sided, with p-values less than 0.05 being considered statistically significant.

Table 1 Summary of demographics and clinical characteristics of ASD cohort (N = 63,886 subjects)

Characteristics	Subjects diagnosed with ASD, N (%)
Age at baseline	
12–14	38,403 (60.1)
15–17	14,982 (23.5)
18–21	10,501 (16.4)
Gender	
Male	51,070 (79.9)
Female	12,816 (20.1)
US census region	
Northeast	13,608 (21.7)
North Central	17,514 (28.0)
South	18,888 (30.1)
West	12,659 (20.2)
Health plan	
HMO	9873 (15.5)
PPO	38,781 (60.7)
Other	15,232 (23.8)
Type of residence	
Urban	55,787 (87.3)
Rural	6904 (10.8)
Unknown	1195 (1.9)
ID	34,029 (53.3)
Type of mental health comorbidity	
Internalizing	7896 (12.4)
Externalizing	10,335 (16.2)
Both	11,751 (18.4)
Neither	33,904 (53.1)
Baseline calender year	
2006	7069 (11.1)
2007	3591 (5.6)
2008	4411 (6.9)
2009	7089 (11.1)
2010	6067 (9.5)
2011	9483 (14.8)
2012	9882 (15.5)
2013	7299 (11.4)
2014	8995 (14.1)

Results

Study Cohort Characteristics

The study cohort consists of 63,886 ASD patients with 181,686 person-year observations. The patients had an average of 4.3 (SD: 2.3) years of follow-up data. Demographics and clinical characteristics were summarized in Table 1. A majority of ASD patients in this study were males (79.9% male vs. 20.1% female). At cohort entry, 60.1% were in the early adolescence group, 23.5% in the middle adolescence age group and 16.4% in the late adolescence age group. As for comorbid mental illnesses, 18.4% had diagnoses of both internalizing and externalizing comorbidities in the study period; 12.4% had internalizing conditions only; 16.2% had externalizing conditions only; and 53.1% had no documented psychiatric comorbidities. In addition, 53.3% had Intellectual Disabilities (ID). The study cohort was well represented by four US census regions, with 30.1% of the sample from the south region, 28.0% of the sample from the north central region, 21.7% of the sample from the northeast region, and 20.2% of the sample from the west region. Only 10.8% of the individuals in the sample resided in rural areas; the remainder resided in urban areas. Most study subjects were insured by PPO (60.7%) or HMO (15.5%); the remainder (23.8%) were insured by one of seven other types of health plans.

Descriptive Analysis of ED Utilization

A total of 7725 qualified index ED visits from 5666 unique patients were examined in this study. Among them, 1656 (21.4%) ED visits were documented with mental health issues as the precipitating reason for the ED visit; while 4966 (64.3%) ED visits were of those who had comorbid ID. The annual ED visit rate was calculated and defined as the number of patients from the study cohort who had ED visit(s) over the total number of person-year counts during that year. In Fig. 1, the *average* annual rates of ED visits, stratified by each factor of interest, were summarized as follows.

Demographics

Adolescents with ASD in older age brackets had a higher frequency of ED visits compared to those in younger age brackets, reaching about 5% annually in late adolescence. On an annual basis, 5.0% of females with ASD had ED visit(s) compared to 4.1% among males. Adolescents with ASD living in the south or northeast had similar rates of annual ED visits, about 5% per year, followed by those from the north central region (4.2%), while those living in the west US census region had markedly low ED visit rate (2.8%). Adolescents with ASD residing in rural areas were found to visit the ED more often (5.0%) than those in the urban areas (4.2%). Adolescents with ASD covered by an HMO were found to have much fewer ED visits (1.8%) than those covered by a PPO (5.0%) or other types of insurance (4.2%).

Comorbid Diagnoses, Psychiatric Service, and Psychotropic Medications

Adolescents with ASD and ID concurrently were more likely to visit ED (5.0%) than those ASD patients without ID (3.4%). Those who concurrently had both internalizing and externalizing comorbid mental health illnesses had a higher frequency of ED visits (6.3%), compared to those having internalizing only (5.4%), externalizing (4.0%) only, or neither (3.4%), respectively. ED visits were higher among ASD patients who visited both PCPs and psychiatrists during the past 6 months (8.1%); followed by those who visited PCPs (5.2%) and those who visited psychiatrists (4.6%), compared to those who visited neither (2.7%). Moreover, the frequency of ED visits increased consistently with the number of different classes of psychotropic medications prescribed in the previous 3 months. Annually, 3.2% of those without any prescribed psychotropic medication had ED visits, increased to 5.0% for those prescribed two classes of drugs, and peaked at 9.6% among those prescribed with 5 or more different classes of drugs.

Multivariable Logistics Regression Analyses of ED Utilization Over Time

Multivariable logistic regression analysis examined the independent effect of each factor on frequency of ED visits (Table 2). As expected, there was a strong correlation between the status of ED visits in two consecutive years. The odds of having ED visits at current year were

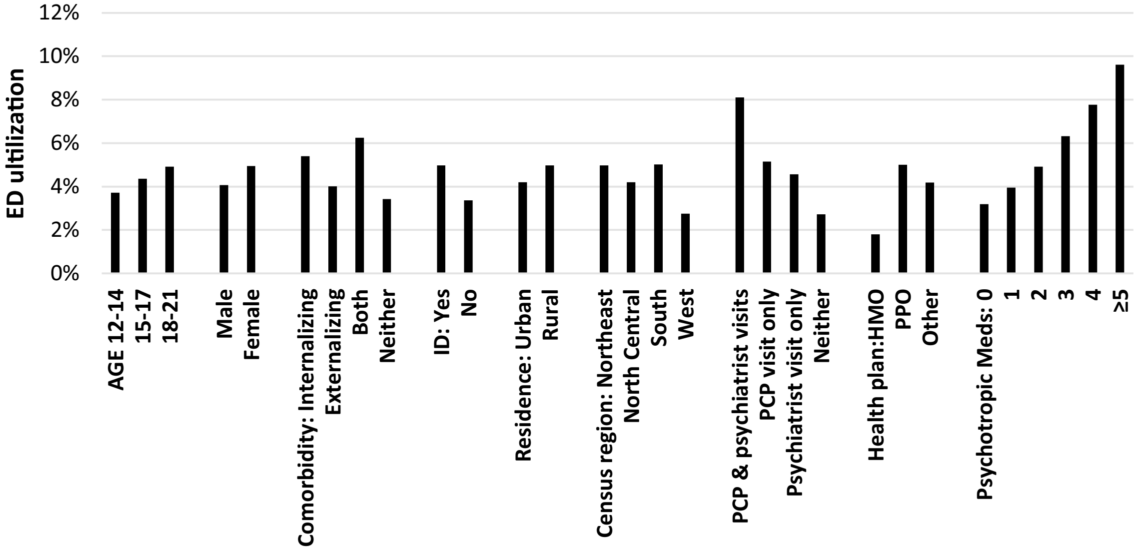

Fig. 1 Average annual ED utilization stratified by demographics and clinical factors

Table 2 Multivariable logistic regression: risk factors of ED visits (N = 181,686 person years)

Covariates	Adjusted odds ratio	95% CI		p value
		Lower limit	Upper limit	
Prior ED visit	9.25	8.64	9.90	< 0.0001
Gender × age bracket				0.04
Gender effect (F vs. M)				
Age: 12–14	1.23	1.12	1.35	< 0.0001
15–17	1.06	0.96	1.16	0.28
18–21	1.21	1.09	1.34	0.0003
Age effect (ref: 12–14)				
Male 15–17	1.16	1.08	1.24	< 0.0001
18–21	1.25	1.14	1.37	< 0.0001
Female 15–17	0.99	0.88	1.12	0.92
18–21	1.23	1.08	1.41	0.003
Prior PCP/psychiatrist visit				< 0.0001
Both PCP and psychiatrist	2.22	2.05	2.40	< 0.0001
PCP only	1.70	1.61	1.81	< 0.0001
Psychiatrist only	1.29	1.19	1.41	< 0.0001
Neither	Reference			
ID	1.24	1.17	1.32	< 0.0001
Mental health comorbidity				< 0.0001
Internalizing	1.15	1.07	1.24	0.0003
Externalizing	0.90	0.83	0.98	0.01
Both	1.12	1.04	1.20	< 0.0001
Neither	Reference			
Types of psychotropic MEDs				< 0.0001
0	Reference			
1	1.00	0.93	1.07	0.93
2	1.09	1.01	1.18	0.02
3	1.29	1.18	1.40	< 0.0001
4	1.49	1.33	1.66	< 0.0001
5 or more	1.58	1.29	1.93	< 0.0001
Health plan				< 0.0001
HMO	Reference			
PPO	2.31	2.09	2.56	< 0.0001
Other	1.95	1.75	2.18	< 0.0001
Region				< 0.0001
Northeast	1.23	1.14	1.32	< 0.0001
South	1.18	1.11	1.26	< 0.0001
West	0.82	0.75	0.89	< 0.0001
North Central	Reference			
Residence: rural versus urban	1.10	1.01	1.19	0.03
Age at baseline	1.00	0.98	1.01	0.52
Calendar year at baseline	0.97	0.96	0.98	< 0.0001

over nine times higher among patients who had an ED visit in the previous year than those who did not [adjusted Odds Ratio (aOR) 9.25; 95% Confidence Interval (CI) [8.64–9.90]).

Comorbid Diagnoses, Psychiatric Service, and Psychotropic Medications

Type of comorbidity, prior visits to PCP/psychiatrists, and number of different classes of psychotropic medications were still significantly associated with ED utilization after adjusting for prior ED visit status, age, gender and other baseline variables. Having a comorbid ID was significantly associated with elevated risk for ED visits (1.24 [1.17–1.32]). Having internalizing comorbidity alone or having concurrently both internalizing and externalizing comorbidities increased the odds of ED visits significantly (both: 1.12 [1.04–1.20]; internalizing only: 1.15 [1.07–1.24]; Reference: neither); but not with the externalizing comorbidity alone (0.90 [0.83–0.98]).

Clearly more categories of psychotropic drugs were associated with higher likelihood of visiting the ED. The odds of an ED visit were nearly 60% higher in those who were prescribed with five or more different psychotropic medications as compared to those without any prescribed psychotropics (1.58 [1.29–1.93]); even prescriptions of just two categories of these medications elevated the odds of ED visit (1.09 [1.01–1.18]).

Finally, patients who visited both PCPs and psychiatrists during the past 6 months were more likely to have an ED visit (2.22 [2.05–2.40]; reference: visited neither); followed by those who visited PCPs only (1.70 [1.61–1.81]) and those who visited psychiatrists only (1.29 [1.19–1.41]).

Gender and Transition Period

There was a significant gender-by-age interaction effect on ED visits ($p = 0.04$). In general, female adolescents with ASD were more likely to visit ED than males. Gender effect was significant in early and late adolescence (early adolescence: 1.23 [1.12–1.35]; late adolescence: 1.21 [1.09–1.34]), but not in middle adolescence (1.06 [0.96–1.16]). Meanwhile, the longitudinal effect of age depends on gender. For females, the odds of ED visits significantly increased when patients entered late stage adolescence (late vs. early: 1.23 [1.08–1.41], middle vs. early: 0.99 [0.88–1.12]). In contrast, the odds of ED visit in males increased monotonically over time (middle vs. early: 1.16 [1.08–1.24]; late vs. early: 1.25 [1.14–1.37]).

Secondary Analysis

A secondary analysis was performed to assess the risk of recurrent ED visit in a year following the ED visit(s) in the previous year. As Table 3 shows, the interaction effect between gender and age bracket remained significant ($p = 0.02$). In particular, the odds of recurrent ED visit were about 40–50% higher in females than males during early and late adolescence (early adolescence: 1.55 [1.23–1.94]; late adolescence: 1.38 [1.12–1.71]), while no significant gender effect was found in middle adolescence (1.03 [0.82–1.28]). In addition, adolescents with ASD who were prescribed three or more different classes of psychotropic medications had higher odds of recurrent ED visits. Seeing both a PCP and a psychiatrist during past 6 months was still significantly associated with recurrent ED visit (2.31 [1.94–2.75]; reference: visited neither); followed by those who visited PCPs only (1.70 [1.49–1.94]) and those who visited psychiatrists only (1.21 [1.00–1.46]). As for type of mental health comorbidity, only patients who concurrently had both internalizing and externalizing diagnoses remained significantly associated with elevated risk of recurrent ED visit (1.18 [1.01–1.39]). Interestingly, the risk of recurrent ED visits was not significantly associated with the type of health plan, type of residence and US census region.

Discussion

The primary goal of this study was to examine risk factors for ED visits among adolescents diagnosed with ASD, using a large, longitudinal, national private insurance claims database (MarketScan®) covering the years from 2005 to 2014. Adolescents with ASD who were older, diagnosed with concurrent internalizing psychiatric comorbidities, and who were taking multiple classes of psychotropic medications were hypothesized to visit the ED more frequently. Furthermore, adolescents who saw a psychiatrist in the previous 6 months were hypothesized to be at reduced risk for ED visits while contact with their primary care provider (PCP) was not thought to be protective.

Females with ASD and older adolescents with ASD, as well as comorbid mental health illnesses, were found to have the highest frequency of ED visits. In particular, comorbid internalizing mental health diagnoses (e.g., anxiety, depression) led to higher risk of ED visits compared to comorbid externalizing mental health diagnoses (e.g., ADHD, ODD, psychosis). However, having both internalizing and externalizing mental health diagnoses concurrent with ASD posed the highest risk for ED visits compared to having diagnoses from either category alone. Adolescents with ASD who saw their PCP and a psychiatrist within the past 6 months were at highest risk for visiting the ED followed next by those who only saw their PCP within the past 6 months. In contrast, adolescents with ASD who only saw a psychiatrist within the past 6 months were at lowest risk for ED visits.

ED Visits by Females with ASD

Consistent themes in the findings from this study were that female adolescents with ASD were more vulnerable for ED visits than males with ASD. In each of the age brackets, females with ASD were more likely to visit the ED during a calendar year. This is consistent with literature suggesting the vulnerability for females presenting to the ED more frequently than males (Liu et al. 2017; Tint et al.

Table 3 Multivariable logistic regression: risk factors of recurrent ED visits (N = 7454 person years)

Covariates	Adjusted odds ratio	95% CI		p-value
		Lower limit	Upper limit	
Gender × age bracket				0.02
Gender effect (F vs. M)				
12–14	1.55	1.23	1.94	0.0002
15–17	1.03	0.82	1.28	0.82
18–21	1.38	1.12	1.71	0.003
Age effect (ref: 12–14)				
Male 15–17	1.39	1.18	1.64	< 0.0001
18–21	1.55	1.25	1.93	< 0.0001
Female 15–17	0.92	0.70	1.21	0.57
18–21	1.38	1.03	1.88	0.03
Prior PCP/psychiatrist visit				< 0.0001
Both PCP and psychiatrist	2.31	1.94	2.75	< 0.0001
PCP only	1.70	1.49	1.94	< 0.0001
Psychiatrist only	1.21	1.00	1.46	0.05
Neither	Reference			
ID	1.23	1.07	1.41	0.003
Mental health comorbidity				0.003
Internalizing	1.09	0.93	1.28	0.31
Externalizing	0.84	0.69	1.03	0.09
Both	1.18	1.01	1.39	0.04
Neither	Reference			
Types of psychotropic MEDs				< 0.0001
0	Reference			
1	0.93	0.79	1.09	0.35
2	1.03	0.87	1.23	0.71
3	1.39	1.15	1.68	0.0008
4	1.62	1.27	2.06	< 0.0001
5 or more	1.76	1.20	2.57	0.004
Health plan				0.49
HMO	Reference			
PPO	1.12	0.91	1.38	0.30
Other	1.06	0.84	1.34	0.62
Region				0.24
Northeast	1.12	0.95	1.33	0.18
South	0.96	0.83	1.11	0.57
West	0.95	0.78	1.16	0.61
North Central	Reference			
Residence: rural versus urban	1.15	0.96	1.37	0.12
Age at baseline	0.98	0.95	1.01	0.25
Calendar year at baseline	1.01	0.99	1.04	0.37

2017). Early conjecture regarding the female presentation of ASD as compared to males speculated that females with ASD present with more significant social communication deficits, greater adaptive deficits, and larger cognitive deficits (Carter et al. 2007; Holtmann et al. 2007; McLennan et al. 1993; Tsai and Beisler 1983). However, other researchers have found that females with milder symptoms and normal intelligence tend to get diagnosed at later ages or are misdiagnosed (Begeer et al. 2013; Siklos and Kerns 2007). These milder presentations may be interpreted as shyness or anxiety by parents, educators, and professionals. Complicating this under-recognition is that females with ASD typically display fewer and less severe restricted and repetitive behaviors (Van Wijngaarden-Cremers et al. 2014), show more interest in social relationships (Attwood 2007), and may have more socially accepted special interests (e.g., horses, celebrities) (Kopp and Gillberg 1992) than males with ASD.

Adolescent females with ASD during times of transition (entering high school during the 12- to 14-year-old age group and exiting high school during the 18- to 21-year-old age group) were found to be particularly vulnerable to repeat ED visits. These transitions mark times when new social relationships need to be established and new skills mastered. Parents of adolescent females with ASD report that their daughters struggle with establishing and maintaining appropriate peer relationships (Holtmann et al. 2007). This may be distressing for female adolescents with ASD as they may have had some success with peers when younger due to shared interests which cannot be sustained secondary to growing social communication deficits (Van Wijngaarden-Cremers et al. 2014).

ED Visits and Mental Health Comorbidities

Over 20% of all ED visits by adolescents with ASD during the study period were documented as resulting from a comorbid mental health concern. This is likely to be an underrepresentation of the impact of mental health comorbidities on ED visit frequency given that seeming physical health presentations (e.g., fractured hand) may stem from mental health challenges (e.g., striking a wall when angry). Additionally, individuals with co-occurring intellectual disability (ID) were found to be at increased risk for ED visits; their developmental challenges from ASD are compounded by cognitive challenges which may lead them particularly vulnerable to mental health crises as their coping abilities may be stressed in multiple domains (e.g., interpersonal, communicative, reasoning, self-awareness). At a minimum, the challenges of living with ASD and potential mental health comorbidities can interfere with obtaining routine outpatient care as caregivers may wish to minimize the risk for aggressive and/or self-injurious behaviors during healthcare visits and adolescents with ASD may wish to avoid the anxiety and stress of unfamiliar environments and expectations.

As with the general population, females with ASD were found to have higher rates of comorbid internalizing disorders compared to externalizing disorders. The symptoms of internalizing disorders may go undetected, undiagnosed, or undertreated and as a result of this may rise to crisis levels resulting in ED visits in comparison to symptoms of externalizing disorders which are more readily detected and lead to referral for outpatient care. Additionally, adolescent females with "internalizing" issues are referred less often for professional assessment than adolescent males with similar problems as these symptoms may be thought of as normal in females (Rucklidge 2010). The result of these factors is a delay to treatment, which may leave females more vulnerable to adolescent pressures where social communication and processing demands increase exponentially while experiencing growing, undetected anxiety and/or depression symptoms.

ED Visits and Healthcare: Prescriptions and Providers

Adolescents who received care from both a psychiatrist and PCP within the previous 6 months were at highest risk for ED visits which might reflect greater needs and vulnerabilities of combined physical and mental health comorbidities. Adolescents who saw their PCP but not a psychiatrist within the previous 6 months were at next highest risk followed by adolescents who saw a psychiatrist but not a PCP. Seeing these isolated care providers may reflect the ubiquitous lack of access to mental health providers, poorly coordinated health care, or under-recognition of developing health concerns. However, it is likely that adolescents with ASD are experiencing a decrease in their current quantity of services (e.g., school-based services, OT, PT, SLP) while coping with rapidly changing social demands and potential new onset of medical and psychiatric comorbidities (Lubetsky et al. 2014). Individuals with more complex needs may be prescribed psychotropic medication(s) in efforts to try and meet their needs in the context of fewer readily available support and therapeutic services. In this study, adolescents with ASD prescribed two or more psychotropic medications have more ED visits possibly reflecting not only complex needs but struggles to access appropriate outpatient care.

Implications for Healthcare

Disengagement from traditional outpatient and preventative healthcare may begin during adolescence for individuals with ASD. A recent scoping review by Krieger et al. determined critical factors for community participation for adolescents with ASD; they determined that providing security, where environments support their needs for meaningful interactions, and supporting connections, when their social and communication challenges are accepted and addressed effectively, are critical for success (Krieger et al. 2018). Frequently, meaningful community participation requires strong advocacy (usually by parents or family members) and willingness by the community setting to adapt to the needs of individual with ASD.

Healthcare settings with traditional clinical operations might have difficulty meeting these needs for security and supported connections. Clinical settings have significant sensory challenges (e.g., unusual lighting, unexpected noises) and are unpredictable (e.g., wait times, examination procedures). The majority of specialized ASD treatment programs and clinical services are aimed at young children with ASD (Lubetsky et al. 2014). Healthcare providers routinely report feeling ill prepared to meet the needs of adolescents and young adults with ASD (Bruder et al. 2012; Golnik et al. 2009). All of this is concerning as adult health outcomes for those living with ASD are poor. Adults with ASD are less likely to have a PCP, more likely to report being dissatisfied with their healthcare providers, and more likely to be hospitalized than the general population (Liptak et al. 2006; Nicolaidis and Raymaker 2013; Lunsky et al. 2013).

Saqr and colleagues examined factors that contributed to success at a specialty clinic aimed at easing the transition between pediatric and adult providers for youth with ASD (Saqr et al. 2018). Clinic coordinators made phone calls to new patients prior to their first clinic visit and conducted a standardized assessment to identify any potential barriers to achieving a successful visit. The individual or a primary caregiver provided the information. The most requested accommodations included bypassing the waiting room to reduce anxiety and adjusting sensory stimuli in the clinic (e.g., reducing lighting, use of white noise machines). The investigators determined that 90% of those requesting accommodations had at least one of the following three characteristics: ID, seizures, and/or history of aggressive behaviors. They recommended that other providers who may be short on clinical resources focus on patients who have one of these characteristics as they may be at high risk for unsuccessful interactions, which may lead to disengagement from needed healthcare.

The U.S. Department of Health and Human Services is recommending increased access to medical homes for children with special healthcare needs as part of the Healthy People 2020 initiative (USDHHS 2010). Additionally, the American Academy of Pediatrics and the American Academy of Family Physicians have also recommended the adoption of medical homes for individuals with ASD (AAP 2013; AAFP 2008). Medical homes (also known as patient-centered medical home) are defined as "where healthcare services are accessible, family centered, continuous, comprehensive, coordinated, and compassionate" (AAP 1992). Coordination of all needed services, including mental health services, and seamless transitions to adult providers are hallmarks of this model. About 19% of children with ASD have access to a medical home (Farmer et al. 2014). Despite being successfully implemented for other specific chronic conditions, such as sickle cell anemia and cystic fibrosis (Hankins et al. 2012; Tuchman and Schwartz 2013), transitioning medical home models, where the focus is on meeting the needs of adolescents with chronic health conditions and ensuring a seamless transition to adult providers, have not been widely adopted for ASD. Preliminary research suggests that children with ASD who are served in medical homes are still vulnerable to poor healthcare engagement as adolescents and have significant challenges finding appropriate adult healthcare providers (Rogers and Zeni 2015).

Healthcare providers might implement some relatively easy to execute changes to their clinical care so as to better meet the needs of adolescents with ASD. Adolescents with ASD, especially females, should be routinely screened for depression and anxiety during key times of transition (e.g., entering high school, preparing to graduate). Similarly, adolescents with ASD who are prescribed multiple classes of psychotropic medications should also be followed more closely. Assess whether an adolescent with ASD is experiencing a reduction in school-based or community-based services as this likely marks a time of particular vulnerability. Determine with patients, especially those with ID, seizures, or a history of aggressive behavior, whether accommodations can be put in place to make the clinic visit more comfortable for them as noted above. More substantive system changes include wider accessibility of medical home models for adolescents with ASD, increased development of specialized transitioning medical home models, and increased education and training for adult providers to be better able to meet the healthcare needs of adults with ASD.

Limitations

There are several limitations to this study that need to be considered when interpreting these findings. First, only subjects with ASD covered by private insurance were in this sample, thus the cohort is not representative of the general US population. Secondly, the lack of details of diagnosis and associated clinical events, an inherent limitation of medical insurance claim databases, may lead to inaccurate assessments of ASD diagnosis, co-occurring mental health conditions, and some risk factors. To minimize diagnostic uncertainty, patients were required to exhibit at least two separate diagnoses of ASD on different dates of documentation. Third, the natural fluctuation in the privately insured population due to enrollment and discontinuation of health insurance may affect the composition of the study sample and the follow-up period of subjects. Finally, this study is a retrospective and secondary data analysis over an existing database. Therefore, findings should be considered as exploratory. More rigorous and prospective studies need to be conducted to further verify these results. Despite the aforementioned limitations, this study still presents new insight on the risk factors for ED visits among ASD adolescents and young adults.

Conclusion

This study reaffirms previous work that has documented higher frequency of ED visits by adolescent females with ASD as compared to males and by older compared to younger adolescents with ASD. Combined externalizing and internalizing psychiatric comorbidities, as well as internalizing conditions alone, correlate with higher frequency of ED visits in this study. Comorbidity severity as demonstrated by increased healthcare provider utilization and use of two or more classes of psychotropic medications also appear to mark vulnerability for high frequency of ED visits. Previous ED visits appear to correlate most strongly for future ED utilization. Future research needs to be done to explore the potential impact of these preliminary findings so as to reduce the healthcare disparities that individuals with ASD currently experience.

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Compliance with Ethical Standards

Conflict of interest All of the authors declare they have no conflict of interest.

Ethical Approval Ethical approval was granted by Penn State University College of Medicine's Institutional Review Board. All procedures performed in this study were in accordance the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent For this type of study formal consent is not required.

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