Improving access to Magnetic Resonance Imaging (MRI) examinations for people with disabilities.

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ABSTRACT

For people with disabilities, accessing healthcare services can be problematic, uncomfortable and potentially unsafe. Whether it is situational, temporary or permanent impairment, disability can affect everyone. When the healthcare company Philips Healthcare embarked on designing their next generation MRI machines, we, the human factors team, applied an inclusive design approach from the outset. In this paper, we will share details of a research study we conducted into how people with disability currently experience MRI. Data were collected via qualitative online interviews, with ten participants experienced disabilities from the UK. The findings showed that access to MRI radiology is an uncomfortable experience, both physically and cognitively. Accessibility issues were found throughout the process from travelling to the appointment, preparing for the scan, accessing and exiting the MRI machine. The general findings from the study are shared and recommendations for how to improve access to MRI radiology are presented.

Introduction

Magnetic Resonance Imaging (MRI) is used in diagnostic medicine as a means of determining the source of illness and symptoms, especially those concerning soft tissue such as tumours, brain, vascular, muscles, etc. Philips has been designing and manufacturing these highly complex machines since the 1980s. In this paper we will describe one of our inclusive design research studies into the accessibility of MRI machines by people with disabilities.

Our primary task as the human factors team was to define the ergonomics and usability specifications. The ambition was clear: to develop an accessible and ergonomic MRI machine for all users. We realised when embarking on writing the specifications that there was a lack of information and data regarding the accessibility needs to radiology of people with disabilities. Literature searches uncovered insufficient data that could be used for the specifications and Philips' MRI application specialists could provide only anecdotal information from their experience when working as MRI technologists. Consequently, we decided to apply a full inclusive design approach to the writing of these specifications and focus our attention on the under-represented and potentially excluded user populations. Holmes (2020) recommends such an approach, whereby teams begin by recognising potential exclusion, learn from those populations and then apply the knowledge to many. In principle, all users should benefit from such an approach.

Considering the prevalence of disability in our society, and numerous legislations concerning accessibility, it is perhaps surprising that the needs of this population for accessing healthcare (radiology in our case) does not appear to be well integrated. With one in five people in the UK (Gov.uk 2020, Ryan 2020) and one in seven people globally (Kupers and Heydt, 2019) having some form of disability, the potential population of this user group is hundreds of millions of people. However, due to their 'vulnerable' status many are not included in research. An example of this data gap is highlighted by Harniss et al (2021) following their investigation into children with special needs and how missing data compromises the ability of health systems to support them. These data gaps are not limited to those with disability but even women in general, as shown by Criado-Perez (2019). Consequently, there is limited availability of representative data from which to write ergonomics and product specifications.

In this paper, we will share how we conducted an online inclusive design interview study with people with disabilities to uncover the needs of this population with regards to accessing MRI. The qualitative data collected was rich in insights and findings that were translated into ergonomics specifications for the new MRI design. While we cannot share the detailed findings that are being used for the new MRI machine's specification at this time due to company confidentiality, we will discuss more general accessibility findings we uncovered that include physical and cognitive factors. These findings could be used to guide those working in healthcare on the issues people with disability may face and provide direction for improvement.

Literature and previous work in this area

Prior to conducting this study, a review of existing literature into this area was performed. Our search criteria included: accessibility to healthcare and radiology; inclusive design studies in healthcare; injury and accessibility; disability lifestyle accounts.

From our search we found only one research paper on the precise subject of disabled access to radiology written by a team from the University of California and Marquette University (Story et al, 2008). They investigated the access of 20 people with mobility disabilities to CT, X-ray and Fluoroscopy scans through simulated examinations. Their participants were video recorded getting on and off the patient tables and they then watched these videos and provided a commentary of their actions. The height of the table, lack of handles, maintaining a posture and fearing they may fall, were the primary causes of discomfort. This study did not include MRI radiology which due to its high magnetic fields requires additional workflow steps that may also result in other accessibility barriers.

Read et al (2018) investigated how hospitals in the UK have applied 'reasonable adjustments' for the accessibility of people with disabilities to hospitals following the UK Equality Act 2010. This study covered the entire journey of accessing the hospital and they found that people with disability continued to experience limited provision of facilities and unpleasant encounters despite the legislation. One of their participants commented on a negative experience with their MRI scan regarding the inability to hear the technologist.

Within the Ergonomics literature, there are numerous papers on the health impact for healthcare employees regarding patient handling and the transfer of people with disability from wheelchairs to beds (McGill and Kavcic 2005, Marras et al 1999, Garg et al 1991). These papers highlight the risk to the lower back during patient transfer and how difficult it can be even with two healthcare employees working together. The need to reduce the risk to the staff when assisting people with disability is also an important requirement.

Taussig (2020) illustrates in her autobiography what life is like for a disabled person and describes how control and independence are often taken away from those with disability by well-meaning people, but this only hinders their ability to achieve a task. This was later confirmed during an interview with Hignett (2021), as background research for this study. From her observations in hospitals, she noted how there seems to be the assumption that controlling the person will speed up workflow. It is unknown if these findings were also applicable to the MRI process.

We also found literature describing the general living and health conditions of people with disability (Ryan 2020, Shakespeare 2017), as well as autobiographical accounts (Taussig, 2020) and calls to action for change (Wong, 2020). These texts highlighted the need to remove the physical and social barriers to healthcare and how those with disabilities were twice as likely to find healthcare provision or equipment to be inadequate to their needs. There was however, no detail for what these physical barriers may be and how we as a healthcare equipment provider can improve our machines. Consequently, the need to design for inclusion was clear, but to do so we needed to invite people with disability into the project so we could learn from them directly.

Sample and study design

The variation in disability is vast since "Disability is multi-factorial. It is a bio-psycho-social model." (Shakespeare, 2017). Moreover, disability can be permanent, temporary or situational depending on the context (Holmes 2020, Shum et al, 2016) as well as being compound whereby people may also have multiple disabilities (Ryan, 2020). Therefore, a truly representative sample group might have required hundreds of participants.

When this study was being planned, the project was in the early phase of designing the major engineering components and thus the engineers needed specifications that would help them determine the mechanics and general form. According to the literature, 30% of disabilities in the UK are related to MSK, arthritis and rheumatism (Shakespeare, 2017) and in the USA 13% have mobility related disabilities (CDC, 2019). The decision was made therefore to focus our research on those with physical and mobility disability as this may have the greatest influence on the mechanics. However, many people with disability have compound issues and so there was a high chance we would meet participants with other disabilities such as sensory impairments. Since this was a specialist sample group, we employed a recruitment agency that had experience with sourcing this type of participant. We recruited ten participants from the UK and they were distributed as follows:

- 50/50 male to female
- 4x 18-30yrs, 1x 30-40yrs, 3x 40-50yrs, and 2x 50-60yrs
- All had physical / mobility disabilities (including, MS, amputee, arthritis, cerebral palsy, spina bifida and 2x also had sensory disability (visual)
- 7x had an MRI scan within the last 6 months and 3x within the previous 12 months

The study design was based on qualitative data collection and thematic analysis. The rationale for applying this approach was that we needed to understand the precise details of a disabled person's interaction with radiology. This would align with the principles of inclusive design which is to 'solve for one, then extend to many'. Thus, a detailed understanding of their interaction and the 'why' behind their actions was important, and qualitative methods are typically most suitable for obtaining this (Cohen et al, 2000).

Read et al (2018) conducted research into the accessibility of the NHS health service in the UK using qualitative data collection methods: face to face and telephone interviews with people who are impaired. These participants provided in depth responses and insights regarding their disability experiences. Data were analysed using thematic analysis. This precedent study demonstrated a seemingly successful approach that we could apply for this investigation.

The interview structure was designed to flow from an open to closed questioning format. The open question approach at the beginning was necessary to avoid undue influence or excessive directing of the participant. For that reason, the interviews were guided as follows:

1. The participants were asked to introduce themselves and to describe their disability.

2. Open questioning regarding their day-to-day life and how their disability affects their way of living.
3. Open questioning on their experience of accessing radiology. We asked them to describe one of their more recent visits to radiology.
4. Depending on the responses from the previous questions the interviewer would ask follow up questions to delve more deeply into their first responses.
5. Finally, the interviewer would check the topic list and ask about remaining topics to see if they were pertinent to that participant or not.

Two co-creation activities followed the interview using the online virtual whiteboard tool Miro. The first was to complete a timeline of when, where, how, (and why) they navigated their journey to and from their radiology appointment. The second was a good, bad and ideal review of existing MRI machines. A green sticker was placed next to attributes they liked and those that might aid their access. A red sticker was used to mark attributes that were less appealing or may hinder their access. The participants were also free to describe what they would really like to see in an ideal world.

Due to the pandemic of 2020/21, it was not possible to meet with these participants in person. Consequently, the method of data collection required remote access via video call. The interview and co-creation activities were therefore designed for this with audio recording and the use of Miro to host and record the co-creation activity.

The raw data collected were ten audio recordings of the interviews, each of approximately 70 minutes, and ten co-creation whiteboards. The audio recordings were transcribed and analysed, along with the corresponding whiteboards, by three human factors experts as well members of the project team who had expertise in engineering and clinical applications. Each reviewer was asked to read through a selection of the transcripts; each transcript was reviewed independently at least twice. A thematic approach was used whereby the reviewers were requested to highlight text that fell into coding criteria, such as: examples of impact of disability on daily life; positive interactions with healthcare / radiology; negative interactions with healthcare / radiology; physical interaction with the MRI machine; suggested improvements for accessibility.

A workshop was held with the reviewers to synthesise the data. The coded transcripts were reviewed, from which findings were deduced, counted, and clustered. From this, improvement areas were agreed upon.

Results and discussion

Prior to discussing the findings, it is necessary to note that the participants did not know or remember the brand of the MRI machines they used. Also, since the participants were located across the UK, and attended different hospital trusts, it is unlikely that they all experienced the same MRI brand. Consequently, these findings are general opinion of accessibility to radiology.

While we cannot share the findings related to the design specifications for the new MRI machine, we also uncovered many interesting findings from other parts of the system and more general access to radiology that we will discuss below. This will be followed by a set of recommendations for how to improve the inclusiveness of radiology.

The ten participants were all experienced with undergoing MRI scans. Collectively, this sample had undergone approximately 130 scans in total, with four participants having more than ten per year, and one having over 20 per year. To put this into perspective, the NHS in 2018 conducted 300,000 MRI scans (NHS England, 2018) for the population of England, this equates to 0.005 scans per person. This concurs with Kuper and Heydt’s report (2019) in so much as those with disabilities are simply more likely to require more healthcare. They live within a narrower margin for health and have a higher risk of unintentional accidents (Shakespeare, 2017).

Despite people with disabilities being a frequent user of healthcare, it appears from our sample that access to radiology is not well designed for them. When asked to tell us about their past experiences of accessing radiology we found that for every positive point the participants made, there were on average three negative points. This increased to five negative points when discussing direct / physical interaction with the MRI. We found that seven of ten participants had experienced physical discomfort and pain when accessing, during, and existing the MRI scan, and nine had experienced anxiety / cognitive discomfort.

The findings pointed towards improvement areas across the radiology system. From an organisational perspective four of the ten participants noted how the scans scheduled in the morning were hard to attend as their bodies "Take time to get going", P1. They required more time for their muscles and limbs to begin functioning and for medication to start working. Travelling to a hospital for an MRI appointment required detailed organisation and effort, such as, arranging accessible taxis, checking the routes for obstacles and that the location of the car park or bus stop is within a distance they can walk. Consequently, many things have the potential to go wrong and the chance of missing an appointment increase.

Due to the powerful magnetic fields of an MRI scanner, it is required that patients undress and wear a gown for the scan. This presented three issues for the participants. Firstly, getting changed in the changing rooms can be difficult and time consuming since they often did not have enough space, handrails or tools to assist them when undressing. Eight of the ten participants had adapted their homes to enable them with (un)dressing and washing, and yet few to none of these aids were available in these facilities.

Secondly, the participants were required to leave behind any form of assistive aids, such as crutches, glasses, prosthetics or wheelchairs that they used. Without their assistive aids, they became more disabled as the environment did not enable them to move easily from the changing room to the MRI scanner. Instead, the participants needed to use a MRI safe wheelchair, if available, but often, they were expected to try and make the walk unaided. People with disability have an increased fear of falling (Hignett, 2013) due to having poor balance and muscle control. The removal of their personal aids further reduces their ability to remain in control and be independent.

Thirdly, five of the ten participants, expressed a fear of losing their assistive aids; that they might be stolen, misplaced, or damaged while they are having their MRI scan. To an onlooker (and even to a MRI technologist), these may appear to be just a pair of crutches or a wheelchair, but to the disabled owner, these items are their security, their safety, their independence and means of survival in an otherwise inaccessible world. Without them they can literally be trapped and unable to help themselves (Taussig, 2020).

Accessing the patient table was particularly unpleasant for these participants. Seven of the ten participants described a situation when getting onto the table that was uncomfortable and painful, with one participant even suffering a dislocated arm. The time required to get on and off the table ranged from a few minutes to over 20 minutes when support or aids were not provided. They wanted to have more handles, grips, and a lower table, which concurred with the results from Story et al (2008). During the scan, four of the ten participants needed to tense their muscles to remain in position, increasing the chance of muscle fatigue, spasms and moving mid scan. Seven participants described situations that would have slowed down workflow and placed organisational stress on the staff. Read et al (2018) found that those in their sample experienced similar situations, where the impaired patient required more assistance.

Anxiety was experienced by nine out of the ten participants before, during or after their scan. The interesting finding was the cause of this anxiety. Typically, MRI related anxiety is often attributed to claustrophobia but that was not the case for these participants. While they found the MRI scan itself unpleasant, their sources of anxiety included: how they were going to get on or off the table; would the staff help them or not; would the staff rush them (social disability); would they embarrass themselves by not being able to do something; would they spasm during the scan; would they fall. During the pandemic of 2020/21 our disabled participants told us how accessibility became even harder when the staff were not permitted to touch or physically support or assist them as much as they did pre-pandemic. This made it physically harder to access radiology and increased their anxiety even further. Many of these concerns concur with the literature, such as losing control and independence (Hignett, 2021), or their condition not being understood or even recognised by the staff (Kuper and Heydt, 2019). One participant, whose disability was not obvious to onlookers, found the social interaction with the staff (social accessibility) very difficult, with this being her primary source of anxiety.

Limitations of the methodology

Holmes (2020) describes the inclusive design process as: recognise exclusion; learn from diversity; solve for one and apply to many. In this study, we recognised the exclusion in the data that was being used to define the new MRI machine's specification. We conducted a study to bring the lived experience into our project so we could learn from these people, and to see how we can design for their needs. The methodology applied worked well, since all the participants were comfortable sharing their experiences with us and they were able to describe their needs in detail. We learnt not to focus on the disabilities as a source of design input, as these varied considerably; instead, we directed our attention to how they were being excluded. Once this was understood we were able to identify commonalities across the sample from which we could more easily deduce design specifications.

Recommendations

From this inclusive design study, we deduced the following recommendations for improving general accessibility to MRI radiology:

- When designing studies, conducting product tests, or assessing hospital facilities, the criteria for sample groups ought to be weighted towards people with disabilities. Listen to them, understand how they are excluded, and then look for design solutions. Focus on the source of exclusion and not their disability.
- Provide more flexibility when scheduling and more time allowance for people with disabilities to travel and prepare for their scan. Include details of what is expected and how they can access the hospital/radiology department.
- Provide changing facilities with more space to manoeuvre and have assistive aids, such as shoehorns, grabbers, a seat, handrails, etc.
- Provide a safe and secure place to store a disabled person's belongings during their scan.
- When possible, allow those with assistive aids to use them for as long as possible before needing to swap to an alternative. Provide good quality alternative aids.
- The route to and from the MRI scanner should also be free from clutter and easy to navigate.
- When accessing the patient table, take the time to lower it, provide assistive aids and supports, as this will help to improve workflow and maintain the schedule, as well as improving the experience for the patient.
- Disabled people are experts in their condition and know what they need (Shakespeare, 2017). Help them stay in control and independent by asking them what they need, rather

than assuming, and giving them time to get comfortable; this could potentially help to improve radiology workflow, reduce anxiety, and improve the MRI experience for those with disability.

- Do not assume anxiety is caused by the MRI scan or claustrophobia, for these participants it was the least of their concerns. Embarrassed of their personal situation, inability to get on or off the table, or not wanting to move during the scan are more troubling; focus on improving social accessibility via staff training.

Concluding remarks

This study into the accessibility of MRI for people with disability has revealed how difficult it is currently for these people to access MRI, but we also uncovered many insights and improvement areas, not only for the MRI machine, but for radiology in general. The findings and subsequent recommendations included aspects relating to physical, cognitive and social barriers to accessing radiology, highlighting the importance of applying a systems thinking approach as the breadth of human experience cannot necessarily be improved from one perspective only. Moreover, working with those who have lived-experience in dealing with disabilities we learnt how our assumptions, e.g. our presumed cause of anxiety, can be incorrect and our participants helped us to identify other misconceptions that as abled bodied people we had not been able to perceive, e.g. the value of an elbow crutch.

Our participants were enthusiastic to share their experiences and stories in detail, which has enabled the designers and engineers to understand how accessibility can be more of a problem than the impairment itself (Shakespeare, 2017). The disability community have a saying, “Nothing about us, without us”, and this study highlighted to many people within the organisation why this is necessary, as it is not possible to imagine how disabled people experience this world. By following the inclusive design approach of Holmes (2020) this study has had a great and positive impact on the design directions of the new MRI machine and empowered the team, with insights and knowledge, to create more inclusive solutions.

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