

CASE STUDY

The vegetative state: A report of two cases with a long-term follow-up

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Abstract

Objectives: To demonstrate that patients with Prolonged Vegetative State (PVS) can show signs of improvements and important changes and, consequently, to strengthen the necessity to evaluate them with long-term serial follow-ups.

Setting: Rehabilitation of patients with severe traumatic brain injury (TBI).

Participants: Two people with severe TBI discharged after a long period of inpatient rehabilitation in a condition of PVS.

Results: After 5 years some important changes happened and the initial prognosis was proved to be wrong.

Conclusion: Sometimes patients declared to be in PVS have the possibility to recover, especially when initial clinical conditions are particularly severe and do not allow the emergence of the state of consciousness. It is important to conduct regular follow-ups to better evaluate changes and, if it is necessary, to re-adjust the rehabilitation accordingly.

Keywords: *Persistent vegetative state, outcome, follow-up, traumatic brain injury*

Introduction

Many investigations have considered the period of unconsciousness as an important base to predict the functional outcome after TBI [1–4]. The duration of the period of unconsciousness, defined as the time-expired from the trauma to the reappearance of the ability to obey verbal commands, is considered important not only to predict the physical and neuropsychological deficits, but mainly to predict the return to work or the possibility of achieving social abilities.

When the period of unconsciousness lasts for several weeks, the possibility to return to an independent life is severely reduced, especially if the patient has significant motor and cognitive impairments. The condition of a prolonged state of unconsciousness, known as PVS (Persistent Vegetative State), is relatively infrequent after a TBI (~2–5% of all patients

with severe TBI after 6 months) [5, 6]. The main features of this condition are [7–9]:

- absence of awareness,
- inability to interact with other people,
- absence of voluntary and intentional behaviour,
- presence of sleep–wake cycles, and
- preserved spinal and cranial nerve reflexes.

This condition can be summarized as a presence of alertness without awareness.

Some physicians distinguish between 'Persistent' and 'Permanent' Vegetative State according to the duration of this condition [10], but more recently most prefer to use simply the term 'Prolonged' VS because this adjective describes the prognosis in a more neutral way. Sometimes people that are considered to be in PVS are capable of minimal responses, but these are always inconsistent and difficult to make out. In actual fact mistakes in

diagnosis are very frequent and the diagnosis of PVS is probably overestimated. As Andrews K. showed '43% of 40 patients referred to be in the PVS were considered as having been misdiagnosed' [10, 11, 12].

The wrong diagnosis often leads to losing all hope of recovering the patients quickly and consequently a change to the rehabilitation programme, so even the patients in Minimally Conscious State (MCS) cannot achieve a satisfactory quality-of-life. Actually in contrast with the relatively good recovery of the patients with VS of shorter duration, the prognosis of those with long-standing VS or MCS is negative [13]. Furthermore, the routine follow-up of these patients is often carried out after a short period of time because they are not of much interest for research.

In the Italian healthcare system, after a variable time in inpatient rehabilitation (on average 6–12 months), young patients in VS are discharged and sometimes it is possible to continue outpatient rehabilitation at home or in other public or private halfway houses [14].

We are going to present two case studies of patients who remained in VS for an extended period of time after a TBI in order to illustrate the changes and progress shown by them after 5 years. The following description of the observed improvements demonstrates the difficulty to make the right prognosis. Consequently, it becomes necessary to choose the rehabilitation treatment by considering both the potential slow recovery and the different conditions at different times that could favour the enhancement.

Method

Both patients considered in this case study experienced a serious TBI and were hospitalized at the Don Calabria Hospital in Negrar (Verona, Italy). They were subjected to intensive care treatments in the Neurosurgery Department and then transferred to the Rehabilitation Department for long-term inpatient rehabilitation. After the discharge, both the patients carried on outpatient treatment even if not continuously. However, the first rehabilitation team regularly monitored their changes for 60 months with regular follow-ups at 6, 12, 36 and 60 months.

The main tools used to monitor patients were: Clinical examinations, EBIS protocol (European Brain Injury Society) [15, 16], LCF scale (Levels of Cognitive Functioning), DRS (Disability Rating Scale), FIM (Functional Independent Measure) and finally the GOS (Glasgow outcome scale) [17–20].

An important aspect to point out is that these patients were considered to be in VS for a long time and, for this reason, they were discharged from the hospital after prolonged inpatient treatment. The aim of this study is to demonstrate that some significant changes are possible also in prolonged VS.

Case 1

F.G., female 21 years old, was hospitalized in the Rehabilitation Department for a severe polytrauma (facial and cranial trauma, immediate coma, multiple fractures) due to a road accident. At the time of the hospitalization in the Neurosurgery Department she had a GCS of 5 (E1, V1, M3) and the CT (Computed Tomography) showed a significant subdural haematoma that was immediately evacuated (Figure 1). She remained in the Intensive Care Unit for 2 months and then she was transferred to the Rehabilitation Centre.

At admission she showed:

- vegetative state,
- severe spastic quadriplegia,
- significant deformities due to contractures,
- tracheostomic cannula,
- percutaneous gastrostomy,
- DRS 23 (vegetative state),
- LCF 2 (generalized response),
- FIM 18/126, and
- GOS 2 (vegetative state).

Six months after the trauma, the tracheostomic cannula was removed and some signs of possible contact with the environment reappeared: The patient showed sustained visual tracking and spontaneous movements with her right hand, but she was

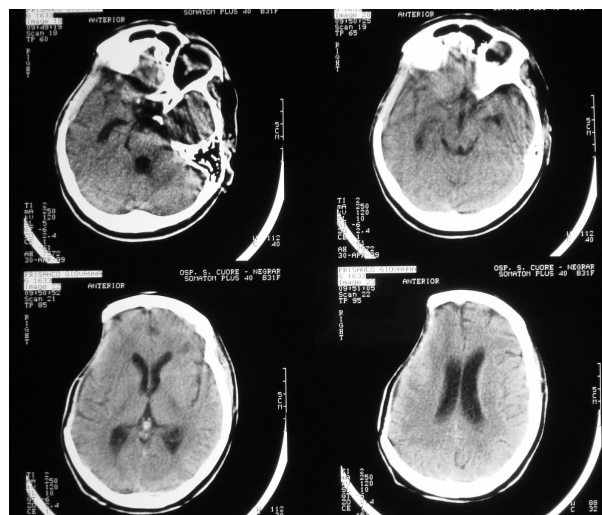


Fig. 1. CT scan done after large decompressive craniectomy and evacuation of subdural haematoma.

unable to perform simple orders. The neurological state was characterized by severe spasticity.

One and a half months later the patient could be discharged. She was minimally responsive but still totally dependent in all ADL (Activities of Daily Living) and still fed by a gastrostomy tube. She did not have trunk control in a seated position and significant contractures were still present. She was unable to speak and to communicate in alternative ways, but the tracking eyes were present and she responded to verbal orders. Prescribed medical therapy included Amantadine and Laevodopa.

After the discharge she continued the treatment in a rehabilitative unit near her house for 2 months and then outpatient rehabilitation for another 3 months. Twelve months after the injury she could communicate with gestures but without vocal emission. She remained totally dependant in ADL. Six months later (18 months after the accident) it was decided to hospitalize her for 3 months because some significant signs of improvement were noticed. She actually had an initial emission of sound and the motor disabilities were improving with a reduction of the spasticity and of the contractures. She was still completely dependent but she showed some voluntary movement in all limbs.

The inpatient treatment lasted 2 months and the orthosis enabled her to stand-up; in this period the trunk control had significantly improved. At the fourth follow-up (36 months after the trauma) she had a sufficient communication—even with dysarthric speech—and good ability to interact. An ecological assessment showed a good level of consciousness and cognitive abilities in progress; the orientation was stable; she was able to move herself around and control her wheelchair.

At the last follow-up (60 months after the trauma) she was able to walk only with a walker due to ataxic movements and required support only for certain daily activities. The language was dysarthric but well comprehensible and the grammar and lexical structures were normal. Mild cognitive impairments were still present but compatible with social activities and unpaid work. Table I presents the main changes according to scales.

Case 2

B.S., male 18 years old, had a motorcycle accident with immediate state of coma. When he arrived at Neurosurgery, he had a GCS score 7 (E1, V1, M5) and CT scan showed an extradural temporal and parietal haematoma on the left side, multiple bilateral lacero-contusive foci and a shift of the medium line towards the right. After the evacuation of the haematoma he was monitored by a Pressure

Table I. Functional outcomes and cognition, 3, 6, 12, 36 and 60 months after brain injury (case 1).

	3 months	6 months	12 months	36 months	60 months
LCF	2	2	5	7	8
DRS	23	23	21	5	3–4
FIM	18/126	18/126	18/126	71/126	109/126
GOS	2	2	3	4	4

LCF = Level of Cognitive Functioning; DRS = Disability Rating Scale; FIM = Functional Independence Measure; GOS = Glasgow Outcome Scale.

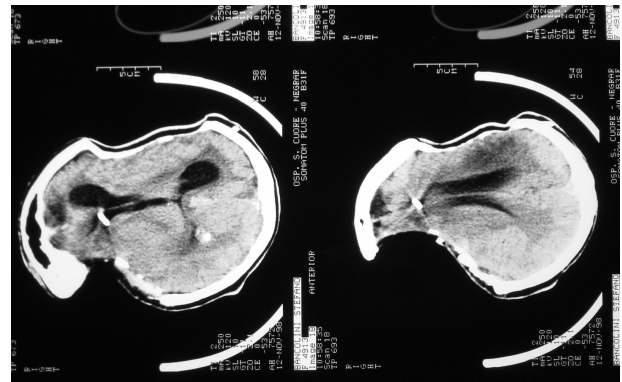


Fig. 2. CT scan done after bilateral decompressive craniectomy, evacuation of extradural haematoma and right frontal polectomy.

Intracranial Control (PIC). Repeated deliquorations were made.

Five days after the trauma, due to worsening of coma (GCS: 3), the patient underwent bilateral decompressive craniectomy; cleaning of contusive temporal foci, polectomy on front right and dural plastic (Figure 2). Four months after trauma, the patient was hospitalized in the Rehabilitation Department. He was still in a vegetative state with posture in decortication and multiple retractions on upper and lower limbs.

Tracheostomic and nasogastric tubes were in use. The score at the main scales was:

- DRS 24 (vegetative state),
- LCF 2 (generalized response),
- FIM 18/126, and
- GOS 2 (vegetative state).

Six months after the trauma, for a short time, the patient appeared to carry out orders, but in a sporadic and uncertain way. Subsequently, this inconsistent voluntary activity disappeared because the patient was in a critical condition with a high body temperature due to a systemic infection and significant weight loss (Figure 3).

Twelve months after trauma, when general conditions were improved, the patient was discharged



Fig. 3. Case 2: the patient six months after the trauma.

from the Rehabilitation Department. His responsiveness remained unaltered as did the serious spastic tetraparesis complicated by multiple myo-articular retractions. The patient was watchful, followed with his eyes and on rare occasions he seemed able to perform minimal movements on request, such as slow extension of fingers of his left hand, slight movements of right foot (data referred by family members). He needed the tracheostomic tube and he still had to be fed through gastrostomy. Surgical intervention (tenotomy of adductors of the hips and both Achille's tendons) was necessary to correct severe retractions.

One year after the trauma, when it was decided to discharge him, his conditions were improved but clinically stabilized. The care team felt there was no possibility of achieving functional results. CT scan at discharge showed enlargement of ventricles and wide frontal hypodensity.

The parents considered the decision to discharge their son to be an abandonment and persisted in asking to continue, at least, the rehabilitation programme at home. Their insistence paid off because after 4 months the patient became responsive and he started to follow simple orders such as turning his head on request and picking up small objects.

Two years after the trauma the tracheostomic cannula and later the gastrostomy tube were removed because the patient was able to swallow. At the third follow-up (36 months after trauma)

he communicated only with gestures, but he still showed severe behavioural disorders such as impulsiveness, aggressiveness and absolute absence of self-control. These behaviours were manifested mainly in unfamiliar situations and in situations in which he was asked to perform a specific task. In these situations the family tended to isolate and ignore him which caused a slight decrease in these behaviours. However, pharmaceutical treatment was still necessary. He continued to use a wheelchair, even if there were significant improvements including a reduction of spasticity and enhancement of motor control.

The parents once again asked for an intensive programme of rehabilitation, so he started to attend an outpatient rehabilitation programme for 2 years. In this context his behavioural problems were not addressed with specific techniques, but through occupational therapy, which allowed him more regular contact with other patients. This context allowed for a gradual increase in participation in simple activities and was compliant with his cognitive and motor therapies.

Sixty months after the trauma the patient was still tetraparetic, especially on the right side, but he had abandoned the wheelchair and he was able to walk with a tripod. His speech was limited to short sentences. The patient's cognitive abilities were seriously impaired and characterized by a frontal syndrome and by limited speech, both in content and structure. Conversely, his behaviour became more manageable. He could stay out of the house for longer periods and it was possible to introduce him to a protected community for 3 hours per day (Figure 4). Table II presents the main changes according to scales.

Discussion

The two cases illustrated are very important to this experience because they allow for some interesting considerations about the prognosis of the PVS. Both subjects, clinically considered in Vegetative State, respectively, 6 and 12 months after the trauma, achieved a significant improvement of motor and cognitive functions, as well as an increased level of autonomy. The process of recovery took a different course for each patient. The severity of the injuries highlighted by various examinations (CT, MRI) did not help to find useful evaluation criteria for prognosis.

Also, the GCS, particularly severe in both cases, cannot be considered a good indicator of outcomes. In actual fact, even if it is known that a poor level



Fig. 4. Case 2: the patient 60 months after the trauma.

Table II. Functional outcomes and cognition, 3, 6, 12, 36 and 60 months after brain injury (case 2).

	3 months	6 months	12 months	36 months	60 months
LCF	2	2	2	4	6
DRS	23	23	23	15	9
FIM	18/126	18/126	18/126	25/126	63/126
GOS	2	2	2	3	3

of the GCS indicates the outcome will be not positive, this is not always true.

In the authors' experience, the periodic clinical evaluation and the simple tools to evaluate the disability are the best indicators to make decisions about the rehabilitation programme. This means that all people who care for these patients need time to discover little but important signs of awakening. The results obtained by the various scales (GOS, DRS, LCF, FIM) in different times demonstrate there is a difference in sensibility. It is actually possible to note how GOS shows an important 'floor' effect and, especially in the second case, it is not sensible to the significant changes during the 2 two years.

However, DRS, FIM and LCF results are more suitable for the evaluation of progression. Specifically, high scores of DRS and FIM allow for easy recognition of some changes in the abilities of daily living [17–20]. When one considers the level of dependence, it is better to use a 'compact' scale like

GOS. However, if one wants to underline progress, it is better to use scales with extended scores that allow one to highlight little changes as well. However, standard tools of evaluation do not permit the description of slow evolutions.

It is important, then, to carry out a complete assessment to give regular and descriptive observations about impairments and abilities, especially when initial conditions are very severe such as in these case studies. These observations, when thoroughly conducted, can show that VS is not always a permanent condition, but a state which will likely undergo temporal evolution and improvement.

Non-stabilized clinical conditions do not always allow the emergence of the state of consciousness. With particular reference to the second patient considered in this study, frequent and serious infections had very likely delayed the improvement. In the same way, the surgical reduction of contractures and deformities due to spasticity can lead to a new experience of movement and thereby improve motor abilities.

When conditions are compatible with a life at home, this choice should be favoured because the influence of the family members and the familiar surrounding certainly help to speed up the whole process of cognitive recovery. Actually it is generally observed that the VS patient acts in a different way when the family is present.

The problem is to convince the family that the return home is not an abandonment, but rather an incentive to improve the patient's quality-of-life, because the environmental and affective memory stimulations can be as important as the nursing care in the hospital. It must be stressed that, even in a situation of dependence, as in the case of the second patient described, going back home signified a definite improvement of the quality of the patient's life and also for his family [21].

It is necessary, however, to support the family for a long time through the different therapeutic groups. Only adequate information and support can allow the reinsertion into the home and the preservation of confidence in the rehabilitation team. In both cases it was also very important to seize the best time to recommence intensive rehabilitation care.

Probably, when the recovery is very slow, intensive rehabilitation becomes inconclusive and can lead to the weakening of the rapport among therapists. It is, therefore, important to remember that the patients in PVS and in MCS may improve very slowly. In any case they can improve and one must take this possibility into consideration!

The question is: When and how does the recovery of these patients end? The long-term follow-up

confirms that the progression course tends to stabilize not to flatten; so it would be very interesting to keep in contact with the patients many years after the trauma in order to have a clear picture of their behaviour and clinical conditions.

One is sure that these patients can not return to their previous health condition because of the serious cognitive, motor or behavioural impairments, but one can suppose that if the rehabilitation stops they would not achieve these little improvements, which are considered to be very important by their families and by the rehabilitation team as well.

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