



AUTISM

ANDREA BRAMMER

Reasonable adjustments, the law and the imaging department.

Children with Autism spectrum disorder (ASD) have difficulty making sense of their environment as well as relating and communicating with other people¹ with research suggesting a current prevalence of one in 68² and a ratio of male to females of 7:1³. Additionally, patients with ASD are known to have associated comorbidities, such as sleep, gastro-intestinal, endocrine, neurological, ophthalmological, ENT, dermatology problems and epilepsy^{4,5}, resulting in increased healthcare needs and a related financial load on the NHS⁶.

THE IMAGING DEPARTMENT

It therefore follows that patients with ASD are increasingly referred for diagnostic imaging, although it could be argued that this cohort of patients were already doing so regardless of a definitive diagnosis of ASD⁷. There is little evidence documenting the number of patients with ASD referred for radiology imaging, although a study in Spain found that 18% of patients with ASD accessed radiology services⁸. However, the author questions if all radiology modalities were included in this study and therefore the proportion could be higher.

Cooperation of the patient is paramount in order to obtain diagnostic images in each modality of the imaging department, requiring them to follow instructions and tolerate procedures on intimidating equipment. However, how often do we stop to consider the patient's journey to our department? Patients with ASD may have difficulty leaving their home; find deviating from their daily routine

particularly distressing; struggle with car journeys and new routes and may not be able to decipher hospital signposting systems due to difficulty interpreting written words⁸.

There is therefore a great risk that patients with ASD may be extremely distressed and presenting with challenging behaviour by the time we meet them in our department. We then frequently expect them to change their clothes, which they may find painful⁹ before we expect them to cooperate with verbal instructions which they struggle to make sense of^{10,11}. Additionally, older children may be expected to undergo their imaging procedure on their own, which adds to their distress due to separation anxiety from their parent/carer¹².

Radiographers' actions may also exacerbate challenging behaviour of patients with ASD¹² due to:

- Fear of dealing with challenging behaviour.
- Lack of understanding of patient's needs.
- 'Controlling parent' behaviour.
- Lack of care.

Ultimately, if children with ASD are unable to tolerate or cooperate for their imaging procedures, their options are:

- They do not have the diagnostic test¹³.
- Immobilisation is used for the imaging procedure¹⁴.
- Referral for sedation or general anaesthetic (chemical restraint)^{15,16}.
- Hospital play specialists (HPS) utilised to enable cooperation¹⁷.

THE LAW

Children, young people and adults with ASD are eligible for the same standard of healthcare that the rest of the population is entitled to¹⁸⁻²⁰; this is reinforced by Autism-Europe²¹. Failure to provide reasonable adjustments for patients with ASD equates to discrimination¹⁸ and healthcare providers need to ensure that patients with ASD receive the care that they are entitled to, in order to ensure that the patient does not experience a delayed or missed diagnosis.

The Autism Act 2009 stipulates that members of the public sector working with adults with ASD must have training in autism awareness¹⁸.

In 2014, the UK Government launched the Adult Autism Strategy²² which is legal guidance on the provision for support for adults with ASD from the public sector. Crucially, this strategy is not applicable for children and the National Autistic Society report that the Government will help children in 'other ways'²³.

It is concerning that both these pieces of legislation do not apply to children and it is difficult to explain this rationale. There has been some debate around the assumption that staff working with children already have the knowledge and skills to work with these patients, although research suggests the contrary⁸.

REASONABLE ADJUSTMENTS/PERSON-CENTRED NEEDS ASSESSMENTS

Reasonable adjustments are actions made to overcome barriers to accessing healthcare. In order to identify what reasonable adjustments are required for each individual, the barriers that prevent them from achieving their goal must be recognised. A person-centred needs assessment is a suitable tool for identifying such. The history of health needs assessments date back to the 1990s and they have developed into a 'person-centred'²⁴ evidence based tool for identifying strategies (reasonable adjustments) to overcome barriers to accessing healthcare²⁵.

In order to overcome the challenges described above, the Royal Manchester Children's Hospital:

- Utilises a hospital play specialist (HPS) in the specialist modalities of MR, CT and nuclear medicine, as well as in the general x-ray area when required.
- Complete person-centred needs assessments (PCNA) with the HPS to identify reasonable adjustments that need to be made in order for the patient to successfully have their imaging procedure.
- Has identified a radiographer as an 'Autism Champion' so that staff have a known person to approach if they need assistance.
- Has a programme of 'autism awareness' training to improve staff knowledge and confidence when dealing with this cohort of patients.
- Provides a range of communication tools that they can employ.
- Develops bespoke pathways for patients with ASD.
- Uses pictorial journeys and social stories.
- Has ratified 'autism standards' to ensure the minimum standard of care that patients with ASD can expect when they visit the hospital.

The work that the Royal Manchester Children's Hospital radiology department does in order to support children with ASD was recognised in 2014, when they successfully won the 'Unite the Union Award for Working Together' at the Advancing Healthcare Awards.

RESEARCH

In 2015, the author undertook a research project for the purpose of completing an MSc in leadership in health and social care. A literature review identified that, despite recommendations, there was no formal research evaluating the impact of reasonable adjustments made for healthcare experiences for patients with ASD^{4,26} and to this end the following research was conducted, evaluating the use of person-centred needs assessments for children with ASD visiting the imaging department at the hospital.

Semi-structured interviews were conducted with parents of

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five children with ASD, to evaluate their experience of visiting the imaging department for an MR scan, with the aim of questioning assumptions made by healthcare professionals as to what reasonable adjustments for children with ASD were required. Semi-structured interviews were chosen as the means of data collection due to the qualitative, in-depth exploration of the participants' views and opinions of the services provided at the Royal Manchester Children's Hospital, exploring the relationship between their experiences²⁷. The study was limited to six families due to the time constraints of the study and judgemental sampling (families chosen from a specific cohort of patients²⁸) was used to invite parents/carers to take part in the study, although only five parents responded to the invitation. Literature suggests that rather than the small number of participants in the study being a limitation, it may provide a wealth of data and more participants may result in saturation of the data²⁸.

Parents were recruited to the study rather than the children with ASD, due to potential problems gaining consent from the children if they lack capacity to understand the information supplied to them and possible communication problems¹⁰. Informed consent was obtained from the participants prior to the study, in order to avoid recruiting vulnerable people. This inclusion criterion for the study is reflective of similar patient groups across the United Kingdom and improves the generalisability of the study.

Bias was reduced by ensuring voluntary participation, obtaining informed consent, informing the participants they could withdraw from the study at any time, the use of open questions and member checking.

Ethical approval was obtained from the University of Bolton and Central Manchester University NHS Foundation Trust, and the interviews were conducted at the parents' choice of location upon response to an invitation to take part in the research.

The interviews were digitally recorded and Colaizzi's seven step approach was used to analyse the data. The seven step approach for analysing data is a recognised method for data analysis of semi-structured interviews²⁹ using thematic analysis and the seven steps are:

1. Transcription of interview.
2. Documentation of significant statements.
3. Formulation of meanings from significant statements.
4. Formulated meanings arranged into themes.
5. Thorough description of the findings drawn through synthesis of the themes.
6. Description of the fundamental structure of the phenomenon.
7. Validation of the findings by member checking with the participants.

The children with ASD ranged from 8-19 years of age and had ASD diagnoses of Atypical Rett syndrome, Atypical autism and autism with severe learning difficulties. The children had attended radiology at RMCH between 2012 and January 2015.

RESULTS

All participants were asked how their experience was in the imaging department and all participants described satisfaction with their last visit to radiology, with one family describing a very poor experience with the anaesthetic team in 2012.

"Last April was okay, actually. In fact, when I say okay, it was 100% better than that first experience."

"I think they've been really good with her..."

"It was okay because she had to sleep, you know, because she can't do it, yet. It was okay."

"I was really pleased with it...there was no pressure for him to perform."



All families confirmed that they were contacted by the HPS prior to their appointment in radiology to identify reasonable adjustments that were required for their visit.

“Her (HPS) preparation was done by telephone.”

“The hospital play specialist would come with us.”

“A hospital play specialist called me and asked what sort of toys or anything she wants.”

“We practiced the MRI scan with the hospital play specialist.”

“We had everything in place for what we were doing.”

Three of the five families reported their child becoming distressed in busy waiting areas.

“Noise when it’s busy and the waiting rooms; she starts hitting everybody and sometimes screaming”.

“We’ll either be in the corridor walking up and down where there are no people or we’ll go somewhere else, where there are no people”.

The interviewees were asked what they thought about the individual needs assessments and a majority of the respondents were happy with the person-centred needs assessment and felt it had a positive effect on their visit to the imaging department. They felt that the person undertaking the assessment was listening to them and appreciating their children’s needs; families reported that whilst procedures had to be followed, it was a case of ‘how do we make these work for you and your child’ and the department was prepared for them in advance of their visit.

All of the families confirmed that the reasonable adjustments that were made were satisfactory, although two families accepted their child being second on the GA list when they had identified that this would be difficult for them.

All of the families interviewed reported that they found the hospital play specialist department useful.

The research also identified the multiple teams that were involved with their children (please see figure 1) and problems that they experienced with inappropriate environment, for example fluorescent lights caused a problem for one patient and the geneticist conducted the consultation in the dark. All patients were under the care of the anaesthetic team for the purpose of their MR scan.

Two families described teams outside radiology who did not listen to them or their concerns; one family reported that whilst the anaesthetic team were considering how to anaesthetise their daughter, a large man quickly forced an anaesthetic mask over her face and pinned her down, and another felt that they had to ‘fight’ to be taken seriously by the gastroenterologist. Both families remain deeply upset by these experiences. One family described a member of the neurophysiology team showing a lack of empathy, telling the child to ‘stop being so silly’.

The research illustrated that short waiting times, the environment and compassion of the radiographers and HPSs, all helped their child’s appointment run smoothly as the parents felt that they had been listened to and understood:

“Nice waiting room and easily accessible toilet.”

“Not being rushed.”

“You don’t have to wait long (in the imaging department).”

“The hospital play specialist was interested and just very understanding and very caring, and you knew that she wanted to get it right.”

“The hospital play specialist was excellent; her link between us and others was really good.”

The research confirmed that person-centred needs assessments were completed, and reasonable adjustments made for children with ASD attending radiology for an MR scan, resulting in a positive experience for the child, ensuring they receive the healthcare that they are entitled to.

The research also confirmed that staff in the imaging department at the Royal Manchester Children’s Hospital have an understanding of ASD and are able to apply their knowledge and skills to ensure a positive experience for the child with ASD and their family/carers.

Additionally, this research confirmed that multidisciplinary working and sharing information between teams is imperative to ensuring reasonable adjustments are made for individual patients.

The author is concerned about the negative experiences that were reported by the interviewees and has begun to share this data with the teams involved.

CONCLUSION

This article has discussed the main characteristics of ASD, associated comorbidities, prevalence and the relevance of these to the imaging department. This demonstrates that it is certain that all radiographers and imaging departments will experience patients with ASD throughout their clinical career and radiology staff need to consider their approach and care of this cohort of patients.

Additionally, healthcare staff are obliged to identify and make reasonable adjustments for patients with ASD according to several acts of parliament¹⁸⁻²³ and failure to do so equates to discrimination.

This article continued to discuss reasonable adjustments and described initiatives that have been implemented at the Royal Manchester Children’s Hospital.

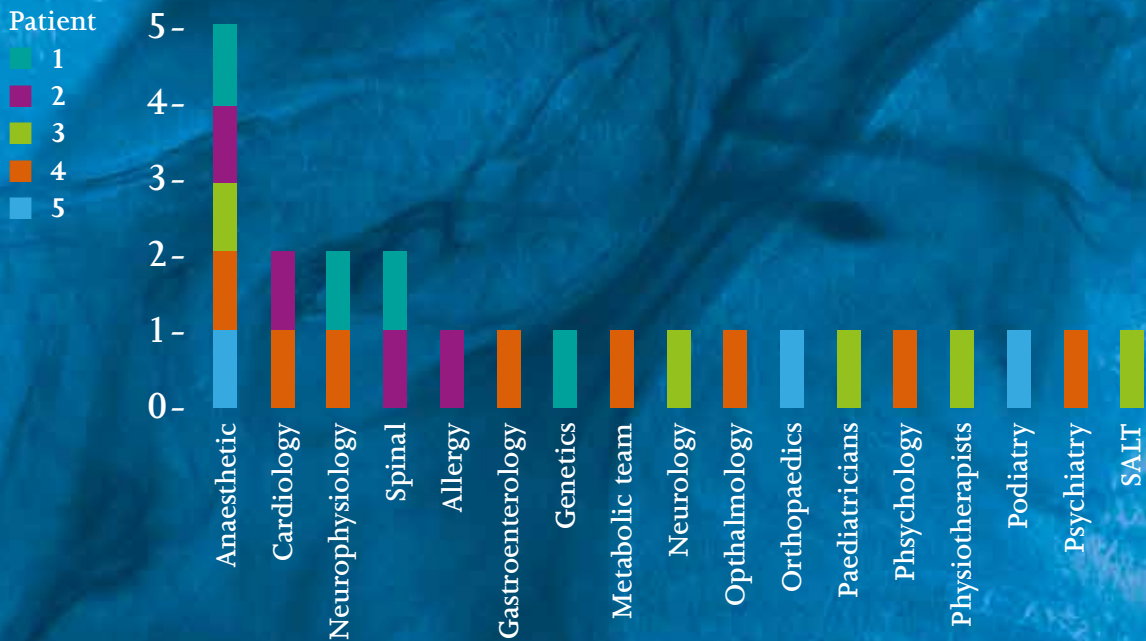
Subsequent qualitative research was conducted evaluating the impact of personal needs assessments in the imaging department finding that the use of person-centred needs assessments, prior to visiting the department, successfully identified any reasonable adjustments that were required and also made effective use of the available resources, reducing cancelled appointments and unnecessary general anaesthesia. Additional information identified problems that the families had experienced in other departments in the hospital and this will be addressed locally.

Whilst the imaging department has a dedicated hospital play specialist, this person is only available during office hours and weekdays and this is mirrored throughout the Hospital; the author suggests that the completion of person-centred needs assessments should be completed on admission to the hospital for children with ASD by the person admitting them.

This research can be generalised and applied to most imaging departments across the UK and could be used to help develop local systems to identify and implement reasonable adjustments for children with ASD. Reasonable adjustments can be as simple as ‘widget’ cards and iPads to aid communication with patients with ASD and do not necessarily require a formal structure to implement small changes.

ABOUT THE AUTHOR

Andrea Brammer MSc, DCR(R), committee member of the Association of Paediatric Radiographers, Radiology Directorate Risk Manager/Clinical Effectiveness Lead at Central Manchester University NHS Foundation Trust, Paediatric Radiographer at the Royal Manchester Children’s Hospital.



▲ Figure 1: Specialist teams involved with patients with Autism.

RECOMMENDATIONS

The author recommends that all imaging departments should:

- Incorporate autism awareness training into their training programme. The author suggests that this should be provided by the training departments of NHS Trusts, as it is recommended that all public sector staff working with patients with ASD should have this training²². Autism awareness training should help staff to recognise and understand autism and help them to adapt their communication and behaviour when dealing with this cohort of patients³⁰.
- Develop a process of identifying and providing reasonable adjustments for children with ASD. This may be in conjunction with existing hospital play specialist departments however, it is acknowledged that not all hospitals have this facility available to them and the author suggests that it may be necessary to discuss this issue with hospital clinical effectiveness teams in order to identify the most appropriate method for developing a consistent approach. Further, the author suggests that all children with ASD should be assessed on admission to hospital as to any required reasonable adjustments and it may be a more appropriate role for nurses on wards and in emergency departments to undertake, as hospital play specialists are rarely available 'out of hours'.
- Exploration of the use of communication tools such as 'widget' and iPads to improve communication with children with ASD.

REFERENCES

<http://www.sor.org//learning/library-publications/itp>
 This article has been prepared following local guidance relating to the use of patient data and medical images.
 To comment on this article, please write to editorial@itpmagazine.co.uk



HOW TO USE THIS ARTICLE FOR CPD

- Can you describe the main characteristic behaviours of a child with autism?
- What challenges might these behaviours present to:
 - a. The child and their family in getting to your imaging department?
 - b. Your imaging department obtaining diagnostic images?
- What reasonable adjustments does your imaging department provide for children/patients with ASD?
 - a. How are the reasonable adjustments identified?
- What are the legal implications of not making reasonable adjustments for children with ASD?
- What improvements can you suggest to provide reasonable adjustments for children with ASD in your imaging department?

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