Improvements in medical techniques over recent decades have led to increased numbers of survivors of all types of brain injury. Many survivors of moderate to severe brain injury will have continuing medical or nursing needs, a degree of dependence on others for self-care tasks, and a range of physical, cognitive, behavioural and emotional changes, which are likely to affect the psychological status of both patients and their families. It has been reported that up to 50% of patients who have suffered a traumatic brain injury (TBI) will suffer subsequently from depression (Fleminger, Oliver, Williams & Evans, 2003). Over one-third of carers of people who have suffered severe traumatic brain injury experience significant symptoms of anxiety and depression (Marsh, Kersel, Havill & Sleigh, 1998). Several studies have reported that behavioural and emotional changes in the patient, such as behaving aggressively in social situations, have a significant impact on carers’ self-reports of burden; these factors have been more consistent in predicting carer burden than factors such as the level of physical disability (Marsh et al, 1998; Allen, Linn & Gutierrez, 1994).

Vegetative state (VS) refers to a condition in which the level of brain injury is so severe that the patient shows no awareness of self or environment and no ability to communicate (Royal College of Physicians, 2003). By definition, patients in VS cannot possess the self-awareness necessary to experience psychological distress. However, a small number of studies have examined the psychological functioning of patients who have emerged from VS, and these are discussed below. Some of the psychological problems commonly experienced by relatives and carers of people who have been diagnosed as being in VS will then be addressed, followed by consideration of some of the sources of potential conflict between relatives and professionals, and the difficulties experienced by professionals working with these patients. Given the relatively limited published research in this area, many of the points made derive from our clinical experience in a specialist unit for the
assessment, rehabilitation and disability management of patients in vegetative and minimally conscious states.

Psychological problems reported by patients who have emerged from VS

Studies of outcome at one month post-injury have shown that approximately 50% of patients diagnosed with VS following traumatic brain injury, but less than 20% of those with non-traumatic brain injury, will show some degree of recovery (Multi-society Task Force on PVS, 1994). These patients generally have considerable physical and cognitive impairments and remain highly dependent on others. McMillan & Herbert (2000) described a woman who had been in VS for approximately 4-5 months, and was thought to have a severely compromised quality of life following her emergence from VS. Some years after the injury, the patient was able to communicate ‘yes’ and ‘no’ by means of a response button, and by use of closed questions, it was established that she experienced subjective low mood and perceived her future as hopeless. However, despite this, she consistently expressed a desire to carry on living, and was able to participate in psychological therapy addressing her thoughts about death and dying.

Another patient has been described who showed a relatively good cognitive recovery (MacNiven, Poz, Bainbridge, Gracey & Wilson, 2003). The patient was reported to be in VS and then a minimally responsive state for a total of approximately 6 months. She then began to make a significant cognitive recovery, but had impaired communication skills for some time. When she was able to communicate, the patient described the psychological distress she suffered during routine nursing care tasks such as suctioning. She was angry that professionals did not routinely tell her what they were doing and why they were doing it. The patient had clear memories of this process being painful, and her only means of communicating this at the time was by behavioural methods such as screaming. She subsequently benefited from psychological therapy including anger management and cognitive therapy techniques, which helped her to focus more optimistically on her present and future.

These studies show that patients can communicate their feelings and benefit from professional help, even when communication is limited. The second study also highlights
the importance of interacting with patients in VS as if they may have some limited awareness, and treating them with the same respect and dignity accorded to other patients.

**Psychological factors in relatives/carers of people with VS**

The psychological reactions of relatives when a family member is in VS have been investigated. Before the relatives are able to accept the situation, they may experience a range of reactions including shock, anxiety, guilt, denial, depression and hostility towards staff caring for the patient (Tzidkiahu, Sazbon & Solzi, 1994; Jacobs, Muir & Cline, 1986).

*Loss without death*

Many patients do not emerge from VS, and recovery is rare more than 12 months after TBI and more than 6 months after non-traumatic brain injury (Royal College of Physicians, 2003). When there is little expectation of significant recovery, the situation for the patient’s family can be compared with bereavement since, even though the patient is still alive, the patient is no longer the person they previously were. However, unlike bereavement, the patient not only remains alive, but also receives an expensive care package with highly skilled nursing staff in attendance. Thus, unless withdrawal of feeding is requested, professionals treat the person with importance in spite of the magnitude of the injury, indicating by their actions hope of recovery, even if not by their words. This may encourage relatives to keep hoping, but also generate feelings of guilt in the absence of hope for recovery and a wish to visit less frequently. Guilt and blame are amongst the most common emotional reactions of relatives of people in VS (Tzidkiahu et al., 1994). Lezak (1988) referred to the difficulty experienced by the relatives of people with severe brain injury who have lost the person they loved but cannot mourn their loss because to mourn while the body remains alive is socially unacceptable.

In our clinical experience, some relatives maintain hope of a significant recovery in the absence of any evidence of improvement over long periods of time. Media portrayals may contribute to this. For example, a recent case of recovery from VS after a period of 18 years was described by one British newspaper, and accompanied by emotive reports of how his mother “refused to give up on him” and how “her faith was repaid” (The Guardian, 2003). While a matter of great joy for the family in question, reports such as this can give the message that there is always hope, in turn preventing an adjustment to the loss.
Professionals should be aware that the knowledge and attitudes of relatives towards brain injury and the chances of recovery are likely to be formed from such media stories and the depiction of brain injury in films or television programmes. In addition, the internet is increasingly a source of information for relatives. While the internet can provide people with extremely valuable information, many relatives do not have the knowledge and experience that would enable them to judge the quality and reliability of the information they obtain. They may also understandably be biased towards any information that fosters hope, regardless of its source.

**Family involvement in withdrawal of feeding decisions**

Once recovery is assessed as unlikely, it is possible that relatives may be asked to give their opinion on issues such as resuscitation status, active treatment and withdrawal of feeding. Even where decisions ultimately rest with the courts or with medical professionals, it is usually considered good practice to discuss them with the family, who may also be asked to estimate the patient’s views in the absence of a formal advance directive. Irrespective of the extent of involvement of relatives, such highly emotive issues lead to psychological distress, primarily in terms of feelings of guilt and responsibility. Within our clinical experience, several relatives have expressed openly that they think it would be better for the patient to be dead than in VS. Many relatives become upset when they express these thoughts because they do not want to abandon hope of recovery, and feel guilty at such open expression.

**Changes in roles and social circumstances**

One of the important similarities with bereavement is the change in family roles that can occur when someone has suffered a brain injury leading to VS. For example, a partner may suddenly become the sole earner in the family at a time when they have also lost their main source of emotional support. Lezak (1988) reported that, even though the changes in the brain-injured individual mean that a former relationship will never be regained, a combination of guilt and responsibility can make it difficult for partners to consider forming new relationships. Nevertheless, for some people the changes in roles may actually have a positive psychological outcome, at least in the short term; some relatives appear to draw strength from developing a caring role for the patient, and may form a new social network with relatives of other patients in a similar state.
For those patients who remain in VS or minimally aware states and for whom feeding and treatment are not withdrawn, relatives will be involved in deciding the plan for their future care. Some relatives decide that they wish to care for the person at home and may give as a reason their opinion that this is what the patient would have wanted. While this may be a viable option for some, it should be balanced against the best interests of both patient and family. By definition, the patient does not experience psychological distress so the quality of physical care is likely to be the only important factor. For the family, even with a 24-hour supportive care package, the burden of care is likely to be considerable, and steps should be taken to ensure that all the options have been considered and that the decision is best for all members of the family. Relatives may be motivated by guilt at the thought of the patient being in long-term institutional care, even if this appears to professionals to be in the patient’s and family’s best interests.

Psychological distress in family members may be a consequence of relatives of the same patient experiencing completely different psychological reactions. As an example, the patient’s partner may be ready to begin accepting the situation earlier than the patient’s parents. The parents may perceive a reduction in visiting by the partner as a betrayal of the patient, and may even believe it to be detrimental to the patient’s chances of recovery. Such conflicts can only add to the distress experienced by all concerned.

Sources of difficulty between relatives and professionals

Sources of difficulty or disagreement between relatives and professionals may exacerbate the distress of either. One common source of such difficulties is a misunderstandings by relatives about the diagnosis of vegetative state. Tresch and others reported that 31 out of 33 relatives interviewed believed their family member was aware of at least some external stimuli (Tresch, Sims, Duthie & Goldstein, 1991). In particular, the degree of cognitive impairment can be very hard for relatives to appreciate, especially if patients exhibit non-purposeful movements or noises. Patients in VS can demonstrate behaviours that are associated in non-brain injured individuals with emotional experience, such as crying, grimacing, smiling, or laughing (Royal College of Physicians, 2003). When the patient fulfils diagnostic criteria for VS, these behaviours must reflect subcortical functions and are not indicative of subjective distress. Not surprisingly, this can be difficult for relatives to
understand, and many families reasonably perceive these behaviours as signs that the patient is intentionally trying to ‘wake up’ (Jacobs et al., 1986).

In our experience, it is very common for relatives to report that the patient is making meaningful responses when these have not been observed by the professionals who have been assessing the patient. This commonly results from a misunderstanding of the nature of the observed behaviour; the relative believes it to be purposeful or environmentally driven, when objective evidence indicates it is not. Sometimes patients’ behaviours are genuinely different when their relatives are present. When relatives are reporting behaviours not observed by professionals, staff should consider observing the patient with the relatives and involving the relatives in some of the formal assessment sessions in order to gain a more comprehensive view of the patients’ behaviour. This can also be advantageous when the relatives have overestimated the patient’s level of awareness as they may come to revise their opinion.

Another source of potential tension between relatives and staff occurs when relatives request the continuation of treatment that will not benefit the patient. Requests for physical treatments such as physiotherapy or occupational therapy may reflect an underlying belief that recovery might be possible if only enough treatment is received. Relatives may believe that physiotherapy will enable the patient to walk again; a belief based on a failure to appreciate the role of the brain in planning physical activities. Others may be denying of the extent of the patient’s impairments and the poor prognosis; denial is commonly reported in relatives of people in VS (Tzidkiahu et al., 1994; Jacobs, et al., 1986). This may be promoted by reports by therapists’ reports of good progress. For the therapist, the goals of prevention of contractures or maintenance of range of motion are being achieved; but for the relatives, the goal of recovery is not being achieved. It is important for therapists to communicate the nature of their goals clearly to the relatives.

Some relatives think that constant stimulation will cure the patient. There are conflicting views on the efficacy of sensory stimulation programmes for patients in VS but it has been argued that there is little reliable evidence to support their use (Lombardi, Taricco, De Tanti, Telaro & Liberati, 2002). It has been argued that constant stimulation may even be detrimental to patients in VS and that care should be taken to ensure that the sensory environment is regulated (Wood, 1991). Patients may have reduced levels of arousal and it
is important to preserve periods for assessment and therapy. Relatives can be encouraged to continue talking to and interacting with the patient, but to moderate their behaviour to take account of the need for clinical procedures and the fact that even with limited awareness there will be significant cognitive impairment.

Relatives not uncommonly make seemingly minor complaints about nursing tasks, or cleaning standards on the ward. We believe that, if the complaint seems unfounded, it is helpful to see repeated complaints as a wish by relatives to do something tangible to assist. There is little that they can do, so they tend to focus on the only tasks over which they can have some control, seemingly becoming fixated on such issues as whether or not the patient’s water was given at exactly at the expected time, or how frequently the ward is cleaned. If professionals take this behaviour at face value, it can be a source of continual frustration at the relatives’ failure to accept the explanations offered by staff. Staff may be assisted by understanding that this behaviour reflects the psychological distress of relatives.

Misunderstandings may arise from a lack of clarity by professionals when explaining the diagnosis to the relatives; in part from the uncertainty of the prognosis. There is no definitive test of whether or not a patient will emerge from VS. Current guidelines for diagnosis of persistent VS are based on the low probability of the condition improving after specified time periods, but not on a certainty that it will not. Professionals may communicate their own lack of certainty when giving the diagnosis and prognosis, leading to false hope by the relatives. Professionals would be advised to refer explicitly to the relevant statistics, so explaining the lack of certainty of outcome, and also the professional’s range of opinion.

**Psychological factors in professionals working with people in VS**

One of the contentious issues in working with patients in VS is withdrawal of tube feeding, as a result of the ethical questions around withdrawal of life-sustaining treatments. This may have a psychological impact on the professionals who have been caring for the patient over a considerable period of time. There is likely to be considerable individual differences based on cultural and religious beliefs and the attitude of staff members towards death and the vegetative state. In our clinical experience, it may be particularly problematic for the most junior health care staff, who may have had the most immediate contact with the patient.
during the caring stage, but who may lack formal training in caring for the dying patient. Staff should be given the choice as to whether or not they will participate; some staff members may see this role as an important part of their duty towards the patient.

Another problem for staff is the source of their job satisfaction. Many people working in health care professions cite the gratitude of patients and the satisfaction of seeing someone get better as sources of job satisfaction. However, these may be absent in working with people in VS. Patients may show no more than very subtle improvements. The quality of supervision for professionals working with this client group may be important in determining whether they are able to gain satisfaction from their work. It is important that professionals working with these patients are able to have pride and satisfaction in providing anticipatory, maintenance and palliative care.

Professionals are also often encouraged to behave towards patients as if they are more aware than they appear to be. This is clearly good practice given the uncertainty of the diagnosis, and is supported by work referred to above. However, it can be difficult in practice to maintain this stance when there is no feedback from the patient. It is important in these circumstances that professionals have had adequate training to understand the rationale behind the request to treat the patient as more aware.

**Conclusion**

In summary, there are several potential sources of psychological distress for patients, relatives and professionals working with this client group. Not all these factors are unique to this patient group. There are some common reactions, but there is no set and predictable pattern; every family is different and factors such as cultural and religious beliefs are likely to contribute to the type of reaction seen. It is important for health care organisations to be aware of the range of psychological reactions, and to have adequate support systems in place for their staff. Organisations should also have a structure in place for supporting relatives, whether this is via in-house professionals such as psychologists, counsellors or social workers, or by linking the relatives to other organisations, in the public or voluntary sectors.
References


The Guardian (11.07.03). “Terry Talks”


