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Wish to die in end-stage ALS

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Abstract

Background—In retrospective studies, estimates of hastened dying among seriously ill patients range from <2% in one national survey to as much as 20% in end-stage disease cohorts.

Objective—To examine, in prospective studies, dying patients in the months before death, in order to understand the wish to die.

Methods—Patients with advanced ALS with a high likelihood of death or need for tracheostomy within 6 months were identified. Patients were assessed monthly with an extensive psychosocial interview, including a diagnostic interview for depression. Family caregivers were interviewed on the same schedule and also after patient deaths.

Results—Eighty patients with ALS were enrolled, 63% of eligible patients; 53 died over follow-up. Ten (18.9%) of the 53 expressed the wish to die, and 3 (5.7%) hastened dying. Patients expressing the wish to die did not differ in sociodemographic features, ALS severity, or perceived burden of family caregivers. They were more likely to meet criteria for depression, but differences were smaller when suicidality was excluded from the depression interview. Patients who expressed the wish to die reported less optimism, less comfort in religion, and greater hopelessness. Compared with patients unable to act on the wish to die, patients who hastened dying reported reduction in suffering and increased perception of control over the disease in the final weeks of life.

Conclusion—These findings suggest caution in concluding that the desire to hasten dying in end-stage disease is simply a feature of depression.

To what extent does the seriously ill patient contemplate the time, place, or circumstances of an impending death? Some patients avoid any thought of death, but others have clear ideas that death could be preferable to the suffering and disability of end-stage disease. These patients think about ending life or take a further step and discuss it with someone or go further still and arrange for death to occur before it would without intervention. The rationality of the wish to die in such cases is subject to debate. Is it pathologic, an expression of suffering and poor mental health? Or could it be a reasonable choice to end suffering? We conducted a prospective study of patients with late-stage ALS to learn more about the wish to die.

Most studies of patients at the end of life have been limited to retrospective accounts. Investigators begin by identifying patients who died and then interview physicians and nurses[1,2] or family caregivers[3] to try to reconstruct the patients' interest in hastening death.

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Reasons for this approach are clear. It is difficult to know who will die, and even when these patients can be identified, it is difficult to recruit them for studies of "end-of-life care." However, starting with decedents and working backward does not reliably capture patterns of patient choice with impending death. The retrospective approach includes patients who die unexpectedly and does not capture variation in the length of time patients have been diagnosed with a terminal disease.[4]

Still, retrospective studies suggest that patients near the end of life do express the wish to die and may act to hasten dying. For example, one-third of Oregon hospice nurses had cared for a patient who had voluntarily stopped eating and drinking within a 4-year period.[1] About 20% of hospice nurses in Oregon reported that patients sought lethal prescriptions, even if they did not use them.[5] The Oregon studies avoided some of the difficulties of the retrospective design because they involved patients receiving hospice care. In contrast, retrospective studies involving outpatients reported lower prevalence of the wish to die. In one national survey of patients identified as terminal by their physicians (which excluded Oregon), only 10.6% thought about ending their lives and 3.1% discussed the option with someone. Among 256 deaths in that sample, fewer than 2% took actions to hasten death.[3] In an Oregon sample, about 2% of dying patients talked to a doctor about the wish to hasten death, but 15% discussed this wish with family.[6]

We have not been able to identify studies that examined dying patients prospectively to evaluate the wish to die. The prospective design offers the important advantage of assessing patient preferences throughout the months before death. It also allows researchers to establish features of the death through interviews with caregivers shortly after the death. We report results of a prospective study of patients with advanced ALS who were followed monthly with an extensive psychosocial interview. Family caregivers were interviewed on the same schedule and also after the death. We undertook this study to establish 1) if the wish to die is associated with depression, 2) if family caregivers are aware of the patient's wishes to die and whether they support or challenge those wishes, and 3) the extent to which patients are able to act on this wish.

Methods

Sample

We interviewed patients with advanced ALS who had a high likelihood of dying within 6 months of study enrollment. Over 90% of patients were enrolled from the Eleanor and Lou Gehrig MDA/ALS Research Center at Columbia University; other patients were enrolled from nearby clinics and hospices. The clinic coordinator identified potential participants who met El Escorial criteria for definite or probable ALS[7] and whose forced vital capacity was <50% of predicted, a value related to risk of hospice admission and death or need for mechanical ventilation within 6 months.[8] Eligible patients did not meet criteria for dementia, spoke English, had an unpaid caregiver who was available for interview, were not using mechanical ventilation at baseline, could communicate at least "yes" and "no," and lived within a 3-hour drive from the medical center. The study began in January 2000 and ended in June 2004. The Institutional Review Boards of Columbia–Presbyterian Medical Center and the New York State Psychiatric Institute approved the research protocol. Given the sensitive nature of the study, we obtained a certificate of confidentiality from the National Institute of Mental Health to protect researchers and participants in the case of potential subpoena of research data.

Procedures

The clinic coordinator identified potential participants, described the study to patients and caregivers, and obtained consent for the research team to make contact. The principal

investigator then called for further explanation, answered questions about the study, and obtained verbal consent. Written informed consent from patients and caregivers was obtained during a home visit, when the baseline interview was conducted. Interviews were scheduled at 1-month intervals until patients met a study endpoint of tracheostomy or death. Patients and caregivers completed separate interviews on the same schedule. Details on the concordance of patient and caregiver reports have been reported.[9] Caregivers also completed an interview after the death of patients.

Measures

To assess the severity of ALS, patients completed the ALS Functional Rating Scale (ALSFRS) [10] at each assessment. The ALSFRS comprises 12 items covering four domains: bulbar functions (speech, salivation, swallowing), fine motor skills (handwriting, handling utensils, dressing/hygiene), gross motor skills (turning in bed, walking, climbing stairs), and respiratory status (breathing). Each item is rated on a 5-point scale, and the sum is computed. Lower scores indicate greater disability.

To assess end-of-life decision making and interest in hastened death, patients completed questions used in a national survey of terminally ill patients.[3] These questions ask the patient "Have you seriously thought about taking your life?" and, further, if they have "discussed taking your life or asking your doctor or others to end your life." Other questions also elicit preferences for end-of-life care.

To assess symptoms of depression, interviewers administered the Beck Depression Inventory[11] (BDI) and Patient Health Questionnaire[12] (PHQ). The BDI is the standard self-rating scale for the presence and severity of depressive symptoms. The PHQ assesses Diagnostic and Statistical Manual for Mental Disorders (4th ed.; DSM-IV) criteria for major and minor depressive disorder. Whereas the Structured Clinical Interview for DSM-IV is the gold standard diagnostic evaluation in psychiatry, it requires interactive queries and follow-up probes. A full diagnostic interview was not feasible in our ALS patients because 40% were unable to speak even at baseline. A clinical psychologist reviewed all PHQ assessments to assign diagnoses consistent with criteria. The PHQ includes sleep, appetite, and motor disturbance as symptoms of depression. In cases where patients attributed these problems to ALS rather than mood disorders, we dropped the items to compute a prorated PHQ total score.

Patients completed the Schedule of Attitudes toward Hastened Death[13] (SAHD) to assess tolerability of symptoms and desire for death and the Beck Hopelessness Scale[14] (BHS) to assess pessimism about the future. Higher scores in the mental health measures indicate greater symptom burden.

To ensure that patients even quite close to death would be able to be evaluated, we administered a set of Visual Analog Scales representing the major domains of interest. Both positive (e.g., wish to live, comfort in spiritual concerns) and negative (e.g., suffering, depression, desire to hasten death) states were assessed. Patients were also asked to rate how burdened they thought their caregiver was in providing care. Each item was read, and the respondent was asked to rate degree of agreement on a 10-point scale ranging from "absent or not at all" to "always or nearly always."

Outcomes

Caregivers were seen after the death of the patient and were asked about the setting of the death (e.g., was the death peaceful? Were key people there?) and their response to it (e.g., sadness, guilt, if they were at peace). With respect to terminal care, caregivers were asked the following set of questions: "Did you increase the dose of any medicine at the end? Was it intended to

make the patient more comfortable? Was it intended to move things along? Was a physician involved?" Responses were recorded verbatim, and most interviews were audio-taped.

We used results from the end-of-life questionnaire,[3] patient reports on the Visual Analog Scale measures, and caregiver reports from the bereavement interview to define the wish to die and cases of hastened death. To be considered a case of hastened death, patients were required to meet two conditions: 1) The patient had to state in an interview before the death that he or she strongly endorsed ending life, which we defined as a score of ≥8 on the 10-point Visual Analog Scale measure, or state that he or she had "seriously discussed taking [his/her] life or asking [his/her] doctor to end [his/her] life"; and 2) an action had to be taken with the intent to relieve suffering and hasten the death. Patients meeting only the first condition were considered to have expressed a wish to die. The second condition was established in the caregiver interview, where caregivers reported that sedatives were increased at some point "to move things along" before the period of active dying had begun. The research team reviewed transcripts from the interview and reached consensus on cases of hastened death.

Analyses

Patients who expressed a wish to die and those who did not were compared at baseline using χ^2 to test for differences in categorical measures and *t* tests to assess differences in continuous measures. Repeated measures analysis of variance models were developed to assess change in the period preceding death.

Results

One hundred forty-four patients were deemed eligible. Forty-seven refused to participate, and 17 died before the first interview. Eighty patients entered the study, yielding a participation rate of 63% (80/[80 + 47]). Participants and refusers did not differ in incident tracheostomy (participants 13.8%, refusers 21.3%; $p = 0.48$) or in hospice use over follow-up (59 vs 57%). Among the 80 patients, 79 had a caregiver who was interviewed at least once.

Fifty-three (66.3%) of the 80 patients enrolled died in the follow-up period, 11 (13.8%) opted for tracheostomy and permanent mechanical ventilation, 10 were alive at the end of follow-up, and 6 dropped out of the study after completing initial assessments. This report focuses on the 53 patients who died. Of these, 23 (43.4%) thought about ending their life and 10 (18.9%) expressed the wish to die to others. Three patients (5.7%) met criteria for hastened death (see figure E-1 on the *Neurology* Web site at www.neurology.org).

In the three cases of hastened death, family caregivers reported that patients requested relief from suffering and persisted in this request even when told by the hospice team that palliation would likely have the secondary effect of reducing the strength of respiratory muscles and hastening death. In these cases, the hospice team titrated sedatives, progressing from oral to transdermal morphine preparations, usually for 2 to 3 days. Family caregivers administered morphine by mouth and by transdermal patches (usually fentanyl) under hospice guidance. Other deaths did not involve use of sedatives or involved sedatives when patients were already within 24 hours of death according to hospice personnel.

Differences between patients who expressed the wish to die and patients who did not

The 10 patients who expressed a wish to die did not differ in study contact from the other 43 patients who died during follow-up (table 1). Times from enrollment to death and also from last assessment to death were similar in the two groups. Both groups were followed for 4 to 5 months before death and were last seen, on average, about 1 month before death. Patients in each group were similar in time from diagnosis to study enrollment (1.2 and 1.5 years) and did

not significantly differ in days of hospice care. Sixty percent of the group who wished to die, and 48.8% of other patients who died used hospice at baseline, a nonsignificant difference.

The groups were also similar in sociodemographic features and level of disability (table 2). Patients who hastened death were not significantly more likely to be male, older, more educated, or live alone, and they did not have more unmet needs or use fewer services than other patients. The two groups did not significantly differ at baseline in mean ALSFRS scores, in bulbar symptoms (speech, swallowing, and salivation), or in severity of dyspnea. The two groups also did not significantly differ in ratings of how burdened they thought their families were in providing care.

Because of research showing a high prevalence of frontotemporal dementia in people with ALS,[15] we asked caregivers to rate patient cognitive ability such as the ability to follow a plot on television and emotional lability. Patients who expressed a wish to die did not differ from other patients according to these caregiver reports (data available upon request).

Patients who expressed a wish to die were less likely at baseline to use interventions to address swallowing or breathing difficulties. Feeding tube (percutaneous endoscopic gastrostomy) and nasal ventilation (bilevel positive pressure ventilation) use were lower in this group, significantly so in the case of nasal ventilation. None of the patients who expressed a wish to die used nasal ventilation compared with more than half of the other patients who died ($p < 0.01$).

Already at baseline, some 4 to 5 months before death, patients who expressed the wish to die over follow-up were significantly more likely to admit to thinking about taking their lives and were more likely to have discussed it with someone. Differences were large: Ninety percent of these patients had thought about taking their lives, and 50% had discussed it; in other patients, only 20% ($p < 0.001$) had considered it, and 7.5% ($p < 0.05$) discussed it. These differences were confirmed in Visual Analog Scale ratings of the “wish to live.” Patients who expressed the wish to die scored lower (4.7 vs 8.2; $p < 0.05$). Patients who expressed a wish to die also scored significantly higher on the SAHD (12.6 vs 4.8; $p < 0.001$). These patients also considered religion less important in their lives (3.3 vs 6.3 on the Visual Analog Scale; $p < 0.05$).

Patients who expressed a wish to die over follow-up were more likely to report depressive symptoms at baseline (table 3), as shown in the PHQ computed total score (13.3 vs 8.0; $p < 0.01$) and clinician diagnosis (40 vs 7.1% major depression), the BDI (21.4 vs 12.8; $p < 0.01$), and Visual Analog Scale rating of “How depressed are you today?” (6.1 vs 3.2; $p < 0.01$). However, differences in particular symptoms assessed in the PHQ achieved statistical significance only in the case of “think you would be better off dead.” Forty percent of patients expressing a wish to die over follow-up said they felt this way everyday compared with 8.0% in other patients ($p < 0.01$). Patients expressing the wish to die also reported significantly more hopelessness and less optimism, as shown by individual items in the BHS.

Preferences for aggressive care between the two groups were similar. Although patients expressing the wish to die were more likely to reject cardiopulmonary resuscitation and surgery as well as less invasive interventions, these differences did not achieve significance (data available upon request).

Differences over follow-up between patients who expressed the wish to die and patients who did not

Thirty-eight of the 53 patients who died were seen more than once: 9 in the wish-to-die group and 29 other patients (see table 1). In patients seen multiple times, disease progression in the final months of life did not differ between patients who expressed a wish to die and patients

who did not. Total ALSFRS scores declined from 26.6 to 20.7 in patients who expressed a wish to die and from 24.4 to 15.8 in patients who did not. In a repeated measures analysis (with time of measurement and wish-to-die status as predictors), the time effect was significant ($p < 0.001$), but neither the group nor the group-by-time interaction was significant.

At the last assessment before death, patients who expressed the wish to die were significantly more likely to report severe depressive symptoms. Five of the nine patients (55.6%) reported they had lost pleasure, felt down or depressed, and thought they would be better off dead nearly everyday in the last 2 weeks. Only 1 of the 29 patients (3.4%) who did not express a wish to die reported this level of depressive symptoms. The mean PHQ sum in the two groups was 15.0 and 5.5 ($p < 0.01$.

Patients who expressed a wish to die continued to assert greater interest in hastened death (8.2 vs 2.5; $p < 0.001$) and less of a wish to live (3.3 vs 7.7; $p < 0.001$) on Visual Analog Scale measures.

Comparisons between patients who expressed a wish to die but did not act on it and patients who hastened death

The three patients who hastened death were all women, and adult children served as caregivers for two of them. They did not differ significantly in age, education, living arrangement, disability, depressive symptoms, or service use from the seven patients who did not act on the wish to die. They reported greater suffering at baseline (9.3 vs 4.6; $p < 0.01$) but otherwise were similar to patients who did not hasten death. None of the three used feeding tubes compared with two of the seven patients who expressed the wish to die but did not act on it.

When family caregivers were asked if “patient and caregiver agreed about what should happen at the end,” all three of these caregivers reported agreement. Agreement was lower in the group that did not act on the wish to die. Of the seven in this group, two reported disagreement, three agreement, and for two we were unable to establish level of agreement. Caregivers themselves did not differ in the proportion who felt guilty, numb, or anxious with regard to the death.

At the last assessment before death, the two groups did not differ in depressive symptoms, though symptom severity was lower in patients who were able to act on the wish to die (computed PHQ sum: 11.3 vs 16.9, NS).

A comparison of change between baseline and the last assessment before death, however, suggests some differences between the groups. Perceptions of control over the management of ALS increased in patients who hastened death (from 1.0, the lowest possible rating, to 5.3 on the 10-point Visual Analog Scale measure) but remained stable in other patients. Multivariate tests and the group-by-time interaction were significant ($p = 0.04$), suggesting that patients who acted on the wish to die perceived more control over the management of ALS as death approached. Change in suffering followed the same pattern. Patients who ultimately hastened death began with the highest ratings of suffering (9.3), which declined as death approached. By contrast, suffering increased in patients who did not act on the wish to die and also in patients who did not express a wish to die. Again, the time-by-group interaction was significant ($p = 0.007$) (see figures E-2 and E-3).

Discussion

In this sample of people confronting death, patients who expressed a wish to die demonstrated a strong commitment to this choice. For example, when an interviewer asked, “Did you increase the dose of medicine at the end? Was it intended to move things along?” one caregiver responded this way: “Yes, she requested to die. Hospice said they could sedate her and it would

have that effect. She agreed. When I gave her the first dose after that decision, she reached out with her mouth to take it." On the whole, these patients insisted that living was unacceptable with this degree of disability, despite love from their families and excellent care.

The 5.7% prevalence for hastened death in this cohort is similar to the 4% prevalence for physician assistance in dying among ALS patients reported for Oregon.[16] Thus, findings from our sample are consistent with reports from the one US jurisdiction where physician assistance in dying is documented. Moreover, the prevalence of 18.9% for the wish to die is consistent with the 20% combined euthanasia and physician-assisted suicide prevalence reported for ALS patients in the Netherlands.[17]

Similar findings have been reported for other patients near death, including people with end-stage cancer,[18] AIDS,[19] ALS,[20,21] and those receiving hospice and in-home palliative care.[22] These studies suggest that one-fourth to one-half of patients consider seeking assistance in dying. In a study conducted before the introduction of antiretroviral medications, as many as 12% of an AIDS sample received increases in medications designed to end suffering that also hastened dying.[19]

Patients in our sample who expressed the wish to die did not differ from other dying patients in socio-demographic features, access to services, or disease severity. However, in one sample of patients who died from ALS, family caregivers reported more insomnia, pain, and discomfort in patients who said they "would consider taking a prescription for a medication whose sole purpose was to end my life."[21] Caregivers in that study also said these patients were more likely to worry about being a burden on their families. The same group found that male and more highly educated ALS patients were more likely to consider assisted suicide.[20] We did not find over-representation of men and more educated patients in the group that expressed the wish to die, but findings from our sample confirm the report of greater hopelessness and interest in suicide and less importance of religion in such patients.

ALS patients in our sample who expressed the wish to die were less likely to use nasal ventilation. None of the 10 patients who expressed the wish to die used nasal ventilation, whereas more than half of the other patients who died did. Although nasal ventilation has not been shown consistently to extend survival in ALS, its use may demonstrate continued interest in living.

People in our sample who expressed the wish to die were more likely to meet criteria for depressive disorders but only because of their more frequent reports that they "would be better off dead." These patients also reported less optimism, less comfort in religion, and greater hopelessness. Together, these findings suggest that depression in end-stage disease is difficult to separate from existential suffering, a more general loss of meaning and purpose.[23,24] This suffering leads patients to question why they should continue to live. Indeed, a common statement from patients who expressed the wish to die was that life with ALS was not "life."

This finding helps shed light on the association between the wish to die and depression in end-stage disease. An association between the desire to hasten death and depression has been reported for people with end-stage cancer,[25–27] cancer pain,[28] HIV infection,[29] multiple sclerosis,[30] and in patients who request assistance in dying.[2] Our findings suggest caution in concluding that the desire to hasten dying is simply a feature of depression. Rather, the wish to die may be part of a broader syndrome of "end-of-life despair."[31] End-of-life despair includes suffering, loss of interest in living, absence of pleasure, loss of interest in activity, and pessimism. Religious sensibility and spirituality are much lower in patients who demonstrate despair, again suggesting the existential roots of the wish to die in end-stage disease. For these patients, gaining control over dying brought mental health benefit, as demonstrated by reduction in suffering and increased perception of control over the disease in the final weeks

of life. Neurologists providing palliative care may want to explore ways to give patients reporting such despair greater control at the end of life. Control can be considered an element of dignity at the end of life.[32]

In our sample, patients who expressed the wish to die and those who acted on that wish differed mainly in family support for hastening death. The three patients who hastened death all had familial approval for this course. Among patients who expressed the wish to die but did not act on it, caregiver reports of agreement with the patient about "what should happen at the end" were less common. Our findings suggest that some of the other patients who expressed the wish to die might have hastened death if their families had supported the wish.

Aside from the difference in patient and caregiver commitment to the choice of hastened death, both sets of patients received sedatives to alleviate dyspnea and anxiety. Family members in the postdeath interview were unable to specify details of sedative use, so it is unclear if the type or amount of sedatives differed between the groups or if the interval between initiation of sedation and death differed. However, family members in the group that hastened death were more likely to administer sedatives themselves (three vs two of seven). Whereas both sets of patients could be considered cases of "terminal sedation," the group that acted on the wish to die differed in the explicit request by patients and support from families for early death. Consistent with our finding that 3 of 10 patients who wished to die made an explicit request for sedatives to hasten dying, 33% of cases of terminal sedation in the Netherlands involved explicit requests by patients.[33]

We note limitations in our study design. For example, we were able to enroll only about two-thirds of the patients we approached, and about 10% of participants dropped out after initial interviews. We could not interview physicians, hospice nurses, or other members of multidisciplinary care teams to determine their roles in patient decision making. However, we did complete clinical interviews with patients over the last months of life, including a diagnostic interview for depression, and we interviewed caregivers after the death.

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Table 1

Timing of initial and final assessments, deaths: living with ALS cohort

	Expressed wish to die over follow-up, n = 10	Did not express wish, n = 43
Days from ALS diagnosis to study enrollment		
Mean (SD)	420.1 (313)	566.7 (399)
Median	324	428
Days between initial assessment and death		
Mean (SD)	122.6 (50.0)	166.9 (165)
Median	78	112
Days between final assessment and death		
Mean (SD)	39.6 (39)	36.7 (33)
Median	28	29
Follow-up status		
Baseline assessment only, n (%)	1 (10)	14 (32.6)
2–3 assessments, n (%)	7 (70)	11 (25.6)
4+ assessments, n (%)	2 (20)	18 (41.8)
Days on hospice		
Mean (SD)	125.9 (106)	161.5 (147)
Median	87	132
Using hospice at baseline, %	60.0	48.8

All differences not significant.

Table 2

Baseline assessment, deaths: living with ALS cohort

	Expressed wish to die over follow-up, n = 10	Did not express wish, n = 43
Demographics		
Age, y	69.4	65.4
Male, %	70.0	51.2
White, %	80.0	90.7
Education, % college graduate	44.4	40.5
Medicaid or SSI, %	22.0	22.2
Paid home care, including hospice, %	77.8	73.5
Spouse as family caregiver, %	66.7	65.8
Live with family, %	88.9	55.8
Reside in nursing home, %	0.0	2.4
Disability		
ALSFRS, mean	25.8	22.5
Bulbar sum, mean	6.7	6.3
Dyspnea at rest, %	20.0	34.9
Patient rating burden on family, VAS mean	7.7	6.5
Interventions		
Feeding tube, %	20.0	41.5
Nasal ventilation, %	0.0	52.5†
Attitudes toward dying		
Seriously thought about ending life, %	90.0	20.0‡
Seriously discussed ending life, %	50.0	7.5†
Interest hastening death, VAS mean	8.1	4.6
Wish to live, VAS mean	4.7	8.2*
Attitudes toward hastened death, SAHD, mean	12.6	4.8‡
Importance of religion, VAS mean	3.3	6.3*

Data unavailable in some comparisons for one person in hastener group and two people in nonhastener group.

* $p < 0.05$.

† $p < 0.01$.

‡ $p < 0.001$.

SSI = Supplemental Security Income; ALSFRS = ALS Functional Rating Scale; VAS = Visual Analog Scale 1–10 (10 = max);; SAHD = Schedule of Attitudes toward Hastened Death.

Table 3

Mental health and depressive symptoms at baseline, deaths

	Expressed wish to die over follow-up, n = 10	Did not express wish, n = 43
Patient Health Questionnaire, % everyday		
Little interest or pleasure	40	16.7
Feeling down or depressed	30	7.1
Feeling bad about yourself, a failure	10	7.1
Trouble concentrating	20	16.7
Think better off dead	40	2.4†
Patient Health Questionnaire, mean	13.3	8.0†
Clinician rating major depression, %	40.0	7.1*
Currently treated for depression, %	30.0	32.0
Beck Depression Inventory, mean	21.4	12.8†
Beck Hopelessness Scale, 10-item mean	6.6	3.4‡
Beck Hopelessness, %		
Look to future with enthusiasm	14.3	67.6†
Might as well give up	71.4	13.5‡
Enough time to accomplish goals	57.1	62.9
Future seems dark	85.7	40.5*
Past prepared me well for future	71.4	81.1
Only unpleasantness ahead	85.7	27.0†
I will be happier in the future	0.0	52.8†
Things don’t work out for me	71.4	48.6
Faith in future	0.0	60.0†
Look forward to more good than bad times	14.3	63.9*
Visual Analog Scale ratings, mean		
Weariness from ALS	7.7	6.7
Optimism	3.1	5.7*
Anger	4.9	2.9
Control over ALS management	2.2	3.5
Suffering	6.0	3.4
Energy	3.9	5.2
Depression	6.1	3.2†
Endicott Quality of Life, mean		
Overall well-being	2.8	3.6
Contentment	2.9	3.7

Visual Analog Scale, 1–10 rating (10 = max); Endicott Scale, 1–5 scale (5 = max); Beck Hopelessness Scale, n = 7 wish to die, n = 37 no wish.

* $p < 0.05$.

† $p < 0.01$.

‡ $p < 0.001$.