CONSCIOUS IN A VEGETATIVE STATE?
A CRITIQUE OF THE PVS CONCEPT

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CONSCIOUS IN A VEGETATIVE STATE? A CRITIQUE OF THE PVS CONCEPT

by

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Peter McCullagh,
Bungendore, April 2004

INTRODUCTION

My awareness of use of the term “vegetative” to describe patients has been aroused in the course of a number of year’s association with the National Brain Injury Foundation, a community based organisation providing support for Australians living with acquired brain injury and for their families. People coming to the Foundation often recounted a story of being told that their family member was “vegetative’. This was regularly converted, presumably in the retelling, to the proposition that he or she was “a vegetable”. Virtually all of these patients had been deemed to be “unsuitable for rehabilitation” within a health care system but had participated in community based rehabilitation programs under the guidance of Dr Ted Freeman.

It is not possible to assure oneself that all of the patients who had been categorised at some stage as “vegetative” had been diagnosed in accordance with world’s best practice. Nevertheless, it is not feasible to dismiss the use of the ‘v’ word as exuberant licence on the part of interns. All of these people had been examined by consultants on one or more occasions. Notwithstanding the use of the verb “to veg out” in vernacular Australian, much in the same way as the referee at a football game is regarded as “brain dead” by half of the spectators, it stretches one’s credulity to source the “vegetative” description of these patients other than to their medical attendants. With this background, it became of interest to enquire more thoroughly into the *real* vegetative states, their scientific basis and their wider influence. This book is the result.

The book has two closely associated aims. The first is to trace the origins of prevailing perceptions about patients who remain unconscious after brain injury and are diagnosed as being in a vegetative state. In doing so, I intend to submit to critical examination many claims that have been made in development of these perceptions of vegetative states. My second aim is to formulate an assessment of the current status of vegetative states in the light of the evidence underpinning them.

My approach to examination of vegetative states will be basically epistemological, namely what are the origins of knowledge of the subject? how was that knowledge obtained? and what are its limitations? This will entail the retrieval of original reports on the subject coupled to an assessment of their evidentiary worth. Anyone who has read even a limited amount of the extensive literature on the subject is likely to have been struck by the mix of data and assumption and, perhaps, by the frequent blurring of the distinction between them. Of its nature, the subject of prolonged loss of consciousness by a patient who appears to retain other functional capacities is likely to raise many questions to which it is not feasible to provide clear answers. However, there has commonly been a failure to retain an adequate awareness of the limitations inherent in much of the primary data when value-based interpretations have been applied to it. The claims have been persistent, but the original limitations to them have generally not been so following their first citation.

The subject of patients in a vegetative state reeks of semantics and examples are discussed at several places in the book. However, in order to write about a subject, it is necessary to operate within the constraints of the commonly used vocabulary, irrespective of one's assessment of its value. The original introduction of the phrase "persistent vegetative state" was intended to facilitate discussion of a group of patients and comparison of clinical data. However, during the ensuing 30 years, the terms "vegetative state" and "persistent vegetative state" have not been applied consistently by different authors. Furthermore, the definitional requirements for their application, for example the interval that must elapse before "vegetative state" has "persistent" prefixed to it, has both varied between institutions and changed over time. The convenient acronym of "PVS" for "persistent vegetative state" has become much less convenient as many authors have used it to denote "permanent vegetative state". In this book, "vegetative state" (while I doubt that the term describes a single condition) will be used as a term descriptive of a set of clinical features, irrespective of their duration. There has been considerable variation and interchange in the use of "vegetative state" and "PVS". In referring to a published report, the terminology of the original is used, unless indicated otherwise. "PVS" will be used exclusively with its original connotation and references to reports concerned with a "permanent vegetative state" will describe it as such.

PVS has bulked large in the discussion, and sometimes in the evolution, of other quite disparate subjects. Examples include decision-making on behalf of incompetent patients, the use of advance directives, determination of a patient's best interests by others, the right to die, euthanasia, resource allocation, personhood and many others. Any one of these topics could be the subject of a book, and all have previously been the subject of many. This book is about people who remain unresponsive for extended periods after brain injury, not primarily about any of the subjects in the preceding list. It is, however, necessary to include some consideration of all of them insofar as they relate to this group of patients.

Each Chapter includes presentation of the prevailing "orthodox" position on its subject together with the background to its development. When I am unconvinced about the validity of the "orthodox" position, my reasons for dissenting are presented in detail. Each of Chapters 2 to 15 will conclude with a short recapitulation which will emphasise the points that I have sought to make in that Chapter. Frequently used names, for example those of professional bodies, are abbreviated when repeatedly used, although generally spelt out in full on the first occasion of use in a Chapter.

The first Chapter considers the origins of the PVS, semantic considerations underlying it and the manner in which the use of terminology has evolved in the course of 30 years. Attention is drawn to the ongoing interrelationship between the concepts of PVS and brain death. The impact of thinking, writing and acting about PVS on other, apparently discrete, issues is also discussed.

The second Chapter summarises the available information on the neuropathological changes observed at autopsy in patients who have been clinically vegetative. In doing this, limitations inherent in the conclusions which have been drawn about the neuropathology of PVS will be identified. The pathological heterogeneity underlying the uniform clinical classification has impeded the establishment of reliable clinicopathological correlations with the confidence possible for many other medical conditions.

Chapter 3 retraces the sequence of statements and guidelines on PVS which have been issued, predominantly in the U.S. These have frequently had the effect of converting primary data, shorn of any qualifications, into authoritative pronouncements. This re-examination entails critical examination of the data citation in some of the most influential statements.

Chapters 4 and 5 deal with two neurophysiological subjects, consciousness and sentience. Both are deemed, by definition, to be lacking in vegetative patients. Their absence has provided the basis for classifying and managing these patients. I believe that information about conscious and sentient status in neurologically intact subjects may be relevant for developing a better understanding of the nature of the disability, and of its management, in vegetative patients.

The variety of technological approaches that have been used in investigation of patients in vegetative states are reviewed in Chapter 6. Whilst their value in diagnosis is usually not considered to be great, some of them offer opportunities for future research to improve understanding of the nature of vegetative states. Notwithstanding their acknowledged diagnostic limitations, the results of some technological procedures have been repeatedly claimed to provide proof of complete unawareness in affected patients. This Chapter questions the scientific validity of claims such as that for a similarity between the levels of unawareness in vegetative states and deep general anaesthesia which has been accorded the status of dogma. This issue is further considered in Chapter 7 when the question of awareness during deep anaesthesia is examined. If, as is claimed, there is a comparable degree of unconsciousness in the two states, information about the nature of one may assist in interpreting the other.

Chapter 8 and 9 are concerned with the diagnosis of vegetative states and the recognition of emergence from them, that is the regaining of consciousness. The reliability with which diagnoses of vegetative states can be made has been called into question in the last decade by reports of a high frequency of misdiagnosis. In some cases, the distinction of initial misdiagnosis from accurate diagnosis followed by emergence can be very difficult. The subsequent course of patients who have regained consciousness and the capacity to communicate with others may provide information that otherwise remains unavailable.

Vegetative patients are regarded as one class of disabled individual in Chapter 10 which examines the question of evaluation of their quality of life by others. In doing so, it runs counter to the strongly expressed opinions of some authors that these patients are “beyond disability” and so cannot validly be compared with those with lesser levels of disability. This is followed in Chapter 11 by an account of the measures which are available in attempting rehabilitation of vegetative patients. The second part of the Chapter outlines the case which is often presented to dismiss any attempts at rehabilitation of vegetative patients as futile.

Chapter 12 presents the evidence, predominantly derived from animal experimentation, which calls into question the common contention that a vegetative patient cannot experience thirst. It is proposed that this contention runs counter to a substantial body of physiological data which implies that the brain lesions commonly found at autopsy of patients who were clinically vegetative do not exclude retention of a capacity for thirst. Chapter 13 extends the subject of the preceding Chapter with an examination of the theoretical and practical issues raised by the practice of withdrawal of food and fluids from vegetative patients.

The issue of health care resource allocation for patients who are in a PVS or who have severe neurological disability with retention of varying degrees of consciousness is the subject of Chapter 14. The reported cost of the care provided to vegetative patients varies as widely as does the associated neuropathology. The difficulties of estimating overall costs to a health care system introduced by this diversity are further compounded by lack of reliable prevalence data relating to these patients.

Compilation of reviews of legal decisions about patients in, and close to, PVS has become a self-sustaining industry. Chapter 15 does not attempt to duplicate the many accounts which have been published on this subject. It will use court proceedings and decisions from some U.K. cases to illustrate what appear to me to be some of the outstanding ambiguities in the manner in which medical aspects of the patients concerned have been dealt with in a legal context.

Finally, Chapter 16 contains some positive suggestions about future management of patients who remain unresponsive for prolonged periods as an outcome of brain injury.

This book is dedicated to a remarkable medical practitioner who learnt from his patients, while bringing hope to them and their families. He sought to teach his colleagues by example, challenged the prevailing paradigms about recovery from brain injury and paid a heavy price for doing so.

CHAPTER 1

HISTORY AND CONTEXT OF THE PERSISTENT VEGETATIVE STATE

1.1 TWENTY-FIVE YEARS ON: AN IDEA

On November 1, 1997, the English medical periodical *The Lancet* published an article from a distinguished international group of 10 authors (Hoffenberg *et al.* 1997) titled: *Should organs from patients in permanent vegetative state be used for transplantation?*. This article appeared a quarter of a century after publication in the same journal of the original article which had launched the *persistent* vegetative state. Between 1972 and 1997, a name suggested to describe a set of clinical features not only changed itself whilst preserving its acronym (PVS) but came to assume a life of its own and influence medical practice well beyond that concerned with affected patients.

The authorship list for the 1997 Lancet article of Hoffenberg *et al.* was collectively described as *The International Forum for Transplant Ethics*. The *International Forum* paper dealt with possible advantages and disadvantages of the course of action queried in its title. Two obstacles to the use of permanent vegetative state patients in organ donation were identified, namely the risk of misdiagnosis and the possibility of late emergence of a patient who had been correctly diagnosed. Hoffenberg *et al.* disposed of these by restricting subsequent discussion to the use of

> "those patients in whom a decision has already been taken to withdraw treatment and allow them to die".

In these circumstances they maintained

> "the actual cause of their unresponsive condition is not in this sense relevant" (ibid: 1320).

Presumably, any mistake in diagnosis or prognosis was to remain the responsibility of an earlier medical attendant.

A major impediment identified by Hoffenberg *et al.* to the use of the organs or, more accurately, to the use of the patients to whom the organs belong was the illegality of causing death by organ removal rather than by withholding fluids and food. Recalling earlier arguments about the practicality of using anencephalic infants as organ donors, Hoffenberg *et al.*, made the point that tissues and organs would no longer be suitable for transplantation if patients were allowed to deteriorate as a consequence of dehydration and starvation and then to die from "natural causes". Three rhetorical questions were asked.

The first question posed by Hoffenberg *et al.* was whether patients should continue to receive fluids and food, until they died naturally? The *International Forum* concurred with the endorsement by many authoritative groups of the practice of withdrawal of hydration and nutrition from PVS patients. Secondly, once a decision has been taken to end the life of a patient, how should this be done? The authors presented a case for "a more speedy termination" than can be accomplished by dehydration and starvation. While acknowledging that patients in a vegetative state are considered to be non-sentient and so unlikely to

> "experience distressing thirst or hunger when food and fluids are withdrawn"

the point was made that, were this to occur,

> "such distress would be a strong argument in favour of a more expeditious mode of death, for example, administration of a lethal drug".

This was followed by the conditional:

> "If patients in a permanent vegetative state are thought to be sentient"

(never mind that, if sentient, they are definitionally *not* in a vegetative state)

> "a strong case would exist for routine analgesic or psychotropic medication" (ibid: 1321).

The third question concerned the legal, moral and practical possibilities of using organs from permanent vegetative state patients for transplantation. Their response to this ran as follows:

> "We believe that, though the means by which death is attained has legal implications, there is no clear moral distinction between allowing to die by omission of treatment and more actively ending life" (ibid: 1321).

In concluding, Hoffenberg *et al.* returned to the issue of use of anencephalic infants as organ donors, and noted that the American Medical Association (A.M.A.) Council on Ethical and Judicial Affairs had stated in 1995 that it was ethically permissible for a newborn anencephalic infant to be used as an organ donor, although still legally alive according to the definition of death.

Illustrating the vagaries of publication, the paper cited by the *International Forum* to document the A.M.A. position was from the American *Neurological* Association and, furthermore, did not include the word "anencephalic" in its text. Wrong authors, wrong page, wrong volume, wrong year and wrong journal: score 0 out of 5. Ten authors with the distinction of the *International Forum* should have been able to do better. The article to which, presumably, it was their intention to refer was published in the *Journal of the American Medical Association* (American

Medical Association Council on Ethical and Judicial Affairs 1995). As a postscript, Hoffenberg *et al.* could have noted that the A.M.A. revisited the issue and, having undertaken

> "review of additional submitted scientific evidence on the condition of anencephaly"

decided to suspend its opinion which had deemed the use of anencephalic organs prior to legal death of the infant ethically permissible (Plows 1996).

1.2 RESPONSES TO AN IDEA

The paper from the *International Forum for Transplant Ethics* evoked some lively responses. The first response in *The Lancet* was from Karlheinz Engelhardt in Kiel, who expressed surprise that a highly contentious article was not accompanied by either an editorial or a commentary. The writer pointed out that, as a German, he was sensitive to promotion of euthanasia (1998). Hoffenberg's response to Engelhardt on behalf of the *International Forum* was first to call for the discussion of issues like this "in a liberal open society" and then to suggest that such debate could still not take place in Germany (Hoffenberg 1998).

A retired neurosurgeon noted Hoffenberg's denial in a newspaper article that, contrary to the impression which many readers had gained from *The Lancet* article, he was not proposing that PVS patients be killed for their organs (King 1998). Reference was made to the case of Anthony Bland, who had remained in a vegetative state for a period in excess of 4 years following a stampede at an English football stadium. A House of Lords, decision had endorsed the withdrawal of hydration and nutrition with the intention of ending his life. Noting that Hoffenberg *et al.* had laid responsibility for sanctioning the ending of Bland's life with the Law Lords with the express implication that "the transplant surgeons would be simply making practical use of the opportunity", this correspondent stressed that legality and morality were separate (and, by inference, that the expertise of their Lordships was confined to the former) (ibid).

A third correspondent from the same Liverpool renal transplant unit as a member of the *International Forum* maintained that Hoffenberg *et al.* held no official positions within the British Transplant Society or the International Transplantation Society. This correspondent considered that the *Lancet* article would "bring transplantation into disrepute" (Bakran 1998). Hoffenberg responded in the following terms:

> "Most of us are not connected with transplantation and it is this multidisciplinary approach that allows us to venture into an area of public and social interest which more closed professional societies might find it difficult to address" (Hoffenberg 1998).

Finally, a letter from David Evans pointed out an inaccuracy in the article from the *International Forum*. In describing the removal of organs from brain dead individuals the article had stated:

> "When cardio-pulmonary support is withdrawn, spontaneous function of the heart and lungs rapidly ceases, the circulation stops and immediate organ retrieval is allowed" (Hoffenberg *et al.* 1997).

This is an accurate description of practice in relation to "cardiac arrest" donors. However, the use of such donors for transplantation of kidney or liver has been abandoned by most transplantation clinics for a quarter of a century in favour of "beating heart" donors whose organs are removed *before* cardiopulmonary support is withdrawn. Procurement of organs from "beating heart" donors entails organ removal *followed* by withdrawal of support, in this instance the disconnection of the ventilator. The significance of this misrepresentation being pointed out by Evans is that he had retired prematurely as a cardiologist working in association with a very high profile British transplant unit precisely because of his concerns about the propriety of the use of "beating heart" donors. In pointing out that people

> "who have signed organ donor register forms in the belief that they are assenting to removal of their organs after circulation has finally ceased…have made their generous offer on a false premise" (Evans 1998),

Evans attracted personal criticism from Hoffenberg.

> "David Evans, who for many years has criticised the brain death criteria, makes a point about the method of retrieval of organs in ventilated patients which does not alter the sense of what we were saying and we do not see why this knowledge should affect those who wish to be donors" (Hoffenberg 1998).

I believe it should have been the accuracy, or otherwise, of what Evans was claiming rather than his persistence with the claim which required a response. Furthermore, incorporation of a patently misleading and inaccurate statement in an article of which at least two of the co-authors claimed transplantation as their medical specialty might occasion concern about the accuracy of the article as a whole.

An administrative approach that could facilitate the use of patients diagnosed as in a PVS as organ donors would be to adjust the definition of brain death to conform with a "higher brain" standard. If this was done, any patient in whom those functions commonly attributed to the cerebral cortex were considered to have been irreversibly lost would satisfy the brain death criteria. Another approach which could, at least theoretically, enable a patient diagnosed as in a PVS, who had previously expressed a wish to become a donor, to accomplish this has been described by Veatch (1999). This would entail the refusal of life support until cardiac function ceased at which time protocols applicable to the "non-heart-beating cadaver" would come into operation. The practical obstacle to this course of action, noted above, would be the deterioration in transplantable organs following withdrawal of fluids and food.

Whilst Hoffenberg *et al.* did not attempt to estimate the possible logistic impact of inclusion of permanent vegetative state patients in the donor pool for transplantation, an earlier article by Youngner and Arnold (1993) calculated that collection of organs from patients who had sustained severe brain damage and were currently ventilator-dependent, but did not meet brain death criteria, could increase the available pool by 25-30%.

1.3 THE NAMING OF PVS

The article *Persistent vegetative state after brain damage. A syndrome in search of a name* was published in *The Lancet* in April, 1972 under the category heading *Points of view*. The critical features of the condition as described by Jennett and Plum were that, after emerging from coma as indicated by opening of their eyes, these patients

> "lie for periods with their eyes open; at other times they seem to sleep…. The eyes are open and may blink to menace, but they are not attentive; although roving movements may briefly seem to follow moving objects, careful observation does not confirm any consistency in this optimistic interpretation. It seems that there is wakefulness without awareness" (Jennett and Plum 1972: 734).

In explaining their reasons for proposing the new name, the authors quoted the advice of an earlier, distinguished neurologist, that one should not be inhibited from applying a name to a concept in order to facilitate its discussion. While not questioning the original validity of their aim, allocation of a memorable descriptive name has served to entrench the perception of a discrete, well demarcated condition. This perception has often been more effective in stifling than in promoting discussion. (As indicated in the Introduction, I will use the acronym 'PVS' only to connote *persistent* vegetative state. The substituted term *permanent* vegetative state will not be so abbreviated).

Jennett and Plum were at pains in their original paper to stress four points. These were that the concept denoted by the term PVS related to behavioural features that could only be observed by clinical means, that its central feature was lack of evidence of a functioning conscious mind, that there was unlikely to be a consistent neuropathological basis for the condition and that the PVS was likely to represent part of a continuum of neurological disability. However, these four caveats, along with other reservations expressed at that time, have frequently been casualties of subsequent discussion of PVS.

The issue of communication, and its inadequacies, has impacted on development and understanding of the concept of vegetative states in more than one way. First, communication in relation both to the definition of a PVS and to its diagnostic recognition in the individual patient was an essential feature of its establishment as an entity. Its naming conferred the capacity to discuss the condition:

> "There is clearly need for an acceptable term to describe their (the patients), state in order to facilitate communication, between doctors or with patients' relatives or intelligent laymen, about its implications" (ibid: 734).

Secondly, the entire concept of a vegetative state has been predicated on equating the inability of the patient to communicate with attending medical personnel with a total lack of any consciousness. The original paper of Jennett and Plum which named PVS referred to:

> "The absence of any evidence of a functioning mind which is either receiving or projecting information" (ibid: 736)

(a statement that has often subsequently been abbreviated to *the absence of a functioning mind*) and to patients' inability to speak or to signal appropriately by eye movements with the attending medical personnel (subsequently equated with a total lack of any consciousness). The presumption that lack of capacity for detectable communication with others is synonymous with total loss of cognition lacks a logical basis. Inability to communicate of itself need not connote complete loss of cognitive capacity in a "vegetative" patient any more than it does in one who is regarded as representing a "total locked-in syndrome". As the first syllable of the word suggests, *co*mmunication is a process which requires participation by two parties and consequently it would seem imprudent on general grounds automatically to attribute its failure to one party.

The disappearance of some of the original caveats of Jennett and Plum concerning the interpretation of clinically observable features has been noted above. The varying connotation attached to the first letter of the acronym "PVS" and the manner in which I propose to use the PVS terminology has been spelt out in the Introduction. However, as policy decisions affecting groups of patients are increasingly being taken on the assured basis that PVS patients are "permanently unconscious", it is necessary to address the question at this stage of whether *everyone* who is diagnosed as in a PVS can be considered with reasonable certainty to be unconscious.

The replacement of the original proposition of "no evidence of a functioning mind" by an unchallenged presumption of "no functioning mind" has been emphasised already. This substitution requires that anyone meeting the clinical criteria for diagnosis as in a PVS, *must* therefore be unconscious. However, a sound basis for this change in interpretation of "PVS" is lacking. New evidence has not been forthcoming to replace the guarded interpretation of conscious status of patients diagnosed as in a PVS that was originally formulated by Jennett and Plum. The interpretation has changed: the data on which it is based has not. In the absence of additional evidence, I find the evolving interpretation unconvincing. However, the entrenchment of a concept of what "PVS" represents has been such that, when presenting the basis for my scepticism in this monograph, it remains necessary to employ the nomenclature that is in common use.

As will be emphasised at a number of places, especially in Chapter 4, consciousness remains a poorly defined entity, the absence of which in another individual can be inferred, but never directly confirmed, by an observer. Apart from the impossibility of formal documentation of permanent absence of consciousness, evidence from several sources leads me to question the invariable reliability of the nexus between vegetative states and unconsciousness. These sources include neurological observations derived from subjects not in a PVS (Chapter 4), the reported frequency of retention of consciousness by people diagnosed as in a PVS (Chapter 8) and the accounts of patients who have emerged from a PVS (Chapter 9).

One consequence of the widespread acceptance of the proposition that there is an entity “PVS”, patients in which must always be unconscious, has been to dismiss every account of retention of consciousness by a patient diagnosed as in a PVS as an instance of misdiagnosis. The alternative response, namely of challenging the validity of the concept of an established and recognisable entity “PVS”, characterised by lack of a functioning mind, is rarely aired. Is a case of PVS, diagnosed in accord with all clinical criteria, invariably accompanied by unconsciousness?

The question of the level of certainty that should be attained before a clinical decision to withhold fluids and food on the basis of irreversible unconsciousness may be made arises in individual cases. The frequent use of sedative and analgesic agents in management of patients deemed to be unconscious after diagnosis of PVS (Chapter 13) sits rather uneasily beside claims that a high degree of certainty of irreversible loss of a functioning mind follows from that diagnosis. However, responses to it in individual cases inevitably influence the development of general policy. Such policy is likely to affect not only patients diagnosed as being in a PVS but any others who are considered to be “sufficiently close” to that condition. In an analogous situation, the perception that certain specified diagnostic criteria must be satisfied before specified procedures may be discontinued has undoubtedly been fostered by the widespread conviction that a definite diagnosis of brain death is a necessary prerequisite to ventilator disconnection. In reality, long before the notion of “brain death” as a formal entity came into existence it was accepted that one could cease treatment (including ventilation) which was not benefiting a patient. The arrival of the brain death concept, and the associated diagnostic criteria, on the scene should not have altered this principle. In the same way, management decisions about any patient (whether diagnosed as in a PVS or not) ought to be made on the merits of the individual case, including efficacy and benefits of any procedures in use. However, the recent trend to attaching the cessation of tube feeding (at least in the first instance) to a diagnosis of PVS *per se*, equated with irreversible unconsciousness, appears to be discarding clinical judgement in favour of a trite formulation. I believe that the precedent of brain death as an instance of making a clinical withdrawal decision conditional upon satisfaction of a set of diagnostic criteria owed much more to affording legal endorsement for organ harvesting than to providing guidance on patient management.

Reflecting my scepticism about the presumptions inherent both in conceptualising the PVS and in deriving policies from that concept, my references to the condition will necessarily be more qualified, and accordingly longer, than would otherwise be necessary. I will use the phrase “diagnosed as in a vegetative state (or a PVS)” rather than simply stating “in a vegetative state” with its connotation of assured unconsciousness. A contention, linked to that of unconsciousness, is that any patient diagnosed as in a PVS will therefore lack capacity for appreciation of sensation, whether generated externally (pain in response to a noxious stimulus) or internally (thirst during dehydration). However, it will be suggested, in Chapters 5 and 12 respectively, that sufficient evidence exists to question whether *all* individuals diagnosed as in a PVS lack these capacities. The retention of sentient capacity in some subjects who, for all intents and purposes, have been regarded as fully anaesthetised and therefore unconscious (Chapter 7) may be relevant to understanding the capacities of some patients diagnosed as in a PVS. Anaesthetised patients have the opportunity subsequently to describe their experience whilst unconscious.

Patients who have been diagnosed as in a "minimally responsive state", that is who evince some detectable signs of consciousness, are often asserted to be more in need of withdrawal of fluids and food, as a means of effecting their death, than others actually diagnosed as being in a PVS. In practice, this proposition leads to another, namely that the retention of some level of consciousness by a patient who has been diagnosed as in a PVS is not significant when withdrawal management decisions are to be made. In contrast with this approach, I do not consider that a tendency to the implementation of a common management strategy for "PVS" and "minimally responsive" patients renders moot the question of whether patients, accurately diagnosed as in a PVS, could retain consciousness.

1.4 PRE-EXISTING NAMES

Any attempt to summarise the evolution of the terminology applied to vegetative states is inevitably bedevilled by the use of the common initial "p" to denote both "persistent" and "permanent". Two articles discussed to this point, namely those of Jennett and Plum and of Hoffenberg *et al.*, illustrate these variant uses. To place the naming of PVS in context, I will consider briefly the situation which existed at that time and the effect of that naming upon the subsequent recognition and diagnosis of previously recognised clinical syndromes. Jennett and Plum noted that existing terms were based either on clinical description of patients or on a neuropathological basis inferred from their clinical features. Whilst brain death and the locked-in syndrome survived the naming of PVS, several other terms subsequently became casualties and ceased to be recognised. Confusion, argument and advocacy concerning the relationship of brain death to PVS have persisted to the time of writing and will be considered below. Whilst the locked-in syndrome, which was first named by Plum and Posner in 1966, will be considered in Chapter 8, occurrence of a "total locked-in syndrome," in which *all* means of communication detectable by an observer have been lost, raises issues of differentiation from PVS, both conceptually and diagnostically.

Several terms describing patients with severe neurological damage were examined by Jennett and Plum in 1972 but considered not to be useful in naming the group of patients about whom they wrote. "Coma" was excluded because of the implication that the eyes were closed, "stupor" on account of its established use in psychiatric practice and "dementia" in view of its connotation of a progressive, rather than a static, condition. The clarity of distinction between dementia and PVS has been slightly blurred with the subsequent description of the latter as a late stage of dementia and by reports of the high risk of misdiagnosis of demented patients as being in a PVS. The distinction has not been materially assisted by Wikler's (1988) reference to PVS as "amentia".

Other descriptive terms which Jennett and Plum considered not to be useful in referring to patients with features defined as PVS included "decerebrate" and "decorticate" states. As the clinical features to which they referred are of motor dysfunction, rather than conscious status and, as variable combinations of neurological abnormality, including motor dysfunction, could be present or absent in patients with the cognitive features specified as the basis for a PVS diagnosis, the terms were of no discriminatory value. Those cognitive features incorporated into its definition, have greatly assisted in the entrenchment and defence of the concept of PVS itself. Thus, in the event that any patient considered by experienced neurologists to be in a vegetative state is shown to have cognitive capacity, he or she is by the common definition *not* vegetative. Irrespective of the frequency with which such patients are detected, the integrity of the state of persistent vegetation remains secure. "Wrong diagnosis" serves to protect the concept.

Two terms for disorders which had been described prior to 1972, namely akinetic mutism (or coma vigil) and apallic syndrome, were considered but excluded by Jennett and Plum when devising the PVS nomenclature. The former condition typically entailed inability to speak or to move by an individual who, nevertheless, appeared to remain attentive. It was regarded as "rather loosely defined and potentially recoverable" and as having variability in its combination of symptoms (ibid: 735). The term "apallic syndrome" referred to patients who were open-eyed, uncommunicative and unresponsive. This term was considered by Jennett and Plum to be likely to cause confusion both because the word apallic (inferring interference with function of the cerebral cortex) was unfamiliar to most clinicians and also because it implied that an unproved neuropathology was responsible for its clinical features.

Reports of further cases described as akinetic mutism appear to have become rare with the introduction of PVS as a diagnosis. Whilst the term "apallic syndrome" has disappeared from the English literature being referred to as "archaic" by the Multi-Society Task Force (M.S.T.F.) on PVS (1994a), its translation has continued to describe PVS in German medical literature. It seems reasonable to conclude that patients who would formerly have been diagnosed as examples of akinetic mutism, or as apallic syndrome (outside Germany) have been thereafter considered to be in a PVS. A 1960 description of patients diagnosed as in akinetic mutism resembled subsequent descriptions of patients in a PVS in their lack of capacity to communicate. However, the *interpretation* of their condition differed markedly from the *concept* of PVS in the inferred retention of awareness:

> "They appeared motionless and speechless as if in coma but their eyes remained open for long periods, moving in all directions.... Although they

> seemed aware of their surroundings, communication through visual and auditory commands could not be established" (Cravioto *et al.* 1960: 20).

The virtual disappearance of case reports of akinetic mutism has been queried by one commentator in 1996 on the basis that, having cognitive features intermediate between the locked-in syndrome and a vegetative state, akinetic mutism might be expected to be diagnosed with an incidence comparable with that of these two conditions (Howsepian 1996). The explanation proposed for the paucity of diagnosis was that, being in a continuum between the locked-in syndrome and a vegetative state, cases of akinetic mutism were likely to be reclassified as the latter. The availability of a neat descriptive title may have led to the artificial imposition of sharp, but illusory, cut-off boundaries on a continuous distribution of clinical disability. Perhaps analyses suggesting that PVS is a "growth stock" which is proliferating in response to refinements in intensive care practice have encouraged the reassignment of other, clinically similar conditions which antedated the introduction of the PVS nomenclature.

Naming and definition of a group of clinical features as a syndrome may have a number of effects. The description of clinical features inherent in the process of definition will clearly assist its further identification. The impact that the naming of the locked-in syndrome had on its ascertainment and reporting has been remarked by neurologists reviewing *that* condition. Thus, Bauer *et al.* (1979) observed that despite several quite extensive reports in the medical literature, the condition "did not become popular among neurologists until Plum and Posner introduced the term" (ibid: 77). It is likely that the naming of PVS 6 years later effected a similar boost in *its* ascertainment. It is difficult to write an account of a series of cases if there is not some common terminology that can be applied to them. It is likely to be even more difficult to have such an account accepted for publication by an editor. In addition to describing *what a condition is*, a definition will probably go some way towards demarcating it from other conditions, that is, to describing *what it is not*. However, if sharply defined categories of classification are imposed on a biological situation, such as a disease state, in order to facilitate description, that classification may engender a misguided sense of precision.

1.5 PERCEPTIONS ENGENDERED BY A NAME

Apart from the possibility that the term PVS may have imposed a sharp distinction where in reality none exists, the actual words selected have attracted considerable unfavourable comment on the grounds that they are likely to generate adverse perceptions of affected individuals. Anticipating the criticism that judgement about a patient's mental activity could not be made solely on observation of behaviour (in a person incapable of communication) as required in the definition and diagnosis of PVS, Jennett and Plum pointed out that no alternative approach was available at the bedside where decisions were required. They also emphasised the desirability of avoiding "the mystique of highly specialized medical jargon". Additionally, the basis for selection of the words "persistent" and "vegetative", but not of "state" was discussed (1972).

In selecting "persistent", Jennett and Plum pointed out that it was safer than "permanent" or "irreversible" until criteria required to support either of the latter terms had been validated. "Prolonged" was not considered to be strong enough. Subsequent events have not validated the appropriate criteria. Nevertheless, "permanent" has been introduced as a category additional to "persistent" and, by the late 1990s, was replacing it. Whilst the medical literature tends to be shaped by the experience of English-speaking practitioners, a significant variation with language exists in the qualifying adjective attached to "vegetative state". For example, the term PVS is replaced in France by "état vegetatif chronique" (O'Connell 1992).

In proposing the adjective "vegetative" as part of their new term, Jennett and Plum cited the Oxford English Dictionary definition of "an organic body capable of growth and development but devoid of sensation and thought". They also noted that this adjective was used to describe functions of the autonomic nervous system (such as temperature and blood pressure regulation) in physiological writing. Application of the term "vegetative" to patients with features similar to those contained in their paper had already occurred. For instance, Shalit *et al.* anticipated that paper by some 3 months in using the heading "chronic vegetative state" to classify a group of patients who were described as having features typical of the yet to be named PVS (Shalit *et al.* 1972). Reasons for the success of the Jennett and Plum term rather than that of Shalit *et al.* in achieving recognition are not clear but may include its incorporation in the title of an article in a widely circulated non-specialised medical journal. Somewhat surprisingly, Jennett and Plum failed to comment upon the predictable effects of application of the adjective to *individuals* diagnosed as being in a vegetative state, as distinct from its use in defining a medical condition. Allowing for the attitudes prevailing in 1972 towards people with disabilities, failure to take account of the probability of transference of the term, and its pejorative implications, from a medical diagnosis to an affected individual may not have been unreasonable. Nevertheless, the demeaning aspects of attaching the word to an individual have caused increasing concern among the families of PVS patients and medical specialists responsible for their longer term care since then.

The full emotive impact that can be extracted from "vegetative", by its conversion to the noun, has been well illustrated by Dworkin (1993) probably not unintentionally:

> "We also dread – some of us dread it more – life as an unthinking yet scrupulously tended vegetable" (ibid: 180),

or again, his reference to "living as a manicured vegetable" (ibid: 192). Some of the most vigorous criticism of "vegetative", has come from Keith Andrews, medical director of the Royal Hospital for Neuro-disability, Putney the major referral centre for patients diagnosed as vegetative in the U.K. In addressing the question of whether PVS patients should be treated, Andrews drew attention to two alternatives to "vegetative" which were less pejorative, namely "post-comatose unawareness" and "reflexive state" (1993c). To date, neither alternative appears likely to supplant the snappy single term "vegetative". Interviewed 3 years later about some of the patients in his care, Andrews was emphatic:

> "I would like to ban the label, along with prevailing prejudices about PVS patients and their prospects. The moment you utter the word 'vegetative' you are in a negative frame of mind which will colour all your attitudes. And the word 'persistent' gives the impression of permanence, which also sets up negative expectations" (Cornwell 1996).

Andrews suggested that the term "PVS" had become a stumbling block in the treatment of brain damage rather than part of the solution.

A review by Jennett, published 25 years after launching of the term "PVS" acknowledged that concern had been expressed about the use of "vegetative" (1997). He noted that an alternative name "the wakeful unconscious state" had been suggested in response to concerns of some commentators that the term "vegetative" could suggest that a patient is a vegetable or is in some way subhuman (this certainly appears to have been precisely what it suggested to Dworkin (1993)). Jennett and Andrews agreed that the term "vegetative" had only been introduced into the medical literature as a descriptive term for some patients with brain injury in the years immediately preceding the naming of the condition. However, earlier transfer of its use from description of the *condition* of patients to description of the patients *themselves*, had generated some remarkably demeaning comments about affected individuals. For example, in a 1949 report entitled: *Operant conditioning of a vegetative human organism* (revealed in the subsequent account to be a child), Fuller noted that:

> "While of normal human parentage, this organism was, behaviourally speaking, considerably lower in the scale than the majority of infra-human organisms used in conditioning experiments – dogs, rats, cats" (Fuller 1949: 590).

Two further articles in which psychological "research" was undertaken on "vegetative subjects" (aka children with mental retardation) (Rice and McDaniel 1966; Rice *et al.* 1967) could be mistaken, in their attitudes towards their subjects, for part and parcel of some of the recent literature characterising PVS patients as "non-persons".

The last word in the term "PVS", although its selection was not discussed by Jennett and Plum, merits more than a passing comment. Reference to "state" rather than terms, such as "syndrome", more commonly used to describe an assembly of medical signs and symptoms, has undoubtedly enhanced the status of the name when it has appeared in non-medical situations, especially courts of law and legal and philosophical commentaries. One presumes that the original intention of using "state" was that it would be taken by a medical readership as little more than a nondescript noun to which the two specific adjectives could be anchored. However, once the PVS attracted the attention of moral and legal philosophers, the potential of the third word has blossomed. I suspect that one of the other connotations of "state", namely that of the "mode of existence of a spiritual being" (again the Oxford English

Dictionary) would convey considerably more to these readers than it did to medical practitioners in 1972. Its inclusion may have helped to fuel some of the debate over PVS in relation to personhood. Apart from implying the existence of a discrete condition rather than a salad of attributes shared with other collations, the use of "state" could be viewed as having "imparted artistic verisimilitude to an otherwise bald and unconvincing narrative" (Gilbert 1885). Syndromes may come and go; states are perceived to have some permanence.

1.6 THE INTERFACE BETWEEN PVS AND BRAIN DEATH

A relationship between brain death and PVS has been maintained at varying levels – semantic, conceptual and advocatory – from the time of definition of each until the present. As recently as 2002, Bernat referred, in an editorial in *Neurology*, to brain death as lying at the most extreme end of "the continuum of brain damage" (Bernat 2002). Having been categorised as absolutely separate and separable two decades ago, the two concepts seem destined soon to collide head-on. If so, it is likely that the immediate future of the two terms may be as inter-related as was their origin. It should be recalled that the opening sentence of the report of the *Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death* established the connection by declaring its primary purpose to be the definition of irreversible coma as a new criterion of death. Several lines later, the report referred to "permanent loss of intellect" (Beecher 1968). If the source were to be concealed from a reader, many of the viewpoints in the report could readily be mistaken for what was to be written a quarter of a century later about individuals diagnosed as vegetative. The issue of whether the distinction between the two conditions is no more than quantitative has been raised by calls for extension of the definition of brain death to embrace PVS, and for the course of patient management in PVS to approach that adopted for the brain dead. Recent historical analyses of the influences underlying the gestation of the brain death concept 30 years previously also reveal some striking background similarities. Attention has been drawn to the trend at the time of the early debate on brain death for the emergence of "other claimants to authority" (Pernick 1999) who disputed the convention of leaving decisions to the discretion of medical practitioners.

The potential for ongoing confusion between brain death and PVS, at least at a semantic level, was well established before the introduction of the latter term. Following introduction of the brain death concept, it was commonly referred to as "cerebral death" rather than "brain death". A large series of patients were described in 1971 as being in irreversible coma and exhibiting "cerebral" death. Reference was made to a large Collaborative Study of Cerebral Death, in progress at that time, and to a four volume collection of reprints, *Bibliography on cerebral death* (Korein and Maccario 1971). Patient descriptions indicated unequivocally that they met the criteria which were to be adopted in defining brain death, in particular the absence of any return of spontaneous respiration (ibid). Clearly, the designation "cerebral" was intended to be an adjective for "brain", perhaps as a means of avoiding the ambiguity subsequently introduced by recruiting that noun for use as an adjective (The expression "brain death" has remained open to interpretation either as *death of*