

To: SELECT COMMITTEE ON THE MENTAL CAPACITY ACT 2005

From: Professor Celia Kitzinger, Department of Sociology, University of York YO10 5DD
email: celia.kitzinger@york.ac.uk

Professor Jenny Kitzinger, JOMEC, Cardiff University, Bute Building, King Edward
VII Ave, Cardiff CF10 3NB email: kitzingerj@cardiff.ac.uk

About us

We are both social science professors with established research careers in the area of health and communication. We are the founding Co-Directors of the York-Cardiff Chronic Disorders of Consciousness Research Centre – an interdisciplinary group of scholars across two universities carrying out research on the historical, sociological, ethical, legal and economic aspects of coma, the vegetative state and the minimally conscious state. More information is available on our websites at:

<http://www.york.ac.uk/sociology/research/current-research/chronic-disorders-of-consciousness-research-centre/> and www.labwales.org.uk/jomec/research/consciousness/index.html

This submission focuses on the implementation of the Mental Capacity Act 2005 in relation to those in long-term vegetative or minimally conscious states. This is a relatively small group of people - perhaps 5000 people in England and Wales. These people have no capacity to make any significant decisions for themselves. They cannot represent themselves in this consultative exercise, nor are they adequately represented by disability groups speaking on behalf of those who have (some) capacity.

We have carried out a review of the literature in this area and have collected a unique data set of 51 in-depth narrative interviews with family members of people in England and Wales who are – or have been – in either a vegetative or a minimally conscious state following severe brain injury. We also have a supplementary data set of 10 interviews with professionals working in the field. We have analysed these data from various perspectives, particularly for what it reveals about family experiences of the Mental Capacity Act and the Court of Protection. We have received funding from the Wellcome Trust and from the Economic and Social Research Council. We are currently preparing a unit on chronic disorders of consciousness for the charity website HealthTalkOnline (<http://www.healthtalkonline.org>). Celia Kitzinger is also Principal Investigator for an ESRC Seminar Series on “Advance Decisions: Informing Implementation Strategies through Interdisciplinary and Cross-national Dialogue” (see our website at <http://www.york.ac.uk/sociology/research/current-research/kitzinger-advance-decisions/>). We have also prepared a leaflet for families based on our research findings (attached).

We launched this research following our own family’s experience of severe brain injury and Jenny Kitzinger is making a separate submission about her first-hand experience as a court-appointed Welfare Deputy. Our comments here relate only to our academic research findings.

2. Which areas of the Act, if any, require amendment; and how?

More clarity is needed about the role of the vegetative or minimally conscious patient’s past values and beliefs in best interests decision-making. Our research shows considerable concern among family members that these are not being taken into account. This concern is reflected in academic commentary by medical ethicists about the judgment in the recent court case concerning a minimally conscious patient (*W v M* [2011] EWHC 2443 (Fam)).

The Act refers to the patient’s “beliefs and values that would be likely to influence his decision if he had capacity” and to the “other facts that he would be likely to consider if he were able to do so”. Patients in chronic disorders of consciousness are unable to express *present* beliefs or values, so in best interests decisions it is essential to consider their past beliefs and values, insofar as these can be ascertained from people to whom they were close when they had capacity. The interviews that we have carried out with family members provide very little evidence that family members are being consulted in this way. It was rare, in the acute phase, for family members to feel they had any role in decision-making at all. In particular, their experience was that life-prolonging measures were routinely provided ‘by default’ without any discussion of whether or not the person would have wanted or consented to them¹. Judicial interpretation (*W v M* [2011] EWHC 2443 (Fam)) of the role of past values and beliefs as not carrying substantial weight when set against the ‘sanctity of life’ has been heavily criticized by medical ethicists². If ‘sanctity of life’ (which does not appear in the Act) will always trump a person’s prior view that they would rather be dead than maintained with a chronic disorder of consciousness, then people’s own values and beliefs clearly carry very little weight at all.

Our interview research shows that family members are very concerned that the PVS/MCS patient’s previously held beliefs and values should be upheld: some clinicians’ apparent lack of interest in the patient’s beliefs and values, and the failure to include these in decision-making, is a source of anger and dismay.

12. Has the MCA fostered appropriate involvement of families in decision-making?

Our research suggests that in some cases there has *not* been appropriate involvement of families in decision-making.

Family members in our study report widely differing experiences. There are some clear examples of their having been appropriately involved in decision-making (e.g., as sources of information about what the patient would have wanted) - especially in preparation for Court of Protection cases. There is also some evidence of inappropriate involvement, for example in situations where it may have been the case that medical teams were persuaded by family intervention to act in ways that may not have been in the patient’s best interests – for example, reversing decisions to withdraw/withhold futile treatment in order to avoid conflict with family members. There are also indications in our data that some clinicians may be making premature decisions to withdraw treatment (i.e. at an early stage when the patient’s prognosis is very uncertain and without a proper best interests meeting involving family members) out of concern to avoid the patient subsequently becoming ‘trapped’ in a vegetative or minimally conscious state³. (This requires further research with clinician interviewees to assess the extent to which this is a problem.)

Overall there was little evidence of family members having been consulted about the patient’s wishes, values or beliefs. Our research suggests that professional understanding of the Act is poor (especially among consultants) and that there are many failures to act in accordance with it. In particular, there seems to be a failure by some clinicians to engage

¹ Clements, L., Kitinger, C. & Kitinger, J. *Serious medical decisions and the Mental Capacity Act in relation to severe brain injury: Family accounts of decision-making* In preparation.

² *Journal of Medical Ethics* Special Issue Vol 39(9) September 2013.

³ Kitinger, J. & Kitinger, C. 2013. The ‘window of opportunity’ for death after severe brain injury, *Sociology of Health and Illness* 35(7) 1095-1112. doi: 10.1111/1467-9566.12020. For similar concerns in the USA context see Cochrane, T.I. 2009. Unnecessary time pressure in refusal of life-sustaining therapies: Fear of missing the opportunity to die, *American Journal of Bioethics* 9(4): 47-54.

best interests decision-making for unconscious severely brain-injured patients – either in intensive care, or subsequently. For example, one father told us that the attitude of the consultant in the weeks after his son’s brain injury came across to him as “you know nothing; leave it to us; we’re the experts here”. He detailed the medical interventions (bolt, intubation, antibiotics for pneumonia, brain surgeries) provided in the first weeks:

- Interviewer: And have you at any point been asked what you as a family think, what information you want?
- Thomas: No.
- Interviewer: What input you’d like?
- Thomas: No. None whatsoever.
- Interviewer: Or anything about [son] as a human being, as a person, his choices?
- Thomas: No.

Some interviewees reported that their relatives had been maintained in vegetative or minimally conscious states for many years without consultants raising any questions as to whether or not the person would have wanted ongoing life-sustaining treatment. In such cases medical treatments, including artificial nutrition and hydration, are being given not only in the absence of consent (since the person lacks capacity) but also the absence of adequate best interests decision-making meetings to establish what the person’s prior values and beliefs might have been in relation to continued treatment.

Families typically find it difficult to raise the possibility of withholding or withdrawing treatment (‘I’d feel like a monster’) – and it is not their legal responsibility to do so. However, in the absence of best interest meetings, some of our interviewees had attempted to initiate a conversation about the possibility of withdrawing or withholding life-prolonging treatments and had then been obstructed by health care professionals. A couple interviewed together described what happened when one of them (Harry) attempted to question what was happening to his sister who was in a permanent vegetative state:

Harry: Apparently after one year they’re supposed to come and ask you, you know what do you want to do, and that never really happened.

Natalie: Well it didn’t happen at all. It was the opposite. On one occasion [...] Harry asked the nurse in charge “Why is this being allowed to continue?” And this particular nurse said “What do *you* know?” Harry said, you know, “She’s not coming out of this is she?” And she [the nurse] said, you know, “Are you a professional? You’re in no position to judge this!” and really took him to task in a way that was totally inappropriate

Another interviewee recalled how she was treated when she tried to ask what could be done differently for her husband in a permanent vegetative state.

I said ‘What if I don’t want this anymore?’ And he [the consultant] immediately responded saying ‘You’d go to prison’. I think maybe they were giving him antibiotics...I felt they were saying, ‘You can’t do it’. And then I just felt, ‘God, is this going to go on forever and forever?’

In such cases the opportunity to hold a best interests meeting about treatment withdrawal has clearly been missed.

It is very likely that non-compliance with the MCA requirement for best interests meetings means that medical treatments are being delivered to patients who would have refused them if they could, and for whom continued treatment is not in their best interests. Research evidence indicates that most people would *not* consent to life-prolonging

treatment if they were in a permanent vegetative state (PVS) or minimally conscious state (MCS)⁴. Extrapolating from this survey suggests that many people currently in a PVS or MCS would have held the view that if they were to be in such a state they would wish treatment to be withdrawn. This is supported by our interview research in which about three-quarters of our interviewees say that their relative would not wish to be maintained in this state⁵. The fact that some PVS patients are being maintained for many years after their families believe they would rather be dead and without any consultation with their families about this is not compliant with the MCA. It also means that doctors are actively involved in giving futile medical treatment. According to the Royal College of Physicians:

When the diagnosis of a permanent VS has been made by establishing the cause of the syndrome so far as possible, by confirming the patient's clinical state and by the passage of time, recovery cannot reasonably be expected, and further therapy is futile. It merely prolongs an insentient life for the patient and a hopeless vigil entailing major emotional costs for relatives and carers⁶.

Some interviewees had the impression that they, as 'next of kin', were responsible for decisions about withdrawing/withholding treatment. They described having been asked for 'consent' for particular treatments and sometimes reported that serious medical decisions had been reversed after they had withheld consent. This is not legally correct – and it is not clear from our data whether some clinicians are in fact giving families decision-making powers that are not legally theirs, or whether families misunderstand the situation⁷. What is clear is that interviewees who believed (whether correctly or not) that they had decision-making rights over withholding or withdrawing treatments felt burdened by the responsibility of making life or death decisions for a loved-one, and were usually left without any support in making these decisions. Research shows that under these circumstances there is likely to be a bias towards overtreatment, as families respond by choosing whichever treatment option minimizes their own sense of responsibility⁸. Clinicians should make clear to families that they are *not* the decision-makers (see our leaflet for families, submitted separately, which explains this). Clinicians need to take the lead in calling properly convened best interests meetings and making clear to families that it is the clinician (or, in ANH withdrawal cases, the judge) who is the decision-maker.

Our findings suggest the importance of regular meetings to discuss patient best interests, with the initiative for raising issues of treatment withdrawal coming from the clinicians. It might also help if ANH withdrawal (e.g. for PVS patients after one year) were possible where there is consensus between clinicians and families, without requiring a court to authorize the decision. Some bioethicists argue that once a PVS diagnosis is confirmed then (in the absence of any advance stated wishes to the contrary) withdrawal of ANH should become the

⁴ Demertzi, A. et al, Attitudes towards end-of-life issues in disorders of consciousness: A European survey, *Journal of Neurology* 258: 1058-1065. This survey of 2,475 health care professionals across Europe found that 82% of respondents would not want to be kept alive in a permanently vegetative state and 67% would not want to be kept alive after one year in a minimally conscious state.

⁵ Kitzinger, J. & Kitzinger, C. 2013. The 'window of opportunity' for death after severe brain injury, *Sociology of Health and Illness* 35(7) 1095-1112. doi: 10.1111/1467-9566.12020

⁶ RCP guidelines, 2003 s. 3.5

⁷ A study in Scotland found that 88% of relatives of intensive care patients falsely believed that they already had the right to consent on behalf of an incapacitated adult. The authors observe "It was our impression that not all doctors were entirely clear on this either" (Booth, M.G., et al, 2004, Relatives' knowledge of decision-making in intensive care, *Journal of Medical Ethics* 30: 459-461).

⁸ Berger, J.T. 2005. Patients' interests in their family members' well-being: An overlooked fundamental consideration within substituted judgements, *Journal of Clinical Ethics* 16: 3-10; Rid, A. & Wendler, D. 2010. Can we improve treatment decision-making for incapacitated patients? *Hastings Center Report* (Sept/Oct): 36-45.

default position with the burden of justification on those who would continue ANH⁹.

There is also a need to clarify the circumstances – if any - under which a person who is in a MCS can be allowed to die. Some commentators have pointed out that it may be *worse* to be in a minimally conscious state than in a vegetative state¹⁰. The judgment in *W v M* [2011] EWHC 2443 (Fam) has led to a widespread perception that the law will not permit withdrawal of artificial nutrition and hydration from these patients. This may mean that instead of a managed death from ANH withdrawal with appropriate palliative care as authorized by the courts MCS patients are allowed to die instead from disease and infection, or even from ‘mercy killings’ (mentioned by many of our interviewees)¹¹.

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

Our research¹² shows that there is a lack of knowledge about advance decisions even among individuals who are exceptionally highly motivated to ensure that they are not kept alive in a permanent vegetative or minimally conscious state. Our interviewees were virtually unanimous that they would not want to be kept alive in a state such as that of their relative – but only 30% had written advance decisions refusing treatment. The main reason given for *not* having written one was not knowing that such a thing was possible. Some interviewees also believed that ‘next-of-kin’ were legally entitled to make decisions on their behalf, and would ensure that their wishes were respected.

Our interviewees reported that advance wishes about end of life care had been communicated to them, but rarely in a form that meets the legal requirements for a valid Advance Decision (AD). The introduction of statutory support for ADs (via the MCA) should not mean that prior wishes and beliefs that do *not* fulfill the legal requirements for formal ADs are given any less weight than under previous common law. In our research only one family reported that the patient had made a valid AD, and in this case, although the family members were certain that he intended it to cover his current circumstances and would have wished to refuse treatment, the AD was found (by the treating clinician) to be not ‘applicable’ to the particular circumstances of treatment refusal. In another case, the written advance refusal of treatment was in the form of a letter and not witnessed, and so not legally valid.

A written statement about what a person would want is valuable for families even if it does not constitute a valid and applicable AD:

I think the fact that he'd written what he wrote helped you cope with it in your head. Because otherwise it would feel like it was more your decision. I mean, it's going to be hard anyway, but it's going to be – it would have been so hard to

⁹ Constable, C. 2012. Withdrawal of artificial nutrition and hydration for patients in a permanent vegetative state: Changing tack, *Bioethics* 26(3): 157-163.

¹⁰ Kahane, G. & Savulescu, J. 2009. Brain damage and the moral significance of consciousness, *Journal of Medicine and Philosophy* 34: 6-26; Wilkinson, D. & Savulescu, J. 2012. Is it better to be minimally conscious than vegetative?, *Journal of Medical Ethics* doi:10.1136/medethics-2012-100954

¹¹ Kitinger, J. & Kitinger, C. 2013. The ‘window of opportunity’ for death after severe brain injury, *Sociology of Health and Illness* 35(7) 1095-1112. doi: 10.1111/1467-9566.12020. There have been two recent reported cases of ‘mercy killings’ of PVS patients by family members: Francis Inglis killed Tom Inglis, her VS son, and is serving a murder sentence (*R v Inglis* [2010] EWCA Crim 2637; Tudor David killed Diane David, his PVS wife, and also himself (<http://news.bbc.co.uk/1/hi/wales/10539093.stm>)

¹² Kitinger, C. & Kitinger, J. 2013. A fate worse than death? End of life planning, severe brain injury and chronic disorders of consciousness, Talk to Practitioner Research Network Meeting, Sue Ryder Care Centre, Queens Medical Centre, 31 January. Downloadable slides at: <http://www.york.ac.uk/media/sociology/research/currentresearch/kitingerconsciousness/Kitinger%20ADs%20and%20CDoCs%20Sue%20Ryder%2031%20Jan%202013.pdf>

live with that, knowing that – almost feeling that you'd sentenced them to death, however much they wanted it

One interviewee, whose relative was in a vegetative state following complications from surgery reflected on a missed opportunity to promote ADs at the point of gaining informed consent for that surgery:

Mary: In hindsight, looking back at what they actually said, frightening him to death literally, him thinking, “oh my God, I'm going to die”, that maybe - if they're going to say that anyway to make sure that they're warning people of every possibility - why don't they suggest that they write the advanced letter is it called?

Int: Advance Decision.

Mary: And maybe give them a leaflet regarding it. Suggest, “Look, why don't you think about doing one of these just in case you can't communicate and then we know exactly how you feel and how – what you would want us to do should you not be able to communicate. Say for instance, say if you were in a coma immediately afterwards, it might be just a temporary thing but we won't know whether you'd want this or want that”

Our findings suggest that ADs have not been sufficiently promoted and that some of those who would very much want to refuse treatment in advance of losing incapacity are missing out on the opportunity to do so because ADs have not been brought to their attention. It is also of some concern that to find that in two families in our sample the person had attempted to draw up a legal document (in one case with the assistance of a solicitor) to ensure their wishes were met and that in neither case did the supposed ‘AD’ lead to the outcome that the family believed the person would have wanted. If this is widespread, it suggests the need for training in the preparation and interpretation of ADs among both solicitors and clinicians.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

There was no involvement of IMCAs in any case in our sample. Since families (in most cases) say that they were not given the opportunity to provide a voice for their patient or to speak on their behalf – at least for some period of time - this may have meant that the PVS/MCS patient was left completely without representation.

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all?

No. We consistently find that even academic audiences are surprised that next-of-kin cannot make decisions for another adult. This erroneous belief is one reason why people either do not write Advance Decisions (i.e. ‘my family knows what I want’) or do not appoint an LPA for Health and Welfare (since they believe the spouse or adult daughter who they would wish to make decisions already has decision-making rights)¹³. There is also a widespread confusion between LPAs for finance and for health, with many believing that the former accord the person decision-making rights over health and welfare.

¹³ Kitinger, C. & Kitinger, J. 2013. A fate worse than death? End of life planning, severe brain injury and chronic disorders of consciousness, Talk to Practitioner Research Network Meeting, Sue Ryder Care Centre, Queens Medical Centre, 31 January. Downloadable slides at: <http://www.york.ac.uk/media/sociology/research/currentresearch/kitingerconsciousness/Kitinger%20ADs%20and%20CDoCs%20Sue%20Ryder%2031%20Jan%202013.pdf>