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ORIGINAL PAPER

Perspectives of Health Care Providers Regarding Emergency Department Care of Children and Youth with Autism Spectrum Disorder

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Abstract This study aimed to characterize the perspectives of health professionals who care for children with autism spectrum disorder (ASD) in the emergency department (ED) and to determine what strategies could optimize care. Ten physicians and twelve nurses were interviewed individually. Questions related to experiences, processes, clinical decision-making and outcomes of children with ASD recently seen in the ED. Interviews were audio recorded, transcribed, and analyzed using a qualitative framework. Participants identified factors that facilitated effective care, including communication strategies, parental involvement and teamwork. Barriers identified included child characteristics, the ED environment, and competing demands. Recommendations included additional staff training and stakeholder engagement. However, making accommodations was often described as being at odds with how the ED functioned, with implications for future service planning.

Keywords Autism · Emergency care · Health care provider · Pediatrics · Grounded theory

Introduction

It is increasingly recognized that the service needs of individuals with autism spectrum disorder (ASD) relate not only to diagnostic features such as social communication deficits, but also to comorbidities which further impact on personal development and family life (Coury 2010). Chronic health problems such as sleep disorders, gastrointestinal problems and epilepsy occur at higher rates in children with ASD compared to their peers, and may exacerbate behavioral symptoms and negatively impact on the child and family's ability to optimally engage in interventions (Richdale et al. 2014). Mental health challenges such as anxiety and mood disorders can further complicate behavioral presentation and response to treatment (Mazzone et al. 2013). Thus, addressing physical health and mental health concerns is essential to care management, and ultimately, to optimizing quality of life for individuals with ASD.

Management of medical conditions may be complicated by behavioral features of ASD. Communication barriers, difficulties with social engagement, and reactivity to changes in routine and to sensations such as touch, sound, light and odor can interfere with assessment and treatment. This may be particularly relevant in acute care settings, with the need for repeated physical examinations and invasive medical procedures (Souders et al. 2002; Seid

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et al. 1997; Van Der Walt and Moran 2001). A recent qualitative study by our group highlighted persistent gaps between the needs of this patient population and current care practices during hospitalization (Muskat et al. 2015). Many parents reported negative and even traumatic experiences when individual needs of hospitalized children with ASD were not recognized, resulting in escalation of disruptive behavior and negative interactions between parents and staff (Muskat et al. 2015). This study, as well as a recent parent survey, highlight the importance of considering the child's communication needs and patterns of sensory reactivity when planning in-patient care (Muskat et al. 2015; Kopecky et al. 2013). Pratt et al. 2012, using a quality improvement framework, reported that the use of a pre-admission checklist based on these needs, and assigning a staff member to ensure follow-through, improved the child and family's experience in hospital.

The emergency department (ED) is potentially an even more challenging environment compared to inpatient wards for patients with ASD, given the acuity of concerns, intensity of the sensory environment (Giarelli et al. 2014; Vaz 2010) and competing demands and pressures on medical staff (McGonigle et al. 2014a). Children with ASD are more likely to visit the ED than children without ASD, with higher expenditures per visit (Wu et al. 2014). However, there is relatively little known about the experiences of individuals with ASD and their caregivers while accessing ED services, and even less about the perspectives of health care providers working with the population in the ED environment. A case study by Quirantes 2009 identified the benefits of multidisciplinary team involvement in providing medical care to a child with ASD and how limiting waiting time can help reduce distress and avoid behavioral dysregulation. Similarly, Owley 2004 presented two vignettes of health care team members working with a child with ASD, generating helpful insights including how a child's lack of communication skills can inhibit reporting pain and distress which in turn, may lead to anxiety and/or behavioral outbursts. Chun and Berrios-Candelaria 2012 also presented two case scenarios and helpful suggestions regarding ED care of patients with ASD. Accordingly, there have been recent efforts to develop training materials for ED personnel. Informed by a state-wide needs survey, McGonigle et al. 2014a developed and evaluated training workshops for emergency medical technicians, paramedics and ED nursing staff that focused on increasing general knowledge and dispelling myths about patients with ASD, raising awareness about common medical issues that may lead to ED visit, and providing guidance to assessment and management within the ED. Participants demonstrated increased knowledge and increased self-reported comfort on pre-post-testing, although training was provided at off-site conferences and the evaluation did not extend to practice change within work settings. McGonigle et al. 2014b also outlined an approach to ASD management within the ED, with a focus on patients presenting in acute behavioral crises. However, a recent chart review of patients with ASD presenting to a tertiary care pediatric ED indicated that only 10 % were primarily related to behavioral concerns, with the majority presenting due to acute injury, neurological symptoms, gastrointestinal concerns and other health concerns similar to those seen in non-autistic patients (e.g., fever, cough/congestion) (Cohen-Silver et al. 2014). Thus, while effective behavioral crisis management is essential due to inherent risks to patients and their families, and also potential concerns for the safety of other patients and health care providers, strategies are needed to manage the broader range of health needs of patients with ASD presenting to the ED.

Optimal care of children with ASD in the ED may benefit from further attention to the perspectives of front-line health care providers (HCPs) including physicians and nursing staff. Although these front-line staff are often regarded has lacking in basic knowledge regarding patients with ASD (McGonigle et al. 2014a), their direct experience with these patients in the ED context and understanding of processes of care in the ED may offer further insights. While the perspectives of children with ASD and their families are also critical, HCPs could provide a unique window into opportunities as well as potential barriers to effective care that may be specific to the ED context. To our knowledge, there are no published quality improvement initiatives that focus on management of patients with ASD in the ED setting, so understanding the experiences of HCPs working in that context could help tailor such efforts. To that end we addressed two specific questions in this study:

1. What challenges do HCPs in the ED face in providing care to children and youth with ASD?
2. What strategies are needed to optimize ED care for children and youth with ASD?

Methods

Participants and Setting

The study took place in two EDs based at high-acuity pediatric health sciences centres. Physicians and nurses at each site were informed of the study at a monthly ED staff meeting, and were eligible to participate if they had provided ED care to a child with ASD (under age 18 years). Participants were recruited around the time of the care encounter, and interviewed within 4 months. The study was linked to a parallel study of parents' perspectives in the context of ED care delivery to their child with ASD, so in some cases, participating HCPs were nominated by parents.

Each participating ED was supported by social work who were available for consultation if the family were in crisis, as well as child life services, although these were limited to 8 h/day on weekdays at one site (‘ED-1’), and 12 h daily at the second site (‘ED-2’). Mental health services were also accessible at each site. At ED-1, mental health nurses were available 15 h/day on weekdays and 8 h/day on weekends, generally reserved for ED patients with a primary mental health complaint. Child psychiatrists were also available for consultation. At ED-2, the child psychiatry consultation service was consulted for patients with a mental health complaint, and provided child and youth workers for patients in need of monitoring. At each site, behavioral emergencies were managed in partnership between ED HCPs, mental health services and if necessary, security services, and acute care beds were sometimes utilized in extreme situations.

Design

This study utilized a grounded theory design, premised on an established approach successfully implemented by our team in a complementary study examining hospital care to children with ASD (Muskat et al. 2015). Grounded theory offers a compendium of methods to systematically elicit theoretical constructs and processes of a phenomenon under study, and is particularly useful when these elements are not well understood (Patton 2002; Corbin and Strauss 2014). The *theory* that is created tends to offer greater depth of understanding, and methodically is inductively derived from, or *grounded* in, careful observation of the phenomena being studied (Patton 2002). A naturalistic inquiry approach (Keating 2000; Lincoln and Guba 1985) was used to develop an in-depth understanding about interactions, processes, practices and systems related to ED care for young persons with ASD (Erlandson et al. 1993) from the perspective of front line HCPs.

Following informed consent, HCPs completed an individual interview conducted by a graduate-level research assistant who was supervised by lead investigators at each site. Based on a semi-structured interview guide using open-ended questions (see Appendix 1), HCP participants were invited to discuss their experiences of providing care to the child with ASD during a particular ED encounter, with a focus on what factors challenged and facilitated effective care. Participants were also asked to comment on strategies or recommendations based on the current or past experiences that might improve ED care for children with ASD and their families. The interview guide included questions related to experiences, processes, relationships, decision-making and outcomes associated with ED services for young persons with ASD. Interviews were digitally recorded to ensure accuracy in data capture.

Clinical descriptive data was obtained from parents regarding patients with ASD that were seen during the care encounters that formed the basis of the current study. Measures were selected that could be feasibly completed by parents during a brief follow-up. Severity of ASD symptoms was measured using the social reciprocity scale (SRS), a parent-report questionnaire covering social domains impacted by ASD including social awareness, social information processing, reciprocal communication, social anxiety or avoidance, and autistic preoccupations and traits (Constantino and Gruber 2005). Higher total scores indicate greater severity of social impairment; with T scores (population mean = 50, 1 SD = 10) of 60–75 consistent with mild-moderate symptoms of ASD (although some children with ASD may have scores between 50 and 65), and scores above 76, considered to be severe. The child behavior checklist (CBCL), a norm-referenced parent-report measure, was used to evaluate comorbid internalizing and externalizing symptoms (Achenbach 1991). Severity of symptoms indexed by the CBCL is also reported as T scores. General adaptive behavior, including daily living, socialization and communication skills (and adaptive behavioral composite), was assessed by semi-structured interview using the Vineland Adaptive Behavior Scales, second edition (VABS II; Sparrow et al. 2005), and reported as standard scores. The VABS II also yields subscale scores, including for expressive and receptive language, which will be reported as age equivalents for descriptive information regarding individual children referred to in the exemplar quotes in Tables 2 and 3. Each of these measures has excellent psychometric properties as applied to children with ASD.

Analytic Approach

Qualitative analysis of verbatim transcripts of interviews was supported by N-Vivo 10 (ref), a computer-based data management and analysis software package. Analyses comprised sequential layers of coding, categorizing, conceptualizing and theorizing, achieved by the following methods: open coding, axial coding and selective coding (Corbin and Strauss 2014). Each of these analytic processes is described below.

(a) *Open coding* Interview transcripts and field notes were analyzed by identifying, categorizing, and describing common processes found throughout the data (e.g., breaking down the data into discrete segments that reflect particular meanings). Common processes were labeled and assembled together through constant comparison to form broad categories.

(b) *Axial coding* Analysis was focused on which types of common processes, conditions and consequences were relevant to the ED care system relative to children and youth with ASD. Axial coding reassembled the data that had been broken down during open coding. Categories and concepts developed during open coding were analyzed as to whether they related to: (1) processes in ED care; (2) causal conditions that led to the occurrence of these processes; (3) intervening conditions by which the processes were influenced; (4) interactional strategies participants used to address the processes; and (5) any outcomes of the actions and interactions of participants or other stakeholders.

(c) *Selective coding* Processes were integrated and refined to form a larger theoretical schema. The process involved the determination of a core phenomenon that unified the decisions/processes identified by study participants. During selective coding, decisions were made regarding data saturation.

Established means of ensuring methodological rigor relative to this research paradigm were followed (Patton 2002; Lincoln and Guba 1985; Sandelowski 1986). The research team met regularly to discuss emergent codes to ensure a coherent and consistent analytic process. Key principles of qualitative rigor and methodological diligence based on the established notion of trustworthiness (Lincoln and Guba 1985) which consists of *credibility* (confidence of findings based on checks for accuracy in the interpretation of data), *transferability* (providing clarity of the context in which findings were achieved and the relevance of study findings for other environments), *dependability* (demonstration of due diligence in data capture and analysis), *confirmability* (confirmation of findings via sufficient demonstration of text quotes), *authenticity* (genuine engagement and benefit for participants) (Erlandson et al. 1993) and *fit* (relevance of findings for understanding the phenomenon in question) (Corbin and Strauss 2014), were upheld. These aims were demonstrated via multiple steps associated with each aim: careful ‘memoing’ of the research process, peer debriefing in which we reviewed emergent findings with clinicians for their ‘fit’ with clinical experience, prolonged engagement which was demonstrated by extensive team member expertise and experience in this clinical area as well as extensive time in the field for data collection, referential adequacy whereby key findings were verified alongside actual transcript data. Researcher biases were examined through the use of *reflexivity* and *bracketing*, established qualitative research processes involving reflection and articulation of experiences and perceptions related to the research topic.

Through this analytic process, we developed an integrated description of HCPs experiences providing care to children with ASD in the ED. These findings, emerging from this qualitative research design, do not enumerate the frequency of factors as would a quantitative study, but rather offer a portrait of identified processes and experiences and how these inter-relate in everyday practice in the ED.

Descriptive data regarding ASD symptom severity, emotional-behavioral symptoms and adaptive functioning of children seen by participating HCPs was summarized on a group basis to provide additional clinical context. As well, information about presenting medical complaints was also summarized, and reported for specific children linked to exemplar quotes highlighted in the Tables.

Results

A total of 22 ED HCPs were interviewed about their experiences and perspectives related to providing a child with ASD during a recent ED visit including 10 physicians and 12 nurses. These individuals reported a wide range of ED experience, from less than a year to over a decade, with the largest group having worked in the ED for 5–10 years. Experience with patients with ASD also varied greatly, with some reporting working with these individuals quite commonly while others reported it to be a rare occurrence. In all but one case (in which the child with ASD was accompanied by a group home worker), at least one parent entered the ED with their child. Some children were brought in by paramedics and met by parents in the ED. Children that were seen by participating HCPs ranged in age from 3 to 17 years of age. Of 22 families whose children were seen by participating HCPs, 13 completed the SRS, CBSL and VABS II at a follow-up in-person or telephone interview within 4 weeks of the ED visit; others declined. Children were characterized across a range of ASD symptom severity (as indexed by the Social Responsiveness Scale; mean T score = 82.3, SD = 10.4; range 53–90) and adaptive functioning (as indexed by the Vineland Adaptive Behavioural Scale–II composite; mean standard score = 74.8, SD = 22.5, range 39–116). As a group, children the children with ASD also had elevated levels of internalizing (mean T score = 61.1, SD = 9.7) and externalizing (mean T score = 59.1, SD = 9.3), only one child presented to the ED primarily for behavioral concerns. A range of presenting concerns was reported to the HCPs including aggression (n = 1), foreign body aspiration ($n = 1$), seizures and other neurological concerns ($n = 2$), bowel issues/dehydration ($n = 5$), respiratory concerns ($n = 6$), musculoskeletal concerns including injuries ($n = 6$) and wound care ($n = 1$). HCPs were interviewed an average of 1.3 months following the ED visit (see Table 1 for details). Themes discussed in the interviews are described below.

Factors Contributing to Challenges in ED Care Provision

HCPs discussed several factors that contributed to challenging care delivery, which are listed in Table 2, along with illustrative quotes. The main factors identified were:

Characteristics of the Child

Participants identified more challenges working with older children due to what they described as youths' larger physical size and periodically increased aggressiveness. Extreme symptom severity and limited verbal communication level were also perceived by some as a challenge to care provision, particularly for children who also exhibited aggressive behavior.

ED is not the Optimal Environment for a Child with ASD

Providers often described the ED as 'a tough place for any child with ASD', full of potential sensory triggers that caused distress and made care provision more difficult. The noise and 'hustle and bustle' of the department was also raised as a concern, as was sensitivity to touch, which made many examinations and procedures difficult. As well, the ED was described as a place that optimally functioned when issues were dealt with quickly and efficiently and by following procedures that were often discordant with the child's preference for their own routines and familiar materials. Additionally, the ED was described as an unfamiliar setting for children, potentially resulting in anxiety. Along with this, participants noted that often the child was seen by multiple unfamiliar HCPs during their visit, sometimes simultaneously, which can be overwhelming.

Challenge of Achieving Ideal Care of Children with ASD due to Competing Demands in the ED

Although participating HCPs related that optimizing the environment, especially sensory aspects, would provide a more positive experience for the child, many observed that it was often challenging to provide the necessary accommodations because of resource (time, staffing, etc.) constraints and the 'need to balance' other patient needs. Some participants expressed that the ED was not conducive to care for children with ASD for these reasons. HCPs also acknowledged that patients' and families' experience and quality of care sometimes depended on which ED staff were involved, due to variability of knowledge and clinical skills pertaining to ASD. Even when a HCP was recognized as having special expertise in working with children with ASD (or conversely, an approach that was perceived as poorly suited to such children), it was often not possible to assign patients accordingly. Fewer HCPs knowledgeable in ASD were reportedly available at night, particularly those in specialist roles such as Child Life. As well, participating HCPs reported that children with ASD had difficulty coping with lengthy waiting times, and that this further compromised the child's emotional state. However, there was often limited flexibility to accommodate children with ASD sooner when the ED was busy with higher acuity patients.

Factors that Facilitated Effective ED Care Provision

In contrast to the barriers described above, HCPs discussed strategies in working with families with a child with ASD that led to effective care. These are listed in Table 3, along with illustrative quotes, and described below:

Communication Strategies

HCPs described taking a variety of approaches to attempt to communicate with patients effectively. For instance, taking more time than usual to communicate with the child was suggested. Paying attention to non-verbal cues was described as especially important if children had limited verbal ability. Assessing anxiety and stress levels while engaging the child were also deemed important.

Involving Parents

Parents and other caregivers were described as essential to successful care delivery in the ED, as they were true 'experts' about their children. Parents were seen as having unique knowledge about their child's likes and dislikes, and what strategies would help calm their child. Participating HCPs reported that caregivers often brought in their child's favorite things, which was helpful especially while waiting and during procedures. Speaking with caregivers enlightened HCPs with regards to what accommodations might be beneficial for their child. HCPs reported relying on parents not only for their knowledge but also, in some instances, as active participants in their child's care (for example, in administering medications) as they were able to work with or speak to their child in the best way for that particular child.

Table 1 Participant characteristics

	n (%)
Study site	
ED-1	14 (64 %)
ED-2	8 (36 %)
Health care provider type	
Physician	10 (45 %)
Registered nurse	12 (56 %)
Health care provider age	
20–30 years	5 (23 %)
30–40 years	11 (50 %)
40–50 years	2 (9 %)
Not reported	4 (18 %)
Health care provider gender	
Male	4 (18 %)
Female	18 (82 %)
Health care provider time in position	
<1 years	1 (5 %)
1–5 years	7 (31 %)
5–10 years	9 (41 %)
>10 years	1 (5 %)
Not reported	4 (18 %)

A Calming Environment

HCPs spoke of the importance of controlling the sensory environment of the ED as much as possible to minimize distress for the child. Private and quiet hospital space was identified as a helpful element; for example, HCPs at both sites reported that they took advantage of private patient rooms for their patients with ASD, when available. Participants also noted that as dedicated pediatric facilities, their EDs ware designed to be welcoming and 'kid-oriented' (e.g., with respect to decor), which they felt also helped put children with ASD at ease. Participants also described that moving slowly through procedures gave children a chance to 'warm up' to procedures (for example, being gentler or not being as 'hands-on' as you normally might) also helped calm their patients with ASD. Using distraction techniques was also described as helpful, including using TVs, toys, and video games to occupy children and alleviate anxiety. It was also suggested by HCPs that sedation techniques be considered for this population, including for procedures where sedation may not typically be used (e.g., examining the ears to remove foreign bodies, stitches in an older child), due to heightened pain responses and anxiety due to difficulty interpreting sensory cues.

Training and Teamwork

Some but not all HCPs shared that their training had prepared them to work with this population. However, many HCPs reported that they drew from past experience, rather than their training, to inform their approach to care of patients with ASD. Collaboration across disciplines was described as beneficial, and it was deemed important to welcome input from various members of the care team (including the parent). Non-traditional members of the ED care team were also highly valued by participants. For example, Child Life specialists were identified by multiple HCPs as being very helpful, providing distraction for the children, respite for caregivers, and helping to defuse challenging situations. Social workers were described as helpful in mediating complex medical situations, and helping the family navigate the hospital and community systems. Several participants mentioned the contributions of ED volunteers, who were able to procure requested items for caregivers, provide respite while the caregiver had to leave, and provide general assistance.

Suggestions to Improve Future ED Care for Children and Youth with ASD

Most participating HCPs provided suggestions for changes to improve the care of children with ASD within the ED, although some felt that change was not required.

Additional Training

Many HCPs reported that they themselves, or their colleagues, desired or needed more training in working with patients with ASD. Suggested topics for education included: approaches in working with this population (e.g., how to communicate), needs and triggers and best how to address these and effectively collaborate with families. As well, participants suggested additional training for residents and students, and for themselves, with an emphasis on available resources and practical applications of research findings. The method of training HCPs and other ED staff was also discussed, with participants suggesting involving caregivers or front line HCPs who worked with children with ASD in other settings, using visual aids, and delivering information in brief sessions (e.g., rounds, lunchtime seminars) with case examples and practical advice, as opposed to lengthy didactic explanations.

Partnering with Experts

HCPs suggested that experts on ASD, including caregivers, should be consulted in order to identify how to provide the best care. For example, it was suggested that the local

Table 2 Health care provider perspectives: challenges in caring for children with ASD in the Emergency Department

Theme	Illustrative quotes	Patient characteristics				
		Age (years)	VABS-II expr lang level (mo.)	VABS-II rec lang level (mo.)	CBCL Intern. T-score	CBCL Extern. T-score
Characteristics of the child influence ease of care	"…he was like a 16 or 17 year-old male who was like, grown man… he was very strong, you could tell that the dad was like struggling to contain him."	16	15	34	58	59
	"…he was very nonverbal…he was very distant from me, like scared of me, so he just sat on the bed and I interacted with his mom and dad…"	3	N/A	N/A	N/A	N/A
ED is not the optimal environment for a child with ASD	"…A lot of those machines, they're on, there's so many machines, high pitched squeals, not good lighting, people talking, lots of people milling about, walking by. It's just everything that you would not want potentially as an individual with autism would be there."					
	"…that child was out in the waiting room for quite a long time and it was during the middle of a very busy shift so lots of children, lots of sound, the TV, there were various illnesses, probably coughing going on in there and constant flow of people going in and out of the doors, so he didn't actually come to my attention until he really started to kick up a fuss, and then by then we could hear the screaming through the double doors."	5	N/A	N/A	N/A	N/A
Challenge of achieving ideal care of children with ASD due to competing demands in the ED	"…if it's really crazy busy, and I just can't, or I don't have the same time or effort to devote that I might have on a quiet day, then sometimes it's hard."					
	"…we had a patient the other day, that like for whatever reason just bonded with one particular nurse, and she spent a lot of time in the room de-escalating him, because he just bonded with her, that that worked really well. But then that takes away from the rest of her assignments, so then we have to balance that out…"					

autism specialty clinic could be further engaged to answer ED HCP questions regarding optimal care of children with ASD. Another suggested that a "life plan" be created for individuals that transferred across all service professionals with whom they interacted in order to keep track of services that a patient received. Specialized staff who could work with this population, or who other staff could turn to for advice, were desired by some HCPs.

Process Changes

Some HCPs desired a way for children with ASD to receive faster service and be triaged quicker in an effort to curb anxiety from the waiting room. Some HCPs described a strategy to "expedite" care to children with ASD by at least offering a private room so as to avoid a long time in the waiting area, although this did not mean that the child would necessarily be assessed sooner than based on their acuity level. Other participants felt that triage decisions, even those related to moving a child from the waiting area to an ED assessment room, should not be based on an ASD diagnosis. One participant reported that one-to-one nursing could be very helpful in establishing rapport with patients, but added that this may be difficult to accomplish given resource constraints. Some participants desired more time flexibility when caring for patients with ASD to establish rapport with the child and parents, and to get feedback from parents on how to approach caring for their child, and

Table 3 Health care provider perspectives: factors that facilitated effective care to children with ASD in the Emergency Department

Theme	Illustrative quotes	Patient characteristics				
		Age (years)	VABS-II expr lang level (mo.)	VABS-II rec lang level (mo.)	CBCL Intern. T-score	CBCL Extern. T-score
Effective communication strategies	"…definitely the physical exam was no issue, that was super easy to do with her. But the communication verbally was a little bit challenging and asking simple questions and non-directing questions were definitely important."	8	79	90	74	69
	"Over the years we have done a bit of trial and error, and we try to be very gentle with them, try to approach them in a very graduated, implemental fashion so that there is maximum cooperation from their side."					
	"Take some time and explain what I'm doing to them, and what's going to happen so that they kind of have a sense of what's going to happen and they maybe have a sense of control over some of the things that are happening."					
Involving parents	"…I really respected the dad's involvement. I took every conscious measure to make sure the dad was involved in all levels of my interaction with the child."	10	78	29	63	51
	"…Mom's presence made a lot of difference, and she could kind of comfort him, and help him relax, and explain to him the way he understood the best…"	13	39	26	63	55
	"…(the patient) was quite reserved so I think she was a little too scared so I had to get Dad to pretty much do all the stuff for me. Like you know give all the medications and all that because it was difficult to, like she was a little too scared and hesitant to cooperate."	9	N/A	N/A	N/A	N/A
A calming environment	"…we shut the lights off, we closed the door, we opened the curtains so that we could see what was going on in the room for safety reasons, but we tried to allow him some time to calm down and get familiar with his circumstances."	12	100	60	70	58
	"…, he paced around the room a little bit and I just said hi to him and almost ignored him just letting him get used to my presence in the room. So it's different from the typical interaction where you walk in, make eye contact with the child, establish a rapport immediately. I gave him some space and time as best as I thought I was doing. Then he actually was quite cooperative for the most part with the exam."	9	52	66	48	66
Training and teamwork	"I do think we graduate from university without the skills to deal with these children. I had next to no pediatric training whatsoever in university and even just coming in here taking courses…that helped. You learn a little bit more about just some of the fundamentals about dealing with children's special needs, but I think as time goes by you get more experience to help deal with them a little bit better."					
	"I'm lucky because I'm partnered with a bunch of clinicians, we have multi-disciplinary teams, so there's a wealth of experience. So I think that's our strength. And our strength is that we have partners at [the hospital] and partners in primary care, and some of what I've described is from what I've learned from other people, from my own observations from what my colleagues are also describing to me. So I guess it's the strength in numbers and the variety of players."					

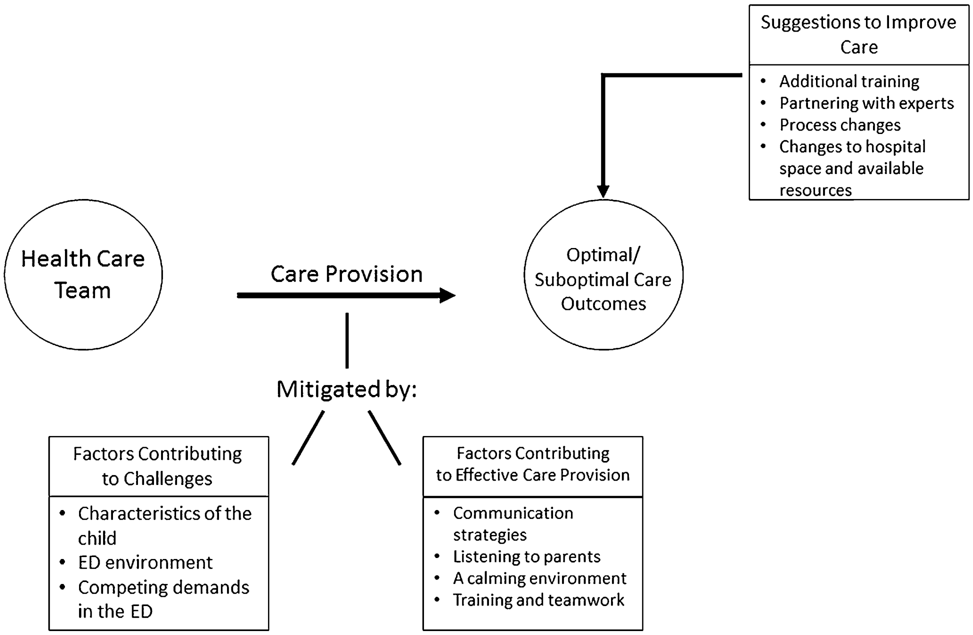

Fig. 1 Relationship of Themes

felt that this would help things go more smoothly and ultimately speed up the process by engaging the child's cooperation.

Changes to Hospital Space and Available Resources

Many participants suggested changes to the hospital environment to address sensory concerns, including the option of private rooms that were in a quiet area and where the lights could be dimmed. Distraction tools were often brought up as a helpful tool in working with this population. Many participating HCPs suggested that more distraction tools be readily available in the ED to use with this population, such as music devices or iPads.

In summary, these emergent elements associated with ED care for children with ASD have implications on and considerations for the quality and process of service delivery, as noted in Fig. 1. Participants offered important information for theorizing factors or elements that purportedly lead to experiences of care that ranged from suboptimal to exemplary. Based on the perspectives of HCPs, child and family experience is mitigated by factors that can challenge care (e.g., characteristics of the child, ED environment, competing demands in the ED). Conversely, family experience may be optimized through strategies that foster effective care including communication strategies, listening to parents, a calming environment, training and teamwork. This range of factors advance areas for practice change such as available resources, recommendations for additional training, partnering with experts, process-based changes related to pathways of healthcare execution in the ED, and helping families transition from within the ED to in-patient hospital space.

Discussion

Participants described several challenges faced by children and youth with ASD seeking emergency medical care. In many cases, these challenges were viewed as related to the physical environment, processes and health care practices within in their EDs, as the ED is designed to efficiently address the health care needs of the patient population as a whole, but often is poorly set up for the unique needs of children with ASD. However, these providers also described several strategies they employed to improve the care of their patents with ASD, and identified priorities for additional changes to both the ED environment and process of care. There were four broad issues that emerged as particularly critical, which when suboptimal, were viewed to negatively impact on the care experience of patients with ASD, but yet when addressed, could substantially improve quality of care. These included (1) the parent-health care provider partnership; (2) the sensory environment; (3) flexibility to accommodate to the individual needs of children with ASD; and (4) capacity with regards to ASD-relevant knowledge and clinical skills within the ED team via training and links to a broader network of professionals.

The importance of acknowledging parents as experts regarding their children has been reported in a number of health care contexts, from early detection (Zwaigenbaum et al. 2009) to recognition of medical comorbidities (Coury 2010) to optimal management during hospitalization (Muskat et al. 2015; Sakai et al. 2014). Participants in this study recognized that parents have a unique understanding of their child's preferences and aversions as well as their preferred modes of communication (and level of understanding), and thus, provide invaluable guidance to HCPs in how to engage with the child. Participants emphasized the importance of respecting parents and inviting them to provide input throughout the ED encounter, but also noted that time pressures and the acuity of the child's medical needs can sometimes interfere with this process. Pratt et al. 2012 reported a quality improvement initiative aimed at optimizing hospital admission for children with ASD that included a parent 'checklist' that asks parents about their child's behavioral triggers, responses to the sensory environment and communication needs (Pratt et al. 2012). Such a checklist might facilitate communication between parents and medical staff within the ED setting as well, although further research on how such information exchange contributes to building trust and therapeutic alliance may be equally essential.

Study participants almost universally identified managing the sensory environment as essential to effective care of children with ASD in the ED. The lights, sounds and smells within the ED easily trigger behavioral outbursts and exacerbate difficulties providing care, and yet, these problems could be avoided using relatively straightforward strategies such as accessing a quiet room with lights that dim. A recent study by Giarelli et al. 2014 confirmed that several locations within a typical ED, including waiting areas, hallways and treatment rooms, are characterized by extreme light intensity and sound levels. Two case studies (Vaz 2010; Quirantes 2009) and a qualitative study of the experiences of children with ASD during hospitalization[7] also emphasize the importance of managing the sensory environment. Although ED policy and triage systems may preclude 'expediting' the care of children with ASD to reduce waiting times, participants offered the potential solution of establishing areas within the ED where sensory input could be more easily monitored and controlled, which might make waiting more tolerable. However, participants described that sensory challenges also occur in the context of care delivery (e.g., response to touch), so effective management requires ongoing attention and sensitivity to this issue as well.

Individuals interviewed in this study observed that children with ASD could benefit from a flexible and individualized approach, but this was often at odds with how the ED typically functions, with the necessity of balancing the needs of the individual with the overarching goal of providing efficient emergency care to a large and diverse patient population. Standard operating procedures often precluded assigning nursing staff recognized as having special sensitivity and expertise in working with patients with ASD. Participants also reported that although accommodations were possible, this was often at the discretion of the individual staff member assigned to the patient. For example, in addition to managing the sensory environment, adopting the child's preferred method of communication (including use of augmentatives) would also optimize information exchange and care delivery, but it was not clear to what extent this was occurring. This suggests that efforts to increase awareness of the needs of children with ASD among ED HCPs (McGonigle et al. 2014a) are more likely to translate into meaningful practice change if accompanied by changes in policies and procedures (for instance, HCP assignment flexible to patient characteristics and needs). Participants indicated that while there was awareness that children with ASD benefited from approaches such as avoiding sensory triggers, the degree to which these accommodations were implemented was highly variable. Process changes, with support from higher levels of management, were felt to be essential. Application of quality improvement techniques could provide a formal structure to facilitate more focused and effective partnerships between frontline clinicians and administrative leadership aimed at implementing specific practice changes to address challenges identified in the current study. Such techniques have been effective in promoting better communication and overall care experience in the hospital ward setting for children with ASD (Pratt et al. 2012). Another consideration is how to optimize the medical management of children with ASD in the community; for example, establishing the option of urgent office-based consultation in the child's 'medical home' by a HCP who knows the child and their needs (Hyman and Johnson 2012) would provide an alternative to an ED visit for non-emergent concerns.

Finally, although the providers who were interviewed generally viewed themselves as aware of challenges associated with caring for children with ASD and approaches that facilitated more effective care, most indicated that they would benefit from further training opportunities. A next step in our research is to further investigate the preferences of ED HCPs regarding how such training should be delivered (and by whom). As well, participants valued input from other professional disciplines such as Child Life and Social Work, consistent with previous published recommendations (Chun and Berrios-Candelaria 2012) and felt that children with ASD often benefited from their involvement. Utilization of Child Life programs has previously been implemented in pediatric EDs to alleviate stress and support children and families (Krebel et al. 1996), although benefits experienced by children with exceptionalities such as ASD have not been specifically evaluated. Of course, implementation of child life and other supports may require investment of new resources, often in short supply, which many participants reported as a barrier to system and practice change.

This study had a number of methodological strengths, including sample size (in the context of a qualitative design), and the involvement of two sites to maximize diversity among participating HCPs, patients with ASD and ED care contexts. That said, both sites were affiliated with academic pediatric centres, which were likely to include more access to expertise and resources than might be available at other EDs, particularly those without a dedicated pediatric service. There were additional limitations that should be acknowledged as well. First, health care providers involved in less positive interactions with children with ASD (and their parents) may have been less likely to participate, and thus, the interviews may not have fully captured the range of challenges experienced in the ED. As well, a more comprehensive understanding of ED experiences would be achieved by comparing and contrasting the perspectives of HCPs with those of parents as well as children and youth with ASD. We are currently in the process of preparing a companion paper based on these informants. Finally, although some HCPs commented on the experience of caring for children being brought to the ED for severe behavioral concerns such as aggression, a fuller range of mental health emergencies was not represented; most children were being seen due to physical health concerns.

Conclusion

Physicians and nurses who participated in this study identified challenges associated with ASD (e.g., sensory reactivity, communication challenges) that can complicate management of health concerns in the ED, and potentially helpful strategies such as engaging parents as experts and modifying their clinical approach and the care environment based on the needs of individual children. However, they also acknowledged that adopting a flexible, child-centered approach was sometimes at odds with how the ED typically functions, and that time and resource constraints sometimes took precedence. Additional training and the involvement of an extended team to provide further support were recommended. Ongoing work with families, health care providers and decision makers including administrative leaders will help inform the process of ensuring that the goals of quality care of children with ASD and of sound ED department management can be achieved together.

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