

PERMANENT VEGETATIVE STATE: USEFULNESS AND LIMITS OF A PROGNOSTIC DEFINITION

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Thirty two years ago, in 1972, Bryan Jennett and Fred Plum proposed the name 'persistent vegetative state' to describe a state that is 'neither unconsciousness nor coma in the usual sense of these terms... <but instead> wakefulness without awareness' (Jennett and Plum, 1972). Definition and discovery are ambiguously linked; the definitions of autism, say, or Down syndrome, are sometimes treated as the discovery of those conditions, in the same way as the mapping by white explorers of a small stream already familiar to the local inhabitants was described as the discovery of the source of the Nile.

Anyone curious about how this insight was achieved will turn to Professor Jennett's recent book "*The Vegetative State*" (Jennett, 2002). The book begins 'When Jennett and Plum in 1972 coined the name persistent vegetative state....'. Professor Jennett speaks of himself in the third person - that is, he claims no privileged access to his own thought processes or his own story, and gives no weight to his own very considerable experience. In this admittedly minor point he flags from the outset the epistemology that governs his researches; that the only reliable approach that we can gain to truth is through publications in refereed journals (newspaper reports, the experiences of people who have been diagnosed as having PVS, and much else of the material I would otherwise wish to deploy, are not regarded as evidence). Bryan Jennett and Fred Plum, as Englishmen of their time and class, may be subject to error or social pressures; 'Jennett and Plum (1972)' is authority – impersonal, unarguable, and timeless.

We should nonetheless persist in attempting to look behind the curtain at the processes that have produced these certainties, asking, for example, "Why was this discovery made at this time?" – or, to put it another way, "What was the problem to which this discovery was a solution?" Jennett and Plum noted in 1972 that new methods of treatment were permitting the survival of patients with devastating brain damage resulting from such

insults as head trauma, brainstem stroke, or hypoxia - conditions that would previously have resulted in rapid death. They saw this situation as creating a need for a new term:

New methods of treatment may, by prolonging the lives of patients with conditions which were formerly fatal, result in situations never previously encountered. And new situations call for new names if they are to be accurately understood and discussed. (Jennett & Plum, 1972)

A situation, however, is not necessarily a problem. The problem was that decisions had to be taken, and there was insufficient agreement on how, or on what grounds, or even on what classes of grounds, they should be taken. And there was one decision that people might want to take that was particularly problematic.

It may well become a matter for discussion how worth while life is for patients whose capacity for meaningful response is very limited.... (Jennett & Plum, 1972)

Two obvious factual difficulties stood in the way of a completely free hand with such decisions. One, it could not be established without doubt that such people would not recover; two, it could not be established absolutely that they were not aware. Jennett and Plum dealt with both objections alike.

In regard to consciousness Jennett and Plum phrase the question as an issue of evidence;

....there is a group of patients who never show evidence of a working mind. This concept may be criticised on the grounds that observation of behaviour is insufficient evidence on which to base a judgement of mental activity; it is our view that there is no reliable alternative available to the doctor at the bedside, which is where decisions have to be made. (Jennett & Plum, 1972, p. 737)

The reasoning is

- We have insufficient evidence to make a judgement; **but**
- Unless we make a judgement we cannot solve the problem; **therefore**
 - (We cannot solve the problem; **but**)
 - (This is absurd, **and so**)
 - (One of the premises must be in error, **and therefore**)
- We have sufficient evidence to make a judgement.

Similarly, when the definitional problem of where to draw the line on a continuum presents itself Jennett and Plum say

Although we would not deny that a continuum must exist between this vegetative state and some of the others described, it seems wise to make an absolute distinction between patients who do make a consistently understandable response to those around them, by word or gesture, and those who never do.(Jennett & Plum, 1972)

The form of reasoning here is similar;

- A continuum exists between PVS and locked-in syndrome;
- Unless we must make an absolute distinction between PVS and locked-in syndrome we cannot solve the problem; **therefore**
 - (We cannot solve the problem; **but**)
 - (This is absurd, **and so**)
 - (One of the premises must be in error, **and therefore**)
- There is not a continuum between PVS and locked-in syndrome, but rather an absolute distinction.

The need, moreover, was for the identification of a state that was not only clearly differentiated but irrecoverable.

Certainly we are concerned to identify an irrecoverable state... (Jennett & Plum, 1972)

The difficulty was that at the time of writing the article Jennett and Plum were unable to do this with confidence in any given case; reliable diagnosis of a 'permanent vegetative state' was admittedly beyond them.

... the criteria needed to establish that prediction [of irrecoverability] reliably have still to be confirmed. (Jennett & Plum, 1972)

Once again, they simply assume the solution to this difficulty.

Exactly how long such a state must persist before it can be confidently declared permanent will have to be determined by careful prospective studies. (Jennett & Plum, 1972)

Jennett and Plum do not contemplate the possibility that uncertainty as to prognosis may be inherent in the condition, and that future experiment may simply document the persistence of this uncertainty. They certainly do not contemplate, or encourage, still less plan for, any improvements in treatment that might alter the prognosis for such cases.

Since 1972 the work of Professor Andrews (Andrews et al, 1996) has brought the issue of reliability into sharp focus, his recorded outcomes casting doubt, one would think, on both the predictive power of the diagnosis and the insentience of the patients - and, of course, suggesting that improved communication techniques can offer considerable promise. Why, then, has Professor Andrews' work been considerably less influential than that of Jennett and Plum? In part the answer is that whether Jennett and Plum have formed the general opinion in this area, or expressed and embodied it, they have unquestionably set the terms of the debate -- largely by their selection of the problem. If the problem is, as Jennett and Plum imply, that we are unable to deal with these cases as we would wish, then Andrews' approach cannot be part of the solution.

On a more general level, however, the comparative lack of influence of Professor Andrews' findings must surely be because they complicate, rather than simplify, the decisions that must be taken. Humanity is generally uncomfortable with uncertainty; Bertrand Russell said, "What men want is not knowledge but certainty" (Lum, 2001), and this has some truth in it. It is certainly true that a doctor who prefaces his words with "I'm not really sure, but I think on balance that the best bet is to do this..." will be more likely to stir up a call for a second opinion, and a judge who said the same thing would invite reversal on appeal. On a slightly wider scale, social institutions such as medicine and law, and perhaps religion, are given our allegiance precisely because they convert the chaos of our lives into comprehensible categories.

The Jennett and Plum formulation also has the advantages and disadvantages of a prognostic definition. On the one hand, there are no clear criteria at any given moment distinguishing patients who have it from patients who do not. The only means, then and now, to distinguish people with persistent vegetative state from people with merely transient vegetative state is to observe them and see whether their vegetative state persists; the longer it persists, the higher the probability that it will continue.

On the other hand, the characteristics of the diagnosis are unusually immune to modification through observation. If you diagnose a number of people as having tuberculosis and all die, the definition of tuberculosis might include the prognostic criterion 'invariably fatal'. If one patient eventually recovers, however, you would modify your criteria to omit the words 'invariably fatal' -- or, if you were following the PVS model of nosology, you would note that having recovered the patient did not meet the criterion of fatality and therefore could not have had tuberculosis in the first place. See, for example, the circular reasoning of the Multi-Disciplinary Task Force (1994):

By definition, [emphasis mine] patients in a persistent vegetative state are unaware of themselves or their environment. They are noncognitive, nonsentient, and incapable of conscious experience. There is, however, a biological limitation to the certainty of this definition, since we can only infer the presence or absence of consciousness in another person. ...an error might occur if a patient in a locked-in state ... was wrongly judged to be unaware. Thus, it is theoretically possible that a patient who appears to be in a persistent vegetative state retains awareness but shows no evidence of it. In the practice of neurology, this possibility is sufficiently rare that it does not interfere with a clinical diagnosis carefully established by experts (Multi-Disciplinary Task Force, 1994).

But how often is such a diagnosis made by experts? Circles of definition emanate from the central core. There are the criteria as presented in Jennett and Plum (1972) itself. There are the subtly modified versions of that definition that have been issued by other medical bodies. There are then the instances where these definitions are applied. I have known these diagnoses to be made by doctors with practices that concentrate on trauma victims, by doctors whose only acquaintance with the condition has been a few brief references in their neurology course, and by nurses who may confuse PVS vaguely with coma or paralysis or even extreme lethargy. We may then move to the disciplines who take the material at second hand – to lawyers and judges impatient with fine distinctions between different varieties of uselessness, or to ethicists who have no patience whatever with any uncertainty that might disturb the symmetry of their syllogisms. And beyond that lie the general public. At the level of public policy the meaning of persistent

vegetative state becomes a vague amalgam of all of these, a tenth carbon of the original Jennett and Plum (1972). At some point along this continuum it becomes possible that the definition of persistent vegetative state will become a self-fulfilling prophesy – that people who it is thought will never recover will not be encouraged to stay.

This attitude is reinforced by the fact that many people have strong feelings about the undesirability of disability. Andrews' positive findings provoked a BMJ editorial by Ronald Cranford;

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.

Some, myself included, might think that Dr. Cranford's opinion on stopping treatment was rather less significant than the opinion of the 17 patients with whom communication had been established. He, however, was a member of the Multi-Disciplinary Task Force and I was not, which may account for its stealthy expansion of the Jennett and Plum definitional criteria –

These data... can be used ... to determine when a persistent vegetative state becomes permanent - that is, when a physician can tell the patient's family ... with a high degree of medical certainty that there is no further hope for recovery of consciousness **or that, if consciousness were recovered, the patient would be left severely disabled.** [emphasis mine] (Multi-Disciplinary Task Force, 1994)

Many people passionately believe, like Jennett, that patients in PVS place a strain on limited resources and that physicians who care for them

sound... a death knell for those who are denied the benefits of appropriate care by [this] spendthrift attitude. (Jennett, 1976)

All these opinions may be valid. It is certainly possible to argue that people with PVS would be better off dead, or that we would all be better off if more money was available for other areas of medical care. The issue that concerns me is that those who hold these views are not prepared to admit that these benefits may have attached costs. They would seem to believe, perhaps rightly, that if they concede any considerable degree of uncertainty in the situation of PVS patients they will not be permitted to bring these benefits about. This means that any such gains - the reassurance of families, the relief of patients, the reform of hospital budgeting - are effective only because they are founded on lies. The truth is surely that none of these benefits can be obtained without taking a high risk that some people who are or will become conscious and aware will be treated as if they were irretrievably insentient.

Again, it is arguable that this is an acceptable risk. It is possible to hold any number of opinions about what should be done with patients who are in post-coma states of disability, and their chances of recovery and their possibilities of awareness are not the only factors to be taken into account. It is possible to decide that whether they recover or not the resources used on their care would still be better employed elsewhere. I do not for my own part believe that life should be preserved in all circumstances and in all cases. I am not, however, prepared to oversimplify the job of making decisions in these cases by accepting a diagnosis of PVS as if it were determinative and abdicating our responsibility for our own actions to the authority of a footnote. In practical terms, I believe that methods of establishing communication with people diagnosed as being in a persistent vegetative state should be pursued vigorously, and that no decision should be made on any such case unless an experienced team specialising in such communication has attempted to elicit the views of the person concerned.

One might now, in 2004, speculate as to what the definition of Persistent Vegetative State might have been if we had had then the knowledge, or the technology, that we have now. I look to recent events in America to propose a new mode altogether of approaching the question of definition. The most primitive form of definition, it is said, is ostensive definition; I say to my Spanish friend, "What is a 'lápiz'?"; he points to a pencil and says,

“This is a ‘lápiz’.” That would be an ostensive definition of ‘lápiz’. The philosophers in Gulliver’s Travels, similarly, talk by carrying around immense sacks of objects, pulling them out and pointing to them to serve as nouns. In the seventeenth century, that was biting satire on the impracticality of metaphysics; for us in the twenty-first century it has almost become possible. A laptop’s hard disc can hold video clips of every entry in the medical dictionary. We can now have an ostensive definition of persistent vegetative state; we may look at the on-line video clips of Terri Schiavo and know that this is what people mean when they use the term. Would there have been more difficulty, or less, in reaching a consensus among medical practitioners and ethicists if video clips, rather than journal publication, had been the initial means of putting the concept forward? What would that consensus have been?

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