Life-Sustaining Technology and the Elderly*

Prolonged Mechanical Ventilation Factors Influencing the Treatment Decision

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In 1985, the Office of Technology Assessment (OTA) was requested by the House and Senate Aging Committees (US Congress) to study implications of life-sustaining technology and the elderly. One concern was mechanical ventilation of patients with critical illness or terminal conditions. Information was requested concerning the factors that influence treatment decisions. This report brings together opinions from medical experts in focus groups about a variety of issues raised by the OTA. The answers to those questions represent the therapeutic dilemma facing the decision-maker dealing with the elderly patient and a condition of prognostic uncertainty. Although a variety of responses is presented, some uniform trends among experts are evident. Considering the current public policy debate concerning catastrophic and long-term care of the elderly, the need is apparent to establish a clearinghouse of information providing documentation, education, and networking. A documentation center would serve as a resource for public policy and program planning to serve the population that requires prolonged mechanical ventilation. (Chest 1988; 94:1277-83)

In September 1984 the Office of Technology Assessment (OTA) was requested by both the House and Senate Aging Committees to study implications of medical technologies that can sustain life in critically or terminally ill elderly patients. The official report, made public in July 1987, covers a wide variety of topics including legal and ethical issues, resuscitation, mechanical ventilation, dialysis, nutritional support and hydration, life-sustaining antibiotic therapy, and manpower and training. The chapter on mechanical ventilation was based in part on a contract study about prolonged mechanical ventilation. The charge of the contract was to describe mechanical ventilation and its application; to conduct a survey to obtain national and regional data on utilization (prevalence and incidence) and cost-reimbursement; to assess medical, social, psychologic, and economic outcomes; to determine factors influencing treatment decisions; and to make recommendations for public policy, community, and private sector action.

During the current public policy debate concerning long-term and catastrophic care, it is essential to understand better the process by which modern life-supportive technologies are considered and applied to elderly patients. The questions asked by the OTA were highly appropriate and provocative. They included: Who is the decision-maker? What factors influence the change of care settings? What is the role of age in decision making? What patient characteristics affect inappropriate attention? How are patients evaluated and how do these evaluations affect decisions? Are decision-makers knowledgeable and open-minded about the issues? How do institutional norms and guidelines affect decisions? How do religious beliefs and cultural values influence treatment decisions? What is the role of persons themselves in decision-making? How and to what extent does practice vary in regions of the United States? How do existing legislation and legal precedents affect decisions? Each question must be considered for a full understanding of the complexity of forces directing medical judgment in clinical situations of prognostic uncertainty.

METHODS

In an attempt to respond to the challenging inquiries of the OTA, a written questionnaire was designed for stimulating open-ended, nondirected responses. This was considered an exploratory endeavor, not descriptive research for coding and statistical analysis. Key expert informants were selected who were known to have firsthand clinical experience. Each was requested to create a "focus group" among their clinical management teams and respond collectively to the issues. These teams were located in regional acute care and rehabilitation medical centers well-recognized for their expertise in the care of long-term mechanical ventilation. Among the participants were members of an ad hoc task force of the Respiratory Care Section, American College of Chest Physicians, who were...
describing guidelines for long-term respiratory support for patients at home or at alternative community settings. In addition, case scenarios were invited to illustrate the perspective of elderly persons who require prolonged mechanical ventilation.

**Case Scenario**

A masters-level nurse, now in her mid-70s, had a professional health care career involving decades of high school, nursing school, and college teaching. Soon after attending a patient with meningocoecal meningitis, she had a sudden cardiovascular collapse and cardiopulmonary arrest. She was resuscitated by her sister, intubated in the local emergency room, and admitted to a regional ICU for acute respiratory failure, which required tracheostomy and prolonged mechanical ventilation (over three months). In addition to her pulmonary problem, severe hypoxia had resulted in abnormal heart, kidney, and spinal cord function. She made no urine for over two months, requiring meticulous attention to her input, output, and weight, as she received daily peritoneal dialysis. She could not move anything but her eyelids, and a world-famous neurologist claimed she never would move again.

After 2½ months of intensive care, a decision had to be made. The coordinating physician (a resident) invited six attending specialist consultants who discussed her prognosis and gave their opinion (50-50). The resident, knowing that further treatment was futile with no urine output, discussed a renal biopsy with the patient, who was alert, awake, and informed of the high risk (at this time, the patient had an increased bleeding tendency). After a discussion (eyelids do permit communication), the decision to do the biopsy led to a favorable diagnosis with a prognosis favoring recovery. Soon movement of the extremities began, and after rehabilitation, the patient is walking and working today. She continues her professional work, which recently focused on socially disturbed children and families and volunteer work with the elderly.

**RESULTS**

**The Decision and Decision-maker**

The decision to institute prolonged mechanical ventilation is often made on an emergency basis; patients are usually intubated and begin receiving mechanical ventilation as an acute, lifesaving measure. Chronic underlying conditions may preexist the emergency, particularly in elderly individuals. In a few such cases, it is later recognized that they cannot be completely weaned from the ventilator. A new set of decisions must then be made, either to withdraw support or to continue prolonged ventilation as a life-sustaining technique.

In an acute-care setting, it is the physician who makes the decision to use mechanical ventilation. The initial decision-maker and specialty background varies with each situation. Decisions are made for postoperative surgical patients by attending surgeons and anesthesiologists. Alternatively, physicians staffing emergency rooms and critical care units are most commonly called. Final decisions for treatment must always be made by the attending physician, who is ultimately responsible for all decisions affecting the patient's care. If a house staff physician makes the decision, it must be reviewed by the attending physician and agreed on before action is taken. Although some believe that decisions should be made in consultation with the patient, the family, and other health care professionals, in practice there is usually a varying amount of input from the "team members."

In contrast, in a long-term setting, decisions are more likely to be made by a rehabilitation team, with input from all team members. The final decision is made by the staff and resident physician and the patient. Patients will likely be "coded" unless they request not to be; the staff tries to ascertain if the patient understands the expected outcome in order to make an informed choice.

**Patient Characteristics Considered**

Currently, in a dire, life-threatening situation and without prior knowledge of the patient's wishes, all available technology is applied. Elderly patients in an emergency setting are given full life-sustaining technology assistance to preserve life. However, if time permits and information can be properly obtained and assessed, specific characteristics are considered in the decision-making process. The most prevalent characteristics are the severity and reversibility of the primary disease process, expected response to treatment, and long-term health status, including underlying diseases which may complicate the use and withdrawal of mechanical ventilation. The decision to treat vigorously is strongly influenced by the patient's desire to live, competence to give truly informed opinion, patient and family wishes (although not always asked), and other psychosocial factors. The quality of life of the patient before the institution of mechanical ventilation and that expected afterward are also taken into account.

Withdrawal decisions are based mainly on clinical improvement, medical stability, and prognosis. Weaning is guided by the measurement of physiologic parameters (pulmonary function tests, arterial blood gas values) and clinical trials, which determine whether mechanical ventilation can be safely withdrawn. The process of weaning may take weeks or months before a final decision can be made. The final decision is a medical judgment.

**Role of Age in the Decision**

In the acute ICU setting, age is not the major limitation on utilization of ventilator care; ICU resource availability limits its use. Nevertheless, age is a factor to consider because of associated irreversible diseases and limited long-term health potential. Many elderly survivors do benefit from ventilator care during acute illness, but few would be well served by a long-term ventilatory lifestyle.

There was divided opinion on whether age is or should be a major determinant in the decision. Older persons may not tolerate major invasive therapies as well as younger patients, and age per se does reduce...
life expectancy. More important than age is the disease process and the potential benefits from short or long-term mechanical ventilation. Age may not play an initial role, but it may make a difference later in priorities, prolongation of care, and placement. Respondents who thought that age was a strong factor believed that this was inappropriate because the individual's condition and prognosis should be more important considerations. Chronologic age alone is not as important as the physiologic age. Age alone should never be the sole factor; it should be considered to the extent that age affects medical prognosis. Each person and situation should be evaluated on his own merit.

**Characteristics of Elderly that May Receive Inappropriate Attention**

Being elderly itself may result in inappropriate attention. The elderly may not have visible relatives concerned about their welfare advocating their wishes. Characteristics that may be incorrectly perceived are often typical of the elderly. Sleep disorders, poor eyesight, and hearing loss may be glossed over and disregarded as merely "old age." Patients who always find fault and are anxious have qualities that lead to avoidance. Authoritarian decision-making (especially concerning initiation or cessation of ventilation) may be more common, because the physician assumes that elderly individuals do not (or cannot) understand available therapeutic options. Physicians tend to focus on one reversible aspect of a patient's disease (eg, pneumonia) while ignoring unrelenting, irreversible processes (cancer, dementia). Long-term health status and quality of life decisions are valid, essential issues when dealing with the elderly.

**Evaluation for Changes in Treatment**

Changes in a patient's management in an acute setting are based on both subjective clinical examination and objective physiologic measurements which are evaluated by a team of health professionals and a physician. In a chronic-care (rehabilitation) setting, decisions are made by the team approach of appropriate physician specialists and allied health professionals. Regular evaluations and status changes affect the level of intensity of care, specific care programs, discharge plans, and the appropriate delivery setting.

**Knowledge and Open-mindedness of Decision-makers**

Some experts respond that health care professionals are open-minded and supportive of their patients regardless of age and their decision on the use of lifesaving equipment. Such physicians try to educate in a nonjudgmental fashion their elderly patients, who may require such support, about their disease, prognosis, and likelihood of weaning. Although physicians are sufficiently aware of the physiologic limits of the elderly, they need, request, and follow consultation on options for ventilatory support. Others believe that decision-makers are not sufficiently knowledgeable about either elderly individuals or the use of prolonged mechanical ventilation whether in the hospital or in the community. The issues are new and relatively few scientific answers are available. Further, although many medical centers and teaching hospitals have experts, residents may be making the decisions. In smaller community hospitals, it may be the generalist or nonpulmonary physician who is not aware of new methods and options.

The diversity of opinions expressed reflects the variations in practice among experts, institutions, and regions. An ultimate goal suggested was to establish designated centers in which expertise could be obtained and guidelines for care could be established. One concern raised was that if open-minded physicians suddenly face widespread available home care programs, physicians may postpone appropriate decision-making. Any system put in place must determine medical necessity and quality assurance.

**Impact of Institutional Norms, Guidelines, and “Do Not Intubate” Orders**

The use of “do-not-intubate” orders and hospital guidelines regarding mechanical ventilation vary widely. Respondents were concerned that these orders would be used to deny acute and possibly long-term benefit to patients simply because they are elderly. Recently created ethics committees facilitate discussion and awareness of such issues as withdrawal of care and consent to treatment.

Some respondents believed that institutional norms and guidelines determine where patients are placed in an institution (ICU vs floor), whether automatic consults go to pulmonary specialists, and whether patients' wishes and do-not-intubate orders are observed. Others believe that no institutional guidelines exist that affect who should or should not receive mechanical ventilation. Do-not-intubate orders are arrived at by physicians after thorough discussion with the family, and, if possible, the patient. In other institutions, norms are created by ethics committees. In such institutions, physicians work within frames of norms and guidelines and try to affect change in them when needed.

**Influence of Religious Beliefs and Cultural Values**

Religious beliefs and cultural lifestyle expectations do influence individual decision-makers, according to some respondents. Respect for the value of life and individual autonomy varies widely. The religious belief of the patient and physician both play a role. The
physician's belief probably plays a bigger role; patients are usually not asked about their religious belief regarding ventilator assistance or death. They are usually not cared for by their family physician when in a hospital or when receiving ventilator care. Often the initiation of ventilation is for an emergency medical condition, and time is not spent discussing the patient's religious beliefs. When there is time and patients are asked, religious, cultural, and societal values are important to patients. For example, individuals from urban centers with more sophisticated technologic background are more likely to accept the use of machines to alter their lives.

Other respondents stated that religious beliefs and cultural values have little influence on treatment decisions. The desire to live or not cuts across religious beliefs and cultural values. While such values may affect a minority of patients, in individual instances they can prevent patients from getting maximum benefits available. The patient's own investment in life is of far greater importance in whether he can visualize himself as having a meaning for existence in these circumstances.

If the religious and cultural beliefs are those of the patient, the patient is unwilling for treatment to be rendered, and if the patient is mentally responsible, such treatment is almost impossible to initiate and to continue. There must be a mechanism to allow the patient's wishes and beliefs to prevail.

**Participation by Elderly Patients in the Decision**

Some elderly patients are active participants in decisions concerning ventilation, and they often do give informed consent. In many cases, issues about life support are discussed well in advance of the need, and the patient's preference concerning such techniques can be known and documented. In other cases, the issues have not been discussed, the patient's preferences are not known, and the patient may be incompetent to give informed consent owing to altered mental status resulting from respiratory failure.

Living wills, other advanced directives, and decisions made by close family members are very important in determining care. However, living wills are accepted on a state-by-state basis with a great deal of variation. In some states where they are not legal, the patient's expressed wishes are still respected or at least considered in context with their legality relative to the acute management required. Interpretation may need to be obtained from the hospital attorney in situations where the will is at variance with the medical opinion or the stated desires of the family.

Although some respondents stated that informed consent and patient participation in decision-making are obtained regardless of age, they seem to depend on the actual or perceived mental competence of the patient. At times, elderly patients are not actively involved because they are thought unable to understand or to communicate or to be "difficult." Others believed that involvement depended on the level of mental competence or clarity. Sometimes the factor to determine treatment was the duration required; the goals of long-term ventilator management could never be accomplished in a patient not desirous of this form of therapy. Chronically ill patients are more often asked their preference. With time, education, and support, the usual answer is "If you think I'll make it, please use the machinery." In contrast, in the acute circumstance, patients are not capable of making this decision alone and consultation with family or the nearest relative is common.

**Variation of Practice**

Practice variations are apparent from the opinions given, which reflect both the individual respondents and the regions from which they come. Some respondents thought that major differences in practice related to the size and capability of the institution. Small and rural hospitals frequently do not have a team adequate to address all the problems relative to long-term ventilation. Larger urban medical centers are more likely to have adequate personnel and skills; in addition, facilities for long-term ventilator care and support services are more likely to be found in these settings. There are individual exceptions in institutions being prepared and willing to entertain this form of therapy. Further, there are tremendous differences from one hospital to another in the same community.

**Impact of Existing Legislation on Legal Precedent**

All contributors agreed that the risk of medical liability is a major issue. Legal precedents are important as more doctors are conscious of their vulnerability for lawsuits. All physicians are concerned about possible malpractice litigation if incorrect and improper decisions are made. Legal precedents especially influence treatment decisions when patients cannot give informed consent and when the desire of the patient is not known. Withdrawal of life-sustaining machines has been a legal dilemma for many physicians owing to recent attempts to sue physicians for criminal intent and murder in cases in which the physician was carrying out the patient's and family wishes (*Barker vs Superior Court of California*).

Prognostic uncertainty is the major issue prompting the use of ventilation in circumstances where therapy is ultimately useless. Legal implications of withdrawing such care then becomes important for the physician decision-maker. Legal precedents make physicians wary of limiting the care if the decision has not been fully discussed before clinical deterioration. Clarification of the patient's legal status would facilitate appro-
appropriate decision-making.

Current reimbursement legislation does not provide financial incentive for mechanical ventilation in the home or at alternative community sites. Under the prospective payment system, hospitals have an incentive for early discharge, but the same incentive does not exist for treatment centers outside the hospital to accept patients who require mechanical ventilation. Often reimbursement is available from more expensive licensed professionals when appropriate care could be rendered by less skilled individuals. Thus, current policy tends to inflate the cost of home care and often leads to exhaustion of available funds.

Such legislation regarding reimbursement does have an impact on treatment decisions. Patients must stay in the hospital longer than necessary if appropriate resources are not available for long-term ventilator care. Alternatively, patients may be discharged from hospitals to sites not adequately prepared for their management.

Consideration Regarding Transfer Among Settings

Elderly patients who are medically stable do not need to be in a hospital ICU. A transfer to home or a less costly, more appropriate community-based option is desirable. If, how, and when such a transfer is possible depends on several considerations, including availability of options; admission criteria; acceptance by the facility (long waiting lists); distance from family home and family preference; and the availability of private, public, or personal funds to pay for the alternative setting. Other factors include the psychologic stability of the patient, the extent of need for medical input, number of hours of nursing care required, the quality of medical care required, and the patient's independence (self-care), prognosis, and quality of life. Medical status, level of care required, suitability of the environment, and financial factors seem to be major issues that influence transfers.

Being at home with family members is always the ideal choice. Factors that influence a decision to send the patient home from the hospital include medical stability, possibility of delivering care at home (family support), and the availability of community-based medical services. A specially designated discharge team selects and prepares the patient and family. Resources for care outside the hospital must be evaluated and assured of reimbursement before discharge.

Nursing homes are the option of choice when the elderly cannot be discharged home. Some patients at home may be transferred to a nursing home when the physical or emotional strain of caring for them becomes too great for the family to bear (respite care, permanent placement). The inability to receive adequate care at home is due to the lack of family members present, inadequate home health services, intensity of care involved, amount of rehabilitation required, and the financial situation.

The nursing home cannot provide care when the patient is medically unstable. Transfers from a nursing home back to a hospital occur with the superimposition of an acute illness and the deterioration of overall health requiring a higher level of skilled care. With DRGs, the patient is referred back to the nursing home as soon as he is relatively stable—often too soon, as noted by quick returns to the hospital.

Commentary

The results reported illustrate the wide variety of opinion among selected experts from a variety of settings (acute/rehabilitation) and regions of the country. The complexity of issues and range of diversity of responses was also evident at an NIH Workshop (Withholding and Withdrawing Mechanical Ventilation) held in October 1985 and summarized in the OTA report's appendix. It is evident that the decision of how and when life-sustaining technologies are applied to "benefit" elderly persons is based on those persons from whom the patient seeks care (or has been led to without choice) and what those persons believe is right.

By far the greatest dilemma is in the acute-care situation, when the element of prognostic uncertainty is greatest and when immediate action is imperative to prevent further damage from inadequate ventilation. Outcomes from ICU care of the elderly do not appear to contradict the intended purposes of such initiatives. However, the decision in favor of prolonged use of medical technology is not urgent and requires a much more thoughtful and deliberated decision-making process. This is especially true since such a large proportion of health care expenditures occur in the last year of a person's life.

An elderly person will be brought to medical facilities near his residence, and local health care providers will be the ones burdened with these decisions. Although this report presented a diversity of approaches even among selected experts, it did make clear that some centers have more familiarity with these issues and, hence, could serve as centers of expertise for professionals, organizations, families, agencies, and others facing alone the choice of the prolonged use of mechanical ventilation.

The means required to obtain the answers to the questions raised by the OTA were modeled after approaches demonstrated by documentation centers abroad which target their mission to creating and making requested information available regarding defined populations. It would be desirable to establish in the United States a clearinghouse of information providing documentation, education, and networking among experts to assist decision-making of those in
search of a solution for persons requiring prolonged mechanical ventilation. Such a documentation center would collect the universal experience and serve as a resource for all concerned parties seeking information for public policy and program planning to serve this population.

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