

## **Media representation of science and health: the case of coma**

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in Miller, T (2014)

The Routledge Companion to Global Popular Culture, Routledge

### **Abstract**

Coma is very common in popular culture. Soap opera characters are regularly left in comatose or vegetative states after accidents or assaults; Newspaper headlines report miracle awakenings, end-of-life court hearings or scientific breakthroughs in detecting consciousness. This chapter reviews studies addressing the media coverage of coma (and coma-like conditions) in order to offer ways of thinking about research into the representation of science and health issues.

### **Introduction**

Media representation of science and health are a key area of concern for researchers interested in the potential of the media to influence society – whether through helping to shape individual behaviours, public debates or the policy agenda. This chapter uses research on ‘coma’ (and associated conditions such as the vegetative state) as a case study for exploring the range of ways in which media coverage can be analysed. I show how researchers from different backgrounds (e.g. film and cultural studies, sociology of science, and scientific/clinical practice) have approached such research and highlight their different research designs and findings. I conclude by highlighting the need to take such disciplinary divisions into account – both when reviewing research into the media representation of science and health *and* when developing such research oneself.

### **Researching media representation of scientific and health issues - questions and methods**

Scholars interested in the representation of science and health issues ask questions such as: how do media accounts compare to the scientific or clinical ‘facts’, or the experience of patients or the range of diverse ethical or political perspectives in society as a whole. Specific analysis may examine: Which issues are given prominence? How are ideas framed? What ‘facts’ are given credence? Whose voice is heard? How is expertise accredited? How are key players represented (e.g. the scientist, medics, patients or their families)? Such scholars are interested in the forces that help shape representation and also implicitly, or explicitly, concerned about the potential impact on individual or collective ways of thinking, talking or acting, or the impact on wider public discourses or policy priorities. Such research includes both quantitative and qualitative analysis and the object of analysis can be any text, including, for example, news reports, magazines, soap opera, science fiction films, home videos or new media. Research designs may simply focus on media texts, but can also include talking to, or observing, media *producers* (e.g. science journalists), examining *source* activity (e.g. press releases from science funding bodies) and looking at ‘public’ opinion or audience reception (e.g. attempting to assess any potential influence upon health behaviours).

The focus of any individual research project, and the methods adopted, often depends on the disciplinary background of the researchers or the priorities of the funding bodies. For example, science organisations often fund research that documents and tries to change the ways in which science is represented; a health charity may particularly want to explore the stigma associated with particular health conditions, and an academic working in a department of bioethics is more likely to be concerned with the framing of the ethics. The variety of questions asked and approaches adopted is well illustrated in media-related research on coma and the vegetative or minimally conscious state.

### **Why is ‘coma’ such an important science/health story?**

Coma is a fascinating case study through which to examine research into the representations of science and health and has increasingly attracted media attention over the last few decades. News stories track the tragic injury of celebrities and headlines profile ‘right-to-die’ cases and scientific ‘breakthroughs’ into investigating consciousness. Coma also serves as a popular plot device in soap opera (conveniently suspending an actor’s role in the series or introducing dramatic tensions), and features as a central focus of some science fiction, crystallising concerns about the uses of modern medical technology’ (Belling 2010). The possibility that someone may be kept alive, but without any consciousness or agency – makes ‘coma’ (and conditions often associated with coma, such as the vegetative state) has significant ramifications. Coma is implicated in debates about the nature of the mind or soul, personhood, dignity, choice and the meaning of life itself and the ability of modern medicine to sustain people in coma-like states means that this is an issue of increasing social importance (with significant economic, social and moral costs) and a key site of contestation.

Public debates about this issue can be traced back to the 1970s – when conditions such as ‘brain death’ and ‘the vegetative state’ started to become the focus of medical, ethical and public concern (e.g. in relation to organ donation and end-of-life decision-making). The medical thriller ‘Coma’ was written (and converted into a film) in the 1970s but the issue of the *vegetative* state did not gain particular public attention until more recently when it burst onto the public scene in the US with the ‘Schiavo case’. Debate centred around a young woman (Terri Schiavo) who had suffered a cardiac arrest in 1990 leaving her in a vegetative state and who became subject to a series of court cases from 1998 onwards. Her husband and her family were in dispute over her level of consciousness, and whether or not she would have wanted life-sustaining treatment. Schiavo was eventually allowed to die in 2005 after her feeding tube was withdrawn. The case became a political and legal minefield and attracted huge amounts of media attention and resulted in controversy across the US and internationally.

### **Some definitions – a briefing on clinical diagnoses**

Before discussing the media representation of Terri Schiavo’s case in particular, and the issues more generally, it is necessary to step back and provide definitions of key medical terms. This is important not least because general understanding (and media representation) of this field often confuse clinically distinct conditions.

A coma is a term which usually only applies to the first few weeks of unconsciousness in most brain injured patients. A comatose patient who does not die (or 'wake up') in the first few weeks usually enters either a vegetative or a minimally conscious state ['VS' or 'MCS']. 'Brain death' is something entirely different, as is 'locked in' syndrome, so these terms are not discussed here.

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 (RCP 2013). The 'minimally conscious state' is a relative new diagnosis only formally defined in 2002. In these cases patients 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).

In the past all such patients would have simply died (e.g. because they can not swallow); however modern technologies, and the way they are deployed, allow some patients to survive. Patients can now be 'brought back to life' after the initial crisis (e.g. being resuscitated after a cardiac arrest) and can then be sustained indefinitely (especially because of improvements in the provision of artificial nutrition and hydration). Advances in medicine ensures some patients have the chance of recovering to a quality of life they would consider worth living (e.g. fully conscious but with limited mobility or memory), but leaves others suspended in limbo in a state they would not have wanted. After 12 months in a vegetative state gaining full consciousness is considered highly unlikely (hence the term '*permanent* vegetative state' - PVS); 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 (e.g. dependent on 24/7 care, with minimal, if any, ability to communicate, and incapable of making their own decisions).

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, however impaired), but because it can have implications for care (e.g. the provision of pain relief) and legal ramifications (e.g. in relation to treatment withdrawal and being allowed to die). However, diagnosis at the borderline of the vegetative state and minimally conscious states is often very challenging and there is a high rate of misdiagnosis. 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). It is the difficulty of diagnosis and the intensity of ethical debates that makes this issue very complex and challenging, and means there is a great deal of interest in the conditions from the media, academic and practitioner stakeholders.

### **Research on coma in the media: three strands of work**

Reviewing the existing literature on media coverage of coma and the vegetative or minimally conscious state identifies particular clusters of enquiry from researchers from diverse backgrounds. Such work can be broadly mapped into the following, far from mutually exclusive, often overlapping, approaches.

**Film and literary studies:** For some literary theorists coma serves as an exemplar through which to explore broader bioethical or political issues. One commentator, Richard Doyal, for example, is a Professor of English, and former editor of the journal *'Philosophy and Rhetoric'*; he is interested in how 'the narratives and practices of molecular biology have shifted the very concept of "life" at play in contemporary culture, as distinctions between "living systems" and "machines" have begun to blur and morph'. He argues that: 'Comatose bodies cultivate yet another, singular execution of an informatic body. Accompanied by more than the visualization of an EEG and the machinic yoga of life support – breathe in! breathe out! – coma victims are connected to multiple rhetorical machines that would govern this strange flesh and enable its narration.' (Doyal 2001:15). His article aims to 'map out some of the capacities and threats posed by those bodies whose vitality is articulated as a signal, "wetwares" through and by which contemporary informatics operate' (Doyal 2001: 15). Other literary or film theorist have focussed on specific films (e.g Belling 2010), books (e.g. Hall 2014), or high profiles stories (such as the Schiavo case e.g. Walker 2006) to draw out the implications for broader theoretical concerns. One interesting collection of articles bring diverse analytical tools to examining the videos of Terri Schiavo released by her family 'purporting to show consciousness and responsiveness' (Waldman, 2006, 1). These family videos were widely disseminated through news outlets including CNN, Fox News, MSNBC, as well as online 'under the assumption that they make it self-evident that Terri could "react purposefully with her environment," that she was not in a persistent vegetative state as neurologists had diagnosed' (Waldman, 2006, 1). This prompted critical academic engagement with the videos, the stills which circulated, and the online commentary the images attracted and led to a special issue of *'Jump Cut'* (a journal 'dedicated to 'looking a media in its social and political context'). This special issue included an analysis of the legal, medical, and political context of the widely-seen Schiavo video excerpts, and engagement with the preferred reading offered by the family and their supporters (Waldman 2006) and a 'cultural biography' of the Schiavo images taken together as a "media event' (Preston 2006) which aimed to 'help us understand the social, cultural, religious, economic, and academic traffic in images: How does analyzing various images of Terri Schiavo help us understand the issues involved in the struggle over this woman's right to die/right to live?' and asked questions such as 'What part might images play in that struggle? What practices or beliefs can be said to have contributed to the images that became salient?' (Preston 2006: 1). This collection includes contributors pointing out that 'the visual is *not* self-evident. What the viewers bring to the image is extremely influential in what they see' (Staiger 2006: 1) Staiger's analysis, for example, highlights how, although her parents were offering the videos as evidence of some mental viability for Schiavo –in opposition to allowing her to die – others disputed the images as displaying consciousness or were horrified by, or dismissive of, anyone being kept alive in such a state (Staiger 2006).

**Sociology of science/health reporting:** The interest of academics has also been engaged by *scientific* developments in the assessment of vegetative patients – especially attempts to detect consciousness. One of the most high-profile developments has been fMRI – functional magnetic resonance imaging – which allows researchers to look at more than simply the physical structures of the brain – giving insight into brain *functioning* (e.g. blood flow to different parts of the brain) in relation to different stimuli. The PR around, and media representation of, such

science/technology is of interest to researchers concerned about the social and ethical implications of science in general, and neurotechnologies in particular. Such researchers are often concerned with analysing issues such as the anticipatory discourse around the promise of neuro-therapies (Pickersgill 2011) and the need for a 'neuroethics' (Illes et al., 2003). Such commentary also links to research interests in the 'sociology of expectations' and related work on the 'political economy of hope' which includes work highlighting how 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 and Palladino 2005: 67).

One example of research pursued under this rubric is the study by Samuel and Kitzinger (2013) which focused on two 'breakthrough' studies where fMRI was used to detect brain activity, or even establish communication' with patients with a vegetative diagnosis. The research was presented in press releases from the funding body with titles such as "Brain scan gives vegetative state patient the power to say Yes and No" (MRC press release 3 February 2010) and generated headlines such as "A voice for the voiceless" and "Brain damage patients CAN 'talk'" (cited in Samuel and Kitzinger, 2013). Samuel and Kitzinger argue that both the press releases and the media reporting of this work involved some over-simplification and 'hype'. They highlight the way in which some representations of the story failed to distinguish between vegetative and minimally conscious patients, exaggerated representations of the patients' potential for recovery and promoted a one-dimensional view of family responses. Samuel and Kitzinger contextualise their analysis of source activity and media reporting by also drawing on interviews with family members. Such work shows, for example, that families with experience of serious brain injury don't simply react to 'breakthroughs' such as fMRI with excitement and hope: some dread the idea that their loved-one may have any awareness, and feel that this is a 'fate worse than death' and that any signs of consciousness will only mean the person is trapped for longer in a more intolerable position than if they were entirely vegetative (Samuel and Kitzinger 2013). Other work with family members also highlights that some are sceptical about the powers of technologies such as fMRI to give 'a voice to the voiceless' or provide people with the 'power to say 'yes' and 'no' given their experience in care homes at the bedside of their severely brain injured relatives. One mother for example, said she hoped her daughter (who was diagnosed as 'vegetative') was entirely unconscious, and would remain so, as she had seen how those who 'recovered' were treated. She referred specifically to one young man in her daughter's care home who had been given a communication aid: "*he had one of these machine and he could say 'I need some attention' and then press the button and in the end, because he liked playing with it, [...] they would switch his machine off, because he was doing it all the time [...] / 'Yeah, "you've got a voice, now you haven't"*" (Kitzinger and Kitzinger 2012). In contrast to the optimistic claims of scientific PR statements about new inventions/technologies/discoveries, families thus locate such inventions in the everyday context of the social, legal, political and economic realities on the ground.

**Practitioner assessments of representation:** The third strand of work produced in this area focuses on the representation (or misrepresentation) of *facts* in the news media and in documentaries. This is often a primary concern for scientists and clinicians in the field of brain injury, sometimes working in multi-disciplinary teams

(e.g. with neuroethicists) and such analysis is often published in science or medical journals. This includes commentaries on the impact of high-profile cases – for example several articles focus on exploring the implications of the Schiavo coverage (Racine et al. 2008) and examining issues such as whether the coverage encouraged people to consider Advance Care Planning to record their own wishes in such situations (e.g. Sudore et al. 2008). It also includes a substantial body of work on fMRI such as: a discussion of the problems of public outreach when doing brain imaging work (Illes, Lau & Giacino 2008), a scientist's reaction to an academic critique of some such outreach (Nachache 2014), and an editorial in the British Medical Journal (BMJ) challenging a TV documentary for the claims made about fMRI's unique diagnostic contribution (Turner-Stokes et al, 2013). Articles in the clinical journals also criticise journalists for using distinct terms like "brain dead," "persistent vegetative state," and coma interchangeably (Wick and Zanni 2009: 874) and highlight the media's failure to represent the profound disabilities that are the most likely outcome after many weeks in a 'coma'. For example, analysis highlights how the media fail to show that survival with catastrophic brain injury is a possible outcome of resuscitation (and over represent the success of such interventions) (Diem 1996) and give excessive or misleading news coverage of 'miracle recoveries'.

A second recurring issue in this literature is the problem of misrepresentation in *fiction*. Casarett et al (2005) for example, examined nine soap operas broadcast in the US between January 1995 and May 2005 and identified 64 characters who experienced 'a period of unconsciousness lasting at least 24 hours' (with some characters waking up or dying while still in a coma, and others entering vegetative states for prolonged periods). This study showed that mortality was significantly lower than would be predicted in real life. Recovery was also unrealistically positive: 'On the day that patients regained consciousness most (49/57: 86%) has no evidence of limited function, cognitive deficit, or residual disability needing rehabilitation' and all 'eventually regained full function' (Casarett et al. 2005, 1). Casarett and colleagues point out that such recovery is very unusual: for instance 'typical rates of full recovery from coma after a non-traumatic injury [e.g. a stroke or cardiac arrest] are usually less than 10%' (Casarett et al. 2005, 2) – and these rates are even lower if the person has moved from being in a short term coma to conditions such as the vegetative state. A patient in a vegetative state for more than a few months is unlikely ever to be able to live independently again, and most will always need 24/7 care.

Similar unrealistic representations of coma and vegetative states have been found in movies – which often show, sudden 'awakenings' from even long comas (i.e. vegetative states), with an immediate ability to talk, walk and with fully intact cognitive functions (Wijdicks and Wijdicks 2006). A study of 30 movies featuring 'prolonged comas' also found that the representation of what a person looked like when they were in such states was very misleading – highlighting how all actors (with one exception) remained beautifully groomed, often muscular and tanned, and was no muscle wastage, contracture, evidence of double incontinence, or even feeding tubes (Wijdicks and Wijdicks 2005). Patients are also shown peaceful, as if asleep, whereas patients in vegetative or minimally conscious states may grimace and appear distressed (e.g. struggling to breathe, moaning or retracting from painful stimuli) and may cough and choke (because they can not swallow their own saliva). Another key finding of this study was that, with one exception, all patients were portrayed with their eyes closed – although a defining feature of the vegetative state is eye-opening.

This is only rarely represented by the media, but can have profound implications for family members who associate eye-opening with ‘waking up’ and the return of consciousness. (Nettleton et al. under review).

Widjicks and Widjicks accompanied their analysis of film with surveys and found that many people thought such grossly over-optimist images were realistic and reported that it would influence their own decision making if they ever had a family member in such a state (Wijdicks and Wijdicks 2005, 1006). Wijdick and Wijdick’s concern echoes those raised by other clinicians/scientists and those working closely with families of brain injured patients that fictional representations could be associated with ‘unrealistic expectations of recovery’ which ‘often contribute to disagreements about treatment’ (Casarett et al, 2005, 1) – a view given support by findings from Kitzinger and Kitzinger who conducted an in-depth interview study with families. They found that many interviewees reported that the media images of coma had left them ill-equipped to face the real challenges of the situation, misinformed them about the possibilities of recovery, and hence led them to insist on life-sustaining treatments they now regret. Interviewees also described feeling isolated – because friends and acquaintances had no real understanding of the situation, and reiterated misleading ideas from the media (Kitzinger and Kitzinger, 2014).

However, other commentators argue that it is important to acknowledge that fictional representations should not simply be judged against clinical realities. Rather, it is important to assess fictional fantasies of ‘waking up’ against social assumptions that vegetative patients have no potential for recovery and are ‘as good as dead’ (or ‘worse than dead’). Jo Fins, is one key commentator here – both as a practising physician in the field and as president of the American Society for Bioethics and Humanities. He responded to the Wijdick and Wijdick analysis of films by arguing that:

Cinematic "distortion" can also be understood as a compensatory artistic device that counters societal perceptions about brain injury which themselves may be inaccurate. From this broader cultural context, poetic license on the part of a filmmaker could be construed as a corrective.’ (Fins 2006)

Fins highlights the ‘metaphorical’ power of the film to allow for hope and argues that a film criticised by Wijdick and Wijdick:

anticipates the emerging diagnostic and prognostic significance of distinguishing the vegetative state from the recently described minimally conscious state. Patients who are minimally conscious may make gains that allow for the recovery of functional communication and some degree of reintegration with their families despite overwhelming levels of disability, generating complex ethical questions about what constitutes an acceptable clinical outcome.

He concludes that the power of film to inspire and instruct may be lost when the critic’s gaze is directed too literally at manifest medical content’ and suggests that ‘A broader cultural lens is required to consider neuropalliative goals of care’ (Fins 2006).

### **Recommendations for future research:**

The brief overview of research into media reporting of ‘coma’ highlights patterns echoed in coverage of other science/health issues, both with regards to the richness of diverse approaches and with regard to the debates around them. Research on ‘coma’, like that around many other science and health issues, addresses a wide range of media genre and analytical questions – from the issue of misrepresentation to the issue of fantasy.

This overview highlights the need to locate any analysis of ‘media representation’ of a scientific/health issue within the history of that particular issue as well as contextualising the coverage through an understanding of the surrounding scientific, clinical or cultural debates. It also suggests how students might read such this literature with attention to the research design and the disciplinary background of the studies’ authors as well as highlighting how researchers might pursue cross-disciplinary and cross-sector collaboration to expand and refine their studies.

### Further reading

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