



**Reporting consciousness in coma:
media framing of neuro-scientific research, hope,
and the response of families with relatives
in vegetative and minimally conscious states**

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Abstract

This paper examines the public representation of, and family responses to, scientific studies into consciousness in coma-like states. We examine the publicity surrounding high-profile studies using functional Magnetic Resonance Imaging (fMRI) on 'vegetative' or 'minimally conscious' patients and compare this with family views. Our findings show how, with a few notable exceptions, the research was presented as an amazing breakthrough offering a potential 'voice' and choice for patients and hope and comfort for their families. We argue that such representations ignored key limitations, evoked unrealistic visions of recovery, and promoted very narrow representations of family reactions. The comparison between public representations of the science and responses from families with experience of this issue highlights the complex social/medical world into which neurotechnologies intervene, and points to the absence of a range of patient/family perspectives in public discourse. We conclude with suggestions for how those promoting the research, and the journalists reporting its implications, could act to ensure more responsible coverage and enhance public debate.

Contributor Note

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Introduction

*'Patient in vegetative state plays tennis
in her head'*

*'Brain scan gives vegetative state
patient the power to say yes and no'*

These are the titles of the two major press releases from the UK's Medical Research Council (in 2006 and 2010 respectively). The press releases highlighted the research the Council had funded with severely brain-injured patients using a novel neurotechnology called functional magnetic resonance imaging (fMRI). This technology enables scientists to go beyond looking at the physical structures of the brain to examine how the brain functions in response to different instructions. The research identified brain activity in 'vegetative' patients, generating a peak in media interest, with headlines including: *'Think tennis for yes and home for no: how man trapped in his body 'spoke''* (Guardian 4 February, 2010); *'For first time, doctors communicate with patient in persistent vegetative state'* (Guardian 8 September, 2006) and *'New hope after brain research'* (Sunday Express, 7 February, 2010).

As social scientists working in the field of serious brain injury we often encounter comments from colleagues and acquaintances suggesting that such coverage left a lasting impression of a technology with great potential to transform the lives of patients and their families. However, our interviews with families with personal experience of this issue presents a far more nuanced picture. This article critically reviews the public representation of these fMRI studies and contextualizes this in relation to the everyday challenges of family experience.

The paper is located within several interlocking strands of sociological and media/cultural research. First, it builds on research into the social and ethical implications of science in general, and neurotechnologies in particular. Such work includes analysis of the history of neuroscience (Abi-Rached & Rose 2010), the construction of the concept of the 'neuro-chemical self' (Rose 2003), the anticipatory discourse around the promise of neuro-therapies (Pickersgill 2011), and the need for a 'neuroethics' (Illes et al 2003). Secondly, this article builds on research into the 'sociology of expectations' and related work on the 'political economy of hope' (Brown 2006; Delvecchio Good et al 1990; Petersen & Seear 2011). Many scholars have argued that a 'political economy' or 'rhetoric' of hope has now become the dominant discourse of science, and research and development is justified by *'the promise of finding miraculous cures for debilitating illnesses'* (Moreira & Palladino 2005: 67). Sociology of expectations scholars note a similar influence via the active generation of promises and positive expectations about new technologies (Brown 2003). As Geels and Smit argue:

Initial promises are set high in order to attract attention from (financial) sponsors, to stimulate agenda-setting processes (both technical and political) and to build 'protected spaces'. Promises thus play a role in the social processes that are part of technological development (Geels & Smit 2000: 881-882).

Such 'promises' can be made via practices in the lab, grant applications, publications, and via press releases and media statements – it is these last two areas which are the focus of this article.

Our work thus also links directly to research on public relations activities and the media which has repeatedly flagged up how public representations of innovative technologies tend to be optimistic, proclaim imminent medical benefits and deploy ‘human interest’ and emotions to sell a story/a technology. This has been applied to a broad range of work including human genetics/stem cell research (e.g. (Conrad 2001; Durant & Hansen 1995; Goodell 1977; Haran et al 2008; Höljer 2010; Mulkay 1994; Nelkin 1996; Peters 1995; Rogers & Chang 1991; Seale 2003; Wahl-Jorgensen 2012; Williams et al 2003) and neuroscience (Racine et al 2005; Racine et al 2007; Racine et al 2010).

The study presented in this article adds to the body of literature outlined above, offering a timely case study of the public relations strategies and media coverage of the rapidly expanding area of ‘brain science’ (see Nuffield Bioethics Council, 2013). An extra dimension is given to the analysis by including reflections from families directly implicated in such developments. Our work thus offers a significant addition to existing research on ‘science in the media’; alongside expanding research on the families of those in vegetative or minimally conscious states. In particular, we would note that research with families has tended to focus on their psychological needs (highlighting issues such as depression or so-called ‘prolonged grief disorder’) – whereas we look to our interviewees as a potential source of insight that might usefully contribute to good practice.

In the sections that follow, we start by outlining the definition of disorders of consciousness such as the ‘vegetative’ state, and summarising the key fMRI studies. We then introduce our research

design and present the analysis of the media coverage and responses from families, before concluding by reflecting on the implications for those involved in promoting and representing scientific work and making recommendations for change.

What are the ‘vegetative’ and the ‘minimally conscious’ states?

The popular image of being in ‘a coma’ is of an individual, supported by machines, lying in a peaceful sleep like state (Wijdicks & Wijdicks 2006). A staple device in fiction (films, TV drama and novels) is to have this patient deliver a coherent monologue (implying a fully functioning consciousness beneath the cloak of unconsciousness) and/or to suddenly ‘wake up’ – often with few outstanding neurological problems except perhaps some memory loss convenient to the plot (Kitzinger & Kitzinger 2012). The factual news media often promote similar images and stories – sometimes presenting scientific inaccuracies and confusing use of terminology (Bernat 2008; Latronico et al 2011; Racine et al 2008) and giving high profile coverage to very rare cases of patients who show some recovery long after clinicians had given up hope (Fins et al 2007).

Although comas lasting a few weeks can, in part, resemble the images in fictional and factual media described above (and there are some well documented cases of ‘miracle’ recoveries), the routine reality of *long term* coma-like conditions is rather different. After a few weeks in a coma a patient who does not die, or wake up, usually enters either a ‘vegetative’ or a ‘minimally conscious’ state. Patients in vegetative states have all their automatic functions such as

being able to breathe and are usually independent of all machines apart from the one delivering artificial nutrition and hydration. They display cycles of eye opening and closing (a sleep-wake cycle), and have reflexes such as retracting from pain; however, they have no apparent awareness of themselves or their environment (Royal College of Physicians 2003). Patients in 'minimally conscious states' (a new diagnosis only formally defined in 2002) appear unconscious much of the time, but occasionally show some minimal awareness e.g. saying words or showing emotional responses to family members (Giacino et al 2002). After 12 months in a vegetative state gaining full consciousness is considered highly unlikely (hence the term '*permanent vegetative state*'); patients can recover full consciousness after much longer in MCS (perhaps even after several years) – however, even if they recover full consciousness they are likely to be left with severe physical and mental disabilities.

The distinction between vegetative and minimally conscious conditions is important not only because it has implications for prognosis (e.g. likelihood of a return to full consciousness), but because it has implications for care (e.g. the provision of pain relief) and legal ramifications (e.g. in relation to treatment withdrawal). However, diagnosis at the borderline of the vegetative state [VS] and minimally conscious states [MCS] can be very challenging and there is a high rate of misdiagnosis (Andrews et al 1996). This may be not least because of the fluctuating nature of awareness for patients in MCS (and potential complicating conditions such as blindness or deafness). Attempts to improve diagnostic accuracy include refining formalised bedside clinical

examination repeated at different times, and taking into account family observations. Incorporating assessment of family interactions with the patient is crucial as although families may sometimes misinterpret mere reflexes, their intimacy with the patient and bedside vigils may mean they trigger, and are there to record, genuine moments of consciousness (Turner-Stokes et al 2012).

What is fMRI and what does fMRI with 'vegetative' and 'minimally conscious' patients demonstrate?

Functional Magnetic Resonance Imaging is a novel brain imaging technique that works by detecting, over time, small changes in blood oxygenation that occur after increased local brain activity. fMRI output data is represented as a digital image – with a number of statistical analyses being conducted between image acquisition and interpretation in order to generate the classic and compelling image of different parts of the brain 'lighting up'. Whilst there have been, and continue to be, many different efforts to use various neurotechnologies to investigate consciousness in severely brain injured patients (Fernandez-Espejo et al 2011; Goldfine et al 2011; John et al 2011), fMRI has been the most high-profile.

The two fMRI scientific papers that first burst into the public domain both involved the neuroscientist Adrian Owen. One study was published in 2006, another in 2010. The 2006 study involved a 23-year old woman who had been diagnosed as vegetative (Owen et al 2006) – fMRI was used to scan the woman's brain whilst she was asked to imagine different tasks. The researchers found that the patient's neural responses

were indistinguishable from those observed in healthy volunteers via fMRI. They concluded that *'this patient retained the ability to understand spoken commands and to respond to them through her brain activity'* and *'confirmed beyond any doubt that she was consciously aware of herself and her surroundings'* (1402).

In 2010 the research went even further (Monti et al 2010) – this time the team reported that fMRI research with 54 patients identified that *'five were able to wilfully modulate their brain activity'* (p. 579). Such brain activity was ascertainable via fMRI even though in two of these cases the patient would have otherwise had a 'vegetative' diagnosis as *'no voluntary behaviour could be detected by means of clinical assessment'* (p. 579). The researchers reported that one man, who at the time of scanning showed *'signs of awareness ... consistent with the minimally conscious state'* (p. 585), was able to use their technique to answer 'yes' or 'no' to questions during the fMRI. The authors concluded that *'with further development this technique could be used by some patients to express their thoughts, control their environment, and increase their quality of life'* (p. 589).

So, how was the 2006 and 2010 research profiled in the media; how were the implications for families presented; and how does this compare to what families in this situation say about the condition of their relative and their expectations for the future? The next section of this paper outlines how we explored these questions.

Methods

The newspaper archive was compiled by searching all UK newspapers via the Nexis database for the month around publication of each of the fMRI studies (i.e., 8 September to 7 October 2006 and 4 February to 3 March 2010). We used the broad search term 'brain' because using the search term 'fMRI' risked missing items where technological acronyms had been avoided. The results from the 'brain' search were then skimmed to locate all articles which discussed the fMRI studies, identifying a total of 51 items (32 straight news reports, 19 commentary pieces). Wherever possible the original version of the reports were also obtained either from hard copy archives or from the paper's own website, allowing us to see layout and images. All reports were then analysed thematically to explore how fMRI was framed and systematically indexed to record any references to limitations of the fMRI studies or their implications; how the media represented the potential future (both for the technology and for the patients); and the portrayal of family reactions.

Family members with personal experience of this issue were reached via a brain injury support group. Six individuals expressed interest and were provided with an information sheet, and consent was gained to interview in each case (one interview was conducted as a joint session with husband and wife). It was not our intention to recruit a representative sample of participants for interview. Rather, these interviews were designed to investigate the experience of specific individuals within this (often neglected) population and to provide a deeper understanding of the views of different individuals' with experience of this issue. As might be expected, given

the declared focus of the research, all six interviewees had been previously aware of fMRI and had considered it for their own relative – in fact three of the patients had undergone an fMRI. At the point of interview, three of the relatives remained in a vegetative or minimally conscious state, one had died while still in a disorder of consciousness, and one had regained full consciousness, although remains severely disabled (see Table 1).

Interviews were semi-structured, face-to-face and lasted between one and two hours, and were conducted by the first author. Interviews took place in a location of the participants' own choosing (usually their home). It was important that we met away from the hospital setting and were not linked to the fMRI experimental studies in any way, which might have inhibited what interviewees felt able to say.

Interviews commenced with a broad discussion about interviewees' experiences of having a relative with a disorder of consciousness, and their understanding and opinions about the use of fMRI with such patients. Following this, participants were shown newspaper articles reporting on the studies conducted by Owen and colleagues. These were taken from the Daily Mail (2006); the Independent (2006); the Mirror (2010) and The Times (2010) – chosen because they provided a variety of articles from broadsheets, mid-range and tabloid newspapers [See Fig 1]. Discussion was then prompted around participants' views about these specific studies and the associated media reporting.

Interviewee (pseudonym)	Patient (pseudonym)	Did the patient have fMRI	Results of fMRI (as reported by interviewee)	Time since injury (at time of interview)	Highest diagnosis reached (according to interviewee)
Alison	Andrew	Yes	No awareness detected	4 years	Permanent Vegetative State [PVS]
Eli	Ethan	Yes	Suggested some awareness	4 years	Minimally Conscious State (now deceased)
Trudy	Tracey	Yes	Suggested some awareness	2 years	Severely disabled
Rachel	Ronald	No – family wanted it, but patient not eligible	n/a	1.5yrs	PVS
Laura and Neil	Lavena	Suggested but not pursued by family	n/a	9 years	PVS

Table 1: Details of the sample (Note: all patients who had an fMRI scan did so within 8 months of injury – i.e., prior to obtaining a 'permanent' vegetative diagnosis)

All interviews were audio recorded and fully transcribed, amounting to 177 pages of transcript. Transcriptions were thematically analysed using NVIVO – each transcript being systematically coded for issues such as how interviewees first heard about fMRI;

interviewees' opinions about the pros and cons of fMRI; and the way they spoke about 'hope'. In the interests of confidentiality, all names used in this article have been changed to pseudonyms. Some other identifying details have also been altered.



Figure 1: Headlines: top left: Mail 2006; top right: Independent 2006; middle: The Times 2010; bottom: Mirror 2010

Findings

The public representation of the fMRI studies

The Medical Research Council's press releases which launched the fMRI studies into the public domain emphasised the originality of the work e.g. a '*new method*' that had '*never before been tried*' (MRC, 2010) and portrayed the results as '*exciting*' (MRC, 2006) and '*startling*' (MRC, 2010). The titles of both press releases foregrounded the personal – framing the results in terms of one individual

patient's ability to think, communicate or make choices e.g., declaring that fMRI bestowed '*the power to say yes and no*' (MRC, 2010). This mood of excitement was closely echoed in the majority of press coverage. Indeed, much of the coverage was largely based on reproducing chunks of the press release – an increasingly common practice of what is known as 'churnalism' (Davies 2009; Williams & Clifford 2009). The studies were described as '*ground-breaking*' (The Times 4 February, 2010), '*epoch-making*' (Independent 5 February, 2010), '*remarkable*' (Guardian 11 September, 2006) and '*spectacular*'

(Telegraph 8 September, 2006). Journalists referred to the scientists as 'shocked' (Mirror 4 February, 2010) and 'stunned' (Morning Star 5 February, 2010) by what they had discovered, and the technology's practical 'medical' implications were emphasised. The Sun, for example, went into hyperbole overload, breathlessly headlining its report: *'Astonishing Breakthrough Medical Miracle'* (4 February, 2010). Reports repeatedly displayed compelling graphic images of brains 'lighting up' and the insights provided by fMRI were presented as a form of mind-reading or what the Sunday Times' headline called a *'Telepathic leap'* (Sunday Times 7 February, 2010). Reporting emphasised the idea of patients gaining a voice through headlines such as: *'Coma woman 'hears and talks' to doctors'* (Express 8 September, 2006); *'Coma victim 'speaks'...*' (Mirror 4 February, 2010) and *'Brain damage patients CAN 'talk''* (Sun 8 September, 2006).

Reports rarely mentioned that only a minority of the patients had responded to the fMRI task and did not discuss the implications for 'non-responders' and their families. Instead there was a tendency to generalize (as if all vegetative patients might have consciousness), to extrapolate or make allusions/associations to other states, and to draw conclusions from such extrapolation. For example, under the headline *'We now know that patients in a vegetative state can hear and think'*, the Daily Mail recorded the personal experience of a journalist who had been in a coma for a month, and recovered without serious problems (a not uncommon outcome after a short coma). On the basis of his experience he concluded by expressing concern about vegetative patients being allowed to die, stating that: *'if it [the fMRI research] leads*

to doctors becoming more cautious about condemning patients, I, for one, will be relieved' (16 September, 2006).

Reporting routinely confused states such as 'coma', 'vegetative' and 'minimally conscious', slipping between the terms in a way that obfuscated the findings of the fMRI research. In addition, journalists used language and metaphors evoking 'locked in syndrome' – the condition made famous by Bauby's 1997 book (and the subsequent film) *'The Diving Bell and the Butterfly'* (Bauby 1997); and more recently by Tony Nicklinson's 'right-to-die' legal case. It is quite possible that severely brain injured individuals are both in disordered states of consciousness and are *also* functionally locked in to some extent, however, the use of the phrase 'locked in' risks implying that patients who show brain activity via fMRI might have fully functioning minds and merely have lost the ability to communicate. The Daily Mail even used the fMRI work with vegetative patients as a hook on which to hang a report about a locked-in individual who had been: *'frozen in his body, unable to move or speak, yearning for someone to hear his silent screams'*, and the headline declared *'But just look at him now...'* – going on to describe how he now works as a website developer and *'is about to embark on a BSc in computer science and be married to a beautiful blond'* (5 February, 2010).

Potential confusion about the level of cognitive ability detected via the fMRI studies was compounded by two senior figures who made public statements (on the Science Media website, and in *Science* respectively (Naccache 2006) suggesting that the fMRI studies revealed the patient's 'rich' or 'complex' inner mental life – quotes which were picked up by newspapers such as The Times

and the Daily Mail (8 September, 2006). Such remarks have been strongly challenged by other experts in the field. Fins and Schiff (2006), for example, comment:

The dramatic assertion ... that 'the fMRI findings indicate the existence of a rich mental life' – is simply unjustifiable. The data do not show this. She may possess a rich mental life, but the more likely scenario is that, like many patients in MCS, this woman can follow commands yet remains unable to communicate and carry out goal-directed and intentional behaviours because of generalized cognitive impairment (Fins & Schiff 2006: 8).

However, most of the press reporting of both the 2006 and the subsequent 2010 scientific papers presented no caveats about the level of cognitive function such patients might possess. Journalists in 2010 also missed the opportunity to note that the 'coma woman' who made headlines in 2006 for being able to 'hear' and 'talk' to doctors reappears in the 2010 study – still in a disordered state of consciousness, and unable to use fMRI for communication. (This fact, which might have presented a different type of story is embedded in the full academic journal, but not commented upon in the press release).

Some of the reporting did not simply neglect to question the level of understanding or potential for communication uncovered by the fMRI research, but actually used language, association or metaphors in ways which implied a quite sophisticated level of thinking.¹ Some journalists attributed

self-reflection to patients, ventriloquising through headlines such as '*I think ... I'm alive*' (Sun February 4, 2010). They suggested that patients might eventually be able to make their own life/death choices² and used words like 'power' to describe what fMRI might unleash. The Times, for example, picked up on the language used in the MRC's 2010 press statement through its headline referring to the patient who 'communicates ...using the power of thought' (4 February, 2010) and other reports characterized fMRI as a liberating technology, reaching '*into the shuttered*

uncovered by the research. For example, four news articles in the 2006 sample picked up on a statement by Paul Matthews (Professor of neuroscience) which had been posted on the UK's Science Media Centre's website. He observed that the authors do not '*establish...that she [the patient] had self-awareness*'. Some guest/specialist writers also unpacked the issue. The Independent's Health Editor, Jeremy Laurance, highlighted that: '*Having awareness is not the same as having a biographical life with feelings, thoughts and memories. A lot more goes into forming the human personality than a mere set of neurons and synapses*' (Independent 5 February, 2010). Similar points were made in guest pieces – one written by Sheila McLean, (Emeritus Professor of Law and Ethics in Medicine), the other by John Harris (Professor of Bioethics).

² The fMRI scientific studies enter the on-going debate about the withdrawal/continuation of life support for patients in a disorder of consciousness (Fisher & Appelbaum 2010) – this debate is beyond the scope of the present article. However, we would note that fMRI is highly unlikely to be a tool to facilitate such patients making their own serious medical treatment decisions because '*the likelihood is that the answers we seek will be vague, misleading, or simply unobtainable, despite all the technology*' (Fins & Schiff 2010: 23) and even those who can exhibit wilful modulation of brain activity '*probably do not possess the legal capacity to fully consent to or refuse life-sustaining treatment because of remaining cognitive deficits and the limits and uncertainties of this communication technique*' (Jox et al. 2012: 734).

¹ Some newspapers (but only a minority; n=10) did question the level of consciousness

world of a lost brain damaged patient' (Herald 4 February, 2010), opening up opportunities for patients who had been '*closed off from the world*' (Express 4 February, 2010), '*unlocking*' the '*inner voice*' (Telegraph 4 February, 2010) and freeing victims who had been '*imprisoned*' (Guardian 11 September, 2006), '*trapped*' and '*shut off from life*' (Guardian 4 February, 2010). In one instance, writing about the 2010 study, Colin Blakemore, Professor of Neuroscience at the Universities of Oxford and Warwick, opened his generally reflective piece with compelling imagery which analogised a vegetative patient with the (fully conscious) victims of the Haiti earthquake. He compared '*the uplifting images of people pulled from the rubble of Haiti*' with '*the extraordinary report from neuroscientists who have used a brain scanner to communicate with a very different kind of trapped victim – a patient in a Persistent Vegetative State*' (Telegraph 5 February, 2010). His imagery captures (perhaps with a deliberate edge of satire) the recurring imagery of rescue which permeated the reporting.

With a few exceptions, then, fMRI was presented with a sense of optimism, offering hope for further recovery and/or hope for a future in which assistive technologies could help patients communicate and make their own choices. 'Hope' was a word repeatedly evoked in the text, and highlighted in captions – the Sun, for example, illustrated its report of the 2006 study with a 'sleeping-beauty' image of a comatose patient with the caption '*Hope*' (see Fig 2). It was rare to see any caveats about the interpretation of the studies, or the extent to which the technology could deliver on the ambitions of the scientists eager to develop its potential. For example, only one journalist – Mark

Henderson (Science Editor for The Times) – commented on the costs and accessibility of fMRI technology – and that was very much in passing: '*an expensive and difficult procedure that can be done only infrequently*' (The Times 4 February, 2010).

In spite of the fact that families of brain injured patients, as well as patients themselves, were the presumed beneficiaries of the amazing breakthroughs, families were not the source of a single direct comment/quote. Like the silent patients, who could not be interviewed because of their condition, families too were silenced or ventriloquised. When families were mentioned, reporting was usually limited to describing the research as giving families '*comfort*' (The Times 4 February, 2010), that they were '*happy*' with the results (Guardian 4 February, 2010) and that the '*revelation*' produced by fMRI '*gives a huge boost to families*' (Sun 8 September, 2006). The findings were said to '*give hope ... that when they talk their loved one might be able to hear their words after all*' (Mail 8 September, 2006), as well as '*hope ... that loved ones ... benefit from their endearments*' (Mail 16 September, 2006).³

³ Only three reports suggested reactions could be more complicated – two examples were from guest writers (e.g. Professor of palliative medicine Ilora Finlay, The Times, 4 February 2010), the other was from specialist Science Editor, Roger Highfield who briefly mentioned that: '*The science team is also uneasy about how the families of vegetative patients will react to the discovery that a patient who...fulfils all the criteria...of vegetative state...could possibly have an inner mental life*' (Telegraph 8 September, 2006).



Hope . . . brain study

Figure 2: The 'sleeping beauty' image of the comatosed patient – with the caption 'Hope' (Sun, 8 September 2006)

Family responses to fMRI and the media coverage

The interviews with family members challenge some of the optimism of the coverage and offer a more nuanced sense of how families anticipate the future heralded by fMRI, the role and possibility of 'hope', and their views and experience of 'recovery'. Family members responded to the fMRI studies with a range of views including both excitement and cynicism, hope and fear, and their comments provide insight into how families negotiate their expectations, alongside the realities of day-to-day life, and offer a powerful correction to simplistic hype about what fMRI will deliver.

All of the interviewees saw some potential benefits from fMRI, at least in theory. They were glad that some attention was being given to a vulnerable population, so often ignored and invisible. Some hoped this might eventually lead to more understanding of brain injury or possibly establishing

some rudimentary communication. Eli, for example, whose husband was in a minimally conscious state, says: *'it's about seeing if you can improve somebody's quality of life... if you can strap them in an MRI scanner ... and say 'are you cold?'*. However, such observations were sometimes tempered by the interviewee's sense that there were already ways of detecting some aspects of their relatives' experience – (e.g. *'she does tell us if she's in pain, she has tears running down her face and bites on her bottom lip.... every part of her is stiff and unyielding'*) and that such clearly communicated needs were not being met. Interviewees also reported break downs in care for their relative due to a lack of staff expertise with *existing* equipment (e.g. the hoists used to move patients around) and failures to provide or repair it (e.g. obtaining and maintain appropriate wheelchairs). They were acutely aware of the context of care delivery, and thus sometimes questioned what fMRI could deliver in practice, even if the scientists were successful in their ambitions to develop its capability in ideal laboratory settings.⁴

⁴ This is a consistent finding in other research with families with severely brain injured relatives – where the recruitment method meant they had no special interest in fMRI. These interviewees expressed cynicism about how fMRI would work in practice making comments such as: *'if she can't even be given a call button that works for her I don't really hold out much hope for the miracles offered by super-duper high powered science brain scanning'*. They also referred to incidents in care homes where they had seen communication aids for severely disabled residents fall into disrepair, be left out of reach, or deliberately removed. Family members of one PVS patient, for example, expressed their lack of hope for any improved quality of life for her, even were she to gain more awareness. Their perspective was partly informed by the distress they could see awareness bring to other patients who emerged from disordered states of consciousness, and partly by their

For some interviewees, however, an immediate benefit of fMRI was that it ensured that their own observations of consciousness were endorsed. For example some thought that they (and often care staff intimately caring for their relative too) saw more consciousness and communication than clinicians acknowledged. As Trudy comments: *'As a mum, you're with them so much more constantly and you see things ... and they [the staff] don't believe you'*. This point was echoed by Eli: *'it was quite obvious to everybody [care staff and family] that he understood what was going on.... I knew he was in there'*, adding *'[the fMRI test meant] they knew he was in there as well'*. However, beyond this strategic view of fMRI, the extent to which they personally pinned their hopes on the research, or felt it offered potential for the future, differed strongly between interviewees, and these views also shifted over time for individuals.

Two of the six interviewees had been very excited by the fMRI research – at least at first. Both had first encountered information about fMRI via the media. Their responses mirrored the sort of family reactions anticipated in newspaper reports – and indeed had been originally directly *triggered* by such reporting:

disillusionment in witnessing, for example, the treatment of a particular young man: *'he had all this awareness, he had one of these machines and he could say 'I need some attention' and then press the button and in the end because he liked playing with it [...] then they would switch his machine off, because he was doing it all the time...'* Bea: *And that upset you a bit didn't it?* Ann: *Yes, I was thinking, how is this affecting him?* Bea: *Yeah – 'you've got a voice, now you haven't'* (Kitzinger & Kitzinger 2012; see also Latchem & Kitzinger 2012).

I was really, really excited I was, that was the first thing, 'cause I wanted to find out if there was anything really going on in Tracey and I can remember saying to the nurses at [the hospital] 'look at this. This is amazing, this is amazing' (Trudy)

I have heard of fMRI when I was looking for miracles ... I thought (loud gasp) 'wow this is it, this is the thing I need for Ronald, it's going to prove everything (Rachel)

Both these women were initially enthusiastic about their relatives' participation in fMRI studies: indeed Rachel had taken the initiative in trying to ensure her relative's inclusion:

I emailed him through the Cambridge website I said 'hello Doctor Adrian Owen' and ... I thought I must be the only one emailing him and the generic email I got back saying 'we receive hundreds of emails from people desperate you know like from families after all this' and I thought 'oh' (laughs) I naively thought ... he would see my case and go 'oh this women, what a horrible time she has, I must ship her here'

Rachel was bitterly disappointed when she learned that it would be difficult to access fMRI because – contrary to the expectations raised in her by media reporting – the imaging was only available as part of scientific studies: *'they [husband's clinical team] said 'look it's not that simple, it's not like there's just one in every hospital' and I'm like 'oh why not? why don't we have these in every hospital?' and then they're like "we haven't been able to arrange it, there's not any studies going on..."*. I was like

"studies? This is life you know it's his life..."

It is noteworthy that both Trudy and Rachel became aware of fMRI work early on after their relative's injury – and this seems to have been one factor in their enthusiastic response at the time. By contrast, other interviewees were more circumspect. This was particularly true of Laura, who first encountered news about fMRI several years after her daughter's injury. She recalls that she was *'not excited, no, more question marks I think... no, I'd never view it as exciting'*. She did question if this was something she would want for her daughter but soon learned about the practical challenges such as the difficulties of moving Lavena, and the challenges of scanning her because of her spasms. After further discussion with her daughter's consultant, she says *'I think my feelings of unease [about fMRI] grew. And a feeling of uncertainty and almost say dread in a way...it's not something that I could personally put Lavena through'*. She reflects that research has to happen, but that *'it's modern technology that has put Lavena where she is today'*. She would rather than technology has not been used to 'save' Lavena's life in the first place and she is cynical about technological solutions to the profound dilemmas she, her daughter, and whole family now face.

Laura's allusion to feelings of *'uncertainty'* and *'almost dread'* indicates far more than a cynicism about fMRI – it expresses her fear that the technology might detect some brain activity, and *'where do they go from there?'* She expands on her concerns:

It's like a double edge sword because if we found that there was nothing there in a way that would've been easier ... how do

we handle it if there is something there but there's not a damn thing that we can do to get to her

In stark contrast to the newspaper's report that the positive fMRI results *'give hope to victims' families that when they talk their loved one might be able to hear their words'*, Laura highlights the double-edged implications as she tries to cope with her life and care for other members of her family who, like her, are suffering the long term implications of having a family member in Lavena's condition: *'...if I knew that things were going on in Lavena I'd spend much more time with her...I'd talk to her a lot more and so on and of course then that would impact on us all'*. She adds that also *'we'd feel so guilty that we haven't tried harder to get through to her but yet we know that everything has been done you know ... so it's quite complicated to unravel'*.

By contrast, another interviewee, Rachel, is fearful about what the fMRI might show for quite a different reason. Rachel was initially very excited by fMRI and determined to access it for her husband. However, her enthusiasm did not last. Indeed, she subsequently became concerned that fMRI might *fail* to detect any brain activity and that this would be a weapon that could be turned against her. The history here is one of conflict with clinicians about her husband's diagnosis and prognosis. Rachel reports: *'... he had an EEG that proved terrible against him ... I decided after that EEG that I did not want the fMRI. I thought 'well I don't want any more evidence against him''*. She also fears an fMRI might potentially 'steal' the hope she has that Ronald will recover: *'you go in there full of hope'*, she said, *'like you're going to get the result ... and then when he doesn't [get the positive result] ... it*

makes me feel a bit downhearted'. She adds: 'whilst it's out there [the possibility of a positive result] it's not dashed it's still a hope, but once you do it... you feel a bit sunken'.

As the above comments make clear, 'hope' is a key issue for these interviewees. It is an important coping mechanism, but also a dangerous need, making them vulnerable to 'false hope' in their search for a solution. Indeed, a determination to hold on to hope can even be implicated in their relatives being subject to interventions that the families later regret (see Kitzinger & Kitzinger 2012)). Laura, for example, remarked: *'we just had...such hope didn't we? [turning to husband] ...we just clung on to everything [...]... in the early stages we would've done anything'.* Rachel echoed this: *'the thing is when you're going through all the distress and the pain you search for anything don't you'.* Some of the interviewees, were concerned about the sense of excitement generated by the coverage of fMRI. Alison, for example, worries that the coverage would cause people to be *'filled with hope and then possibly to be let down'.* She also expresses concern that the media coverage fuels the misunderstanding of friends and relatives who make glib comments like *'where there's life there's hope'.* Alison comments: *'for just an ordinary person who had absolutely no understanding of it whatsoever that [the reporting] would probably be 'wow you know look what they can do now'.* Two of the interviewees had become critical of the media coverage that had previously inspired them:

They [the newspaper articles] are really misleading because they give you hope and I suppose whilst all you cry for is a bit of hope I do

understand why they [doctors] don't give you it because when you get given it ...you make your own conclusions don't you? And you twist what's been said ... that's what doctors don't want you to do, they don't want you to hear something different from what they're saying and that's what the media does. It changes everything and makes you think there's answers out there that just aren't (Rachel)

All of the family members who took part in this study had, by the time of interview, reached a point far removed from any fantasies of, for example, their relative recovering such that he might *'embark on a BSc in computer science and be married to a beautiful blond'* (as happened to the locked-in syndrome individual who featured in one of the press reports in our sample). Exposure to information from clinicians has given them the understanding that any patient who has been vegetative or minimally conscious for a long time is never likely to make a complete recovery – for example, even if they do recover full consciousness they will not fully recover physical abilities or memory, and may be left with severe neurological deficits. Most will always require 24/7 care and never regain the cognitive ability to make their own serious medical decisions, let alone be restored to who they had been in other ways. Interviewees had not only learned about this reality from their clinical teams, they had also seen what recovery meant through their experiences in care homes, and what they had witnessed in other families that they now knew. In this sense they all felt their relative was irretrievably lost (at least in their previous form of existence) (Holland et al in press). Interviewees stressed, however, that this was a

realisation that usually took time to accept:

In the first year you're not really ready to hear how difficult it's going to be 'cos I know I used to think – 'this is [Andrew] he's big, he's strong, he'll fight back, you know, he'll come back to us' and it takes quite a while to kind of get that wiped out of you if you like [...] You do recognise I think that you're never going to get that person back again as they were. (Alison)

In this context interviewees told a very different story of recovery than that implied in the newspaper coverage. While worried that their relative might, in some sense, be 'trapped', they did not see fMRI as providing a 'telepathic leap', bringing their loved one back to them. They did not think the technology could find the person who was lost, unlocking their prison or rescuing them from the rubble. Their ambitions are more modest – that their relative might, for example, be able to clearly indicate whether they were too hot or too cold. A number of interviewees spoke about the improvements they had witnessed in their relatives' conditions, giving a picture of what recovery meant to them that was very far removed from that conjured up in some media reports. They made comments such as *'he yawns now, he never used to yawn...'* or referred to the progress that the patient could now stick her tongue out, but none (with the possible exception of Rachel) now believed that their relative would 'come back' as they were. Trudy, for example, speaks excitedly about the progression her daughter, Tracey, has made and her sense of future possibilities: *'at one point the speech and language therapist said she couldn't really move her mouth at*

all, she couldn't poke her tongue out...oh my goodness she does all sorts now, so never say never' (Trudy). However, at the same time she suggests in some ways she will never 'recover' her daughter, even though her daughter has, in some ways, recovered (she is now fully conscious). While committed to being positive about Tracey's progress she expresses a deep sense of loss:

You're always mourning the person you've lost so in a way, it's going to sound horrible but death would have been an easier option ...you're mourning all the time for that lost daughter but ... how we dealt with it [is], I lost her, I lost that daughter, but I got another one (Trudy)

Eli similarly reported some minimal progress in husband's condition as the months turned into years: *'he could turn his head and he would watch and um, once or twice...he tried to talk*. However, over time, with this slow and minimal progress, and a sense of the narrowing possibilities, hope becoming exhausted. Her perspective is vividly illustrated in her account of her husband's eventual death. She had rushed to his bedside, filled with grief, but when he appeared to rally for a moment she was also aware that she had no hope left:

He'd calmed down to very light breathing, and it was fairly normal and I actually sat there and in my head I thought 'Don't do this to us. Don't recover and then three months later do it again, and then six months later do it again. That's not fair on me or the family'. So, I didn't wish him dead..., but yes, [the media implies] 'where there is life there is hope' – Hope of what? What are you hoping for? ... When [my daughters] says 'oh Mummy

do you miss my Daddy', I say I do but I wouldn't have him back like that. That was not fair on him, let alone us (Eli)

This interviewee also explicitly critiques the glib use of the term 'hope' in media reports:

I'm struggling with that word, not that I don't believe in an afterlife but it [what the article is referring to] is hope for this life. [...] my question would be there's hope for whom? For [the patient] to make any further recovery? Probably not. [...] ...so basically hope for what? (Eli)

Discussion and conclusion: 'hope for whom? ... hope for what?'

Our analysis of media coverage has highlighted the generally optimistic nature of reporting – adding a timely example to existing research on the 'hype' around science. Such hype, we would argue, is not simply 'media sensationalism' produced by journalists, but (taking a view from within the 'sociology of expectations' framework) is part of a deliberate effort by *scientists* (and science funding bodies) to promote their work and enrol support and resources for its development. The analysis presented in this article has illustrated some of the ways in which this strategy was pursued in relation to the novel neurotechnology of fMRI.

Our research also highlights the gap between how fMRI was promoted in much of the coverage, and the experiences of families who have to face the question 'hope for whom' and 'hope for what?' The public representation of fMRI breakthroughs generally conveyed a simple story of excitement and hope, but

relatives of patients in disordered states of consciousness grapple with the everyday realities. They face the fact, ignored by much of the reporting, that access to fMRI is currently not available outside certain studies (*'studies? This is life you know it's his life'*) and that not all patients can be scanned (spasms and metal plates in the skull can make patients ineligible and even transporting them to an fMRI location may present insurmountable challenges (Tovino 2008)). Families live with the knowledge that 'recovering' their lost loved one is not an option and that they need to think of 'recovery', if it happens at all, in terms of small steps unlikely to go beyond a type of severe disability that remains invisible in media reports. They also have to deal with the emotional complexity of brain activity being detected, or not, and have often become acutely aware that there are no easy answers (*'that's what the media does...makes you think there's answers out there that just aren't'*). The interviewees are also operating in a world of disempowerment – struggling with what counts as evidence of consciousness (e.g. whether or not clinicians take into account family observations); what consequences will follow from fMRI results (what options are available and who makes treatment decisions) and questions about the role of technological advances in general and the very definition of hope itself.

Our analysis has implications for those promoting scientific research – underlining the need to take into account a range of ethical, social and economic factors before making pronouncements about the role and 'promise' of such interventions. As Fins and Schiff declare, *'despite neuroimaging's investigative promise, like most technologies, we also need to*

determine when it need not be used (Fins & Schiff 2010: 23; see also Jox et al 2012). Our research has particular implications for all those representing and reporting neuro-scientific work via the mass media: funding bodies, scientists, press officers and journalists (from headline writers to editors). These implications include the responsibility, as has been noted by many recommendations before, to avoid generating ‘false hope’ and be wary of over-claiming for stories (e.g. Science Media Centre 2013). Beyond this our analysis also highlights the need to: be careful with terminology and metaphors (e.g. the language of ‘locked in’); beware of making inappropriate comparisons (e.g. with the short term coma experiences); consider the potentially misleading power of images (e.g. the brain ‘lighting up’); reflect on the wider social context in which technologies will (or will not) be made available; and seek out a wider range of comment (including accessing the perspectives of patients, carers, and families where possible). For those working in the media our analysis particularly highlights the need to avoid churnalism (merely reproducing the core press release). It also, as shown by previous work on science reporting, underlines the value of specialist journalists, and the potentially enriching contribution of guest writers (suggesting a role for academics and practitioners writing responses to news reporting of science).

While summarising such recommendations we are aware of the context in which public representation of science occurs. This includes the fact that: journalists are working under difficult circumstances and competing to gain space and attract audiences (Williams & Clifford 2009); funding bodies and scientists are competing to demonstrate

the impact of their research; and that fundamental to the profession of science press officers is the necessity to write press releases which are alluring to journalists. At each level, then, there are *‘institutional and structural forces to add a ‘pinch of hype’* (Nuffield Council on Bioethics 2013: 219), and it is the cumulative effect of this hype that is evident in the final media representations. We suggest, therefore, on a grand, long-term scale, that there needs to be more questioning of the fundamental structures and agendas involved in disseminating science to the public. More short-term, and easier to implement, we suggest that scientific press releases, especially those which report work with ambitions to bring ‘real world’ social benefits, should include comments from social science researchers with expertise in the area – not just scientists. Indeed, perhaps a database of social science experts to draw upon for quotations or expert commentary about science – similar to the scientist database created by the UK’s Science Media Centre – should be a priority (indeed this might usefully be developed by a body such as the Science Media Centre to complement their existing work). It may also be that funding bodies could all agree on a new format for press releases that would routinely include a clear statement of limitations rather than simply putting the most positive spin possible on what has been achieved. This would, we suggest, be an appropriate way for funding bodies to take responsibility for the fact that many science PR materials now end up translated directly into media output with little modification. In conclusion, the science of fMRI is fascinating, and may have the potential to increase understanding and improve treatment and decision-making for severely brain injured individuals – it could also do

harm. There is a need for great care in how this is explored and translated into the public domain.

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