ETHICAL DILEMMAS IN THE NEUROLOGIC ICU: WITHDRAWING LIFE-SUPPORT MEASURES AFTER DEVASTATING BRAIN INJURY

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ABSTRACT

Withholding aggressive treatments and withdrawing life-support measures are common in patients with devastating acute brain injury. Yet, guiding families who make these decisions is often very challenging. Ethical questions arise when the level of care requested by the family does not agree with the prognosis estimated by the clinician. There is also concern that communicating a pessimistic prognosis to families might produce a self-fulfilling prophecy by leading to restriction of intensive care. Understanding the limitations of our prognostic information and the factors that influence the decision to withhold or withdraw care in the neurologic intensive care unit is crucial to ensure honest and effective communication with families.


Note: Text referenced in the Quintessentials Preferred Responses, which appear later in this issue, is indicated in yellow shading throughout this chapter.

Among the various ethical dilemmas neurointensivists must confront, perhaps none is as common and multifaceted as those presented by decisions to continue or withdraw life-sustaining interventions. Because the withdrawal of life support exemplifies some of the most complex ethical challenges in the neurologic intensive care unit (NICU), this chapter will focus on the clinical problem of withholding or withdrawing life support when further efforts to improve the outcome of a patient with severe brain illness are considered unlikely to achieve the goals of care.

Requesting withdrawal or withholding of life-support treatments is a right of patients, based in the ethical principle of autonomy. When patients lose decision-making capacity, as often happens with critical neurologic illness, their autonomy is not lost. Instead, their autonomy is (or can be) expressed by a surrogate decision maker, who is often a family member but can be anyone the patient has previously

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selected if done in accordance with state law. Families confronted with the prospect of a very unfavorable prognosis for meaningful functional recovery often choose to limit or withdraw treatment, including life-support treatments. As a consequence, withdrawal of life support is the most common immediate cause of death in the NICU (Diringer et al, 2001; Mayer and Kossoff, 1999; Zurasky et al, 2005).

Providing a prognosis is a fundamental role of neurologists attending critically ill neurologic patients. Families seek guidance from the neurologist to make decisions on the appropriateness of invasive procedures and life-sustaining measures. When a poor prognosis leads to limitations in the level of care or withdrawal of life support, it may create a self-fulfilling prophecy (Becker et al, 2001). In other words, prognosis may determine the fatal outcome.

This possibility is particularly concerning because prognosis in critical neurologic disease is rarely certain. For instance, indicators of unfavorable prognosis are known for the major forms of acute stroke, but their presence does not predict death invariably (Wijdicks and Rabinstein, 2004). Patients with several of these variables may survive, however, and even achieve acceptable functional recovery with moderate degrees of disability (Becker et al, 2001). Even some selected patients with massive ICH causing clinical and radiologic signs of herniation can have relatively favorable outcomes after emergency evacuation of the hematoma (Rabinstein et al, 2002). Only the combination of coma, loss of all pontomesencephalic reflexes, and absent response to pain is uniformly predictive of death in these patients (Rabinstein et al, 2002).

Similar uncertainties apply to other types of acute stroke. However, there are a few exceptions. Massive pontine hemorrhages are almost invariably fatal (Wijdicks and St Louis, 1997). In patients with global brain anoxia after cardiac arrest, absent pupillary light and corneal reflexes plus absent motor response to pain 5 days after the anoxic insult, myoclonic status epilepticus, bilaterally absent cortical responses on somatosensory evoked potentials, and perhaps a very elevated level of serum neuron-specific enolase reliably indicate that coma will be irreversible (Wijdicks et al, 2006) (Appendix B). Conversely, prognosis in cases of traumatic brain injury is much less conclusive, especially in young patients (Hukkelhoven et al, 2003). Even older patients with traumatic brain injury can achieve favorable recovery when care is provided by a multidisciplinary team of specialists (Thompson et al, 2008).
The Risk of the Self-fulfilling Prophecy

Several studies have concluded that limitation of care is a major determinant of fatal outcome in patients with ICH (Becker et al, 2001; Hemphill et al, 2004; Zahuranec et al, 2007), irrespective of whether the limitations of care consist of withdrawal of life support (Becker et al, 2001) or do-not-resuscitate (DNR) orders (Hemphill et al, 2004), or a combination of both as a combined variable (Zahuranec et al, 2007). Hence, it has been contended that limitation of care leads to a self-fulfilling prophecy. Although studies have focused on ICH, a similar situation could apply to other forms of acute brain illness, such as ischemic stroke (in which hemicraniectomy can be lifesaving and allow relatively favorable functional outcomes in young patients) (Vahedi et al, 2007) and poor-grade subarachnoid hemorrhage (in which more aggressive care can result in good outcomes in selected patients) (Le Roux and Winn, 1999).

The matter becomes particularly concerning because the studies evaluating prognostic indicators in acute brain illnesses typically have not taken into account the effects of withdrawal or withholding life-sustaining treatment. In other words, the indicators of poor prognosis that we use in practice are based on studies in which the presence of those factors may have led to withdrawal of treatment rather than directly to death, which adversely influences the prognostic model. It is then possible that we are perpetuating a bias. The argument goes like this: We believe that comatose patients with large hematomas are not going to recover, and we are less aggressive in their management. Subsequently we collect information on a series of such patients and conclude that coma and large hematoma volume portend very high chances of fatal outcome. We then use these reported data to provide unwarrantedly pessimistic prognoses that lead families to decide to withhold or withdraw life-sustaining treatment in those patients.

A solution to this problem is hard to find. In order to obtain reliable information on the value of prognostic variables in a certain illness, we should be able to study a population of patients with the condition who are treated without restrictions regardless of the perceived prognosis. But performing such a study is not feasible in our society because of various social, ethical, and economic arguments, especially because it would override the principle of patient autonomy. Studies from countries where restriction of life-sustaining treatments is not practiced could be very valuable. In the meantime, we need to use the information we have but be mindful of its limitations (Rabinstein and Diringer, 2007).

There is, however, another aspect to this issue. Studies assessing the concept of self-fulfilling prophecy in ICH have used mortality as the primary end point (Becker et al, 2001; Hemphill et al, 2004; Zahuranec et al, 2007). In practice, most often the real question is not whether the patient can survive the acute neurologic insult, but whether survival could be compatible with a quality of life that would be acceptable to the patient. Withholding aggressive treatments or withdrawal of life-support measures is frequently requested when families are informed that survival is possible, but severe disability is almost certain. Thus, studies on prognostic indicators are flawed because of the bias created by the lack of control for restrictions of life-sustaining treatments. Yet, the studies arguing that limitations of life-sustaining treatments lead to a self-fulfilling prophecy are also suboptimal, as long as they do not consider the end point that matters most to patients and families: functional recovery.

KEY POINTS

- Limitation of care prompted by estimated poor prognosis may determine fatal outcome by causing a self-fulfilling prophecy.
- Studies evaluating prognostic indicators in acute brain illnesses have often failed to consider the impact of withdrawal or withholding of life-sustaining treatment.
- Studies concluding that limitation of care may lead to a self-fulfilling prophecy frequently used mortality rather than functional outcome as the main end point.
FACTORS INFLUENCING WITHDRAWAL OF LIFE-SUSTAINING TREATMENTS IN THE NEUROLOGIC INTENSIVE CARE UNIT

Particular characteristics in the NICU population differentiate withdrawal of life-sustaining treatments in the NICU from that taking place in other ICUs. Catastrophic neurologic injury tends to occur suddenly and lead to emergent institution of life-sustaining measures before prognosis can be ascertained or any consideration can be given to the wishes of the patient. In addition, the brain insult often causes severe neurologic deficits, but progression to death is unlikely unless medical care is restricted. Most patients become immediately incapable of making their own decisions, and families have to deal with the terrible news of the devastating disease of their loved ones and also decide on their behalf, with very little time to adjust to the situation, what level of care should be provided. Limited, but valuable, research is available on the factors that influence the decision to withdraw life-sustaining interventions in acutely ill neurologic patients. Mayer and Kossoff (1999) reported on 105 patients in their NICU, of whom 50 had a medical intervention withheld or withdrawn prior to death. Only 16% of these patients had written advance directives, and the decision to withhold or withdraw treatment was usually made by a close family member. There were no differences in age, gender, diagnosis, insurance status, or level of consciousness on admission (as measured by the Glasgow Coma Scale [GCS]) between patients for whom life-sustaining therapy was withdrawn and those who suffered cardiac death while receiving mechanical ventilation. The only significant difference between these two populations was that African American patients were less likely to undergo terminal extubation. As part of this study, 24 surrogate decision makers for patients who had life-sustaining therapy withdrawn completed a survey to ascertain what influenced their decision and how they felt about the decision some time later. Most respondents answered that unacceptable quality of life was one of the main factors that had influenced their decision. However, almost all of the respondents understood that the expected prognosis was death or persistent vegetative state rather than severe disability. Seventeen percent judged the timing of the initial discussion regarding withdrawal of life-sustaining treatments as premature, and 21% felt uncomfortable or guilty about the decision they had made, but only one respondent (4%) would not have made the same decision again.

Diringer and colleagues (2001) published an analysis of 2109 nonelective admissions to their NICU over 82 months. Of patients studied, 81% were functionally normal prior to admission. Life-sustaining therapy was withdrawn in 284 patients, including 35% of non-survivors. Older age, lower admission GCS score, subarachnoid hemorrhage, ischemic stroke, and higher Acute Physiology and Chronic Health Evaluation (APACHE) II probability of death were associated with increased likelihood of having life-sustaining therapy withdrawn. Conversely, African American patients and patients who had undergone a major surgical intervention were less likely to have such treatment discontinued. In this series, an additional 20% of patients died after having aggressive care restricted (do-not-resuscitate order).

An excellent study conducted by the Canadian Critical Care Trials Group evaluated 851 mechanically ventilated patients in 15 general ICUs across different countries, including 130 patients (15.3%) admitted with primary diagnosis of CNS disease (Cook et al, 2003). Nearly 20% of all patients had mechanical ventilation withdrawn; that...
is slightly over half of all patients who died in the ICU. Among the 300 patients with worst predicted outcome, the rate of withdrawal of mechanical ventilation was 36%. CNS disease was the disease category most commonly associated with withdrawal of mechanical ventilation, apart from cardiac arrest (anoxic encephalopathy). On multivariate analysis, the factors associated with withdrawal of mechanical ventilation were (in order of strength of association) the physician’s perception of the patient’s preference about use of life support, the physician’s prediction of the likelihood of patient’s survival in the ICU, use of inotropes or vasopressors, and the physician’s prediction of the patient’s cognitive function 1 month after discharge. Hence, the main determinants of withdrawal of mechanical ventilation were the perceived wishes of the patient and the prognosis of the physician rather than objective markers of illness severity or organ dysfunction.

Another study analyzed the impact of neurologic prognostication on the decision to withdraw life-sustaining therapies in comatose patients resuscitated after cardiac arrest (Geocadin et al, 2005). Most deaths (83%) occurred after withdrawal of life-sustaining therapies. The result of cortical evoked potentials was the factor most strongly correlated with the time until life-sustaining therapies were withdrawn.

These studies provide helpful insight into the complex factors that influence the decision to withdraw life support in critically ill patients in general and critical neurologic patients in particular. However, many other factors that could not be assessed in these studies may also be relevant, such as religious beliefs, level of education, cultural background, the institutional approach regarding aggressiveness of care of specific critical illnesses, and attitudes of family and physicians toward withdrawal of life-sustaining treatments (Curlin et al, 2007; Diringer et al, 2001; Hemphill et al, 2004; White et al, 2006; White et al, 2007).

**FUTILITY: AN EVASIVE CONCEPT**

The concept of futility has proven extremely difficult to define (Burns and Truog, 2007). In our daily practice, we tend to consider a treatment futile when it cannot improve the condition of the patient. It follows that such treatment should not be attempted and physicians should not have an ethical obligation to provide it. However, this approach is overly simplistic (Bernat, 2005). Is a treatment futile if it will only allow keeping the patient alive but permanently dependent on mechanical ventilation? The answer implies a judgment on quality of life, and it is, therefore, subjective. Furthermore, and even closer to our specialty, should we continue medical treatments in patients who are permanently unconscious? Some may feel it is inhumane to do so. Others strongly believe that physicians do not have the right to decide what quality of survival justifies continuation of unrestricted care.

Futility has been defined qualitatively as any treatment that merely preserves “permanent unconsciousness or fails to end a patient’s total dependence on intensive care” (Schneiderman et al, 1990). This qualitative definition is loaded with preconceptions. A quantitative definition has also been proposed that deems a treatment futile “when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of published empiric data) that in the last 100 similar cases the treatment has been useless” (Schneiderman et al, 1990). However, this quantitative definition has been criticized because it relies on probabilities and assumes that a treatment conferring chances of improvement lower than 1% is not worth pursuing.

Physiologic definitions of futility have also been problematic. Various
prognostic scores have been developed to grade the severity of illness in critical patients, but none has achieved the degree of certainty required to regard further treatment as futile (Helft et al, 2000). Treatment may be considered futile when it is ineffective in reversing the physiologic disturbance it should treat (Truog et al, 1992) (eg, mannitol can be considered futile in a patient with refractory intracranial hypertension), but for the most part this definition can only be applied to rapidly deteriorating patients whose demise is inevitable and imminent regardless of the intensity of treatment.

The concept of futility has often been confused with rationing of limited medical resources. The notion of futility should only focus on the chances that the treatment may help the patient; it should not consider economic cost. It was carefully stated by the Society of Critical Care Medicine Ethics Committee that “treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile.” Futility and rationing should remain separate concepts. Failure to make this distinction renders the motivation of the proponents of futility suspect.

As the concept of futility is not established with unquestionable solidity, its use to unilaterally force withdrawal of life-sustaining treatments should be avoided. Disputes regarding the appropriateness of aggressive treatments in specific cases typically result from breakdown in communication between health care providers and families (Fins and Solomon, 2001). Consequently, it is essential to do everything possible to optimize communication with families at every stage of the care of critically ill patients.

**COMMUNICATION WITH FAMILIES**

Discussing prognosis with families is one of the central roles of any neurologist caring for critically ill patients. Families expect the neurologist to provide a prognosis, even if uncertainties exist. Some families immediately understand their role as surrogate decision makers, while others have difficulty assuming this responsibility. But at the end, the decisions on whether to continue aggressive medical or surgical interventions or to withhold or withdraw treatments largely depend on their understanding of the diagnosis and most likely prognosis of the patient (Bernat, 2004; Curtis, 2004).

Written advance directives are too often unhelpful. They are typically worded in a manner that only applies to extreme situations (Rabinstein and Diringer, 2007). In the much more common scenario in which functional prognosis is very poor, but some degree of recovery is possible, advance directives do not always provide clear guidance. Moreover, documented advance directives are frequently not available. Their absence should not be considered an indication that the patient wanted aggressive medical treatment in all situations, as the proportion of people who prepare advance directives remains relatively small (Wijdicks and Rabinstein, 2007).

Surrogate decision makers need to be guided on how to make the decision on behalf of their loved one who is incapacitated (Bernat, 2004). They should be told in simple terms that they should always try to follow the patient’s wishes, whether expressed in writing or verbally. If the patient never made his or her wishes explicit, the surrogate (representing the family) should attempt to reproduce the decision the patient would have made in the current situation, by applying the knowledge of the patient’s values and preferences (doctrine of substituted judgment) (Bernat, 2004). If the value system of the patient is not known to the surrogate, the decisions on level of care have to be guided by
weighing the balance between anticipated benefits and burdens of the treatments available, keeping the focus on protecting the patient’s best interest (Bernat, 2004).

When communicating bad news to families, physicians should be honest and compassionate. Unless forced by the necessity to make emergent decisions (eg, endotracheal intubation in a patient who cannot protect the airway any longer), families should be helped to understand the gravity of the situation gradually. If the ICU team senses that the family is ambivalent or feels insecure about making the decision to withdraw life-sustaining therapies, it is advisable to continue full treatment until the family can overcome their doubts and reach the decision with conviction. Otherwise, the family may feel pressured to stop life support and start resisting the guidance of the health care team or resent it after the patient dies. Family conferences should not be rushed, and they should take place in adequate environments, such as quiet rooms or conference rooms specifically dedicated to this function. Understanding the complex dynamics at play between family members with different expectations is crucial to ensure fluent and productive communication (Wijdicks and Rabinstein, 2007). All points of view should be heard, and the physician should always attempt to convey a balanced message.

**INDIVIDUALIZED PROGNOSIS**

Prognostic uncertainties, the possibility of creating a self-fulfilling prophecy by conveying an unfavorable prognosis, studies showing that decisions to withdraw mechanical ventilation are often based on rather subjective measures, and the debate surrounding the concept of futility may discourage physicians from recommending or even accepting restrictions in the level of care. But, although prediction of outcome in most major acute brain illnesses is not absolutely certain, various prognosticators of poor outcome are well established by consistent findings across multiple studies and years of collective experience.

Studies addressing the possibility of self-fulfilling prophecy used mortality as the primary end point instead of functional outcome, which is the most relevant outcome for most people. Futility may defy a straightforward definition, but practitioners attending critically ill patients often encounter situations in which aggressive treatments are consistently unhelpful. Withdrawal of life support may not follow strict criteria founded on “hard data,” but respecting the patient’s wishes and incorporating the clinician’s perceived prognosis for the patient’s survival and functional outcome are appropriate attitudes.

When assessing a prognosis, the experienced clinician considers the patient integrally. Even the best statistical analysis may be insufficient to adjust for the combined and possibly synergistic effect produced by the coexistence of multiple indicators of poor outcome (ie, the actual severity of the prognosis of an elderly, comatose, chronically ill patient with a massive cerebral hematoma, intraventricular invasion, and obstructive hydrocephalus may not be adequately estimated by considering each poor prognostic factor in isolation). Good intensivists use the available data from published studies, acknowledging the persisting uncertainties, and incorporate their own experience to estimate a prognosis based on the medical condition of each patient. Then they advise the family, taking into consideration the patient’s preference with regard to level of care.

**Cases 1-1, 1-2, and 1-3** illustrate various situations that may be encountered in an NICU when communicating prognosis to the family of acutely ill neurologic patients. Although the severity and outcome of the cases differ,
Case 1-1

An 83-year-old man with history of labile hypertension, coronary artery disease (with recurrent myocardial infarctions treated with triple-vessel bypass surgery and subsequent stents for unstable angina), poorly controlled diabetes mellitus type 2, peripheral vascular claudication, and progressive cognitive decline was found obtunded by the nursing home staff and transported rapidly to the emergency department. Upon arrival, he was comatose, had a right dilated and unreactive pupil, extensor motor response on the right arm, and flexor response on the left (GCS sum score 5). He was tachycardic, hypertensive (204/100), and had irregular breathing pattern with borderline pulse oximetry. He was emergently intubated. His CT scan (Figure 1-1) showed an 80-cc hemorrhage in the right basal ganglia with 15-mm shift of the septum pellucidum, associated intraventricular hemorrhage, and incipient hydrocephalus from trapping of the left lateral ventricle. He was admitted to the NICU, where his blood pressure was controlled and his oxygenation optimized.

When his wife, son, and daughters were informed of the grave situation, they indicated that the patient had signed advance directives stating that he did not wish to be resuscitated or maintained alive by artificial means in case he did not have chances of recovery. As is often the case, the document was written without providing details on the degree of possible recovery considered acceptable to justify life-support measures. Nonetheless, all family members agreed that the patient’s quality of life had already declined substantially before the ICH and further functional impairment would have been unacceptable to him. The neurosurgeons discussed the option of surgical evacuation with the family, but it was mutually agreed not to proceed with an operation.

Full supportive care was continued for 24 hours because the family requested to wait for the arrival of additional relatives, but the patient failed to recover and his condition continued to worsen, as manifested by the presence of bilateral extensor responses to pain the following morning. The neurologist met again with the family and informed them of the unfavorable evolution. They requested withdrawal of life-support measures. The patient died within 3 hours of extubation.

Comment. This case illustrates a common scenario in the NICU. An elderly patient with multiple medical problems and previous substantial functional impairment is admitted with devastating acute brain disease. The unfavorable prognosis is immediately evident. In my experience, most families adopt a realistic position when approached honestly and compassionately. Although advance directives may be insufficient to guide the decision to withdraw life support, they provide helpful insight into the patient’s wishes. Conversation with families about the values and preferences of the patient, as in this case, is often invaluable, especially if the advance directive does not seem to adequately address the situation at hand.

FIGURE 1-1 Extensive right basal ganglia hemorrhage with regional mass effect and shift of the septum pellucidum (A) and intraventricular extension (B).
**Case 1-2**

A 56-year-old diabetic man with previous kidney–pancreas transplantation on long-term immunosuppression developed new headache, malaise, neck stiffness, and dizziness over 3 to 4 weeks. Upon admission to another hospital, he was febrile and soon became suddenly hemiparetic on the left side. CT scan of the brain performed at that time revealed multifocal infarctions. CSF had predominantly neutrophilic pleocytosis, and the patient was started on a broad regimen of antimicrobials, including antifungal agents. Nonetheless, the patient continued to worsen and became progressively less responsive. On examination at that time he was unresponsive to verbal stimuli, had right third nerve palsy, absent right corneal reflex, and left hemiplegia. MRI of the brain disclosed multiple infarctions, involving the right mid and upper brainstem and cerebral hemispheres. Transesophageal echocardiogram showed no vegetations. Catheter cerebral angiogram revealed changes suggestive of severe multifocal vasculitis. A sample from a sphenoid sinus biopsy contained abundant hyphae, and *Aspergillus fumigatus* grew from the cultures of the material. Despite aggressive antifungal therapy, the patient remained comatose and subsequently developed bilateral extensor posturing. Repeat CT scan showed massive hemorrhagic lesions with hydrocephalus (Figure 1-2).

The patient had no explicitly written advance directives, but he had appointed his wife as his health care proxy. On repeated meetings with the entire family, the unfavorable evolution and poor prognosis of the patient were discussed in detail. The family insisted that aggressive care be continued even after the massive brain hemorrhages had occurred. Although in the physician’s opinion further efforts were most likely futile, he respected the family’s decision while maintaining regular communication to help them understand the extreme severity and irreversibility of the patient’s brain injury. Soon it became clear that only the patient’s wife wanted to continue full care while the rest of the family favored comfort measures. A private meeting with the wife allowed her to reveal that she had promised her husband that she would always “fight to make him well.” Helping her understand that the situation in which she had made that promise years ago (before his transplantation) was profoundly different from the one she was confronting now led her to join the rest of the family in the request to withdraw life support. Brain necropsy confirmed the diagnosis of invasive aspergillosis with widespread vascular invasion and destruction. Months after the death of her husband she wrote to thank the health care team for helping her make the right decision for her husband.

**Comment.** When families are opposed to the option of limitation of aggressive care or withdrawal of life support despite the presence of clear indicators of very poor prognosis and professional agreement that further treatments are futile, it is always best to avoid confrontation. Keeping communication channels open and healthy often allows families to reach better understanding of the situation. Providing continuous emotional support to these families in distress is crucial. Families should feel confident that they can trust the health care team and that everybody is working for the benefit of the patient. Resolution of these dilemmas is usually successful for all sides except when families perceive a defensive or antagonistic attitude from physicians. An ethics consultation could have been pertinent in this case, but patience and trust in the value of frequent and open communication proved effective.
Case 1-3
A 79-year-old woman with hypertension developed acute headache and vomiting while attending mass at her church. Shortly after, she became confused and then drowsy. Upon arrival at the emergency department, she was intubated for airway protection. On examination, she awoke to tactile stimulation and could follow simple commands with repeated prompting. Brainstem reflexes were preserved, and she had left hemiparesis. CT scan (Figure 1-3) showed a right thalamic hemorrhage with ventricular extension, including complete filling of the fourth ventricle causing hydrocephalus. Her son arrived and reported that his mother did not have a written advance directive. He immediately requested withdrawal of life-support measures, stating that his mother would have never wanted to be kept alive by artificial means. He also expressed that she was fiercely independent and would never accept any disability. A detailed conversation with him explained that her condition could improve substantially with adequate care, including ventricular drainage and ventilatory support. However, he insisted that his mother be extubated without delay.

After extubation, the patient maintained good ventilation and oxygenation. The following day she started to improve. Her son agreed to the resumption of IV fluids. Three days later the patient was asking for food. She was discharged to rehabilitation 7 days after her admission with good cognitive function and relatively mild hemiparesis.

Comment. Sometimes the reverse of the situation feared to provoke a self-fulfilling prophecy occurs when the patient’s surrogate demands restriction in the level of care that does not appear justified by the anticipated prognosis of the patient. These situations can be very frustrating to physicians. When physicians believe they can help an acutely ill patient recover well, it is very hard for them to accept not being able to offer treatment. Yet, in the case described the physician felt that the son was acting honestly on his mother’s best interest according to his interpretation of her strong attachment to complete independence.

It does not matter whether the discrepancy is because aggressive care is demanded after being deemed futile or restricted despite possible recovery. Being mindful of the limitations of our prognostic assessments and committed to respect the wishes of the family are effective guards against confrontation. In circumstances where the team caring for the patient is uncomfortable with the position of the surrogates, members have the option to request an ethics consultation. In that circumstance, professionals experienced in dealing with thorny ethical issues and not affected by their direct role in the situation can often help reach a decision with which all parties are comfortable.
they all exemplify the respect for the right of the family to make a decision on behalf of the patient.

**CONCLUSIONS**

It is the duty of neurologists to guide families in the process of deciding the level of care to be provided to a patient with severe acute neurologic disease. Premature restrictions of care should be discouraged, as seemingly desperate cases may improve with aggressive treatments over the first few hours. When conveying the prognosis, physicians should rely on their best estimate based on available published evidence and personal experience. Prognostic uncertainties must be acknowledged, and the possibility of producing a self-fulfilling prophecy should be kept in mind.

It is crucial to establish open and honest communication with the family, appreciate cultural differences, and respect the family’s values and wishes. Empathy and compassion are readily noticed by families but they also perceive negative attitudes. Thus, the physician should always avoid being judgmental or confrontational, even if the decision of the family is strongly contrary to his or her professional advice. Failing to do so will close the channel of communication and result in otherwise preventable disputes.

All too often the health care team is unable to improve the condition of patients with devastating acute neurologic disease. In those situations, guiding families to make the best decision on the patient’s behalf becomes our main role. When, after open and comprehensive discussions, the family exercises the right to request withdrawal of life support, the team should be supportive and fulfill their wishes. Preserving the quality of life and the dignity of death are the physician’s irrevocable responsibilities.

**REFERENCES**


**KEY POINTS**

- The wishes of the patient should always be respected.
- Maintaining regular and honest communication with families is the best way to avoid confrontation.
- Our professional responsibility is to preserve the quality of life of our patients.


