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Predictors of Emergency Department Use by Adolescents and Adults with Autism Spectrum Disorder: A Prospective Cohort Study

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Abstract

Objectives: To determine predictors of emergency department (ED) visits in a cohort of adolescents and adults with autism spectrum disorder (ASD).

Design: Prospective cohort study.

Setting: Community based study from Ontario, Canada.

Participants: Parents reported on their adult sons and daughters with ASD living in the community (n = 284).

Main outcome measures: ED visits for any reason, ED visits for medical reasons, and ED visits for psychiatric reasons over one year.

Results: Among individuals with ASD, those with ED visits for any reason were reported to have greater family distress at baseline, a history of visiting the ED during the year prior, and to have experienced two or more negative life events at baseline as compared to those who did not visit the ED. Unique predictors of medical versus psychiatric ED visits emerged. Low neighborhood income and living in a rural neighborhood were associated with medical but not psychiatric ED visits, whereas a history of aggression as well as being from an immigrant family predicted psychiatric but not medical emergencies.

Conclusions: A combination of individual and contextual variables may be important for targeting preventative community-based supports for individuals with ASD and their families. In particular, attention should be paid to how caregiver supports, integrative crisis planning, and community-based services may assist in preventing or minimizing ED use for this vulnerable population.

Strengths and limitations of this study:

- This is one of the first published studies to date to compare the profiles individuals with ASD who did and did not the ED.
- A convenience sample in a setting with universal health insurance was used and may be limited in its generalizability.
- Data were based on parent self-report rather than on chart abstraction, and so may be susceptible to biases.

INTRODUCTION

Across childhood, adolescence and adulthood, individuals with Autism Spectrum Disorder (ASD) are more likely to visit the emergency department (ED) than their typically developing peers, for both medical and psychiatric reasons (1-6). The high intensity environment of an ED visit can be extremely challenging for individuals with ASD, who may present with sensory, social-communication and behavioral difficulties (7). Perhaps representative of these challenges, individuals with ASD are restrained or sedated in approximately one in four ED visits (8). ASD knowledge gaps and inadequate professional training often compound these negative experiences for affected individuals and their family caregivers (9,10). From a systemic perspective, frequent ED use is costly and ED over-crowding and long wait times are key system level challenges in most jurisdictions (11,12). The number of ED visits by individuals with ASD is increasing (5), and it is important to better understand predictors of ED visits among individuals with ASD to assist in appropriate provision of community-based care.

Individuals with ASD often have complex care needs and can visit the ED for a host of psychiatric and medical concerns. In addition to an increased risk of developing co-occurring mental health concerns such as anxiety and depression (13,14), youth and adults with ASD often display problem behaviours, including elopement, aggression, and self-harming behaviours (15-17), which frequently necessitate emergency care (2,3,8). Gastrointestinal issues (e.g., abdominal pain, nausea, vomiting) and neurological symptoms and disorders (e.g., seizures and epilepsy) are common comorbid medical concerns among individuals with ASD and account for a large proportion of medical related ED visits in this population (1,2,5,18,19). Youth with ASD may also be at high risk for ED visits due to accidents and injury (20-22). Medical issues can be further complicated by atypical clinical presentations, such that problem behaviors can sometimes mask underlying medical conditions (23,24).

In recent years, several studies have compared ED patterns in those with and without ASD (1-6); however, we know very little about what differentiates individuals with ASD who use the ED compared to those with ASD who do not use the ED. Additionally, the majority of what is known about emergency service use patterns in individuals with ASD comes from the analysis of administrative data. This type of analysis is limited in its ability to describe situational and family centered variables that are not typically documented in insurance claims or medical records. Our previous retrospective, cross-sectional study on ED use in ASD (8) demonstrated that factors such as previous ED visits, lack of meaningful day time activities, and a history of hurting others were related to emergency service use, whereas demographic variables were not. This study, however, was limited in that it did not explore how these variables impact ED use over a longer period of time.

The current study investigates predictors of ED use in adolescents and adults with ASD based on parent reported data. As a secondary exploratory aim, we sought to separately examine predictors of medically related ED visits and predictors of psychiatric related ED visits to determine if they were distinct. For these analyses, a modified version of Andersen's Behavioral Model of Health Services Use (25) was used to group predictors into three categories: 1) predisposing factors (i.e., static demographic characteristics that describe the likelihood an individual will seek health care in a given situation); 2) enabling factors (i.e., environmental characteristics and resources available); and 3) need variables (i.e., events or medical/psychological conditions that might facilitate a greater need for services).

METHODS

Participants

Parents of adolescents and adults with ASD age 12 years and up were recruited from across Ontario, Canada, between December 2010 and October 2012. Parents were recruited from flyers and websites of collaborating community agencies, recreation programs and schools that support individuals with ASD, as well as through every local chapter of the provincial ASD organization. To be eligible for the study, individuals with ASD needed to: 1) be living in Ontario; 2) be 12 years of age or older; 3) have a clinical diagnosis of ASD; 4) exceed the recommended cut-off score of 12 on the Social Communication Questionnaire-Lifetime Version (SCQ; 26,27), a standardized ASD screening tool. A total of 514 families consented to participate in the study and 462 completed the baseline survey; 396 of these participants met the age and SCQ cutoffs. Families were contacted every two months to report on their ED use and were contacted approximately one year after baseline to fill out a final survey. To be included in the current study, parents were required to complete the final survey within 18 months of their baseline date. The final sample for the current study consisted of 284 individuals with ASD (Mean age = 18.41, *SD* = 6.16; 223 Males, 61 Females). There were no significant differences between the final sample (n = 284) and those who did not complete the final survey within the required time period (n = 112) with respect to most individual and parent demographics (individual age, individual gender, individual place of residence, parent age, parent marital status, parent education, neighborhood income) or clinical needs (individual ASD severity, individual ID status, individual medical and psychiatric diagnoses; all p's > 0.05). However, a significantly greater proportion of non-responders identified as non-Caucasian (26.6% vs 17.0%, p = 0.03).

The majority of survey respondents were mothers (93.7%) and nearly half reported that their dependent with ASD was 18 years or older (44.7%). Most individuals with ASD lived with family (91.2%) at time of baseline survey completion, the remaining were reported to reside in group homes or other supported living situations (6.4%), in treatment facilities (0.7%), or independently (1.8%).

Measures

Predictor Variables

All predictor variables were collected as part of the baseline survey.

Predisposing Variables. We included both individual and parent predisposing factors in the analysis. Individual predisposing variables included age, gender, intellectual disability (ID) status and ASD severity. ID status was split into those who had an ID (i.e., mild to profound ID) and those who did not (i.e., gifted, normal and borderline intelligence). ASD severity was measured using the SCQ (26), with higher scores reflective of more severe symptomology. The SCQ is reported to have good internal consistency (alpha coefficients 0.81-0.93); and external validity (27). In the current study, internal consistency for the overall scale was strong (Cronbach's alpha = 0.81).

Enabling Variables. Parent enabling variables included marital status (married/living with partner or single), education level, and if they were born in Canada (yes/no). Parent education level was dichotomized into high education (college diploma or higher) or low education (some college or university education or lower). Household income of each family was estimated based on the median income of the respondent's postal code region according to census data (28; range $33,030.00 – $107,742.00, *M* = $65,597.12, *SD* = $15,970.27). Since the neighborhood income in our sample was higher than the national mean ($53,634), we compared families whose neighborhood income fell into the bottom quartile to those that fell in the top three quartiles of our sample. Postal codes were also used to determine rural status (rural vs. urban) based on Statistics Canada's definition of rurality (29). Individuals were classified as either having or not having 'structured' daytime activities based on parents' responses to the question "What does your child do during his/her typical day? (i.e., school, working, volunteering or job training, day program, no structured daytime activity or other)". Family distress was measured at baseline using the 10-point Brief Family Distress Scale (BFDS; 30) which asks 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'.

*Need Variables***.** Parents were asked to provide current medical (e.g., gastrointestinal, skin conditions) and psychiatric diagnoses (e.g., anxiety, depression) for their child with ASD. Comorbid medical and psychiatric diagnoses were each dichotomized as has been done in many large-scale parent report surveys (31,32). Parents also indicated (yes/no) whether their child had a history of aggression, and whether they visited the ED in the year prior to the baseline survey.

Parents also completed a modified version of the negative life events checklist from the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (PASADD; 33), in which they were to check off any of the significant life events that their child experienced in the two months prior to baseline (e.g., death of a family member, change in residence, loss of a job). For this analysis the 'injury to self' item was excluded as injuries may directly cause an ED visit. The checklist was dichotomized into individuals that had two or more negative life events prior to beginning the survey and those that had fewer than two, similar to prior studies using this measure (34,35).

Dependent Variables

*Primary outcome variable (ED Visit)***.** In each of the follow-up surveys, parents were asked to indicate (yes/no) whether their child used the ED in the last two months. Parents were also asked in the final survey about whether their child had any ED visits in the previous year. Individuals with ASD were dichotomized into individuals with and without any ED visit during the past year. To ensure that the sampling period for visits was standardized across participants, only ED visits during the year that preceded participants' final survey were included. All participants were therefore sampled for 12 months.

Secondary outcome variables (Medical or Psychiatric ED Visits). Parent descriptions of visits were coded independently by two authors (MPS and AT) as being either medical or psychiatric in nature with 98% inter-rater agreement. Any disagreements were resolved through discussion with the senior author (YL). If parents provided detailed descriptions of more than one ED visit, each visit was coded separately. Thus, the same individual could be classified as having both a medical emergency and a psychiatric emergency (n = 3). Some parents failed to provide enough descriptive information about emergencies in their bimonthly form for these emergencies to be coded (n =17) so these cases were excluded from the secondary analysis of emergency type.

PROCEDURE

The university and hospital research ethics boards approved this research. Consenting parents were sent their baseline survey electronically or on paper. The majority of participants (n = 223; 78.5%) completed online surveys. Parents who completed the surveys online (M = 48.67 years, SD = 6.88) were significantly younger than parents who completed the surveys via mail or telephone interview (n = 61; M = 52.36 years, SD = 8.44, p = .001); no other parent or individual demographic variables differed according to survey response method. Participants had a unique identifier that was linked to their information and every two months following the completion of their last survey, they received another follow up survey. At their final time point, they received a longer measure to complete. Participants received payment ($20) upon completing baseline information and subsequent payment when they completed their final measure.

Data Analysis

A bivariate analysis compared the groups with and without ED visits using single predictor logistic regression models. From these models we derived odds ratios to demonstrate the relationship between each predictor variable and the likelihood of having any ED use. To identify the relative influence of these variables we then ran two adjusted logistic regression explanatory models predicting any ED use. The first included all the variables that had a *p*-value of 0.20 or lower in the bivariate analysis, as well as the age variable that did not meet this threshold, but was included since it is a potential confounder. The second adjusted logistic regression model included all predictor variables.

Subsequently, we examined if different variables were associated with medical ED visits compared to psychiatric ED visits. To do this, we again ran single predictor logistic regression models on two different subsets of the sample. First, these models were used to compare individuals with any medical ED visits to individuals with no medical ED visits. Second, we used these models to compare individuals with any psychiatric ED use relative to individuals with no psychiatric ED use. Adjusted logistic regressions could not be conducted as part of this analysis due to the small number who presented with each type of visit.

For all of the models, individuals with missing data for ID status ($n = 31$) were included, but individuals with missing data for parental education ($n = 2$) were excluded since it was not sufficiently large to be included as its own category. Analyses were conducted using SPSS version 24.

RESULTS

Emergency department use

Of the cohort of 284 individuals, 63 (22.2%) reported ED use during the year following their baseline data collection and 221 (77.8%) reported no ED use during that year. Participant demographic and clinical characteristics according to ED outcome are shown in Table 1.

In the bivariate analysis, higher family distress, living in a rural area, being on medication, having ED visits in past year and having two or more negative life events were significant at the 0.05 level. In addition, gender, neighourhood income, daytime activity, and psychiatric comorbidity had p-values larger than 0.05 but less than 0.20 (Table 2). Despite the two adjusted models including different predictors (the first included predictors with a p-value of less than 0.20 in the bivariate analysis, and the second model included all predictor variables), both models yielded similar results. In both models, clinical need variables (having an ED visit in the year prior to the study and reporting 2 or more significant life events at baseline) and one enabling variable (family distress) predicted having any ED use, when controlling for other variables (see Table 2).

Medical and psychiatric ED visits

Forty-six of the 63 parents who reported that their child visited the ED provided a detailed description of at least one such visit. Three parents described separate psychiatric and medical visits. For the purposes of the following analyses, we included only the first medical and first psychiatric visit described by each parent for a total of 49 descriptions of ED visits. Of the 49 described ED visits, 31 visits related to medical issues and 18 visits related to psychiatric issues. The most common type of medical visit was injury ($n = 10$), followed by gastrointestinal issues ($n = 4$) and infections ($n = 4$). The most common reason for psychiatric ED visits was related to self-harm and/or suicidality ($n = 5$) followed by physical assault towards family members ($n = 3$) and three incidents where parents described individuals as both a danger to self and others.

As shown in Table 3, bivariate analyses indicate medical ED visits were associated with living in a lower income neighborhood, living in a rural area, and family distress at baseline (enabling factors), along with two or more negative life events, being on medication at baseline, and visiting the ED in the year prior to data collection (need factors). Two enabling factors (parent immigrant status and family distress) predicted having a psychiatric ED visit in the follow up period (see Table 3). Clinical need variables, such as being on medication, having a history of aggression, and having two or more negative life events were also significantly associated with psychiatric emergencies.

DISCUSSION

Principal findings

Approximately 22% of individuals with ASD went to the ED at least once in a 12-month period. The results suggest that a combination of enabling (family distress) and need variables (visiting the ED in the year prior, and having two or more negative life events at baseline) predicted ED use. In the secondary analysis, family distress, life events, and being on medication were associated with having both medical and psychiatric emergencies at the bivariate level. Interestingly, low income and living in a rural area were associated with medical but not psychiatric emergencies. Conversely, having a history of aggression, as well as being from an immigrant family, predicted psychiatric but not medical emergencies.

Study strengths and limitations

This is the first study to examine ED visits in adolescents and adults with ASD prospectively based on families' reports. Other studies have focused primarily on emergencies in children and youth with ASD without including both family and individual variables. We examined how a wide range of predisposing, enabling, and need factors contributed to ED use in this population. We also identified unique contributors to medical and to psychiatric emergencies, although our sample size did not allow for these results to be based on an adjusted analysis.

Although the findings were robust as demonstrated by two different adjusted models yielding the same results, caution is needed when interpreting the study findings due to important limitations. Our sample largely consisted of parent respondents who identified as Caucasian with high levels of education. Additionally, we were reliant on parent report of ASD severity, ID status, and medical and psychiatric comorbid diagnoses. Similarly, categorization of ED visit type was based on parent report, not chart audits. Although we tried to improve accuracy of parent reporting by engaging in regular follow up, their responses may still be vulnerable to recall bias. Further research combining parent perspectives with administrative health data would be valuable. Finally, our results are based on a small cohort and replication with a larger sample is warranted. Future work with larger sample sizes would also enable more detailed analyses, such as ED predictors separated by age group as well as by outcome (e.g., hospital admission) or ID status.

Similarities and Differences to Prior Research

The likelihood of ED use in the current study was not related to age, ID status, or ASD severity. Previous research on predictors of ED use among individuals with ASD and other populations has shown mixed results with respect to the role of predisposing demographic factors (1-6). For instance, some studies report a greater likelihood of ED visits in older individuals with ASD (2,4), but others do not (6). Our cohort may be too small to detect these types of patterns, or indeed, they may not be the drivers of such visits when multivariate analyses include a wider combination of variables.

Only one enabling variable predicted ED use while controlling for predisposing and need variables. Parents who reported that their families were experiencing significant distress at baseline reported that their son or daughter was more likely to visit the ED during the study period. Higher rates of family stress are associated with increased ED use among parents of youth with psychiatric conditions (36) and higher rates of general health service use among parents of youth with ASD (37). This is the first study to report an association between family distress and future ED use in the ASD literature.

With respect to clinical need variables, ED use in the previous year was the strongest predictor of ED visits in the year studied. This is similar to other studies that examine ED use in individuals with ID (38), and our previous study that examined ED use in individuals with ASD over a two-month period (8). Reporting two or more negative life events at baseline more than doubled the likelihood that an individual would visit the ED in the follow-up period. This aligns with previous research showing that life events predicted ED visits in individuals with ID (34). Individuals with ASD experience a high frequency of negative life events, trauma, and greater stress when compared to typically developing peers (39-41). These stressors, in turn, are associated with decreases in social functioning (39), and depression (42), which may lead to greater ED use.

When looking at unique predictors of each of medical and psychiatric ED visits, distinct enabling variables, like low income and living in a rural area, were associated with medical but not psychiatric emergencies. It is well recognized that some health care services are less available in rural areas of Ontario (43). In the general population, having lower social economic status is strongly correlated with adverse health outcomes (44). Neighborhood income also predicts preventable hospitalizations in adults with ID (45). In our study, it may be that individuals with greater financial means and those who live in urban areas are more able to access specialized medical care, and as such may require less ED support. Not surprisingly, a history of aggression uniquely predicted psychiatric but not medical emergencies. This aligns closely with previous work looking at the predictors of psychiatric hospitalizations in children with ASD, which also pinpoint aggression as a strong predictor (46,47). Interestingly, being from an immigrant family was associated with psychiatric ED use but was not associated with medical ED visits. This begs the question of how well these families are engaged with and proactively accessing mental health services for their sons or daughters. Individuals who have recently immigrated might have less knowledge of the mental health care system and resources to effectively find and accessible and appropriate community support services for their child with ASD (48).

Implications

Our findings replicate what others have reported regarding frequent ED use among individuals with ASD (1-6) and identified a combination of enabling and need variables that may be important for targeting preventative community-based supports. For instance, parents who reported higher family distress were more likely to bring their son or daughter to the ED. Caring for a child with ASD can bring many challenges, which persist across the life course (49). When parents indicate that they are approaching crisis, this can also signal future emergencies, and community-based clinicians need to proactively help such families. Brief family distress measures can assist clinicians in determining the severity of the crisis state and in the selection of appropriate interventions (30). Likewise, family members themselves can be taught to self-monitor their own distress levels and effective methods of seeking help apart from visiting the ED. From a systemic perspective, policy practices need to expand beyond the identified individual with ASD and include family focused care. Community-based services that provide relief to families, such as respite care, can help reduce stress on families, and in turn, reduce emergency service use for individuals with ASD (50).

It is equally important for community based service providers to acknowledge the impact of negative life events on individuals with ASD and their families. Yerkey and Wildman (51) found that primary care physicians improved their identification rates for youth mental health problems using knowledge of negative life events. Increased clinical knowledge of the difficulties many individuals with ASD experience during transitions, and provision of appropriate community mental health care targeted at building the resiliency of individuals with ASD when exposed to negative life events, may alleviate some need for ED services among this population.

Considering the link between previous and future ED visits, effective care plans need to be in place following the first ED visit to help deal with future crises. Clinical practice guidelines for this population (52) indicate for ED staff to recommend families work with their community care providers to prepare proactive care plans as part of the discharge process. Further, to ensure individuals with ASD receive appropriate care in the ED, and potentially negate the need for repeat visits, families can make use of hospital passports and other patient information tools to assist ED staff in better understanding an individual's specific care needs (53).

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COMPETING INTERESTS

There are no competing interests on the part of any of the authors of this manuscript.

AUTHOR CONTRIBUTIONS

Y. Lunsky, J.A.Weiss, A.M. Palucka and E. Bradley were the primary creators of the concept and design of this study. The analytic approach was created by Y. Lunsky and J.A. Weiss, and carried out by M. Paquette-Smith, A. Durbin, and A. Tint. Y. Lunsky, M. Paquette-Smith, A. Durbin and A. Tint were responsible for drafting the manuscript and integrating all co-author input. All co-authors contributed substantively to the interpretation of the results and to draft revisions, and have approved the final version of the manuscript.

DATA SHARING STATEMENT

No additional data are available.

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Table 1. Demographic and clinical characteristics of 284 youth and adults with autism spectrum disorder living in Ontario with and without ED visits

		Total Sample (*n*=284) *n* (%)	Visited ED (*n*=63) *n* (%)	Did Not Visit ED (*n*= 221) *n* (%)
Predisposing				
Age	Mean (SD)	18.4(6.2)	18.8(5.9)	18.3(6.3)
Gender	Female	61(21.5)	19(30.2)	42(19.0)
	Male	223(78.5)	44(69.8)	179(81.0)
SCQ score	Mean (SD)	22.6(6.3)	22.5(6.7)	22.6(6.2)
ID	ID	132(46.5)	29(46.0)	103(46.6)
	No ID	121(42.6)	30(47.6)	91(41.2)
	Missing	31(10.9)	4(6.3)	27(12.2)
Enabling				
Parent marital status	Unmarried	67(23.6)	18(28.6)	49(22.2)
	Married/living with partner	217(76.4)	45(71.4)	172(77.8)
Parent immigrated	Yes	67(23.6)	15(23.8)	52(23.5)
	No	217(76.4)	48(76.2)	169(76.5)
Parental education	High education	211(74.3)	48(76.2)	163(73.8)
	Low education	71(25.0)	56(23.8)	56(25.3)
	Missing	2(0.7)	0	2(0.9)
Neighborhood income	Low	59(20.8)	18(28.6)	41(18.6)
	High	225(79.2)	45(71.4)	180(81.4)
Daytime activity	Unstructured	39(13.7)	13(20.6)	26(11.8)
	Structured	245(86.3)	50(79.4)	195(88.2)
Family distress	Mean (SD)	4.2(1.8)	5.0(1.9)	3.9(1.7)
Urban-rural residence	Urban	254(89.4)	52(82.5)	202(91.4)
	Rural	30(10.5)	11(17.5)	19(8.6)
Need				
Medical comorbidity	Yes	98(34.5)	23(36.5)	75(33.9)
	No	186(65.5)	40(63.5)	146(66.1)
Psychiatric comorbidity	Yes	132(46.5)	36(57.1)	96(43.4)
	No	152(53.5)	27(42.9)	125(56.6)
On medication	Yes	162(57.0)	46(73.0)	116(52.5)
	No	122(43.0)	17(27.0)	105(47.5)
History of aggression	Yes	180(63.4)	42(66.7)	138(62.4)
	No	104(36.6)	21(33.3)	83(37.6)
ED visit in past year	Yes	67(23.6)	30(47.6)	37(16.7)
	No	217(76.2)	33(52.4)	184(83.3)
2+ Negative life events	Yes	68(23.9)	26(41.3)	42(19.0)
	No	216(76.9)	37(58.7)	179(81.0)

Note: SCQ = Social Communication Questionnaire; ID = intellectual disability

Table 2. Odds ratios and 95% confidence intervals (CIs) from bivariate and multivariate analyses predicting ED visits among 284 youth and adults with autism spectrum disorder living in Ontario

		Bivariate analysis	Significant predictor only +age model	Fully adjusted model
		Odds Ratio+ 95% CI[‡]	Odds Ratio+ 95% CI[‖]	Odds Ratio+ 95% CI[ǂ]
Predisposing				
Age (years)		1.0(1.0, 1.1)	1.0(1.0, 1.1)	1.0(0.9, 1.1)
Gender	Female	1.8(1.0, 3.5)[§]	1.8(0.9, 3.7)[§]	1.8(0.9, 3.8)[§]
	Male	1.0	1.0	1.0
SCQ score		1.0(0.9, 1.0)		1.0(0.9, 1.0)
ID status	ID (mild to profound ID)	1.0		1.0
	No ID	1.2(0.7, 2.1)		1.1(0.5, 2.3)
	Missing	0.5(0.2, 1.6)		0.5(0.1, 1.7)
Enabling				
Parent marital status	Unmarried	1.4(0.8, 2.6)		1.2(0.5, 2.5)
	Married/living with partner	1.0		1.0
Parent immigrated	Yes	1.0(0.5, 2.0)		1.2(0.6, 2.6)
	No	1.0		1.0
Parental education	High education	1.1(0.6, 2.1)		1.4(0.6, 2.9)
	Low education	1.0		1.0
Neighborhood income	Low	1.8(0.9,3.3)[§]	1.8(0.9, 3.8)[§]	1.7(0.8, 3.6)[§]
	High	1.0	1.0	1.0
Daytime activity	Unstructured	2.0(0.9,4.1)[§]	1.1(0.4, 2.9)	1.1(0.4, 3.2)
	Structured	1.0	1.0	1.0
Family distress		1.4(1.2, 1.6)***	1.3(1.1, 1.5)**	1.3(1.1, 1.5)**
Urban-rural residence	Urban	1.0	1.0	1.0
	Rural	2.3(1.0, 5.0)*	2.0(0.8, 4.9)[§]	2.1(0.8, 5.4)[§]

Need				
Medical comorbidity	Yes	1.1(0.6, 2.0)		0.8(0.4, 1.7)
	No	1.0		1.0
Psychiatric comorbidity	Yes	1.7(1.0, 3.1)§	1.0(0.5, 2.0)	0.9(0.4, 1.9)
	No	1.0	1.0	1.0
On medication	Yes	2.5(1.3, 4.5)**	1.4(0.7, 2.9)	1.6(0.8, 3.5)§
	No	1.0	1.0	1.0
History of aggression	Yes	1.2(0.7, 2.2)		0.8(0.4, 1.7)
	No	1.0		1.0
ED visit in past year	Yes	4.5(2.5, 8.3)***	2.7(1.4, 5.5)**	2.9(1.4, 5.9)**
	No	1.0	1.0	1.0
2+ Negative life events	Yes	3.0(1.6,5.5) ***	2.5(1.2, 5.2)*	2.5(1.2, 5.3)*
	No	1.0	1.0	1.0

Note: SCQ = Social Communication Questionnaire; ID = intellectual disability

§<0.20, *p<0.05,** p <0.01, ***p <0.001

‡ Derived from single predictor models

ǀ Derived from a model that included predictors with a p value of 0.020 or lower in the bivariate analysis: Age; Gender; Neighborhood Income, Typical Day; Family Distress, Urban-rural residence; Psychiatric Comorbidity; ED visit in past year; 2+ Negative life events

ǂ Derived from a model that included all predictors, n = 282 due to missing data

Table 3. Odds ratios and 95% confidence intervals (CIs) from bivariate analyses predicting medical and psychiatric ED visits among 284 youth and adults with autism spectrum disorder living in Ontario

		Medical ED Visit			Psychiatric ED Visit		
		Medical ED Visit (*n* = 31) *n*(%)	No Medical ED Visit (*n* = 236) *n*(%)	Odds Ratio+ 95% CI	Psychiatric ED Visit (*n* = 18) *n*(%)	No Psychiatric ED Visit (*n* = 249) *n*(%)	Odds Ratio+ 95% CI
Predisposing							
Age	*M*(*SD*)	17.7(4.5)	18.3(6.3)	1.0(0.9, 1.1)	18.6(6.6)	18.2(6.6)	1.0(0.9,1.1)
Gender	Female	7(22.6)	47(19.9)	1.2(0.5, 2.9)	6(33.3)	48(19.3)	2.1(0.7, 5.9)
	Male	24(77.4)	189(80.1)	1.0	12(66.7)	201(80.7)	1.0
SCQ score	*M*(*SD*)	22.5(7.2)	22.6(6.1)	1.0(0.9, 1.1)	20.8(4.7)	22.7(6.3)	1.0(0.9, 1.0)
ID status	ID (mild to profound ID)	14(45.2)	110(46.6)	1.00	8(44.4)	116(46.6)	1.0
	No ID	15(48.4)	98(41.5)	1.2(0.6, 2.6)	9(50.0)	104(41.8)	1.3(0.5, 3.4)
	Missing	2(6.5)	28(11.9)	0.6(0.1, 2.6)	1(5.6)	29(11.6)	0.5(0.1, 4.2)
Enabling							
Parent marital status	Unmarried	10(32.3)	53(22.5)	1.6(0.7, 3.7)	7(38.9)	56(22.5)	2.2(0.8, 5.9)
	Married/living with partner	21(67.7)	183(77.5)	1.0	11(61.1)	193(77.5)	1.0
Parent immigrated	Yes	4(12.9)	60(25.4)	0.4(0.2, 1.3)	8(44.4)	56(22.5)	2.8(1.0,7.3)*
	No	27(87.1)	176(74.6)	1.0	10(55.6)	193(77.5)	1.0
Parental education	High education	25(80.6)	173(73.3)	1.47(0.6, 3.8)	12(66.7)	186(74.7)	0.7(0.2,1.8)
	Low education	6(19.4)	61(25.8)	1.0	5(33.3)	61(24.5)	1.0
	Missing	0	2(0.8)		0	2(0.8)	
Neighborhood income	Low	13(41.9)	41(17.4)	3.4(1.6, 7.6)**	2(11.1)	52(20.9)	0.5(0.1, 2.1)
	High	18(58.1)	195(82.6)	1.0	16(88.9)	197(79.1)	1.0
Daytime activity	Unstructured	6(19.4)	207(87.7)	1.7(0.7, 4.5)	5(27.8)	30(12.0)	2.8(0.9, 8.4)
	Structured	25(80.6)	29(12.3)	1.0	13(72.2)	219(88.0)	1.0

Family distress	*M*(*SD*)	5.1(2.1)	4.0(1.7)	1.4(1.1, 1.6)**	5.3(1.5)	4.0(1.8)	1.4(1.1, 1.8)**
Urban-rural residence	Urban	24(77.4)	216(91.5)	1.0	16(88.9)	224(90.0)	1.0
	Rural	7(22.6)	20(8.5)	3.2(1.2, 8.2)*	2(11.1)	25(10.0)	1.1(0.2, 5.2)
Need							
Medical comorbidity	Yes	12(38.7)	79(33.5)	1.3(0.6, 2.7)	4(22.2)	87(34.9)	0.5(0.2, 1.7)
	No	19(61.3)	157(66.5)	1.0	14(77.8)	162(65.1)	1.0
Psychiatric comorbidity	Yes	18(58.1)	105(44.5)	1.7(0.8, 3.7)	11(61.1)	112(45.0)	1.9(0.7, 5.1)
	No	13(41.9)	131(44.5)	1.0	7(38.9)	137(55.0)	1.0
On medication	Yes	23(74.2)	129(54.7)	2.4(1.0, 5.6)*	16(88.9)	136(54.6)	6.7(1.5, 29.5)*
	No	8(25.8)	107(45.3)	1.0	2(11.1)	113(45.4)	1.0
History of aggression	Yes	21(67.7)	151(64.0)	1.2(0.5, 2.6)	16(88.9)	156(62.7)	4.8(1.1, 21.2)*
	No	10(32.3)	85(36.0)	1.0	2(11.1)	93(37.3)	1.0
ED visit in past year	Yes	15(48.4)	41(17.4)	4.5(2.0, 9.7)***	7(38.9)	49(19.7)	2.6(1.0, 7.1)
	No	16(51.6)	195(82.6)	1.0	11(61.1)	200(80.3)	1.0
2+ Negative life events	Yes	14(45.2)	49(20.8)	3.1(1.5, 6.8)**	8(44.4)	55(22.1)	2.8(1.1, 7.5)*
	No	17(54.8)	187(79.2)	1.0	10(55.6)	194(77.9)	1.0

Note: SCQ = Social Communication Questionnaire; ID = intellectual disability
p*<0.05 , *p* <0.01, ****p* <0.001

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Predictors of Emergency Department Use by Adolescents and Adults with Autism Spectrum Disorder: A Prospective Cohort Study

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Abstract

Objectives: To determine predictors of emergency department (ED) visits in a cohort of adolescents and adults with autism spectrum disorder (ASD).

Design: Prospective cohort study.

Setting: Community based study from Ontario, Canada.

Participants: Parents reported on their adult sons and daughters with ASD living in the community (n = 284).

Main outcome measures: ED visits for any reason, ED visits for medical reasons, and ED visits for psychiatric reasons over one year.

Results: Among individuals with ASD, those with ED visits for any reason were reported to have greater family distress at baseline ($p <. 01$), a history of visiting the ED during the year prior ($p <. 01$), and to have experienced two or more negative life events at baseline ($p <. 05$) as compared to those who did not visit the ED. Unique predictors of medical versus psychiatric ED visits emerged. Low neighbourhood income ($p <. 01$) and living in a rural neighbourhood ($p <. 05$) were associated with medical but not psychiatric ED visits, whereas a history of aggression ($p <. 05$) as well as being from an immigrant family ($p <. 05$) predicted psychiatric but not medical emergencies.

Conclusions: A combination of individual and contextual variables may be important for targeting preventative community-based supports for individuals with ASD and their families. In particular, attention should be paid to how caregiver supports, integrative crisis planning, and community-based services may assist in preventing or minimizing ED use for this vulnerable population.

Strengths and limitations of this study:

- This is one of the first published studies to date to compare the profiles of individuals with ASD who did and did not visit the ED.
- A convenience sample in a setting with universal health insurance was used and may be limited in its generalizability.
- Data were based on parent self-report rather than on chart abstraction, and so may be susceptible to biases.

INTRODUCTION

Across childhood, adolescence, and adulthood, individuals with Autism Spectrum Disorder (ASD) are more likely to visit the emergency department (ED) than their typically developing peers for both medical and psychiatric reasons (1-6). The high intensity environment of an ED visit can be extremely challenging for individuals with ASD, who may present with sensory, social-communication and behavioral difficulties (7). Perhaps representative of these challenges, individuals with ASD are restrained or sedated in approximately one in four ED visits (8). ASD knowledge gaps and inadequate professional training often compound these negative experiences for affected individuals and their family caregivers (9,10). From a systemic perspective, frequent ED use is costly and ED over-crowding and long wait times are key system level challenges in most jurisdictions (11,12). The number of ED visits by individuals with ASD is increasing (5), and it is important to better understand predictors of ED visits among individuals with ASD to assist in appropriate provision of community-based care.

Individuals with ASD often have complex care needs and can visit the ED for a host of psychiatric and medical concerns. In addition to an increased risk of developing co-occurring mental health concerns such as anxiety and depression (13,14), youth and adults with ASD often display problem behaviours, including elopement, aggression, and self-harming behaviours (15-17), which frequently necessitate emergency care (2,3,8). Gastrointestinal issues (e.g., abdominal pain, nausea, vomiting) and neurological symptoms and disorders (e.g., seizures and epilepsy) are common comorbid medical concerns among individuals with ASD and account for a large proportion of medical related ED visits in this population (1,2,5,18,19). Youth with ASD may also be at high risk for ED visits due to accidents and injury (20-22). Medical issues can be further complicated by atypical clinical presentations, such that problem behaviours can sometimes mask underlying medical conditions (23,24).

In recent years, several studies have compared ED patterns in those with and without ASD (1-6); however, we know very little about what differentiates individuals with ASD who use the ED compared to those with ASD who do not use the ED. Additionally, the majority of what is known about emergency service use patterns in individuals with ASD comes from the analysis of administrative data. This type of analysis is limited in its ability to describe situational and family centered variables that are not typically documented in insurance claims or medical records. Our previous retrospective, cross-sectional study on ED use in ASD (8) demonstrated that factors such as previous ED visits, lack of meaningful day time activities, and a history of hurting others were related to emergency service use, whereas demographic variables were not. This study, however, was limited in that it did not explore how these variables impact ED use over a longer period of time.

The current study investigates predictors of ED use in adolescents and adults with ASD based on parent reported data. As a secondary exploratory aim, we sought to separately examine predictors of medically related ED visits and predictors of psychiatric related ED visits to determine if they were distinct. For these analyses, a modified version of Andersen's Behavioural Model of Health Services Use (25) was used to group predictors into three categories: 1) predisposing factors (i.e., static demographic characteristics that describe the likelihood an individual will seek health care in a given situation); 2) enabling factors (i.e., environmental characteristics and available resources); and 3) need variables (i.e., events or medical/psychological conditions that might facilitate a greater need for services).

METHODS

Participants

Parents of adolescents and adults with ASD age 12 years and up were recruited from across Ontario, Canada, between December 2010 and October 2012. Parents were recruited from flyers and websites of collaborating community agencies, recreation programs and schools that support individuals with ASD, as well as through every local chapter of the provincial ASD organization. To be eligible for the study, individuals with ASD needed to: 1) be living in Ontario; 2) be 12 years of age or older; 3) have a clinical diagnosis of ASD; 4) exceed the recommended cut-off score of 12 on the Social Communication Questionnaire-Lifetime Version (SCQ; 26,27), a standardized ASD screening tool. A total of 514 families consented to participate in the study and 462 completed the baseline survey; 396 of these participants met the age and SCQ cutoffs. Families were contacted every two months to report on their ED use and were contacted approximately one year after baseline to fill out a final survey. To be included in the current study, parents were required to complete the final survey within 18 months of their baseline date. The final sample for the current study consisted of 284 individuals with ASD (Mean age = 18.41, *SD* = 6.16; 223 males, 61 females). There were no significant differences between the final sample (n = 284) and those who did not complete the final survey within the required time period (n = 112) with respect to most individual and parent demographics (individual age, individual gender, individual place of residence, parent age, parent marital status, parent education, neighbourhood income) or clinical needs (individual ASD severity, individual ID status, individual medical and psychiatric diagnoses; all p's > 0.05). However, a significantly greater proportion of non-responders identified as non-Caucasian (26.6% vs 17.0%, p = 0.03).

The majority of survey respondents were mothers (93.7%) and nearly half reported that their dependent with ASD was 18 years or older (44.7%). Most individuals with ASD lived with family (91.2%) at time of baseline survey completion, the remaining were reported to reside in group homes or other supported living situations (6.4%), in treatment facilities (0.7%), or independently (1.8%).

Measures

Predictor Variables

All predictor variables were collected as part of the baseline survey.

Predisposing Variables. Individual predisposing variables included age, gender, intellectual disability (ID) status and ASD severity. ID status was split into those who had an ID (i.e., mild to profound ID) and those who did not (i.e., gifted, normal and borderline intelligence). ASD severity was measured using the SCQ (26), with higher scores reflective of more severe symptomology. The SCQ is reported to have good internal consistency (alpha coefficients 0.81-0.93); and external validity (27). In the current study, internal consistency for the overall scale was strong (Cronbach's alpha = 0.81).

Enabling Variables. Parent enabling variables included marital status (married/living with partner or single), education level, and if they were born in Canada (yes/no). Parent education level was dichotomized into high education (college diploma or higher) or low education (some college or university education or lower). Household income of each family was estimated based on the median income of the respondent's postal code region according to census data (28; range $33,030.00 – $107,742.00, *M* = $65,597.12, *SD* = $15,970.27). Since the neighbourhood income in our sample was higher than the national mean ($53,634), we compared families whose neighbourhood income fell into the bottom quartile to those that fell in the top three quartiles of our sample. Postal codes were also used to determine rural status (rural vs. urban) based on Statistics Canada's definition of rurality (29). Individuals were classified as either having or not having 'structured' daytime activities based on parents' responses to the question "What does your child do during his/her typical day? (i.e., school, working, volunteering or job training, day program, no structured daytime activity or other)". Family distress was measured at baseline using the 10-point Brief Family Distress Scale (BFDS; 30) which asks 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'.

*Need Variables***.** Parents were asked to provide current medical (e.g., gastrointestinal, skin conditions) and psychiatric diagnoses (e.g., anxiety, depression) for their child with ASD. Comorbid medical and psychiatric diagnoses were each dichotomized as has been done in many large-scale parent report surveys (31,32). Parents also indicated (yes/no) whether their child had a history of aggression, and whether they visited the ED in the year prior to the baseline survey.

Parents also completed a modified version of the negative life events checklist from the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (PAS-ADD; 33), in which they were to check off any of the significant life events that their child experienced in the two months prior to baseline (e.g., death of a family member, change in residence, loss of a job). For this analysis, the 'injury to self' item was excluded as injuries may directly cause an ED visit. The checklist was dichotomized into individuals that had two or more negative life events prior to beginning the survey and those that had fewer than two, similar to past studies using this measure (34,35).

Dependent Variables

*Primary outcome variable (ED Visit)***.** In each of the follow-up surveys, parents were asked to indicate (yes/no) whether their child used the ED in the last two months. Parents were also asked in the final survey about whether their child had any ED visits in the previous year. Individuals with ASD were dichotomized into individuals with and without any ED visit during the past year. To ensure that the sampling period for visits was standardized across participants, only ED visits during the year that preceded participants' final survey were included. All participants were therefore sampled for 12 months.

Secondary outcome variables (Medical or Psychiatric ED Visits). Parent descriptions of visits were coded independently by two authors (MPS and AT) as being either medical or psychiatric in nature with 98% inter-rater agreement. Any disagreements were resolved through discussion with the senior author (YL). If parents provided detailed descriptions of more than one ED visit, each visit was coded separately. Thus, the same individual could be classified as having both a medical emergency and a psychiatric emergency (n = 3). Some parents failed to provide enough descriptive information about emergencies in their bimonthly form for these emergencies to be coded (n =17) so these cases were excluded from the secondary analysis of emergency type.

PROCEDURE

The York University and Centre for Addiction and Mental Health research ethics boards approved this research. Consenting parents were sent their baseline survey electronically or on paper. The majority of participants (n = 223; 78.5%) completed online surveys. Parents who completed the surveys online (M = 48.67 years, SD = 6.88) were significantly younger than parents who completed the surveys via mail or telephone interview (n = 61; M = 52.36 years, SD = 8.44, p = .001); no other parent or individual demographic variables differed according to survey response method. Participants had a unique identifier that was linked to their information and every two months following the completion of their last survey, they received another follow up survey. At their final time point, they received a longer measure to complete. Participants received payment ($20) upon completing baseline information and subsequent payment ($20) when they completed their final measure.

Data Analysis

A bivariate analysis compared the groups with and without ED visits using single predictor logistic regression models. From these models we derived odds ratios to demonstrate the relationship between each predictor variable and the likelihood of having any ED use. To identify the relative influence of these variables we then ran two adjusted logistic regression explanatory models predicting any ED use. The first included all the variables that had a *p*-value of 0.20 or lower in the bivariate analysis, as well as the age variable that did not meet this threshold, but was included since it is a potential confounder. The second adjusted logistic regression model included all predictor variables.

Subsequently, we examined if different variables were associated with medical ED visits compared to psychiatric ED visits. To do this, we again ran single predictor logistic regression models on two different subsets of the sample. First, these models were used to compare individuals with any medical ED visits to individuals with no medical ED visits. Second, we used these models to compare individuals with any psychiatric ED use relative to individuals with no psychiatric ED use. Adjusted logistic regressions could not be conducted as part of this analysis due to the small number who presented with each type of visit.

For all of the models, individuals with missing data for ID status ($n = 31$) were included, but individuals with missing data for parental education ($n = 2$) were excluded since it was not sufficiently large to be included as its own category. Analyses were conducted using SPSS version 24.

RESULTS

Emergency department use

Of the cohort of 284 individuals, 63 (22.2%) reported ED use during the year following their baseline data collection and 221 (77.8%) reported no ED use during that year. Participant demographic and clinical characteristics according to ED outcome are shown in Table 1.

In the bivariate analysis, higher family distress, living in a rural area, being on medication, having ED visits in past year and having two or more negative life events were significant at the 0.05 level. In addition, gender, neighbourhood income, daytime activity, and psychiatric comorbidity had p-values larger than 0.05 but less than 0.20 (Table 2). Despite the two adjusted models including different predictors (the first included predictors with a p-value of less than 0.20 in the bivariate analysis, and the second model included all predictor variables), both models yielded similar results. In both models, clinical need variables (having an ED visit in the year prior to the study and reporting 2 or more significant life events at baseline) and one enabling variable (family distress) predicted having any ED use, when controlling for other variables (see Table 2).

Medical and psychiatric ED visits

Forty-six of the 63 parents who reported that their child visited the ED provided a detailed description of at least one such visit. Three parents described separate psychiatric and medical visits. For the purposes of the following analyses, we included only the first medical and first psychiatric visit described by each parent for a total of 49 descriptions of ED visits. Of the 49 described ED visits, 31 visits related to medical issues and 18 visits related to psychiatric issues. The most common type of medical visit was injury ($n = 10$), followed by gastrointestinal issues ($n = 4$) and infections ($n = 4$). The most common reason for psychiatric ED visits was related to self-harm and/or suicidality ($n = 5$) followed by physical assault towards family members ($n = 3$) and three incidents where parents described individuals as both a danger to self and others.

As shown in Table 3, bivariate analyses indicate medical ED visits were associated with living in a lower income neighbourhood, living in a rural area, and family distress at baseline (enabling factors), along with two or more negative life events, being on medication at baseline, and visiting the ED in the year prior to data collection (need factors). Two enabling factors (parent immigrant status and family distress) predicted having a psychiatric ED visit in the follow up period (see Table 3). Clinical need variables, such as being on medication, having a history of aggression, and having two or more negative life events were also significantly associated with psychiatric emergencies.

DISCUSSION

Principal findings

Approximately 22% of individuals with ASD went to the ED at least once in a 12-month period. The results suggest that a combination of enabling (family distress) and need variables (visiting the ED in the year prior, and having two or more negative life events at baseline) predicted ED use. In the secondary analysis, family distress, life events, and being on medication were associated with having both medical and psychiatric emergencies at the bivariate level. Interestingly, low income and living in a rural area were associated with medical but not psychiatric emergencies. Conversely, having a history of aggression, as well as being from an immigrant family, predicted psychiatric but not medical emergencies.

Study strengths and limitations

This is the first study to examine ED visits in adolescents and adults with ASD prospectively based on families' reports. Other studies have focused primarily on emergencies in children and youth with ASD without including both family and individual variables. We examined how a wide range of predisposing, enabling, and need factors contributed to ED use in this population. We also identified unique contributors to medical and to psychiatric emergencies, although our sample size did not allow for these results to be based on an adjusted analysis.

Although the findings were robust as demonstrated by two different adjusted models yielding the same results, caution is needed when interpreting the study findings due to important limitations. Our sample largely consisted of parent respondents who identified as Caucasian with high levels of education. Additionally, we were reliant on parent report of ASD severity, ID status, and medical and psychiatric comorbid diagnoses. Similarly, categorization of ED visit type was based on parent report, not chart audits. Although we tried to improve accuracy of parent reporting by engaging in regular follow up, their responses may still be vulnerable to recall bias. Further research combining parent perspectives with administrative health data would be valuable. Finally, our results are based on a small cohort and replication with a larger sample is warranted. Future work with larger sample sizes would also enable more detailed analyses, such as ED predictors separated by age group as well as by outcome (e.g., hospital admission) or ID status.

Similarities and differences to prior research

The likelihood of ED use in the current study was not related to age, ID status, or ASD severity. Previous research on predictors of ED use among individuals with ASD and other populations has shown mixed results with respect to the role of predisposing demographic factors (1-6). For instance, some studies report a greater likelihood of ED visits in older individuals with ASD (2,4), but others do not (6). Our cohort may be too small to detect these types of patterns, or indeed, they may not be the drivers of such visits when multivariate analyses include a wider combination of variables.

Only one enabling variable predicted ED use while controlling for predisposing and need variables. Parents who reported that their families were experiencing significant distress at baseline reported that their son or daughter was more likely to visit the ED during the study period. Higher rates of family stress are associated with increased ED use among parents of youth with psychiatric conditions (36) and higher rates of general health service use among parents of youth with ASD (37). This is the first study to report an association between family distress and future ED use in the ASD literature.

With respect to clinical need variables, ED use in the previous year was the strongest predictor of ED visits in the year studied. This is similar to other studies that examine ED use in individuals with ID (38), and our previous study that examined ED use in individuals with ASD over a two-month period (8). Reporting two or more negative life events at baseline more than doubled the likelihood that an individual would visit the ED in the follow-up period. This aligns with previous research showing that life events predicted ED visits in individuals with ID (34). Individuals with ASD experience a high frequency of negative life events, trauma, and greater stress when compared to typically developing peers (39-41). These stressors, in turn, are associated with decreases in social functioning (39), and depression (42), which may lead to greater ED use.

When looking at unique predictors of each of medical and psychiatric ED visits, distinct enabling variables, like low income and living in a rural area, were associated with medical but not psychiatric emergencies. It is well recognized that some health care services are less available in rural areas of Ontario (43). In the general population, having lower social economic status is strongly correlated with adverse health outcomes (44). Neighbourhood income also predicts preventable hospitalizations in adults with ID (45). In our study, it may be that individuals with greater financial means and those who live in urban areas are more able to access specialized medical care, and as such may require less ED support. Not surprisingly, a history of aggression uniquely predicted psychiatric but not medical emergencies. This aligns closely with previous work looking at the predictors of psychiatric hospitalizations in children with ASD, which also pinpoint aggression as a strong predictor (46,47). Interestingly, being from an immigrant family was associated with psychiatric ED use but was not associated with medical ED visits. This begs the question of how well these families are engaged with and proactively accessing mental health services for their sons or daughters. Individuals who have recently immigrated might have less knowledge of the mental health care system and resources to effectively find accessible and appropriate community support services for their child with ASD (48).

Implications

Our findings replicate what others have reported regarding frequent ED use among individuals with ASD (1-6) and identified a combination of enabling and need variables that may be important for targeting preventative community-based supports. For instance, parents who reported higher family distress were more likely to bring their son or daughter to the ED. Caring for a child with ASD can bring many challenges, which persist across the life course (49). When parents indicate that they are approaching crisis, this can also signal future emergencies, and community-based clinicians need to proactively help such families. Brief family distress measures can assist clinicians in determining the severity of the crisis state and in the selection of appropriate interventions (30). Likewise, family members themselves can be taught to self-monitor their own distress levels and effective methods of seeking help apart from visiting the ED. From a systemic perspective, policy practices need to expand beyond the identified individual with ASD and include family focused care. Community-based services that provide relief to families, such as respite care, can help reduce stress on families, and in turn, reduce emergency service use for individuals with ASD (50).

It is equally important for community based service providers to acknowledge the impact of negative life events on individuals with ASD and their families. Yerkey and Wildman (51) found that primary care physicians improved their identification rates for youth mental health problems using knowledge of negative life events. Increased clinical knowledge of the difficulties many individuals with ASD experience during transitions, and provision of appropriate community mental health care targeted at building the resiliency of individuals with ASD when exposed to negative life events, may alleviate some need for ED services among this population.

Considering the link between previous and future ED visits, effective care plans need to be in place following the first ED visit to help deal with future crises. Clinical practice guidelines for this population (52) indicate for ED staff to recommend families work with their community care providers to prepare proactive care plans as part of the discharge process. Further, to ensure individuals with ASD receive appropriate care in the ED, and potentially negate the need for repeat visits, families can make use of hospital passports and other patient information tools to assist ED staff in better understanding an individual’s specific care needs (53).

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COMPETING INTERESTS

There are no competing interests on the part of any of the authors of this manuscript.

AUTHOR CONTRIBUTIONS

Y. Lunsky, J.A.Weiss, A.M. Palucka and E. Bradley were the primary creators of the concept and design of this study. The analytic approach was created by Y. Lunsky and J.A. Weiss, and carried out by M. Paquette-Smith, A. Durbin, and A. Tint. Y. Lunsky, M. Paquette-Smith, A. Durbin and A. Tint were responsible for drafting the manuscript and integrating all co-author input. All co-authors contributed substantively to the interpretation of the results and to draft revisions, and have approved the final version of the manuscript.

DATA SHARING STATEMENT

No additional data are available.

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Table 1. Demographic and clinical characteristics of 284 youth and adults with autism spectrum disorder living in Ontario with and without ED visits

		Total Sample (*n*=284) *n* (%)	Visited ED (*n*=63) *n* (%)	Did Not Visit ED (*n*= 221) *n* (%)
Predisposing				
Age	Mean (SD)	18.4(6.2)	18.8(5.9)	18.3(6.3)
Gender	Female	61(21.5)	19(30.2)	42(19.0)
	Male	223(78.5)	44(69.8)	179(81.0)
SCQ score	Mean (SD)	22.6(6.3)	22.5(6.7)	22.6(6.2)
ID	ID	132(46.5)	29(46.0)	103(46.6)
	No ID	121(42.6)	30(47.6)	91(41.2)
	Missing	31(10.9)	4(6.3)	27(12.2)
Enabling				
Parent marital status	Unmarried	67(23.6)	18(28.6)	49(22.2)
	Married/living with partner	217(76.4)	45(71.4)	172(77.8)
Parent immigrated	Yes	67(23.6)	15(23.8)	52(23.5)
	No	217(76.4)	48(76.2)	169(76.5)
Parental education	High education	211(74.3)	48(76.2)	163(73.8)
	Low education	71(25.0)	56(23.8)	56(25.3)
	Missing	2(0.7)	0	2(0.9)
Neighbourhood income	Low	59(20.8)	18(28.6)	41(18.6)
	High	225(79.2)	45(71.4)	180(81.4)
Daytime activity	Unstructured	39(13.7)	13(20.6)	26(11.8)
	Structured	245(86.3)	50(79.4)	195(88.2)
Family distress	Mean (SD)	4.2(1.8)	5.0(1.9)	3.9(1.7)
Urban-rural residence	Urban	254(89.4)	52(82.5)	202(91.4)
	Rural	30(10.5)	11(17.5)	19(8.6)
Need				
Medical comorbidity	Yes	98(34.5)	23(36.5)	75(33.9)
	No	186(65.5)	40(63.5)	146(66.1)
Psychiatric comorbidity	Yes	132(46.5)	36(57.1)	96(43.4)
	No	152(53.5)	27(42.9)	125(56.6)
On medication	Yes	162(57.0)	46(73.0)	116(52.5)
	No	122(43.0)	17(27.0)	105(47.5)
History of aggression	Yes	180(63.4)	42(66.7)	138(62.4)
	No	104(36.6)	21(33.3)	83(37.6)
ED visit in past year	Yes	67(23.6)	30(47.6)	37(16.7)
	No	217(76.2)	33(52.4)	184(83.3)
2+ Negative life events	Yes	68(23.9)	26(41.3)	42(19.0)
	No	216(76.9)	37(58.7)	179(81.0)

Note: SCQ = Social Communication Questionnaire; ID = intellectual disability

Table 2. Odds ratios and 95% confidence intervals (CIs) from bivariate and multivariate analyses predicting ED visits among 284 youth and adults with autism spectrum disorder living in Ontario

		Bivariate analysis	Significant predictor only +age model	Fully adjusted model
		Odds Ratio+ 95% CI[‡]	Odds Ratio+ 95% CI[‖]	Odds Ratio+ 95% CI[‡]
Predisposing				
Age (years)		1.0(1.0, 1.1)	1.0(1.0, 1.1)	1.0(0.9, 1.1)
Gender	Female	1.8(1.0, 3.5)[§]	1.8(0.9, 3.7)[§]	1.8(0.9, 3.8)[§]
	Male	1.0	1.0	1.0
SCQ score		1.0(0.9, 1.0)		1.0(0.9, 1.0)
ID status	ID (mild to profound ID)	1.0		1.0
	No ID	1.2(0.7, 2.1)		1.1(0.5, 2.3)
	Missing	0.5(0.2, 1.6)		0.5(0.1, 1.7)
Enabling				
Parent marital status	Unmarried	1.4(0.8, 2.6)		1.2(0.5, 2.5)
	Married/living with partner	1.0		1.0
Parent immigrated	Yes	1.0(0.5, 2.0)		1.2(0.6, 2.6)
	No	1.0		1.0
Parental education	High education	1.1(0.6, 2.1)		1.4(0.6, 2.9)
	Low education	1.0		1.0
Neighbourhood income	Low	1.8(0.9,3.3)[§]	1.8(0.9, 3.8)[§]	1.7(0.8, 3.6)[§]
	High	1.0	1.0	1.0
Daytime activity	Unstructured	2.0(0.9,4.1)[§]	1.1(0.4, 2.9)	1.1(0.4, 3.2)
	Structured	1.0	1.0	1.0
Family distress		1.4(1.2, 1.6)***	1.3(1.1, 1.5)**	1.3(1.1, 1.5)**
Urban-rural residence	Urban	1.0	1.0	1.0
	Rural	2.3(1.0, 5.0)*	2.0(0.8, 4.9)[§]	2.1(0.8, 5.4)[§]

Need				
Medical comorbidity	Yes	1.1(0.6, 2.0)		0.8(0.4, 1.7)
	No	1.0		1.0
Psychiatric comorbidity	Yes	1.7(1.0, 3.1)§	1.0(0.5, 2.0)	0.9(0.4, 1.9)
	No	1.0	1.0	1.0
On medication	Yes	2.5(1.3, 4.5)**	1.4(0.7, 2.9)	1.6(0.8, 3.5)§
	No	1.0	1.0	1.0
History of aggression	Yes	1.2(0.7, 2.2)		0.8(0.4, 1.7)
	No	1.0		1.0
ED visit in past year	Yes	4.5(2.5, 8.3)***	2.7(1.4, 5.5)**	2.9(1.4, 5.9)**
	No	1.0	1.0	1.0
2+ Negative life events	Yes	3.0(1.6,5.5) ***	2.5(1.2, 5.2)*	2.5(1.2, 5.3)*
	No	1.0	1.0	1.0

Note: SCQ = Social Communication Questionnaire; ID = intellectual disability

§<0.20, *$p<0.05$,** $p<0.01$, ***$p<0.001$

‡ Derived from single predictor models

‖ Derived from a model that included predictors with a p value of 0.020 or lower in the bivariate analysis: Age; Gender; Neighbourhood Income, Typical Day; Family Distress, Urban-rural residence; Psychiatric Comorbidity; ED visit in past year; 2+ Negative life events

ǂ Derived from a model that included all predictors, *n* = 282 due to missing data

Table 3. Odds ratios and 95% confidence intervals (CIs) from bivariate analyses predicting medical and psychiatric ED visits among 284 youth and adults with autism spectrum disorder living in Ontario

		Medical ED Visit			Psychiatric ED Visit		
		Medical ED Visit (*n* = 31) *n*(%)	No Medical ED Visit (*n* = 236) *n*(%)	Odds Ratio+ 95% CI	Psychiatric ED Visit (*n* = 18) *n*(%)	No Psychiatric ED Visit (*n* = 249) *n*(%)	Odds Ratio+ 95% CI
Predisposing							
Age	*M*(*SD*)	17.7(4.5)	18.3(6.3)	1.0(0.9, 1.1)	18.6(6.6)	18.2(6.6)	1.0(0.9,1.1)
Gender	Female	7(22.6)	47(19.9)	1.2(0.5, 2.9)	6(33.3)	48(19.3)	2.1(0.7, 5.9)
	Male	24(77.4)	189(80.1)	1.0	12(66.7)	201(80.7)	1.0
SCQ score	*M*(*SD*)	22.5(7.2)	22.6(6.1)	1.0(0.9, 1.1)	20.8(4.7)	22.7(6.3)	1.0(0.9, 1.0)
ID status	ID (mild to profound ID)	14(45.2)	110(46.6)	1.00	8(44.4)	116(46.6)	1.0
	No ID	15(48.4)	98(41.5)	1.2(0.6, 2.6)	9(50.0)	104(41.8)	1.3(0.5, 3.4)
	Missing	2(6.5)	28(11.9)	0.6(0.1, 2.6)	1(5.6)	29(11.6)	0.5(0.1, 4.2)
Enabling							
Parent marital status	Unmarried	10(32.3)	53(22.5)	1.6(0.7, 3.7)	7(38.9)	56(22.5)	2.2(0.8, 5.9)
	Married/living with partner	21(67.7)	183(77.5)	1.0	11(61.1)	193(77.5)	1.0
Parent immigrated	Yes	4(12.9)	60(25.4)	0.4(0.2, 1.3)	8(44.4)	56(22.5)	2.8(1.0,7.3)*
	No	27(87.1)	176(74.6)	1.0	10(55.6)	193(77.5)	1.0
Parental education	High education	25(80.6)	173(73.3)	1.47(0.6, 3.8)	12(66.7)	186(74.7)	0.7(0.2,1.8)
	Low education	6(19.4)	61(25.8)	1.0	5(33.3)	61(24.5)	1.0
	Missing	0	2(0.8)		0	2(0.8)	
Neighbourhood income	Low	13(41.9)	41(17.4)	3.4(1.6, 7.6)**	2(11.1)	52(20.9)	0.5(0.1, 2.1)
	High	18(58.1)	195(82.6)	1.0	16(88.9)	197(79.1)	1.0
Daytime activity	Unstructured	6(19.4)	207(87.7)	1.7(0.7, 4.5)	5(27.8)	30(12.0)	2.8(0.9, 8.4)
	Structured	25(80.6)	29(12.3)	1.0	13(72.2)	219(88.0)	1.0

Family distress	*M*(*SD*)	5.1(2.1)	4.0(1.7)	1.4(1.1, 1.6)**	5.3(1.5)	4.0(1.8)	1.4(1.1, 1.8)**
Urban-rural residence	Urban	24(77.4)	216(91.5)	1.0	16(88.9)	224(90.0)	1.0
	Rural	7(22.6)	20(8.5)	3.2(1.2, 8.2)*	2(11.1)	25(10.0)	1.1(0.2, 5.2)
Need							
Medical comorbidity	Yes	12(38.7)	79(33.5)	1.3(0.6, 2.7)	4(22.2)	87(34.9)	0.5(0.2, 1.7)
	No	19(61.3)	157(66.5)	1.0	14(77.8)	162(65.1)	1.0
Psychiatric comorbidity	Yes	18(58.1)	105(44.5)	1.7(0.8, 3.7)	11(61.1)	112(45.0)	1.9(0.7, 5.1)
	No	13(41.9)	131(44.5)	1.0	7(38.9)	137(55.0)	1.0
On medication	Yes	23(74.2)	129(54.7)	2.4(1.0, 5.6)*	16(88.9)	136(54.6)	6.7(1.5, 29.5)*
	No	8(25.8)	107(45.3)	1.0	2(11.1)	113(45.4)	1.0
History of aggression	Yes	21(67.7)	151(64.0)	1.2(0.5, 2.6)	16(88.9)	156(62.7)	4.8(1.1, 21.2)*
	No	10(32.3)	85(36.0)	1.0	2(11.1)	93(37.3)	1.0
ED visit in past year	Yes	15(48.4)	41(17.4)	4.5(2.0, 9.7)***	7(38.9)	49(19.7)	2.6(1.0, 7.1)
	No	16(51.6)	195(82.6)	1.0	11(61.1)	200(80.3)	1.0
2+ Negative life events	Yes	14(45.2)	49(20.8)	3.1(1.5, 6.8)**	8(44.4)	55(22.1)	2.8(1.1, 7.5)*
	No	17(54.8)	187(79.2)	1.0	10(55.6)	194(77.9)	1.0

Note: SCQ = Social Communication Questionnaire; ID = intellectual disability
p*<0.05 , *p* <0.01, ****p* <0.001

STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	**Recommendation**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract **[Within title page, page 1]**
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found **[Within abstract results, page 2]**
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported **[page 3]**
Objectives	3	State specific objectives, including any prespecified hypotheses **[page 3]**
Methods		
Study design	4	Present key elements of study design early in the paper **[page 4-5]**
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection **[page 4]**
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up **[page 4]**
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed **[n/a]**
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable **[page 4-5]**
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group **[page 4-5]**
Bias	9	Describe any efforts to address potential sources of bias **[page 4-5]**
Study size	10	Explain how the study size was arrived at **[page 4]**
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why **[page 6]**
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding **[page 6-7]**
		(*b*) Describe any methods used to examine subgroups and interactions **[n/a]**
		(*c*) Explain how missing data were addressed **[page 6]**
		(*d*) If applicable, explain how loss to follow-up was addressed **[page 4]**
		(*e*) Describe any sensitivity analyses **[n/a]**
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed **[page 4]**
		(b) Give reasons for non-participation at each stage **[n/a]**
		(c) Consider use of a flow diagram **[n/a]**
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders **[page 4]**
		(b) Indicate number of participants with missing data for each variable of interest **[page 6]**
		(c) Summarise follow-up time (eg, average and total amount) **[page 4]**
Outcome data	15*	Report numbers of outcome events or summary measures over time **[page 6]**
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included **[Tables 2-3]**

		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period **[n/a]**
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses **[n/a]**
Discussion		
Key results	18	Summarise key results with reference to study objectives **[page 7]**
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias **[page 7]**
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence **[page 7-9]**
Generalisability	21	Discuss the generalisability (external validity) of the study results **[page 7-9]**
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based **[page 9]**

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.