



Reporting Consciousness in Coma



EXECUTIVE SUMMARY

Purpose of this document

- to summarise an analysis of media representation, and family reactions, to novel neuro-technology studies on patients in vegetative or minimally conscious states
- to draw out the implications for those involved in promoting/representing science.

Full article: Samuel, G and Kitinger, J (2013) 'Reporting Consciousness in Coma'
www.cardiff.ac.uk/jomec/research/journalsandpublications/jomecjournal/3-june2013/index.html

Contact: kitzingerj@cardiff.ac.uk or gabrielle.samuel@brunel.ac.uk

The research

Novel neuro-technology studies attempting to detect consciousness in apparently vegetative patients is a high-profile and on-going area of scientific enquiry. We examined the public representation of two key studies which used functional Magnetic Resonance Imaging (fMRI) to examine brain activity in vegetative or minimally conscious patients. We also interviewed family members with severely brain injured relatives, some of whom had undergone fMRI.

The research findings

The press releases produced by the Medical Research Council (MRC) which funded the scientific studies were very optimistic about the significance of the findings. Under the headings: '*Patient in vegetative state plays tennis in her head*' (2006) and '*Brain scan gives vegetative state patient the power to say yes and no*' (2010) the press releases highlighted the implications for patients, and lacked caveats about the implications of the work, or its potential application.

The press coverage often:

- relied extensively on the press releases from the MRC, echoing their optimism
- failed to distinguish between 'vegetative' and 'minimally conscious' states and sometimes used the language of 'locked in'
- failed to mention that only a minority of the patients diagnosed via bedside examination as vegetative demonstrated brain activity, and sometimes inappropriately generalized findings (as if all vegetative patients might have consciousness)
- presented an exaggerated impression of the patients' likely cognitive abilities and potential for recovery
- presented a one-dimensional view of family reactions – emphasizing that the research offered families 'hope', without considering more complex reactions.

Family members interviewed for this study offered a range of perspectives:

- *Positive* views included a sense of excitement about fMRI, hope that fMRI of their relative might potentially confirm their own observations of consciousness and that it might offer an avenue to enable communication.
- *Reservations* included disappointment and criticism of ‘false hope’, and cynicism about the practicality of using ‘brain reading’ equipment outside the research setting (based on their experience in care settings of difficulties in accessing, maintaining and operating even basic equipment such as wheelchairs).
- *Concerns* included:
 - one interviewee was fearful that fMRI might *fail* to detect any brain activity in her husband and that might be used to justify ending treatment;
 - another was concerned that if fMRI *succeeded* in detecting some brain activity this would be of little use to her daughter who would remain unreachable, and would have devastating implications for the rest of the family.

Recommendations

For journalists and press officers:

- Be precise in use of language and metaphors (e.g. avoid evoking the popular image of the locked in syndrome patient when discussing vegetative states).
- When pronouncing on the ‘promise’ of research and what it might deliver, consider including comments from social science researchers with expertise on how technologies move from ‘bench’ to ‘bedside’. A data base of such experts might usefully be established to engage with journalists.
- Include diverse perspectives from families implicated in the research goals.

For science funding bodies/science PR departments:

- Reduce the pressures on everyone involved to promote every scientific study as if it had highly significant benefits.
- Consider a new format for press releases that would routinely include a clear set of definitions, caveats and statement of limitations.

Acknowledgments:

Gabrielle Samuel, Brunel University, was supported by a Wellcome Trust Biomedical Ethics Strategic Award 086034. Jenny Kitinger was supported by Cardiff University and a Rockefeller residential fellowship.

.....

The production of this executive summary was funded by the Wellcome Trust [ref: 097829/Z/11/A]

Further copies of this summary, and further information about our work on the vegetative and minimally conscious state is available from: www.york.ac.uk/cdoc and www.cardiff.ac.uk/jomec/research/consciousness/index.html