

Predictors of emergency service use in adolescents and adults with autism spectrum disorder living with family

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ABSTRACT

Introduction The use of emergency services among adolescents and adults with autism spectrum disorder (ASD) transitioning into adult health services has not been well described.

Objectives To describe emergency service use including emergency departments (EDs), paramedics, and police involvement among adolescents and adults with ASD and to examine predictors of using emergency services.

Methods Caregivers of 396 adolescents and adults with ASD were recruited through autism advocacy agencies and support programmes in Ontario to complete a survey about their child's health service use. Surveys were completed online, by mail and over the phone between December 2010 and October 2012. Parents were asked to describe their child's emergency service use and provide information about potential predictive factors including predisposing, enabling and clinical need variables.

Results According to parents, 13% of their children with ASD used at least one emergency service in a 2-month period. Sedation or restraints were used 23% of the time. A combination of need and enabling variables predicted emergency service use with previous ED use in the last year (OR 3.4, 95% CI 1.7 to 6.8), a history of hurting others (OR 2.3, 95% CI 1.2 to 4.7) and having no structured daytime activities (OR 3.2, 95% CI 1.4 to 7.0) being the strongest multivariate predictors in the model.

Conclusions Patients with ASD and their families are likely to engage with paramedics or police or visit the ED. Further education and support to families and emergency clinicians are needed to improve and, when possible, prevent such occurrences.

INTRODUCTION

Individuals with autism spectrum disorder (ASD) require considerable health services across their lifespan. In childhood alone, individuals with ASD are estimated to have 2.5 times higher hospitalisation costs per year and six times higher medical expenses than typically developing children.^{1 2} Individuals with ASD are also more likely to use emergency services than the general population.³

Hospitalisation and emergency department (ED) visits are usually classified as resulting from either mental health or medical issues. It has been reported that mental health issues account for 13% of ED visits among children with ASD,⁴ with over 10% of youth with ASD experiencing at least one psychiatric hospitalisation before the age of 21.⁵ Individuals with ASD are also known to have

Key messages

What is already known on this subject

- ▶ Individuals with autism spectrum disorder (ASD) are also more likely to use emergency services than the general population.
- ▶ Most of what we know about hospitalisations and emergency use in individuals with ASD comes from the analysis of administrative health which speaks of the magnitude of the issue (ie, high rates of use), but does not provide indepth clinical information on what leads to these visits or details about the visits themselves.
- ▶ No studies have examined predictors of emergency department (ED) visits among adolescents or adults with ASD.

What this study adds

- ▶ Our study suggests that a combination of need and enabling variables predicted emergency service use, with previous ED use in the last year, a history of hurting others and having no structured daytime activities being the strongest multivariate predictors.
- ▶ Predictors of emergency service use in adolescents and adults with ASD living with family.

higher rates of comorbid medical disorders (such as seizures and gastrointestinal problems),⁶ sustain more frequent injuries than typically developing peers,⁷ and have a higher risk of having medical emergencies that require hospital treatment.⁸ However, because of the socio-communicative impairments associated with ASD, differentiating between medical and psychiatric causes of behaviour is a significant challenge in these patients. This frequently leads to misdiagnosis and, too often, tragic adverse outcomes.⁹ One strategy to improve care is the establishment of care plans that are shared between the family and all healthcare providers. These plans should be updated regularly and incorporate information on how to best communicate and interact with the individual with ASD during health encounters.¹⁰ While these patients may have well established care plans at specialised paediatric centres, as these patients age out of paediatric services, their complex care must be assumed by adult emergency services that are less familiar with their specific care needs. This can result in suboptimal care for patients and their families.

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Virtually no studies have examined predictors of ED visits among children or adults with ASD. Most of what we know about hospitalisations and emergency use in individuals with ASD comes from the analysis of administrative health data,^{1 3 4 11} which speak to the magnitude of the issue (ie, high rates of use), but do not provide in-depth clinical information on what leads to these visits or details about the visits themselves. The purpose of this study was to report the rate of emergency services use in a large sample of adolescents and adults with ASD and describe their experience with emergency services, according to parent report. We used Andersen's Behavioral Model of Health Service Use,¹² a commonly adopted theoretical framework, to describe the predisposing, enabling and need predictors of emergency service use. Predictors were selected based on our prior quantitative and qualitative research on predictors of emergency service use,¹³ and on the health services experience of parents of youth and adults with ASD.¹⁴

METHOD

Participants

Participants were recruited from across the province of Ontario, Canada, between December 2010 and October 2012. Family members were recruited from flyers and websites of collaborating community agencies, recreation programmes and schools that support individuals with ASD, as well as through every local chapter of the provincial autism organisation. A total of 517 parents consented to participate in the study, 462 of whom completed the questionnaire. To be eligible for the study, family members had to identify themselves as a caregiver of an individual with ASD who was over the age of 12 and report that the individual had an ASD diagnosis. Diagnoses were confirmed using a standardised validated scale, which is designed for completion by parent informants (Social Communication Questionnaire-Lifetime Version (SCQ)¹⁵). To be included in the study, SCQ scores had to exceed the recommended adolescent and adult SCQ cut-off score of 12 or greater.¹⁶ Parents of 396 individuals with ASD between the ages of 12 and 56 years (mean age=18.3; SD=6.0; 316 males, 80 females) met the above criteria and were included in the current study about their ED use.

Measures

Parents completed a questionnaire about health service use, their child with ASD and themselves. Items from this questionnaire were based in part on a related questionnaire for paid staff of adults with intellectual disabilities.¹³ Parent related questions came from previous research of two of the authors (YL and JAW) who have been studying the experience of parents of individuals with ASD.¹⁴ An effort was made to include items that captured all aspects of Andersen's Behavioral Model of Health Service Use.¹² Final questionnaire items were piloted with six parents to ascertain readability, clarity and time for survey completion. To meet diverse parent needs, parents were given the option to complete the surveys online, by mail or over the phone. The majority of parents opted to complete the survey online. There were no demographic differences between parents who chose different methods of survey completion, except that parents who opted for paper or phone methods tended to be older, $t(370)=3.14$, $p<0.01$.

Emergency service use

Parents were asked whether their family member with ASD had used any of the following emergency services in the prior

2 months: paramedics, police or ED visit. The 2-month period was selected as a window of analysis because of research suggesting that recall is relatively accurate in a 2-month interval and that under-reporting of medical events increases over time.¹⁷ Parents who indicated that their child had visited the ED in the 2-month period were asked to answer a series of yes/no and short answer questions about the visit including method of transportation, reason for visit, time spent waiting, decisions made by medical staff and treatments provided. Parents who indicated their child was involved with police were also asked what happened during the visit, whether restraints were used and whether charges were laid. However, not all parents who indicated that their child had ED or police use in the 2-month period provided subsequent details.

Predictor variables of emergency service use

The modified Andersen's Behavioral Model of Health Services Use is the most commonly used theoretical framework to describe factors predicting healthcare use¹² and groups predictors into three categories: predisposing factors (ie, static demographic characteristics that describe the likelihood an individual will seek healthcare in a given situation), enabling factors (ie, environment and resources available) and need variables (ie, events or medical/psychological conditions that might facilitate a greater need for services).

Predisposing variables

We examined the demographic variables of age, gender, intellectual disability status and ASD severity. Parents were asked to indicate their child's level of cognitive functioning on a scale from gifted to profound intellectual disability. Individuals were classified into those who have an intellectual disability (ie, mild to profound intellectual disability) and those who do not (ie, gifted, normal and borderline intelligence). ASD severity was measured using the SCQ,¹⁵ with higher scores reflective of more severe symptoms. The SCQ is reported to have good internal consistency (α coefficients 0.81–0.93) and external validity.¹⁸

Enabling variables

Parent marital status was dichotomised into parents who indicated they were 'married or common-law' and those who were not. The household income of each family was estimated based on the mean income of the resident's postal code region.¹⁹ Family distress was measured using the 10-point Brief Family Distress Scale¹⁴ which asked parents to indicate their level of distress on a scale from 1 ('everything is fine, we are not in crisis at all') to 10 ('we are currently in crisis, and it could not get any worse'). Ratings of 7 and above were coded as 'in crisis' (7 indicates that if one more thing goes wrong they will be in crisis).¹⁸ Families were also asked to indicate what their child did during the day (ie, school, working, volunteering or job training, day programme, no structured daytime activity or other). Responses were coded into those who had 'structured daytime activities' and those who did not. Parents were also asked to indicate (yes or no) whether they had received social services (respite or case management) in the 2-month period prior to baseline completion.

Need variables

The child's current comorbid psychiatric diagnoses, medical conditions and medications reported by parents were coded into dichotomous variables (presence/absence). Parents also indicated whether their child had a history of 'hurting them self' or

'hurting others' and whether they had visited the ED in the past year (excluding visits that occurred in the last 2 months).

Data analysis

Descriptive statistics and 95% CIs were used to characterise ED and police visits. To determine predictors, the total sample of 396 was divided into two groups: those who reported using an emergency service in the last 2 months and those who did not. Bivariate relations among predictor variables and emergency service use were examined using independent samples *t* tests (continuous variables) and χ^2 tests (dichotomous variables). Significant bivariate predictors ($p < 0.05$) were entered into a logistic regression model predicting emergency service use.

RESULTS

Emergency service use

In the year prior, 18.4% of individuals visited the ED at least once. In a 2-month window, 50 of the 396 individuals with ASD (12.6%, 95% CI 9.4% to 15.9%) used at least one emergency service, with a detailed breakdown of overlapping use provided in [figure 1](#): 35 used the ED (12 of whom also used paramedics and/or police), 18 were attended by paramedic services (of whom eight were transported to the ED) and 17 had police involvement (of whom four were transported to the ED). A third of the individuals (6/18) who used paramedics were not transported to the ED.

Description of ED visits

In terms of what occurred at the hospital, 26 (74.3%) out of the 35 individuals who reported visiting the ED in the 2-month period responded to questions about their visit (mean age=19.2, SD=5.7; 18 males, eight females). One individual visited the ED twice for the same issue; for this analysis, we only described the details of their first visit.

Arrival and wait times

Most patients were driven to the ED by a caregiver or family member (69.2%). The remaining 30.8% of patients arrived by ambulance. We obtained detailed information on the day of the week and time of arrival for 81% of visits. The majority of these visits occurred in the evening between 18:00 and 00:00

(52.4%), 38.1% occurred in the afternoon (12:00–18:00) and 9.5% in the morning (06:00–12:00). The day of the week that the visits occurred on varied, with over half (62%) occurring on weekdays. The length of stay ranged from 1 to over 24 h. Length of stay was more variable for mental health visits (range 1–24+ hours, median=5, SD=14.4) than for medical visits (range 1–12 h, median=3, SD=3.2).

Presenting problems

Similar to the methodology adopted in a previous paper,²⁰ ED descriptions were classified by two independent coders (MP-S, YL) as being caused by a medical or mental health issue; where there were discrepancies, the case was discussed until consensus was reached. The majority of the emergencies were classified as medical in nature (65.4%), with injury accounting for 58.8% of medical ED visits. Mental health crises (which included psychiatric issues or clinically significant behavioural issues) accounted for 34.6% of the visits described. The most common reasons for mental health visits were aggression (33.3%) and issues with psychotropic medication (33.3%). Although visits were classified by the most severe presenting issue (ie, the issue that caused the visit), in 4/17 (23.5%) of medical emergencies, parents described behavioural issues that were associated with their child's ED visit. For example, one individual banged his/her forehead in anger and required stitches; another individual with an unrecognised urinary tract infection was agitated and acting aggressively. Over 70% of those who visited the ED were prescribed at least one medication and 19.2% of the visits were related to medication issues (including side effects and medication overdoses).

Family involvement

In 88.5% of visits, hospital staff spoke with families or caregivers, and in all but two visits the hospital staff interviewed the individual with ASD as part of the assessment. One of the individuals with ASD who was not interviewed directly was non-verbal. In 5/26 cases, parents identified a need for better training of hospital staff in dealing with individuals with ASD, and some parents commented that their suggestions for the care of their child were not taken into consideration. For example, in one case the child was not allowed to have an iPod to relax although parents emphasised its importance as a coping tool, and in another incident a child who could not tolerate crowds was asked to remain in a crowded waiting room despite parents asking that the child be moved.

Restraints used and medication to calm

In six of the visits (23%), parents reported that medication was used to sedate their child. In two of these visits, medication was combined with mechanical or physical restraints. Security staff or police were involved with four patients.

Description of police involvement

Of the 17 individuals who were involved with police in the 2-month period, eight provided information about those instances. In three cases, police assessed the crisis and left; in one case, they escorted the individual to the hospital ED; and in another, the child was escorted back to the family home. In three cases, the individual was taken into custody or temporarily removed from the situation (eg, taken to a shelter). In addition to being taken into custody, one of these individuals was restrained and charges were laid.

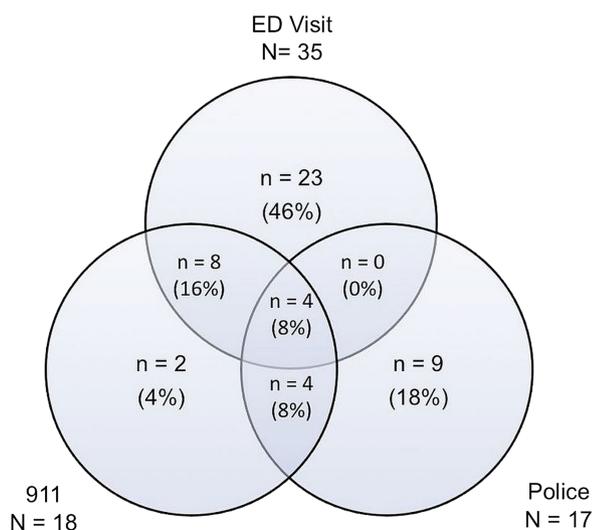


Figure 1 Service use patterns in individuals who accessed an emergency service in the 2-month period.

Predictors of emergency service use

As shown in [table 1](#), a number of predisposing, enabling and clinical need factors were related to emergency service use at the bivariate level. Emergency service use was associated with: greater ASD severity (a predisposing factor); having a family in crisis and not being involved in structured daytime activities (enabling factors); and presence of medical comorbidities, taking medication, a history of hurting others and having visited the ED in the past year (need factors).

The seven variables that were significantly ($p < 0.05$) associated with emergency service use were entered into a logistic regression (see [table 2](#)). The multivariate analysis revealed that when adjusting for the other predictors in the model, using the ED in the past year was the strongest predictor of using an emergency service in the 2-month period. Individuals who used the ED in the 10 months prior to the study period were 3.4 times more likely to use an emergency service. Having no structured daytime activities and a history of hurting others were also significant predictors.

Table 1 Differences between individuals with autism spectrum disorder (ASD) who used emergency services in the past 2 months and those who did not, bivariate analysis

Predictor variables	N (%) Emergency services users (N=50)	Emergency service non-users (N=346)	p Value†	OR (95% CI)
<i>Predisposing</i>				
Age, mean (SD)‡	19.2 (5.8)	18.2 (6.0)	0.26	1.2 (−0.8 to 2.8)
Gender				
Male	38 (76.0)	278 (80.3)	0.47	1.3 (0.6 to 2.6)
Female	12 (24.0)	68 (19.7)		1 (reference)
Intellectual disability§				
Yes	26 (61.9)	155 (50.2)	0.15	1.6 (0.8 to 3.1)
No	16 (38.1)	154 (49.8)		1 (reference)
ASD severity, Mean (SD)‡	25.4 (6.1)	22.50 (6.2)	<0.01*	2.9 (1.0 to 4.7)
<i>Enabling</i>				
Family income, M \$ thousands (SD)‡	66.6 (16.7)	65.4 (15.9)	0.63	1.2 (−3.6 to 5.9)
Parent marital status				
Single	16 (32.0)	73 (21.1)	0.08	1.8 (0.9 to 3.4)
Married/common-law	34 (68.0)	273 (78.9)		1 (reference)
Crisis scale¶				
Family in crisis	11 (22.0)	26 (7.6)	<0.001**	3.4 (1.6 to 7.5)
Family not in crisis	39 (78.0)	316 (92.4)		1 (reference)
Daytime activities				
Unstructured	15 (30.0)	37 (10.7)	<0.001**	3.6 (1.8 to 7.2)
Structured	35 (70.0)	309 (89.3)		1 (reference)
Social services				
No	11 (22.0)	118 (34.1)	0.09	0.5 (0.3 to 1.1)
Yes	39 (78.0)	228 (65.9)		1 (reference)
<i>Need</i>				
Psychiatric comorbidity				
Yes	24 (48.0)	173 (50.0)	0.79	0.9 (0.5 to 1.7)
No	26 (52.0)	173 (50.0)		1 (reference)
Medical comorbidity				
Yes	25 (50.0)	109 (31.5)	0.01*	2.2 (1.2 to 4.0)
No	25 (50.0)	237 (68.5)		1 (reference)
On medication				
Yes	37 (74.0)	195 (56.4)	0.02*	2.2 (1.1 to 4.3)
No	13 (26.0)	151 (43.6)		1 (reference)
History of hurting self				
Yes	27 (54.0)	158 (45.7)	0.27	1.4 (0.8 to 2.5)
No	23 (46.0)	188 (54.3)		1 (reference)
History of hurting others				
Yes	34 (68.0)	144 (41.6)	<0.001**	3.0 (1.6 to 5.6)
No	16 (32.0)	202 (58.4)		1 (reference)
ED visit in last year				
Yes	23 (45.1)	50 (14.5)	<0.001**	5.0 (2.7 to 9.5)
No	27 (54.0)	296 (85.5)		1 (reference)

* $p < 0.05$, ** $p < 0.01$.

† χ^2 and t tests were used to calculate p values.

‡Continuous variable; mean difference and CI are reported instead of an OR.

§N=351 for this question.

¶N=392 for this question.

Table 2 Multivariate logistic regression of predisposing, enabling and need predictors of emergency service use by individuals with autism spectrum disorders (ASDs)

Predictor variables	p Value	Odds (95% CI)
Predisposing		
ASD severity	0.08	1.1 (1.0 to 1.1)
Enabling		
Family in crisis	0.09	2.1 (0.9 to 5.1)
Unstructured daytime activities	0.004	3.2 (1.4 to 7.0)
Need		
Medical comorbidity	0.54	1.2 (0.6 to 2.5)
On medication	0.43	1.4 (0.6 to 2.8)
History of hurting others	0.02*	2.3 (1.2 to 4.7)
ED visit in last year	0.001**	3.4 (1.7 to 6.8)

*p<0.05, **p<0.01.

DISCUSSION

Overall, 13% of individuals with ASD used an emergency service in our 2-month sampling period, with the most commonly accessed service being the ED. It is likely that this number would increase if patients were followed for a year. In the case of ED visits, medical reasons were more common than mental health ones, but qualitative descriptions would suggest that some medical presentations contained behavioural elements. When controlling for other variables, a combination of need and enabling variables predicted emergency service use (ie, previous ED use in the last year, a history of hurting others and having no structured daytime activities). This is the first study to examine factors related to recent emergency service use in adolescents and adults with ASD, and implicates multiple variables. Findings from this research speak to the need to work with families and hospital staff to develop effective strategies to minimise emergency service use when possible.

Similar to previous research on ED use in individuals with intellectual disabilities who may not have ASD, we found the most common medical presentation was injury, and one of the most common mental health presentations was aggression.²⁰ There were situations where emotional distress led to the medical emergency and instances where an unaddressed medical concern presented as self-injury or aggression. Recognising the overlap between medical and behavioural issues is challenging in patients with communication impairments and our data highlight the importance of having a high clinical suspicion for medical contributors when assessing and treating patients with ASD. In addition, clinicians should be aware of the impact of medication use on emergency presentations. In our sample, 19% of the ED visits described were related to medication issues. Medication use is common in individuals with ASD²¹ and difficulties in communicating symptoms and side effects may exacerbate risks in prescribing to this population.

According to parent descriptions, caregivers almost always reported being involved in their child's emergency assessment and treatment. However, there were several incidents in which parents felt that their suggestions on how to meet their child's needs were ignored. Given the challenges individuals with ASD might face in the emergency situations due to communication difficulties, sensitivity to overstimulating environments,^{4 22} and complex psychiatric and medical presentations,^{6 7 23} proactive care plan tools may be especially important. Another study found that not having a care plan predicted ED use in adults with intellectual disability.¹³ Hospital Passports, patient

information tools widely used in the UK among individuals with intellectual disability, have been shown to be helpful to hospital staff.¹⁰ Given that having a previous ED visit was the strongest predictor of emergency service use in this study, following the first emergency, families should be prompted to engage in future care planning, if they have not done so already. As recommended in clinical practice guidelines for this population,²⁴ hospital staff can suggest that families work with their community healthcare providers to prepare care plans as part of the discharge process.¹⁰

Consistent with previous intellectual disability and autism research,^{5 23} indicators of 'need' were the strongest predictors of recent emergencies, including a history of previous emergency service use and having a history of behavioural issues, like aggression. Although it seems logical that higher 'needs' would prompt more frequent use of services, repeated emergency use within a 1-year period may also be an indication that follow-up services are not responsive enough the first time to prevent future emergencies.

A strength of the current study was that we collected data on family and environmental factors that are related to emergency service use rather than considering only demographic and clinical factors. We found that individuals with no structured daytime activities were 3.2 times more likely to access emergency services. It may be that a lack of structured community-based activities puts additional strain on families, leading to more emergencies. It could also be the case that these individuals cannot engage in regular community-based activities because of severe behavioural or medical issues. Given the importance of structure for those with ASD and their caregivers, it is important to assess psychosocial contributors, such as having no structured daily activities, in any emergency assessment. While it is not the job of EDs to create these programmes, being aware of existing community services and having the capability to direct parents to such services is a reasonable expectation. Involvement of the social work department may be an important first step in linking individuals with ASD with needed community supports. It is important for the ED to know what services are available in their region, and to have someone in the hospital designated to speak with patients and their families, or else patients will return.

Limitations

This is the first study to begin exploring emergency service use in individuals with ASD in a systematic way. The study is limited, however, in that it only looks at emergency service use over a 2-month period. It is important to monitor emergency service use over a longer period of time and to follow-up with families to learn more about interventions that occurred in response to the emergency. It would also be beneficial to verify parent reports and fill in missing data using hospital chart audits. Even though attempts were made to attain a representative sample of this population, it is possible that the individuals in our sample could have more or fewer mental health issues or medical conditions than the general population with ASD. In a brief survey, we could only look at a limited number of variables that the literature⁵ and our previous research suggest^{13 20} would be relevant predictors in this population; however, there may be other predictors of ED visits that were not examined in this study. This being said, the current study has important clinical implications.

There is a need to train hospital-based and other emergency personnel (police, paramedics) to work with patients with ASD and to provide them with further support to do so. In some

jurisdictions, like the UK, certain hospitals have liaison staff available to advocate for patients, such as those with ASD, when visiting the hospital.²⁵ Parallel training should also be implemented for individuals and families to be better prepared for emergencies.¹⁰

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