

The authors emphasise the importance of getting the diagnosis right, and few would argue with them. But it is interesting to note that all 17 patients who were found to be conscious were severely disabled; all were severely paralysed and anarthric, most were either blind or severely visually impaired, some were substantially cognitively impaired, and all were presumably dependent on feeding tubes. Reasonable people may differ in their views of the quality of life of these conscious individuals, but I would speculate that most people would find this condition far more horrifying than the vegetative state itself, and some might think it an even stronger reason for stopping treatment than complete unconsciousness.

But whether being in the vegetative state is viewed as preferable to being just outside it, and whatever your views on withdrawal of tube feeding in such patients, careful examination of every patient is essential to determine their consciousness and ability to suffer. It would be dreadful indeed to stop treatment in patients who were thought to be unconscious but who could in fact experience thirst and hunger when treatment, including artificial nutrition and hydration, was stopped. Equally important is the need to maximise quality of life for those who are capable of communicating. Some may even be able to contribute to decisions about their medical treatment.

Professor Andrews and his colleagues should be congratulated on their detailed and careful evaluation of patients with severe brain damage. Their work will help us to unravel the mysteries of the vegetative state for the welfare of patients, their families, and society. With more experience, we may develop a better sense of the value of the buzzer switch system, and if the rate of misdiagnosis of vegetative state is as high as this article suggests, others should be able to duplicate their results.

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Measuring health outcomes

Sum 29

Condition specific and patient specific measures are of limited use when allocating resources

Despite widespread agreement on the need to consider quality of life in health care decisions, there is little agreement over which of a growing list of measures of quality of life should be used. There is no agreement over broad issues such as whose values should be incorporated in the measures and how different values should be weighted.

Literally hundreds of condition specific and patient specific measures have been developed. Condition specific measures are popular in part because they offer the scope to capture the many different aspects of health that might influence quality of life. When compared with generic measures, which can be applied to all conditions, they seem more sensitive to changes in a patient's underlying state of health. Rather less common are what might be called patient specific measures of outcome. Here, patients choose the dimensions of concern and the weighting of these dimensions and assess their own quality of life within this framework.¹⁻³ In this week's *BMJ*, Hickey *et al* describe their use of a patient specific measure of quality of life in a cohort of patients with HIV infection or AIDS (p 29).⁴

Most health economists consider both condition specific and patient specific measures to have severe limitations. The fundamental problem is that, unlike the quality adjusted life year (QALY), neither of them can be used to inform decisions about resource allocation.⁵ The QALY combines quantity of life and health related quality. A single index number representing health related quality of life enables adjustment of the quantity of life. It also allows economists to aggregate health gains from many patients and to compare outcomes of different interventions for a particular patient.

Most condition specific measures have been constructed without direct reference to patients' preferences. This means that they might show an improvement while a patient accurately reports that he or she is worse off. In principle it is possible to construct condition specific QALYs. It is difficult, however, to ensure that those for different conditions would be comparable. It would be very attractive if condition specific QALYs were like different currencies that could be translated one into another using

exchange rates. Failing this, they are likely to be of use only in a narrow range of health care decisions.

Patient specific measures, by letting individual patients choose the dimensions and the weight attached to each dimension, may increase the ability of a measure to grade the likely benefit from different interventions. Moreover, patients themselves are probably in the best position to assess their quality of life. A potential difficulty is that patients' views might change as their disease or condition develops. But patient specific measures have an advantage in that they do not force valuations to be independent of a patient's history or prognosis.

Patient specific outcomes do, however, seem to be measured with an elastic ruler. Different patients might be in essentially the same state of health but have different quality of life scores, and changes in these scores could occur without changes in the underlying state of health. When the focus is on the individual patient this may not be a weakness. However, most economic purposes involve the comparison of the costs and benefits to different groups of patients, and it is hard to see how patient specific measures could reasonably fill this role. Condition and patient specific measures have advantages, but their use is likely to remain limited, especially when allocating resources, until their properties are clarified and some basis for comparing different measures is established.

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