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Amyotroph Lateral Scler. Author manuscript; available in PMC 2010 June 21.

Published in final edited form as:
Amyotroph Lateral Scler. 2009 ; 10(5-6): 448–455. doi:10.3109/17482960802459889.

How common is depression among ALS caregivers? A longitudinal study

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Abstract

Our objective was to assess the impact of personal, situational and patient characteristics on mood, and changes over time, among ALS caregivers. Seventy-one patient-caregiver pairs were interviewed once and 51 (72%) monthly until endpoints of death or tracheostomy for long-term mechanical ventilation (LTMV). Depressive symptoms and DSM-IV disorders, coping strategies, caregiver burden, satisfaction with care-giving, and patient disease severity were assessed. At baseline, 13% of caregivers had major depression, and 10% had minor depression. Rates declined at last visit before death or LTMV (median interval three months), as did depressive symptoms. Correlates of caregiver depression included reliance on avoidance, perceived burden, fatigue, and feeling that the patient was critical and unappreciative. Half of the 14 caregivers of patients who planned LTMV were depressed at baseline, declining to 8% at endpoint, versus 16% (9/57) among caregivers of patients who died, declining non-significantly to 11%. While few personal or situational factors were correlated with caregiver distress, patients' plans and degree of supportiveness influenced caregiver mood. Verbal comments of caregivers clarified the distinction between sadness and psychiatric depression. The high baseline rate of depression among caregivers of patients who planned tracheostomy decreased as caregivers instituted major changes in patient care or personal counseling.

Keywords

ALS; caregivers; depression; LTMV; stressors

Introduction

Family caregivers are key figures in ALS care. They provide emotional and physical support for patients and often play a central role in clinical decision making. As patients proceed from diagnosis to progressive disability, and ultimately to decisions about death or tracheostomy, families make a parallel journey.

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Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Although an extensive literature documents the levels of distress among caregivers of patients with progressive or terminal illness, less attention has been directed to determinants of caregiver mood and adjustment, including the patient's influence. In the general medical literature, most studies focus on caregivers of patients with dementia (1,2). Care-givers of patients with AIDS (3), cancer (4), brain injury (5,6), and multiple sclerosis (7) also show high levels of distress, sadness and depressive symptoms. However, distress among caregivers is not universal, leading to questions about factors that might protect the caregiver's well-being or that are associated with lower levels of distress.

No caregivers are challenged more than those of ALS patients (8). Patients with ALS need increasing assistance with all activities of daily living, their ability to speak or write diminishes, and the physical demands of their care become more onerous just when it becomes riskier to leave them unattended. Even with paid assistance, it has been estimated that ALS caregivers spend 11 h every day with the patient (9) and feel a strong sense of responsibility for their care and indeed survival, especially when mechanical ventilation is used.

Studies of ALS patients and caregivers conducted on a single occasion provide information about risk and protective factors for ALS care-givers, but causal relationships cannot be determined without knowing antecedents. The most commonly reported associations with caregiver burden are the extent and duration of the patient's functional impairment (10-12), although Lo Coco et al. (13) did not observe this association. Cognitive impairment, apathy, diminished intimacy, communication problems, and emotional lability in the patient also have been associated with caregiver distress (10,14).

Goldstein et al. (14) interviewed 50 spousal caregivers of people with ALS, and followed 21 on two additional occasions for about six months apart. Caregivers' perceived burden increased even though anxiety and depression symptoms did not. At baseline, 10% were classified as having a 'moderate mood disturbance', which increased to 19% by the third interview. ALS severity scores and caregiver gender were not related to the mood of caregiver or patient.

Another study (15) evaluated 31 ALS patient-caregiver pairs, nine months apart, to assess depression, burden and quality of life. They found a significant and progressive increase in depressive symptoms among caregivers, although scores remained in the 'not depressed' range. Patient ratings of depression were slightly higher than those of caregivers on both occasions, but the change over time was not significant, and the mean scores also remained within the 'not depressed' range on both occasions. Caregivers reported an increase over time in total burden and emotional burden; quality of life scores did not change. Caregiver depression and burden ratings were significantly correlated.

Findings have been inconsistent about a possible relationship between patient and caregiver depression levels; some investigators (12,16) found an association, while others (17) did not. Gauthier et al. (15) found a positive relationship at study entry but not nine months later. Studies involving care giving for other conditions suggest similarly inconsistent relationships (4,18).

Study goals were as follows: 1) to describe levels of depression and distress among ALS caregivers at study entry, and also to assess changes in mood over time; 2) to identify personal, situational (e.g. insurance, hospice, household income, paid assistance) and paired patient-caregiver characteristics that might influence caregiver distress and satisfaction; and 3) to examine caregiver mood of the patients who chose tracheostomy compared to caregivers of patients who died, both at study entry and final interview.

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Methods

Sample

We studied 80 patients, 95% of whom were recruited from the Eleanor and Lou Gehrig MDA/ALS Research Center at Columbia University (NY). The clinic coordinator identified potential candidates whose forced vital capacity was <50%, a value related to Medicare eligibility for hospice admission and need for mechanical ventilation or death within six months (19). Of 144 consecutive patients identified as potentially eligible, 47 refused participation and 17 died before the first interview; 80 (63%) were enrolled. ‘Refusers’ did not differ from participants on the demographic or medical variables assessed (see 17, Table I, for comparative data). Eligible patients had a non-paid caregiver who agreed to participate, were not using invasive mechanical ventilation at study entry, could communicate at least “yes” and “no”, were not overtly demented, spoke or understood English, and lived within a 3-h drive from our medical center. The study was conducted between 2000 and June 2004.

Measures

Unless otherwise noted, higher scores signify more of the construct indicated by the scale name. More detailed descriptions have been published elsewhere (17).

Patient Health Questionnaire (PHQ-9)—The PHQ-9 (20) was used to assess the nine criteria for major depressive disorder and minor depressive disorder. Presence of 5+ items is required for a diagnosis of major depression, and 3 or 4 for a diagnosis of minor depression. In addition, item scores are summed to generate a numerical score. Diagnoses require, in addition to symptoms, some impairment in functioning.

Beck Depression Inventory Revised (BDI-II) (21)—The BDI is the ‘gold standard’ of self-report scales intended to assess severity of depressive symptoms, if present. Total scores can range from 0 to 63 on the standard 21-item scale. Scores under 14 are considered ‘minimal’; 14–19, mild; 20–28, moderate; and 29+, severe. Scores over 19 indicate possible depression.

Manne scales of positive and negative Dyad support (22)—The scale has seven positive support items (e.g. “showed appreciation for my effort”) and seven negative items (e.g. “seemed impatient with me”). The subscale scores are summed separately, with a range of 7 to 28 each.

Caregiver burden and satisfaction—We used 10 items, five indicators of care-giving burden from the Zarit Burden Scale (23) and five items from Folkman’s measure of caregiver satisfaction (24).

ALSFRS-R (25)—The 12 items of the ALS Functional Rating Scale-Revised assess disease severity in the domains of fine motor, gross motor, bulbar, and respiratory function. Lower scores signify greater disability; scores under 30 signify shorter survival.

Chalder Fatigue Scale (26)—We used the self-report seven-item physical fatigue subscale, scored 1= never/minimal to 6=almost always/severe. Score range is 7 to 42.

Coping—Using 21 items from Folkman’s Ways of Coping scale (27), we examined caregivers’ endorsement of different strategies to deal with stress. Items cover positive appraisal, avoidance, religious faith, and problem solving. Factor analyses did not suggest obvious subscales, so items were considered separately. This was administered only at study baseline.

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In addition to administration of these standardized measures, both patients and caregivers were separately interviewed at monthly intervals until patients died or had a tracheostomy. The interview included open-ended queries to learn about changing circumstances and events since the last study visit. In addition, after every interview, interviewers wrote a narrative that included description of the current patient-caregiver situation, the caregiver's 'adjustment, and psychological status' and the interviewer's overall impressions of how the care-giver was managing.

Procedures

After the clinic coordinator identified possible participants, they were called for description of the study and to give pre-consent for the research team to make contact. They were then called by the principal investigator (SA) for further explanation, and gave their name(s) to interviewers. Interviews were scheduled at the patient's and caregiver's convenience and almost always at home.

Statistical analysis

Categorical data were analyzed using χ^2 tests, and *t*-tests were used for comparison of continuous variables. Pearson correlations were used to analyze relationships between measures of distress and resilience. Repeated measures analyses were used to assess change over time. All tests were two-tailed, $p=0.05$.

We were particularly interested in differences between the baseline assessment and last assessment to see whether mood status is stable or declines with ALS progression. We also examined two subgroups of patient-caregiver pairs based on study endpoint — patients who died during follow-up, and patients who elected tracheostomy for long-term mechanical ventilation (LTMV).

Results

Patients

This report is based on the 71 caregivers of patients who reached the study endpoints of death or LTMV. During the period of observation, 57 patients died and 14 had tracheostomy for LTMV. Of these, caregivers of 38 patients who died and 13 who chose LTMV were seen more than once with a median of three assessments (mean duration of follow-up was 5.3 months, range 2–18 months). While six couples dropped out after the first interview, attrition was largely due to the death of the patient. Comparing the 20 couples without follow-up to the 51 who were seen more than once, mean time to death, respectively, was 46 days (SD=29) and 201 days (SD=158).

Fifty-seven per cent of patients were men. Mean age was 62 years (range 27–85 years); 20% were under 50 years of age and one-third was over 70 years. Eighty-seven per cent were white; the others were African-American, Hispanic, or Asian. Only 8% had less than high school education and 23% had a graduate degree. Catholicism was the most common religion.

Patients were for the most part severely disabled. At study entry, 50% had impaired or absent speech; 45% had excessive saliva, including 15% with constant drooling; 33% used enteral feeding; 40% could not write; and 50% were totally dependent for self care. While only three patients at study entry required 24 h/day use of non-invasive positive pressure ventilation, 53% used it intermittently. The mean ALSFRS-R score at baseline was 23.6 (SD=7.8, range=7–41). Of those seen more than once (n=51), mean ALSFRS-R score at the last study visit was 17.4 (SD=7.4), and 69% were totally dependent for self care. At study entry, 76% of patients (n=51) received help from a paid home attendant, ranging from 1 to 168 h/week (mean= 28, SD=20).

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All patients had health insurance, including Medicare (74%), Medicaid (16%) or private disability insurance (76%).

Caregivers

The mean caregiver age was 57 years (SD=15); 15% were younger than 40 years of age, 50% were aged 40–65 years, and 35% over age 65 years. Seventy-four per cent were women, and 90% were white; the others were African-American, Asian, or Hispanic. Again, Catholicism was the most common religion (41%). Nearly half were college graduates, including 30% with graduate degrees. Median annual household income was $60,000, and 25% reported incomes over $80,000. Forty-nine per cent of caregivers were employed full time or part time at study baseline. The 20 caregivers seen only once were younger (mean age 51 vs. 60 years, p=0.02) and less educated (60% had high school education or less, vs. 29%, p=0.01) than those with follow-up. The two groups did not differ on any other socio-economic indicator, nor did they differ at baseline on measures of distress, coping or support.

In terms of relationship to patient, 63% (n=44) were spouses or partners, 7% (n=5) were offspring, 14% (n=11) were parents, and the others (n=11) were friends or other relatives. Caregivers spent an average of 15 h/day with the patient (SD=8) and 8 h/day providing direct help (SD=7.0; range 0–24). For 38 families there were no out-of-pocket expenses; for the rest, weekly costs ranged from $10 to $1200 per week.

Question 1A: Psychological status of caregivers at baseline

Depressive disorders and symptoms—At baseline, 77% of caregivers (55/71) had no depressive disorder, 10% (n=7/71) had minor depression, and 13% (9/71) had symptoms consistent with major depression based on PHQ diagnostic approximations. This was essentially the same as the rates for patients at their first assessment (72% had no depression diagnosis, 15% had minor depression and 13% had major depression). The mean BDI score was 11.2 (SD=8.7, range=0–49), which is in the ‘minimal symptom’ range, with 12% scoring over 19, the cut-off for likely depression. Among patients, baseline mean BDI score was 13. Limiting the sample to spouses revealed a similar distribution on mental health measures (data not shown).

Question 1B: Change in caregiver mood over time

For the 50 caregivers seen more than once with complete data, depressive disorders declined from first to final visit, from 23% (n=7), to 10% (n=3), including both major and minor depression (FETNS). Trend results were found using the self-report BDI: scores declined from 11.8 (9.0) at study entry to 9.5 (6.7) at final visit, adjusting for duration of follow-up by repeated measures test (F-test, 3.48, p=0.07). Patient depression was largely stable over time: 22% had major or minor depression at baseline and 24% at last assessment. Two of the six patients depressed at baseline remitted, while five of the 39 initially without depression became depressed.

Question 2: Personal and situational correlates of caregiver mood

Personal and situational characteristics—Age, gender, education, income, relationship to patient and marital status were unrelated to caregiver depression. Similarly, caregiver depression was not correlated with access to resources, as indicated by hospice enrollment, family income, or weekly hours of paid help. Among the 21 indicators of coping style, depressed caregivers were less likely to report that they “had a plan of action” or “paid attention to good areas of life” (0.34, p=0.02). They were more likely to endorse the item, “I wished the situation would go away or somehow be over with” (r=+ 0.53, p<0.001) Depressed caregivers reported less satisfaction with every item in the Quality of Life measure, including ratings of

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overall well-being ($r = -(0.44$, $p=0.039$) and life satisfaction (r=−0.47, $p=+0.001$). They also reported significantly more fatigue than non-depressed caregivers (mean=26 (4.8) vs. 19.8 (3.7), $p<0.001$) and greater caregiving burden ($p<0.001$).

Relation between patient characteristics and caregiver depression at baseline—The only significant correlation with caregiver depressive symptoms was the caregiver's (but not the patient's) rating of patient depression. On a visual analog scale (1 to 10) of how depressed caregivers thought patients were, depressed caregivers reported a mean of 6.3 compared to 3.9 among non-depressed caregivers ($p<0.01$). There was a moderate association between ratings of patients' own depression and caregivers' ratings of the patient's depression (r=+0.39 (p<0.001).

Relation between caregiver and patient mood status at baseline—While the rates between patient and caregiver broadly corresponded (phi=0.52, $p=0.02$), this association was due to the large absolute number of dyads with no depression diagnosis (58%). Nine patients and nine caregivers met criteria for major depression but both members met criteria at the same visit in only one pair. Caregiver and patient BDI scores were modestly correlated ($r=+0.36$, $p=0.027$).

Relationship appraisal at baseline—Mean scores rating the positive and negative aspects of their relationship were similar between pairs of patients and caregivers. The correlation between patient and caregiver appraisal of positive support was +0.47 ($p=0.002$) and negative support also +0.47 ($p=0.001$), reflecting moderate agreement about the nature of their relationship. Caregivers reporting depressive symptoms were more likely to report negative appraisals of relationship with the patient (16.5 (SD=5.4) vs. 12.0 (SD=4.5), $t=3.1$, $p=0.003$) and caregiving burden (13.9 (SD 3.2) compared to 8.0 (SD 4.4), $t=4.5$, $p<0.001$). Caregiver depressive symptoms were not associated with satisfaction in caregiving.

Concordance of relationship appraisal as a correlate of caregiver mood—We examined disparities in caregiver and patient appraisals to see if these might be associated with greater depressive symptoms in caregivers. We computed the difference scores between patient and caregiver appraisals of positive and negative support as well as burden, and examined correlations between these differences and level of caregiver depressive symptoms. Disparities in appraisal were not associated with depressive symptoms (data not shown).

Perceptions of burden and satisfaction in care giving—Using visual analog scales, patients were asked how burdened they thought family or friend caregivers were in providing care. Caregivers were asked to rate their burden directly. The two measures were modestly correlated (r=+0.29, $p=0.014$). Depressed caregivers rated their burden as greater than did caregivers who were not depressed (6.3 (SD 3.2) vs. 4.6 (SD 2.9), $t=2.0$, $p=0.046$).

Question 3: Differences at baseline according to patient outcome during follow-up

Baseline—Table I summarizes differences at baseline between caregiver and patient groups according to whether patients died or planned on LTMV over follow-up. (As a rule, patients who opted for LTMV made this decision early in the illness.)

Patients who opted for LTMV were younger (51 (SD=12) vs. 64.5 (SD=13.6), $p<0.01$), and reported higher annual income (58% vs. 19% with income over $80,000, $p<0.01$). Those choosing LTMV were less likely to report depressive symptoms and their caregivers were less likely to report cognitive problems in the patient, but these differences were at trend levels only ($p<0.10$).

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The caregivers of patients who opted for LTMV were more highly educated and more remained employed than caregivers of patients who died. At study entry, they were also more likely to be depressed (including major or minor depression) − 50% vs. 8% of caregivers whose patients died. In addition, they reported more fatigue (23.5 (SD 4.4) vs. 20.5 (SD 5.2), t=1.7,df=56) and more negative appraisals of relationships with patients (15.7 (SD 6.1) vs. 12.6 (SD 4.7) t=1.8, df=54) but these differences were not significant (p<0.10).

Change over time—We then compared caregiver status for the two groups at baseline and the final visit (Table II). At the last assessment, groups did not differ in rates of depressive disorder (8.3% in caregivers of patients choosing LTMV, vs. 10.5% among caregivers whose patients died (X^2 =0.05, p=0.83)). BDI scores declined from 10.4 to 9.4 among caregivers of patients who died, and from 15.9 to 9.8 in caregivers of patients choosing LTMV. In repeated measures analyses, the overall decline was statistically significant (F=6.8, p=0.012) but the two caregiver groups did not differ (F=1.8, p= 0.19). There were also declines in perceived partner support (Manne Scale), as well as fatigue, only among caregivers of LTMV patients.

Using BDI score distributions, we found that two caregivers' initially extremely high scores accounted for the group's elevated baseline BDI ratings; in both cases, their scores decreased dramatically (from 49 to 13 in one case, and from 34 to 1 in the other) because of major changes in circumstances (in the first pair the wife left the patient, her husband, and was replaced by his brother as caregiver; in the other, the patient entered a nursing home thereby relieving the care-giver of daily responsibilities). When these two caregiver scores were excluded, the mean BDI at baseline for the remaining 11 patients did not differ significantly from the final BDI of 10.3 for this subset.

Discussion

Among caregivers of ALS patients, depressive disorders were present at study entry for a sizeable minority of caregivers and the rate remained essentially stable regardless of patient outcome (LTMV or death). Relatively low scores on symptom scales and infrequent diagnoses of psychopathology do not, however, reflect the complete reality of family caregiving in ALS. Qualitative data reveal a more comprehensive picture. For example, when caregivers were asked, "How are you getting along", representative answers were: "To see him deteriorate is terrible", "I'm surviving but it's not getting any easier", "I don't have a life any more", "It's painful, sad, frustrating", "I'm doing it. It's the toughest thing in my life", "Sometimes I'm upset with the world. Sometimes I'm accepting this is God's will". The overall picture is one of realistic appraisal of an extraordinarily difficult situation, reflecting keen awareness of pain in the context of resilience. The predominant picture then is one of distress rather than psychopathology.

In contrast to standard psychiatric nomenclature in which the cause of distress is not considered, some have argued that the diagnosis of major depression should be excluded if symptoms result from major life events (28). The circumstances of ALS care-givers may be considered in this context, particularly since, for some, depression was ameliorated after major changes in care-giving roles.

When asked, "What keeps you going?", several caregivers said knowing that the disease was time limited was helpful: "looking ahead to having a life again", "the knowledge that this will end". Among reported goals were, "to live through this and get my life back together", and "get ready for him to die and think about my future without him".

Correlates of caregiver depression included the caregiver's perception that the patient was not supportive (e.g. "complained about the way I helped with a task", "criticized the way I handled

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the disease or the treatment", "unaffectionate, unappreciative of my efforts, not interested in my well-being"). Another characteristic of depressed caregivers was reliance on avoidance of a difficult situation rather than figuring out what to do about it (problem solving). In a study of caregiver-patient pairs where the patient had cancer, Manne et al. (29) found that partner criticism was associated with negative mood indirectly through avoidant coping strategies such as "I distracted myself with fun things", and positive mood indirectly through positively-focused coping (e.g. "I rediscovered what is important in life"). These findings suggest that patients have an important role in providing positive feedback to the caregiver, and that the dyadic relationship needs to be mutually supportive rather than one-sided where the caregiver 'gives' and the patient is the beneficiary.

We did not find relationships between the patient's degree of disability and caregiver depression or perceived burden (r between ALSFRS and caregiver BDI scores=−0.04, p=0.76; r between ALSFRS and caregiver perceived burden=−.13, p=0.30). In contrast, Goldstein et al. (14) did find an association between greater patient functional impairment (lower scores) and higher caregiver depression scores (r=−0.46, p<0.05), and both Hecht et al. (11) and Chio et al. (12) found positive associations between functional impairment and perceived burden. Perhaps our failure to observe such associations is at least partly attributable to the uniformly low ALSFRS scores of our late-stage patients, all of whom were hospice eligible at study entry. The studies used different measures for both functional impairment and depressive symptoms, which also may modestly contribute to the disparate findings.

We planned to compare the mood status of caregivers whose patients wanted LTMV to the caregivers whose patients died, anticipating that caregivers of patients who died would become increasingly distressed as death approached, while caregivers whose patients planned LTMV would not show increased distress. We actually found a different and initially puzzling pattern: baseline evaluation of caregivers whose patients planned on LTMV was significantly more depressed than the other caregivers, but this difference was lost over time. Distress levels declined in both groups but more so in caregivers of patients planning LTMV. This seems counterintuitive, but a possible explanation is that the caregivers of future LTMV patients may recognize that relief does not lie in the foreseeable future, and therefore may make major changes that provide respite. In fact, this was the case for virtually all caregivers of pre-tracheostomy patients who were initially depressed but whose mood improved. Among these depressed 'pre-tracheostomy' caregivers, one wife with a two-year old child left her husband, the patient, and was replaced as caregiver by his brother. In another family, a distraught wife finally obtained relief when her adult son moved back home and she arranged for full-time paid staff. Another wife, with an extremely angry, critical husband, entered counseling and started anti-depressant medication. Another patient entered a nursing home, to the relief of her husband who was contending with a job and two small children. In another family, additional home care approved by the insurance company permitted the husband to sleep through the night, be relieved of most responsibilities for his wife's care, and 'get on with his own life', as he wished. While management and personal changes were also made by caregivers of patients who died, they were far less common. Evidently, these caregivers accommodated to the idea of the patient's indefinite survival by making major changes in the circumstances that had generated their distress. The implication for clinicians is to suggest to severely distressed caregivers that some kind of significant change is indicated both for their benefit and that of the patient.

These findings should be interpreted in light of several study limitations. Nearly all patients and caregivers were recruited from a single multidisciplinary ALS center. Centers of this kind often have a more positive approach and offer more support and practical assistance than other sites of care (30); this may be beneficial and may even extend survival (31). More depressed patients and caregivers may be less willing to participate in a project described as 'studying

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how people cope with serious illness'. (One or both members of 47 pairs declined to participate in this study and although they did not differ from participants on any chart measure, we did not assess their mood status.) Another limitation might be that nearly all patients and caregivers were white, middle class and educated. In addition, we may not have measured all salient variables, such as quality of caregiver-patient relationship before illness onset, or impact of care-giving on self-esteem. Finally, since we wished to use the same measures with patients and caregivers, our assessment measures were restricted, given the substantial impairments in communication among these late-stage patients.

In contrast, several features of the study offer support for our findings. We used several measures of depression whose findings converged. The sample was relatively large, and voluntary attrition was low. We found that, although distress is not uncommon, clinical depression among caregivers of late-stage ALS patients is the exception, and does not increase as the patient's death approaches. We conclude that the distinction between distress and psychopathology is important in considering interventions to support caregivers of these disabled patients. While depressive disorders warrant psychiatric care, perhaps including psychotropic medications, distress (sadness, feeling under pressure, lacking time for personal needs, physical exhaustion, isolation) may more effectively be ameliorated by modifying the circumstances of care-giving. These may include obtaining paid aides when financially feasible, rallying family and friends to offset the social isolation common among caregivers of housebound patients, and in general providing care for the caregiver as well as the patient. Psychological support for caregivers also should be provided by health professionals caring for the patient; ALS is, after all, a family disease.

Acknowledgments

This research was supported by NIH, SM Albert. The authors thank Ita O'Sullivan, MS, NP-P and Toby Tider, MSW for their invaluable role as study interviewers, and the caregivers and patients who participated in this study.

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Table I

Baseline status of caregivers by patient outcome over follow-up.

	Patients dying over follow-up, *n*=57	**Patients choosing tracheostomy/ LTMV, *n*=14**
Patient sociodemographic status		
Age	64.5±13.6	51.4±12.4**
Male,%	61.4	42.9
College,%	49.1	71.4
Non-white,%	8.8	14.3
Private insurance,%	75.0	84.6
Medicaid,%	17.5	8.3
Income>$80,000/year	18.8	58.3**
Patient clinical status		
ALSFRS-R	22.3±8.1	21.3±7.0
Any cognitive symptom,%	20.0	0.0+
Lability,%	43.6	23.1
Major or minor depression,%	20.4	0.0+
Years since diagnosis	1.6±1.2	2.2±1.7
Years since first symptoms	2.5±1.4	2.9±1.6
Caregiver sociodemographic status		
Age	57.6±15.3	56.1±12.1
Female,%	77.2	64.3
College,%	56.1	85.7*
Working,%	40.4	78.6*
Spouse or partner,%	60.7	71.4
Caregiver clinical status		
Major depression,%	10.5	21.4
Depression diagnosis (minor, or major)	15.8	50.0**
Beck Depression Inventory (range 0-49)	10.2 (±6.8)	15.5 (±14.1)+
Caregiver Burden (range 0-19)	8.9 (±4.4)	10.8 (±6.6)
Caregiver Satisfaction (range 4-20)	13.9 (±4.2)	14.2 (±5.5)

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	Patients dying over follow-up, *n*=57	**Patients choosing tracheostomy/ LTMV, *n*=14**
Fatigue (range 13-35)	20.5 (±5.2)	23.5 (±4.4)$^{+}$
Perceived Positive Patient Support (range 11-28)	22.3 (±4.9)	21.7 (±6.2)
Perceived Negative Patient Support (range 7-27)	12.6 (±4.7)	15.7 (±6.1)$^{+}$

[+] $p<0.10$

[*] $p<0.05$

[**] $p<0.01$ by *t*-test (continuous measures), χ^2 (proportions), or Kruskal-Wallis test (medians).

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Table II

Change in caregiver distress and perceived quality of relationship with approach of death or LTMV: baseline and last interviews.

	Death (n=38)		LTMV (n=13)	
	Baseline	**Last**	**Baseline**	**Last**
Depression Diagnosis	16%	10.5%	50%	8.3%
*BDI	10.4	9.4	15.9	9.8
CG Satisfaction	13.9	13.4	13.7	13.4
Caregiver Burden	9.0	9.1	12.3	9.9
*Manne Positive Support	21.8	21.4	22.3	18.9
Manne Negative Support	13.0	13.5	15.3	16.7
*Fatigue	21.1	21.1	24.6	20.8

[*] Significant declines over time for BDI, positive social support, and fatigue ($p<0.05$ in repeated measures ANOVA), driven mostly by greater declines in LTMV group, but group differences and interactions not significant in any comparison.