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Emergency Department Use among Adults with Autism Spectrum Disorders (ASD)

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Abstract

A cross-sectional analyses using Nationwide Emergency Department Sample (2006-2011) was conducted to examine the trends, type of ED visits, and mean total ED charges for adults aged 22-64 years with and without ASD (matched 1:3). Around 0.4% ED visits (n = 25,527) were associated with any ASD and rates of such visits more than doubled from 2006 to 2011 (2,549 to 6,087 per 100,000 admissions). Adults with ASD visited ED for: primary psychiatric disorder ($15\%_{ASD}$ vs. $4.2\%_{noASD}$), primary non-psychiatric disorder ($16\%_{ASD}$ vs. $14\%_{noASD}$), and any injury ($24\%_{ASD}$ vs. $28\%_{noASD}$). Mean total ED charges for adults with ASD were 2.3 times higher than adults without ASD. Findings emphasize the need to examine the extent of frequent ED use in this population.

Keywords

Autism; Emergency Department; Emergency Room; Autism Trends; Expenditures; Adult Autism; Autism Injury; Medical Conditions in Autism

The burden of emergency department (ED) use in the US is high and the total number of national ED visits in the year 2005 ranged from 109.2 million to 116.3 million (Owens et al. 2010; Tang et al. 2010). According to a report by Choudhry et al. (2007) on association of community affiliated plans, at least one-third of ED visits were avoidable/non-urgent/ ambulatory care sensitive and treatable in primary care settings. Surprisingly, over $18 billion dollars are spent annually on such avoidable ED visits in the US (Choudhry et al.

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Informed Consent: There was no requirement of an informed consent, since the discharge-level data is publicly available and did not involve direct participation of patients. The primary author of the study has completed a data user agreement with the HCUP-NEDS, AHRQ to obtain the de-identified dataset.

2007). Since ED is often the most critical point of healthcare delivery and for many individuals the only point of healthcare delivery, it is important to document the extent of ED utilization among patients with high healthcare needs and among those who are at high risk of frequent returns.

Even though adults with ASD have considerable healthcare needs (Billstedt et al. 2005; Magiati et al. 2014), there is a lack of comprehensive documentation of characteristics and patterns of ED use among this group. Previous studies on use of ED services among individuals with ASD have been either restricted to pediatric/adolescent population (Croen et al. 2006; Kalb et al. 2012; Wharff et al. 2011) and/or examination of ED use as a part of a bigger study with no specific details on types of ED visits (Croen et al. 2006; Kato et al. 2013; Nicolaidis et al. 2013). Nonetheless, such studies have provided insights which corroborate the hypothesis that adults with ASD are at high risk of ED use. Recently, a brief report by Iannuzzi et al. (2015) using 2010 Nationwide Emergency Department database examined most common reasons for ED visits among individuals (all ages) with and without ASD. The authors of the study found that epilepsy was the most common reason for an ED visit among all age groups and psychiatric ED visits were more common in the younger age group of 12-15 years. Nicolaidis et al. (2013) examined the healthcare experiences of adults with and without ASD via an online cross sectional survey and found that adults with ASD had greater odds of using an ED as compared to adults without ASD (OR = 2.1, 95% CI = 1.8-3.8). Kato et al. (2013) compared the characteristics of suicide attempts in a hospital emergency room between adults with and without ASD. The authors found that about 7.3% of patients with suicidal emergencies had ASD, and those with ASD had a significantly greater prevalence of adjustment disorders (70%) and a longer length of stay in the intensive care unit/hospital as compared to adults without ASD. The authors suggested that patients with ASD, due to impulsive behavior and aggression tendencies may be more likely to choose lethal methods of suicide, and may even be more likely to succeed in their first suicidal attempt in cases where stressors are not spontaneous, and when there is a lack of psychiatric treatment in the recent past. Despite such studies, there is a need to characterize preponderant ED visits among adults with ASD and compare them to adults without ASD because the former has various concerns that puts them at a greater risk of worse ED outcomes:

Comorbidities

Adults with ASD have extensive comorbidities such as intellectual disabilities, depression, anxiety, ADHD, and substance dependence disorder (Hofvander et al. 2009; Lugnegard et al. 2011) along with core autistic symptoms that present greater challenges in care as compared to adults without ASD (Pines et al. 2011). A study by Williams et al. (2001) found high prevalence of anxiety and depressive disorders among frequent attenders of ED. Substance abuse also influences ED use over a period of time for adults with other psychiatric illness (OR = 4.9, 95% CI = 3.5–6.9) (Curran et al. 2003). In addition, some studies have shown that many patients (as high as 24%) with depressive disorders (comorbid or not) present to the ED for traumatic physical injuries/self-inflicted injuries (Doshi et al. 2005; Richmond et al. 2007). This indicates that adults with ASD may have a higher risk of injuries not only because of their own behavioral tendencies but also because of high prevalence of comorbid

depression (Lugnegard et al. 2011; Lunsky et al. 2009). A very recent study by Croen and colleagues (Croen et al. 2015) showed that adults with ASD are also more likely to have greater prevalence of non-psychiatric comorbidities such as diabetes, cardiovascular conditions, and high cholesterol, which may also be contribute to an increase in ED use and worsen ED experiences for adults with ASD.

Disruptive Behaviors and Injuries

Individuals with ASD are affected by challenging behaviors such as aggression, destruction, self-inflicted injuries, and other disruptive behaviors (Matson and Rivet, 2008) that many a time require emergent care. Doshi et al. (2005) used the National Hospital Ambulatory Medical Care Survey (NHAMCS) to examine the ED visit patterns for attempted suicide and self-inflicted injuries which accounted for more than 400,000 ED visits per year (0.4% of all ED visits). The most common cases in the ED were treated for poisoning (28% by unspecified drugs or medicinal substances, 27% tranquilizers and other psychotropic agents and 25% by analgesics/antipyretics/anti-rheumatics) followed by cutting or piercing. Knowing that individuals with ASD frequently engage in disruptive behaviors (Matson and Rivet, 2008), it is very likely that they may present to ED with extreme self-inflicted injuries. Since, some adults with ASD have communication difficulties, providing care in ED for injuries, may also be a bigger challenge for ED primary care providers.

Paucity of Trained Professionals

Lack of trained psychiatrists, other mental health professionals, and mental health facilities that can manage specific ASD issues in outpatient primary care or specialty settings (Mauch et al. 2011) may also lead to greater ED use. Many studies have also shown that physicians and other healthcare providers often report a lack of self-perceived competency and knowledge in treating adults with ASD (Bruder et al. 2012; Golnik et al. 2009; Miller, 2015; Oskoui and Wolfson, 2012). With no clarity on adult ASD treatment guidelines and possible delayed/foregone care due to low access to services in many states/regions may put adults with ASD at a substantial risk of high ED use and costs. Our hypothesis is also supported by other studies (Williams et al. 2001, Soto et al. 2009) which have shown that strong predictors of frequent and inappropriate ED use among individuals needing psychiatric care include lack of a coordinated community program for mental health and outpatient psychiatric services that can provide timely care to individuals with psychiatric disorders such as ASD. Studies have also underlined that many such psychiatric ED cases could have been handled well in an outpatient primary setting due to the non-urgent nature of the complaint (Sills and Bland, 2002; Soto et al. 2009). The Emergency Medical Treatment and Labor Act (EMTALA) (Zibulewsky, 2001), whereby in the US any patient requesting examination/treatment for any health condition must be provided with medical/psychiatric evaluation in an emergency situation, many a time makes ED a source of primary care for those with psychiatric needs such as ASD in absence of other mental health facilities in the region.

The current study aims to address the gaps in literature on ED utilization among adults with ASD. Even though the brief report by Iannuzzi et al. (2015) informs on the most common

ED visits among individuals with ASD of all ages, the study was restricted by one year of data and no analyses of trends and/or ED costs. Our study not only compares the trends in ED rates for adults with ASD across a span of six years using the Nationwide Emergency Department Sample (NEDS) 2006-2011 (Healthcare Cost and Utilization Project (HCUP), 2011), but also determines the differences in rates and costs of specific ED visits such as psychiatric, non-psychiatric, and injury visits across adults with and without ASD. Examination of ED use will help highlight the deficits (if any) in quality of care/care coordination for adults with ASD provided in the primary care setting that possibly contributes to greater ED use and inpatient hospitalizations (Soto et al. 2009; Williams et al. 2001). Due to the rise in adult ASD cases (Brugha et al. 2011) and with greater number of individuals receiving ASD diagnoses than ever before, we hypothesized that rates of ED visits with ASD diagnosis will increase over the six year period. In addition, we also expected that adults with ASD will be more likely to have psychiatric, non-psychiatric, as well as injury visits as compared to adults without ASD.

Method

Study Population & Design

Any ED visits among adults aged 22-64 years was the study population. A cross-sectional matched case-control design was used. Trend analyses was conducted with each year selected as a distinct data point in the study (2006-2011). For objectives other than trends, a pooled sample was used. If any variable had missingness ≥0.5%, we created a missing indicator to account for any differences caused by missingness in our major independent variables.

Data Source

We used the Nationwide Emergency Department Sample (NEDS) 2006-2011, largest all payer ED database including national estimates for hospital based ED data visits created for the Healthcare Cost and Utilization Project, Agency of Healthcare and Research Quality (Healthcare Cost and Utilization Project (HCUP), 2011). NEDS compiles discharge data collected from hospital billing records from both state emergency department databases (SEDD) and state inpatient databases (SID). The SID contains information on patients initially seen in the ED and then admitted to the same hospital. The SEDD capture information on ED visits that do not result in an admission (i.e., treat-and-release visits and transfers to another hospital).

The NEDS is built using a 20% stratified sample of institutions and collects data from 951 hospitals located in 30 states with an unweighted 30 million discharges each year. The NEDS presents rich information on type of ED visits (psychiatric, injury, etc.) along with up to 15 diagnoses associated with each visit, geographic information, hospital characteristics, and total charges for each ED visit. We expect that high proportion of adults with ASD will present to the ED, utilize ED services frequently, and are possibly associated with an increased risk of subsequent hospitalizations as compared to adults without ASD. Using a database such as NEDS not only helps understand the extent and patterns of ED use among adults with ASD but also provides additional information on reasons for these visits such as

type of injuries (which has not been previously reported in any study on adults with ASD), primary diagnosis for the ED visit, and the outcome(s) of the ED visits (e.g. treated and released, transfer to home health, or inpatient hospitalizations etc.). Since the NEDS is a publicly available database and does not contain unique patient identifiers, Institutional Review Board approval was not required for the study (In compliance with federal regulations; CFR Title 45 Section 46.101 subparagraph (b) (4)).

Dependent Variables

Psychiatric visit (yes/no)—A psychiatric visit was identified by an ED visit with a principal diagnosis of a psychiatry disorder, other than ASD. The NEDS includes the single level clinical classification software (CCS) provided by Agency for Healthcare Research and Quality (Healthcare Cost and Utilization Project (HCUP), 2011) (https://www.hcupus.ahrq.gov/toolssoftware/CCS/AppendixASingleDX.txt) to categorize diagnosis and procedure codes to clinically meaningful categories. We used nine broad categories of psychiatric disorders: adjustment disorders (CCS code: 650), alcohol use disorders (AUD; CCS code: 660), anxiety disorders (CCS code: 651), attention deficit disorders & conduct behavior disorders (ADD; CCS code: 652), developmental disorders (CCS code: 654), mood disorders including depressive disorders and bipolar disorder (CCS code: 6571,6572), personality disorders (CCS code: 658), schizophrenia & other psychotic disorders (CCS code: 659), and substance use disorders (SUD; CCS code: 661).

Non-psychiatric visit (yes/no)—A non-psychiatric visit was identified as an ED visit with a principal diagnosis of a non-psychiatric disorder. We used six broad categories of non-psychiatric disorders some of which have been found to be very common among adults with ASD in a recent study (Croen et al., 2015): cancer (CCS code: 11-37, 39, 40-43), cardiovascular disease (CCS code: 100, 101, 105, 106, 108, 53, 98, 99, 109, 110-112), diabetes (CCS code: 49, 50), epilepsy (CCS code: 83), gastrointestinal disease (CCS code: 138-140, 141), and respiratory disease (CCS code: 125-128, 132-134).

Injury visit (yes/no)—NEDS 2006-2009 reported external causes of injuries in form of CCS ecodes (4 possible ecodes on each record), but 2009 onwards the NEDS reported injuries as a separate variable (injury on principal diagnosis, injury on other diagnoses, and no injury). Each type of injury was identified using CCS ecodes/ICD-9-CM codes prior to 2009 and by an injury variable after the year 2009 to create a single binary indicator for any injury (yes/no). Any visit with a record of the following codes qualified as an injury visit: cutting (CCS ecode: 2601), drowning (CCS ecode: 2602), fall (CCS ecode: 2603), fire (CCS ecode: 2604), machinery (CCS ecode: 2606), poison (CCS ecode: 2613), struck (struck by lightning or an object; CCS ecode: 2614), and suffocation (CCS ecode: 2615). Additional critical injury characteristics such as assault (by intent; yes/no), self-harm (by intent; CCS ecode: 662 excluding V6284), and suicidal ideation (ICD9-CM code: V6284) are also included in the study. We also report the severity of injury associated with an ED visit by examining presence of multiple cause of injuries (none or one, 2 or more), which indicates the total number of external cause of injury ecodes (valid and invalid).

Total ED Charges—The edited total charges for ED services associated with each visit was used to identify economic burden of ED visits. Total ED charges included both "treat and release" ED visits as well as ED visits that led to a hospitalization in the same hospital. The total ED charges were expressed in constant dollars to adjust for inflation over the period of six years. "Medical care services" part of the annual consumer price index (CPI) was utilized to transform/convert total charges to 2011 constant dollars. The CPI was obtained from the Bureau of Labor Statistics (Bureau of Labor Statistics, US Department of Labor, 2014).

Independent variables

ASD (yes/no)—The NEDS provides up to 15 possible diagnoses recorded on each ED visit. Adults with ASD were identified using an ICD-9-CM diagnosis code in any position for: 299.xx (which includes autistic disorder, Asperger's syndrome, and other pervasive developmental disorders).

Other independent variables—Age (22-40, 41-54, and 55-64) and gender (male and female) were included as demographic characteristics. Due to the lack of literature on age variations in development, symptomatology, and patterns of healthcare services' use among adults with ASD, the study used age groupings based on sample distribution of ASD cases, matching efficiency, and were mainly exploratory in nature. The socio-economic status was described using median household income for patient's zip code which was assigned as quartiles by the HCUP for each year (For e.g. in the 2011 NEDS, the median income was divided into: $1 - $38,999, $39,000 - $47,999, $48,000 - $63,999, and $64,000 or more). We used the median household income for patient's zip code and categorized it into four major quartiles (Q1, Q2, Q3, Q4, and missing). Health insurance coverage selected as a primary payer for the ED visit was categorized into: public (Medicare/Medicaid), private, self-pay/other/no charge. Hospital characteristics included region (Northeast, Midwest, South, and West) and hospital location (rural, urban, and missing). Patient disposition characteristics included the type of ED event (treat and release, inpatient admission, transfer to another short term hospital/home health, and died/other). A mortality event was defined as any record of patient death reported on the ED visit (yes/no).

Matching

The ASD cases (1) and no ASD controls (3) were matched by age and gender using propensity score matching method with GREEDY algorithm. Predicted probabilities from a multivariate logistic regression analysis on ASD status (yes, no) were used to identify and match the "nearest neighbor" with an ASD to a visit with no ASD, where one ASD case was matched to three no ASD controls using 8 to 1 GREEDY matching technique. An 8 to 1 GREEDY matching technique involves matching the cases and controls with same propensity score till the 8^{th} digit, and if 8^{th} digit match is unsuccessful, the algorithm attempts to match on 7-digits, and so on. The GREEDY matching algorithm employs a sample without replacement and if there are more than one matches then selection of control becomes random. Such an approach for propensity score matching is used to reduce the effects of bias and confounding in observational studies (Austin, 2011).

Statistical Analyses

We conducted two sample chi-square tests to present trends in ED use and multivariate logistic regression to assess the significance of trends. Weighted rates for adults with ASD were calculated using number of ED visits with any ASD diagnosis (numerator) and total number of ED visits in the sample (denominator). Weighted rates for specific ED visits, for example psychiatric visits were calculated using number of psychiatric ED visits with any ASD diagnoses (numerator) and total number of psychiatric ED visits in the sample (denominator). For examining sub-group differences across adults with and without ASD in the pooled sample, bivariate analyses were conducted (Chi-square for categorical and t-tests for continuous variables). Numbers and weighted percentages are reported for each type of visit by ASD status. Unadjusted and multivariate adjusted logistic regressions were run for binary dependent variables (psychiatric, non-psychiatric, and injury visits). All procedures accounted for NEDS complex survey design. For all analyses, SAS v9.4 was used.

Results

Trend Analyses

Weighted rates of ED visits for adults with ASD increased from 2,549 to 6,087 per every 100,000 ED visits from the years 2006 to 2011. Psychiatric visit rates for adults with ASD exhibited the steepest rise from 5,261 to 13,706 per every 100,000 psychiatric ED visits, as compared to all other specific ED visits. Despite the actual rise in rates for all, psychiatric, non-psychiatric, and injury visits, none of the trends were significantly different from trends for adults without ASD.

Pooled Study Sample (table not shown here)

In the pooled study sample 25,257 ED visits were among adults with ASD (0.4% in unmatched sample). The ED visits were primarily among male gender (67%) and age group 22-40 years (72%). Most of the ED visits in the sample were treat and release (86%) and 0.3% visits were associated with a mortality event. Most common ED visits in the pooled sample were associated with an injury (n = 27,193, 26%), followed by a non-psychiatric disorder (n = 14,574, 14%), and a psychiatry disorder (n = 7,005, 7%).

Sample Description by ASD status (Table 1)—Around 80% of adults with ASD had public health insurance as a primary payer as compared to only 26% adults without ASD. One-third of ED visits among adults with ASD led to an inpatient admission (34%) as compared to one-tenth of ED visits among adults without ASD. Approximately one percent of adults with ASD had a mortality event after an ED visit as compared to 0.3% adults without ASD.

Type of ED Visits by ASD status (Table 2)—Fifteen percent of adults with ASD had a psychiatric visit as compared to 4.2% adults without ASD. Proportion of adults with ASD with an injury visit was significantly less as compared to adults without ASD ($23.7\%_{ASD}$ vs. $27.7\%_{NoASD}$). However, non-psychiatric visits (16.1%) were much more common among adults with ASD as compared to adults without ASD (13.6%). Within psychiatric visits, a majority of adults with ASD came to ED with a principal diagnosis of: schizophrenia

(3.8%), followed by bipolar disorder (3.2%), depression (2.5%), and intellectual disabilities (1.6%). Even though the rates of injury visits were much lower among adults with ASD as compared to adults without ASD, there were certain injuries that were more common in the former group. Adults with ASD had higher rates of injuries due to falls (6.5%ASD vs. $5.0\%_{noASD}$), poisoning ($1.4\%_{ASD}$ vs. $0.8\%_{noASD}$), self-harm ($1.9\%_{ASD}$ vs. $0.5\%_{noASD}$), and suicidal ideation (2.6%ASD vs. 0.9%noASD). Adults with ASD also had significantly greater rates of non-psychiatric visits with a principal diagnosis of cancer ($0.3\%_{ASD}$ vs. $0.2\%_{noASD}$), diabetes ($1.1\%_{ASD}$ vs. $0.8\%_{noASD}$), and epilepsy ($8.8\%_{ASD}$ vs. $1.0\%_{noASD}$).

In the adjusted logistic regression analyses (Table 3, 4, and 5), adults with ASD were found to be more likely to have a psychiatric visit (AOR = 2.63, 95% CI = 2.41-2.88), a non-psychiatric visit (AOR = 1.07, 95% CI = 1.01-1.14), as well as an injury visit (AOR = 1.10, 95% CI = 1.04-1.16) as compared to adults without ASD. However, they were significantly less likely to have a psychiatric visit with AUD (AOR = 0.22, 95% CI = 0.16- 0.29) and SUD (AOR = 0.19, 95%CI = 0.14 −0.26). Adults with ASD were also significantly more likely to have injury visits due to falls (AOR = 1.48, 95% CI = 1.34-1.62), self-harm (AOR = 2.95, 95% CI = 2.33-3.75), and suicidal ideation (AOR = 1.88, 95% CI = 1.56-2.26) as compared to adults without ASD. In addition, adults with ASD were more likely to have multiple cause of injuries as compared to adults without ASD (AOR = 1.12, 95% CI = 1.04-1.19). Although non-psychiatric ED rates for certain visits were lower among adults with ASD, they were seven times more likely to have an ED visit with a principal diagnosis of epilepsy, as compared to adults without ASD (AOR = 7.15, 95% CI = 6.28-8.13).

Mean Total Charges (Table 1 and 6)—Mean total ED charges for adults with ASD were significantly higher as compared to adults without ASD ($mean_{ASD}$= $14,289, SE = $418 vs. meannoASD = $6,196, SE = $165). Table 6 shows the means and standard errors (SE's) for mean total ED charges among adults with and without ASD by type of ED visits. The mean total charges for a psychiatric visit among adults with ASD were significantly higher as compared to adults without ASD ($mean_{ASD}$= $12,506, SE = $559vs. $mean_{noASD}$= $7,238, SE = $359, $p<0.001$). Despite a lower proportion of adults with ASD having a non-psychiatric visit in the sample, their associated mean total charges were significantly higher ($mean_{ASD}$= $3,662, SE = $681 vs. $mean_{noASD}$= $9,521, SE = $454, $p<0.001$) when compared to adults without ASD. Injury visits also costed more for adults with ASD as compared to adults without ASD ($mean_{ASD}$= $12,912, SE = $715 vs. $mean_{noASD}$= $5,842, SE = $345, $p<0.001$).

One of the highest costing ED visit for both adults with (mean = $75,352, SE = $10,528) and without ASD (mean = $67,434, SE = $7,907) was an ED visit with a primary diagnosis of cancer. However, ED visit with a cardiovascular disease had higher mean total ED charges for adults with ASD (mean = $ 39,432, SE = $3,671) as compared to adults without ASD (mean = $27,181, SE = $1,893). Mean total ED charges for schizophrenia, which was the costliest psychiatric ED visit among adults with ASD (mean = $20,336, SE = $1,168), were significantly greater than mean charges for adults without ASD (mean = $12,183, SE = $1,088). Injury visits such as those associated with self-harm also had greater mean total ED charges for adults with ASD (mean = $13,001, SE = $1,106) as compared to adults without ASD (mean = $11,560, SE = $1,810), even though the difference did not reach statistical

significance. Falls among adults with ASD were also associated with significantly greater mean total ED charges (mean = $11,230, SE = $934) as compared to falls among adults without ASD (mean = $5,880, SE = $475).

Discussion

Our study is a unique contribution to the literature providing information on extent and types of ED use among adults with ASD along with their ED costs. A very recent study showed that an ASD diagnosis was very strongly associated with frequent ED use as well as hospital readmissions (Smith et al. 2015), therefore we expected that the trends of ED visits among adults with ASD will increase. The rates of ED visits with an ASD diagnosis more than doubled in a period of six years in the current study, highlighting a rise in resource utilization among adults with ASD.

In the pooled study sample, ED visits with ASD formed 0.4% of the total study sample (unmatched). There were two critical findings in the descriptive analyses: 1) Majority (80%) of adults with ASD were covered by a public health insurance as compared to one-quarter (25%) adults without ASD. This finding reflects that public payers still account for covering ED and inpatient services among majority of adults with mental health issues such as ASD, consistent with previous studies (Ruble et al. 2005; Semansky et al. 2011); and 2) Another intriguing observation in the study was the difference in rates of inpatient admissions after an ED use among adults with and without ASD. Around one-third of ED visits among adults with ASD led to an inpatient admission as compared to one-tenth of adults without ASD. This indicates that higher ED use among adults with ASD may also lead to greater hospitalization rates which is associated with high hospitalization costs (Lokhandwala et al. 2012).

ED visits

The second part of our study focused on identifying the common ED visits among adults with ASD and compare their occurrences to adults without ASD. We found that non-psychiatric (16%) and psychiatric (15%) visits were more common among adults with ASD as compared to adults without ASD. The most commonly associated reasons for ED visits among adults with ASD included: epilepsy (8.8%), falls (6.5%), schizophrenia (3.8%), respiratory disorders (3.8%), bipolar disorders (3.2%), and depression (2.5%). These rates support the findings regarding comorbid diagnoses among adults with ASD from many other studies (Ahmedani and Hock, 2012; Leyfer et al. 2006; Maski et al. 2011; Simonoff et al. 2008; White et al. 2009; Zafeiriou et al. 2007). The rates of epilepsy and schizophrenia related ED visits are also similar to the findings of a recent study conducted by Iannuzzi et al. (2015) on adults with ASD (19 years and above).

Psychiatric visit—It is well known that adults with ASD are extensively affected by psychiatric comorbidity, with 90% reporting at least one DSM-IV psychiatric disorder and our findings indicate that 15% of adults with ASD are visiting ED due to psychiatric reasons (Leyfer et al. 2006; Lunsky et al. 2009; Palucka and Lunsky, 2007; Simonoff et al. 2008). Some psychiatric visits were less common among adults with ASD as compared to adults without ASD. These visits were associated with behavioral disorders such as AUD

(0.4%$_{ASD}$ vs. 1.5%$_{noASD}$) and SUD (0.3%$_{ASD}$ vs 0.9%$_{noASD}$). Literature has shown that usually individuals with ASD are less prone to use of drugs/alcohol, however, individuals on the higher functioning spectrum may frequently engage in alcohol consumption to help alleviate the social difficulties they experience (Santosh and Mijovic, 2006; Sizoo et al. 2009). Although the prevalence of SUD in our study and in a previous study by Santosh and Mijovic was low (0.3%), another study by (Sizoo et al. 2009) has shown a higher prevalence rate (30%) of substance abuse among adults with ASD. Since SUD is associated with greater healthcare resource utilization and worse outcomes (Smith et al. 2015), greater attention and monitoring may be needed to identify SUD among adults with ASD so that timely counseling can be provided.

Non-psychiatric visit—Fewer adults with ASD had a non-psychiatric visit with cardiovascular disease (1.4%), gastrointestinal disease (0.8%), and respiratory disorder (3.8%) as compared to adults with ASD. On the other hand, significantly greater proportion of adults with ASD came to the ED with a principal diagnosis of diabetes (1.1%), epilepsy (8.8%), and cancer (0.3%). Our findings indicate that adults with ASD if not more likely, are at least equally likely to have non-psychiatric needs as compared to adults without ASD when presenting to the ED. Other than epilepsy, most non-psychiatric disorders among adults with ASD have received little attention, especially in the ED settings. Additional healthcare needs associated with non-psychiatric disorders will only increase the healthcare needs, utilization, and expenditures of adults with ASD.

Injury visit—Adults with ASD had lower rates of injury visits as compared to adults without ASD. Nonetheless, a few specific injury visits were more common in the ASD group. For example, significantly greater proportion of adults with ASD had an injury visit with poisoning (1.4%$_{ASD}$vs. 0.8%$_{noASD}$), self-harm (1.9% $_{ASD}$ vs. 0.5% $_{noASD}$), and suicidal ideation (2.6% $_{ASD}$ vs.0.9% $_{noASD}$). This finding is complementary to our hypothesis that some of the major reasons for ED use among adults with ASD are disruptive behaviors and self-inflicting injuries. Even after adjusting for other study variables, adults with ASD were more likely to visit ED with a fall injury (AOR = 1.5), self-harm (AOR = 2.95), and suicidal ideation (AOR = 1.88). Most studies have examined injuries, especially falls among patients with developmental disabilities (DD), where the prevalence of injuries have ranged from 11%-20% (Finlayson et al. 2010; Hsieh et al. 2001). The primary risk factors for an injury among adults with DD are higher frequency of seizures, destructive behaviors, and use of antipsychotic drugs. Knowing that adults with ASD may be at a greater risk of all the above factors (Billstedt et al. 2007; Esbensen et al. 2009; Levy et al. 2010), their probability of a fall injury and a subsequent ED visit is also very high.

In the current study, although the rates of injuries due to assault were lower among adults with ASD as compared to adults without ASD, further investigation is needed to corroborate this finding using other data (for e.g., police records). This is a critical type of injury especially for adults with ASD who many a time have difficulty communicating their needs and experiences resulting in frustration, anger, aggression, and self-injurious behaviors. Future studies should focus on examining the gravity of such communication impediments

on both self-inflictions as well as receipt of aggression by others during ED visits and hospitalizations.

Total ED Charges

Our study also compared mean total ED charges for adults with and without ASD. Adults with ASD, in general had higher ED costs compared to adults without ASD (ratio of $means_{ASD\ vs.\ NoASD} = 2.30$, $p<0.001$). The ratio of meansASD vs. NoASD for specific ED visits (psychiatric disorders = 1.7; non-psychiatric disorders = 1.4; and injuries = 2.2) indicated that the biggest difference in mean total ED charges between ASD and no ASD group was attributed to injuries. Mean charges for injuries due to falls among adults with ASD was almost double the costs for falls among adults without ASD ($p<0.001$). Mean charges of ED visit with suicidal ideation, which is a common diagnosis among adults with ASD, was also significantly higher among the ASD group as compared to the no ASD group (ratio of $means_{ASD\ vs.\ NoASD} = 1.56$, $p<0.001$). These findings indicate that injuries are common among adults with ASD (Kato et al. 2013) and are associated with high ED utilization and costs. Since, one-third of adults with ASD in the sample had an inpatient admission after using ED, the higher mean total ED charges not only reflect outpatient ED costs, but also indicate costs contributed by hospitalizations.

Implications

The current study has implications for policy discussions related to quality of care and care coordination in a primary care/specialty care setting for adults with ASD. Our study sheds light on the need for better guidelines and greater support for incorporating ASD related training of physicians and other healthcare providers who usually report lack of self-perceived competency in treating and diagnosing adults with ASD (Bruder et al. 2012; Golnik et al. 2009; Oskoui and Wolfson, 2012). Miller (2015) examined the extent of ASD knowledge among nurses working in an ED and found that more than half of ED nurses surveyed reported having accurate knowledge, correctly identified causes of visit and comorbidities, and chose appropriate interventions for ASD cases. However, nurses still reported having limited knowledge and resources available to them and felt a need for ASD education early on in their training. This perceived need to overcome gaps in ASD related care among nurses may also be true for physicians and other healthcare providers. Future studies should examine the association of quality and consistency of care received by adults with ASD in the primary setting with a patient's subsequent ED use, frequency of ED use, hospital admissions, and healthcare costs.

Limitations

Despite many advantages, the NEDS data is limited by use of a discharge level rather than a person level data. Therefore, multiple visits by a much sicker population could not be distinguished. Similar to Kalb et al. (2012) study, where authors utilized the NEDS for examining ED visits among children with ASD, we defined ASD as any of the 15 possible diagnoses rather than a primary diagnosis. However, this algorithm has not been validated in survey research and may have its own drawbacks. In this study we also assumed that ED visits with a primary psychiatric disorder and non-psychiatric disorder was actually correlated with a patient's psychiatric and non-psychiatric needs at the time of the visit. It is

quite possible that the reason(s) for an ED visit might have been completely different than the principal diagnosis on the record, which could have been used purely for billing purposes.

The data allowed only for capturing the total ED charges for the services used/billed. We could not manipulate the data to deliver cost/expenditure, which is a better and a more meaningful concept. However, the requirement of the study was to identify the excess healthcare utilization and total charges for the ASD group as compared to the no ASD group and using charges sufficed the need of the current study goals. We also could not account for the charges that were not included in the ED and inpatient charges (such as professional fees), expenditures paid by the payer, and/or out of pocket expenditures for the patients, which would provide the cost sharing burden among patients with or without ASD. The data also was limited by the absence of patient reported health behaviors (such as smoking, tobacco use, and drug abuse), physician review charts, and other additional information that could help validate the reasons for ED visits. Finally, racial/ethnic differences could not be accounted for in the study due to the lack of information on race in the available data.

Conclusion

Rates of ED visits among adults with ASD are on the rise. Adults with ASD use ED for different reasons which are not restricted to psychiatric needs, but also extend to non-psychiatric needs and injuries. ED visits among adults with ASD are also associated with significantly greater hospitalization rates as compared to adults without ASD. Mean total ED charges for adults with ASD are almost twice as high as charges for adults without ASD. Prevalence, risk factors, and burden of ED utilization among adults with ASD is understudied and future studies should examine the impact of such ED utilization on long term healthcare costs.

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Table 1

Description of Pooled Study Sample Characteristics by ASD status Adults with and without ASD matched on age and gender 2006-2011 Nationwide Emergency Department Sample (n =102,108)

		ASD		No ASD		Sig.
		N	Col. Wt. %	N	Col. Wt. %	
Sex						
	Male	19,286	75.5	57,858	75.7	ns
	Female	6,241	24.5	18,723	24.3	
Age (in years)						
	22-40	17,961	70.2	53,883	70.3	ns
	41-54	5,575	21.8	16,725	21.9	
	55-64	1,991	8.0	5,973	7.8	
Income Groups (quartiles)						***
	Q1	5,364	21.2	24,787	32.4	
	Q2	6,230	24.5	20,783	27.2	
	Q3	6,590	25.8	16,848	21.9	
	Q4	6,612	25.8	12,119	15.8	
	Missing	731	2.8	2,044	2.7	
Primary Payer						***
	Public	20,483	80.4	19,496	25.7	
	Private	3,764	14.7	25,938	34.3	
	Self-Charge	807	3.2	23,934	31.1	
	No Charge/Other	424	1.7	6,763	9.0	
Hospital Region						***
	North-east	7,453	29.6	15,211	20.5	
	Mid-west	6,446	27.0	16,366	23.5	
	South	7,476	27.1	32,132	38.8	
	West	4,152	16.3	12,872	17.2	
Hospital Location						
	Rural	945	4.0	5,345	7.3	***
	Urban	24,459	95.5	70,503	91.8	
	Missing	123	0.5	733	1.0	
ED Event						***
	Treat and release	16,340	64.0	66,751	87.1	
	Inpatient admission	8,651	33.9	8,136	10.6	
	Transfer	326	1.3	804	1.1	
	Died/other	210	0.8	890	1.2	
Mortality Events		181	0.7	16,186	0.3	***
Mean total ED charges mean (SE)		$14,289 ($418)		$6,196 ($165)		***

The estimates are provided from NEDS representing ED visits with adults aged 22-64 years from the years 2006-2011; ED visits with and without ASD were matched on age and gender; Col. Wt. %: Column weighted percentages; SE: Standard errors; ns: not significant at p<0.05 level.

Sig.:

**0.001 ≤ P < 0.01; * 0.01 ≤ P < 0.05.

*** P < 0.001;

Table 2

Type of ED Visits in the Pooled Study Sample by ASD Status Adults with and without ASD matched on age and gender 2006-2011 Nationwide Emergency Department Sample (n =102,108)

		ASD		No ASD		Sig.
		N	Col. Wt.%	N	Col. Wt.%	
Psychiatric Visit		*3,831*	*15.1*	*3,174*	*4.2*	***
	ADD/ADHD	328	1.3	27	0.0	***
	Adjustment Disorders	137	0.5	91	0.1	***
	Anxiety Disorders	376	1.5	675	0.9	***
	AUD	97	0.4	1,099	1.5	***
	Bipolar Disorder	825	3.2	326	0.4	***
	Depression	608	2.5	717	1.0	***
	Intellectual Disabilities	399	1.6	22	0.0	***
	Personality Disorders	113	0.4	11	0.0	***
	Schizophrenia	971	3.8	619	0.8	***
	SUD	74	0.3	686	0.9	***
Injury Visit[§§]		*6,076*	*23.7*	*21,117*	*27.7*	***
	Assault[€§§]	146	0.9	901	1.9	***
	Cut	346	1.3	2,270	3.0	***
	Drown	5	0.0	6	0.0	nc
	Fall	1,655	6.5	3,751	5.0	***
	Fire	52	0.2	323	0.4	***
	Machinery	1	0.0	177	0.2	nc
	Poison	368	1.4	567	0.8	***
	Self-harm[§§]	475	1.9	371	0.5	***
	Struck	832	3.3	3,337	4.4	***
	Suffocation	66	0.3	24	0.0	***
	Suicidal Ideation[§§]	650	2.6	683	0.9	***
	Multiple Injuries[§§]	3,754	14.7	12,180	16.3	***
Non-psychiatric Visit		*4,130*	*16.1*	*10,444*	*13.6*	***
	Cancer	70	0.3	147	0.2	**
	Cardiovascular Disease	369	1.4	1,867	2.5	***
	Diabetes	274	1.1	628	0.8	**
	Epilepsy	2,253	8.8	793	1.0	**
	Gastrointestinal Disease	188	0.8	765	1.0	**
	Respiratory Disease	976	3.8	6,244	8.1	**

The estimates are provided from NEDS representing ED visits with adults aged 22-64 years from the years 2006-2011; ED visits with and without ASD were matched on age and gender; nc: Not conclusive. Tests not feasible due to low cell sizes; ADD/ADHD: Attention deficit disorders/ attention deficit hyperactivity disorders; AUD: Alcohol use disorders; SUD: Substance use disorders.

Col. Wt. %: Column weighted percentages. Represents percentages within ASD and no ASD ED visits that were associated with each individual diagnoses. The denominator is the total number of ED visits with an ASD diagnosis (n = 25,527) and without an ASD diagnosis (n =76,581).

Sig.:

* $0.01 \leq P < 0.05$.

§§ Not included as part of an injury visit.

€ Data on assault intent was only available for the years 2009-2011.

*** $P < 0.001$;

** $0.001 \leq P < 0.01$;

Table 3

Odds Ratios and Confidence Intervals from Multivariate Logistic Regressions for Psychiatric Visits Adults with and without ASD matched on age and gender 2006-2011 Nationwide Emergency Department Sample (n =102,108)

	OR	95% CI	Sig.	AOR	95% CI	Sig.
Any	4.03	(3.74 , 4.34)	***	2.63	(2.41 , 2.88)	***
Schizophrenia	4.77	(4.17 , 5.46)	***	1.90	(1.61 , 2.23)	***
ADD/ADHD	38.64	(25.96 , 57.51)	***	33.82	(22.01 , 51.97)	***
Adjustment Disorders	4.33	(3.25 , 5.77)	***	4.04	(2.62 , 6.23)	***
Anxiety	1.70	(1.46 , 1.99)	***	1.93	(1.58 , 2.36)	***
AUD	0.26	(0.20 , 0.33)	***	0.22	(0.16 , 0.29)	***
Bipolar Disorders	7.84	(6.71 , 9.16)	***	3.83	(3.15 , 4.66)	***
Depression	2.57	(2.24 , 2.96)	***	1.86	(1.54 , 2.24)	***
Intellectual Disabilities	54.12	(35.24 , 83.12)	***	41.31	(24.56 , 69.48)	***
Personality Disorders	30.55	(16.02 , 58.24)	***	24.57	(11.22 , 53.80)	***
SUD	0.30	(0.24 , 0.40)	***	0.19	(0.14 , 0.26)	***

The estimates are provided from NEDS representing ED visits with adults aged 22-64 years from the years 2006-2011; ED visits with and without ASD were matched on age and gender; ADD/ADHD: Attention deficit disorders/attention deficit hyperactivity disorders; AUD: Alcohol use disorders; SUD: Substance use disorders.

OR: Odds ratios; AOR: Adjusted odds ratios; CI: Confidence Intervals.

Multivariate logistic regressions were adjusted for sex, age, NEDS year, income groups, primary payer, hospital region, hospital location, and ED event.

Sig.:

** $0.001 \leq P < 0.01$;

*$0.01 \leq P < 0.05$.

*** $P < 0.001$;

Table 4

Odds Ratios and Confidence Intervals from Multivariate Logistic Regressions for Non-Psychiatric Visits Adults with and without ASD matched on age and gender 2006-2011 Nationwide Emergency Department Sample (n =102,108)

	OR	95% CI	Sig.	AOR	95% CI	Sig.
Any	1.22	(1.16 , 1.29)	***	1.07	(1.01 , 1.14)	*
Cancer	1.50	(1.11 , 2.02)	**	0.65	(0.46 , 0.91)	*
Cardiovascular Disease	0.58	(0.51 , 0.66)	***	0.39	(0.33 , 0.45)	***
Diabetes	1.32	(1.10 , 1.57)	**	0.75	(0.61 , 0.93)	**
Epilepsy	9.26	(8.36 , 10.27)	***	7.15	(6.28 , 8.13)	***
Gastrointestinal Disease	0.76	(0.64 , 0.91)	**	0.66	(0.54 , 0.82)	***
Respiratory Disease	0.45	(0.41 , 0.49)	***	0.53	(0.48 , 0.58)	***

The estimates are provided from NEDS representing ED visits with adults aged 22-64 years from the years 2006-2011; ED visits with and without ASD were matched on age and gender; OR: Odds ratios; AOR: Adjusted odds ratios; CI: Confidence Intervals.

Multivariate logistic regressions were adjusted for sex, age, NEDS year, income groups, primary payer, hospital region, hospital location, and ED event.

Sig.:

*** $P < 0.001$;

** $0.001 \leq P < 0.01$;

* $0.01 \leq P < 0.05$.

Table 5

Odds Ratios and Confidence Intervals from Multivariate Logistic Regressions for Injury Visits Adults with and without ASD matched on age and gender 2006-2011 Nationwide Emergency Department Sample (n =102,108)

	OR	95% CI	Sig.	AOR	95% CI	Sig.
Any[§§]	0.81	(0.78 , 0.85)	***	1.10	(1.04 , 1.16)	***
Assault	0.47	(0.38 , 0.57)	***	0.61	(0.49 , 0.77)	***
Cut	0.44	(0.38 , 0.50)	***	0.75	(0.65 , 0.86)	***
Fall	1.33	(1.23 , 1.44)	***	1.48	(1.34 , 1.62)	***
Poison	1.91	(1.66 , 2.20)	***	1.21	(1.00 , 1.46)	ns
Self-harm	3.90	(3.30 , 4.60)	***	2.95	(2.33 , 3.75)	***
Struck	0.74	(0.67 , 0.82)	***	1.10	(0.99 , 1.22)	ns
Suicidal Ideation	2.96	(2.59 , 3.40)	***	1.88	(1.56 , 2.26)	***
Multiple Injuries	0.89	(0.84 , 0.95)	***	1.12	(1.04 , 1.19)	**

The estimates are provided from NEDS representing ED visits with adults aged 22-64 years from the years 2006-2011; ED visits with and without ASD were matched on age and gender; OR: Odds ratios; AOR: Adjusted odds ratios; CI: Confidence Intervals.

Multivariate logistic regressions were adjusted for sex, age, NEDS year, income groups, primary payer, hospital region, hospital location, and ED event.

Sig.:

* $0.01 \leq P < 0.05$.

ns: not significant

[§§] Any injury visit variable does not include assault, self-harm, suicidal ideation, and multiple injuries.

*** $P < 0.001$;

** $0.001 \leq P < 0.01$;

Table 6

Type Of Visits And Mean Total ED Charges in the Pooled Study Sample Adults with and without ASD matched on age and gender 2006-2011 Nationwide Emergency Department Sample (n =102,108)

	ASD		No ASD		Sig.
	Mean	**SE**	**Mean**	**SE**	
Psychiatric Visit	$12,506	$559	$7,238	$359	***
ADD/ADHD	$4,963	$1,341	$1,510	$267	*
Adjustment Disorders[a]	$10,362	$3,583	$4,119	$562	ns
Anxiety Disorders	$5,651	$1,481	$2,217	$184	*
AUD	$14,486	$3,324	$6,462	$555	*
Bipolar Disorder	$15,576	$876	$10,136	$1,069	***
Depression	$10,241	$616	$5,582	$366	***
Intellectual Disabilities	$3,759	$418	$3,061	$787	ns
Personality Disorders	$9,078	$2,350	$3,299	$931	*
Schizophrenia	$20,336	$1,168	$12,183	$1,088	***
SUD	$11,581	$1,384	$8,523	$789	*
Injury Visit	$12,912	$715	$5,842	$345	***
Assault[§]	$8,174	$1,872	$8,836	$1,218	ns
Cut	$4,953	$944	$2,221	$135	**
Drown[a]	$17,044	$1,155	$2,534	$759	**
Fall	$11,230	$934	$5,880	$475	***
Fire[a]	$20,605	$8,333	$2,890	$558	*
Machinery[b]	$18,562	$0	$5,248	$528	nc
Poison	$11,790	$1,252	$13,201	$1,451	ns
Self-harm	$13,001	$1,106	$11,560	$1,810	ns
Struck	$3,672	$406	$3,087	$390	ns
Suffocation[a]	$53,110	$6,129	$42,061	$17,630	ns
Suicidal Ideation	$12,579	$701	$8,013	$481	***
Non-psychiatric Visit	$13,662	$681	$9,521	$454	***
Cancer	$75,352	$10,528	$67,434	$7,907	ns
Cardiovascular Disease	$39,432	$3,671	$27,181	$1,893	**
Diabetes	$19,574	$2,194	$16,146	$1,955	ns
Epilepsy	$9,551	$553	$6,238	$435	***
Gastrointestinal Disease	$16,224	$2,263	$7,032	$568	***
Respiratory Disease	$5,431	$745	$2,455	$135	***

The estimates are provided from NEDS representing ED visits with adults aged 22-64 years from the years 2006-2011; ED visits with and without ASD were matched on age and gender;

Sig.:

nc: not conclusive. Tests are not feasible because of low numbers.

ns: not significant

[a] Relative standard errors >30%. Estimates may not be precise.

[b] Only 1 individual with ASD reported having machinery associated injury.

[§] Data on assault intent was only available for the years 2009-2011.

*** $P < 0.001$;

** $0.001 \leq P < 0.01$;

* $0.01 \leq P < 0.05$.