

**Special Feature**

# MedicoLegal Aspects of Severe Traumatic Brain Injury

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**S**evere functional disability following catastrophic brain injury, although not common, must be

appreciated by both health care professionals and trial lawyers. There must be an understanding of the nature of the injury and its sequelae, life expectancy prognostication, and determination of future medicals well as non-medical lifetime needs. There must also be a sensitivity to the ethical and moral dilemmas of treating professionals, family and legal counsel for the person with the injury. This article will summarize medical, legal and ethical issues germane to working with this challenging patient population as well as practical suggestions for optimizing communication with families of persons with severe acquired brain injury (ABI).

## **Nature of Injury and Sequelae**

### **History and Overview**

To the reader's potential surprise, cases of prolonged unconsciousness have only recently started to appear in the medical literature. Probably, the first such documentation was made by Rosenblath in 1899. The

patient was a young acrobat who incurred a severe traumatic brain injury (TBI) in a fall, leaving him “as if asleep.” There was hardly any mention of states of protracted unconsciousness and unawareness following brain injury in the medical literature through the early part of this century. Most authors described their patients based on clinical observations. Although a variety of terms were coined to label such patients, there was no consistency across publications regarding the nomenclature used. Many of the terms used persisted in the literature for some time, others were as transient as the one publication in which they appeared. Some of the terms used to describe individuals who were arousable but unaware included: apallic syndrome, anoetic syndrome, coma prolonge, protracted unconsciousness, long lasting unconsciousness, rotracted comatose states, prolonged disorders of responsiveness, prolonged post-traumatic unawareness (PPTU), post-coma unawareness PCU), continuous or prolonged hypersomnia, hypertonic post-comatose stupor, decerebrate state, vegetative life, vigilant coma and chronic brain stem syndrome. What became clearer, as we entered the latter part of the 20th century, was that there were serious problems with the terminology being utilized as well as a lack of consistency within and outside the field of neuromedical specialties relative to understanding the nomenclature being utilized and the conditions being described.<sup>1</sup> Jennett and Plum attempted to correct this problem with the introduction of the term persistent vegetative state in 1972.<sup>2</sup> The authors attempted to define this condition with fairly specific behavioral parameters and without an attempt to correlate neuropathology. They also were astute to point out that there was not adequate data to determine absolute irreversibility of the condition. Clearly, however, there were problems with this terminology relative to inferences regarding prognosis that less sophisticated clinicians and certainly payers and family members might find misleading. Specifically, many patients did not “persist” in this state and went on to make further neurological improvement, some to the point of good functional outcomes by such measures as the Glasgow Outcome Scale. Some clinicians strongly believe that PVS became the most widely misused term relevant to the clinical diagnosis and care of the severely impaired patient following brain injury. The potential consequences of such misuse have many times been seen in clinical practice; including, but not limited to, withdrawal and withholding of care, failure to refer for rehabilitation services, discontinuation of rehabilitation efforts and tendencies towards less aggressive management of comorbidity factors due to the label of “PVS.” Until quite recently, clinicians seemed satisfied with the phraseology of “PVS” to describe patients following brain trauma and other conditions who had protracted periods of wakeful unconsciousness (that is they were aroused but not aware). Most recently, there have been further attempts to address nomenclature, diagnosis and treatment of persons following severe acquired brain injury including publication in 1994 of the MultiSociety Task Force (MSTF) document.<sup>3</sup> These and other efforts have been spearheaded by several “special interest groups” within the neuroscience community.<sup>4</sup> These groups initially worked within their own camps but more recently have joined forces to produce what will hopefully be an ongoing collaborative effort. Ongoing clinical and ethical debate during the last decade has produced further evolution of the literature germane to low level neurologic states (LLNS) following brain injury including birth of the new phrase “minimally conscious state.”<sup>5</sup> There remains, however, much debate in areas of medical, legal, and ethical aspects of the assessment of this special patient population.<sup>6</sup>

### **Description of clinical features**

Vegetative state (VS) patients demonstrate arousal without concurrent awareness. Neurobehaviorally, vegetative state patients have periods of eye opening, either spontaneously or following stimulation; may demonstrate subcortical responses to external stimulation including generalized physiologic responses to pain such as posturing, tachycardia, and diaphoresis as well as sub-cortical motor responses such as a grasp reflex; demonstrate return of so-called vegetative (autonomic) functions including sleep wake cycles, and normalization of respiratory and digestive system functions; and may show roving eye movements without concomitant visual tracking ability. The presence of sub-cortical responses should not be considered as pathognomonic of VS as these findings may also be seen in minimally responsive patients. Additionally, there is no definitive way to clinically assess “internal awareness” in a patient otherwise unable to express awareness relative to external environmental stimuli. Thus, it is theoretically possible that some patients who are indeed conscious are labeled incorrectly as being in a vegetative state. Practitioners should also understand that there is no neurodiagnostic or laboratory test that allows the clinician to diagnose VS *per se*, the diagnosis is one that is ideally made by serial bedside neurobehavioral assessment.<sup>7</sup> Patients in “persistent” and “permanent” vegetative state meet all the criteria neurobehaviorally that patients in vegetative state do. Generally, the modifier “persistent” is endorsed when VS has lasted for at least a

month, however, there is so little agreement, in practice, regarding how this term is applied that it should probably be removed from the current neuromedical vocabulary. In general, a time frame of one year for traumatic and three months for hypoxic-ischemic brain injury (HIBI) should be utilized for prognostic purposes relative to determining that emergence from vegetative state is statistically highly unlikely. There have been recent documents espousing a longer period of observation following HIBI, specifically six months, prior to labeling a patient as in a permanent vegetative state.<sup>8</sup> Consensus opinion has dictated that after these time frames, it is appropriate to use the phrase “permanent vegetative state.” We would note, however, that the word “permanent” is a relative misnomer as there is no way to predict with 100 percent accuracy whether someone will emerge into a state of consciousness from an otherwise vegetative state. Additionally, clinicians should only determine prognosis for a patient who is vegetative at one year following trauma or three (and possibly up to six) months following hypoxic-ischemic injury if there has been an adequate period of extended patient observation and sufficient neuromedical assessment to rule-out conditions potentially adversely affecting ongoing neurorecovery and/or neurobehavioral assessment.<sup>9</sup> Minimally conscious state (MCS) patients are no longer in coma or VS but demonstrate low level neurobehavioral responses consistent with severe neurologic impairment and disability. Patients who are in MCS are able to demonstrate, albeit intermittently and possibly incompletely, some level of awareness to environmental stimulation consistent with the presence of cognitive function. The examining clinician must take into consideration both the frequency and the context of the behavioral response in order to interpret the meaningfulness and/or purposefulness of a given behavior.<sup>10</sup> All patients in MCS produce, by definition, inconsistent responses to their environment that do not reach threshold for reliable and/or consistent communication.<sup>11</sup> Akinetic mutism (AM) is neurobehavioral condition marked by severe disturbances in behavioral drive. In actuality, AM is a neurobehavioral subset of the MCS sub-group. Generally, a minimal degree of movement (kinesis) and speech is elicitable. As opposed to most other low level neurobehavioral disorders, akinetic mutism is associated with damage to dopaminergic pathways including the mesoceruleal, diencephalospinal, and/or mesocorticolimbic.<sup>12</sup> Patients with frontal AM tend to be more vigilant than those with midbrain AM and may even demonstrate episodic agitation. Patients with AM typically demonstrate: eye opening with visual tracking; little to no spontaneous speech; and infrequent as well as minimal command following. Locked-in syndrome (LIS) is a relatively rare albeit important neurobehavioral condition associated with lesions of the ventral pons, more commonly associated with cerebrovascular disease (*i.e.*, stroke) than TBI. Clinically, patients with LIS present with anarthria (*e.g.*, lack of ability to speak) and quadriplegia (*e.g.*, lack of ability to move extremities due to paralysis) in the “complete form” of the condition. Disruption of corticospinal and corticobulbar pathways at the level of the pons results in preservation of rostral and health care providers and the lay community at large. One must admit, however, that there is still much that is unknown regarding long term recovery from LLNS.

### **Areas of controversy and continued debate**

Recovery patterns are quite variable following severe brain injury, whether due to trauma or HIBI. Patients who initially are comatose may die, transition into a vegetative state and never emerge from that state, or progress to some level of conscious awareness. Patients may emerge from VS and slowly progress through various degrees of conscious awareness with rates of emergence and general recovery being variable. Some patients who emerge from VS may remain in a MCS, whereas, others may go on to make functional recoveries, return to work, drive and live independently. There are other patients who recover nearly normal levels of awareness but remain fully dependent for all basic activities of daily living (feeding, toileting, grooming, dressing), as well as, all mobility. Families and patients are generally very interested in prognosis. Prognoses must be communicated in some understandable fashion. Characterizing recovery as the probability of attaining a certain functional level translates prognosis into a more understandable phenomena. In order to do so, however, one must understand the neurological natural history of severe alterations in consciousness following acquired brain injury and the implications of nomenclature relative to prognosis.<sup>15</sup> Misperceptions continue to abound among the lay and professional community regarding many of the terms utilized in providing prognostic information including the vegetative state. Vegetative state is thought by many to imply that the patient is a “vegetable;” a far cry from the original intent of the term. Such misinterpretation has led to the call for doing away with the term by various different groups. If one uses the term, then one is certainly obliged to explain it properly to avoid misinterpretation. Many note that in this climate of patient autonomy, informed consent and decision making, practitioners have a responsibility to provide upper boundaries for recovery translated to terminology that describes the probabilities of attaining levels of future function. Only with this information can families make informed

decisions concerning levels of treatment and society through a redistribution of resources provide adequate rehabilitative care for patients with highest potential for functional recovery. As opposed to opinions conveyed by the Multi-Society Task Force (MSTF), it is the opinion of some clinicians that there is not sufficient methodologically sound research to label vegetative state patients (either individually or as a dorsal pontine function; thereby, implying generally intact cognitive function and arousal. Vertical eye movements and blinking are preserved; yet, there is typically significant lower cranial nerve and sleep wake cycle dysfunction.<sup>13</sup> Unfortunately, the media in the United States often inaccurately reports information regarding late recoveries following brain injury as apparent “miracles” even when provided with contrary information and/or professional input suggesting alternative explanations. Late recoveries that appear to be “miracles” do occur and seemingly more commonly in minimally conscious patients who are often claimed to have been comatose or vegetative for extended periods of time when in fact the evaluating clinicians simply did an inadequate assessment.<sup>14</sup> All too often inadequate information is provided regarding prior neuromedical findings and work-up, present medications, and injury history. This type of “media hype” only serves to promulgate unfortunate misconceptions among less sophisticated group) beyond one year post-injury as “permanently” vegetative thereby implying no potential for further improvement. In part, these criticisms are raised based on the relatively small sample of patients tracked in the Multi-Society Task Force data analysis beyond one year post-trauma. Use of such nomenclature as “permanent vegetative state” may only serve to create a self-prophesying environment which does not encourage clinicians and scientists to pursue treatments which may ameliorate the condition. The MSTF argued for an upper boundary supported by their review of the literature’s prognostic studies and consensus of expert opinion. They posited that the three months for non-traumatic VS and 12 months for traumatic VS offered upper limit boundaries that established high probabilities for permanency of the vegetative state in each circumstance. One might argue that the upper boundaries are necessary and represent the highest probability that recovery will not take place or if it does, that it will be to a level that is associated with severe functional disability and handicap. Some clinicians also have expressed concerns that the MSTF devalued the concept of severe disability as an outcome. Even within the Glasgow Outcome Scale category of “severe,” one must understand the implications of the term “severe” relative to the fact that there is a wide range of impairment and associated functional disability seen in this group of patients, as previously noted. Many of these individuals may be quite communicative and able to assist with daily care, as well as, self-mobility. Many clinicians would be quick to assume that a GOS of severe disability could not be compatible with any meaningful quality of life, yet many clinicians in the field of neurorehabilitation would argue otherwise as would a number of patients in this outcome category and their family members. Although sophisticated clinicians will be less likely to misdiagnose patients who are in MCS as being vegetative, misdiagnosis as VS in the presence of hallmarks of conscious behaviors remains, unfortunately, rampant.<sup>16</sup> With as much confusion as there still is regarding such basic things as how to perform a bedside assessment of a patient in a LLNS, we still have much to learn about the neurological and neurophysiological substrates of this class of neurobehavioral disorders. There have been recent developments that further expand our understanding regarding brain function in patients who appear to be “functionally vegetative” but may in fact be in a MCS, as well as, in patients who are likely both neurologically and functionally vegetative. Recent work by Schiff and colleagues at Cornell suggests that there may be wide variations in brain metabolism in PVS and that some cerebral regions can actually retain partial function.<sup>17</sup> Work by Laureys and his colleagues in Belgium has demonstrated that painful somatosensory stimulation can produce increased neuronal activity in primary somatosensory cortex in patients who are otherwise labeled as PVS, even when resting brain metabolism was severely impaired; yet, this activation was felt to occur in seeming isolation and dissociation from higher-order associative cortices thought to be necessary for conscious perception.<sup>18</sup> Further PET work by Laureys’ group, that is even more profound in its implications relative to garnering an understanding of VS emergence, demonstrates that recovery of consciousness is paralleled by restoration of cortico-thalamo-cortical interaction.<sup>19</sup> These studies provide further data that question long standing neurological dogma regarding the accuracy of the bedside assessment for VS diagnosis. Such work should beg the question of how much we truly understand about VS and what the specificity and sensitivity is of our traditional bedside neurobehavioral assessment methods for defining conscious awareness in patients who may otherwise appear vegetative.

## **Prognostication**

### **Summary of prognostic parameters**

Prognostic variables that are commonly used to predict neurologic and functional outcome have been categorized into six broad categories based on: demographic variables, severity indices, neurological signs, neuroimaging studies, neuromedical markers and psychosocial ratings.<sup>20</sup> Of the demographic factors, the relation between age and outcome has received the most attention. Generally very young (less than 2 years of age) or very old (greater than 60 years of age) have worse outcomes, particularly relative to chance for survival. The duration of the vegetative state may be one of the strongest predictors of long term neurological and functional outcome measures after severe acquired brain injury. Research has demonstrated that severity indices hold the highest level of predictability when utilized within the first 2 weeks post-injury. Some of the factors that *may* correlate with poorer outcome and higher levels of acute mortality, include, Glasgow Coma Scale (GCS) score of 5 or less, prolonged post-traumatic amnesia, abnormal brainstem findings, and elevated intracranial pressures, particularly when greater than 40 mm Hg.<sup>21</sup> Multimodal evoked potentials (MMEPs), as well as, electroencephalography (EEG) have both been used to assist with outcome prediction in patients in coma, as well as, the vegetative state.<sup>22</sup> Recent research by Lew and colleagues has demonstrated that cognitive event related potentials (ERPs) may also be quite helpful in predicting outcome after severe TBI.<sup>23</sup> Some researchers are also looking at specific auditory EPs related to temporal sound pattern processing as a means of detecting evidence of conscious awareness in persons presenting as “functionally vegetative.”<sup>24</sup> The role, if any, for static imaging as a means of outcome prediction remains debateable. Functional imaging on the other hand, may have a greater utility in this role; however, work is still in the early stages in this area of neuroscience. The role of magnetic resonance spectroscopy (MRS) is yet to be defined in this group of patients, however, early research is promising, at least as a marker of injury severity and potential for emergence from VS.<sup>25</sup> A variety of laboratory measures, including, but not limited to, ventricular CSF neurotransmitter metabolites, myelin basic proteins, creatine kinase and lactate levels, have also been studied relative to their predictive validity for neurologic outcome following severe TBI.<sup>26</sup> A variety of neuromedical factors have been found to correlate in a negative fashion with good outcome following severe TBI including systolic hypertension, acidosis, disseminated intravascular coagulation, central dysautonomia, disturbances in motor reactivity, communicating hydrocephalus, late posttraumatic epilepsy (more than one seizure beyond the first week) and abnormal respiratory drive patterns.<sup>27</sup> When analyzing prognostic data, it has been found that multifactorial/multidimensional analyses seem to allow for better outcome prediction accuracy.<sup>28</sup> Lastly, studies to date suggest that serial as opposed to static assessment yields better outcome prediction validity relative to the ability to account for rate of change in prognostic markers over time;<sup>29</sup> however, in the context of medicolegal assessments this is often not possible. The prognosis for emergence from the vegetative state is not only dependent upon the etiology of the insult, but also the time post-insult. Specifically, the longer from onset of injury, the worse the prognosis for emergence and once emerged the worse the prognosis for a better than worst functional outcome. The best prognosis is associated with recovery of consciousness within the first several days to two weeks. Recovery of consciousness after a month is associated with a higher probability of dependency for basic activities of daily living and mobility.<sup>30</sup> The best recovery, based on analysis of the MSTF document, occurred in those patients who emerged from the vegetative state within six months and this certainly parallels clinical experience. Those patients recovering towards the end of a year typically had severe, long term, functional disability. The MSTF reviewed all the literature, reports in the lay press and attempted to document all cases of late recovery. They could find no cases of recovery after one year that were associated with significant functional recovery, *e.g.* any outcome better than a Glasgow Outcome Scale (GOS) category of severe disability. One must recognize, however, that the sample size of the group of patients followed beyond one year relative to making this determination and any statements regarding prognosis for life expectancy (*e.g.*, population based average survival time) was very small (clearly less than 30 patients).

### **Time of prediction**

There are obvious inherent differences in outcome prediction for comatose, vegetative and minimally conscious patients, regardless of etiology, related to the time post-injury. Clinicians should be aware of what factors are the most valid prognostic indicators at any given time post-injury. These factors will obviously change relative to the acute, sub-acute and chronic phases post-insult. Most of the injury severity measures continue to be relevant prognostic factors even in the latter stages of post-injury care except for possibly age and initial intracranial pressure. There are, however, no methodologically sound studies available that provide any specific temporal framework for utilizing specific prognostic indicators at given time frames post-injury.

### **Type of etiology**

Differences exist relative to comparative prognosis across different groups of patients with brain injury depending upon numerous factors including the etiology of the brain insult. Assuming all other factors are constant, hypoxic/anoxic and/or ischemic brain injuries (HIBI) have a much poorer neurological and functional prognosis than traumatic brain injury without secondary brain insult regardless of the type of primary brain injury incurred i.e. diffuse axonal injury (DAI) versus focal injury, or both. Clinicians should avoid making clinical and prognostic decisions based on literature garnered from studying TBI populations if the patient in question had a HIBI. Although there are some parallels between traumatically induced low level states and those that occur as a consequence of hypoxic injury, there are multiple major differences. Some of these major differences include neuropathologic findings, associated clinical impairments, and short, as well as, long term neurologic and functional outcomes. From a neuropathological standpoint, post-trauma patients who remain minimally conscious or vegetative following severe brain injury typically have significant diffuse axonal injury with depth of parenchymal involvement being directly correlated with the magnitude of the original forces applied to the brain. Hypoxic brain injury results in a very distinct and disparate type of neuropathologic picture with diffuse or multi-focal laminar cortical necrosis with certain areas of the brain being more prone to hypoxic insult than others including the hippocampi, basal ganglia, hypothalamus and purkinje fibers.

### **Role of rehabilitation in low level states**

One of the criticisms of the Multi-society document was the lack of discussion, if not exclusion, of information regarding the role of rehabilitation outside of a cursory review of “coma stimulation” literature and a brief mention of possible pharmacotherapeutic interventions.<sup>31</sup> Interdisciplinary rehabilitative management of this patient population involves preventing potential morbidity issues as well as providing appropriate neuromedical and rehabilitative interventions to maximize potential neurologic and functional outcome. Rational neuromedical and rehabilitation management of this patient population has been delineated in several articles.<sup>32</sup> A full neuromedical work-up must be performed prior to labeling any patient as vegetative. Adequate understanding of the “late” neuromedical sequelae of traumatic brain injury is essential in the care and treatment of the this population. Medical conditions such as post-traumatic epilepsy, particularly of the non-convulsive type, post-traumatic hydrocephalus, neuroendocrine dysfunction, occult infection, late subdural hematomas, and iatrogenically induced problems related to inappropriate use of pharmacological agents may all cause an individual to “look” vegetative when indeed they are not.<sup>33</sup> Appropriate care should emphasize minimizing morbidity and treating any underlying condition(s) potentially suppressing neural recovery potential, good nursing care with an emphasis on skin, respiratory, on bowel/bladder care, and appropriate and timely prescription of adaptive equipment including seating and orthotics.<sup>34</sup> Family involvement, education, and counseling should also be an integral part of *any* “early recovery management program” (ERMP). The issue of whether so-called structured sensory stimulation (SSS) can in any way actually be a negative factor in recovery has only recently been theorized. Such issues of how stimulation may cause over-arousal and increase fatigue, decrease seizure threshold and/or increase maladaptive plasticity including spasticity definitely need to be looked at more critically. Nonetheless, the literature supporting a utility for such structured stimulation programs is lacking and most clinicians in the field would acknowledge that SSS probably has no effect on either rate or eventual plateau of neural recovery.<sup>35</sup> If sensory stimulation is offered, it should be done in a cost-efficient, ethical, and responsible fashion, not as the major component of the total program and should be geared more towards tracking of neurobehavioral status than as a treatment intervention, per se. The exact role of other, more controversial interventions, such as neural stimulation and pharmacotherapy, for promoting recovery from VS remains unanswered but definitely warrants further research in a controlled, blinded fashion to establish the efficacy of these interventions.<sup>36</sup>

As a community of health care providers, rehabilitation clinicians have sufficient experiential consensus, as well as, a growing base of prospective data regarding the efficacy of early and intensive rehabilitative treatment to minimize shortas well as long term morbidity, decrease health care costs, and optimize long term functional outcomes.

## **Quality of life issues**

Issues regarding quality of outcome must also be broached particularly given the statements made in the Multi-society document implying that “severe disability”, presumptively as defined by the GOS was as bad a functional outcome as VS. Those of us who have worked with enough patients with severe disability know that there is a wide range of functional capabilities within the severe disability category (by GOS or any other grading system). Clinically, and in our opinion, ethically, quality of life issues must be seen first from the standpoint of the patient and second from the standpoint of the family. Clinician opinions should rank tertiary, with payor opinions last. Severe disability may seem like a poor quality of life to one person but quite acceptable to another given the potential options including VS and/or death.

## **Life expectancy issues**

Life expectancy determinations must be made on an individual basis. There is some data on life expectancy determination in severely disabled patients following acquired brain injury, specifically, in persons in vegetative state but this data must be interpreted cautiously due to methodological concerns and small sample size issues. The most widely disseminated treatise on this topic was published by the Multi-Society Task Force Document published in the NEJM in 1994 which noted that the average life expectancy for a patient in a vegetative state was 3-5 years and that a life expectancy beyond 10 years was rare.<sup>37</sup> There is also an excellent study published by Ashwal, Eyman and Call in 1994 examining life expectancy in children in PVS. A number of studies are also commonly quoted by experts in severe brain injury, where life expectancy questions arise. Many of these articles are population based studies on life expectancy in immobile institutionalized individuals without traumatic brain injury that demonstrate an overall trend to early demise.<sup>38</sup> Until recently, there was no literature that looked at specific morbidity risk factors and/or quality of care after severe brain injury in either vegetative or “minimally conscious” individuals. A recent study published in the Archives of Physical Medicine and Rehabilitation did examine the long term survival of children and adolescents after severe traumatic brain injury.<sup>39</sup> This study found that the chief predictors of mortality were basic functional skills such as mobility and self-feeding. For those individuals who had no mobility and were six months post-injury, the study found that their remaining life expectancy was only 15 years. Many experts use the life expectancy data from the NEJM Multisociety Task Force document to “predict” the life expectancy of a given individual. Firstly, we would note that “life expectancy” is a population based phenomena, therefore its use in this application is erroneous. Additionally, we would caution using population based studies alone to determine one specific person’s median survival time. Such a practice clearly goes against both one’s intuitive logic and clinical acumen as individual survival time prediction must subsume delineation of specific risk factors and historical events of significance relative to health related morbidity for the particular person in question. These types of injuries are so heterogeneous as are the associated impairments and disabilities that it just does not make sense to say “everyone is the same” and thereby justify the use of general population based estimates to calculate one particular person’s future survival time with a degree of medical probability. A good analogy would be telling a particular patient that they will probably die by the age of 74 because that is the average life expectancy of people in our country without checking on their past medical history, family history, high risk practices (unsafe sex, tobacco, alcohol, or illicit drug use; parachuting, fast driving, etc.), exposure to environmental pollutants or other risk factors and general family longevity. Dr. Zasler has followed several patients who have been vegetative or minimally conscious for nearly 20 years; this fact neither means that the data is wrong or that it is right, it may simply mean that there are outliers to general trends in survival time that must be considered when providing determinations of survival time either in a clinical or medicolegal context. Even given these facts, there are still limitations to what one can and cannot say about life expectancy in an individual in a LLNS. Appropriately conducted survival time estimates must consider the historical record for past and current risk factors for medical morbidity, as well as, the frequency, type and severity of all infections and complications documented post-injury. Risk factors for medical morbidity such as significant swallowing dysfunction and risk for aspiration, poor oral secretion control, absent or severely diminished gag or cough reflex, significant myostatic contractures and/or severe spasticity all decrease median survival time in and of themselves as related to their correlation with morbidity and therefore mortality. Another factor to analyze is the temporal relationship of illness to injury, that is, whether the examinee is more or less medically stable over time. The quality of care has historically been used as a justification for placement in

specialized and expensive programs, however, existing data does not seem to support that the type, intensity, training of staff providing care and location, among other determinants impacts on morbidity and mortality risk factors. Another very important factor is the individual's relative degree of immobility and the implications for cardiopulmonary, gastrointestinal, musculoskeletal, and genitourinary morbidity and/or mortality. Neurologic deterioration over time is clearly a strong predictor and harbinger for a shorter than longer life expectancy. At the most severe end of the disability spectrum, the permanent vegetative state (PVS), life expectancy has been shown to be at most 12 years without significant sex differences.<sup>40</sup> Persons in MCS seem to have a similar albeit maybe slightly longer life expectancy. A study of infants who were immobile and in the MCS ("IMCS") found that their survival was only slightly better than those in PVS.<sup>41</sup> Thus, once again, mobility is seen to be a more important predictor of survival than cognitive function. An analysis of 2,534 children and adults who were in MCS produced parallel findings.<sup>42</sup>

### **Practical issues in dealing with the patient and family**

The catastrophic nature of a severe brain injury presents unique and profound challenges and consequences to the patient and family. Clinicians and trial lawyers must be sensitive to these consequences.

Professionals cannot act in a vacuum, but instead, must be ready to address the concerns and questions of the patient and family. When someone suffers a severe traumatic brain injury, it is only natural for the patient and family to turn to the professionals around them for support and advice. The empathy and counsel provided by the clinician and trial lawyer may be an invaluable source of support and comfort to these individuals. In the time frame immediately after someone suffers a severe brain injury, the family typically experiences a range of emotions, usually shock and disbelief initially, followed by anger and denial. During this period of time, it is especially difficult for the family to act and think clearly. At this stage, usually no lawyer has been contacted, so the clinician is the professional to whom the family generally turns for advice. It is important that the clinician be direct and candid with the family about the patient's diagnosis and prognosis. The clinician should not be overly optimistic or pessimistic. In many instances, especially with comatose patients, the clinician is unable to make an early prognosis, and it should be fully explained to the family why it may take some time before a more accurate prognosis can be made. Only with full and accurate information can the family properly assess the many issues they will later face. Typically, it is after the immediate medical concerns have been addressed that the family seeks a trial lawyer to represent the patient in any tort litigation. If the patient is expected to be unable to manage his or her affairs for an extended period of time, which is not uncommon after severe TBI, the trial lawyer should quickly take steps to have the patient adjudicated as incompetent and have a legal fiduciary appointed. Only the duly appointed fiduciary has the authority to actually engage the trial lawyer to represent the incompetent person. Additionally, the fiduciary may serve as the patient's surrogate for other purposes, such as handling financial transactions, entering into agreements, initiating lawsuits, and, most importantly, making medical decisions. In advising the family about the appointment of a legal fiduciary, the trial lawyer should have a thorough understanding of the applicable right to die and related statutes.

The trial lawyer who is hired to handle the patient's tort litigation must know where to direct the family for a host of other legal issues. These issues include, for example, the claims for benefits from Workers' Compensation, Social Security, disability insurance, Medicaid, Medicare, and health insurance. The family of a patient with severe TBI usually needs someone to quarterback the myriad of legal needs they face, and usually the individual best suited for that position is the trial lawyer. As quarterback, the trial lawyer may not handle any of these issues, but should know where to refer the family for assistance. In the situation where the patient has been in a vegetative state for a prolonged period, the lawyer should be prepared to fully educate the family about the applicable right to die statutes. Although the trial lawyer has been hired to handle the tort case, he cannot disregard the issue of his client's right to die. The trial lawyer has a duty to represent the best interests of his client. Consequently, even though the value of the tort case may likely decrease if the client dies before trial, the trial lawyer should explain to the family that the client's living will or advance directive to withhold or withdraw medical treatment should be honored, in conformity with the applicable law. Often in cases of severe TBI, the patient's family members have basic disagreements about the patient's level of medical care and right to die. In such instances, the clinician and trial lawyer must consistently act in the patient's best interests and be careful not to choose sides. Many statutes, such as Virginia Code §54.1-2986, actually specify an order of priority of persons who may act as the patient's surrogate for decisions regarding withholding or withdrawing medical treatment in situations where the



patient has not made an advance directive regarding their right to die. Since Virginia's statute lists the patient's guardian or committee as the first person in this priority list, the family should be made aware of this right to die statute when the guardian is first appointed. The family members of a vegetative or MCS patient endure a tremendous amount of stress. It is often helpful for these individuals to seek professional counseling to help them cope with this stress. While the counselors are the professionals who are directly assisting these individuals in dealing with the ordeal, the clinician and trial lawyer may also help the family by providing clear, frank and candid responses to their questions. Even though such responses may be pessimistic and not what the family wants to hear, in the long run, the family is best served by learning the truth about their loved one's condition. The death of a loved one may result in a variety of emotions felt by the family, ranging from emptiness to relief. In this emotional period following death, the family typically must face a number of legal issues which arise as a result of the death. It is not uncommon for the family to turn to the trial lawyer for advice on these legal issues, which may include: the survival of the tort action, probate of the estate, obtaining the benefits of life insurance, and the tax consequences of the patient's death. The trial lawyer again should be prepared to refer the family to other professionals who can assist them with these issues. The professional who is attuned to, and prepared to deal with, the many practical questions and concerns of the patient and family may be an invaluable asset to these individuals whose lives have been altered by a severe traumatic brain injury. Additionally, such attention on the part of the clinician and trial lawyer may lead to a professional relationship with the patient and family which proves rewarding for all involved.

***Often in cases of severe TBI, the patient's family members have basic disagreements about the patient's level of medical care and right to die. In such instances, the clinician and trial lawyer must consistently act in the patient's best interests and be careful not to choose sides.***

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#### **Determining future medical, vocational and lifetime needs**

Perhaps the most important and challenging task facing clinicians and trial lawyers dealing with those who have suffered severe brain injuries is the determination of the future needs of such persons. Most individuals who have suffered a severe brain injury have significant and devastating deficits which have shattered or greatly altered their lives. There are a myriad of needs and expenses which such persons and their families will undoubtedly face. It is incumbent on the clinician and trial lawyer to utilize a team approach to determine these needs and expenses, obtaining input from the client's family, employer, healthcare providers, as well as a life care planner, vocational consultant, and other professionals. Some persons who have suffered a severe brain injury will display early signs of potential for recovery and, with aggressive treatment, may be able to return to an independent lifestyle and gainful employment. Even though such individuals may achieve impressive recoveries, they may still also be a valuable resource to the trial lawyer in developing a life care plan (LCP). The LCP should outline all future care that can be stated to be medically likely to be needed, along with the frequency and projected costs of such treatment. For the vegetative or minimally conscious patient, there may be little or no chance to return to an independent functional status. These persons require daily care-taking, which is often tedious and intensive. They also are at risk for numerous complications, such as infections, skin breakdowns, and contractures. The future medical needs of these patients are enormous. In order to fully present these future needs at trial, it is almost always necessary to have an experienced case manager present a systematic compilation of such needs. Many lawyers now also require that a physician review such life care plans to endorse the proposed plan as both consistent with what is medically probable for that particular patient and also to endorse that all recommendations made were indeed medically appropriate given the neuromedical and functional status of the patient. A large number of persons who have suffered severe TBI require placement in a long term care facility. Among the options available to the severe TBI patient are assisted living programs, community-based residential programs, subacute programs and skilled nursing facilities. The placement

option chosen will be dependent upon the functional level of the patient. For example, someone in a permanent vegetative state would not generally be considered a viable candidate for an assisted living program. One should be aware, however, that there is a growing trend towards community based placements of such individuals, as well as, others in LLNSs with evidence that such care can provide for a better quality environment with lower long term payor costs and accrued medical morbidity. On the other end of the spectrum, a patient who is ambulatory but not functionally independent due to cognitive and/or behavioral impairments should not be “housed” in a nursing home but rather considered for an assisted living or a community based residential program. Some of the factors to consider in analyzing the appropriateness of the specific placement include: physician and/or staff coverage and experience with similar type patients; proximity to needed ancillary services; reputation and track record of facility; and proximity to patient’s family and significant others. The cost of the long term care is typically the largest component of the life care plan. The clinician, any expert witnesses and trial lawyer must be prepared to explain at trial why the option chosen makes sense for the patient and that there are not other more cost efficient alternatives available. We discourage analyzing such placement needs based on cost issues alone as specialized care is generally more

***The trial lawyer must be cognizant of the future problems facing such patients in order to fully present the patient’s damages at trial.***

have significant physical (e.g., paralysis, ataxia), cognitive and emotional sequelae as a result of their injuries. Certainly this is understandable for a person who has suffered a substantial brain injury. A sampling of some of the problems that have been seen in those who have achieved significant recoveries after severe brain injuries include: seizure disorders (sometimes requiring lifetime medication); loss or disruption of smell and taste; disturbances of vision or hearing; speech disorders; problems with memory; concentration and attention; and emotional problems (sometimes so severe that they are disabling in and of themselves). Obviously, problems such as these can result in enormous future medical expenses, lost wages, and loss of earning capacity. The trial lawyer must be cognizant of the future problems facing such patients in order to fully present the patient’s damages at trial. Neuropsychological evaluation is typically necessary to identify the cognitive and emotional impairments of the patient. Additionally, it is usually helpful, if not essential, for the trial lawyer to employ the services of a case manager and/or life care planner. The case manager can coordinate the difficult process of health care follow-along as well as serve as a primary resource for the injured person and their family. An experienced case manager may be more expensive than non-specialized care. There is a wide continuum of vocational rehabilitation programs for patients after severe TBI assuming they recover enough to be considered a candidate for such programs. These include sheltered workshops, supported employment, work hardening programs, selective competitive employment, and part-time, as well as, full-time competitive employment. An experienced vocational expert can assist the trial lawyer and clinician in identifying the best approach for the patient, the estimated length of time of the rehabilitation, and the projected outcome. The trial lawyer may also employ an economist to quantify the future lost wages and loss of earning capacity of the patient. Persons who have suffered severe brain injuries usually have future medical, vocational and lifetime expenses and/or losses that are more financially staggering than most people would expect. In order to fully present both the current and future damages at trial, the jury must be sufficiently educated about the injury and its myriad consequences and motivated to return a verdict sufficient to adequately compensate the injured person. This process requires testimony not only by the expert witnesses, but perhaps even more importantly, by the lay witnesses who lived and/or worked day to day with the injured person preinjury and can therefore compare and contrast the person’s life post-injury with their pre-injury status.

**Ethical and moral dilemmas**

When someone suffers a catastrophic brain injury, there are tremendous consequences not only to the patient, but also to the family, the healthcare providers, and many others who have a connection to the patient. Hopelessness, futility, and despair are common emotions felt by these persons. In this framework, ethical and moral dilemmas abound. There is a wide spectrum of recovery after severe brain injury, ranging from the person who substantially regains his or her pre-morbid level of functioning to the person who has remains in a VS or dies. Moreover, predicting outcome after traumatic brain injury can be difficult. The authors have seen patients whose recoveries far exceeded what any clinicians had expected. Consequently,

extreme caution should be followed by those considering quality of life and right to die issues. One's quality of life is a personal and subjective determination. Obviously, the patient's awareness of his environment is a key factor in this determination. In patients in permanent vegetative state, questions arise on both personal and societal levels. Should the patient be kept alive by artificial means or be allowed to die? Does it make sense to continue to provide the enormous costs necessary to keep the patient alive or should our limited societal resources be used for others who have a better medical and functional prognosis? Such questions have even come up in legal challenges involving patients in MCS, where there is clearly more ethical debate in the medical community at large regarding issues of medical futility. One significant area of debate in VS cases is often whether or not a patient should be made a "DNR" (do not resuscitate) and if so, when. There actually exists a continuum of medical orders which will and/or could result in death to the patient in VS: (1) do not resuscitate orders ("DNR"); (2) withholding medical treatment such as antibiotics or surgery; (3) removing a feeding tube; (4) removing from a respirator; and (5) withholding or withdrawing other life sustaining care. Some have argued on the ethical differences between withholding versus withdrawing care, noting that withdrawing care reaches a greater level of potential moral and ethical compromise than that of withholding care. The decision to take such actions, first and foremost, belongs to the patient, and if the patient is incapable of making an informed decision, or had no advance directive, then to his surrogate, usually his family. Most states have laws regarding one's right to die based upon the person's autonomy, in which living wills or advance directives are recognized as valid. If the patient does not have a living will or advance directive, then any decision to withhold or withdraw medical treatment is based upon the patient's previously expressed preferences. Most states further provide that the attending physician may withhold or withdraw medical treatment upon compliance with the applicable state law and the proper authorization of the patient's surrogate. In Virginia, Va. Code §54.1-2986 enumerates an order of priority of persons who may be such surrogate, beginning with the patient's guardian or committee and then to the patient's next of kin. The Virginia statute dictates that where the patient has not previously expressed a preference regarding withholding or withdrawing medical treatment, the surrogate "shall (i) prior to giving consent, make a good faith effort to ascertain the risks and benefits of and alternatives to the treatment and the religious beliefs and basic values of the patient receiving treatment... and (ii) base his decision on the patient's religious beliefs and basic values and any preferences previously expressed by the patient regarding such treatment to the extent they are known, and if unknown or unclear, on the patient's best interests."<sup>43</sup> Virginia's Durable Do Not Resuscitate Order Statute<sup>44</sup> provides, among other things, that a physician may issue a durable do not resuscitate order "for his patient with whom he has a *bona fide* physician/patient relationship as defined in the guidelines of the Board of Medicine, and only with the consent of the patient or, if the patient is a minor or is otherwise incapable of making an informed decision regarding consent for such an order, upon the request of and with the consent of the person authorized to consent on the patient's behalf." In *Cruzan v. Director, Missouri Department of Health*,<sup>45</sup> the U.S. Supreme Court stated that a person has a constitutionally protected right to refuse lifesaving medical care, including hydration and nutrition. With regard to an incompetent person, such as Nancy Cruzan who was presumptively in a vegetative state (although experts on the two sides debated this), the State of Missouri had a statutory scheme which allowed a surrogate to elect to withdraw hydration and nutrition and thus cause death upon clear and convincing proof that such withdrawal was what the incompetent desired. The Supreme Court upheld the statute as constitutional in a case where the surrogates, Nancy Cruzan's parents, requested withdrawal of hydration and nutrition, but failed to meet the clear and convincing standard embodied in the Missouri statute. In a dissenting opinion, Justice Brennan argued that the incompetent should not have such "improperly biased procedural obstacles" preventing her from dying with dignity.<sup>46</sup> He pointed out that "Missouri is virtually the only state to have fashioned a rule that lessens the likelihood of accurate determinations" because of its heightened evidentiary standard.<sup>47</sup> Virginia, like most of the states, has a statute which does not contain a heightened evidentiary standard such as Missouri's statute, which was the subject of *Cruzan*. Rather, Virginia's statute simply provides the surrogate shall "make a good faith effort" in analyzing the factors enumerated in the statute.<sup>48</sup> The statute further provides that anyone may petition the court to enjoin the withdrawal of medical care "upon finding by a preponderance of the evidence that the action is not lawfully authorized by this article or by other state or federal law."<sup>49</sup> In two 1997 cases, *Washington v. Glucksberg*<sup>50</sup> and *Vacco v. Ouill*,<sup>51</sup> the U.S. Supreme Court held that state statutes banning assisted suicide are constitutional. In both cases, Chief Justice Rehnquist, citing *Cruzan*, emphasized that there was a "distinction between letting a patient die and making that patient die,"<sup>52</sup> (*i.e.*, echoing the prior distinction raised in this paper regarding withholding versus withdrawing care). Although a constitutionally protected framework exists in most

states for the patient's family to elect to withdraw medical care of patient who is deemed incompetent, it is still extremely difficult for the family to make such an election. The family often cannot emotionally accept the futility of the situation even if they intellectually understand it. This may be true even where the family has been previously told by the patient that he or she would want to be allowed to die if in a vegetative condition. The conflict experienced by the family may be immense. There may be disagreement among family members regarding termination of treatment. Many states, including Virginia, set forth a priority of persons, based upon kinship, who have the authority to make the decision. Nonetheless, as a practical matter, even if the ultimate decision maker wants to terminate treatment, he or she will often defer to those other family members who do not want to terminate treatment. In one highly publicized case in Virginia, *Gilmore v. Finn*,<sup>53</sup> Governor James Gilmore actually filed a petition to enjoin the withdrawal of hydration and nutrition to a patient in a vegetative condition where there was disagreement between the patient's wife and guardian and the patient's parents and sibling regarding whether the patient should be allowed to die. Ultimately, the court held that while the Governor had the right to intervene in the case in order to seek an "authoritative construction" of Virginia's right to die statute, the patient's wife and guardian indeed had the authority to direct her husband's physicians to withdraw hydration and nutrition for him since she was the first person in priority as enumerated in Virginia Code §54.1- 2986.<sup>54</sup> In the context of the dilemmas which arise in such cases, the clinician should be honest and direct in conveying diagnostic and prognostic information to the family. If the physician is not comfortable providing such information, then an adequately qualified professional should be consulted. Likewise, the trial lawyer, too, should be forthright in his discussions with the family about the legal directives which are in place. At the same time, both the clinician and trial lawyer must be sensitive to the family's emotional needs and dynamics.

## **Conclusion**

Professionals and families dealing with individuals in prolonged VS following severe brain injury are faced with many issues, including but not limited to, withdrawal and withholding of care, as well as, ethicolegal aspects of long term care.<sup>55</sup> We can only broach these issues if we have a full and collective understanding of the issues at hand, including a commitment to (a) continue efforts at researching better ways to manage such patients, and (b) developing methodologies to explore novel treatment approaches to facilitate emergence from VS. The field of rehabilitation has clearly made critical contributions to the care of this special population including development of neurobehavioral assessment measures, formulation of interventions to decrease morbidity and coordination of life care planning. The rehabilitation community strongly encourages all clinicians and trial lawyers to advocate for consensus regarding guidelines for diagnosis, prognosis and treatment of patients in coma, VS and MCS. Without involvement of all relevant parties in the process of guideline development, one runs the risk of adversely effecting the quality of health care service provided to this sector of patients. Multidisciplinary research efforts sponsored and endorsed by the major medical organizations (AAPM&R, AAN, AANS) should be encouraged. Ultimately, society's best interests would be served through more intensive collaborative efforts directed at promoting our understanding of the pathophysiology, diagnosis and treatment of vegetative state, regardless of its duration. Clearly, the experience of both authors is that the earlier well versed clinicians and lawyers become involved with patients following catastrophic brain injury, regardless of their ultimate level of functional outcome, the better off the patient, as well as, their family will be. Trial lawyers must be familiar with the standard of practice as germane to treatment of this special population of survivors of severe brain injury (including issues of potentially withholding and withdrawal of care where appropriate). They must ultimately have an intimate medicolegal understanding of the injury etiology, long term needs, and prognosis to best advocate for their client's case. Lastly, an understanding of the legal and medical ethics germane to working with patients in LLNSs and their families is crucial to optimize communication, as well as, adequately protect client interests.

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Lawyers involved in neurolitigation should also be aware of these patient and family resources:

Brain Injury Association of Virginia

3212 Cutshaw Avenue, Suite 315

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(804) 355-5748 or 1-800-334-8443

email [info@biav.net](mailto:info@biav.net)

Brain Injury Association of America

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