

NIH Workshop Summary: Withholding and Withdrawing Mechanical Ventilation

In October 1985, a workshop entitled "Withholding and Withdrawing Mechanical Ventilation" was sponsored by the National Heart, Lung, and Blood Institute, American Association of Critical-Care Nurses, American Association for Respiratory Care, American College of Chest Physicians, American Thoracic Society, and the Puritan Bennett Foundation. The 3-day meeting brought together clinicians, researchers, lawyers, ethicists, and others.¹

Proceedings of the workshop, as summarized in an article in *American Review of Respiratory Diseases*, are reproduced here.² They focus on the difficulty of arriving at optimal treatment decisions and the use of institutional policies and other means to help patients and caregivers make better-informed decisions regarding the use of mechanical ventilation.

Introduction

The second half of the 20th century has seen a movement toward shared decisionmaking between physician and patient in medical care. This welcome trend has caused that include rapid technological advances, a more health-conscious public, better understanding of the limitations of health care, and the emergence of less autocratic health-care providers. However, these developments have been accompanied by a new way of dying in that the last days of life are often spent in an expensive hospital environment in which the patient, through mental incompetence or physical incapacity, is unable to make decisions about personal medical care.

The widespread use of mechanical ventilation has occurred in the last two decades. Mechanical ventilation first became available outside the operating room and recovery room in the mid-1960s. At that time each major hospital usually had one intensive care unit, and patients were admitted based on the judgment of the director and the family physician. This resource was applied only to patients who seemed likely to recover. Today the situation has changed, although mechanical ventilation remains only supportive, until the pa-

tient's underlying disorder of the central nervous system, neuromusculature, or lung improves spontaneously or responds to specific therapy. Every hospital now has the capacity to institute mechanical ventilation, and paramedical personnel often initiate the process by manual ventilation in the home as part of cardiopulmonary resuscitation. Endotracheal intubation and mechanical ventilation are frequently instituted by medical personnel who have little previous knowledge of the patient, and since this therapy is immediately life sustaining, it is often impossible to contact the family, surrogate, or personal physician prior to its initiation. As a result, the ability to prolong life or the dying process is no longer in the hands of a few, select medical personnel but is available in every medical facility where emergency medicine is practiced and in most mobile life support units. This capability, although beneficial in many cases, carries with it the potential for overwhelming emotional hardship, agonizing pain, and devastating financial cost for the patient and the patient's family.

Prognosticating Outcome in the Severely Ill

Decisionmaking about life-sustaining therapy is complicated by our inability to prognosticate outcome in the severely ill or injured person. Subgroups of patients with particularly poor prognoses who undergo mechanical ventilation have been difficult to identify. For instance, it is common knowledge that severely immunosuppressed individuals and those with liver failure who develop acute respiratory failure have a

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poor prognosis, but these perceptions are based on limited anecdotal evidence from a few medical centers. In this regard, physiologic scoring systems such as the APACHE II scheme may prove useful to categorize severity of illness and help predict outcome (1). The most useful prognostic data have been obtained on patients with coma (2). In this large series, less than 2 percent of patients with nontraumatic, nondrug-induced coma, who lacked at least two of corneal, pupillary, and oculovestibular responses within hours of the onset of coma, ever regained independent function. However, most patients who receive mechanical ventilation have less predictable outcomes.

The Persistent Vegetative State

Decisionmaking about mechanical ventilation often concerns patients in a persistent vegetative state, since many patients in this state are maintained on ventilators. These individuals are not brain dead, but rather appear to be awake with open eyes and sleep-wake cycles. They can be seen to follow movement with their eyes and sometimes will swallow food placed in their mouths. However, they neither speak, follow commands, nor show cognitive awareness of themselves or their surroundings. This state may rapidly follow coma, and if it persists for more than a few weeks, usually indicates an extremely poor chance for recovery of independent function (3). Unfortunately, the onset of this state is difficult to predict and its outcome only becomes apparent after weeks of therapy.

For most patients who are supported by mechanical ventilation, the prognosis is less clear. Furthermore, for some individuals with more favorable prognoses, mechanical ventilation and other intensive medical treatment may be perceived as so burdensome that it is declined by the patient or the surrogate. In each of these circumstances, health care professionals are increasingly called on to provide counsel and advice about withholding or withdrawing mechanical ventilation and other life-sustaining therapy. What are the elements involved in making and implementing these decisions? Can high-quality patient care be maintained? Detailed answers to these questions were originally given in a publication of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research entitled "Deciding To Forego Life-Sustaining Treatment" (4). In the following sections we describe some procedures for making and implementing these decisions, and we outline topics that require further study and development.

Withholding and Withdrawing Therapy

Mechanical ventilation is an example of life-sustaining therapy because it substitutes for an essential physiologic process that is not functioning properly. However, the simplest supportive measures can place undesirable and intolerable burdens on the dying or irreversibly incapacitated patient by unnecessarily prolonging suffering. In such a patient, intravenous feeding, antibiotic therapy, and even enteral feeding are now regarded by many as appropriate for withdrawal when the burden of the treatment outweighs any benefit the patient can derive. It has become increasingly acceptable to contrast the benefit and the burden of specific treatment rather than regard it as ordinary or extraordinary (5). In this way an extremely painful or invasive treatment might be advocated if it were likely to result in significant improvement, but even a minimally supportive treatment might not be condoned if the prognosis were dismal (6,7).

With mechanical ventilation, however, we deal with immediacy, literally with the breath of life. Because of this immediacy we are often reluctant to withhold this treatment, and we are even more ambiguous about withdrawing mechanical ventilation. Our reluctance and ambiguity have practical reasons. First, the decision to withdraw is more often made by a surrogate, whereas the decision to withhold is more likely to be made by the patient. Surrogate decisionmaking is less precise. It is more likely to be tediously scrutinized by the press, the courts, and other parties. Decisions to withdraw take longer to implement; the family and usually the entire intensive care unit team must be prepared more carefully. Finally, withdrawing therapy is humiliating to many physicians. Withholding therapy always leaves a doubt about whether the therapy might have worked, but withdrawing is the public admission that therapy has failed, which may be difficult for the treating physician to accept. Withdrawal of mechanical ventilation is particularly poignant since it often leads quickly to death. However, these differences are practical and emotional. There are no ethical or legal differences between withdrawing and withholding mechanical ventilation.

Decisions to withhold or withdraw mechanical ventilation must be based on an essentially similar decisionmaking process. The decision to withhold generally deserves more scrutiny than the decision to withdraw, but rarely gets it. A rationale for withholding therapy is also adequate for withdrawing it. Furthermore, the

act of withdrawal is generally a more informed act because the therapy has been initiated and shown not to work. It is clear in medicine that a therapy should be discontinued when it is not working or is so burdensome to the patient that it cannot be tolerated. Finally, the decision to withdraw mechanical ventilation from a dying or irreversibly incapacitated patient cannot be said to cause death. It merely allows death to occur from whatever necessitated mechanical ventilation in the first place (4).

That the patient can refuse treatment of any kind is regarded as a fundamental legal right in our society. It is relatively easy to respect the decision of the competent patient who can understand the prognosis, is informed of the therapeutic alternatives, and voluntarily makes a decision regarding medical care. In cases where a physician cannot in conscience comply with the decision, the patient's care should be transferred to another physician. However, decision-making for the person who is not legally dead but is incompetent or incapacitated becomes more difficult.

In recent years two powerful instruments have emerged that allow the individual more control in circumstances when competence or physical capacity may be compromised. These instruments are the living will (8) and the durable power of attorney (9,10). The living will is a written and witnessed document that expresses the patient's desires about medical care in the event of incompetence or incapacity. The living will generally cannot specify the exact circumstances under which an individual would want therapy withheld, although health care professionals have in some instances prepared very detailed living wills for themselves. Being an advance directive it lacks the moral force of contemporaneous decisionmaking by the patient. A physician might consider it inappropriate for fulfill the directive of a living will because its general language does not reflect a full understanding of the specific treatment decision to be made and the benefit that might be obtained. It should be noted, however, that no civil or criminal action has been successfully brought against a practitioner for following the instructions of a living will.

In an effort to codify the concepts of the living will, currently 35 States and the District of Columbia have enacted laws related to a patient's legal right to refuse medical treatment. Even in States which have no legislation, living wills are being recognized as an indication of the patient's intentions, including the right to refuse treatment. These laws are widely known as natural death acts, and although they give some legal foundation to the concept of the living will, they also raise as many questions as they answer (11,12). Perhaps

most importantly, few of these laws provide for appointment of a proxy decisionmaker in the event of a patient's incompetence or incapacity. In response to this need, the concept of durable power of attorney is being increasingly used to provide for a surrogate decisionmaker. The word "durable" means that the authority of the surrogate continues to be effective when the patient becomes incompetent or incapacitated. Unlike the common law nondurable power of attorney, the surrogate has authority when it is most needed. This concept is legally accepted in all States with the exception of the District of Columbia, which has no enabling legislation. It is a somewhat stronger idea than the living will because it allows for more flexibility in the decisionmaking process in response to the circumstances that affect the patient. Previously, durable power of attorney was used more often to protect an individual's business and financial interests, and consequently the application of this instrument to decisionmaking on health care matters is relatively new. Living wills and durable power of attorney generally apply only in the event of the patient's incompetence and each is easily revokable. It must be recognized that in each State there will be differences in the applicability of laws relating to durable power of attorney and living wills. More uniformity across the States in regard to these acts is needed (see proposed "Uniform Rights of the Terminally Ill Act" by the National Conference of Commissioners on Uniform State Laws, 645 N. Michigan Avenue, Suite 510, Chicago, IL 60611, (312) 321-9710).

Making and Implementing the Decision To Withhold Cardiopulmonary Resuscitation and Mechanical Ventilation

The decision to withhold cardiopulmonary resuscitation and mechanical ventilation is not a trivial one and should not be rushed by the caregiver. In many instances a minimum of several discussions with the patient, family, and other interested parties over a few days is necessary. For the competent patient or the incompetent patient's legally recognized surrogate, the decision must be **voluntary** after full **disclosure** about **prognosis** and **therapeutic alternatives**. The caregiver may make medical recommendations but must not impose personal opinions about quality of life on the decisionmaker. In all instances it is desirable that there be unanimity about the decision among family and other interested parties. The need for unanimity becomes crucial when the patient is incompetent and there is

no legally authorized surrogate, since unhappy family members or caregivers who were not included in the decisionmaking process can unnecessarily complicate it. When irreconcilable differences exist between parties interested in this decisionmaking process, introduction of a *facilitator* in the form of a clergy member or ethicist can be extremely useful.

While competent patients are legally entitled to refuse any treatment, including those that sustain life (such as mechanical ventilation), physicians serve patients best by maintaining a presumption in favor of sustaining life and rendering optimal treatment. In other words, when in doubt, the physician should err in favor of sustaining the life of a patient for whom there may be a question of competency or other problems that cannot be easily resolved. In the case of an incompetent patient, treatment could be revoked later by a recognized surrogate. This revocation could be based on specific instructions from the patient or on the patient's best interests if no clear prior directive had been given to the surrogate.

Given the desire of many patients to take an active role in the decisionmaking processes related to their health care, physicians and nurses should take the necessary time to discuss life-sustaining treatment with patients so that well-informed decisions about treatment can be made in advance. The attending physician, who presumably has established a prior relationship with the patient, should initiate these discussions, possibly in the presence of close family members, and most importantly before any emergent, life-sustaining intervention becomes necessary. The patient can best communicate this decision by making an explicit statement to the physician and at the same time executing a prior directive, such as durable power of attorney or a living will. Resolving the logistics of carrying out the directive falls on the patient, physician, hospital, and particularly, emergency room personnel. If possible, copies of prior directives should be made part of the patient's medical record. More readily available means to communicate a prior directive such as a necklace or bracelet, a microfilm chip attached to the driver's license, or similar identification should be widely available. Health care institutions have an obligation to establish clear procedures for communicating the existence of such a directive as well as providing for its implementation.

Patients, family members, and health care professionals are often uncomfortable discussing life-sustaining treatments such as cardiopulmonary resuscitation and mechanical ventilation when the patient is feeling well. Historically, medical and nursing education has provided little training in this area. The uncertainty of medical prognostication, as well as the reluctance

of physicians and family members to accept responsibility for value judgments of this type also contribute to the uneasiness. Many patients, however, have definite opinions regarding cardiopulmonary resuscitation and mechanical ventilation and are willing to discuss these when asked. For example, in patients with a chronic illness such as advanced chronic obstructive pulmonary disease, which is likely to progress to the point where mechanical ventilation will be necessary to sustain life, open discussion among physician, patient, and family is essential. A second example is that of the healthy elderly. Discussions about a future catastrophic event, while often uncomfortable, can potentially prevent much pain and suffering. The use of prior directives regarding cardiopulmonary resuscitation and mechanical ventilation is appropriate in both instances.

Although economic considerations pervade many aspects of health care, caregivers should not allow the cost of treatment to dominate decisionmaking about withholding mechanical ventilation. On the other hand, the patient may factor into a prior directive the dire financial consequences that prolonged hospitalization might have on loved ones and refuse treatment on that basis.

There are many areas of potential conflict in decisions to withhold mechanical ventilation that require further clarification. Decisions about allocation of life-sustaining resources are implicitly made daily in medical practice. However, institutional policies that take into account both ethical and legal aspects of withholding therapy should be clarified and declared. Mechanisms for communication of advance directives among institutions, physicians, patients, and their families need to be developed.

Implementing the Decision To Withdraw Mechanical Ventilation

The decision to withdraw mechanical ventilation is usually made after a patient has received this and other treatment in an intensive care unit. Many individuals can be involved in the process, but a surrogate frequently makes the decision because the patient is incompetent or incapacitated. When it becomes clear to the health care team and family that mechanical ventilation is no longer benefiting or is excessively burdensome to the patient, a representative of the provider team, usually the attending physician or the responsible critical care unit physician, should meet with the patient and the family. The representative describes the options and the medical implications of continuing or withdrawing mechanical ventilation. The representative may give a medical recommendation, but

the decision to withdraw or to continue resides with the patient if competent, or with a surrogate if the patient is incompetent or incapacitated. Living wills and durable power of attorney can greatly facilitate this decisionmaking process, but the steps are generally the same whether or not a prior directive exists. The following recommendations outline the decisionmaking process and its implementation.

It is the responsibility of the individual institution to assure the existence of written policies about withdrawing mechanical ventilation. These procedures must be consonant with appropriate ethical principles and with legal precedents that pertain to that locale. Important elements include:

1. Provision for continuing communication and consultation among all parties of interest. These include the patient, the family, physicians, nurses, respiratory therapists, social workers, and others.

2. These deliberations should result in a general agreement about withdrawing or continuing therapy. When they do not, some mechanism of resolution of conflict should exist. In some hospitals this may be a standing ethics committee. In other hospitals it could be an *ad hoc* committee. In many instances it is clergy known to the family. In a few instances, the courts have been involved in this decisionmaking process, although it is generally agreed that the courts are not well equipped to deal with this problem and their intervention should only be sought when an irreconcilable conflict arises.

3. When and if a consensus is reached that further ventilator support is neither benefiting nor is desirable for the patient, the following events should occur.

4. A signed and witnessed note should be placed in the medical progress notes by the responsible physician that it is the patient's or the surrogate's decision that mechanical ventilation will be withdrawn. This documentation can briefly outline the events that led up to the decision, the patient's likely prognosis, and the parties to the decisionmaking process.

5. Once the documentation has occurred in the medical progress notes, an order can then be written to withdraw mechanical ventilation. This withdrawal procedure should provide for the patient's comfort and dignity. Although no details of a recommended withdrawal procedure are given here, in most cases the responsible physician should direct the procedure personally. Withdrawal procedures that result in great dyspnea or discomfort to the patient should be avoided, and the use of narcotics to blunt dyspnea and discomfort may be desirable.

Further Studies and New Directions

A diversity of further studies is needed. The medical literature is still imprecise about prognosis in many severe illnesses. More precise prediction of outcome is needed in both adult and pediatric illnesses that necessitate mechanical ventilation. Early predictors of the emergence of a persistent vegetative state would be useful. Subgroups of patients requiring mechanical ventilation who have a particularly high mortality rate or permanent loss of cognitive function (nearly 100 percent) need early identification.

There is a lack of study of the psychosocial implications of withholding and withdrawing mechanical ventilation. Very little is known about the perceptions of the healthy elderly and their desires regarding critical care and withdrawing and withholding mechanical ventilation. Most medical orders that withhold resuscitation or mechanical ventilation are ambiguous, and it is not clear to many physicians how to write a "do not resuscitate" order (13,14). Physicians perceive many problems when they withhold and withdraw mechanical ventilation. Their perceptions and fears are not well understood and only recently have studies begun to explore this area (15,16). While there are no ethical or legal differences between withholding or withdrawing mechanical ventilation, caregivers continue to be confused about the legal significance of withdrawal of therapy, and efforts should be undertaken to correct this misunderstanding (17).

In a practical manner it is difficult to communicate advance directives to emergency medical and intensive care unit personnel. Innovative devices and procedures are needed in this area. Few people know about living wills and durable power of attorney and how to implement them. Health care professionals should be encouraged to include information about prior directives with maintenance medical programs for chronically ill patients.

Careful collection of information about functional status and quality of life following weaning from mechanical ventilation would be useful since there is widespread fear that data about quality of life is currently being misinterpreted and inappropriately applied. With the extensive use of home ventilator therapy in this country, studies are needed of the psychosocial implications of long-term ventilation. There is little pub-

lished information on the social adjustment of premature infants or adults who receive long-term mechanical ventilation. Reimbursement schemes for patients receiving mechanical ventilation at home are poorly developed. Some of this information will be difficult to obtain and much of it is subject to change as new technology and treatments are applied. However, taken as a whole, this body of information will help patients and caregivers make more informed decisions about life-sustaining treatments.

Appendix E References

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