We also emphasise that a quarter of those diagnosed as vegetative by the referring team remained vegetative and were almost certainly, from our experience, likely to remain so. These findings are therefore not an argument against the withdrawal of artificial nutrition and hydration but do emphasise the importance of accurate diagnosis of the vegetative state being made after expert assessment and provision of a rehabilitation programme by a very experienced team.

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Commentary: The importance of patients' consent for publication

Richard Smith

This paper made us think hard about the issue of getting consent from patients for publication of identifiable information about them. Obvious identifying information has been removed, but these patients cannot be considered to be truly anonymised. After much discussion, the editorial team and the authors agreed that we should get witnessed consent for publication from those patients in the series who were capable of giving consent and agreement to publication from the relatives of those not able to give informed consent. The authors did this, and one set of relatives did not agree to publication. The details of the patient whose relatives did not agree have been removed from the paper.

Getting consent for the publication of a series of patients in medical journals has not been usual, and readers, future authors, and other editors may find it useful if we describe the thinking that went into getting consent for this paper. We start from the premise that information that emerges from the doctor-patient relationship is confidential information. The doctor-patient relationship is built on trust, including the trust of patients that information they disclose will remain confidential. This information should not be revealed to third parties in an identifiable form unless patients give consent or there is overwhelming reason to break the confidentiality without patients' consent. It is hard to imagine circumstances in which publication in a medical journal would be so important that confidentiality could be broken without the patient's consent, although minimising the danger of just one patient being misdiagnosed as being in a vegetative state might to some people justify breaking patient confidentiality. Another premise is that everybody has a right to privacy. This right applies beyond the doctor-patient relationship. That right may be overridden in some circumstances, but why should publication of details about you in a medical journal override your right to privacy?

A problem with publication of a series of cases as in this paper is that these are unusual cases, and they have all been managed at some stage in one hospital. Some people will be able to recognise these patients. The media have already gathered details. Clearly there is much discussion about the definition of identifiable—do we mean identifiable to the average reader, one or two readers, the patient, other family members, friends, or the nursing staff who cared for the patient? We have experienced cases where only the patient has recognised the report but has nevertheless been deeply disturbed.

There were arguments against getting consent. The first argument is that under English law, relatives cannot give consent for patients who cannot themselves give

consent. But would we want to publish details of a patient if the relatives did not want us to? We decided we would not. A second argument is that by requesting consent we complicate the process of publishing medical papers. This may result in some papers not being published. We could not convince ourselves that these steps would stop important papers being published. Most patients, we have discovered, will give consent. A third argument is the slippery slope argument. Where will we draw the line? If we have an epidemiological paper with data on 5000 individuals, will we require consent from all of these people? The answer will always be no when, as is usual, the data are presented in a combined form: no individual is identifiable.

The fourth argument came in various forms but was essentially the argument that getting consent was a lot of trouble: the patients are now scattered; it might take a long time to get consent from some of them; it would be necessary to be clear who could give consent and who couldn't; publication would be slowed; and the media were already pursuing the authors and editors. Expediency is not a good reason to override ethical issues.

So our conclusion was that we must get consent from patients and agreement to publication from relatives, and we are grateful to the authors for doing that.

Problems of confidentiality arise in many series of cases, and authors and editors need to sensitise themselves to the problems. There is a particular problem with family pedigrees, in which information may be disclosed on relatives of patients. Indeed, the possibility arises that family members may learn something important to themselves for the first time through publication of pedigrees in medical journals.

A current issue where problems may arise surrounds the publication of data on Creutzfeldt-Jakob disease. The British government announced at the end of June that it would publish data on definite and probable cases every three months. There will obviously be intense interest in these data, particularly in the cases of the new variant of the disease. And this is a topic where in the early days of what may prove an epidemic every case will matter greatly. Leaving out just one or two cases from the data may confuse the developing picture. There were three deaths among people with new variants of the disease in 1995 and six so far in 1996. "Clearly," said Sir Kenneth Calman, the chief medical officer, "with the present intense interest in the disease, there is a need to put statistics into the public domain more frequently. Personal details will not be included. There is a difficult balance to be struck between the legitimate need for public information and patient confidentiality."