Institution: Cardiff University

Unit of Assessment: 36

Title of case study: Improving decision-making about treatment for people in vegetative and minimally conscious states

1. Summary of the impact This research stimulated debate about the treatment of people in vegetative and minimally conscious states, created new cultural representations and informed interventions to enhance decision-making processes. **Professor Jenny Kitzinger** [JK], the lead researcher, was invited onto the Royal College of Physicians' Working Party revising the College's treatment and communication guidelines. The research generated intense engagement from key stakeholders (e.g. medical and policy experts), prompted changes in thinking among clinicians and informed new training and support materials for both clinicians and families. The findings also enriched public discussion about this highly contentious area of medicine and ethics e.g. through a series of media/cultural interventions and through community engagement events which had a documented impact on participants' knowledge and feelings.

2. Underpinning research The *'Risk, Science, Health, and Media'* research group within the Cardiff School of Journalism, Media and Cultural Studies (JOMEC) has a long-standing tradition of examining the communication and representation of health/science issues. Under the directorship of JK (Professor of Communication Research in JOMEC, 2003 onwards) we have focused on enriching public/policy debate about ethics, cultural representation and the social context of medicine/science (see REF3a). The case study presented here highlights one such initiative, focussed on vegetative/minimally conscious states. Such states are a shifting scientific, socio-political phenomenon, with a complex cultural history. Increasing numbers of people are now surviving catastrophic brain injuries - partly because of developments in medical technologies. The 'vegetative' state was identified in 1972, the 'minimally conscious' state in 2002 (to describe patients who display very minimal/intermittent consciousness). Treatment decisions about these patients involve difficult clinical, ethical and risk judgments and are subject to intense media interest, rapidly evolving legal/policy rulings (e.g. recent court cases) and scientific enquiry (e.g. fMRI brain scans of 'vegetative' patients). A portfolio of 4 initiatives was developed by JK involving:

- ***Project 1***: a review of existing literature on vegetative/minimally conscious states mapping out issues and gaps from a humanities/social science perspective. This was circulated to key practitioners in 2010 and underpinned a successful bid by JK to the Wellcome Trust for a symposium with leading stakeholders (see Section 3, publication 1).
- ***Project 2***: an analysis of media reporting and press releases, focusing on the reporting of emerging brain technologies for vegetative patients, combined with interviewing families with experience of such technologies (2011-12) (see Section 3, publication 2).
- ***Project 3***: an in-depth interview/focus group study in three specialist neurological units – examining experiences of long-term care provision (2011-12) (see Section 3, publication 3).
- ***Project 4***: an interview study with over 50 clinicians and families - focusing on decision-making processes, from intensive care to courts (2010-present) (see Section 3, publication 4).

Researchers involved: *Project 1*: JK solely responsible. *Project 2:* Collaboration between JK and Gabby Samuels, Brunel University - Samuels conducted the interviews, JK led on designing the project and developing the media coding and co-wrote the final analysis. *Project 3:* Collaboration between JK and Julie Latchem, clinician at a neuro-specialist care home - both equally involved in all aspects of the project (design, data collection, analysis and writing up). *Project 4:* collaboration between JK and Celia Kitzinger, Sociology Professor, University of York - both equally involved in all aspects of project (design, data collection, analysis and writing up).

Findings: This portfolio of research gave a multi-dimensional view of the profound challenges for service-users, care-providers and policy makers and identified gaps and tensions in clinician-family communication, media representation and the surrounding public, legal, professional and policy debates. Key findings included:

- Media stereotypes of the vegetative patient e.g. such patients are routinely shown on television as if asleep with their eyes closed, but eye-opening is a defining feature of the condition, and patients may move and make sounds – a mismatch which contributes to conflict between popular/family expectations and mainstream clinical diagnoses/prognoses.

- Lack of clarity in reporting new scientific developments such as fMRI scans on 'vegetative' brains (e.g. failing to distinguish the 'vegetative' from the 'minimally conscious' state) and a lack of cultural representation of profound impairments associated with recovery from the vegetative state – which has implications for how families imagine possible outcomes and impacts on clinician-family communication and negotiation.
- Lack of accessible and accurate information for families, and lack of support for families and clinicians making difficult decisions, combined with misunderstandings about the legal framework for treatment under the Mental Capacity Act 2005 (e.g. the media-promoted misconception that 'next of kin' can consent to treatment on an adult relative's behalf – which is not the case in the UK).
- Fragmentation of decision-making between different clinicians and different professions (e.g. clinical and legal) and concerns about continuity and quality of long-term care.
- A cultural taboo about discussing end-of-life wishes, and a lack of public information about how to draft legally binding advance decisions in relation to medical treatment (e.g. some patients had previously expressed strong views regarding refusing treatment in such situations, but these were not legally binding because not in writing with a witness signature).
- Cultural/psychological/clinical/legal issues around the role of risk and 'hope' and tensions around the 'windows of opportunity' for treatment withdrawal and the uncertainty of prognosis early on (i.e. efforts to sustain life and allow a full assessment early on can leave some patients suspended in states incompatible with their prior expressed wishes - by which point they have become physiologically stable).

This multi-pronged initiative created an unprecedented in-depth study of service-users/family experience; produced a detailed examination of the media/cultural framing of these issues and compared these to both family/clinical experience and the scientific research. It also tracked decision-making over time and space (crucially across different treatment/decision-making sites); and located these processes in their cultural/medico-legal context in England and Wales since the implementation of the Mental Capacity Act [MCA] 2005. The breadth and depth of the research portfolio allowed for the development of a series of strategies for enriching media representation, improving professional/public debate and supporting good practice.

3. References to the research

1. **Kitzinger, J** (2010) '*Disorders of consciousness – shaping a medical humanities initiative*', Cardiff University (http://bit.ly/HsHmfc). Evidence of quality*:* enrolled key figures and formed the basis for successful application to the Wellcome Trust (£5K symposium award, 'Coma, consciousness and serious brain injury', 28.3.11 - 27.9.11) (**Project 1**).
2. Samuel, G and **Kitzinger, J** (2013) 'Reporting consciousness in coma: media framing of neuro-scientific research, hope and the response of families with relatives in vegetative and minimally conscious states*', JOMEC Journal* pp. 1-15 (http://bit.ly/17wUbBa) Peer reviewed (**Project 2**).
3. Latchem, J and **Kitzinger, J** (2012) *'What is important to residents with neurological conditions and their relatives in long-term care centres?'*, Research Report, Cardiff University (www.cardiff.ac.uk/jomec/resources/Long_Term_Care.pdf). Evidence of quality: positive response from staff /service users and cited in new guidelines from the British Society for Rehabilitation Medicine (see section 5, document 5) (**Project 3**).
4. **Kitzinger, J** and Kitzinger, C (2013) 'The "Window of Opportunity' for death after severe brain injury: family experiences', *Sociology of Health and Illness*. 35(7): 1095-1112 (Available online since 2012) DOI:10.1111/1467-9566.12020 (Output listed in REF2 - 4082). Evidence of quality: peer reviewed, also formed the basis for a successful bid to the Rockefeller foundation for a residential scholarship (November 2011) (**Project 4**).

4. Details of the impact

1. **Developed new networks and initiatives among stakeholders:** JK's (2010) review paper (publication 3.1 above) initiated dialogue between medical and legal experts and the subsequent Wellcome Trust funded symposium she organised brought 18 key stakeholders together for intensive (over two days) and Chatham House rule discussion. (For public record of symposium see http://bit.ly/1gUFEmJ). Subsequent initiatives prompted by this included two participants who met via the symposium working together to pilot the use of 'patient advocates' in intensive care (Lee, Mental Capacity Advocate Expert and Chatfield, Clinical Research Sister, Critical Care) and two others becoming involved in an ESRC seminar series

to look at the role of advance decisions (Clements, Solicitor/Law professor and Bell, consultant in intensive care). Another participant, Ethics Manager at the British Medical Association (BMA), blogged about the symposium and went on to organise an event for doctors to debate the issues raised (after the 'M' court case in Autumn 2011 – the first ever court case considering the potential withdrawal of artificial nutrition and hydration from a 'minimally conscious' patient).

2. **Informed debate and guideline development:** The research was recognised early on as having great potential to inform debate and guideline development. For example, a barrister emailed in response to the circulation of a draft paper: **'***This article is really extraordinary. I am absolutely certain that it must be put before any judge who looks at an MCS [minimally conscious] case in the future. When it is published, please would you send me the citation so that I can send it to the Official Solicitor and other barristers and solicitors who work in this area'* (Butler-Cole, leading barrister - see 'Sources to corroborate' 5.8). A clinician and member of The European Task Force on Disorders of Consciousness wrote: *'we start where others stop (neurologist). And we have to face with families the consequences of early decisions. So I use your work. It's part of every presentation in and outside the Netherlands. And part of ethical debates we have in nursing homes who care for patients'* (see 5.9). The research was used in drawing up new nursing home guidelines developed by the British Society of Rehabilitation Medicine (BSRM) and JK was invited onto the core editorial group of the *Royal College of Physicians'* Working Party on the vegetative state (rewriting guidelines which are the touchstone for good practice and for the courts). She was also asked to join the *Nuffield Council on Bioethics* investigation into 'novel interventions into the brain' – leading to the development of guidelines for journalists/press officers/scientists. Documentary evidence of impact includes citations of Project 2 in the Nuffield Report; Project 3 in the BSRM guidelines and Project 4 in the RCP guidelines - see Section 5, corroborating documents 3, 5 and 1.
3. **Contributed to new support/training resources:** The research informed the drafting of a 'best interest' decision pro-forma for clinicians developed with a neuro-rehab specialist and JK was asked to advise on a piece of educational theatre about family experiences performed at the 2012 *'Medical Ethics and Law'* conference (which was filmed and made available as an on-line teaching/debating tool by the BMA). She also advised on a leaflet produced by Headway (the brain injury support charity) on '*Supporting People to Make Decisions'* (document 5.4) and wrote a booklet about the experience of families in decision-making for vegetative patients which was adopted as an official supplement to the new Royal College of Physicians' guidelines (document 5.2). She is now working on an ESRC-funded initiative (with the DIPEx charity and University of York and Oxford) to build a multi-media internet resource for families and professional training (launch in 2014) (http://bit.ly/1a9F0rK).
4. **Prompted reflection and change among health practitioners:** The research was presented, by invitation, to a wide range of practitioners e.g. a 'Masterclass' at the *Institute of Medical Ethics* [IME] Annual Conference and talks to the Brighton and Sussex Medical School and the Yale School of Medicine (as part of professional development accredited courses). Presentations between 2010 (when the first research began) and July 2013 (the REF impact cut-off) directly reached over 500 practitioners (e.g. GPs and intensive care, neurosurgery, rehabilitation and palliative care specialists). Feedback surveys by event organisers demonstrated impact on clinicians both professionally and personally. Comments included: *'Very thought provoking – interesting, emotionally and intellectually challenging and I need/want to go away and reflect deeply on my view of the MCA [Mental Capacity Act] and its application because I believe my opinion may have altered slightly*' and *'Really brought the Mental Capacity Act and communication between medics and families into the real world. Definitely going to go home and make an advance decision'* (BMA evaluation report about JK's session at the IME conference). Practitioners were also influenced by an exhibition developed as part of the research that involved family members writing short messages and selecting images (chosen or drawn/photographed) to represent their experiences. The resulting 'Postcard' exhibition has been displayed at over two dozen venues and events (e.g. requested twice for display at the BMA's London headquarters). Feedback from event organisers, and comments in the guest book (e.g. 'haunting', 'learned a lot', 'unforgettable') suggest that the exhibition ensured that the voice of families directly affected now has a presence at key meetings where professionals debate relevant issues.

5. **Enriched public representation/debate**: In addition to working with stakeholders as outlined above, JK has been consulted by journalists/documentary makers and engaged in debate with them. For example, she co-authored a critical analysis of a Panorama programme about the vegetative state that was published as an editorial in the British Medical Journal (www.bmj.com/content/345/bmj.e8045). She has also been consulted by fiction writers (e.g. influencing the representation of a coma ward in the detective novel '*Rubberneck*') and served on the advisory board of a Wellcome Trust funded '*Theatre of Debate*' play about neurotechnologies (which won a 'Science Goes to the Movies' award from the British Science Association). The research led to the creation of a set of sonnets through a collaboration with a poet to transform interview material into poetry (see www.youtube.com/watch?v=HqA-vjB1OvQ/). It was also presented to a general public via a series of 6 community events as part of a festival organised by JK - the evaluation of which identified clear impact on attendees e.g. 93% indicated that attending had impacted on their thoughts or feelings, and 79% reported they would share the information gained in their professional or personal lives (http://bit.ly/16ruO0K). JK was commissioned to produce and present a half-hour programme about the research for BBC Radio Wales (produced in July 2013, broadcast August 2013), has been shortlisted to create a feature for Radio 3 on translating research into creative cultural outputs and is currently in discussion with BBC's '*Casualty'* about a potential storyline about the minimally conscious state.

This research has impacted upon a wide range of stakeholders involved in the care/representation of severely brain injured patients and has led to the establishment of a new cross-University Research Centre (Cardiff-York) involving a collaboration of diverse practitioners and disciplines (including literature, cultural studies, history and philosophy).

Although targeted at addressing the socio-cultural context of the UK, the research has had an effect internationally. This is evidenced by requests to translate executive summaries of the research for practitioners, the use of the research to inform guidelines in the US (see 'Factual Statement' from source 5.7) and the Rockefeller Foundation's production of a video-interview about part of the research under their *'Innovative Ideas with Global Impact'* insignia (youtube.com/watch?v=kS1yZzrKSNg&feature=youtu.be).

5. Sources to corroborate the impact

Documents:

1. Royal College of Physicians (2013) *Report on the management of prolonged disorders of consciousness*. (www.rcplondon.ac.uk/pdoc). See especially chp 4, chp 5 and p120 where it acknowledges that the guidelines 'drew extensively' on our research.
2. RCP Report Supplement (2013) *Serious medical decisions regarding people in vegetative or minimally conscious states: the role of family and friends*. (www.rcplondon.ac.uk/pdoc/family). This booklet for families was initiated by JK, based on the research findings (see pp: 1-4) and developed in consultation with the RCP working party.
3. Nuffield Council on Bioethics (2013) *Novel neurotechnologies: intervening in the brain*. (http://bit.ly/17Bqxc0). See especially pp. ix, 192-217 and 222–235.
4. Headway (2013) *Supporting People to Make Decisions* (www.headway.org.uk/shop/supporting-people-to-make-decisions.aspx). See acknowledgements page 52 for evidence of JK's input.
5. British Society of Rehabilitation Medicine (2013) *'Specialist nursing home care for people with complex neurological disability: guidance to best practice'* (www.bsrm.co.uk/Publications/Publications.htm). See refs to our research, pp.18, 19, 20, 30.

***Individuals contactable or supplying testimony to corroborate impact*:**

6. Chair, Royal College of Physicians' Working Party on prolonged disorders of consciousness (can be contacted to corroborate impact on RCP guidelines).
7. Deputy Director, The Hastings Center for Biomedical Ethics, USA (provided statement corroborating international significance and impact on public debate).
8. Barrister (can be contacted to corroborate impact among legal practitioners).
9. Physician, project leader: '*Long-term care of severe brain injury'* (can be contacted to corroborate impact on clinical debate).

All documents and contact details are available from HEI upon request.