When a patient has suffered a severe stroke, investigations and treatments should be terminated when they no longer are useful. This statement, simple as it may seem, has many intricate ethical implications that are discussed in this article.

As consulting physicians caring for stroke patients, we often encounter patients for whom it is difficult to determine what investigations, treatments, and basic life support measures should be instituted and what measures should be withheld. When are investigations and treatments no longer useful? How certain can we be in determining the prognosis of an individual patient? Is there any outcome other than early death that is so grave that life support may be withheld or withdrawn? These are some of the questions we address in this article. A brief case history serves as a focus for our discussion.

Case History

A married man born in 1911 had polio at the age of 30 years. He was left with a slight-to-moderate weakness of his right leg. He also had hypertension and non-insulin-dependent diabetes.

He was admitted to the stroke unit of Umeå University Hospital on January 9, 1988, because of the sudden onset of total aphasia and the inability to rise from bed. On admission, he had a flaccid paresis in his right arm and leg and was stuporous and unable to take any liquid by mouth. His condition remained essentially unchanged and he was stuporous and unable to take any liquid by mouth. His level of consciousness fluctuated between stupor and somnolence until his death on April 5, 1988.

His wife visited him once or twice a week during the first month, then less frequently. She found the visits to be traumatic. In Sweden, the attending physician has the formal responsibility for decisions on life support if the patient is incompetent. The patient’s wife was therefore not part of the formal decision-making process. However, when she was asked to express an opinion, she declined to take a firm position, saying “It is up to the physicians to decide.” She reported no conversations with her husband about these matters prior to the present stroke. After 2 weeks of intensive medical and physical treatment, the treatment team judged the patient’s prognosis for survival to be extremely poor and therapeutic efforts were reduced. A “do-not-resuscitate” order was given.

The following nursing procedures and treatments were applied: the patient’s position in bed was changed every 3 hours throughout his 12 weeks in the hospital; intravenous fluids (salts and glucose) were given in volumes of 1,000–3,000 ml/day from admission until death with no attempt to give either enteral or total parenteral nutrition; the patient’s first episode of fever was treated with cefuroxim infusions, but later episodes were not treated. The patient’s body temperature was not monitored during the last 3 weeks; blood glucose concentration was measured on >100 occasions during his hospital stay, and insulin was given when his blood glucose concentration was >15 mmol/l; prophylaxis against contractions was applied by physical therapists; the patient was on a tip board daily for the first 6 weeks, but this treatment was then abandoned; the patient first had diapers, but when a cutaneous fungal infection affecting his genitalia and groin occurred an indwelling catheter was applied.

While the patient was still alive, we presented the case history and a 10-minute videotape on essential components of his care on two separate occasions, first to a group of 110 consultants in internal medicine participating in a postgraduate course on cerebrovascular disorders and then to 30 medical students in their fourth year of medical school.

The general reaction was that this patient had not been managed adequately from an ethical perspective. However, opinions on what would be proper management were widely divergent, with several in the audience advocating much more intense medical, nutritional, and reactivation treatment. Others expressed serious concern about the ethics of keeping this patient alive. These proponents felt that his prognosis for survival was so poor that our mode of management only prolonged the suffering for the patient and his wife. In general, a more “active”
approach was advocated by the internists, whereas most of the medical students felt that life support measures should be withdrawn.

In these discussions, interest focused on two ethical issues: supply of fluids/nutrients and prognosis. These issues will be addressed in more detail after a discussion of the type of patient considered in this article and of ethical decision-making in general.

We began to explore these two ethical issues in a more systematic manner by reviewing our experiences with a particular group of stroke cases in which we found it difficult to determine the level at which investigational and therapeutic activities should be kept. Often we considered withdrawal of basic life support. The common characteristics of most of these patients were that they remained somnolent, semicomatose, or comatose (often fluctuating between different levels of lowered consciousness) for at least 1 week after the stroke. A few individuals were fully awake or only slightly somnolent but had the combination of total hemiparesis, total aphasia, total absence of all meaningful communication, and total dependence on others for all of their activities of daily living (ADL). These patients did not, however, fulfill the criteria of persistent vegetative state.1

In ethical decision-making, it is preferable that reasoning be based on some basic theoretical structure such as the model of conflicting values, which states that "... there are a number of very distinct but equally legitimate and nonreducible moral appeals that need to be employed in the evaluation of a particular case."2 The appeals concern the consequences for the patient, the family, the providers, and society as a whole. The appeals also concern legal and moral rights, respect for persons, virtues such as integrity, compassion, courage, justice, and even cost-effectiveness.2 The significance of each appeal must be assessed for each case, and the model requires a final judgment (for which there is no algorithm) about which course of action has the greatest support.2

As physicians, we have a foundation of ethical principles that often differ from our ethical experiences.3 The ethical principles are verbally expressed, take a more or less programmatic form, and are commonly accepted by many individuals. Ethical experiences, on the other hand, are unique to each of us. We gather new experiences when we, as physicians, private persons, or social beings, face new ethical dilemmas. The ethical principles and the ethical experiences are kept in an ever-evolving equilibrium that minimizes anxiety,4 and each ethical decision must remain personal to the patient, his family members, and the physician.

Having made these important reservations, we nevertheless feel that attempts to define the points of disagreement may help structure our clinical thinking on patients with severe stroke. Indeed, any personal ethical decision must be based on all available knowledge as well as on professional moral integrity.3

Critical Issue 1: Supply of Fluids and Nutrients

In patients with stroke, undernutrition is associated with poor outcome.4 Poor nutrition impairs the cell-mediated immune response (promoting infections), reduces muscle strength (impairing motor reactivation and cough mechanisms), and affects mentation (conferring apathy and depression-like symptoms). For a review, see Reference 5.

An immediate conclusion would perhaps be that adequate nutrient intake should be ensured in all stroke patients, yet there are objections to this reasoning: 1) in patients with impaired consciousness, oral nutrition is often impossible for practical reasons; 2) long-term total parenteral nutrition by a peripheral route is not feasible because total parenteral nutrition by a central venous line can cause complications, implies a dubious escalation of therapeutic measures toward an intensive care situation, is expensive, and requires considerable manpower resources; 3) feeding by the enteral route (using a tube or a Witzel fistula) may be very difficult in a disoriented patient who does not accept the feeding tubes, and there is a risk that the appearance of the tubes, and catheters enhances the patient’s and the family members’ feelings of agony; and 4) there is as yet no indication that better nutrition affects the brain lesion. Therefore, in patients with extensive cerebral lesions and very severe impairments, attempts to improve nutrition pose a dilemma that is not easily resolved. If the prognosis is very poor (see below), we believe that complicated methods of nutrition may be witheld. The question of giving fluids is even more difficult. In most emergency care settings, the common practice is to administer fluids intravenously to all patients who have an insufficient oral intake. Since it is often impossible to accurately estimate the prognosis when a stroke patient is admitted to the hospital, this practice seems ethically justified. The more pressing ethical dilemma involves the withdrawal of ongoing fluid administration when a patient’s general condition remains very poor, when the peripheral routes of fluid administration can no longer be used, or when a patient is annoyed by the intravenous line.

Administration of fluids prolongs the death process. The patients we discuss here cannot communicate their views, but family members may express a wish that dying not be prolonged by “artificial” means, often based on the patient’s outspoken opinion before the stroke. In some states in the USA, it has been ruled that the family has a legal responsibility to decide about medical care on behalf of a patient who cannot express his own will.6-9 However, even within the USA, there is limited ethical and legal consensus on who should act as an incompetent patient’s surrogate.7,8 In many other countries, the medicolegal situation is even less

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**Critical Issue 2: Supply of Fluids and Nutrients**

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clear. If the attending physician has the formal responsibility for decisions on life support, the attitudes of close family members must nonetheless be of major weight in the ethical decision-making.

If the prognosis is dismal, prolonged fluid administration would be meaningful only if it alleviates the patient’s suffering. Is death from fluid depletion painful? Patients in a vegetative state cannot, by definition, experience pain or suffering,1 and it is highly likely that the same applies to stroke patients with severely impaired consciousness levels. While severe thirst is most distressful in conscious individuals, it is likely that as consciousness becomes impaired, the perception of thirst may be reduced. Even experienced health professionals caring for demented patients who no longer take fluids voluntarily are in doubt as to whether thirst is painful in advanced dementia.10 In an individual patient, the mere possibility that he suffers from severe thirst is often the justification for not withdrawing fluids. The major reason for such a “safe” attitude may actually be to reduce anxiety among the health professionals and the family. The possible relief of thirst by the administration of fluids must be weighed against the suffering involved in a prolonged process of dying.

Can we as physicians ever gain realistic insight into the severely brain-lesioned patient’s perception of thirst and his suffering? If not, who has a better insight? In this troublesome ethical balancing act, in our opinion, it can sometimes be ethically justified to withhold or withdraw the administration of fluids when a patient’s prognosis is very poor. This view has also been expressed by ethics and human rights committees in the USA.6,9

Critical Issue 2: Prognosis

What prognosis would signify that treatment is not meaningful? One end of the spectrum may be a patient in whom death is imminent with absolute certainty. Any treatment or prevention of complications would be futile, and management should be restricted to attempts to give maximal comfort to the patient and his family members. The other end of the spectrum may be represented by a surviving patient in whom death is imminent with absolute certainty. Any treatment or prevention of complications would be futile, and management should be restricted to attempts to give maximal comfort to the patient and his family members.

The prognosis in groups of stroke patients may be reasonably estimated by their level of consciousness, their eye movements, and the extent of paresis of their extremities11 or by a more detailed prognostic score.12 Table 1 shows the prognosis for survival in several stroke populations in relation to level of consciousness or other simple criteria on admission to hospital. Table 1 has no pretensions to be complete but presents data from many stroke populations over the last 3 decades in several industrialized countries.

The information in Table 1 underscores the difficulty of establishing the prognosis for individual patients at the time of admission, at least when prognostication is based solely on the level of consciousness. A crude overall estimate is that the short-term case-fatality rate (during the first few weeks after the onset of the stroke) is approximately 80% in comatose, 60% in stuporous, and 40% in somnolent patients, if all ages are considered. However, the ranges are very wide (50–100%, 34–90%, and 19–71%, respectively), often because the patient populations are composed differently. The 3-month case-fatality rate is approximately 90% in patients who presented with coma, 70% in those with stupor, and 50% in patients who initially were somnolent. Information on the survivors, especially if they were in a coma, a stupor, or a vegetative state, is missing in most studies.

There are several factors making prognostication difficult very early after the onset of stroke. A large proportion of patients deteriorate during the first few days,13 although very early spontaneous recovery is not unusual in patients presenting with severe symptoms at onset. Occasionally, in patients found at home with stroke and profound dehydration, fluid administration after admission to the hospital may alleviate severe neurologic symptoms. Epileptic seizures may confuse the clinical picture by affecting the level of consciousness in patients with less severe stroke, but after a few days’ observation the effect of epilepsy can be estimated more easily. Overall, it would seem that prognosis may be estimated with greater accuracy when it is based on the patient’s status approximately 5–7 days after onset, although data observed at this time are scarce.14,15 It is evident that we need more solid scientific data to predict clinical outcome at different intervals after the onset of stroke. Until then, we must rely on the limited data available and on our own clinical experiences when we decide how to care for an individual patient.

Three months after stroke onset would seem to be a reasonable time to estimate outcome when assessing the prognosis of patients with severe stroke. During the first 3 months, most mortality and morbidity may be attributed directly to the presenting stroke or its immediate complications (such as bronchopneumonia or pulmonary embolism), whereas later predictions may be influenced by new cardiovascular events and other causes of death and morbidity.16,17

As a common basis for prognostication to be used in decisions on life support in patients with severe stroke, we propose that 1) either death or the combination of total dependence on others for all ADL and the lack of all meaningful communication should be used as outcome criteria, 2) 3 months after stroke onset is a reasonable end point for estimation of outcome, and 3) prognostication should be made 5–7 days after stroke onset or earlier if forthcoming data show this to be feasible. With these consider-
<table>
<thead>
<tr>
<th>Year</th>
<th>Reference</th>
<th>End point*</th>
<th>Status on admission</th>
<th>n</th>
<th>Case-fatality rate (%)</th>
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<tr>
<td>1957</td>
<td>Rankin23</td>
<td>2–3 weeks</td>
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<td>79</td>
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<td>3 weeks</td>
<td>Coma</td>
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<td>1975</td>
<td>Oxbury et al11</td>
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<td>Coma</td>
<td>6</td>
<td>50</td>
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<td>1975</td>
<td>Matthews and Oxbury25</td>
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<td>1976</td>
<td>Frithz and Werner26</td>
<td>&quot;In hospital&quot;</td>
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<td>1977</td>
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<td>1977</td>
<td>Hier et al28</td>
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<td>6</td>
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<td>Only patients with putaminal hemorrhage</td>
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<tr>
<td>1978</td>
<td>Abu-Zeid et al29</td>
<td>1 year</td>
<td>&quot;Coma or unconsciousness&quot;</td>
<td>307</td>
<td>55</td>
<td>Patients with brain infarction (before computed tomography era)</td>
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<td>1 year</td>
<td>&quot;Coma or unconsciousness&quot;</td>
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<td>Patients with intracerebral or subarachnoid hemorrhage (before computed tomography era)</td>
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<td>1981</td>
<td>Terént and Andersson30</td>
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<td>Estimations by life table technique</td>
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<td>Gårde et al31</td>
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<td>Coma</td>
<td>3</td>
<td>100</td>
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<td>52</td>
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<td>Hungerbühler et al32</td>
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<td>Coma</td>
<td>26</td>
<td>73</td>
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<td>Mayr et al33</td>
<td>&quot;Acute&quot;</td>
<td>Coma</td>
<td>24</td>
<td>88</td>
<td>Only patients with intracerebral hemorrhage; some patients operated</td>
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<td>Stupor</td>
<td>17</td>
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<td>36</td>
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<td>1983</td>
<td>Miah et al34</td>
<td>&quot;Hospital stay&quot;</td>
<td>&lt;15 of 100 points$</td>
<td>4</td>
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<td>&lt;25 of 100 points$</td>
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<td>1983</td>
<td>Nath et al35</td>
<td>&quot;Acute&quot; (?)</td>
<td>Score 3–5$</td>
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<td>69</td>
<td>Only patients with intracerebral hemorrhage; 27% operated</td>
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<td>Score 6–8$</td>
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<td>Score 13–15$</td>
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<td>Harmsen and Wilhelmson36</td>
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<td>161</td>
<td>63</td>
<td>Only patients aged 15–65 years</td>
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<td>1985</td>
<td>Wade and Hewer38</td>
<td>6 months</td>
<td>&quot;Impaired consciousness&quot;</td>
<td>157</td>
<td>61</td>
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<td>Bonita et al39</td>
<td>6 months</td>
<td>&quot;Unconscious&quot;</td>
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<td>80–93</td>
<td>Life table estimations; different prognosis for patients at home or in institution when stroke occurred</td>
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<td>1988</td>
<td>Fullerton et al40</td>
<td>6 months</td>
<td>Coma</td>
<td>37</td>
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<td>Viitanen et al41</td>
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<td>Coma</td>
<td>12</td>
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<td></td>
<td>Somnolence</td>
<td>69</td>
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*When several end points were given, that closest to 3 months was chosen.
†Neurologic score modified from Mathew et al.42
‡Glasgow Coma Scale score.43
lations in mind, our definition of a very poor prognosis is very high probability of death within 3 months; in surviving patients, total dependence on others for ADL with a lack of all meaningful communication 3 months after the stroke.

Severe concomitant diseases are also important ethical and prognostic considerations. When a disorder such as advanced dementia, malignancy, or severe cardiac failure is present, there may be less motivation for life-support measures. Advanced age may be a less important predictor of death early after stroke, but it has been suggested that age should be regarded as a biographical rather than a medical standard when life-sustaining technologies are considered in very old people: "After a person has lived out a natural life span, medical care should no longer be oriented to resisting death." Medical care in the very old may be more oriented toward the relief of suffering. This does not diminish the value of life in old age, which remains until the very end.

Ethical Action

We originally attempted to define provisional guidelines by suggesting that in carefully selected patients with impaired consciousness 1 week after the stroke, the total inability to communicate in a meaningful manner combined with no self-care ability, life-prolonging and preventive measures (except for symptomatic treatment, nursing care, and perhaps fluid support) might be withdrawn. We also proposed that additional factors such as the patient’s expressed wishes, previous permanent morbidity, family attitudes, ethical principles and experiences of the attending physician and medical staff, and different cross-cultural ethical standards should be considered in ethical decision-making. We emphasized that since so much scientific information was missing, these guidelines were provisional. We have since realized that explicit guidelines may be provocative since the ability of such guidelines to establish a correct prognosis for an individual patient may not always be accurate. This is one of the reasons why it must remain up to family members or the attending physician to reach an individually based decision in ethical matters. Today, recommendations to apply or withhold treatment and interventions in critically ill patients are very often too imprecise and poorly documented.

Another argument against ethical guidelines on life-sustaining measures for physicians has been termed the “demedicalization of the right to die,” meaning that the medical perspective is becoming less important. In many countries, this decision lies with the patient and his family. Court rulings, hospital regulations, declarations of professional groups, and even financial incentives combine to demedicalize the making of decisions about critically ill patients.

The decision to withhold or withdraw active life support has been denoted nontreatment, a term that implies a narrow medical perspective and no consideration of the nursing aspect. In the present context, nontreatment means withdrawal of all medical and surgical intervention aimed at prolonging life but does not exclude symptomatic treatment or nursing intervention aimed at maximal comfort and caring.

In a nontreatment approach, the focus is on symptomatic measures. These include regular change of the patient’s position in the bed; careful mouth hygiene and moistening of oral mucosal surfaces; withdrawal of parenteral fluids in meticulously selected patients (e.g., in the presence of coma, very high age, or severe complicating disorders); suction of the oropharynx when needed; morphine (or analogues) rather than diuretics when pulmonary edema or secretion stagnation develops; morphine (or analogues) against pain and restlessness; withholding antibiotics; use of a tepid sponge or a warm alcohol rub if the patient appears distressed from fever; the presence of a nurse or family members at the bedside; close relations between physicians, ward staff, and family members throughout the process of dying; and a “do-not-resuscitate” order.

It is evident that there is a definite need for more solid scientific data on issues related to making ethical decisions about patients with severe stroke. Some of the questions that need to be answered are:

1) At what time after the stroke can prognostication be made with maximum accuracy? 2) Of the survivors, how many remain in coma, stupor, or vegetative state at different times after the stroke? 3) Can stroke patients with impaired consciousness suffer from thirst? 4) How should the quality of life be estimated in surviving stroke patients who are totally dependent on others for all care and who lack the ability for meaningful communication? 5) How can the physician act in the best interest of a patient in societies in which the family has no legal responsibility to decide on prolongation or withdrawal of life support? What is the impact on the family of prolonging the process of dying by basic life support? What is the impact on the family of withdrawal of life support? 6) What are the ethical implications of different systems for legal responsibility (family members versus physicians) concerning decisions on behalf of an incompetent patient?

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