

“Steps Toward Inclusivity”: How to Improve the MRI Experience for Patients on the Autism Spectrum

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Abstract

Inclusion in healthcare management continues to be researched, developed, and integrated into practice. Hospitals can be an overwhelming experience for any patient, but they can be almost unbearable for patients with sensory sensitivities and communication difficulties such as autism spectrum disorder (ASD). More specifically, this commentary explores issues that often arise during an MRI scan for patients with ASD and methods that healthcare workers can implement to better accommodate these patients. Three main themes of accommodation during MRI scans for individuals with ASD are communication, sensory friendly environment, and pre-visits. Additional research is needed to evaluate these methods in the adult population and better refine their use to develop broad guidelines for practitioners.

Autism spectrum disorder (ASD) is characterized by varying degrees of cognitive and social deficits along with different repetitive behaviors. Over time, as tools have improved for diagnosing ASD, the reported prevalence in the population has increased. The incidence of ASD has changed from four cases per 10000 recorded 40 years ago to a range of 30-60 cases per 10000 today (Rutter, 2005). As diagnosing ASD improves and the incidence of ASD increases, it is becoming even more crucial to better our understanding of managing ASD symptoms in the medical setting.

Management of ASD symptoms and features in the healthcare field can be a daunting and complex task. This is due to the inherent nature of what a diagnosis of ASD

often entails. A diagnosis of being on the Autism spectrum according to the DSM-V is based on features of social difficulties, such as communication, and non-social difficulties, such as sensory sensitivities (CDC, 2022; Hamilton & Pelphrey, 2018). Communication- and sensory-related struggles that often underlie an ASD diagnosis can be further exacerbated in a medical setting. To complicate matters, certain medical procedures are often even more necessary and essential in this already medically challenging population. For example, gastrointestinal issues, other genetic or neurological disorders, allergies, and inflammatory conditions (Al-Beltagi, 2021) are some of the comorbidities associated with ASD. Such chronic and co-existing medical conditions can require more frequent visits to

the physician and/or hospital with additional need for procedure-based tests or care—including endoscopies, colonoscopies, ultrasounds, phlebotomy, magnetic resonance imaging (MRI), etc. These procedures, although not comfortable for the general population, can be even more distressing for an individual with ASD who already struggles with communication difficulties and/or sensory sensitivities.

This commentary focuses on MRI use in individuals with ASD. MRIs can be particularly disruptive for those with ASD as the process can be complicated to explain, involve long periods of time in a confined space, and include loud auditory stimuli. Furthermore, individuals with ASD may be more likely to require an MRI in their lifetime because in addition to common clinical concerns that need MRI evaluations, this population has a higher chance of comorbid neurological disorders such as epilepsy (Al-Beltagi, 2021; Aylward et al., 2002; Carlier et al., 2022; Ismail et al., 2016). Additionally, as MRIs play an important role in brain-related evaluations, MRIs can even be used as diagnostic follow-up or research purposes for the ASD diagnosis itself.

Methods

Via a brief literature search on PubMed and Google Scholar four papers were selected that discussed methods to better accommodate people with ASD during an MRI scan. Papers were selected that were within the last 15 years and specifically addressed the topic at hand (Berglund et al., 2017; Nordahl et al., 2008; Pua et al., 2020;

Stogiannos et al., 2022). These papers focused on our target population and involved conducting original research on the use of accommodations during MRI scanning.

Three central themes for ASD accommodations in MRI scans arose from reading the four papers: 1) communication, 2) sensory friendly environment, and 3) pre-visits. All four papers discussed the use of good communication. Three of the four papers explored the use of a sensory friendly environment. Three of the four papers investigated use of visiting the MRI/facilities prior to the procedure. All three central themes as they were explained in their respective studies will be discussed separately below. In addition, there were several more unique and interesting measures implemented or discussed in some of the papers, such as flexible scheduling, MRI audio clips, and an MRI game-based app which will also be briefly described.

1. Communication

Communication is key to successfully perform MRIs in individuals with ASD (Berglund et al., 2017; Nordahl et al., 2008; Pua et al., 2020; Stogiannos et al., 2022). The study by Pua and colleagues was conducted in Australia and included six pairs of twins between the ages 5-18 (n=12)—for three of the pairs both children had an ASD diagnosis and for the other three pairs one of the twins had an ASD diagnosis. The research team conducted interviews with each family prior to the MRI scan day thus facilitating communication between the team and patient while also formulating a customized

plan for the child. This interview included a board-certified psychologist. The day of the MRI also included an orientation session where children and caregivers were explained the schedule for the day and given the space to ask questions (Pua et al., 2020). Although this study did not specifically assess communication on its own, every step of the way was guided by this principle. A notable critique to the study is that a positive outcome of the experiment was defined as improved MRI imaging quality as compared to a national database of brain images from individuals with ASD. Although this remains undoubtedly important, the study failed to assess the changes in emotional stress or discomfort experienced by individuals with ASD given this new MRI preparation and implementation format. Although most likely a positive change given the improved imaging quality due to less participant movement and interruption in the MRI, this change was not formally assessed.

Nordahl et al. conducted a study with 45 participants (25 with ASD, 4 developmentally delayed, and 16 controls) and included a pre-interview, Mock MRI, and nocturnal MRI scan. Although the study did not discuss communication as its central theme, it is clear from the setup that the study took the time to establish rapport and an understanding between themselves and the families throughout the process. Similarly to the study by Pua et al., families went to an interview two weeks prior to the MRI to start the open line of communication. Results showed that only 3 out of the 45 participants were unable to complete the MRIs. Unlike

Pua et al., in addition to assessing the MRI's success via the images, this study surveyed parents to elicit feedback regarding the importance of the MRI preparatory steps. Such feedback indicated that 97% of the families were either very satisfied or satisfied (5-likert point scale) with the experience. Furthermore, the open-ended comments portion of the feedback included descriptions of the team as "helpful" and comforting.

Stogiannos et al. surveyed radiographers (n=130) in the United Kingdom regarding their experience and/or perspective on working with patients with ASD during MRI use. Survey responses regarding both pre-screening measures and concurrent scanning measures (n=109) determined adjustment of communication style as the most cited (84.4%) necessity for a successful MRI scan. The second most cited answer at 80.7% also centered around communication and was devoting time to explain procedures to the individual and their careers.

Berglund et al. surveyed 21 radiology experts who work with children with ASD in Sweden. Although not only specific to MRI use, the survey implemented the Delphi method to create a list of guidelines for conducting radiological imaging studies in the population in question. The guidelines created included 5 important areas to consider during radiologic procedures on children with ASD, such as communication. More specifically, having the proper tools to communicate with patients depending on their individualized needs—such as photos or the use of simple/concrete language.

2. Sensory Friendly Environment

Many patients may find undergoing an MRI scan difficult due to confined space, loud noises, and the need to stay still for an extended period of time. This can be even more difficult for patients that are hypersensitive to sensory input. As such, a discussion regarding different strategies to help provide a sensory friendly environment for patients undergoing an MRI is important.

Stogiannos et al. found adjusting the MRI environment helped complete a safe and effective scan. The survey of radiographers reported 69.7% adjusted lights in the room and 63.3% adjusted the volume/ tone of their voices during the exam. The majority of radiographers optimized the MRI examination by using motion-resistant sequences or motion-correction software. Radiographers also reported making adjustments such as reducing the scan duration or reducing the acoustic noise during the procedure (Stogiannos et al., 2022). Similarly, Berglund et al. discussed the importance of providing a separate sensory friendly space with adjustable lights and reduced noise for patients with ASD. However, this study additionally notes that parents should be encouraged to bring their child's favorite toy/item (Berglund et al., 2017).

Conversely, Nordhal et al. described several strategies that achieved a high-quality MRI scan of children with ASD without the use of sedation, which given its efficiency and accessibility remains a common practice today (Nordahl et al., 2008;

Stogiannos et al., 2022). The main strategy discussed was to conduct MRIs in the evening after the child normal bedtime to eliminate the need for major changes to the scan itself. An alternative strategy for older and higher functioning children was to conduct the MRI while watching a video as a form of distraction.

3. Pre-visits

The concept of pre-visits for long and/or frightening procedures is not specific for individuals with ASD. In fact, this concept has been explored in a more general sense for children and adolescents (Byars et al., 2002; Carter et al., 2010). The investigation by Pau and colleagues and the Nordahl team implemented mock MRIs in their respective studies while Stagiannos and colleagues conducted a survey to better understand the utilization of pre-visits across radiographers in the United Kingdom (Pua et al., 2020; Stogiannos et al., 2022).

Although the focus of the Pau et. al. research study was effective communication and environment accommodations, as previously discussed, a piece of that system was to include a mock MRI training session the morning of the actual scan (Pua et al., 2020). The Mock MRI session contributed two-fold to the increased comfortability of the patient with ASD. First, it allowed the individual to familiarize themselves with the equipment and staff. The participant and/or family member could then make known any potential problems—specifically with the environment. For example, knowing the child's specific triggers and accounting for

them during the Mock MRI allowed the team to test effective strategies and prepare to mitigate any issues that would arise. Second, staff used the time to build rapport with parent and child to better customize the future MRI test—circling back to the central theme of improved communication. As such, it is evident that the success behind the Mock MRI was due to communication and subsequent accommodation implemented by the staff in the following real MRI scan. Meaning, the Mock MRI appears to be a continuation, not stand alone, to the overall concept of good communication and sensory friendly environment creation as previously discussed.

Similarly, Nordahl et al. also conducted a Mock MRI, but it was on a different day and included a train themed set-up (Nordahl et al., 2008). Although this Mock MRI was conducted during the day, the families were instructed to bring the child in their pajamas and go through their normal bedtime routine to prepare for the real MRI which took place at night in this study. Interestingly, in the feedback back 5-point Likert scale survey the Mock MRI was one of only two components of the day to receive a single rating of ‘not important’.

Instead of assessing the experimental value of MRI accommodations, the survey by Stogiannos et al. assessed the use of such accommodation techniques from radiographers in the United Kingdom. As previously mentioned, communication and environmental adjustments remain a large component of successful and comfortable MRI scanning in the ASD population.

However, this study also found that 57.7% of respondents allowed patients a pre-visit to the department prior to their MRI scan to get accommodated with the equipment (Stogiannos et al., 2022).

Additional Measures

In addition to the three central themes discussed above, other interesting measures were taken that did not fit into the above categories. Pua et al. found that using tactics to familiarize younger patients to MRI scanners can increase the likelihood of a successful scan (Pua et al., 2020). Two methods described were the use of audio clips and gaming apps. Parents were given audio clips of noises produced by MRI scanner. The parents were instructed to familiarize their child with the MRI sound clips every day slowly increasing in length and intensity over a week period. Furthermore, an imaging app called Okee medical contains training and adventure games for kids aimed to familiarize children with MRI scanners (Pua et al., 2020). This app helps teach children to keep still when instructed and practice holding their breath which is vital for a successful scan. The writers of this commentary downloaded and tested the app to confirm that is free to use and functional.

Conclusion

Our commentary focuses on accommodations to implement in the radiology department when caring for patients’ with ASD with the goal to improve patient safety and patient-centered care. The

three main themes of accommodations discussed were communication, sensory friendly environment, and pre-visits.

All studies discussed above included the importance of communication in obtaining a successful MRI scan. Health care workers may need to adjust their communication style when caring for patients with ASD. Additionally, it may be necessary to adjust communication based on patients' individual needs. The lack of training among healthcare workers on effective management of patient with ASD may play a role in reduced quality of care. Therefore, it may be necessary to provide training to healthcare workers on effective communication styles when caring for patients with ASD.

Most studies discussed recommend the need to develop guidelines to improve the care of patients with ASD undergoing radiographic procedures. However, it is important to caution that guidelines should remain general/broad to allow for the individualization of care. As Masi et al. stated "no two individuals on the ASD spectrum are alike...the expression of core symptoms in each child with ASD is likely to be idiosyncratic due to the complex phenotypic heterogeneity of the condition" (Masi et al., 2017).

Given that the papers discussed here go back fifteen years, the oldest of which being Nordahl et al. published in 2008, it is important to remember the dynamic and improving nature of this field. As new radiographic imaging technologies continue

to be invented and improved upon within the medical field, accommodations for certain populations need to be addressed. As mentioned above, anesthesia and sedation is a common method used for patients who are unable to tolerate MRIs. Although this may be necessary to some extent in emergent situations, that should not be the case for elective procedures with adequate time to prepare and address patient needs. The techniques described here remain the beginning of this ongoing discussion.

It is important to acknowledge several limitations to management options discussed. Several strategies such as pre-visits, familiarization with MRI procedure, and desensitization to MRI noises assumes ample preparation time. As mentioned, there may be emergency situations that do not allow for a preparation period; however, radiographers can still make some adjustments in communication style. Additionally, most of the experimental studies discussed only included children with ASD. It is important to acknowledge that optimal management strategies may vary between different age groups. Therefore, future studies should also focus on management strategies in the adult population as well. Further studies are also needed to optimize adjustments to the MRI examination such as reducing exam time without compromising the quality of MRI scans.

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