



## Exploring the experiences of parents of Autistic children when attending the diagnostic imaging department for an X-ray examination



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### ABSTRACT

**Introduction:** Autism is a neuro-developmental condition which affects the social-emotional skills, behaviour, language, communication skills and flexibility of thoughts of an individual and their sensory processing. This can result in Autistic service users finding it difficult to navigate current healthcare provision and cope with the unpredictable environment. This paper explores the experiences of parents of Autistic children when attending the diagnostic imaging department for an X-ray examination.

**Methods:** A cross sectional, mixed methods approach was adopted and the initial phase consisting of an online survey for parents to complete is the subject of this paper. The quantitative data was analysed using descriptive statistics and cross comparison between questions was also completed. Thematic analysis was taken to analyse the data from the two open questions at the end of the survey.

**Results:** The online survey results are presented in this paper under four key themes; waiting times and environment, forms of communication, lack of understanding of staff regarding Autism and preparation for the X-ray examination.

**Conclusion:** The overall rating of the parents' experience whilst in the X-ray/diagnostic imaging department was positive, however there are several areas which received low scores which need further attention. These were waiting areas, waiting times, staff development and patient preparation.

**Implications for practice:** The development of more inclusive waiting areas is needed, more effective lines of communication between staff to expedite the patient journey where possible, staff development of both radiographers and also support staff and the review of design of more accessible and inclusive patient information.

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### Introduction

Autism is a spectrum disorder, part of the Autism Spectrum Disorder (ASD). It is a neuro-developmental condition which affects the social-emotional skills, behaviour, language, communication skills and flexibility of thoughts of an individual and their sensory processing.<sup>1</sup> Additionally, individuals with Autism may have

difficulties with their fine and gross motor coordination and organisational skills.<sup>2</sup> This results in people with ASD being more likely to suffer ill health because their difficulties can cause them to be unable to predict the consequences of their actions which may result in dangerous situations.<sup>3</sup>

Autism affects over 700,000 people in the UK, which is more than 1 in 100 and is three times more prevalent in males than females.<sup>2</sup> People with ASD have greater health care needs compared with the rest of the population; they are more prone to develop chronic health problems, mental health illness, physical and sensory impairments.<sup>4</sup>

This paper shares the survey data from the first stage of a mixed methods study which explored the experiences of Autistic children

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and their parents when attending a diagnostic imaging department for an X-ray examination. As such it will focus on the parent's perspective of their child's experience whilst visiting the imaging department. The qualitative data from the second stage of the study will form the basis of a following paper.

## Literature review

Current literature has identified a range of issues which both Autistic individuals and their carers experience in a healthcare setting. Bultas and McMillan<sup>5</sup> found that carers of children with ASD experienced healthcare professionals who demonstrated a lack of confidence, knowledge and skills in managing Autistic behaviours. The environment is highlighted as one of the main triggers to behavioural issues and it was found that there are several improvements which could be made by healthcare professionals by undertaking an initial assessment with the patient. This would allow healthcare professionals to: identify the most effective form of communication to use; decide on what type of motive reinforcement to adopt; make appropriate changes to the environment to reduce hypersensitivity; allow the use of personal items such as blankets, toys, earphones etc., and the removal of certain objects from the vicinity.<sup>6</sup> The issue of environment was also highlighted as a major source of stress for Autistic individuals in medical settings in America. Specific causes were identified as being busy/overcrowded waiting rooms, suboptimal lighting (too bright or too dark) and noise levels. The stimuli caused by these conditions can often trigger anxiety and behavioural issues in Autistic children.<sup>7–9</sup>

In their work, Scarpinato et al.,<sup>10</sup> suggest a transcript of questions is used by practitioners during the initial assessment of Autistic children when hospitalised. This set of questions allows a needs assessment to be carried out which can then be shared with other healthcare professionals involved in the child's care. This ensures that the care given to the child is individually tailored to the unique needs of each child and their carers and improves their overall experience. This is an approach that could be adopted by a diagnostic imaging department and may well improve the experience of Autistic children when attending for an imaging procedure.

A study undertaken in Canada across two healthcare providers in Canadian hospitals has also identified common challenges in line with other studies already mentioned.<sup>11</sup> These were; communication, sensory processing, challenges working with the healthcare team, waiting/transitioning and (in)flexibility. Additionally, helpful approaches were suggested by the participants such as recognising parent expertise, knowing the child and preparation. There were several system changes proposed as result of this work; the provision of resource packs for practitioners, improved communication and staff education and training.<sup>11</sup> The lack of education and training of healthcare professionals has been highlighted by several studies where it has been noted that it results in a lack of ability by practitioners to manage Autistic patients and adapt their communication strategies to effectively care for the Autistic individual and ensure a successful outcome.<sup>12–15</sup>

Research undertaken by Bjorkman et al., in Sweden<sup>15</sup> presented the findings of a survey of 84 radiology departments. Of the 46 departments that examined children with ASD, none had any existing guidelines for radiographers to assist them in preparing for and undertaking imaging procedures for patients with ASD. This work was followed up with the production of guidelines and a checklist which were designed by a panel of experts currently working with children with ASD in several anaesthesia and radiology departments throughout Sweden.<sup>16</sup> There have been two studies undertaken in the UK which have explored the experiences of imaging patients with ASD, both from the parent's

perspective.<sup>17,18</sup> Both suggest ways to improve communication with children with ASD, incorporating further training and development for radiographers and agreeing a process by which each child's needs can be assessed. Bond<sup>18</sup> also produced a visual aid which could be used by parents and children to explain the process of an X-ray examination to the child.

It is evident from the literature search that there is a lack of research exploring the experiences of Autistic children and their parents when attending for an X-ray examination. The gap in current clearly identifies the need for this paper.

## Research approach and methods

This research was placed in the pragmatic paradigm<sup>19</sup> and adopted a mixed methods approach, allowing the collation of quantitative and qualitative data.<sup>20</sup> This research was a cross sectional study<sup>21</sup> in that data was collected from a group of individuals at one point in time, asking them to recall their experiences of attending a diagnostic imaging department.<sup>21</sup>

The quantitative data was collected via an online Survey and was aimed at parents of Autistic children who had attended a diagnostic imaging department for an X-ray examination, seeking their perceptions of their child's experience. Participants who completed the online survey were asked if they would be willing for their child to take part in an interview where the issues raised in the survey were explored in more depth and offered the perspective of the child.<sup>22</sup>

The online survey was formulated and hosted by Survey Monkey and an invitation was sent out via the Autism & ADHD email list and other social media platforms. Due to the way in which the invitation to participate was circulated, there is no data on the participants who could have selected to take part but did not do so. Therefore, the response rate of the questionnaire is not identifiable. Service user representatives from the Autism community worked with the research team to advise on and contribute to the design of the online survey, using their knowledge and experience alongside the findings from the literature review to co-create the interview questions.

The questionnaire consisted of 17 Likert scale questions,<sup>23</sup> one rating question and two open questions requiring free text relating to areas of good practice and areas that could be improved in the future. A five-point Likert scale was used to decrease confusion and increase the response rate of the participants. Using an odd number of responses allows a neutral stance to be taken by the participant and collate more meaningful data.<sup>24</sup> Some demographic details were also collected at the beginning of the questionnaire but this was only related to the children. A small pilot study was undertaken to test the reliability and validity of the survey and no changes were deemed necessary.

The survey targeted those families who have attended a diagnostic imaging department for projection imaging in the last 24 months. The following inclusion/exclusion criteria were utilised:

### Inclusion criteria

- Parents of an Autistic child between the ages of 6–12 years
- The child must have visited a diagnostic imaging department for projection imaging within the last 24 months

### Exclusion criteria

- Parents of an Autistic child with another learning need in addition to Autism
- Parents of an Autistic child who are non-verbal. This decision was taken as lessons need to be learned about the various fears and anxieties from verbal children so that resources can then be made to support all children with ASD including those who are non-verbal.

The age range of 6–12 years was chosen following advice from the CEO of Autism and ADHD. In this age group, children have begun to strive for independence and are generally able to articulate their feelings and emotions about an experience in some way, either verbally or through distressed behaviours. It was also decided to restrict the age range due the wide spectrum of needs and behaviours and the span of six years was chosen as a narrow window of difference. The cut-off point of 12 years of age was chosen to reduce the influence of puberty which can affect the behaviour of all children and as such it was decided to remove this possible variable.

Confidentiality and anonymity are important issues and it was the researchers' responsibility that all details regarding the participants was kept confidential and when the findings were shared that anonymity was maintained. The assurance of confidentiality and anonymity was clearly stated in the information sheet and ethical approval was granted for the study by the host university.

All electronic data was stored on a password locked memory stick and backed-up using a secure cloud storage system. All interview tapes, transcripts etc. were coded so that the participants cannot be identified in any way. Principles of data protection and anonymity were followed according to the Data Protection Act<sup>24</sup> and the Human Rights Act.<sup>25</sup>

The quantitative data collated through the survey was analysed using descriptive statistics and the identified themes were utilised by the working party to design the interview questions. Using the framework devised by Braun and Clarke<sup>26</sup> the responses to each open question were analysed, allowing common themes to be identified from the data. These offered further insight into the parents' experiences and provided additional learning opportunities for radiographers and other healthcare staff.

**Results**

There were 28 completed surveys and the results can be found in the following histograms. The demographic details of the children represented are displayed in Table 1.

The majority of children were referred through Accident and Emergency, followed by Outpatients.

The results for Statements 1–17 are presented in Fig. 1 below in order of from Statement 1 to 17 (top to bottom):

Further detailed survey responses to Statements 2, 16 and 17 are presented in Figs. 2–4. These specific statements have been selected as the responses provided the most interesting data in terms of gender difference and also in relation to the findings from the literature review.

Fig. 2 demonstrates that overall, there was a low perceived awareness of the child's specific needs. Within the non-male children 100% of respondents reported disagreement, possibly

suggesting males are more likely to be understood to be autistic than females.

In Fig. 3 it can be seen that the majority of parents (81%) did not feel that the waiting area was a comfortable place for their child to wait and did not consider their sensory needs.

Fig. 4 illustrates that 56% of parents felt that the radiographer understood what their child might be frightened or anxious about. Three parents selected not applicable, but it is not clear why they felt that were unable to respond to this question.

Fig. 5 shows that 50% of the parents thought that the process of how and when to get the results of the X-ray examination was explained to their child in a way that they could understand.

Figs. 6 and 7 illustrate the themes identified in the open questions relating to good practice and areas for improvement.

The participants were asked to rate their overall experience in the Imaging/X-ray department using a scale of 1–10, 1 being poor and 10 being outstanding. The scores are presented in Fig. 8.

**Discussion**

The findings will be discussed under four main themes which collate the findings from the survey data. These are; waiting times and environment, forms of communication, lack of understanding of staff regarding Autism and preparation for the X-ray examination.

*Waiting times and environment*

The length of waiting times and the environment in which patients wait and are treated are important factors across all sections of the population. However, research has demonstrated that in Autistic individuals these can be a major source of stress, often triggering anxiety<sup>7,8,9</sup>.

It was evident within the results of the survey that parents (62%) felt that the reception staff were unaware that their child had specific needs, related to their diagnosis. Although this also links to the theme knowledge and understanding it also resulted in longer than optimal waiting times and an often, unsuitable environment in which to wait for their child's X-ray examination. This was reinforced by the strongly disagree and disagree response (73%) to the statement 'the staff seemed to understand why my child would need to be seen quickly.' Furthermore, the need for shorter waiting times was a theme highlighted as good practice by parents and the reduction of waiting times was recommended as an area for improvement.

The waiting environment was poorly evaluated by the parents in the survey when only 17% agreed that the waiting room was a comfortable place for their child to wait until their X-ray examination. Feedback indicated that waiting areas in both the Diagnostic Imaging and Accident and Emergency Departments are not

**Table 1**  
Demographic information of participants and the children they represent.

Gender	Male 21	Female 6	Other 1		
Age of Child (in years)	6–7 3	8–9 12	10–11 3	12 10	
Referral Details	Accident and Emergency 17	General Practitioner 2	Outpatient 8	Inpatient 1	
Anatomical Area Imaged	Lower Limb 8	Upper Limb 6	Abdomen/Chest 8	Head/Spine 4	Multiple 2

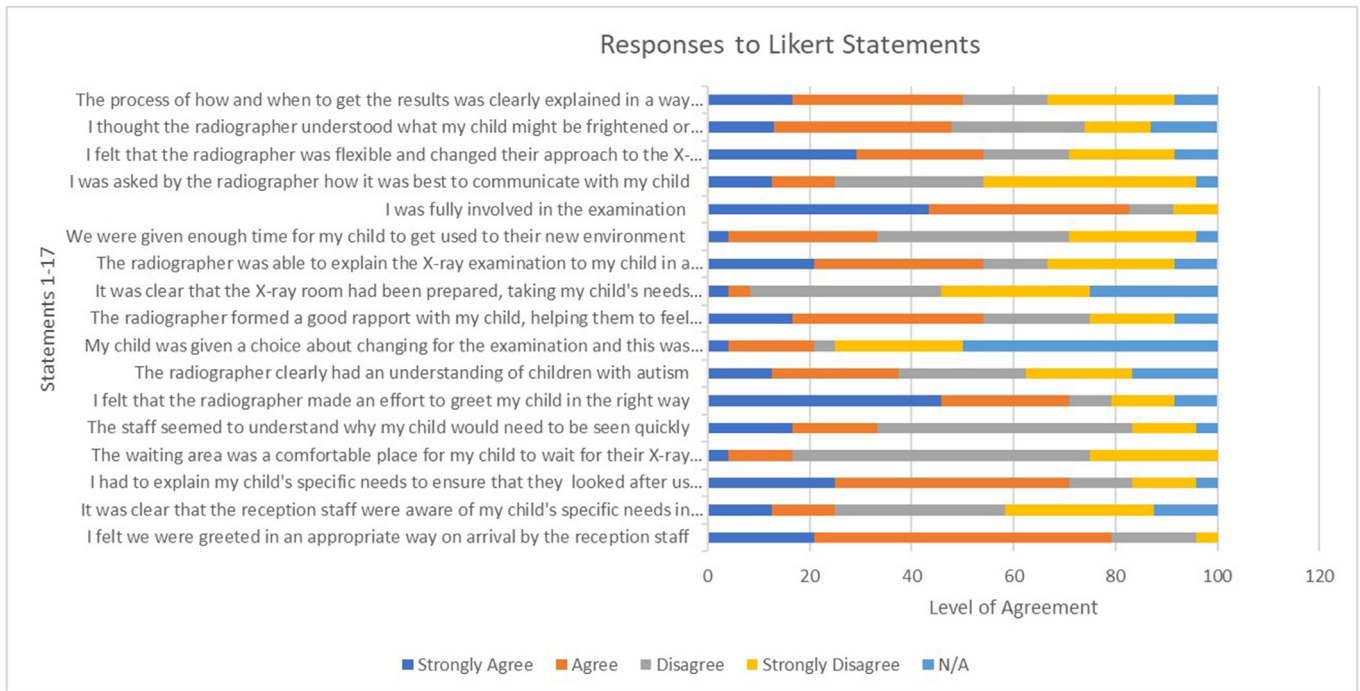


Figure 1. Responses to statements 1–17.

currently fit for purpose for paediatric Autistic patients as they are often noisy, busy and intense with fixed unnatural lighting. Areas of improvement suggested by parents included adaptations to the environment and the use of personal items to decrease the stress and anxiety that can be caused by an unsuitable waiting environment<sup>6,7,8,9</sup>.

*Forms of communication*

There was some good practice identified in some of the statements related to communication. The majority the parents (79%) felt that they were greeted appropriately by reception staff. However, 71% of parents did feel that they had to explain their child's

specific needs as they did not think that the reception staff (25%) were fully aware of these. This relies on the parent being both confident and proactive in disclosing their child's diagnosis in what is often a busy, noisy and stressful environment. This could be facilitated with the use of an initial needs assessment proposed in the study by Scarpinato et al.<sup>10</sup>

The way in which the radiographer greeted their child was highly rated by the parents with 71% feeling that this was undertaken appropriately and 54% agreed that the radiographer formed a good rapport with their child. This is reinforced by 54% parents rating the statement 'the radiographer was able to explain the X-ray examination to my child in a way that they understood what was going to happen.' Although both these statements were 54%

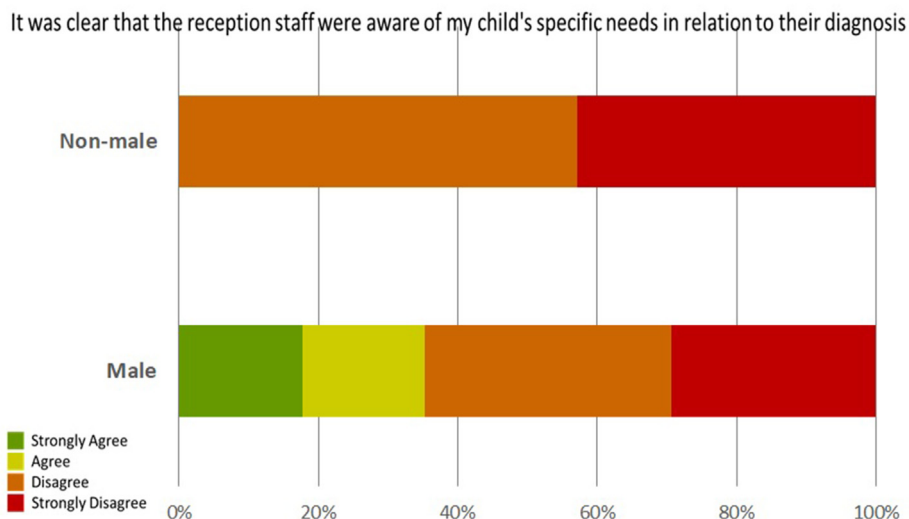


Figure 2. Responses to Statement 2 with gender differentiation.

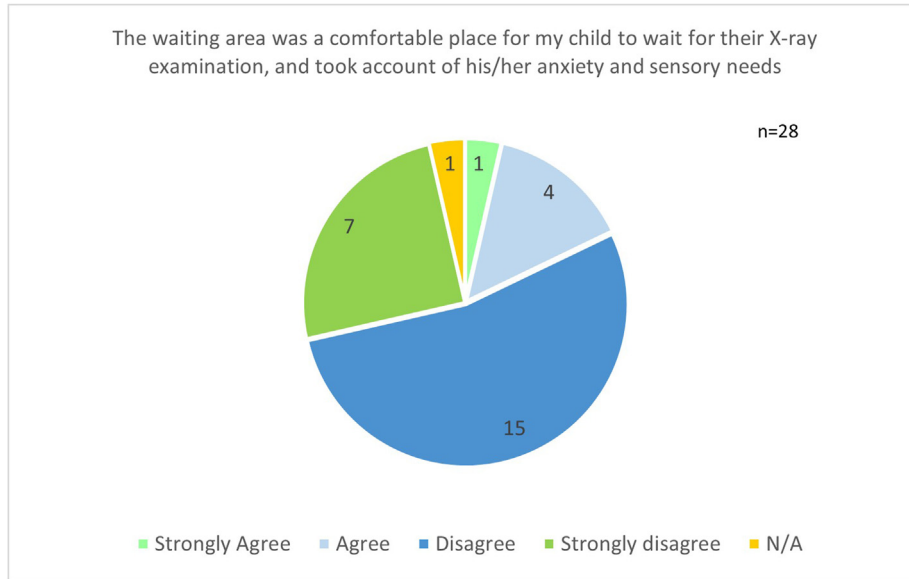


Figure 3. Responses to statement 4.

positive, this indicates that there is clear room to enhance practice and correlates with findings of previous studies which have found that effective communication is often an area identified for improvement.<sup>6,11</sup> Interestingly, the final statement ‘the process of how and when to get the results was clearly explained in a way my child could understand’ had a 50% strongly agree and agree rating. This statement was the one that was most closely correlated to the

rating given to their overall experience in the diagnostic imaging/X-ray department.

Involvement of the parent received mixed feedback. It was encouraging to see that 83% of parents felt that they were fully involved in the examination. However, only 25% were asked by the radiographer how best to communicate with their child. This correlates with the findings of Scarpinato et al.<sup>10</sup> suggesting the

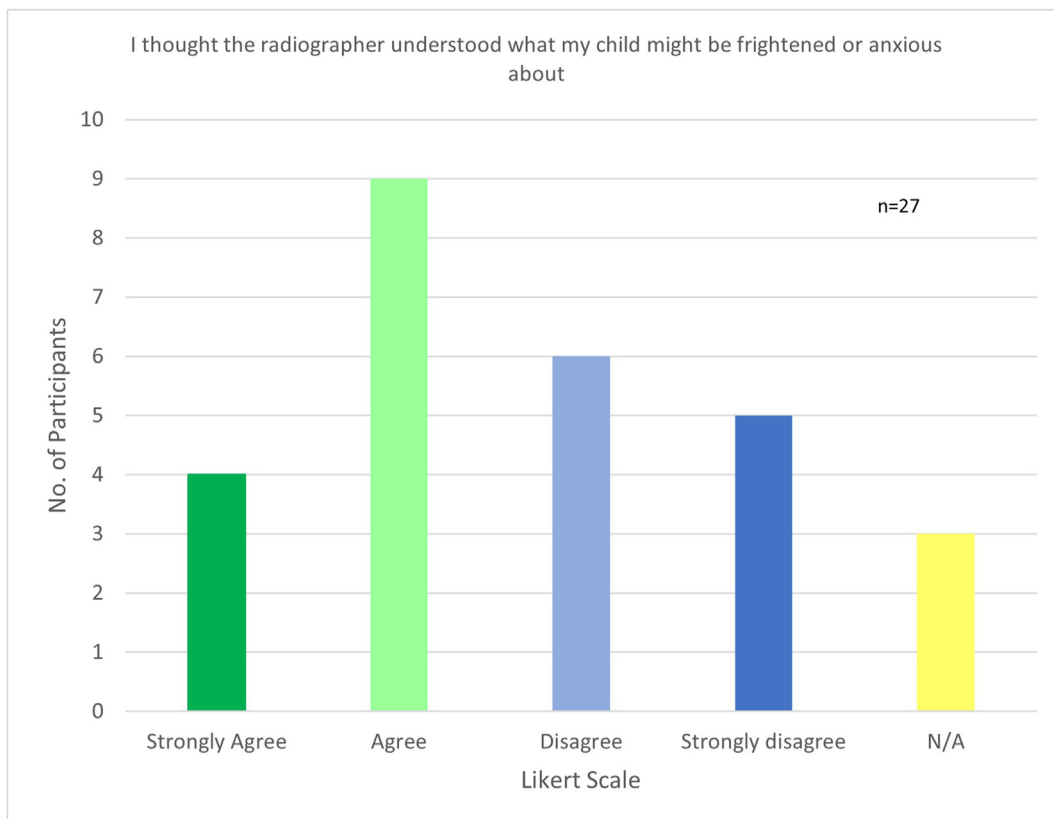


Figure 4. Responses to statement 16.



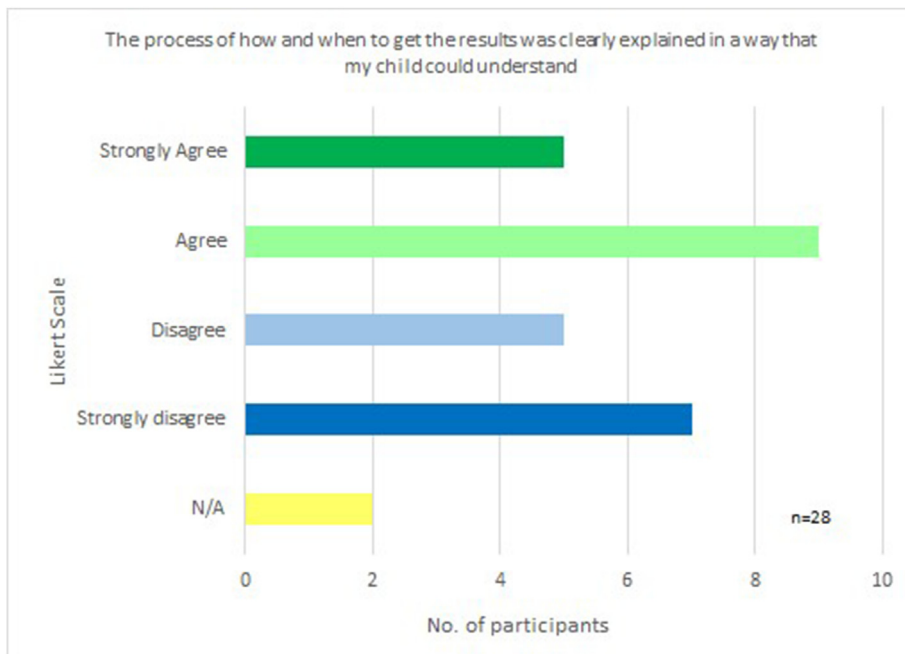


Figure 5. Responses to statement 17.

use of a needs assessment but also the work by Muskat et al. in Canada<sup>11</sup> which highlighted the need for health professionals to recognise and utilise parent expertise.

The areas of good practice which were highlighted by parents include the direct and effective communication with the child and the staff having a calm and compassionate attitude. There were some areas identified for improvement such as more effective communication between staff as many parents felt that they often had to repeat information to different staff; the need for the organisation to encourage parents to be proactive in stating their child's needs and for staff to communicate directly with the child and not through the parent where possible.

*Lack of understanding of staff regarding Autism*

As previously mentioned, parents deemed the awareness of reception staff to their child's needs was low with a 25% agreement to this statement. In addition, only 33% of parents felt that staff understood the need for their child to be seen quickly. This directly correlates to the findings of study in Canada<sup>11</sup> which concluded that there was need for further resources and improved education and training for staff. These findings emphasise the need for all staff working within a healthcare environment to develop a knowledge and understanding of Autism. This would underpin effective communication between professionals and ensure that the child and

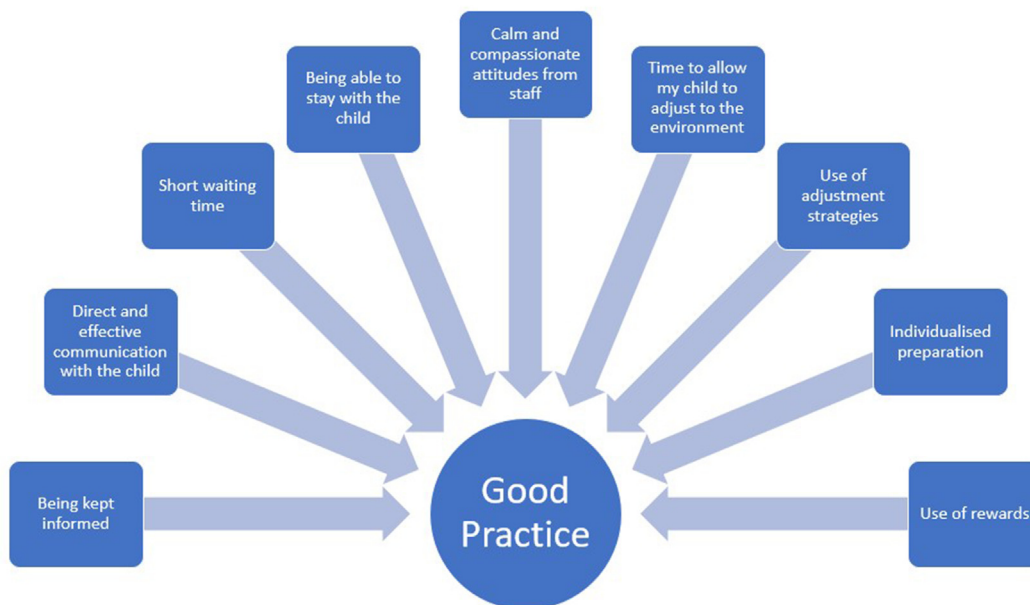


Figure 6. Areas of good practice highlighted by parents.

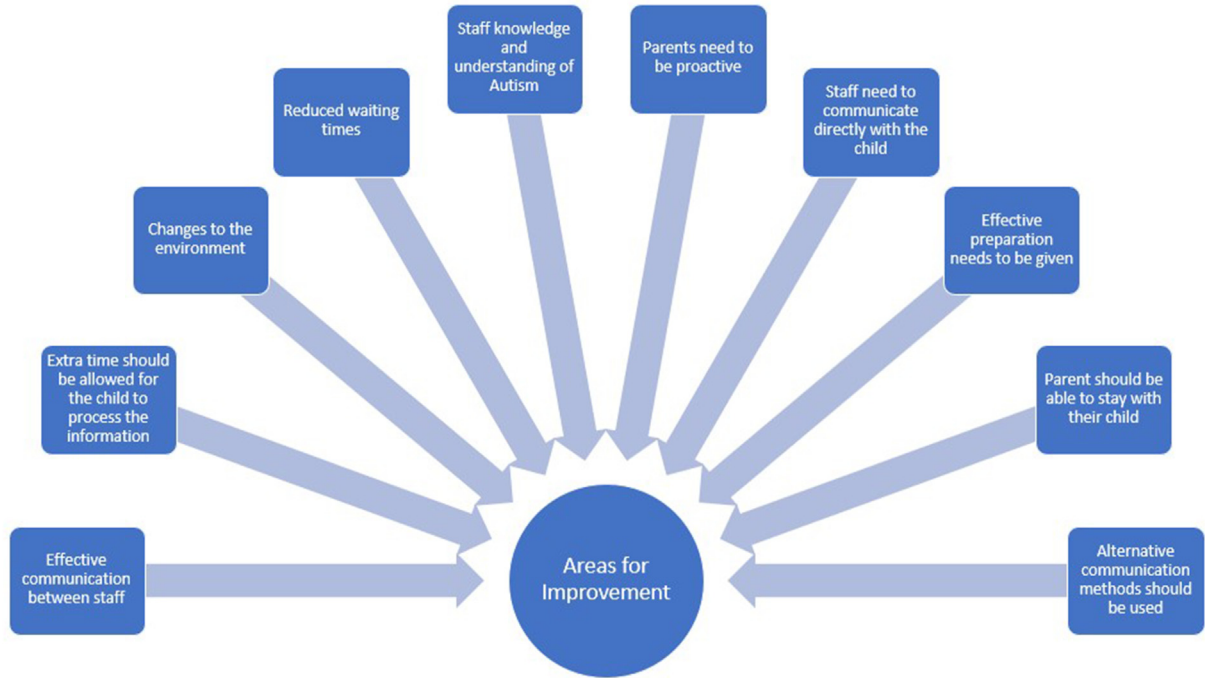


Figure 7. Recommended areas for improvement by parents.

their parents receive an optimum level of care and that their pathway is expedited appropriately.

The statements specifically relating to radiographers gleaned mixed results with no statement receiving over 54% strongly agree or agree. Only 38% of parents agreed with the statement ‘the radiographer clearly has an understanding of children with Autism.’ Further examination of the responses to this question, evidenced that there was less appreciation from the radiographer that the child may be frightened or anxious the older they were, specifically over the age of ten.

This was followed by 54% of respondents feeling that the radiographer was flexible and changed their approach in meeting their child’s needs and 48% of parents perceiving that the radiographer

understood what they child may be frightened or anxious of. Again, these findings clearly indicate the need for further education and training for radiographers in line with the aforementioned Canadian study.<sup>11</sup>

Good practice highlighted by parents included: the use of adjustment strategies such a different distraction techniques; allowing parents to stay with their child and the radiographer working with them to support their child; and finally, the use of rewards such as stickers and viewing their images. Enabling the child to view their image at the end of the examination was frequently mentioned and seen as a reward. It is thought that it would help the child understand the experience that they had just been through and potentially have a positive impact on future attendance.

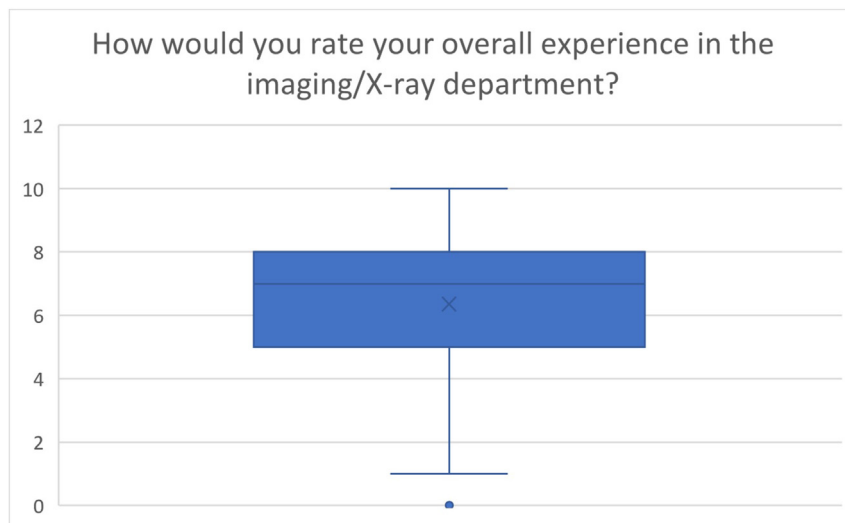


Figure 8. Overall rating of experience in the imaging/X-ray department.

There were two areas for improvement offered by the parents. Firstly, to increase the knowledge and understanding of Autism amongst not only healthcare professionals but also support staff. Secondly, the use of alternative communication methods which included the use of simple pictures, explanation of the equipment and provision of an information leaflet using for example social scripting.

#### Preparation for the X-ray examination

The majority of children were referred through Accident and Emergency, followed by Outpatients. This has potential significance in relation to the both the patient preparation but also the provision of information. The statements pertaining to the preparation for the X-ray examination generally scored low in terms of agreement by the parents. Statement 8 related to the child needing to change for the examination which should be noted only applied to 50% of cases. However, parents felt that overall their child had not been given either a choice about changing for their examination or it had not been explained to them in a way that their child could understand. Significantly, only 8% of parents believed the X-ray room had been prepared according to their child's needs. This was the lowest level of agreement to any of the statements in the survey. 33% of respondents also thought that their child had not been given enough time to adjust to the new environment. The nature of the environment has been identified as one of the main influencers of behavioural issues in Autistic children and therefore the preparation of the room and allowing time for the child to adjust to their new environment is fundamental to the success of an X-ray examination. Prior preparation for the examination is also important as it links to the theme of understanding in that Autistic children and their parents need to be as fully informed as possible before attending for their examination, therefore calling for the use of alternative methods of communication to ensure that the information given is both accessible and inclusive.

Good areas of practice highlighted were the use of individualised preparation and being kept informed regarding possible waiting times and changes. Suggestions made to improve practice included making changes to the environment such as noise reduction, light modification and the use of sensory toys e.g. fidget spinners. All sensory changes should be considered to ensure an optimal experience for the child and their parent. In addition, there were several other recommendations made to enhance the preparation for the X-ray examination such as the use of alternative communication strategies and reviewing the current patient information. Additional suggestions were made including informative literature in the room to explain about X-rays, children being able to bring in their own change of clothes and personal items and allowing children to wear noise reduction earphones, play music etc.

The overall rating of the experience in the diagnostic imaging/X-ray department is seen in Fig. 8 with the mean being 6.35, the mode 8 and the median 7. These scores are above 5 and seen to be in the main indicative of a positive overall experience. Interestingly, there was a marked correlation with the overall rating of the service and the child understanding the steps in the patient pathway.

#### Conclusion

The findings of this study indicate that the waiting rooms utilised by both the Diagnostic Imaging Departments and/or ED are not currently fit for purpose for paediatric patients with Autism. The feedback indicates that they are often noisy, busy with intense, fixed and unnatural lighting, all of which need adjustment. Excessive waiting times in this environment can trigger increased stress and anxiety in the child and therefore there needs to be strategies

in place to expedite the patient through their pathway. This requires a good understanding of Autism and effective lines of communication between staff.

Overall, it was felt that better preparation is needed before the X-ray examination and a review of the current information given to patients is recommended. Consideration of the adoption of alternative communication media should be given to ensure that the information provided is both accessible and inclusive. It is recommended that the future design of any information should be co-produced with representatives from the Autistic community to ensure that it is appropriate.

In the case of ensuring that the X-ray room is a conducive environment for the child, further staff training would address this and equip radiographers with the skills needed to effectively communicate with Autistic children regardless of their age in order to provide optimum patient care. Training is also needed for support staff and there needs to be established clear lines of communication to ensure that appropriate information is cascaded to the relevant staff to expedite and improve the patient pathway.

It is important to acknowledge that this was a small-scale study with only 28 respondents, demonstrating that there clearly needs to be further work undertaken by health care professionals to find more effective ways to engage with the Autistic population. Strategies need to be developed to help Autistic people and their carers to increase their confidence to more openly disclose their specific needs.

This study was also dependent on the recall of the parents which has the potential of bias or misunderstanding. Data was not collected from the staff involved but the purpose of the study was to focus solely on the experience of the parents without making a comparison to staff experiences. It is important to recognise that the patient voice is impactful irrespective of the limitations of this study and there are important lessons to be learned from the findings of this survey.

#### Conflict of interest statement

None.

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