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MRI for fetal developmental brain abnormalities: perspectives from the pregnant patient

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Abstract

Ultrasound is routinely used as a prenatal screening and diagnostic tool but has limitations. Some anomalies in the developing fetal brain can be difficult to detect, and in utero MRI (iuMRI) is increasingly used as an adjunct to ultrasound. However, understandings of patient perspectives of iuMRI technology are still developing. Our qualitative study of 41 mothers who experienced iuMRI was embedded in a diagnostic accuracy trial, and aimed to inform policy recommendations that might stem from the clinical findings. Our analysis suggests that iuMRI is seen as useful, offering valuable additional information, and helping women make decisions about care options at a difficult time. However, patients' experiences demonstrated the uncertainty and anxiety associated with the prenatal diagnosis (PND) process relating to brain anomalies including the challenges of their embodied contributions. Our findings suggest more could be done to reduce the impact on pregnant women during an already difficult, anxious period.

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Background

From the early 1990s ultrasound scanning (US) developed to become the standard method of detecting fetal structural abnormalities (Getz & Kirkengen, 2003) and it is now a routine part of antenatal care. In the UK, US is routinely offered at 18-20 weeks (NHS Fetal Anomaly Screening Programme, 2015) and includes screening for brain abnormalities. Despite improving techniques, sonographers still face factors that impact on the quality of imaging (e.g. position of the fetus (fetal lie); physical characteristics of the mother). Anomalies in the developing fetal brain can be subtle, difficult to detect, and open to clinical interpretation (Bijma, Wildschut, van der Heide, van der Maas, & Wladimiroff, 2004; Blondiaux & Garel, 2013). The development of methods of acquiring MR data very quicklyⁱ has led the way to magnetic resonance imaging (MRI) of the fetus, including the fetal brain. In utero MRI (iuMRI)ⁱⁱ has overcome problems presented by fetal lie and maternal body shape, while the development of ultrafast imaging methods negates many of the obstacles associated with fetal movement. IuMRI of fetal brain abnormalities is a clinically useful adjunct to diagnostic ultrasound from as early as 18 weeks gestational age (Blondiaux & Garel, 2013; Griffiths et al., 2017; Saleem, 2013); in cases of apparently isolated ventriculomegaly (VM)ⁱⁱⁱ diagnosed by US, iuMRI has been shown to increase the detection of other brain abnormalities particularly agenesis of the corpus callosum^{iv} (Blaicher et al., 2003). IuMRI thus has the potential to influence clinical management (Griffiths et al., 2017; Saleem, 2013).

Questions of accuracy and clinical utility of US and iuMRI in prenatal diagnoses raise queries about the impact of new healthcare technologies on patients, in a complex area of health care provision. Decision-making following a diagnosis of fetal abnormality generates significant research and debate about the emotions and dilemmas that parents and clinicians encounter. Parents report being ill-prepared for a prenatal diagnosis (Ahman, Runestam, & Sarkadi, 2010; Lalor & Begley, 2006; Mitchell, 2004) and clinicians face complex ethical decisions and may experience personal conflicts (Garel, Gosme-Seguret, Kaminski, & Cuttini, 2002). Getz and Kirkengen (2003) highlight the importance of distinguishing between technology development and technology implementation in prenatal diagnosis, and argue for more research into parents' experiences. For example, in a qualitative study of prenatal US experience, researchers found that sonographers' behaviour figured prominently in women's accounts of experiencing an unexpected fetal diagnosis (Van der Zalm & Byrne, 2006). More recently, an ethnographic study of a fetal medicine clinic employing iuMRI suggested that clinical uncertainty could be positively mediated by the radiologist's use of the technology (Reed, Kochetkova, & Whitby, 2016). Reed et al (2016) note in their conclusion that health professionals see iuMRI images as a bridging technology that aided translation across medical specialties, but also assisted clinicians in counselling patients.

Understanding how patients experience the process is ethically imperative if proposing changes in clinical practice. Williams et al (2006) in particular have raised concerns about how new technologies in fetal medicine tend to emerge into clinical practice prior to understanding the broader consequences for patients. An early study of 32 women undergoing iuMRI found that while ultrasonography was preferred, most patients felt relaxed and comfortable (Duncan, Baker, Johnson, & Gowland, 1996). More recent findings suggest that iuMRI is more stressful than US; a prospective questionnaire study of 100 patients (Adamsbaum, Garel, & Legros, 2008) found that iuMRI increased anxiety by its setting and the uncertainties about fetal risk. Another study (Leithner, Pörnbacher, Assem-Hilger, Krampfl-Bettelheim, & Prayer, 2009; Leithner et al., 2008) reported that 58% of 62 women interviewed were concerned by the intensified fetal body movements in response to the noise^v and vibration during the scan. Nevertheless, overall 63% reported that iuMRI was ‘easy to tolerate’ and a follow-up study of 36 women one year after the investigation (Leithner et al., 2013) reported that acceptance of iuMRI was very high. However, for some women, the noise, physical restraints, and duration of the examination (Leithner et al., 2008) seemed to have lasting effects in the form of enduring psychological distress (Leithner et al., 2013).

MERIDIAN is a diagnostic accuracy trial funded by the UK National Institute for Health Research (NIHR) Health Technology Assessment Programme [project number 09/06/01] to assess iuMRI as a technology to aid in the prenatal diagnosis of fetal

developmental brain abnormalities. The clinical trial was complemented by an economic analysis of provision, and a qualitative study of patient and health professional experiences of receiving and providing iuMRI. The clinical study encompassed many clinical units across the UK, offering a unique opportunity to explore the impact of introducing new or revised care pathway developments in practice, and the feasibility of further policy development for iuMRI provision in the UK. The qualitative study was made up of three parts, each involving the collection of primary data. Part 1 involved asking all patients to complete two questionnaires (Survey One shortly after a decision about the affected pregnancy having been made; Survey Two some weeks after pregnancy completion). Part 2 involved interviewing a subsection of those who completed the surveys, where participants could express an interest in taking part at the end of Survey Two. Part 3 involved interviewing health professionals providing iuMRI, in the first and third year of recruitment to the clinical study.

In this article we report the results of the qualitative interviews with patients. Our findings explore women's embodied experiences of iuMRI in their accounts of receiving prenatal diagnosis care. Whilst iuMRI is of interest to social scientists for many reasons, we wanted to focus on women's experiences first, and then to determine where iuMRI fits into the bigger picture for the women interviewed. Drawing on existing sociological literature^{vi}, we explore the complexity of women's experiences

evident in data from in-depth interviews. Our aim was to explore whether iuMRI offered meaningful benefits for these pregnant women, and whether their experience of the procedure could be improved.

Research context and methods

(i) *The clinical context:* In the UK (NHS England, 2013) ultrasound screening is offered to women at 11-14 and 18-20 weeks of pregnancy. If an anomaly is identified or suspected, the woman is referred to a second sonographer or consultant, and (if the woman consents to it) referral to an in-house consultant with fetal medicine experience or to a specialised fetal medicine unit (FMU). If an anomaly is confirmed, the patient may be offered relevant prenatal investigations such as maternal blood-testing, karyotyping/chromosomal microarray, or iuMRI where available. Within the UK National Health Service, this care pathway is publicly funded. Women's iuMRI experience differs from ultrasound. Not all clinicians choose to make use of (or have easy access to) iuMRI, so provision is variable. Then, during the scan, women have to remain still for 20-40 minutes, lying on their back in a confined space. The imaging process can be loud, warm, claustrophobic and/or uncomfortable, particularly as pregnancy advances. Understanding women's experiences of this care is important in informing future policy, given that comprehensive national provision of iuMRI is still developing.

The MERIDIAN study is a multi-centre prospective observational study of the diagnostic accuracy of iuMRI for fetal developmental brain abnormalities. The study recruited women with an US diagnosis of a fetal brain abnormality from 16 FMUs in the UK between 2011 and 2015. Recruited women attended one of six centres for their iuMRI.

(ii) *The research project context:* The clinical study included a three-part social scientific qualitative element exploring patient and professional experiences of iuMRI as part of the prenatal diagnosis pathway for brain anomalies. The aims of the parent experience aspect of the qualitative study were:

1. To describe, explore and understand how women (and their partners/relatives) experience an iuMRI scan as part of the fetal diagnosis care pathway
2. To give an account of perceptions of iuMRI on decision making
3. To gain insights into the impact of developments in technology and medical knowledge

The purpose therefore of this parent-focused part of the qualitative study was to complement the clinical study, by looking at women's experiences of the prenatal diagnosis experience from a more critical, social science perspective. Currently iuMRI in antenatal care is variable in how it is managed and delivered^{vii}, and future policy on iuMRI provision is likely to reduce variability in provision. Our research explores a

range of women's experiences, from different care pathways, to inform any policy developments stemming from clinical efficacy study^{viii}.

Approval for the sub-study was obtained from the UK NHS South Yorkshire Research Ethics Committee (Dated 3 March 2011, Ref 11/YH/0006). Women were approached for the qualitative study after recruitment to the trial, following the initial iuMRI and counselling. Particular care was taken that women had enough time after the pregnancy outcome to consider participation before written consent was taken. Because of the sensitivity of the topic, research midwives were allowed discretion about whether and how to approach individual women especially if they had suffered pregnancy loss soon after their iuMRI. Following entry to the qualitative study, women were given a survey questionnaire collecting socio-demographic data, overall satisfaction with care, and perceived utility of the iuMRI results. A second questionnaire was administered three to six months after the pregnancy outcome was known. This included an open text question to allow participants to raise issues they felt important to their health care experience; and a filter question to allow women to express an interest (EOI) in taking part in a qualitative in-depth interview. We received 108 EOIs from 14 FMUs. We drew on the questionnaire and clinical data about research participants to generate a sufficiently diverse sample for the interviews. This was needed because the study findings were intended to inform policy developments, should the clinical case for expanding access to iuMRI be found valid at the end of the clinical trial.^{ix} Initially the

sampling strategy for interviews covered three specific FMUs representing different models of iuMRI provision (iuMRI provided locally; iuMRI provided at a central iuMRI site where patients travel; or a hybrid model with both local and regional iuMRI). We added a fourth sub-group to the interview sample, made up of patients from several of the smaller FMUs, to further enhance understandings of patient experience of centralised technology in the context of secondary level (rather than tertiary level) care provision. The sample for the interview study was therefore diverse in that it encompassed participants from different types of care pathway. Because a small number of sites were added towards the end of the trial and after the survey closed, there was representation from only 13 of the 16 FMUs, and 3 out of 6 of the MRI centres.

The ultrasound diagnosis, participant's age, gestation at MRI scan, and outcome were also considered in the course of sampling from trial data (see Table 1 in supplementary file). Gravidity and parity were not available to be included because they were not directly relevant to the primary and secondary outcomes of the trial.

(iii) The parent interview data collection process: As the researcher responsible for the qualitative study of patients, Mabel Lie had password protected access to relevant sections of the central database managed by the MERIDIAN study team at the Sheffield University Clinical Trials Research Unit (CTRU).

Altogether forty-four interviews were conducted between September 2012 and December 2013. Twenty-five women were interviewed individually, 16 were joint interviews with partners or mothers mainly to support them (Zarhin, 2018), while two interviews were conducted with partners on their own. An additional interview was with a partner who requested that his wife (who had been interviewed separately) be present with him. Interviews were conducted in participants' homes and recorded on an encrypted digital voice recorder. All participants were asked to sign a separate qualitative interview consent form. A narrative approach to interviewing was adopted, allowing participants to develop their own account of their 'story' of their pregnancy. This allowed us to consider how the iuMRI experience fitted into the participant's broader perspective of their antenatal care. The topic guide was used to prompt the participant to discuss key issues e.g. learning about the abnormality, undergoing the iuMRI scan, and decision making about the pregnancy, differences between US and iuMRI, information seeking, and support. The audio recordings of the interviews^x lasting between 1-2 hours, were transcribed by two research secretaries. The transcripts (stored on a secure server) were then checked and anonymised by Mabel, and uploaded into qualitative data management software (Atlas.ti) for indexing and retrieval.

(iv) The parent interview study data analysis: In his classic text *Interpreting Qualitative Data*, Silverman (2006, p. 119) outlines a threefold typology of positivism, emotionalism and constructionism as frameworks for analysing qualitative interview

data. Of particular interest to us is his analytic distinction between an emotionalist approach (which aims to understand authentic experiences), and the constructionist approach (which assumes that meaning in the data is mutually constructed). Our approach encompasses elements of both emotionalism and constructionism, but constructionism is the more dominant element. The women we interviewed had experienced prenatal diagnosis of a brain anomaly, and then iuMRI as part of the PND process, which is not universally available to all women whose baby is at risk of a brain anomaly. They therefore had a unique perspective to offer us, but such perspectives are difficult to access because prenatal diagnosis is a sensitive topic. The authentic experience that Silverman (2006) characterises as associated with emotionalism was important to us, but we aimed to take the authenticity expressed in interviews and reflect on it as socially constructed and contextualised. Constructionist thought drives the analysis, but it contains elements associated with a more emotionalist approach, creating analytic tensions that were ultimately productive.

The semi-structured interview transcripts allowed us to start our analysis from women's experiences of the relative importance of iuMRI in the context of the prenatal diagnosis pathway overall, rather than leading the interview with our interests in iuMRI. Information was also collected on key aspects that are important from a policy perspective that would be part of any future policy work in iuMRI provision.

Our work is informed by two strands of medical sociology thinking. First, our approach draws inspiration from Frank's (1995) notion of illness narratives. Secondly, the strand of work that focuses on embodied experience was also important, given the emphasis in women's accounts of their embodied experiences during the scanning process. These perspectives provide an element of 'standpoint' epistemology (Harding, 1991) to the analysis. This blend of theoretical influences maps well to the complexities of iuMRI in the context of prenatal diagnosis of brain anomalies. The narrative elements allow us to contextualise the phenomenon of iuMRI as part of a much more complex process, but foregrounding embodied experiences, to represent and evaluate women's experiences on their own terms. At the same time, the more interrogative aspects of viewing abnormality as socially constructed allows us to more fully explore the inherent uncertainties associated with prenatal diagnostic categories. Together, these theoretical influences provide a framework that encompasses the analysis of both representations of highly personalised experiences alongside a critically interrogative exploration of patterns of meanings.

Given this blend of theoretical influences, we used thematic analysis as the practical framework with which to conduct the formal analysis of the data. Thematic coding is used in a variety of theoretical traditions, so it is well suited to the demands of our blend of theoretical influences. Drawing on the six stage process set out by Braun and Clarke (2006), we analysed the interview data to encompass both the emotional and embodied

standpoints of participants as well as our interpretations of their socially constructed perspectives of the value and role of iuMRI.

The interview transcripts were grouped according to MRI centre and pregnancy outcome. A generative thematic analysis (Braun & Clarke, 2006, 2014) and an inductive-abductive strategy influenced by grounded theory (Charmaz, 2006) was used to interrogate the data. Gerunds were employed as codes, which were grouped into thematic families. Codes within these families were checked for consistency, and compared for similarities and differences across families. Broader themes were then developed from these codes to make up the overall thematic framework (Charmaz, 1983, 2006). Synopses of each interview were composed by Mabel, and read by Ruth Graham for an overview of all the interview cases. In addition, data meetings within the sub-study team (Ruth, Mabel and Stephen Robson) provided a qualitative form of inter-rater reliability (Silverman, 2006) for the coding frame and interpretive analysis. The thematically organised data were then used as the basis of an interdisciplinary meeting with the wider study team members, to review the final thematic framework.

As the descriptive coding framework developed and remained stable following additional interview data, recruitment was ceased. Theme summaries were developed (led by Mabel with input from Ruth). Relatively descriptive themes were refined and re-ordered in such a way as to begin the process of building towards a more explanatory perspective. This was an in-depth, systematic analysis of the interview data by the two

sociologists on the research team, with further refinement and sharpening of the thematic groupings through input from a broader group that included clinicians and researchers from other disciplines involved with the study to boost the pragmatic utility of our findings for future policy development.

We aimed to describe and explain the role of iuMRI in the prenatal diagnosis pathway and its impact on the women involved, to inform decision making about future policy developments on the basis of a rigorous social science analysis, rather than to generate specific theoretical constructs about iuMRI. We present the findings of our analysis in this article under the three main thematic headings generated from the data: Themes 1, 2 and 3.

[Interview study findings^{xi}](#)

Theme 1 – The subjective embodied experiences of iuMRI scanning

The provision of the iuMRI scan varied within and between MRI centres, and was also impacted by issues such as women's gestation, their BMI, and other medical problems e.g. diabetes. One iuMRI centre was an academic radiological unit (Site A) and had a different clinical protocol to the two other iuMRI sites (D and M); at Site A women had the opportunity to view the iuMR images directly after the scan, in discussion with the academic radiologist. At other sites, the iuMR images were sent to the FM specialist with a report and a consultation with the patient was arranged sometime after the scan. Here we offer an insight into the common experiences of the women across the sites.

The findings suggest that the women's subjective embodied experiences of the scanning process were impacted by their status as pregnant, and became more problematic as their gestation (and therefore size) increased.

1.1 Willingness to tolerate emotional and physical discomfort: The iuMRI sessions lasted from around half an hour to over an hour. Two key issues could lengthen the scan: how well the individual woman tolerated the scan (and if she needed breaks); and how active the fetus was during the scan (which may delay the capture of accurate iuMR data). All the women were well aware that the purpose of undergoing the iuMRI was because their baby had been found to have a brain abnormality, and getting information to find out more about their baby's condition was the focus of their concerns. As a result, they were often highly motivated to assist in achieving a successful scan, despite their anxiety and discomfort:

..because it was [Baby] everything became more scary and more frightening and more upsetting even though I knew I was perfectly safe and I knew there was no risk to him, it was still the 'I'm really scared about what it's going to show' [] and rather than the actual thing itself so.....had I been pregnant with [Baby] and [Baby] was perfectly healthy, I probably wouldn't have been that bothered. It was more the fact that I knew he wasn't well – (Site D, 19 weeks, IVM)^{xii}

In most of the women's accounts, descriptions of their discomfort appeared to be related to their pregnant condition, which was exacerbated by the noise, heat, and enclosed space in the machine:

...when you are pregnant, I think, I think when I'm pregnant I'm a much more erm, sort of spatially sensitive. I need my own space a lot more. [] Probably hormonal - (Site D, 22 weeks, nVM)

Challenging experiences in the iuMRI scanner were more common in those who were over 24 weeks' gestation. Not only did their increased girth lead to more discomfort but the emotional impact of being in a tightly enclosed space could lead to additional anxiety:

But that was the only problem that I had like it was I felt very, I felt unsafe if you know what I, but I'm sure that any, anybody who's that's heavily pregnant going in to a machine like that and you know feeling like you're gonna get trapped in there cos you've got such a big belly – (Site A, 36 weeks, IVM)

Women described their experience of pain because of how cramped they were in the machine or because of pregnancy-related pelvic pain. This was exacerbated by the 'frame' that was placed across their abdomen^{xiii}

But it was quite uncomfortable and I had to lie on my back which was very painful and then they had the, the cage thing over my stomach which was quite heavy and

it was very uncomfortable and it was very hot and I was still having morning sickness it was just.... – (Site M, 32 weeks, nVM)

The majority of women strived to keep as still as possible so that the data for the images could be obtained as quickly as possible. A few were concerned about the noise being harmful to their fetus. Most women described actively resisting the urge to come out of the scanner and tolerated any discomfort they experienced, because taking a break would only delay the process:

There were headphones and music, I remember that and I was given a button to press. I spent the whole time trying to make myself not press the button. Tried to last as long as I could [laugh]. – (Site D, 22 weeks, IVM)

These accounts point to the extent of the discomforts of being in the machine and the way women tolerated them, which can often be overlooked in the diagnostic process.

1.2 Aids to tolerating discomfort: Some women described ways in which their intense experience of the iuMRI scan became more tolerable. For example, women were particularly grateful for their partner's presence during the scan:

...allowing [Husband] in there to like, have a hold of my hand and stroke my hair, well all he could reach was my hair so he was patting my head, ... made it a much more tolerable experience. – (Site D, 19 weeks, IVM)

Other instances included interaction with health professionals during the scan. For example, some participants reflected on how the radiographer helped to make them comfortable, and briefed them about the procedure before and during the scan via the headphones:

no it was a bit strange experience but it wasn't unpleasant or pleasant. It was just a different experience for the first time... And then it went du, du, du, du, du, du, du, du. Right we are blasting off in a minute. We were making jokes kind of thing. ... It didn't upset me or scare me or anything. – (Site M, 23 weeks, IVM)

Women who were less advanced in their pregnancy seemed to have had a more positive experience of being in the scanner. For example, even though Emma (22 weeks) suffered pelvic pain which caused her discomfort, she managed to fall asleep in the scanner. Sue (20 weeks) who was used to running around looking after her three year old, described the experience of lying in the machine as restful, while Sarah (25 weeks) felt the vibrations were like a massage in bed.

In general, women were willing to undergo discomfort because of the concern for their baby, and their desire to get more information. The following was a typical response:

I think again because you're focussed on, because you are worried about your baby, again I think I would have gone in a much smaller tunnel through the water if necessary – (Site A, 29 weeks, IVM)

Nevertheless, the narratives point to the subjective embodied experiences of different women who share the common condition of being pregnant and desperate to know if their baby has a serious problem. Pregnancy-related conditions especially musculoskeletal pain can heighten negative experiences of the procedure. Further, perceptions that fetuses reacted to the noise of the scanner provoked anxiety in some women. To balance these accounts of women's physical and emotional experiences of iuMRI, we now consider women's motivation for undergoing the scan.

Theme 2 – Negotiating the developmental uncertainty of fetal diagnosis

The diagnosis and counselling of a fetal brain abnormality is challenging partly because of the multiple pathologies that can co-exist but also because 'developmental' brain abnormalities can change or evolve over gestation (Hannon et al., 2012; Sethna, Tennant, Rankin, & Robson, 2011). Coupled with this are the differing skills and knowledge of the health care professionals involved (Prasad, 2005). This area of medicine can become baffling for patients and their partners, as they contemplate their wanted pregnancy through a series of incremental steps that aim to reduce uncertainty. The care pathway for a fetal brain abnormality would usually include follow up US scans to monitor the abnormality and for some pregnancies, a second or third iuMRI at later gestations, with the aim of reaching a more definitive diagnosis and/or prognosis. However, even if a definitive diagnosis can be reached, the prognosis is often limited to a risk-based analysis of the probable impact on the future child.

2.1 Understanding and monitoring the abnormality: For most parents, the offer of an amniocentesis (to exclude a chromosomal abnormality) and then an iuMRI to determine the characteristics of the abnormality, were then followed by an emotional journey of monitoring scans and experiencing ongoing uncertainty about the future. For example, in the case of isolated VM, the initial prognosis is highly dependent on the ventricular size; ranging from at least a 90% chance of normal development when the ventricle measurement is 10-12 mm to less than 50% chance of normal development if the measurement is > 15 mm (Gaglioti, Oberto, & Todros, 2009). Parents understood that the risk to their baby depended on the ventricular measurement, which could stay the same, increase or decrease. For parents where the ventricular size remained constant, this was seen as being of less cause for alarm, but for parents where the measurements increased over time, it clearly represented a worsening of the condition.

when it was diagnosed it was ten and a half and twelve and a half or something like that ... you know one was mild and one was moderate ... so the next time one was moderate and one was heading towards severe you know it was [] and when, we went once and it was they were both over fifteen [] both left and right were both over fifteen and I was, I cried at that one because I knew that, that was severe and it wasn't decreasing it was getting worse – (Site A, 22 weeks, IVM)

Parents described a roller coaster of emotions, especially when the measurements changed in a short space of time:

Then it was twelve point eight, nineteen ... twenty eight point five and ...twenty three []. So it just got bigger and bigger and bigger and last time we had his MRI they said it was thirty two wasn't it? – (Site M, 25 weeks, VM+, Infant with a disability)

Because of what they understood about VM, the experience of follow-up scans, whether iuMRI or US, could be the most stressful part of the patient's journey. For several parents, the iuMRI scan was just one appointment of many along the care pathway. In addition, the clarity of the imaging cannot ameliorate the inherent uncertainty of eventual outcome, as some infants will have a normal outcome despite having enlarged ventricles.

In cases where the diagnosis was 'non-isolated VM', many parents described the experience of monitoring not only the size of the ventricles but also other structural abnormalities. Together with referrals to other specialists, and understanding that it could develop in different ways with the prognosis being uncertain, the process took a huge toll on parents. The majority of these cases of non-isolated VM were serious brain abnormalities that ended with a termination of pregnancy, a non-surviving or infant with a disability. As compared with VM, other fetal brain abnormalities were less common and often required less monitoring.

2.2 Understanding and tolerating uncertainty: The parents' accounts suggested that whilst clinicians made some attempt at explaining the condition, they also admitted the limits of their own clinical understanding.

..because the brain is such an unknown scientific thing, they can't, there's not much, you know, there's not much research on the brain ... that they couldn't pinpoint anything -- (Site A, 20 weeks, IVM)

Apart from unanswered questions as to aetiology, there was also the question of the long term outcome. The following case concerned the discovery of bilateral abnormalities (cysts and abnormal brightness [echogenicity] in the cerebral cortex of the frontal and occipital lobes), and attempts to understand the condition and how it was affecting the fetus in its development.

They then said they didn't know what these cysts meant so we should still go for the MRI because they, they didn't know they'd not. She hadn't personally seen them before, she hadn't even seen them in the literature. When we went to the MRI scanner they found the cysts and they still didn't know what they meant -- (Site A, 29 weeks, nVM)

But more important to parents was their need for a definitive prognosis, including what it could mean for the viability of the pregnancy, the baby's postnatal development and how as parents they would manage:

I mean we were kind of saying well, how is this gonna affect my baby know like we don't know [] we don't know what it is, so we, we, we, we don't have anything to tell you - (Site M, 32 weeks, nVM, Infant with a disability)

Arriving at a definitive prognosis was difficult especially in the case of VM where the degree of abnormality could vary over time – for some, ventricles that are of abnormal size may return to within the normal range at a later point in pregnancy. For those parents who were focused on the risks associated with an abnormality (e.g. ventricle size), the risks are not definitive in terms of impact on prognosis, and so remain open to further interpretation. Where uncertainties were difficult to explain, the MRI image could be a useful tool to aid understanding of diagnosis and as a result explain prognosis in some cases. This is explored in the next theme.

Theme 3 – Qualifying the beneficial role of the iuMRI

Participants' experiences of managing the uncertainties associated with PND for brain anomalies highlighted the contradictory role that iuMRI played in both extending, and limiting, the scope of uncertainty associated with the prenatal diagnosis of a brain abnormality in the fetus.

3.1 Reassurance without risk: Of the 11 parents in the interview study who reported undergoing an amniocentesis, none had a baby with a chromosomal abnormality. As for parents who had decided against an amniocentesis, they seemed to place a greater reliance on the iuMRI findings.

P43, who was carrying twins, described their reliance on the iuMRI, as they decided not to have an amniocentesis because of the increased risks of miscarriage. The parents reported that the iuMRI suggested that there were no abnormalities other than VM, and the corpus callosum (which was not seen on US) was present. This had provided reassurance that the VM abnormalities were not also an ‘indicator’ of a more widespread problem with the baby’s brain. For these parents, the iuMRI was a crucial element in reducing uncertainty:

before the MRI was done you know to be told it could be fifty, fifty or it could be ninety to ten you know is a big difference []. Because they can’t say without having additional information of knowing if everything else is ok or if there’s other issues with the brain they’re not gonna know. So you know by having the MRI those percentages made more of a sense erm before the percentage you might as well of just said pick a number out the air. – (Site M, 21 weeks, IVM)

In contrast, for those cases where the brain abnormality was likely to result in a disability, it was a matter of the degree of severity, rather than a question of whether there would be an impact on the baby.

3.2 Limits to the acceptability of iuMRI: Parents face difficult and complex decisions about what is best for their baby, and their family. In such instances, the iuMRI usually played an important part in parental decision-making, as parents carefully weighed up the known and unknown aspects of their baby’s prognosis. For one participant who

decided to continue with her pregnancy, the iuMRI confirmed the overall brain structure was normal, whereas the US was only able to indicate the size of the ventricles.

However, to some parents, the iuMRI offered information to confirm what the ultrasound scan revealed, but did not provide additional substantive information.

Nevertheless it was still appreciated because it ‘confirmed what the ultrasound had already seen’, Mandy (Site M, 21 weeks, IVM)

For some parents though, there was little perceived benefit as a result of the iuMRI. For them, the anxieties and discomfort of the iuMRI scan, together with what could be conceptualised as unnecessary worry, figured more prominently in their accounts of the PND experience overall. A minority of respondents felt they would not undertake iuMRI in the future, should a similar situation arise, but this minority gave important insights into their thinking about this possibility:

*I was massive and I got, I got crushed in there so when I come out I was crying
[Mabel: were you crying?] yeah I got crushed so I couldn't, I had to lie a certain
way erm obviously with how big my belly was – (Site M, 29 weeks, IVM)*

The following is an exchange between the couple (Site M, 20 weeks, VM+) and the interviewer:

*Partner the MRI is an intimidating machine it's an intimidating noise
and you've got to be still*

Patient You've got to keep nice and still.....

Mabel do you feel like you were put through unnecessary worry?

Patient You say that all the time don't you [yeah] yeah. He says it all the time.

Some parents highlighted the fact that iuMRI was able to generate hundreds of images from various angles, demonstrating that they understood this was a qualitatively different form of imaging to US. Those at Site A were also given access to the images and the possibility of a video clip. These parents were also able to contrast the clarity of the iuMRI images with those of the US scan, which they felt contributed to greater accuracy and information for the clinicians. Others with an increased BMI described the iuMRI having the capability to obtain the images which in their experience the US had failed to do. This suggested that the perceived benefit of the iuMRI image was enhanced if parents had the opportunity to see and discuss their iuMRI with a clinician.

Evaluating the use of health care technology is often focused on clinical outcomes using statistical measures of accuracy and cost effectiveness. Our data suggest that, in the case of iuMRI for diagnosing fetal brain abnormalities, understanding patient experiences of the prenatal diagnosis care pathway is an important facet in the evaluation of a new health care technology. While a certain amount of uncertainty is often unavoidable in prenatal diagnosis, the accounts from participants pointed to the benefits of iuMRI in providing a different type of image and offering the potential for better experiences of

care during a period of difficult decision making. However, a minority of parents also offered understandable reasons for not choosing this option again, should a similar situation arise.

Discussion

The literature on the topic of iuMRI in prenatal diagnosis is limited and confined mainly to clinical and psychological studies of the impact of this new technology on women (Adamsbaum et al., 2008; Leithner et al., 2008; Saleem, 2013). On the other hand, there is an extensive literature on patients' experiences of US in prenatal screening and diagnosis, (Ahman et al., 2010; Lalor & Begley, 2006; Mitchell, 2004; Van der Zalm & Byrne, 2006). Social constructionism in particular is a key theoretical perspective that has helped shed light on key aspects of antenatal screening and testing^{xiv}. Coinciding with the more explicit developing interest in the sociology of diagnosis (Jutel & Nettleton, 2010), the combined interest in diagnosis, medical imaging and the fetus as patient has prompted some fascinating and highly productive work on the use of iuMRI in pregnancy. Reed et al.'s work (2016; 2016) in particular is noteworthy in terms of how social constructionist accounts of pregnancy have been used to inform critical evaluation of this emerging technology. Practically speaking, the issues raised highlight the need for parents to be better prepared to face 'bad' news and ongoing uncertainty, and for clinicians to be more equipped to counsel patients. Our analysis suggests that the contribution of iuMRI is in providing improved information, not only to clinicians

but to parents as well, particularly if the visual data are made available to them. This is consistent with findings suggested in Reed et al (2016) that iuMR images can allow both the patient and the professional to navigate clinical uncertainty in a productive way. Our study of a wider sample of women adds to this work by providing insights into the patient experience of the physical discomforts of iuMRI and, in several cases, an emotional roller coaster during their prenatal diagnostic pathway. As such, it points to the importance of patient-professional interaction in healthcare where not only the emotional but the embodied needs of the patient are acknowledged.

An established body of literature that ranges from critiques of philosophical interpretations of pregnancy, to feminist counter interpretations of the social realities of being pregnant testify to pregnancy as an embodied experience (Mullin, 2002).

Neiterman (2012) claims that the physiological changes of pregnancy such as weight gain and sickness are neglected in most studies of pregnancy. In the literature on patient experiences of US and MRI, it is often the case that the physical condition of pregnancy is rarely mentioned, with the focus being on the mechanical and psychological effects of the scan. The physical and emotional ‘labour’ that women do in pregnancy such as dealing with nausea and vomiting, fatigue and physical pain is rendered ‘invisible’. This may be a result of a general belief that women are able or expected to bear pain better than men as part of their natural constitution (Bendelow & Williams, 1998).

Alternatively, it may also be that the focus is on the fetus as a patient (Casper, 1998;

Duden, 1993; Harrison, Golbus, & Filly, 1990) and shifted away from the embodied experience of the pregnant woman.

Following the idea that all human perception is embodied, this article highlights the patient experience of iuMRI for fetal brain abnormalities. Women and their partners on this pathway are full of expectation, anticipation and anxiety. As pregnant women they are experiencing numerous physiological changes and for some, physical discomfort. However, although pregnancy is often conceptualised as a site of legitimate medical intervention, notions of pregnancy have moved away from an illness model. In addition, the emergence of the fetus as an (unborn) patient introduces a tension in how clinicians deal with occasions where the needs of the two patients are in conflict (Casper, 1998). The interview data also illustrate the intimate and embodied interactions between the fetus and the patient relative to the physical effects of being in the MRI machine. The physical and emotional ‘invisible’ work that many pregnant women do extends to being the compliant patient and enduring the physical restraints of the scan machine, and keeping ‘nice and still’. This is because their overriding concern is the health of their unborn baby. In offering our interpretation of women’s accounts of their experiences of iuMRI, we aim to enhance existing understandings of women’s experiences of prenatal diagnosis.

Much has been written about decision making in relation to termination of pregnancy following prenatal diagnoses (Benute et al., 2012; Bijma, van der Heide, & Wildschut,

2008; Werner-Lin et al., 2016). The main conclusions from these studies are that information from medical technologies can not only help inform but also complicate decision-making. MERIDIAN is a study of a technology that has yet to be rolled out across the NHS. In the light of existing studies, it is important to evaluate the impact of new fetal diagnostic procedures on pregnant women; it is their body that is subjected to any physical procedure, and within the options available under UK law, they are the primary decision makers about the future of the pregnancy in the context of a serious fetal abnormality.

Drawing on these findings, we are able to offer insights into the experiences of pregnant women, prior to the formulation of further national or centralised NHS policy on this procedure. We conclude that the offer of a diagnostic MRI as an adjunct to US in the existing care pathway is well received by women and their partners, but the experience can be a big ‘ask’ in physical and emotional terms for many. While the research reported here is a limited study of women undergoing MRI at three sites, we are able to draw on the commonalities to highlight specific policy relevant themes. Firstly, many women are very willing to tolerate discomfort to try and resolve uncertainty because of what it can mean for decision making about the future of their baby. Secondly, in an information-hungry social context, women often feel that they have no choice but to tolerate uncertainty in prenatal diagnosis because of clinical and technological limitations. All this is in the context of the possibility of a termination which most

women understood to be legal only up to 24 weeks, not being aware that it is allowed for serious fetal abnormalities beyond this.^{xv} Thus the role of the iuMRI in providing information and insight has to be seen within the context of this perceived time limit as well as some women's preference to avoid amniocentesis. The question that could be asked is whether clinicians should recommend that women undergo an experience that can have such physical and emotional effects in order to come to a diagnosis.

MERIDIAN has shown that there are many informational benefits from an iuMRI but care should be taken about assumptions that women will want to have the information regardless of the difficulties experienced during the scan.

Clinical Implications

The MERIDIAN study has shown that the iuMRI has significant utility with regards to diagnostic accuracy and for many women, the information from the MRI scan was perceived to be very helpful. What the qualitative sub-study results reveal however is that more could be done to improve women's experience of iuMR imaging as part of the prenatal diagnosis pathway. This is ethically desirable because of the impact that emotional disturbance can have both on the patient as well as the fetus in utero (Ding et al., 2014; Dubber, Reck, Mueller, & Gawlik, 2015). Prior to undergoing iuMRI, it is important that health care providers take steps to reduce patient anxiety and acknowledge that some characteristics e.g. increased BMI, advanced gestation and pregnancy-related symptoms impact on the experience of MRI. Their briefing of women

should ideally include reassurances of the (minimal) effect that the machine can have on the fetus (Baker, Johnson, Harvey, Gowland, & Mansfield, 1994; Clements et al., 2000) and on the women themselves. During the scanning process, health care providers should be aiming to give women a patient-friendly experience (Duncan et al., 1996). On-going commentary during the scan can help allay fears and the presence of a supportive partner can help women cope better with discomfort, thereby increasing the likelihood of the scan being completed successfully. After the procedure, women appreciated having some idea of how the scan went, and when results could be expected. If these conditions were present, not only would they improve the patient experience but they would also acknowledge the embodied experience of pregnancy as well as the need for an equal focus on both mother and fetus within the fraught circumstances of having to make a life-changing decision.

Concluding summary

From a clinical perspective, our article has established the significance of iuMRI for the accurate diagnosis of fetal brain anomalies and in reassuring and/or satisfying parents' needs for information regarding their developing child. While we have provided recommendations for improved practice, further research could be conducted into how useful our recommendations have been for both the clinical community and patient advocates. From an academic perspective, the use of iuMRI is a new and growing area of research, especially so in social science approaches to prenatal diagnosis. On this

specific topic, there is very little relating to decision making, both for clinicians and parents, making this a useful area for future research. As social constructionism is a key feature of medical sociology more generally and there is a significant amount of literature relating to the social construction of pregnancy, there is scope beyond this article to utilise this epistemology in further theoretical work on the impact of new scanning technologies in prenatal diagnosis.

Declaration of conflicting interests

The authors declare that there are no conflicting interests.

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ⁱ These methods include improved gradient performance in hardware and the development of 'ultrafast' sequences such as single shot Fast Spin Echo and Steady State acquisitions.

ⁱⁱ We use the term intra uterine MRI (iuMR Imaging or iuMRI) to indicate that our research focuses on the experiences of women undergoing MR imaging of a live fetus in-utero. This term is used in preference to fetal MRI, which is a broader term encompassing other forms of MR imaging, such as imaging the fetus post mortem.

ⁱⁱⁱ The cerebral ventricles are a communicating network of spaces in the brain filled with cerebral spinal fluid. Ventriculomegaly (VM), defined as a lateral ventricle width ≥ 10 mm (Saleem, 2013), occurs in up to 2.5 per 1000 pregnancies and is one of the most common brain abnormalities detected (Hannon, Tennant, Rankin, & Robson, 2012). VM is associated with other structural abnormalities, such as spina bifida, chromosomal abnormalities, such as trisomy 21, and congenital infection. Where other central nervous system (CNS) abnormalities are found in conjunction with VM, there is a higher risk of poor outcome.

^{iv} The most common additional brain abnormality found with VM is agenesis of the corpus callosum (ACC) (Blaicher et al., 2003). The corpus callosum is the largest fibre tract in the CNS and connects the two cerebral hemispheres.

^v A rhythmic thumping noise is produced by a pump for liquid helium in the refrigeration system for the scanner. Women are offered headphones but not sedation.

^{vi} Much of the existing sociological work on antenatal testing has tended to see routine screening (e.g. ultrasound or blood tests) and specific diagnostic testing (e.g. iuMRI or amniocentesis) as parts of one broader phenomenon. Whilst we would agree that this body of work has been very productive for how understandings of visualising the fetus (Roberts, 2012) have developed, we offer a slightly different perspective on iuMRI in this article. Our analysis stems from a more explicit analytic distinction between the phenomenon of screening and the phenomenon of diagnostic imaging in pregnancy. This distinction is important when considering women's experiences of their health care, because the risk-based decisions being made might be considered qualitatively distinct. Visualising the fetus in routine screening has become the norm and an accepted social event, whereas diagnostic imaging based on an identified anomaly is a rare occurrence and characterised by heightened anxieties particularly around the possibility of survival and decision-making about termination. Our work places this distinction centre-stage, and provides an analysis of women's experiences in the context of this specific form of uncertainty, where the materiality of the anomaly is more tangible.

^{vii} Existing services have developed in areas that have idiosyncratic characteristics (for example, a specialist radiologist, and access to MRI equipment).

^{viii} This would, in part, potentially help address Williams et al's concern (2006) about the speed with which technological changes are implemented without understanding the impact on user experiences.

^{ix} Given the expense associated with developing iuMRI care delivery, any national policy would need to encompass the existing variations in UK delivery to be economically viable.

^x The interviews were mainly conducted by Mabel Lie (41 interviews) except for a period of sick leave when Dr Emma Clavering conducted three interviews.

^{xi} This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, MRC, CCF, NETSCC, the HTA programme or the Department of Health.

^{xii} See explanations of abbreviations in Table 1.

^{xiii} This piece of equipment contains radio frequency receiver coils to improve signal reception.

^{xiv} For example, social constructionist perspectives on disability to evaluate prenatal screening and prenatal diagnosis in relation to social expectations (e.g. Asch, (1999)) has highlighted how social contextual issues impact on women's choices about diagnostic testing (e.g. Rapp (1998)). More recently, the debates about the socially constructed nature of antenatal testing in particular, and of pregnancy more generally, have developed to encompass a growing interest in embodiment in the social sciences. For example, Williams' (2006) milestone work analyses routine antenatal screening and innovative fetal surgery as parts of the same shift toward the construction of the fetus as patient. The literature on visual representations in antenatal testing are informed by a broader literature on visualisation and technology, and for MRI, Joyce's (2005, 2006) work has been seminal.

^{xv} In the UK, decisions about whether a specific fetal anomaly is a legitimate basis for termination of pregnancy on the grounds of fetal anomaly fall within the jurisdiction of clinical opinion, rather than there being a codified list of anomalies. Two clinicians with relevant expertise must agree that the requirement is met for any termination of pregnancy for fetal anomaly before the termination is permitted.