

RUNNING HEAD: EMERGENCY SERVICE EXPERIENCES

Short Report: Emergency Service Experiences of Adults with Autism Spectrum Disorder
without Intellectual Disability

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Abstract

This study aimed to describe patterns of emergency department use and police interactions, as well as satisfaction with emergency services of 40 adults with autism spectrum disorder without intellectual disability over 12 to 18 months. Approximately 42.5% of the sample reported visiting the emergency department and 32.5% reported interactions with police during the study period. Presenting concerns for emergency department use and police interactions varied widely, highlighting the heterogeneous needs of this population. On average, participants reported being dissatisfied with care received in the emergency department while police interactions were rated relatively more favourably.

Keywords: autism spectrum disorder, adults, service use, emergency department, police

Emergency Service Experiences of Adults with Autism Spectrum Disorder without Intellectual Disability

Individuals with Autism Spectrum Disorder (ASD) interact with emergency services, such as emergency departments (ED) and police, at higher rates than typically developing peers (Rava et al., 2017; Vohra, Madhavan, & Sambamoorthi, 2016). A substantial proportion of adults with ASD do not have an intellectual disability (ID; Brugha et al., 2016), yet research regarding the emergency service use by adults with ASD without ID is limited.

ED Use

Adults with ASD may present to the ED as a result of a range of care needs. Recent work identified the most prevalent complaints leading to ED use among adults with ASD to include epilepsy, psychiatric concerns, and injury (Iannuzzi, Cheng, Broder-Fingert, & Bauman, 2015; Vohra et al., 2016). These visits can be extremely stressful, with one caregiver report survey indicating individuals with ASD are restrained or sedated in approximately one in four ED visits (Lunsky et al., 2015). However, no research to date has included the perspectives of adults with ASD.

Police Involvement

While little evidence exists of the overrepresentation of individuals with ASD in the criminal justice system (King & Murphy, 2014), 20% of youth with ASD in the U.S. have interacted with law enforcement officers by the age of 21 (Rava et al., 2017). A UK-based survey found 69% of adults with ASD and 74% of parents were dissatisfied with police interactions, citing perceived discrimination, a lack of information provided by police, and inappropriate physical accommodations (Crane et al. 2016). Participants in this study, however, were self-selecting and further information about the range of police experiences among this population is needed.

Current Study

We aimed to describe rates of emergency service use, and satisfaction with care received in the ED and/or interactions with police, from the perspectives of Canadian adults with ASD without ID.

Methods

Participants

Data for this study was collected as part of a larger project examining service use in adults with ASD from across Ontario, Canada. Inclusion criteria for the current study were met if individuals: (a) were older than 17 years of age; (b) reported to have received a formal ASD diagnosis; (c) did not report a diagnosis of ID; (d) had the capacity to self-report on their health history and service use; (e) exceeded the recommended cut-off score of ≥ 26 on the Autism Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), a standardized ASD self-report screening tool. Participants provided baseline information at the first time point and then completed bimonthly surveys concerning service use during the preceding two months, for a possible total of seven surveys. Data were only retained for the current study if the length of time between participants' completed baseline and final follow up surveys was no more than 18 months. A total of 66 adults participated in the larger project; 12 of these individuals did not meet the AQ cut-off score and an additional 14 did not complete the follow-up surveys within the required time period.

The final sample consisted of 40 adults with ASD without ID ($n = 18$ male) ranging in age from 18-61 years ($M = 35.88$, $SD = 11.70$). The majority of individuals identified as Caucasian (87.5%) and single or never married (60.0%). The forward sortation index (first three digits) of participants' postal codes was used to find the median neighbourhood income

from the Canadian Census (Statistics Canada, 2006); median neighbourhood incomes ranged from CAN \$39,160 to CAN \$97,706. See Vogan et al., 2017 for more information.

Procedure

The university and hospital research ethics boards approved this research. Participants were recruited from postings on ASD support organizations' websites and through associated email lists to participate in a study concerning their experiences with health services with the aim of improving service provision. All participants were given the option of completing surveys via mail, telephone interview, or online, and provided informed consent prior to completing the initial survey. Participants completed measures regarding emergency services with reference to the past two months at each time point. Most (97.5%) completed online surveys. On average, participants completed a total of 5.3 surveys ($SD = 1.7$) over 15.3 months ($SD = 1.3$).

Measures

Emergency service use. In each of the surveys participants were asked to indicate (yes/no) whether they had involvement with police and/or visited the emergency department in the last two months. We reported on how many individuals used each individual service at least once during the study period.

Satisfaction with emergency service use. Among those who indicated that they had used an emergency service, participants were asked to rate their overall satisfaction with each of the services based on a five-point Likert scale with higher scores indicative of greater satisfaction. An average satisfaction rating was calculated across time points for each individual service (police and ED).

Emergency service descriptions. Participants who indicated they used at least one emergency service during the follow-up surveys were asked to describe each individual

service encounter in further detail. For ED visits, this included how they arrived at the ED, primary reason for going to the ED, and whether interventions to calm were implemented in the ED (e.g., individuals were taken to a separate quiet room, mechanical or physical restraints were used, medication to sedate was given). Participants were asked to indicate the primary reason for their visit with the following response options: 1) danger to others; 2) danger to self; 3) unable to take care of self; 4) other.

Individuals who were involved with police were similarly asked for details concerning the encounter with police, including police officers' response upon arrival and individuals' feelings about the police officers' response. Response options included: 1) police assessed the crisis situation and left; 2) police escorted the individual to the emergency department; 3) police took the individual into custody; or 4) other. Individuals indicated their feelings about the police response based on the following three responses: 1) the police response had a calming effect; 2) the police response increased agitation; or 3) the police response had no effect. Individuals were also asked whether physical or chemical restraints were used and if criminal charges were filed following the incident.

Results

Emergency Service Use and Service Satisfaction

Approximately 58.0% ($n = 23$) of the sample reported using at least one emergency service over the course of the study period. Emergency department services were used by 42.5% of participants ($n = 17$) and 32.5% ($n = 13$) reported involvement with police; seven individuals used both police and ED services at least once during the study period.

Satisfaction scores for both ED and police services ranged from 1 to 5. ED services received a median score of 2.50 (*dissatisfied*; $M = 2.73$, $SD = 1.35$) while police service satisfaction scores received a median score of 4.00 (*satisfied*; $M = 3.68$, $SD = 1.48$).

Descriptions of Emergency Service Use

ED use. Of the 17 individuals who reported ED use during the study period, 11 provided details for a combined total of 25 ED visits. The number of ED visits per individual ranged from one to seven; seven individuals visited the ED more than once during the study period. Presenting concerns are shown in Table 1. Out of the total 25 ED visits, over half ($n = 14, 56.0\%$) were due to individuals presenting as a danger to themselves. With respect to mode of arrival, individuals arrived at the ED: by their own accord ($n = 14, 56.0\%$); escorted by emergency personnel (i.e., police and/or paramedics; $n = 6, 24.0\%$); brought by friends and/or family ($n = 4, 16.0\%$); or unknown means ($n = 1, 4.0\%$). In 12 (48.0%) of the visits (involving nine individuals) individuals were taken to a separate quiet room. In nine (36.0%) of the visits (involving five individuals) medication to sedate was provided, while in six visits (24.0%; involving four individuals), mechanical or physical restraints were used.

Insert Table 1

Police involvement. Of the 13 individuals who reported involvement with police during the study period, 10 individuals provided details of a combined total of 16 police incidents. Three of these individuals provided details concerning more than one incident with police; the total number of police incidents per individual ranged from one to three. Reasons for police involvement varied widely (see Table 2). In the majority of incidents ($n = 10, 62.5\%$), police assessed the situation and left without any further action. During one incident (6.3%) an individual was taken to the ED, and five incidents (31.3%) were noted as ‘other’ dispositions (e.g., someone other than the individual with ASD was taken to the ED or into police custody). In one incident, an individual was placed in handcuffs; no incidents resulted

in criminal charges. Overall, individuals indicated that police involvement increased their agitation during seven incidents (43.8%), had no effect in five incidents (31.3%), and had a calming effect in four incidents (25.0%).

Insert Table 2

Discussion

Findings from this study highlight the frequency of emergency service use of adults with ASD without ID. Presenting concerns and satisfaction with services varied and speak to the importance of general preparedness and widespread prevention efforts in the ASD community and among emergency service personnel.

ED Use

Several ED visits were precipitated by individuals indicating that they were a danger to themselves. Researchers have recently underscored the need for future work focused on understanding suicidality in ASD, as well as evidence-based prevention strategies (Cassidy & Rodgers, 2017). Overall, participants reported being somewhat dissatisfied with the care they received in the ED. Initial support has been found for research-based curriculum for clinicians on caring for individuals with ASD in the hospital environment (Carter et al., 2017); however, existing tools tend to focus on children and individuals with ID. The extent to which these efforts target adults with ASD without caregiver input is unknown. Important research to date has explored ways to help adults with ASD without ID prepare for routine and primary care procedures (e.g., Nicolaidis et al., 2016) and similar efforts are needed for emergency care.

Police Involvement

In contrast to past research focused on families of individuals with ASD (Tint et al., 2017), few police interactions in the current study were associated with psychiatric concerns. This finding may be an artifact of our sampling and self-report methods, however, the wide range of presenting concerns necessitating police contact in the current study remains informative. Police officers play a multitude of roles in the community and initial results report a lack of role-specific ASD training (Crane et al., 2016). Various means for individuals to assist police in identifying their ASD and individualized communication needs are available (e.g., identification cards, Debbaudt, 2006). However, Crane et al. (2016) found many adults with ASD were hesitant to disclose their diagnosis to police; future collaborative work with adults with ASD and police is needed to help inform resources geared towards promoting safe interactions.

Limitations

This study provided the first detailed account of emergency service use of adults with ASD without ID; however, it also had several limitations. Our data were reliant on self-report, including diagnosis of ASD without ID. Emergency service use, although collected at regular time points in an effort to reduce error, may be susceptible to recall bias. Satisfaction scores were based on a single item measure and may not have fully captured individuals' experiences. Our sample was comprised of a small cohort who identified primarily as Caucasian and reported relatively high neighborhood incomes. Women were also overrepresented in our sample relative to the expected male to female ratios prevalence in ASD (Loomes, Hull, & Mandy, 2017). As such, our findings may not generalize to the larger population of adults with ASD without ID and future work with larger representative samples is needed. Additionally, it will be important for future work to explore individuals' service satisfaction in a more comprehensive manner, including associated factors.

Conclusion

Given the frequent and heterogeneous emergency service experiences of adults with ASD without ID, it is imperative for future work to include individuals across a range of abilities to improve preventative efforts and care provision.

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Table 1. Emergency department visit presenting concerns ($n = 25$)

Presenting Concern	$n(\%)$ visits	Example
Harm to self	14(56.0)	Individual experienced suicidal ideations
Harm to others	2(8.0)	Individual engaged in destruction of property in the community
Required medication	1(4.0)	Individual required a prescription refill for psychiatric medication
Medical issue	8(32.0)	Individual experienced allergic contact dermatitis

Table 2. Police involvement presenting concerns ($n = 14$ incidents)¹

Presenting Concern	<i>n</i> incidents	Example
Breach of court order	4	Individual's spouse violated a custody arrangement
Care of other	4	Individual's neighbor was unwell
Psychiatric crisis	3	Individual was experiencing symptoms of mania
Miscellaneous	2	Individual was waiting for a tow truck
Victim of verbal aggression	1	Individual was verbally threatened by a passenger on public transportation

¹ 2 incidents were unable to be classified due to insufficient information