Family Practice Grand Rounds

Severe Cerebral Injury and Brain Death: Management of the Patient's Family

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DR. LANYARD DIAL *(Fellow, Department of Family Practice)*: The discussion today will focus on difficult issues surrounding management of patients with severe cerebral injury. Specifically, the discussion will concern management of the patient's family. When patients are deeply comatose and not expected to survive or are brain dead, their families are often cast into a unique form of grieving. Dr. Horton will present the case.

DR. LYNN HORTON *(Second-year resident in Family Practice)*: A 32-year-old right-handed woman was admitted to the hospital because of a severe head injury. She had been well until the night of admission when, driving at speeds of 80 to 90 miles an hour, her vehicle overturned. She was thrown from the car and was rendered immediately unconscious. She was transported to this institution by ambulance.

She had not been hospitalized previously and had not undergone surgery. She was married and successfully employed in the motion picture industry, and was, according to her husband, intermittently habituated to intravenous narcotics.

Physical examination disclosed a deeply comatose woman. The blood pressure was 150/80 mmHg, the pulse was 80/min, the respirations regular at 16/min. The extremities were warm. Examination of the head and neck disclosed bloody drainage from the left ear. There was a large, profusely bleeding stellate laceration over the right occiput. Periosteum was visible through the wound, and there was a palpable fracture line. Other than a small ecchymosis over the upper midsternum, the chest appeared normal. Examination of the skin showed multiple needle track marks in both antecubital fossae. Cardiac examination was normal. The pulses were full and symmetrical. The abdomen was scaphoid without masses or organomegaly.

Neurological examination disclosed that the patient was deeply comatose, but responded to painful stimuli by the presence of myoclonic jerks. There was no decorticate or decerebrate posturing. The extremities were flaccid. The pupils were equal, 5 mm, and fixed. Corneal reflexes were absent, as were oculocephalic reflexes. Deep tendon reflexes were 1+ at the knees and ankles but unobtainable at the biceps. There were bilateral Babinski signs, and with stimulation there was withdrawal of the left foot. Funduscopic examination revealed a blurred disc on the right with retinal hemorrhages bilaterally. A cough reflex was present.

Immediately on admission large-bore intravenous catheters were placed but volume resuscitation was minimized. Findings on portable x-ray films of the cervical spine were normal. A nasotracheal tube was placed, and following this, a nasogastric tube and Foley catheter. A portable

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chest x-ray film showed satisfactory position of the endotracheal tube and was otherwise interpreted as normal. The white cell count was 28 × $10^3/\mu L$ and the hematocrit was 46 percent. The electrolytes were normal. Creatinine was 0.8 mg/dL. The SGOT was 118 U/L and the SGPT was 94 U/L. Blood alcohol was 98 mg/dL. Glucose levels were normal. An electrocardiogram was within normal limits. A computerized tomographic (CT) study of the brain revealed a fracture of the left occipital bone. There was no definite midline shift. A hemorrhagic density was present in the right frontal lobe, though no definite subdural or epidural collections were noted.

The patient was placed on a ventilator and hyperventilated to achieve a carbon dioxide (PCO_2) reading of 24 mmHg, which yielded a pH of 7.46 with a satisfactory oxygen (PO_2) level. The occipital laceration was irrigated and repaired, and penicillin was begun by vein.

Within four hours of admission, the rectal temperature increased to 104° F. Associated with the rise in temperature was a progressive increase in the diastolic blood pressure to 120 mmHg. Within 12 hours of admission, the temperature began to fluctuate markedly, dropping as low as 95° F rectally, and the blood pressure rose and fell precipitously. Fourteen hours following admission, the blood pressure fell to 70/50 mmHg associated with a sinus tachycardia. The central venous pressure was 3 cm of water. A dopamine infusion was begun. The hemoglobin was noted to have declined by 6 g/dL. The physical examination and repeat CT scan were unchanged.

Thirty-six hours following admission the neurologic examination revealed that the patient was deeply comatose. There were occasional spontaneous myoclonic jerks. The pupils were fixed in midposition with no spontaneous movement. Corneal reflexes were absent, as were the oculocephalic and oculovestibular reflexes. No cough or gag reflex could be elicited. A Battle sign was present on the left. There were flaccid paresis of the lower extremities and symmetric myotactic reflexes in the upper extremities. There were no abdominal reflexes. Funduscopy revealed hemorrhages bilaterally. There was occasional withdrawal of the left foot with stimulation. No Babinski signs or clonus was elicited. Serum potassium was maintained at a low normal level, central venous pressure at 5 cm of water, urinary output at 0.3 to 0.5 cc/kg/h. The PCO_2 was maintained below 30 mmHg with the pH between 7.4 to 7.5. The hematocrit was maintained at 38 percent. On the morning of the third hospital day, neurologic examination showed areflexia, and there were no efforts at spontaneous respirations. A diagnosis of clinical brain death was made. The patient's extended family rejected the advice of discontinuance of life support. On the fourth hospital day an electroencephalogram (EEG) was isoelectric. On the sixth hospital day a repeat EEG was unchanged. On the seventh hospital day, the patient's family accepted a recommendation of discontinuation of life support. The ventilator was removed and asystole occurred shortly thereafter.

DR. DIAL: Thank you, Dr. Horton. We have asked Dr. Moustapha Abou-Samra to discuss his experience in the management of such patients' families. We have also asked Dr. Ronald Bale to comment from his perspective.

DR. MOUSTAPHA ABOU-SAMRA *(Consulting Neurosurgeon, Ventura County Medical Center)*: This clinical case presentation exemplifies the problems faced when managing patients with severe brain injury who become brain dead. Very frequently such injuries involve young and otherwise perfectly healthy individuals. Always it is a tragic situation. Occasionally, the patient's family is not, prior to the accident, in close contact with the patient. These factors play very significant roles in the family's reaction and behavior after such an injury.

The physician's duties are divided into two components: first, to the patient, and second, to the family. As far as the patient is concerned, the physician must know exactly the circumstances of the injury and its extent. Drug overdose must be excluded as a contributing cause of coma. Further, the physician must have a very clear understanding of brain death. Briefly, brain death represents the cessation of all functions of the brain.[1] This state can be confirmed by clinical examination and by electroencephalography. The electrical indication of brain death is an isoelectric EEG, and clinical indications include the following: (1) complete coma, (2) fixed and nonreactive pupils, (3) absent oculocephalic and vestibular reflexes, (4) absent corneal reflexes, (5) absent cough reflexes, and (6) complete apnea. Brain death can also be con-

firmed by the cessation of cerebral perfusion as demonstrated by radionuclear flow study or arteriography.

One of the critical criteria for determining brain death is to allow an interval of time between examinations, most commonly 12 hours, to confirm that the clinical findings have remained unchanged. Once the findings have been firmly established, the patient may be pronounced brain dead. In California, a clinically brain dead patient is considered legally dead, and EEGs are not required, though at times they may be helpful.

Thus we come to the second aspect of our responsibility: management of the family. First, explain to the family in no uncertain terms that the patient has no remaining brain function despite all monitors indicating normal heart function. Second, do not under any circumstances hedge, give false hope, or allow the family to expect miracles once the determination of brain death is made. Third, do not offer the family choices, such as agreement to a nonresuscitation order, or options with respect to continuing medication regimens, as these are medical decisions that do not require consent from the family. Certainly if a family member is given an option, it only serves to inhibit their understanding the concept of brain death.

The next point is to recognize that at least initially the family does not hear or appreciate the full impact of the diagnosis. Therefore, plan on returning and discussing further the fact that the patient is, indeed, brain dead. If there are many family members available, select one or two people with whom to carry out the discussion and formulate plans. Identify an intelligent person who is able to communicate with the rest of the family and who does not seem completely overwhelmed by the tragic occurrence. Finally, it is very helpful if only one physician discusses issues with the family. With the threatened loss of loved ones, families will often be vigilant for signs of hope and may detect even subtle differences between one physician's explanation and another's. These nuances may be interpreted by surviving family members that there exists differences of opinion with respect to prognosis.

DR. RON BALE *(Clinical Psychologist, Department of Family Practice)*: I have been asked to comment on the psychological factors involved in this case. There is very little written in the medical literature that addresses the psychological issue; most of the published work concerns the debate over what constitutes death. This debate seems to have been resolved fairly well by the Harvard criteria that were described in 1968.[2] It is interesting to note, however, that despite a relatively concrete presentation of the Harvard criteria, there is still a considerable amount of disagreement as to when to discontinue life support. The results of a poll of a group of neurosurgical residents and faculty at the University of Pittsburgh School of Medicine revealed a lack of consensus as to when one should discontinue life support and how this is managed in the context of the patient's family.[3] There was also considerable disagreement as to the nature of consultation one would require prior to making a final decision.

The first thing to consider is that when you are dealing with the family, they become your new "patient." Your responsibility is to help the family come to grips with the situation and manage their anxiety. The sudden, unexpected loss of a relative who hours earlier was a healthy, viable, functioning person is extremely traumatic and anxiety provoking. Anything that you can do to alleviate anxiety and uncertainty will help to restore family members to their premorbid level of functioning. As you would with any patient, it is important to assess such factors as intellectual capacity and socioeconomic status, which will help achieve a sense of their sophistication and capacity to understand what you have to say. The family's cultural and religious background will give a clue as to their expectations and resources available to them.

Most people are unfamiliar with the concept of "brain death." Death is usually conceptualized in traditional cardiovascular or respiratory dimensions. To the nonmedically trained person, the sight of a loved one lying in bed with good color and respiratory movements and the cardiac monitors emitting their regular and reassuring beeping, all represent a "live patient." To tell a family member that their loved one is dead, despite this overwhelming visual, auditory, and even tactile evidence to the contrary, is to give them data that do not compute. Superimpose this on the overwhelming wish that the loved one not die, and the result is a feeling of disbelief and psychological

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denial. It is important to keep in mind that the family is in an alien environment. They are in a hospital, which may be very comfortable and familiar to you as the physician, but the various tubes, monitors, and equipment create an environment with which they are totally unfamiliar. This environment serves to further aggravate any anxiety already present.

There are principles in managing anxiety that are useful in managing a victim's family. When in an anxiety state, a person perceives his environment differently than he would when in a state of calm. People will not be able to grasp and incorporate large amounts of information while anxious. Provide smaller bits of information and do your best to maintain patience. Cases such as the one presented today tend to engender a feeling of helplessness in professional staffs, and it is very easy to displace that onto the family in the form of impatience or abruptness.

Regarding the state of grief, there is characteristically an initial stage of shock, or disbelief, followed by a period of "numbed reaction," which may manifest itself either by complete immobility or a rather mechanical attending to details. This stage is usually followed by open anguish as the numbness wears off. It is common for some to experience feelings of rage during the grief process; as the authority figure, some of the rage may be directed toward you. It is extremely important to not personalize this response. How the grief manifests itself is often culturally based. Some cultures allow and, in fact, insist on open and rather vocal displays of anguish, while others pride themselves in their stoicism.

It is important to not give up your responsibility as the skilled medical expert when engaging the family in decision making. It is bad judgment to allow the family to have a "vote" in major medical decisions. This is not a time for diagnosis or treatment by democratic action.

DR. DIAL: Dr. Prichard, you were involved, along with the house staff, in the management of this patient. Would you comment on the family's concerns and management difficulties.

DR. JOHN G. PRICHARD *(Assistant Director, Medical Education)*: Many of the thoughtful comments by Dr. Abou-Samra and Dr. Bale pertained in this case. On the night of admission, the patient's family was informed that the prognosis was grave. Over the next two days, her neurological condition deteriorated, and on the third hospital day it was clear that she had cessation of all brain activity. It was four days after brain death occurred that her extended family was able to accept the diagnosis and life support was withdrawn.

Many of the members in this extended family came to the hospital from long distances. They varied in age, level of medical sophistication, and religious perspectives. The patient's husband knew of her drug use, but others did not. Confounding the loss was the nature of the accident, perhaps a nagging suspicion of suicide, and that the patient appeared uninjured apart from the bandage about her head.

During the four days following brain death, the patient's family questioned house staff, nurses, and consultants about the significance of each change in vital signs and the persisting spinal reflexes. They waited with hopeful countenances and would measure carefully each of the physician's words. Despite unchanging pronouncements, the family trusted that tomorrow would bring some improvement.

It was evident that we were dealing with massive denial, which serves a number of purposes for survivors.[4] The major risk in management at this point was to ignore the denial with the potential of alienating the patient's survivors and having them view us in some way other than helpful, caring, or competent. Our approach was fundamentally one of empathy and support while maintaining the certainty that the patient was, in fact, dead. We assumed that the denial, once no longer essential, would give way to acceptance and active grieving.

The nursing and medical staff purposefully expressed interest in the patient's personality and life achievements. She was referred to by name, and the family was reassured that she was not suffering. Importantly, their own loss was verbally acknowledged. By keeping them informed and predicting changes in clinical status before they occurred, we maintained their confidence. I would emphasize that nursing staff clearly have much more contact with these patients' families than do physicians. To manage these difficult cases properly, communication between physicians and nurses must be ongoing and detailed. All of the individuals caring for this patient and her family

had a clear understanding of the diagnosis and its intended course of management.

The seemingly long interval between clinical brain death and removal of life support was essential to the management of this family. Brain death was not viewed as an emergency; the natural history of the survivor's adaptation to a tragic situation was not impeded to suit our needs.

DR. DIAL: We need to remain cognizant of our own feelings concerning loss of these young patients and our own feelings toward brain death.[5] For the physician, the difficult task of communicating with these patients' families can become less anxiety provoking and more effective as one gains experience and refines skills. Finally a scheduled follow-up appointment with the patient's survivors may be helpful. At that time, unanswered questions may be sought and the process of grieving assessed.[6]

In summary, the principle is to conceptualize the family as your new patient. One must do an assessment of them as you would on evaluating any new patient. The psychological phenomena most often encountered include shock, denial, and grief. Typically feelings of rage and helplessness are involved, and it is crucial not to take the expressions of these feelings personally. It is important to communicate with families in a concise, simple, and consistent manner. Do nothing to give hope where there is room for none. The factors that contribute to successful management are empathetic professional staff, competent consultants, and appreciating the varied manner by which families adapt to tragic situations.

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