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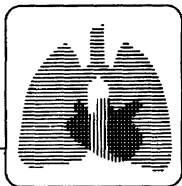
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ethics in cardiopulmonary medicine

Patients With Amyotrophic Lateral Sclerosis Receiving Long-term Mechanical Ventilation*

Advance Care Planning and Outcomes

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Objective: To examine advance care planning and outcomes of patients with amyotrophic lateral sclerosis (ALS) receiving long-term mechanical ventilation (LTMV).

Design: Case series.

Setting: Population-based study in homes and chronic care facilities in four states, and Home Ventilator Program of California Kaiser Permanente.

Patients: Seventy-five ALS patients receiving LTMV were identified; 11 died prior to interview, and 6 were totally locked in; 50 of 58 (86%) who were able to communicate consented to structured interviews, of whom 36 lived at home and 14 in an institution.

Results: Thirty-eight patients (76%) had completed advance directives, and 96% wanted them. Thirty-eight patients wished to stop LTMV in certain circumstances, of whom 30 had completed advance directives. Those who had completed advance directives were more likely to have communicated their preference to stop LTMV to family and physician than those who had not (76 vs 29%; $p=0.05$). Patients living at home rated their quality of life on a 10-point scale better than those in an institution (7.2 vs 5.6; $p=0.0052$), and their yearly expenses were less (\$136,560 vs \$366,852; $p=0.0018$).

Conclusions: Most ALS patients receiving LTMV would want to stop it under certain circumstances, and the process of advance care planning enhances communication of patient preferences to family and physicians. Home-based LTMV is less costly and associated with greater patient satisfaction. (CHEST 1996; 110:249-55)

Key words: advance directives; amyotrophic lateral sclerosis; decision making; ethics; mechanical ventilation; outcomes

Abbreviations: ALS=amyotrophic lateral sclerosis; CPR=cardiopulmonary resuscitation; LTMV=long-term mechanical ventilation; QOL=quality of life

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Patients with amyotrophic lateral sclerosis (ALS) usually die of respiratory failure unless they are treated with long-term mechanical ventilation (LTMV).¹ Previous studies have documented that LTMV can be quite successful in keeping ALS patients alive for a number of years²⁻⁴ but that only a small percentage of ALS patients choose to live on LTMV.^{5,6} Because of the inevitability of respiratory failure in most ALS patients, the usually slow rate of progression of ALS, and patients' retention of cognitive abilities, there is time for physicians to discuss with patients and their fami-

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lies the benefits and burdens of LTMV and for patients to reach unhurried advance decisions about its use.⁷ Despite this opportunity, relatively little is known about how ALS patients make decisions for or against LTMV,⁸ and initial observations suggest that only a minority of ALS patients receiving LTMV have made a decision for LTMV in advance.^{6,9}

After patients start any life-sustaining treatment, including LTMV, they may subsequently decide to stop it. For example, discontinuation of dialysis is the third most common cause of death for patients with end-stage renal disease.¹⁰ Surveys of patients with a variety of medical conditions indicate that most would want to stop life support under certain conditions.¹¹⁻¹³ A few cases of ALS patients who have chosen to stop LTMV have been reported,¹⁴⁻¹⁷ but to our knowledge, there has been no systematic study of ALS patients on LTMV to determine how many would want to stop LTMV in certain contingencies and for what reasons. This issue of advance planning is especially important in ALS because some patients will progress to a totally locked-in state in which effective communication becomes impossible.^{4,5,7,18,19}

The treatment of ALS patients with LTMV is labor intensive and very expensive, and much of this treatment has been provided in patient homes.^{4,6,20} Families of ALS patients receiving LTMV have reported that caring for their family member is burdensome,⁷ and in one study, all patients and families indicated that they would not be able to afford home LTMV without insurance coverage.⁶ As the cost of health care becomes an increasingly important consideration, we must learn more about the financial and human costs of providing LTMV to ALS patients, both to better prepare to serve this population and to formulate public policy for using limited resources prudently.²¹

We conducted this study to enhance our understanding of these three concerns—decision making, advance directives, and patient outcomes—to provide these patients with better, more cost-effective care.

MATERIALS AND METHODS

Subject Identification and Solicitation

We identified all ALS patients on LTMV and their caregivers in two regions known to have large numbers of ALS patients on LTMV, northern Illinois and the tri-state area that includes Ohio, western Pennsylvania, and West Virginia. We also identified all such patients in one large geographically based program, the Kaiser Permanente Home Ventilator Program in California. The patients in the two regions were located through the ALS Association, Muscular Dystrophy Association programs, and tertiary-care center clinics for patients with neuromuscular disease and through home-care companies and institutions—nursing homes and long-term care hospitals—in the regions that treat patients receiving LTMV. The patients identified in California were all those with ALS enrolled in the Kaiser Permanente Home Ventilator Program. The patients were receiving positive pressure mechanical ventilation

either through a tracheostomy or via a noninvasive means (nasal-intermittent positive pressure ventilation).²²

We sent letters describing our study to all identified ALS patients on LTMV in northern Illinois and California on January 1, 1993, and in the tri-state region on January 1, 1994. We called them 2 weeks later to request their participation and, if they consented, to schedule an interview. One of us (P.C.) performed the interviews in northern Illinois and trained two home health nurses who interviewed the patients in California. One of us (P.A.C.) who has worked as an ALS nurse specialist for 10 years conducted the interviews in the tri-state region.

Interviews and Questionnaires

The patient interviews were structured and included open- and closed-ended questions. We asked patients about demographic items, functional abilities, means of LTMV, the LTMV decision, attitudes toward life on LTMV, circumstances under which they would want to stop LTMV, advance directives, and communication with physicians and others about advance directives.

In separate interviews, we asked family members (usually spouses or adult children) or other caregivers most closely associated with the patient's treatment about their attitudes toward LTMV both for the patient and for themselves (if they developed ALS), the benefits and burdens of the patient's LTMV for families, LTMV costs, and insurance coverage. Yearly LTMV costs were determined by adding together the average monthly cost for all associated ventilator expenses, supplies and medication, other equipment costs, and nursing expenses, and multiplying by 12.

Statistical Analysis

Comparisons between categorical variables were made with the χ^2 test or Fisher's Exact Test, each with Yates' correction. The costs of treatment and the quality of life (QOL) scores for patients at home and in an institution were compared with the Student's *t* test and the median test, respectively. Comparison of QOL scores based on insurance status was performed with one-way analysis of variance (SAS Institute Inc; Gary, NC).

Research Ethics

The West Virginia University and Kaiser Permanente Northern and Southern California Institutional Review Boards for the Protection of Human Subjects approved this study. Under the terms of the approval, patients and caregivers were not required to answer a question if they chose not to. Therefore, the number of responses to some questions was fewer than 50.

RESULTS

Subjects

Seventy-five patients with ALS receiving LTMV were identified, of whom 17 lived in California, 27 in northern Illinois, and 31 in the tri-state region. All the patients in California, 16 of the 27 in northern Illinois, and 15 of the 31 in the tri-state region resided at home. The remainder lived in institutions. Six (8%) were totally locked in (alert but unable to communicate by any means), and 11 died prior to interview. Of 58 patients able to communicate, 50 (86%) agreed to participate. Forty were receiving mechanical ventilation 24 h/d, and 10 were receiving mechanical ventilation from 7 to 23 h/d. There were 43 patients who were ventilated via

a tracheostomy and 7 by noninvasive means. Significantly more patients with a tracheostomy were ventilated 24 h/d compared with those undergoing noninvasive ventilation (86% vs 43%; $p=0.023$), and there was a trend for patients ventilated via a tracheostomy to have been receiving LTMV longer (mean, 40 vs 15 months; $p=0.096$). Patient demographic characteristics and functional status (at the time of the interview) are presented in Tables 1 and 2.

The Mechanical Ventilation Decision

To make a decision about undergoing LTMV, patients have to know that a decision is necessary. Seventy-two percent of patients were aware of the likelihood that ALS would eventually cause respiratory failure, and 48% said they had learned this information from a physician. In advance of their own decision about LTMV, 32% of patients had used respiratory equipment and 10% had communicated with patients receiving LTMV. Forty-two percent decided in advance to undergo LTMV when respiratory failure developed, 42% decided at the time of a respiratory crisis, 8% were started on a regimen of LTMV without their own consent but with consent of their family, and 8% were placed on a regimen of LTMV by a physician without consent from themselves or their family.

Patient Satisfaction With the LTMV Decision

Patients were generally satisfied with the decision about LTMV. In response to the question, "Are you glad you are alive on mechanical ventilation?," 88% said "yes," and 80% indicated they would choose to go on a regimen of LTMV if they had the decision to make over again. When asked to rate their satisfaction with their QOL on a 10-point scale with 10 being very satisfied, the mean score for all patients was 6.7 (range, 1 to 10). Only 8% said they had considered stopping LTMV very seriously.

Patients living at home were more satisfied with their life than those living in an institution. They rated their quality of life higher than those living in an institution (7.2 vs 5.6; $p=0.0052$). Of those living at home, there was a trend for patients in California or Illinois to be more satisfied with their quality of life than those in Ohio, Pennsylvania, or West Virginia (8.0 vs 5.9; $p=0.12$). Patients who had insurance through a health maintenance organization tended to be more satisfied with their QOL than those who had either private or public (Medicaid) insurance (8.1 vs 6.8 vs 5.9; $p=0.11$). All the patients who had insurance with a health maintenance organization (HMO) lived at home, and 11 of the 12 lived in California. Eighty-six percent of

Table 1—Demographic Characteristics of Patients With ALS Receiving Long-term Mechanical Ventilation (n=50)

Characteristic	No. (%)
Mean age, yr (range)	59 (30-88)
Gender	
Men	34 (68)
Women	16 (32)
Education	
Some high school	5 (10)
High school graduate	10 (20)
College	13 (27)
College graduate	15 (31)
Graduate degree	6 (12)
Mean duration of ALS, mo (range)	71 (7-195)
Mean duration of LTMV, mo (range)	36 (2-159)

patients living at home said they would choose LTMV again compared with 69% living in an institution, but this difference did not reach statistical significance ($p=0.22$). Fifty-one percent of patients living at home said they would want to undergo cardiopulmonary resuscitation (CPR) compared with 23% in an institution ($p=0.11$). There was no difference in satisfaction with QOL based on education or financial means.

All 7 patients being ventilated by noninvasive means said they would choose to start LTMV again, and their mean score for quality of life was 7.3.

The 8 patients who had not personally given consent for the initiation of LTMV were not nearly so satisfied with the decision as the 42 who had. Only 3 of the 8 (37.5%) would choose LTMV again compared with 37 of the 42 (88%) who had consented themselves ($p=0.005$), and their mean score for their satisfaction with their QOL was lower (5.0 vs 6.9; $p=0.13$).

Advance Directives

Forty-eight patients answered questions about advance directives. Thirty-eight (79%) had completed a written advance directive. Three created one before the diagnosis of ALS, 17 after the diagnosis of ALS but

Table 2—Functional Status of Patients With ALS (n=50)

Status	%
Communication	
Talks or mouths words	42
Eye blinks	24
Computer assisted	18
Other*	16
Motor function	
Quadriplegic	46
Some use of arms	42
Some use of legs	36
Feeding tube	72

*Communication board, electric larynx, or handwritten answers.

Table 3—Advance Directives Regarding LTMV and CPR* (n=50)

Directives	%
Would want to stop LTMV under certain circumstances	76
Permanent unconsciousness	68
Inability to communicate	42
Burdensome to family	24
No caregiver help available	24
Insufficient funds	18
Loss of insurance	16
LTMV wishes written into advance directive	66
Would not want CPR	58

before initiating LTMV, and 18 after starting LTMV. Of the 10 patients who had not completed a written advance directive, only 2 (4% of the 50) did not want to execute one.

Most patients would want to stop LTMV under certain circumstances, and 58% did not want to undergo CPR (Table 3). Patients who wanted to stop LTMV under certain circumstances and who had completed a written advance directive were more likely to have verbally informed their family and physician of their preference than those who had not completed an advance directive (22/29 [76%] vs 2/7 [29%]; $p=0.05$). Nineteen of 29 patients (66%) wrote into their advance directives their preference for stopping LTMV under certain circumstances. Patients were more likely to have expressed their preferences about LTMV and CPR to their families than to their physicians (Table 4).

Family Attitudes Toward Mechanical Ventilation

Of the 36 families who cared for the patient at home, 15 (42%) considered having the patient at home receiving LTMV a major burden, because it changed their entire life and was very stressful. Twenty-eight family caregivers (78%) indicated that insurance was “essential” for them to be able to afford LTMV. Thirty family caregivers (83%) would encourage their family member with ALS to choose LTMV again.

Expenses at Home and in Institutions

The mean yearly expense of LTMV was \$180,120, with a range of \$696 (a patient receiving noninvasive

Table 4—Patient Communications of Oral Advance Directives About LTMV and CPR to Families and Physicians

Oral Advance Directive	Family, %	Physician, %	p Value
Stop LTMV under conditions (n=38)	53	26	0.033
Withhold CPR (n=47)	70	34	0.0014

ventilation at home who was completely cared for by family without nursing help and who had purchased the ventilator outright) to \$1,080,000 (a patient in a hospital). On average, 91% of patient expenses were covered by insurance. Fifty-four percent of patients had more than 1 type of insurance: 44% had private insurance, 42% had Medicare, 26% had Medicaid, and 24% had managed care (all but 1 of these were Kaiser Permanente). The mean yearly out-of-pocket expense to families was \$10,356 with a range of \$0 to \$240,000.

Thirty-six patients underwent LTMV at home and 14 in an institution. There were significant differences between the patients treated at home vs those in institutions (Table 5). Patients being treated in institutions tended to be single, widowed, or divorced, and to not have caregivers available to help them with LTMV at home.

DISCUSSION

This study contributes new information about four aspects of the care of patients with ALS receiving LTMV: the decision-making process that results in LTMV being started; patients' use of advance directives; patient preferences for the withdrawal of LTMV under certain circumstances; and the divergent attitudes and outcomes—including costs—of patients treated in an institution compared with those treated at home.

Most patients reported they were not well prepared to reach a decision about LTMV. Only three quarters were aware they would likely develop respiratory failure, and only 48% said they had discussed this possibility with a physician. Although patients had ALS for an average of 3 years before starting LTMV, only 21 patients (42%) had made the decision for LTMV in advance of a crisis. Twenty-one consented in an emergency. Eight patients were placed on a regimen of LTMV without their consent, and five of these eight said they would not want to undergo it if they could make the decision over again. Because most patients

Table 5—Comparison of Patients With ALS Receiving Mechanical Ventilation at Home and in an Institution

	Home (n=36)	Institution (n=14)	p Value
Expenses per year, \$	136,560	366,852	0.0018
Private insurance, %	91	8	<0.0001
Insurance coverage >94% of expenses, %	64	100	0.042
Education beyond high school, %	80	43	0.017
Men, %	75	50	0.11
QOL, mean*	7.2	5.6	0.0052

*QOL=satisfaction with QOL on a 10-point scale with 10 being very satisfied.

had not made a decision about LTMV in advance and because some regretted the decision that was made for them, physicians who care for ALS patients should discuss the eventual likelihood of respiratory failure with these patients and inform them about the physical, psychosocial, and financial aspects of LTMV to assure that only patients who desire LTMV are started on it.

These discussions have not been held in the past for several reasons. First, physicians' communicative practices tend to concentrate more on the immediate and the known than on that which is less certain for the particular patient in the future.²³ Second, physicians are reluctant to convey bad news,²⁴ and patients with ALS may want to avoid discussion of future disease progression,⁶ even though such discussions are essential to good decision making and care. Third, it may not be clear who is responsible to initiate such a discussion—the primary care physician, the neurologist, the pulmonologist, the nurse specialist, or the social worker—and consequently it may not occur at all. In this regard, a team approach to the care of these patients with clearly delineated responsibilities is helpful.

Our study indicates that, unlike the general patient population^{25,26} or even patients with a specific chronic life-threatening disease,²⁷ advance directives are widely used by ALS patients receiving LTMV. Because only 6% had executed an advance directive prior to diagnosis of ALS, yet 76% had one at the time of the study, apparently patient anticipation of a life-threatening situation after diagnosis of ALS or after initiation of LTMV led patients to complete an advance directive. Furthermore, of those who had not completed one, all but two indicated that they wanted to do so. The attitude of neurologists and chest physicians to encourage patients to complete an advance directive may have influenced patients' decisions.^{7,19,28} However, the advance directives were not being used to their maximum advantage, because one third of patients had not included specific preferences about stopping LTMV.

The process of advance care planning that led to the completion of the advance directives had a beneficial effect on communication between patients and caregivers—both physicians and family—because more patients who had completed advance directives reported discussing their preferences to stop LTMV under certain circumstances with their caregivers than those who had not.

Most patients in this study wanted to place limits on the use of LTMV. In common with most elderly patients²⁹⁻³¹ but in contrast with other patient populations,^{32,33} the majority also did not want CPR. Although the American Academy of Neurology, the American College of Chest Physicians, and the Society of Critical Care Medicine have stated that physicians have an

ethical obligation to respect the wishes of competent and previously competent patients who have indicated orally or in writing their desire to have life support withdrawn,^{28,34,35} most patients had not discussed these matters with their physicians even though only physicians can legally issue an order to withdraw LTMV or withhold CPR.

The essential need for patients to communicate their wishes to have life support limited is underscored by our finding that six patients receiving LTMV had progressed to a totally locked-in state. The only way for physicians to ensure that they know and respect their patients' wishes is to discuss with patients circumstances in which they might want LTMV stopped and to ask them their preferences.

Recently researchers have noted a substantial increase in the number of patients receiving LTMV in institutional settings,³⁶ including a striking rise in ALS patients (Alexander B. Adams, MPH, personal communication, February 21, 1995). This trend is troubling because our study demonstrated important differences in both cost and patient outcomes for patients being treated in an institution vs those being treated at home. In our study, all but one of the patients being treated in an institution were supported by Medicaid or a state agency, and the mean expenses per year for treatment in this setting, \$366,852, were almost 3 times higher than those for patients treated at home. To lower costs, home-based LTMV care alternatives to institutional treatment have been utilized in California and New York. These states now allow the employment of trained unlicensed personal care attendants for treatment of patients receiving LTMV at home.³⁷⁻³⁹

We also documented that patients with ALS receiving LTMV at home were more satisfied with the quality of their lives than those living in an institution. Two previous studies have indicated that ALS patients view life on LTMV in a nursing home negatively.^{4,27} Patients living at home in California and Illinois seemed to be the most satisfied, probably because these patients were treated through programs that have a team approach to managing and supporting patients receiving home mechanical ventilation and their families.

There are several limitations to this study. First, we were unable to interview one third (25) of the patients with ALS receiving LTMV that we identified, half (13 of 25) of whom were being treated in institutions. We cannot comment on the 11 patients who died prior to an interview, but it is almost certain that the attitudes toward life on LTMV of the other 14 patients (8 who refused and 6 who were totally locked in) would have been less positive than those of the patients we interviewed. We base this conclusion on the unfavorable comments of the families of patients who refused to be interviewed, on the preferences of many patients in our

study to stop LTMV if they became locked in, and on the lower satisfaction with QOL reported by the patients we interviewed in institutions. Second, in the regions and the home ventilator program in this study, there are experienced resource personnel available for those who chose LTMV. Because of this support, our patient attitudes might not be representative of those receiving LTMV throughout the country. Third, since four different investigators conducted interviews, there is the possibility of interviewer bias. However, this bias was minimized, because the interview was conducted from a script with a standard set of questions, and the responses were recorded verbatim.

CONCLUSION

Earlier and better communication between physician and patient is needed so that ALS patients can decide about LTMV in advance. In this communication process, information about the patient's expected course, the burdens to the family, and the major expenses involved need to be disclosed. For patients who choose LTMV, physicians need to ask about limits to LTMV and to encourage completion of written advance directives that state the patient's preferences regarding stopping LTMV, because most want to stop LTMV under certain circumstances and some will become unable to communicate. Because most families are either unable to care for the patient at home or else consider it a major burden and because home-based LTMV costs on average one third of the amount of LTMV in an institution, more assistance needs to be provided to families.

Finally, to respect individual patient preferences in advance care planning in view of the lower patient satisfaction associated with institutional care, ALS patients should be asked whether they would want to refuse or stop LTMV if receiving it would require admission to a long-term care hospital or nursing home.

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