

Original Article

Improving the care of children with autism and related neurodevelopmental disorders in emergency department settings: Understanding the knowledge-to-practice continuum of emergency department providers

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ABSTRACT

Objectives: Emergency department (ED) healthcare providers (HCPs) frequently describe a lack of knowledge in caring for children with autism spectrum disorder (ASD) and related neurodevelopmental disorders (NDD). Our primary objective is to explore gaps in training and clinical exposure reported by ED HCPs caring for children with ASD/NDD.

Methods: A two-phase, mixed-methods cross-sectional study was conducted. In phase 1, an interprofessional sample of tertiary care paediatric ED HCPs (physicians, nurses, social workers, and child life specialists) were surveyed about their experiences and perceived gaps in managing children with ASD/NDD. These responses informed phase 2, where six semi-structured interviews were conducted. Interview transcripts were analyzed to determine themes around the discomfort of ED HCPs caring for children with ASD/NDD.

Results: The majority, 54/78 (69%) of eligible staff completed the survey. A minority (42.5%) of HCPs had mandatory training on ASD/NDD, and 80% would value continuing education. Some ED HCPs (41.2%) had previous personal or professional experiences with children with ASD/NDD that facilitated deeper empathy and awareness of system challenges. Interviews revealed four themes of ED HCP discomfort with this population: 1) added considerations of interacting with children and families with ASD/NDD; 2) the ED as a single touch point in complex and limited healthcare systems; 3) recognizing comfort in discomfort; and 4) the need to implement practical interventions to improve care.

Conclusions: ED HCPs are motivated to improve care for children with ASD/NDD. Alongside broader systems interventions, future educational interventions can narrow ED HCP gaps identified through this work.

Keywords: Autism spectrum disorder; Continuing education; Educational Needs Assessment; Emergency medicine; Paediatrics; Paediatric emergency medicine.

The prevalence of autism spectrum disorder (ASD) diagnoses is increasing (1). Between 2012 and 2021, the global prevalence of ASD rose from 62 to 100 per 10,000 children (1,2). Unfortunately, in systems hindered by delays in accessing primary care providers and specialists, this rising prevalence

translates into rising emergency department (ED) utilization for acute medical concerns and co-occurring issues related to ASD (3).

ASD is a neurodevelopmental disorder (NDD) where individuals experience various levels of social communication

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impairments, reliance on routine, and frequently have repetitive behaviours and restricted interests (4). These features can make navigating chaotic ED environments challenging for children with ASD/NDD. In addition to experiencing an acute illness, patients with ASD seen in EDs are exposed to high-sensory stimuli, unanticipated disruptions in their routines, and prolonged wait times (5). Adding to these difficulties, health-care providers (HCPs) often report a lack of knowledge when caring for individuals with ASD/NDD in EDs (6). These factors can escalate into aggressive/disruptive behaviours and poor interactions between families and HCPs (6).

To address these challenges, a number of studies have examined improving the care of children with ASD/NDD in ED settings. Previous studies suggest interventions targeting improved management of agitation, creating neurodiverse-friendly environments, and supporting patient/family communication (3,7). The present study specifically explores gaps in training and clinical exposure leading to ED HCP discomfort caring for children with ASD/NDD and potential education interventions that narrow these gaps and improve ED care of children with ASD/NDD (8).

METHODS

Design

We conducted a single-centre, two-phase, mixed-methods, cross-sectional, explanatory study. In phase 1, an interprofessional cohort of tertiary care paediatric ED HCPs was surveyed about their training experiences and perceived gaps in managing children with ASD/NDD. These responses informed phase 2, where interprofessional semi-structured interviews were conducted. Ethics approval was obtained through the Hamilton Integrated Research Ethics Board (HIREB#11394).

Study sample and inclusion/exclusion criteria

We recruited a convenience sample of HCPs from a large single-centre, Canadian tertiary paediatric ED with ~50,000 visits per year. This paediatric ED serves as the level-1 trauma centre and scheduled mental health facility for a region with ~2.5 million people. Eligible participants included actively employed, independently practicing physicians (MDs), registered social workers (SWs), registered nurses (RNs), and child life specialists (CLSs). Trainees were excluded. In phase 2, volunteer phase 1 participants completed semi-structured interviews. Initial participants included three MDs, two CLSs, and one SW. Additional RN and SW participants were purposefully approached and recruited by a study member (JL) to ensure the sample was representative of the ED setting.

Data collection

For phase 1, participants completed a 21-item survey exploring ED HCP background and perceived gaps in managing children with ASD/NDD (Supplementary Appendix 1). This survey was developed *a priori*, based on the understanding of literature from an unpublished scoping review completed by two team members (JL and MZ), and their direct experience working with children with ASD/NDD and in ED settings. This survey was piloted and refined with four volunteer ED MDs and RNs

for general readability and applicability prior to broader dissemination according to best practices (9). Survey data was electronically collected and managed using REDCap (Research Electronic Data Capture, Vanderbilt University, USA) hosted at McMaster University. Survey responses that authors felt required additional exploration were developed into standardized phase 2 questions regarding stories and memorable experiences with children with ASD/NDD; conceptualizing ED HCP 'comfort'; perceived enablers and barriers to quality care; and suggestions for education interventions (Supplementary Appendix 1). Interviews were conducted using a combination of videoconference (Zoom®) and in-person digital audio recordings. Phase 1 was completed between November 19, 2020 and January 12, 2021. Phase 2 began on January 26, 2021, with 60% of participants interviewed before March 2022. Unfortunately, the occurrence of the COVID-19 global pandemic disrupted data collection, with the final standardized interview completed on October 4, 2022.

Data analysis

Descriptive survey statistics were analyzed using Microsoft Excel® (Microsoft Corporation, Washington, Version 16.72). Recorded interviews were transcribed verbatim via a professional transcriptionist on Microsoft Word (Microsoft Corporation, Washington, USA, Version 16.72). Transcripts were independently analyzed using a qualitative, inductive reasoning, and grounded theory approach (10). All transcripts were analyzed by at least two members of the research team. One researcher (JN) analyzed all six transcripts, while other members analyzed two (JL), and three (MZ) transcripts, respectively. Representative transcript quotes of each theme were also independently identified by members of the research team. Team members maintained written journals while analyzing transcripts, and themes were determined by unanimous consensus.

RESULTS

Fifty-four of 78 (69%) eligible HCPs completed the survey, with 45 participants (83.3%) completing it entirely. Ten participants completed phase 2. Participant demographic data are shown in Table 1.

Phase 1: Survey

Fifty-six percent (30/54) HCPs had mandatory instruction in child development, with 67% (20/30) covering ASD/NDD. Free-text comments revealed: extensive child development and ASD/NDD training for CLSs (9/12, 75%) and limited exposure to developmental paediatrics for RNs and MDs in training (21/42, 50%).

Regarding the lived personal experiences of HCPs, 39% (21/54) of respondents reported knowing children with ASD/NDD outside work. These personal experiences impacted attitudes by increasing empathy and patience for challenges faced by families and perceived judgements/dismissals received at healthcare institutions; increasing awareness for early intervention; and being better attuned to the needs of children. Furthermore, 31% (17/54) of respondents had work experiences with children with ASD/NDD prior to their current ED employment including camp counseling (20%, 11/54),

Table 1. Participant demographics and information

	Phase 1 survey	Phase 2 interviews
Participant demographics (%)		
Physician (MD)	15 (29)	3 (30)
Registered Nurse (RN)	18 (35)	3 (30)
Child Life Specialist (CLS)	12 (24)	2 (20)
Registered Social Worker (RSW)	4 (8)	2 (20)
Registered Respiratory Therapist (RRT)	2 (4)	0 (0)
Total	51	10
Years in clinical practice (not including training) (%)		
0–5 years	13 (25)	1 (10)
6–10 years	22 (43)	5 (50)
11–15 years	7 (14)	2 (20)
>15 years	9 (18)	2 (20)

Survey responses regarding the training and personal lived experiences of ED HCPs are shown in [Table 2](#)

early childhood education (11%, 6), teaching (4%, 2), and research (4%, 2).

All survey participants were probed regarding their top five sources of discomfort when managing children with ASD/NDD from a pre-populated list ([Figure 1](#)).

Phase 2: Interviews

To accommodate schedules during the global coronavirus pandemic (COVID-19), participants were interviewed in groups of 1 to 3 based on their availability. Six semi-structured interviews were conducted yielding six transcripts. Three interviews were conducted with one participant (RN, SW, and MD).

Qualitative analysis revealed four themes regarding ED HCP discomfort. [Table 3](#) shows key sub-themes and corresponding representative quotes. Additional insightful transcript quotes are found in [Supplementary Appendix 2](#). Of note, for authenticity, data from quotes are presented without substitutions/edits. As such, language contained in quotes may not adhere to recommended guidelines in autism research (11). Language considerations will be important to address in future ED HCP educational interventions.

Theme 1: Added considerations of interacting with children and families with ASD/NDD.

HCPs report additional considerations when interacting with children with ASD/NDD. HCPs reported intent to engage caregivers (i.e., parents) as team members and experts on their children, but uncertainty in how to work with them most effectively as they typically have no pre-existing interactions with them. HCPs recognize the essential role of caregivers. In particular, the importance of this role is highlighted when caregivers are burnt out and unable to assist in ED care. In these cases, ED HCPs are forced to operate with incomplete information and feel less confident in their interactions.

HCPs recognized that the ED was not an ideal environment for children with ASD/NDD. Participants expressed the key roles of CLSs and sensory carts in inclusive and non-stimulating

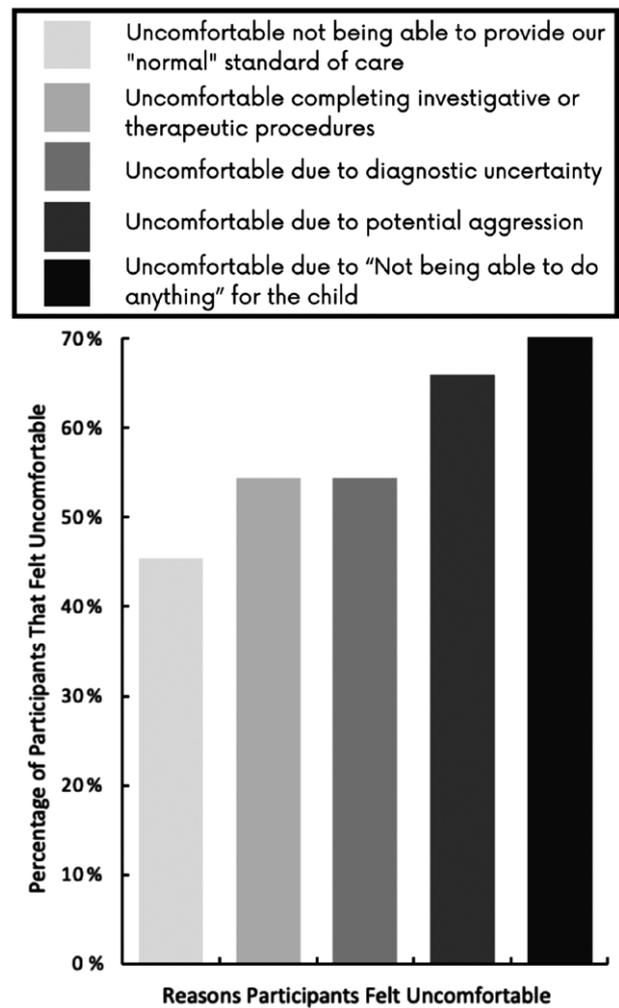


Figure 1. Top five ranking of factors contributing to participants feeling uncomfortable when managing children with ASD/NDD in emergency departments (n = 51)

environments for children, within existing spaces. While HCPs valued sensory rooms, they highlighted limitations affecting large architectural initiatives at individual provider levels.

Finally, HCPs were concerned about being injured by aggressive patients with ASD/NDD during routine ED interventions. These safety concerns increased along with patients' age and size. In particular, the combination of a predisposition of males with autism and a majority of female-identifying ED HCPs was a source of discomfort. Communication with aggressive non-verbal patients was an added challenge. To mitigate these concerns, chemical sedation was discussed as a last resort option.

Overarching all these additional considerations, participants noted the unique clinical pressure of EDs: busy clinical environments with limited time for individual encounters.

Theme 2: ED as a single touch point in complex and limited health-care systems.

HCPs frequently highlight gaps in knowledge and challenges in providing care to children with complex neurodevelopmental needs within a complex and limited healthcare system.

Table 2. ED HCP survey responses regarding training, lived experiences, comfort, and preferred educational interventions

Training experience survey items	Response	Number of respondents (%)	
“My training included mandatory instruction on child/youth development.” (n = 54)	Yes	30 (56) - Lecture 20 (37) - Course 12 (22) - Clinical Rotation 11 (20) - Workshop 5 (9) - Simulation 4 (7)	
	No	17 (31)	
	No response	7 (13)	
	(If yes to above) “Did this instruction include content on ASD/NDD?” (n = 30)	Yes	20 (67)
		No	5 (17)
Unsure		5 (17)	
“While you were training ... did you participate in any optional/elective instruction on child/youth development?” (n = 54)	Yes	17 (31) - Lecture 4 (7) - Course 9 (17) - Clinical Rotation 5 (9) - Workshop 2 (4) - Simulation 2 (4)	
	No	30 (56)	
	No response	7 (13)	
	Personal lived experiences survey items		
	“Do you know anyone with ASD/NDD outside of your career/practice?” (n = 54)	Yes	21 (39)
No		30 (56)	
No response		3 (6)	
“Prior to starting your current healthcare profession, did you have experience working with children with ASD/NDD (i.e., researcher, early childhood educator)?” (n = 54)	Yes	17 (31)	
	No	29 (54)	
	Unsure	1 (2)	
No response		6 (11)	
	Comfort with caring for children with ASD/NDD presentations		
“What is your comfort level in managing children with ASD/NDDs presenting with acute MEDICAL concerns to the ED (i.e. laceration repair, fever, abdominal pain, chest pain)?” (n = 54)	Extremely comfortable (Likert 7)	7 (13)	
	Somewhat comfortable	20 (37)	
	Minimally comfortable	5 (9)	
	Neither comfortable nor uncomfortable	7 (13)	
	Minimally comfortable	2 (4)	
	Somewhat uncomfortable	2 (4)	
	Extremely uncomfortable (Likert 1)	0	
	No response	11 (20)	
“What is your comfort level in managing children with ASD/NDDs presenting with acute BEHAVIOURAL concerns to the ED (i.e., nonspecific crying, disruptive behaviours, social distress)?” (n = 54)	Extremely comfortable (Likert 7)	7 (13)	
	Somewhat comfortable	16 (30)	
	Minimally comfortable	8 (15)	
	Neither comfortable nor uncomfortable	4 (7)	
	Minimally comfortable	4 (7)	
	Somewhat uncomfortable	4 (7)	
	Extremely uncomfortable (Likert 1)	1 (2)	
	No response	10 (19)	
Future educational interventions			
“Would continuing education/professional development activities focused on caring for children and youth with ASD/NDDs be valuable to you if offered?” (n = 54)	Yes	36 (67)	
	No	4 (7)	
	Unsure	5 (9)	
	No response	10 (19)	
“What educational method would you like these continuing education/professional developmental activities to use?” (select all that apply) (n = 54)	Lecture	24 (44)	
	Small group	33 (61)	
	Simulation	17 (31)	
	Other	2 (4)	

Table 3. Themes and demonstrative concepts from semi-structured interviews

Key sub-theme	Representative quote
Theme 1: Added considerations of interacting with children and families with ASD/NDD	
Navigating how to best treat caregivers as experts of their children	<i>"I think there are some things that we do okay with. I also feel the nature of work itself, there is always room for growth and opportunities where we can do things better. I think one of the things that we try to exercise is open communication with the parents, especially as they are the experts on the child and on what works for them. So, understanding okay what are your youth's triggers? What would be considered sensory overload for your child if they are in the emergency department? What are the cues that we should look out for? What are the behavioural techniques and tools that we can incorporate while they are in the emergency room as they are waiting to be seen by a physician or another staff? Or even in those interactions that they are having with the interdisciplinary team?" (Social Worker [SW] 2)</i>
Challenge of treating children with ASD when their caregivers/parents are burnt out	<i>"If they are burnt-out you may not get the richness of what's happening [and].... you don't get that fulsome history and start making management decisions that are based on incomplete knowledge... There is a bit of the feeling from some families who are there like you are never going to figure this out. The system has failed me repeatedly... When that happens it inevitably affects you as well. You feel a bit frustrated with the encounter, everyone is frustrated. The child isn't getting any help and they are continuing to cry or scream or look uncomfortable. It sets up a bad relationship." (SW 1)</i>
Mitigating suboptimal effects of the physical ED environment	<i>"...the architecture of the department in terms of being able to take someone for a walk, in a sort of safe way. And we know that things like sensory rooms are helpful, but we just don't have the space." (Physician 1)</i>
Concern of physical harm from aggressive patients	<i>"Sometimes I find our more aggressive older male patients... [they] need help to be held down in order to give the intranasal or intramuscular [medication]. I worry about that. I don't know how to do better ... because we need to hold them. Then I feel that is quite scary. If they can't communicate with us, what do we do when we need to keep ourselves safe? But we also have to do these investigations to find out what's wrong ... it doesn't feel good holding kids down to do that." (Child Life Specialist 1)</i>
Theme 2: ED as a single touch point in complex and limited healthcare systems	
Addressing behavioural and complex needs beyond the capacity of a single ED visit to address	<i>"The hardest thing is looking at the family who is desperate for help and knowing that we are sending them out the door and they are no further ahead. Knowing that they need resources, whether it's looking at [a residential] facility now because they just can't manage this at home. And then if we do know of a place where they go on a list or if there are resources available then that list is extremely long... So, what are they doing in the interim? Which I think is what causes the cycle of them [returning] back to the emerg... And they don't fall in the category of mental health. ... And so, they kind of fall in, like, the grey area... especially when it's a violent situation. ... And now we are saying you are going to go home with this child. And I have parents looking at me like, well, he is going to grab the steering wheel while I am driving home." (Nurse 1)</i>
Managing and supporting children that may be autistic but have no formal diagnosis	<i>"Sometimes, as a staff member you attend [to] a child in the interaction and ... the words are like no, you are not right. Like this child is not right, there is something wrong. And the parents sometimes are not aware at all... And I don't know if it's a little bit more of awareness around this or better access to resources and diagnoses, but the amount of kids with autism that we do see now is insane, where you think what is happening? Why are we seeing this many kids?" (SW 1)</i>
Advocating for children in an ED model of intermittent care with limited continuity	<i>"In terms of the folks falling through the cracks[...], what do I do as I wait? Because the system is the way it is. And I would love for there to be rapid access for families with barriers. But there isn't[...], What is the optimal plan in the meantime[...], because the system is almost built as if these people don't exist." (SW1)</i>
Positive and memorable patient interactions when continuity of care occurs in ED settings	<i>"I think what makes it memorable is because I have met her a couple of times and she's remembered me... We have been able to help or expedite them... We can enhance his care a little bit better... because I have a history with him. Which isn't a normal thing in the emergency department. We definitely see some of the same kids over and over again. But to actually have a little bit of our relationship with the parents, I find that really interesting." (CLS 1)</i>
Theme 3: Recognizing comfort in discomfort	
Communication barriers that impact the ability of HCPs to connect with their patients, compared to neurotypical patients	<i>"... In general, with neurotypical patients, even if they are 3 years old, I try and address things [to the] patient themselves. Because whether it's counseling or getting a history from them, at all ages kids can give you a ton of information. I really don't like having to look towards their parents. That is what I mean, where I don't have an opportunity to connect with the child... I think that there is a lot of therapy that comes from talk and from that interaction." (Physician 2)</i>

Table 3. Continued

Key sub-theme	Representative quote
Difficulty performing acute care procedures and interventions when ability to communicate with children with ASD is impaired	<i>"I would tell you that my experiences have been very similar where there is a patient who has needed interventions and because of their developmental status it is not always easy to get investigations as an outpatient. I have had a couple of different versions of this story. One version of this story is where they are in the paedics emerge. I have access to all of the paediatrics-specific resources in the emergency department. I have Child Life. I have nurses, rad techs and Child Life Specialists that are all attuned to the needs of the patient and the family. They can help to navigate that. I have also had similar experiences, though when they age out they no longer come to the Children's Hospital. I have the same patient at the General [Hospital], where I don't necessarily have Child Life, nurses who are used to working with children. Or techs that are used to doing CT scans on patients that may need some extra help and handholding in terms of doing the tests. So, you know, I think that the fact that I work in the Children's Hospital has helped in terms of trying to problem-solve that."</i> (Physician 1)
Comfort when developmentally appropriate communication is possible with the child with ASD	<i>"When I feel like I can direct something towards my patient as opposed to just constantly looking towards the parents, that's when I know that I am in my sweet spot... when I feel like I can reliably get information from that patient, that is when I know that my comfort has come to a level and that I can sort of address them like any other child in my practice."</i> (Physician 2)
Theme 4: Need to implement practical educational interventions	
Collaboration with other departments/ services to develop and deliver focused content to ED HCPs	<i>"Having actual proven strategies that work with children with autism and maybe doing training or having somebody come in and teach us ways of going about working with children with autism, I think would be super beneficial..."</i> (Nurse 3)
Collaboration with patients and families to design and deliver educational interventions	<i>"It would be good [to have] continuing education or a focus group of patients who have been here and experienced certain things and get their feedback on how they think that went... Is there something that we could do differently, or was there a certain technique that we used or the way that we [can] approach the situation that is most beneficial?"</i> (Nurse 1)

HCPs highlighted several situations where parents sought ED care as a last resort. Examples of these cases typically included behaviourally escalating children with increasing aggression who are physically harming caregivers and themselves. Many of these children had complex behavioural needs beyond the capacity of a single ED visit or acute medical hospitalization to effectively address.

HCPs also highlighted the challenges of encountering children with characteristic ASD/NDD features impacting their quality of life, but no formal diagnosis. The system is not set up to accommodate children with ASD/NDD, especially when undiagnosed. Many participants also stated it is unfortunate that if you do connect and establish rapport with a child, you may never see them again. For these patients, HCPs repeatedly advocate to better understand pathways to help receive a proper diagnosis and treatment. Participants suggested that if there was a way to fast-track an appointment to connect these patients to specialists, that could provide long-term care. Episodic ED is challenging and translates into patients being lost to follow-up.

Theme 3: Recognizing comfort in discomfort.

Multiple HCPs identified having to provide the best possible acute care despite their own personal discomforts interacting with children with ASD/NDD. Almost all HCPs identified communication barriers as contributors to their discomfort. This discomfort was compounded in acute ED situations requiring measures that may be interpreted as more invasive (i.e., bloodwork, imaging, intravenous medications). In contrast, when verbal connection is possible, HCPs felt 'deeper' connections with children.

Theme 4: Need to implement practical educational interventions.

All participants expressed the need for additional/on-going training in the care of children with ASD/NDD. HCPs expressed that more experiential/hands-on learning experiences would be beneficial. HCPs advocated that this training occur in collaboration with paediatric development and rehabilitation specialists as well as with patients and families. This approach can help HCPs understand referral pathways and the resources available to children and their families once they leave the ED. HCPs recognized the uniqueness of each individual child and the importance of adapting approaches and drawing from previous interactions. Many participants identified that the majority of cases when caring for children with ASD/NDD involved the parent intervening and providing suggestions on methods to calm their child that have proven to work in the past. One practical intervention recommended by a participant was the use of 'cheat sheets'. These sheets are quick reference guides created by caregivers detailing individualized tips on how to connect and communicate with their children.

DISCUSSION

To our knowledge, this is the first study to explore, in-depth, the education and training gaps of front-line ED HCPs caring for children with ASD/NDD. Previous studies interviewing ED MDs and RNs focused on barriers and enablers to effective care (3). By including ED-specific contextual considerations and the need for additional training, our study provides examples of how clinicians, including CLSs and SWs, navigate uncertainty and discomfort in complex

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