

Some families would consider terminal sedation for kin in a permanent vegetative state

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The families of some very severely brain injured patients believe that once all treatment options are exhausted, allowing their relatives to die with the help of terminal sedation would be a humane and compassionate option, research carried out by the University of York and Cardiff University has revealed.

The study, based on interviews with the families of patients in a vegetative or minimally conscious state, found some relatives believed euthanasia by sedation would be preferable to withholding or withdrawing treatment.

Currently, the withdrawal of treatment such as artificial nutrition and hydration is the only legal method guaranteed to allow death in patients in a vegetative state.

The research paper *Withdrawing Artificial Nutrition and Hydration from Minimally Conscious and Vegetative Patients: Family Perspectives* is published today (15 January 2014) in the *Journal of Medical Ethics*.

The study was carried out by Professor Celia Kitzinger from the Department of Sociology at York and Professor Jenny Kitzinger, at the School of Journalism, Media and Cultural Studies at Cardiff University. Celia Kitzinger and Jenny Kitzinger, who are sisters, are co-directors of the York-Cardiff Chronic Disorders of Consciousness Research Centre

(CDoC) which explores the social and ethical challenges of the vegetative and minimally conscious state.

The researchers' sister, Polly, was severely brain injured in a car accident in 2009.

Celia Kitinger said: "At the moment it is legal to allow people to die by withdrawing artificial nutrition and hydration, but that can mean watching a long, slow death which many relatives just cannot bear the thought of.

"If a court is going to take a decision to allow someone to die, why not do it in a way that's less prolonged for the patient, or, if the patient is entirely unaware, then at least less distressing for their family? There must be a more merciful way of allowing people to die. It's a message about being merciful and reducing suffering.

"We suggest that the lived reality of the families facing these decisions should be taken into account and that other ways of bringing about the death of severely brain damaged patients should be given full ethical consideration."

The study found that, although two thirds of 51 individuals questioned believed their relative would rather be dead than stay alive in a long-term vegetative or minimally conscious state, far fewer were willing to consider an application for withdrawal of artificial nutrition and hydration to allow death.

Celia and Jenny Kitinger say the views of relatives should be given ethical consideration in legal and medical debates on [treatment options](#).

Jenny Kitinger explained: "The withdrawal of artificial nutrition and hydration is currently the only legally available and certain exit route for

such severely brain injured patients. But failing to provide food or water to a loved one, even because of the conviction that they would prefer to be allowed to die, is a highly emotive issue with deep cultural resonance. Many of the people we interviewed were concerned that, even with a confirmed [vegetative state](#) diagnosis, their relatives would experience pain and suffering if nutrition and hydration were withdrawn or that it would be distressing for other family members to watch.

"There was a widespread perception that lethal injections would be more humane, compassionate and dignified than what they worried was 'death from neglect' as a result of treatment withdrawal."

One interviewee told the researchers: "I would view a lethal injection as a kinder decision, because if you stop feeding them, they are going to die. If you've made that decision, you might as well do it as humanely as you possibly can. To starve somebody to death seems a particularly cruel thing to do."

Some interviewees told the researchers they fought for medical interventions in the early stages of the injury or trauma in the hope their relative might recover. Some now regretted this believing the patient had suffered a fate worse than death. Many said that, rather than actively seek withdrawal of artificial nutrition and hydration, they were waiting for a natural death with some working with doctors on agreements not to resuscitate patients if they suffered a cardiac arrest or not to treat life-threatening infections with antibiotics.

One interviewee said: "I don't feel it's my place to go to a court and say 'I want his nutrition withdrawn'. I don't think I could do that. But I don't think it's right or fair to actively take steps to prolong this life. I suppose I'm waiting for [him] to die naturally'."

Provided by University of York

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