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Improving the Emergency Department Journey for Children with Autism

Lisa Dann[1], **Peter Tormey**[1]*
and Orla Flanagan[1,2]

1 Faculty of Education, Department of Paediatrics, University Hospital of Galway, Ireland
2 Brothers of Charity, Galway, Ireland

***Corresponding author:** Peter Tormey

petertormey@rcsi.ie

Faculty of Education, Department of Paediatrics, University Hospital of Galway, Ireland.

Tel: +353 91 524 222

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Abstract

Introduction: Children with autism are frequently seen in the Emergency Department (ED). This can be an extremely distressing experience for them and many EDs are ill-prepared to manage these children.

Objectives: The objective of this study is to obtain parental feedback and utilise it to improve the management of children with autism in ED.

Methods: Parental questionnaires were distributed by post to parents of children with ASD. The voluntary and anonymous nature of the questionnaires was explained.

Results: 124/370 (33%) parental questionnaires were returned providing comprehensive feedback and suggestions for improvement.

Intervention: Education and autism awareness sessions were arranged for Pediatric and ED staff based on parental feedback.

Conclusion: The Emergency Department is a stressful environment for everyone but this is particularly true for those with autism. Simple measures can be instituted to improve patient and parental experience. Autism awareness is vital amongst healthcare staff to ensure a smooth and efficient journey for children with autism.

Keywords: Autism; Emergency department; Paediatrics

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Introduction

Autism Spectrum Disorder (ASD) is a chronic, neuro-developmental disorder that comprises significant impairments in social communication, as well as restricted, repetitive patterns of behaviour [1].

Children with ASD are frequently seen in the ED. It is estimated that 1.5% of Irish children have ASD [2]. It is thought the true figure is even higher as this doesn't account for undiagnosed children or children who are not currently engaged with services [2]. Internationally, the prevalence of ASD varies between studies. Baxter [3] performed a systematic review, estimating a global prevalence of 7.6 cases per 1000 children.

There is an increased acknowledgement that the ED presents a particularly difficult environment for individuals with ASD [4]. Children with ASD frequently have hypersensitivity to sounds, lighting, touch and transition [4], all of which are commonplace in ED. This hypersensitivity frequently manifests as behaviour that can be challenging. Children with ASD can present with uncommon presentations (e.g. catatonia, self-injurious behaviour) or atypical presentations of common conditions (e.g. abdominal pain, dental pain) [5].

Extreme anxiety experienced by children with ASD in new environments and situations, such as the ED, often manifest as difficult behaviour which can prove challenging for parents and hospital staff [6]. It is our duty of care to alleviate as much of this anxiety as possible. There have been several simple methods instituted in the literature which have been shown to improve patient and parental experience and to assist healthcare staff. Some of these include the availability of an ASD passport (including methods of communication), sensory toys, dimming lights and noise cancelling head phones.

- Children with ASD can be difficult to assess and manage in ED
- Autism awareness and the implementation of simple measures in the ED can improve both the patient and staff experience and result in improved outcomes.

What this study adds

- This study provides a parental perspective on improving the ED for children with ASD.
- This study provides a framework for EDs to improve autism awareness and the management of children with ASD.

Objectives

The objective of this study is to obtain feedback from parents of children with autism on recent ED visits and to seek recommendations for improvement. The information gathered will be used to affect change in our ED and improve the ED experience for these children. We also hope to promote autism awareness in the ED internationally.

Research Methodology

Study design

This study is a prospective, questionnaire-based quality improvement initiative.

Setting

This study took place in a University Teaching Hospital. The hospital has a General ED which treats adults and children. The paediatric ED cares for 16,500 children (0-16 years old) annually. There are no dedicated paediatric ED doctors; patients with a medical issue are seen directly by the in-house paediatric team and children with trauma or a surgical issue are seen by the adult ED staff. The nursing staff covering the paediatric ED consists of paediatric-trained nurses and general nurses.

Participants

The questionnaire was sent to parents of children with ASD, selected from the caseload of our Neurodevelopment Team.

Questionnaires

The questionnaires consisted of tick boxes options, likert scales and free text options. A study information leaflet was included which provided a description of the study and explained that participation was voluntary and anonymous.

Data storage and analysis

No identifiable staff or patient information was recorded. The data was stored on a password protected computer. Only the study investigators had access to the computer. The data was coded, stored and analysed in Microsoft Excel.

Results

124/370 (33.5%) questionnaires were returned. There were 75 male patients and 49 female. The age range was from 19 months to 21 years, with a median age of child of 9.7 years.

The median duration since the child's last ED presentation was 1.5 years (IQR 6months to 3 years) with an average number of attendances in the last 2 years of 2 attendances. Over a third of children had not attended the ED in the last 2 years (n=47/37.9%). The most common reasons for ED attendance were: seizures (27.0%), fevers (18.0%), vomiting/diarrhoea (18.0%) and various injuries (15.4%). The remainder attended for a wide variety of reasons from appendicitis to nasal foreign bodies.

Parents were asked to rate the various stages of a journey through the emergency department in terms of level of stress. They ranked this on a Likert scale with 5 being the most stressful and 1 being the least. The mean scores awarded are displayed in **Table 1.**

Parents were also asked about their interaction with medical staff. On average 2 doctors were seen but this ranged hugely from 1-6 doctors. 55.6% of parents felt the doctor understood their child's needs. 29.0% of parents felt the doctor was rushed when their child was being seen. 60.5% of parents were not asked about the best way to communicate with their child. Parents felt their child was not included in the consultation in 49.2% of cases. Sedation was used in 10.4% of cases where phlebotomy was required.

Free text sections were also available where the parents could discuss the best and worst parts about attending the ED. These were divided into common themes to facilitate analysis. Common themes for the best and worst parts of the ED journey can be seen in **Table 2.**

Parents were also asked to make suggestions for improvements. These suggestions included:

1. Have history on file to avoid repeating it
2. Prioritise patients with ASD to avoid prolong waiting times
3. Liaison nurse in ED with training in ASD
4. Fast tract system for reception, triage and physician review
5. Consider use of sedation for bloods
6. Try avoid admission if possible
7. Use of a patient passport, including: past medical history,

Table 1: Mean scores rating stressfulness of different aspects of ED journey.

Area/Procedure	Mean Likert score (1-5, 5 being most stressful)
Reception	2.25
Triage	2.5
Waiting room	3.9
Waiting in treatment area	3.6
Doctor's history	2.9
Doctor's exam	3.1
Phlebotomy	3.7
Radiography	2.8
Decision to admit	3.4
Waiting for transfer to ward	3.5

Table 2: Themes for the best and worst part of the ED journey.

Negative Themes	N= (%)
Waiting for too long	32 (25.8%)
Waiting room being too noisy/loud	23 (18.54%)
Inappropriate waiting room/bathroom facilities	21 (16.9%)
Difficulty occupying child while waiting	13 (10.4%)
Not knowing the duration of wait times	4 (3.2%)
Positive Themes	**N= (%)**
Staff- kind/helpful/attentive	45 (36%)
Being seen quickly	18 (14.5%)
Being facilitated to wait in separate room/area	5 (4%)

medications, things that scare them and successful methods of communication

Discussion

Children with ASD can find the ED very stressful. The sensory overload is frequently overwhelming. This can manifest as challenging behaviour rendering clinical assessment difficult. As healthcare providers we have a duty to be aware of these difficulties and to do what we can to ease the stress and streamline their ED visit. This study highlights areas that patients with ASD find most stressful and provides practical tips to help minimise these difficulties. Parents know their children best and by taking on board the advice they have provided we can improve the ED journey for these patients.

Based on our findings we arranged 1 hour education sessions, for ED and paediatric staff. The sessions involved providing background information about ASD to promote awareness and increased understanding. We then provided a summary of the negative and postivie comments received from parents and provided practical tips on how best to manage these children in future.

Limitations

The response rate for our questionnaire was 33.5% which is suboptimal. Furthermore, parents who had particularly positive or negative experiences in the ED may be more likely to respond, which may introduce bias. 37.9% of our respondents had not been to ED in the previous 2 years and based their experience on visits prior to this. This may have led to inaccurate recollection of events. The qualitative nature of parts of the questionnaire can lead to inconsistent themes and results that are difficult to compare and to extrapolate to different populations.

Conclusion

The ED is a stressful environment for everyone but this is particularly true for children with ASD. Simple measures can be instituted to improve patient and parental experience. Autism awareness is vital amongst healthcare staff to ensure a smooth and efficient journey for children with autism Awareness sessions should be held regularly for all healthcare staff.

Ethical Approval

Ethical approval was granted by the Clinical Research Ethics Committee, University Hospital of Galway. (Reference no. C.A 2096).

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