Towards autism-friendly MRI: Exploring autistic individuals' experiences of MRI scans in the UK, a cross-sectional survey

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Abstract

Background: Autistic individuals might undergo a magnetic resonance imaging (MRI) examination for clinical concerns or research. Increased sensory stimulation, lack of appropriate environmental adjustments or lack of streamlined communication in the MRI suite may pose challenges to autistic patients and render MRI scans inaccessible. This study aimed to i) explore the MRI scan experiences of autistic adults in the UK, ii) identify barriers and enablers towards successful and safe MRI examinations, iii) assess autistic individuals' satisfaction with MRI service, and iv) inform future recommendations for practice improvement.

Methods: We distributed an online survey to the autistic community on social media, using snowball sampling. Inclusion criteria were: being older than 16, have an autism diagnosis or self-diagnosis, self-reported capacity to consent and having had an MRI scan in the UK. We used descriptive statistics for demographics, inferential statistics for group comparisons/correlations, and content analysis for qualitative data.

Results: We received 112 responses. A total of 29.6% of the respondents reported not being sent any information before the scan. Most participants (68%) confirmed that radiographers provided detailed information on the day of the examination but only 17.1% reported that radiographers offered some reasonable environmental adjustments. Only 23.2% of them confirmed they disclosed their autistic identity when booking MRI scanning. We found that quality of communication, physical environment, patient emotions, staff training and confounding societal factors impacted autistic people's experiences. Autistic individuals rated their overall MRI experience as neutral and reported high levels of claustrophobia (44.8%).

Conclusion: The study highlighted a lack of effective communication and coordination of care, either between healthcare services or between patients and radiographers, and lack of reasonable adjustments as vital for more accessible and person-centred MRI scanning for autistic individuals. Enablers of successful scans included effective communication, adjusted MRI environment, scans tailored to individuals' needs/preferences, and well-trained staff.

Community brief

Why is this an important issue?

Magnetic resonance imaging (MRI) is an examination that shows human anatomy and may explain the causes of symptoms. Autistic people may need MRI scans for various reasons, such as low back pain, headaches, accidents or epilepsy. They have known sensitivities to sound, light, smell or touch and increased anxiety,so the narrow, loud, isolating, unfamiliar MRI environment may be overwhelming to them. If MRI scans are, for these reasons, inaccessible, many autistic people will have to live with long-standing conditions, pain or other symptoms, or have delayed treatment, with impact on their quality of life, and life expectancy.

What was the purpose of this study?

We tried to understand how autistic people perceive MRI examinations, things that work and the challenges they face. We also asked for their suggestions to improve practice and accessibility.

What did we do?

We distributed an online questionnaire to autistic adults through social media. We analysed the data using appropriate statistical and text analysis methods.

What were the results of the study?

We received 112 responses. Autistic people rated their overall MRI experience as average. Nearly a third (29.6%) reported they were not sent any information before MRI and only 17.1% reported that radiographers offered some reasonable environmental adjustments. Most participants (68%) reported that radiographers provided detailed information on the day of the scan. Only 23.2% of them disclosed their autistic identity when booking MRIs . We found the quality of communication, physical environment, patient emotions, staff training, stigma, and timely autism diagnosis, impacted their MRI experiences.

What do these findings add to what was already known?

Autistic people MRI scan experiences are at the heart of this project. Our project shows that MRI for common symptoms is often inaccessible by autistic people. We should improve the MRI environment, adjust communication format/content for them, and deliver person-centred care in MRI. Healthcare professionals should receive relevant training, to understand the challenges autistic people might face and better support them in MRI scanning.

What are potential weaknesses in the study?

The pandemic has impacted participant recruitment; therefore, the results of this sample may not reflect the full impact on the wider autistic population or adequately represent the autistic community, due to small size and including only people who could consent.

These results come from different centres, so there is a lot of variation in the use of MRI equipment.

How will these findings help autistic adults now or in the future?

We outline the main challenges associated with MRI, so autistic adults and their families/carers understand more of what they could expect in future examinations; hopefully researchers and scanner manufacturers will try to tackle these challenges to make MRI scans truly accessible for autistic people.

We shared this knowledge with stakeholders to develop guidelines and started using it in training. We want to ensure that MRI is person-centred and more accessible for autistic patients.

Background

Sensory overload and communication barriers remain two of the most important challenges to address when it comes to accessible healthcare for autistic individuals.[1] These barriers and challenges are significant and have profound impact on healthcare delivery, patient and service user experience, physical and mental wellbeing, quality of life and life expectancy for autistic individuals.[2-4] Recent studies have shown that, because of these challenges and lack of reasonable adjustments in healthcare settings, autistic adults experienced difficulties in making healthcare appointments by telephone (62%), in feeling heard and understood (56%), difficulty in communicating with their doctor (53%) and experiencing anxiety in the waiting room environment (51%).[3] There is therefore great need for person-centred reasonable adjustments to ensure equity of healthcare provision for all service users.[4-7]

Magnetic resonance imaging (MRI) is a medical imaging examination used for a wide range of clinical conditions, that allows delineation of fine anatomical details in the human body and therefore enables optimal diagnosis and treatment. However, as we explain below, it remains a lengthy, anxiety-provoking, challenging examination with moderate acceptance from patients,[8] despite some early efforts to optimise its clinical practice for the general population[9-11] and for autistic people, in particular. [12,13]

Autistic people may need to undergo MRI examinations, either as part of a research project studying autism, or for clinical concerns, such as persistent headaches, low back pain, injuries, accidents, or falls. Researchers use MRI of the brain frequently for autism research.[12,14-16] Furthermore, we use MRI to assist in the diagnosis and monitoring of autism-related co-occurring conditions, such as epilepsy.[17]

Recent research has shown that autistic individuals have higher co-occurrence of conditions such as epilepsy, that require medical attention and often MRI scanning.[18,19] However, autistic individuals may face several challenges when accessing healthcare. These include lack of accessibility of services, lack of coordination or continuity of care, sub-optimal patient-provider communication, stigmatisation (including from healthcare professionals), poor staff awareness of sensory sensitivities that might impact autistic service users, lack of clinical staff understanding of autistic people's needs and general lack of knowledge regarding autism.[20,21] Despite the increase in the number of autism-related research studies, there is still much to learn and understand about the barriers that autistic individuals face when accessing healthcare,[22] and also about the reasonable adjustments required to ensure they have a positive experience.[4,23,24] For all these reasons, autistic service users cannot access healthcare provisions with the same ease as neurotypical individuals, resulting in unmet needs. This may also explain the lower quality of life, and increased overall mortality among autistic populations.[25,26]

Despite its clinical usefulness, MRI scanning can feel overwhelming for anyone wishing to undergo this medical examination. This is mainly because of the narrow structure of the MRI scanner, the loud noise during the scan, and the relatively long scan duration,[27] all of which may increase the risk of patient anxiety or claustrophobia.[28-30] This might be further exacerbated among autistic individuals, who typically show higher levels of anxiety than the general population.[31] Claustrophobia, which may affect around 10% of neurotypical patients,[32] can adversely affect scan completion rates, increase scan repeats, impact workflows and patient experience, with such data for autistic individuals still lacking. The need to administer intravenous contrast, to achieve optimal diagnosis in some MRI scans, and to optimally position a patient on the MRI examination table, so they can remain still for longer, may also pose further challenges to autistic individuals, exacerbating their sensory overload.

These issues emphasise the need for an individualised, person-centred approach for autistic individuals undergoing MRI scanning for a safe, accessible, and successful examination. To address these issues, we aimed to gain an understanding of the main barriers to and enabling features of MRI scanning in the UK, as autistic adults reported, alongside mapping out their needs, preferences, and experiences during MRI examinations.

This work is part of a wider project that received funding from the Society and College of Radiographers, aiming to improve MRI scanning for autistic individuals. In this wider project we included a systematic review, which identified all reasonable adjustments currently used when autistic patients undergo MRI examinations.[24] It also included a UK-wide survey investigating current practice and knowledge of radiographers, highlighting knowledge gaps of healthcare practitioners due to insufficient training.[33] The aim of this work was i) to explore the MRI scan experiences of autistic adults in the UK, ii) to identify barriers and enablers towards a successful and safe MRI examination, iii) to assess autistic individuals' satisfaction with MRI service, and iv) to inform future recommendations for practice improvement.

Methods

Methodology:

We adopted the pragmatic paradigm, in which we employed a combination of quantitative and qualitative data collection methods.

The study aligns with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional studies,[34] the American Psychological Association (APA) guidelines for paper format,[35] and the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) for online surveys.[36]

Participants:

Participants were autistic individuals over the age of 16 years. Inclusion criteria were an autism diagnosis or self-diagnosis of autism, self-reported capacity to

consent and a prior MRI scan experience in the UK. For autism diagnosis, we did not administer any screening questionnaires, or other means to confirm/reject diagnosis of autism. Of an initial sample of 122 survey respondents, we excluded 10 because they only completed demographic information but no other survey questions. The final sample included 112 autistic adults with demographic characteristics as follows (Table 1).

The majority (88.4%) of autistic adults in this study did not report having any perceived or diagnosed disabilities; six reported having dyslexia, four also had attention deficit hyperactivity disorder (ADHD), two dyspraxia, two dyscalculia, two sensory processing disorders and one dysgraphia.

Materials:

We designed an online survey on Qualtrics (Qualtrics, Provo, Utah, USA). We included quantitative Likert scale questions, as well as open-ended questions that prompted a qualitative response. We employed adaptive questioning to reduce number and complexity of the questions.[36]

A team of experts in autism research and MRI scanning designed the survey questions with input from autistic consultants and autistic service users on the content and design of the questionnaire. The survey questions built on previous work, which identified the reasonable adjustments required for autistic adults in health care[37] or when scanning autistic individuals with MRI[24] as well as the enablers and challenges of MRI scanning based on practitioners' perspectives.[33] We conducted a pilot survey with the help of autistic individuals (n=4), who provided detailed written and verbal feedback, that we included in the final survey.

The questions covered: 1) basic participants' demographic data, 2) information about their MRI scan experience (number of scans, duration, anatomy that was examined, communication with the MRI personnel, provision of vital information on the scan requirements, environmental adjustments before, during, and after the scan, patient satisfaction metrics), 3) recommendations for improvements addressed to healthcare practitioners and 4) suggestions and advice to other autistic service users.

We offered visual mapping of survey completion rates and workflow adjustments to allow free movement through the questions (both forward and backwards) to make the survey more accessible to the participants. We worded all questions using neurodiversity-friendly, identity-first language. We did not offer any incentives to participants.

Procedures:

a. Data collection

We collected data between February 17th and April 30th 2021, using the snowball sampling technique[38] to facilitate recruitment of participants who may be hard-to-reach. We distributed the survey electronically through the National Autistic Society, the London Autism Group charity, the researchers'

professional networks and the autistic community on Twitter, LinkedIn and Facebook, with a clear note of the study being only open to autistic participants with experience of an MRI scan in the UK. We used electronic reminders and regular re-sharing on social media to increase the uptake.[39]

b. Patient public and community engagement

We employed patient and public involvement during research planning, survey design, piloting and data collection, data analysis and drafting of this work, to ensure that we actively involved autistic individuals in this project from start to end as co-producers. A team of 7 radiographers and 1 nurse worked with 4 autism researchers, 2 autistic consultants and 3 autistic service users to discuss pre-study considerations, co-produce and revise survey items, discuss recruitment of participants, and post-study considerations. Following AASPIRE's guidelines,[7] we strove to use flexible modalities, to provide sufficient processing time, to encourage transparency and power sharing, and to disseminate findings collaboratively. Co-authors include 2 autistic people who worked closely with the team as research collaborators.

We achieved direct feedback from the autistic community through one-to-one online discussions with service users and autistic consultants, group online discussions and presentation of the work in two live online events with a strong autistic community representation in the audience. We also placed an announcement on Twitter using the hashtag #actuallyautistic #autismfriendlymri seeking feedback from the autistic community. We used similar hashtags on other social media, including the social media channels by the London Autism Group.

c. Ethics and governance

We received ethics approval prior to this study by City, University of London Health Sciences Research Ethics Committee (ETH2021-0950). We obtained electronic informed consent at the beginning of the survey via a dedicated question. Participants had access to an information sheet on the first page of the survey containing all the essential information for the study and had access to an email address for any enquiries. Anonymity of the participants was vital to create a safe environment, enabling the authenticity of the responses. If participants felt secure in the knowledge that their responses could not be traced back to them, we thought that this was more likely to encourage honest feedback and authentic dialogue. Data collection and data storage followed the research institution's protocols.

Quantitative analysis:

We used the Statistical Package for the Social Sciences (SPSS), version 26 (IBM, SPSS Inc., Chicago, USA) for quantitative analyses. We reported descriptive statistics in terms of absolute numbers and/or frequencies of responses for categorical data and means and standard deviations for the continuous ratings of patient experience. As survey questions did not force a response and most questions provided an option for participants to indicate that

they could not recall relevant details, therefore relevant frequencies do not always sum to the full sample size. To further characterise the patterns of observation in the descriptive data, we explored associations between variables through non-parametric Spearman's rank-order correlations or chi-square tests. Where appropriate, we used t-tests for sub-group comparisons, and we reported Cohen's d effect sizes to quantify the magnitude of the differences we observed. We set the level of statistical significance at $p<0.05$ and generated graphs to highlight any relevant findings.

Qualitative analysis:

We employed content analysis to analyse the answers to the open-ended questions of the survey. In particularly we used conceptual content analysis, to determine the occurrence and frequency of concepts in this free text[40]. To achieve this, we used a process of selective reduction of the concepts identified in explicit terms. We moved from initially coding explicit terms into topic categories, which shared a commonality with each other, in a way that was, as possible, exhaustive but not mutually exclusive. We then worked to derive more generic themes, each one of which encompassed interconnected topic categories[41].

These open-ended survey questions related to a) descriptions of individual MRI scan experiences and b) suggestions for future improvement of practice as the autistic service users suggested. Two researchers performed the analysis; one (ToR) employed the NVivo software (QSR International Pty Ltd.) and the other (JHL) used manual analysis, both underpinned by the principles of content analysis.[41,42] The two researchers read and re-read data in an inductive approach, which consisted of the researchers familiarising themselves with the data and noting initial ideas; coding the data according to ideas, interesting features, and consistent patterns; reviewing the codes resulting in consolidation and grouping into categories and then, as the analysis progressed, into comprehensive themes; finally, the researchers re-read data to check for perceived analytical gaps and to validate the themes. To emphasise the participants' voices in results, we also read through and highlighted pertinent quotes from the data and added a pictorial representation of the overall themes and categories. Finally, we produced a table with frequencies for each category. Different types of qualitative analyses have employed this approach in the past, to help introduce a "weighting" between different themes and categories, particularly when it comes to amplifying service user experiences and highlighting priorities for practice change [43-46] (corresponding to those categories with the highest frequency in the data).

To ensure trustworthiness, intra-coder agreement exercises took place to promote researchers' reflexivity.[47] We facilitated data interpretation using group discussions within the research team, and CM and NS conducted a credibility check of themes.[42] A final consultation with the whole team followed to discuss specific theme descriptions and select the most relevant quotes.

Convergence of results:

We attempted to integrate the qualitative and quantitative results and converge them into the recommendations for future practice section further below.

Results

MRI scan characteristics:

Nearly half of the autistic adults (47.3%) had experienced between 2-5 MRI examinations, 37.5% had only one, and 15.2% more than five. The number of previous MRI scans did not relate to the overall MRI experience as the adult respondents rated (r_S = 0.07*; n* = 104; *p* = 0.46). In terms of scan durations 21.9% of participants reported that their most recent scan was 10-20 minutes long, for 28.9% of them scans lasted 20-30 minutes and 32% reported scans longer than 30 minutes. Across all participants who could recall scan durations there was no correlation between the duration and overall MRI experience (r_S = 0.11*; n* = 98; *p* = 0.91)

Most autistic adults (71.5%) who reported multiple scans said that they had their MRI scans at different hospitals/departments and the majority of scans (58.1%) took place in the last 2 years.

MRI scan referrals:

Musculoskeletal concerns, low back pain, headaches, and injuries were the main reasons to refer participants for MRI examinations (Supplemental material 1).

Communication and flow of information before, during, and after the MRI scan:

A minority of autistic adults (23.2%) reported that they (or in one case someone on their behalf) informed the department about their diagnosis when scheduling the MRI examination. Across the entire sample, of those who disclosed their autistic identity, 31% were asked about needs or preferences for the scan, whereas of those who did not disclose their diagnosis only 4% were asked about needs or scan preferences. A significant effect of good communication and attention to the patients' needs and preferences was related to the likelihood of them disclosing their autistic identity, x^2(1, n=105) = 15.22, p<.001). Interestingly, the 28 participants who reported disclosing their diagnosis rated their overall scanning experience as marginally worse (M = 37.89, SD = 28.63) than the 71 participants who did not (M = 49.69, SD = 29.24) (t = 1.82, df = 97, p = 0.072) with a moderate effect size of Cohen's *d* = .41. By contrast, the 11 participants who reported being asked about their needs and preferences reported significantly higher scan satisfaction (M = 65.00, SD = 25.87) than the 88 participants who reported not being asked (M = 44.02, SD = 29.12) (t = 2.28, df = 97, p = 0.025) with a large effect size of Cohen's *d* = 0.73. Sample sizes were too small to draw definitive conclusions on the interaction between disclosure and being asked about personal preferences.

In terms of type of information prior to scan, 55.4% of participants reported being sent an information leaflet, 14.9% were offered verbal information over the phone, and a further 1.6% of the respondents were sent a link with an informative video to watch at home. None of them was offered a pre-visit to the MRI department and nearly a third of the respondents (29.6%) reported they were not sent any information at all.

Most participants (68%) reported that radiographers tried to provide detailed information to them on the day of the examination. Also, most autistic service users (85.8%) reported that they understood what was required of them during the scan.

Regarding communication between the radiographer and the patient during the scan, 41.5% of autistic adults reported that the radiographer tried to maintain regular communication with them. Most of the autistic adults (70.8%) reported that they did not have any way to know how much time was left when inside the MRI scanner, a factor considered vital to manage their anxiety.

After the MRI scan, slightly over half of autistic individuals (52.5%) reported receiving sufficient information as to what to expect next.

Personalising the patient's MRI journey:

Only 15.2% of autistic adults were asked to bring their favourite music to listen to during the scan. Nearly half of the respondents (48.4%) reported a lack of Special Educational Needs (SEN) specialists onsite.

Accompanying persons were allowed into the MRI room for 30.4% of autistic adults. Over half of the autistic adults in this sample size (51.8%) reported being very independent, therefore they did not request an accompanying person for the scan.

Only 17.1% of respondents reported that radiographers offered some reasonable environmental adjustments, which included i) allowing more time to ask questions and get explanations (21%), ii) music played through the headphones (14.8%), iii) offering a blanket (11%), iv) making efforts to reduce noises (11%), v) adjusting lighting in the room (7.8%), vi) adjusting temperature (6.2%), vii) offering more pillows (4.6%), viii) allowing more time for familiarisation (3.9%), ix) trying to reduce number of people in the room (2.3%), and x) offering a video to watch during the scan (1.6%).

A total of 36.8% of adult autistic service users reported that they were offered headphones for use during the scan, only 34% of them were offered music and 6.4% said they had the option to watch a movie during scanning.

Patients' ratings of their MRI experience:

We also asked autistic adults (n=112) to rate their experience (from 0 to 100, where 0 = poor experience, 50 = moderate 100 = excellent) in relation to the MRI unit environment (Figure 1). Overall autistic adults highly rated the cleanliness and tidiness in the MRI room; however, experiences in relation to

acoustic noise levels in the scanning area, comfort when lying down on the scanner examination table and availability of quiet areas to relax were rated as very poor by most autistic adults.

A total of 44.8% of respondents reported experiencing claustrophobia during the MRI scan. Although only 17% of the 17 adults who had undergone more than 5 scans reported claustrophobia compared to the 38.3% of the 42 who had only one scan, overall, the relation between number of scans and reports of claustrophobia was not statistically significant (r_s= 0.007, n =72, p = 0.95).

Finally, we asked the respondents to rate their overall MRI experience from 0 to 100, and on average they rated their experience as neutral (mean=48.54±30.14).

Qualitative results:

Figure 2 demonstrates the themes and categories of the content analysis.

The categories that emerged from the content analysis of the open-ended questions can also be viewed in supplemental material 2 in descending order of frequency based on their occurrence in the data. The data related to a) descriptions of MRI scan experiences and b) suggestions for improvement of these experiences to other autistic service users and to healthcare practitioners. Furthermore, table 2 below depicts some representative quotes on the five more frequently discussed categories.

Discussion

While many studies use MRI to study the neurological correlates of autism, to our knowledge, this study is the first of its kind that directly highlights the experiences of autistic service users when undergoing MRI examinations. The results of this study point to a range of interesting, albeit concerning, findings with clear implications for future practice.

Communication and flow of information between healthcare practitioners and autistic service users:

From the combined results of this work and previous literature[24,33] communication between healthcare services and autistic service users scheduled for MRI examinations is vital and it needs further improvements. This observation relates not only to the lack of information to the service users beforehand, but also lack of communication between healthcare services (e.g. referring consultants and radiology practitioners) and suboptimal information exchanges before and on the day of the examination. Recent research corroborates this, as autistic service users have been found to largely report communication challenges alongside other barriers when accessing healthcare.[3,21,48] Poor patient-healthcare provider communication leads to lower satisfaction for autistic patients because of more unmet needs during their care compared to non-autistic users.[21] If a radiographer is not aware of all the required information prior to the patient attending for MRI scanning, they have

very limited options and time to customise the MRI scan for the patient on the day of the examination. Also, and perhaps most importantly, providing a lot of new information to autistic individuals on the day of the MRI scan, and not before, could further increase their anxiety and make the whole experience overwhelming. Therefore, it is essential to provide them with accurate and meaningful information in a timely manner.

MRI departments should engage with autistic service users by employing a personalised communication approach during pre-visits, such as obtaining critical information about the autistic patient's needs and preferences prior to the examination.[12,13,48] Effective communication should also include clear and detailed information provided to autistic individuals well before the examination in an inclusive way: we must also consider the timing and format (orally, in writing, with the use of flashcards, and/or with the facilitation of a specialist), since customisation of the experience correlates with improved healthcare outcomes.[49,50] Useful to note that many autistic individuals prefer other ways to communicate than the phone, due to social anxiety and other reasons.[51]

Impact of masking:

Most of the adults in our study (53.6%) did not disclose their autistic identity when booking the examination with the MRI department. This may be because of concerns about being stigmatised, lack of adequate information provided from healthcare services and masking.[52] Some respondents explained that they felt embarrassed to disclose they were autistic before the MRI scan, because of fear of how this could affect their care. Our results substantiate that, when prompted by healthcare practitioners, autistic services users in our study were at least twice as likely to disclose their identity before the MRI scan compared to those who were not prompted by a healthcare professional. Social camouflaging, often with masking behaviours, is used by many autistic individuals to hide their autistic identity during social interactions.[52] Very importantly, camouflaging or masking may limit the availability or range of provisions and adjustments and, subsequently, impact service user experience. Interestingly, disclosing a diagnosis and individualised needs and preferences may lead to a worse scanning experience than not disclosing at all, as this study has showed. This may be because the expectations for service provision increase when an autistic person discloses their identity and preferences; however, the link between expectations and satisfaction in healthcare remains weak and not sufficiently studied.[53]

We must still do a lot of work to support and empower autistic patients to disclose their identity when using healthcare services, to ensure their individual needs and preferences are met and their experience is humanised.[54] Finally, we can also attribute the lack of customised communication approaches or reasonable environmental adjustments to the lack of a formal autism diagnosis at the time of MRI scanning which might impact overall experience.

Communication and coordination between healthcare services:

The examples of poor communication before, during, and after the scan from this study also indicate a lack of coordinated care, and lack of effective communication between healthcare services. Previous research has similarly reported a lack of support from general practitioners towards autistic individuals,[55] and highlighted the need for cross-disciplinary coordination for continuity of care of autistic patients.[20]

The lack of early vital information reaching healthcare practitioners makes it more challenging for booking staff, receptionists, and radiographers to co-ordinate a plan and prepare personalised strategies for communication and reasonable environment adjustments. The lack of appropriate staff training in autism further accentuates these challenges.[33]

Despite the lack of sufficient information prior to MRI scanning, most of the respondents received adequate information during scanning (e.g. on how to use the MRI call button in case they felt unwell), in line with current MRI safety requirements prior to MRI scan.[56] Although most of the autistic participants reported not having regular communication with the radiographer during the scan, some explained it was their choice as they preferred to minimise distractions during the examination.

Personalising the autistic patient's MRI journey:

Customising the patient's journey is vital for their experience in MRI; we can achieve this in different ways,[24] including audiovisual material, pre-visits and other familiarisation techniques, distraction techniques and in-scan optimisation, including noise reduction and faster scanning techniques.[57,58]

In the present study most MRI radiographers did not adjust the MRI unit environment for autistic individuals, and we can attribute this either to lack of knowledge of the patient's needs, lack of training, lack of resources or lack of time during the busy clinical MRI slots.[33] These adjustments are, however, vital for a successful examination, given sensory processing sensitivities of autistic people,[59] atypical visual behaviour, auditory sensory processing sensitivities, and potential difficulties in processing simultaneous visual, auditory, and tactile inputs.[60] Based on this evidence, MRI departments should invest in staff training, patient preparation/communication, equipment e.g. adjustable lighting and temperature systems, spaces e.g. quiet areas, and finally develop strategies and make use of available hardware/software to reduce the noise. Moreover, visual timers could help alleviate some of the anxiety as they could offer some indication of the remaining time in the scanner for those who wish to know.

The literature reports hearing loss as an MRI-related complication.[61] The reduced use of headphones during MRI scanning, as autistic service users reported in this study, raises serious concerns regarding the lack of basic provisions of essential MRI safety equipment. However, this may be due to the use of earplugs instead or other noise cancelling techniques during scanning

or of inherently quieter MRI sequences.[62,63] This could also be due to inability to fit the headphones in the head coil due to coil design. This concerning finding is something that warrants further investigation in future studies.

Our results indicate that nearly half of the patients were not offered music, despite its known benefits to minimise anxiety and offer some distraction.[13,64,65] However, resourcing allocations or equipment functionality may limit the use of audio or visual hardware and software, so we must interpret the results under this lens.

Most patients in this study did not require the use of sedation or general anaesthesia (GA) before their examination. Sedation or GA have been used when scanning autistic individuals (mainly children) in the MRI environment.[66,67] However, these strategies carry their own potential risks,[68] and we should reserve them only for patients not able to undergo the examination fully awake, after a careful risk-benefit analysis on a case-by-case basis and in discussion with the service user and their carer, where appropriate.[69]

Patient satisfaction and ratings of MRI scan experience:

Research has indicated that patients undergoing MRI examinations can be influenced by prior personal experience or by the experiences of others.[70] MRI-related anxiety is higher during the first MRI scan.[71] We should take all these into account when customising the patient's MRI scan.

Autistic service users also reported a positive experience regarding the cleanliness and tidiness of the MRI room. Previous research findings highlight the impact of clean healthcare environments on reducing healthcare-associated infections[72] and improving patient satisfaction with the healthcare service.[73] Our study might include more MRI scans taking place around the COVID-19 pandemic, so our participants might have experienced an environment where enhanced universal cleaning and disinfection techniques were applying.

Autistic individuals rated excessive noise and the lack of quiet rooms as the most negative aspects of their MRI experience. Noise during MRI scans can reach above 100db[74] and it is a major factor of patient anxiety in hospital settings in general.[70] Autistic individuals are known to present more frequently than the general population with different levels of hearing loss, hyperacusis or other hearing conditions and sensitivities,[75] so efforts should be focused on improving these aspects during their MRI scans.

In addition, ensuring the patient's physical comfort when lying down inside the scanner is vital for an improved patient experience, for high-quality scans without motion artefacts, elimination of scan repeats and recalls.[76] Hence, we could employ lightweight and flexible coils, softer examination table mattresses, better and more customisable patient positioning provisions or wider magnet bores, including open-MRI and upright MRI solutions, to improve patient comfort.[77,78]

Autistic participants rated their overall MRI experience as moderate. This was attributed mainly to the lack of reasonable adjustments during the scan. Patient satisfaction with MRI examinations varies, as previous studies in the general population have reported, vastly related to individual patient experiences and environments.[79,80]

We noted a larger incidence of claustrophobia (44.8%) among autistic service users in our study compared to studies in the neurotypical population (10%).[30] We can attribute this to the complex sensory sensitivities and higher levels of anxiety experienced by autistic service users, which might increase prevalence of claustrophobia, but it may also be that this survey was completed predominantly by people who wanted to raise a concern in relation to their MRI scan experience, so we should interpret it with caution.

The results of the present study constitute valuable pilot data for larger scale prospective studies to optimise radiography practice, communication, software and hardware capabilities to better serve the autistic community, but also the general population.

Importantly, there are yet no data that report the numbers of autistic individuals who cannot undergo MRI scanning because of lack of accessibility. Autistic individuals living with chronic pain and various undiagnosed conditions, who have not been able to have any MRI examinations and therefore not eligible to participate in this study, have contacted us via social media to voice their concerns for the lack of accessibility of MRI examinations and the challenges they faced.

We hope that this and future studies will raise awareness of the poor experiences of autistic individuals undertaking MRI scanning and the lack of accessibility of MRI provisions and inform recommendations for MRI practice improvement.

Recommendations for practice:

Table 3 summarises some key recommendations for practice highlighted by our qualitative and quantitative data and supported by other literature as well. While many of these recommendations relate directly to better and more resourcing, their deployment may allow for more efficient and effective use of MRI scan time.

Limitations

Sampling:

This study used convenience sampling and numbers of respondents do not represent the large UK autistic population, so we should interpret the results with caution. Also lack of access to social media, through which we distributed the study, might have prevented the participation of some individuals. Finally, as this study only included autistic people with the capacity to self-consent, the results cannot be confidently generalised beyond autistic people whose

intellectual disability prevents them from possessing the capacity to self-consent.

Demographics:

The predominance of female autistic adults over male respondents in this study (3 females to 1 male) is not consistent with population estimates (3 autistic males to 1 female), although the latter are based largely on formal diagnoses and not self-identification, so may underestimate true numbers of autistic female individuals.[81,82] Previous studies suggest that females are frequently undiagnosed and under-represented in various research settings, such as clinical trials, and that some gender-related discrepancies in recruitment still exist.[83,84] For the current study, we are unsure if this occurred because women are more likely to participate in research than men,[85] or if it is because more autistic women undertake MRI scanning as part of their care.

Impact of covid-19 pandemic on this study:

We designed and conducted this study during the third lockdown of the COVID-19 pandemic in the UK, which inevitably affected participant recruitment, research design and methodology. The research team had to adjust to social distancing and other health, safety and infection control restrictions. Moreover, during that challenging time, the autistic community was disproportionately affected by the pandemic[86,87] and priority has shifted to mental and physical health, social distancing and face mask use, employment, and home-schooling. Inevitably workflow and some practices for MRI scans may have changed during that period; we do not have enough data to study the effect of this change on our study.

Retrospective study design:

This retrospective study sample is highly heterogeneous, as the respondents have been scanned by different MRI teams, in different MRI scanners, at different hospitals, and for different medical conditions or anatomical areas, all factors which can impact patient experience. Given this heterogeneity, it is difficult to identify the specific combination of factors that are of most importance in determining a positive patient experience. Hence, there is a need to prospectively examine the usefulness of different adjustments in a standardised clinical environment in future studies.

Conclusion

The findings of this study have highlighted the need for coordinated, customised, person-centred care and communication, availability of provisions and of reasonable adjustments during MRI scanning for autistic individuals, as central to service users' experience. We should encourage and empower service users to disclose their preferences and needs early before the scan, to ensure adequate provisions are available for them, as required. MRI departments should be equipped with all the necessary software and hardware for MRI scan facilitation and offer specific training to relevant staff to meet the

needs of every patient, including autistic patients. Time spent in the preparation and customisation of a scan is time well invested towards improving patient experiences and outcome of MRI examinations. Such adjustments to improve accessibility for autistic individuals can also serve a wider population with anxiety when attending for an MRI scan, helping to universally optimise patient experience.

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Authorship Contribution Statement

Conceptualization of the study and study ethics and design was performed by C.M. The manuscript was drafted by N.S and C.M. Qualitative data was analysed by J.H.L. and T.O. and reviewed by GP, and all quantitative analyses were performed by N.S. and S.G. Community involvement was through the autistic community on twitter, but also facilitated by KM and SP as coauthors of this work. All authors edited and approved the final manuscript.

Author Disclosure Statement

No competing financial interests exist.

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Figures

Figure 1. Mean experience ratings on a 1-100 point scale (1=very poor, 100=excellent) and standard deviation (SD) related to the MRI unit environment, as rated by autistic adults. The y-axis relates to mean experience ratings and the x-axis presents different physical environment characteristics, that participants were asked to rate in the MRI unit.

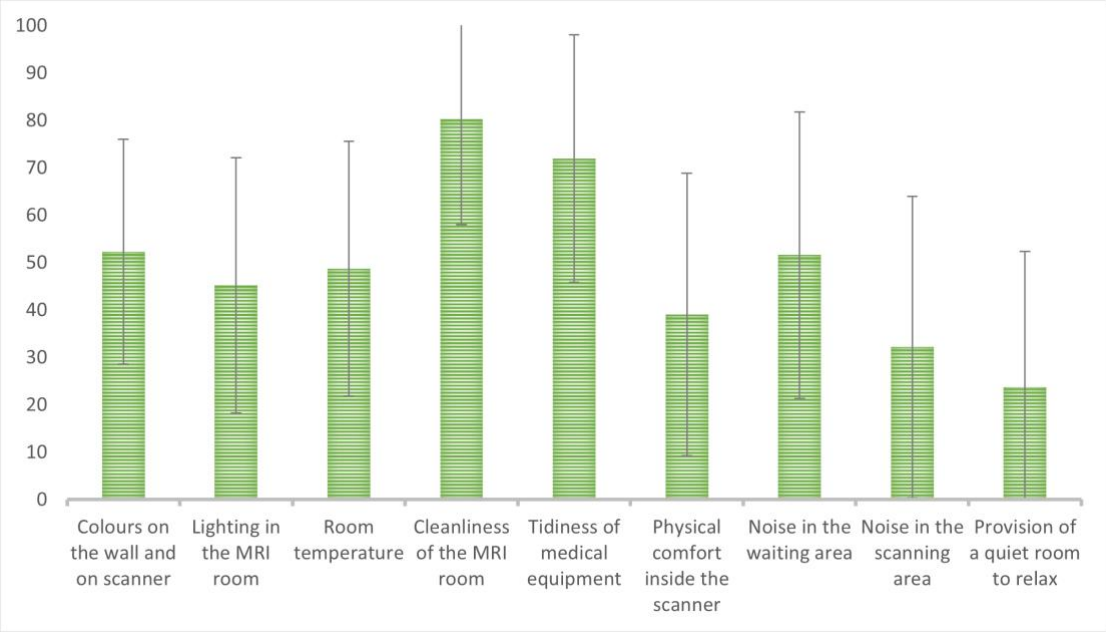
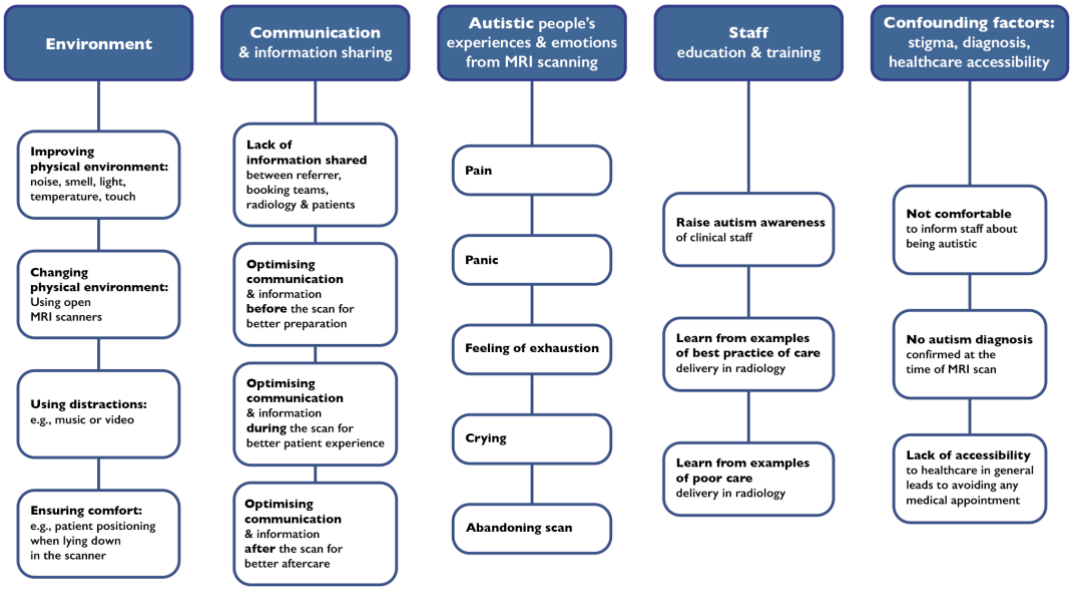


Figure 2. Themes (in blue background) and respective categories (in white background) emerging from content analysis.



Tables

Table 1. Demographic data of autistic adults (n=112)		
Gender	**N**	**%**
Female	69	61.7
Male	23	20.5
Non-binary	17	15.1
Other, please explain	2	1.8
Prefer not to say	1	0.8
Age	**N**	**%**
16-17 years old	2	1.8
18-30 years old	29	25.9
31-40 years old	28	25.0
41-50 years old	33	29.5
51-60 years old	17	15.2
60+ years old	3	2.7

Table 2. Representative quotes for the top 5 emerging categories as derived from content analysis (see also figure 2)	
IMPROVEMENTS TO PHYSICAL ENVIRONMENT	‘’ A quiet space to wait, not having to change in a cubical with staff members coming in without asking, having music or something that you can listen to and a choice of earbud or can protection’’. ‘’ Explain how noisy it will be. Have nice people carry out the scan. Ask the person what music or thing they want. Give a choice if they have the weird mirror thing because that was really awful and disorientating - I’d much rather see the top of the tube than a confusing view of the room that’s not actually above my head. Ask the person if they want to be talked to regularly or left alone. Have a timer or give verbal timing reminders if the autistic person wants that. Give them a space to relax after if they want it; offer a drink or something. Tell them (if they want you to talk to them) when they can relax or move and things like that. Ask them if they are happy to continue. Really it was so noisy and the mirrors so unsettling I was in a complete panic but frozen with fear. Honest explanation would’ve helped’’. ‘’ Give a visual schedule of all the steps. Give a visual and auditory representation of how much time has passed and how much time is left. Only offering ‘’emergency buzzer’’ to stop the procedure is a huge barrier because we will try to avoid doing that at all costs...which leads to a lot of unnecessary suffering’’. ‘’ My main issue with hospital appointment is the bright lights, the noise, and the smells. Everything is very full-on in the sense, and I’m quickly overwhelmed. A quieter, darker area to wait in would be so helpful’’. ‘’Have a selection of items that autistic people can use in the scans such as fidget toys music movies’’.

	‘’ Slow everything down and give us time to adjust to our surroundings at every stage. When you move us from place to place in the dept tell us where we are going, why and what’s going to happen. Again, do so slowly and calmly and ask us if that is okay. Give us options, like a blanket or clothing we could keep on that would be safe in MR so we don’t have to get changed. Offer us earplugs OR headphones which I think worsen the feeling of claustrophobia. The main thing for me though is to do everything slowly. Speech, explanations and even just walking through the department. Ask if we want you to repeat what you’ve just said. For me, it keeps everything calm and less stressful but I appreciate everyone is different’’.
PANIC	’ The technician might do this many times a day, but each patient is special and for the patient it can be a huge experience (teamed with general anxiety about health)’’. ‘’ I was not able to speak within a few moments of the scan starting. From the time they left the room to the time I came out of the machine I was entirely alone apart from with xxxx. I didn’t know my carer was in the room’’. ‘’I was frightened of how little space I had and felt claustrophobic. I also struggled with being told not to move as I fidget and also got instantly itchy knowing I couldn’t scratch. I also stim when I need to calm down, which I couldn’t do because I was told not to move’’.
USE OF MUSIC	‘’They provided headphones and said music would play but it was silent, I heard everything’’. ‘’Strongly encourage bringing music of your choice in an acceptable format’’. ‘’The headphones provided did not work’’. ‘’Be prepared for how loud it is and don’t choose music that has a range of volumes, just pick something that can be turned up loud’’.
LACK OF INFORMATION	‘’They tried I think, but info was very sparse and poorly communicated, with no time for me to process it’’. ‘’Ask about disability beforehand. Specifically ask about sensory processing if someone ticks the ASD box. Send written pamphlets out with appointments. Have pictures of what a scanner looks like. Encourage radiographers to get creative about how they get their pictures’’. ‘’Information. Need to know how long the waiting is beforehand. Not knowing how many more minutes until something starts causes me great anxiety’’. ‘’Take your time explaining things. Use direct language. Do not rush people. Acknowledge that this is going to be a hideous experience for some autistic people and try to show them empathy without being patronising. Do not treat autistic adults like children. We are not children. Be kind’’.

	‘’Show me a video or pictures of what will happen and don’t assume I understand what to do if something goes wrong. Give me regular reassurance that you are still there. Explain afterwards when and how to leave’’.
COMFORT	‘’Allow lenience for individuals who may need more patience or adjustments - asking if someone is comfortable or needs anything adjusting is a small thing that may help them a lot!’’. ‘’ A blanket to wrap up in if needed as the room is freezing and adds to my anxiety and I end up shivering uncontrollably, more regular contact of how long left, dim lights, mindfulness audio etc’’. ‘’Headphones, blanket, possibility of having additional pillows to support body’’. ‘’ Is it possible to wear your own clothes instead of the hospital gown? The knots in the back are uncomfortable and sometimes the material is new and stiff, or old and bobbly. You could tell people to bring comfy pjs without metal buttons or eyelets, or joggers and a t-shirt’’. ‘’ Request a private waiting room, if possible. Use any relaxation aids that they can provide. Make sure staff know of any autism-related factors you have, e.g. hyperacusis; it’s LOUD in there’’.

Table 3. Key recommendations for practice.

Challenge	Implication	Recommendations
• Poor communication and lack of adequate information provided to service user by radiology prior to scanning.	• Poor preparation of MRI scanning processes, lack of available experts, equipment or time, lack of reasonable adjustments, impact on service users and staff anxiety.	• Ensure adequate, and optimally delivered information sent to all patients before the scan.[49,50] • Adjust communication style to the individual.[10,21]
• Poor communication between referring consultant and Radiology. • Autistic service users not asked about their scan preferences and needs.	• Inability to offer personalised care and person-centred service. • Lack of adequate time in MRI scanning slots. • Lack of sedation or anaesthesia provision in cases	• Ensure communication and coordination of services between GPs/referring consultants and Radiology.[24] • Implement tailored pre-scan communication

	where it is truly needed.	and assessment checklists.[12,13] • Empower autistic individuals to disclose their identity and personal needs and preferences.[54] • Staff training needed.[10,22]
• Masking and non-disclosure of autism by service users.	• Poor service provision, poor service user experience.	• Empower service users to disclose their identity.[54] • Implement tailored pre-scan communication and assessment checklists.[12,13] • Ensure communication and coordination of services between GPs/referring consultants and Radiology.[24]
• An increase in claustrophobia among autistic service users.	• Increase in non-shows and decrease in scan completion rates. • Emotional trauma experienced by service users, their families, and their carers.	• Invest in open bore, wide bore, upright MRI scanners.[77] • Clear communication and tailored environment adjustments needed.[10,24] • Use distraction and relaxation techniques: music, movie, self-hypnosis.[11,13,64]
• Lack of reasonable adjustments e.g. increased noise in MRI	• Anxiety propagates, poor patient experience, poor image quality and	• Adequate acoustic noise reduction strategies (headphones, earplugs) with

environments, lack of quiet spaces to relax, reduced use of headphones, uncomfortable examination table.	low scan completion rates more scan recalls and repeats.	respect to the sensory sensitivities of each patient.[24,70] • Sequence modification to reduce noise.[70] • Industry to consider using more effective noise cancelling materials, more comfortable positioning aids and examination tables, and better designed headphones and head coils.[12] • Availability and provision of quiet rooms needs to be considered. • An experience-sensitive approach in co-defining accommodations that improve patient experience by considering their sense of meaning making, uniqueness of each autistic person, sense of comfort (senses, sense of belonging) to avoid one size fits all approach.

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