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ORIGINAL ARTICLE

Life factors affecting depression and burden in amyotrophic lateral sclerosis caregivers

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Abstract

Our objective was to determine which factors contribute to depression symptoms or increased burden in caregivers of amyotrophic lateral sclerosis (ALS) patients. The five factors assessed were financial status, social support, employment status, religious denomination, and patient disease severity. A prospective, cross-sectional study of 50 caregivers was performed using the Beck Depression Inventory (BDI), Zarit-Burden Interview (ZBI), a demographic survey, and patient ALS functional rating scale, revised (ALSFRS-R) scores. Younger age, female gender, higher financial burden, type of religious denomination, and longer daily hours spent both with the patient and caregiving were associated with BDI scores, indicating they are significant risk factors for depression symptoms. Both younger age and the daily hours spent caregiving, as well as being employed and having less social support, were associated with ZBI scores and higher burden. Adequate social support was the only protective factor in caregivers' lives, having an association with lower burden levels. There was no statistically significant association between a caregiver's BDI or ZBI score and patient ALSFRS-R scores. In conclusion, we identified factors associated with depression symptoms and increased burden in ALS caregivers. Interventions should be designed to target the modifiable factors in order to prevent depression symptoms and minimize burden in caregivers at risk.

Key words: *ALS, caregivers, depression, burden*

Introduction

Progression of amyotrophic lateral sclerosis (ALS) typically leads to loss of ambulation, dysarthria or anarthria, and the inability to perform activities of daily living. Caregivers provide a crucial component of care, providing both emotional and physical support. In general, most (62%) primary caregivers are spouses, and 59% maintain employment (1,2). Caregiving duties are often added to other commitments and responsibilities, causing significant stress and anxiety. In a report presented by the Cleveland Clinic Foundation, primary caregivers of individuals with ALS spent a median of 11 h per day providing care, regardless of additional home-care assistance (3). Most individuals with ALS are cared for at home until their death (4).

Given the extensive time-commitment of caregiving and its significant emotional burden, much research has been conducted to evaluate caregiver

depression. However, results have been variable and contradictory. Studies conducted by Rabkin et al., Ganzini et al., and Gauthier et al. have identified that ALS caregivers experience depression (5–7). Conversely, Mockford et al., Trail et al., and Schulz et al. reported that caregivers had very few depression symptoms (8–10). Multiple studies have also examined the relationship between a patient's disease progression and caregiver depression. Chio et al. and Pagnini et al. noted that the patient's severity of disease correlated with caregiver depression, while Rabkin et al. found no association (5,11,12).

Time commitment and responsibilities of the caregiver increase throughout disease progression, often causing the caregiver significant stress and anxiety. This burden is not a psychological diagnosis like depression, but the perpetual pressure and stress associated with caregiving has a substantial impact on caregiver health.

Some studies have begun to look beyond depression and burden and are beginning to identify its causes in caregivers. Calvo et al. reported that caregivers' quality of life was related to their private religiousness, while Ray and Street studied the relationship between social support systems and caregiver burden (13,14). However, there is a paucity of research in this area. In particular, factors in the caregivers' lives that contribute to depression and burden have not been well studied. We sought to further evaluate depression and its risk factors in ALS caregivers and to examine factors that affect caregiver burden, in order to ultimately identify modifiable factors that can be targeted to alleviate overall caregiver stress.

Materials and methods

Sample

This study population consisted of 50 caregivers who were recruited from the Muscular Dystrophy Association-ALS Center multidisciplinary clinic at the University of Pittsburgh Medical Center, a clinic that regularly serves approximately 90 motor neuron disease patients comprising about 50% of all ALS patients in a wide referral area. Patients with primary muscular atrophy, primary lateral sclerosis, and some inherited motor neuron diseases are also seen in the clinic. Some ALS patients lacked caregivers or were in nursing homes. We identified caregivers who met the study criteria; participants were recruited primarily in clinic and less often by phone. Caregivers had to be over the age of 18 years, be unpaid, and spend a minimum of at least 3 h per day caring for the patient. Care could include, but was not limited to, bathing, dressing, feeding, transporting, and providing emotional support. If a patient had multiple caregivers meeting the study requirements, only the caregiver who spent the greatest amount of time caring for the patient was permitted to participate. Of the 63 caregivers identified as eligible, 45 were approached during clinic visits. Forty-three consented and two refused participation. Surveys were mailed to 18 caregivers who were not approached during clinic for various reasons, especially time-constraints. Seven of 18 surveys were returned, and phone and written consent were obtained. The overall participation rate was 79%. Both caregivers and the patients they cared for had to provide consent in order to be eligible for the study. Patients had a diagnosis of possible, probable, or definite ALS according to the El Escorial criteria, but were not excluded if they had additional diagnoses. However, none of the enrolled patients had dementia or a life-threatening illness other than ALS. The study was conducted between May 2012 and February 2013 and was approved by the University of Pittsburgh Institutional Review Board.

Measures

Beck Depression Inventory Revised (BDI-II) (15,16). The BDI is a well established 21-item self-reporting scale intended to assess changes and severity of depression symptoms. Total BDI scores range from 0 to 63. There is some variable use of the range of cut-off scores used to characterize severity of depression. We used scores of 0–9 indicating minimal or no depression, 10–16 indicating mild depression, 17–29 indicating moderate depression, and 30–63 indicating severe depression (17).

Zarit-Burden Interview (18). The ZBI is a widely used 22-item self-reporting scale intended to establish burden associated with behavioral impairments and the home-care situation. Questions on the ZBI ask about the emotions of the caregiver, as well as his or her perceptions of social life and overall health. Total ZBI scores range from 0 to 88, with scores of 0–20 indicating little to no burden, 21–40 indicating mild to moderate burden, 41–60 indicating moderate to severe burden, and 61–88 indicating severe burden.

ALSFRS-R (19). The 12 items on the ALS Functional Rating Scale-Revised assess disease severity of a patient, analyzing fine motor skills, gross motor skills, bulbar, and respiratory function. Each of the 12 items is scored from 0 to 4, for an overall possible total of 48. Lower scores indicate greater disability and an estimated shorter survival period.

Demographic survey. This self-administered survey collected general demographic information, including gender and age. Employment status, education level, annual household income, hours providing care, living situation, available social support, and religious denomination, were also included. All survey questions were closed-ended. When queried about the number of hours care was provided, what constituted 'care' was left to the discretion of the caregiver and may include bathing, dressing, feeding, toileting, transporting, and emotional support. Similarly, social support was defined by the individual and captured the personal feelings of the caregiver.

Statistical analysis

The data were analyzed using *t*-tests, regression analysis, and ANOVA using a statistical significance criterion of $p < 0.05$. Education, financial burden, and religious denomination were analyzed using ANOVA; gender, employment status, living arrangement, social support, and religion as a part of daily life were all factors analyzed using *t*-tests. The remaining factors were evaluated using regression.

Table I. Caregiver demographics.

	Means	BDI <i>p</i> -value	ZBI <i>p</i> -value
ALSFRS score	34.10 (range 13–47)	0.3758	0.0632
Age ¹	60.80 years	0.0359	0.0049
Gender ²	34% male	0.0391	0.0588
	66% female		
Employment status ³	36% employed	0.7072	0.0399
	64% unemployed/retired		
Education level	36% high school diploma	0.3263	0.9488
	30% some college		
	30% college degree		
	2% graduate degree		
Household income	11% <\$20,000 US	0.0931	0.3335
	30% \$20,001 – 40,000		
	25% \$40,001 – 60,000		
	14% \$60,001 – 80,000		
	7% \$80,001 – 100,000		
	4% \$100,001 – 120,000		
	2% \$120,001 – 140,000		
	7% > \$140,001		
Financial burden	8% Significant burden	0.0296	0.3082
	24% small burden		
	68% no burden		
Living arrangement	67% living with spouse/partner only	0.8288	0.3470
Daily hours spent with patient	16.80	0.0058	0.6941
Daily hours caring for patient	8.22	0.0071	0.0479
Percentage of daily time spent caregiving	7.86%	0.2023	0.0534
Outside help received	37% yes	0.4230	0.4061
	63% no		
Hours of outside help received per week	7.71	0.9471	0.4098
Adequate social support	79% receive adequate social support	0.1100	0.0210 ⁴
Religious denomination	44% Catholic	0.0055 ⁵	0.0531
	33% Protestant		
	17% other Christian		
	6% atheist/agnostic/other		
Religion as a part of daily life	54% believe religion is a part of their daily life	0.6185	0.3307
	46% do not consider religion a part of their daily life		
Religiosity	25% not religious	0.9750	0.6758
	17% a little religious		
	37% religious		
	21% very religious		

¹Younger ages corresponded with higher BDI and ZBI scores.

²Females had higher BDI scores.

³Caregivers retaining employment had greater ZBI scores.

⁴Caregivers reporting adequate social support had lower ZBI scores.

⁵Catholic and Protestant caregivers had lower BDI scores than caregivers reporting other Christian religions. Since only three individuals reported atheist, agnostic, and other, these categories were not included in the statistical analysis.

Results

Caregiver demographics

Fifty ALS caregivers participated, and the demographics of the study population are summarized in Table I.

Patient demographics

The ALS patients were 64% male. Mean age was 63 years (range 28–85 years). Median duration of symptoms was 26 months; the mean was 37 months with a range of 3–268 months.

Psychological status of caregivers

Caregiver depression and burden. At the time of the survey, 55% of caregivers scored no depression symptoms; 25% scored mild depression symptoms; and 20% scored moderate depression symptoms. None of the caregivers scored severe depression symptoms. The average BDI score was 9.55 (range 0–29), a score indicating no or low depression symptoms. Evaluating burden, 50% of caregivers scored little to no burden; 30% scored mild to moderate burden; 20% scored moderate to severe burden. None of the caregivers surveyed scored severe burden. The average ZBI score was 23.56

(range 3–52), indicating that most caregivers experience some level of burden. BDI and ZBI scores were determined to be directly correlated ($p < 0.0001$) (Figure 1). However, there was no statistically significant association between a caregiver's BDI or ZBI score and the disease severity of the patient.

Other life factors

Significant association with depression. Age, gender, financial burden, religious denomination, total daily hours spent with the patient per day, and total daily hours spent providing care to the patient per day were all statistically significant predictors of caregiver depression symptoms (Table I). Younger, female caregivers were more likely to have higher BDI scores than older caregivers or male caregivers. Caregivers who reported having adequate finances had lower BDI scores than caregivers who reported either a small or significant financial burden. When asked their religious denomination, caregivers reported only the following denominations: Catholic, Protestant, other Christian, agnostic, atheist, and other. As only one caregiver chose each of the latter three categories, those denominations were excluded from the statistical analysis. Comparing Catholic, Protestant, and other Christian, Catholics and Protestant caregivers had lower BDI scores than caregivers identifying as other Christian. A relationship was also present between BDI and the number of hours caregivers spent with the patient each day (Figure 2), and the number of hours caregivers spent providing care each day. Caregivers who spent more hours per day with the patient, and who spent more hours per day providing care to the patient, had higher BDI scores.

Significant association with burden. Age, employment status, total daily hours spent providing care to the patient per day, and social support were all statistically significant predictors of caregiver burden (Table I). As with the BDI scores, younger caregivers had higher ZBI scores. Maintaining

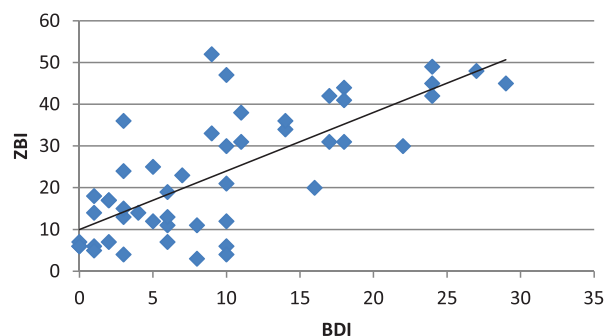


Figure 1. Correlation between depression symptoms (Beck Depression Inventory (BDI)) and caregiver burden (Zarit Burden Interview (ZBI)) scores. The relationship between depression symptoms of a caregiver and his/her level of burden is highly significant ($p < 0.0001$).

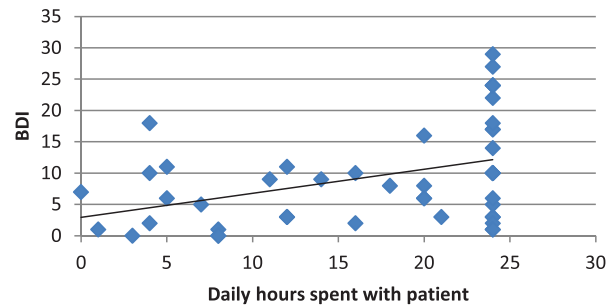


Figure 2. Correlation between depression symptoms (Beck Depression Inventory (BDI)) and the number of hours a caregiver spends with the patient per day. The more hours a caregiver spends with the patient per day, the greater the number of depression symptoms he/she exhibits ($p = 0.0058$). Many of the surveyed caregivers were spouses and therefore recorded spending 24 h per day with the patient.

employment, regardless of whether part-time or full-time, was associated with higher ZBI scores. The daily hours spent caring for the patient was also a statistically significant predictor of ZBI scores. However, unlike the BDI results, there was not a statistically significant correlation between the total daily hours spent with a patient and caregiver burden. Instead, the percentage of daily time spent caregiving for the patient was almost significant.

While the above associations can be thought of as risk factors for either depression symptoms or burden, social support was found to be a protective factor with respect to caregiver burden. Caregivers were asked "Do you feel you receive adequate support from family and friends on a regular basis?" and were able to indicate "yes" or "no". Caregivers citing adequate social support systems had lower ZBI scores than caregivers who reported inadequate social support.

Non-statistically significant factors

No statistical significance was established with regard to weekly hours receiving outside caregiving assistance, living arrangement, annual household income, or education level for either BDI or ZBI scores. No statistically significant association was identified between patient disease severity based on the ALSFRS-R and caregiver depression symptoms or burden.

Discussion

Among caregivers of ALS patients, none registered in either the severe depression or severe burden categories. However, there were a substantial number of caregivers with some depression symptoms and mild to moderate burden levels. The large range of BDI and ZBI scores reinforces that depression symptoms and burden are not universal among caregivers, stressing that more specific factors are likely contributory to depression symptoms and burden.

In previous reports, no relationships between caregiver depression and caregiver age or gender had been established (5,12). On the contrary, we found that younger caregivers, under the age of 55 years, were shown to have higher depression symptoms and burden scores. Examining the BDI results from caregivers ranging in age from 25 to 84 years, depression symptoms decreased starting in the mid-50s age category. We speculate that this phenomenon could be occurring for a variety of reasons. Older caregivers may have more experience with handling distress and illness. For a younger person, caregiving for an ALS patient could be their first difficult, life-changing event, and his/her coping skills may be poor. Additionally, younger caregivers may still have children at home, may still be establishing their careers, and may be in a worse financial position compared to an older couple. Ray and Street noted that younger caregivers have less stable support systems and more fluctuations in their personal relationships (14). Since adequate social support is a protective factor for burden, it is logical that younger caregivers without established social support networks may experience more depression symptoms and burden.

Female caregivers were found to have higher BDI scores than their male counterparts. Of the 16 male caregivers surveyed, only one caregiver had a score greater than 10. Conversely, many female caregivers scored much higher, and there was a larger range in overall scores of female caregivers.

Total daily hours spent providing care and total daily hours spent with the patient were also associated with increased BDI scores. ZBI scores were also higher for individuals with more daily hours spent providing care to the patient. Some caregivers reported being with the patient for 24 h a day consistently. Most of these caregivers were spouses and spent all of their time with their loved one. Even if they are not providing constant care, there is little or no relief from the situation and there is very limited time to oneself. Of note, Belden et al. estimated that about 20% of caregivers put in a minimum of 40 h of time weekly to caregiving duties (2).

Financial burden was also associated with BDI scores. Inadequate finances contribute to increased stress and anxiety; therefore, it is not surprising to find these increased depression symptoms in caregivers. Caregivers who maintained outside employment also had higher ZBI scores. Increased burden came from dealing with the stressors of home life, with the addition of job related stress.

Finding that religious denomination was correlated with BDI scores was more surprising. Due to sample-size constraints, only Christian caregivers were used in the statistical analysis, specifically 25 Catholic caregivers, 16 Protestant caregivers, and nine caregivers identifying as Other Christian. The three caregivers who answered atheist, agnostic, and other were not included as there was only

one individual in each category. Finding that Catholic and Protestant caregivers have less depression symptoms than caregivers of other Christian denominations could be a result of different coping skills attributed to a specific religious belief or stronger community support, but this finding should be confirmed in a larger study. Previously, Calvo et al. noted similar findings, concluding that caregiver quality of life was associated with caregiver religiousness (13).

While only age and the total daily hours spent providing care to the patient were statistically significant predictors of both BDI and ZBI scores, gender and religious denomination had some association with ZBI. With non-statistically significant *p*-values of 0.059 and 0.053 for gender and religious denomination, respectively, a stronger correlation may have been seen if the caregivers had been surveyed at a different time or a larger sample size had been obtained. In this study, only three male caregivers had a ZBI score above 20, while many female caregivers were well above that value. Similarly, while there were Catholic and Protestant caregivers with high burden scores, many Catholic or Protestant caregivers had very low burden scores under 20. Caregivers identifying as Other Christian all had ZBI scores of 20 or higher.

No significant relationship was established between patient progression based on ALSFRS-R scores, weekly hours receiving outside caregiving assistance, living arrangement, household income, or education level compared with depression symptoms or burden levels. Previous research by Rabkin had also found no relationship between education level and household income with caregiver depression (5).

The importance of establishing factors in a caregiver's life that are contributory to increased symptoms of caregiver depression and/or burden is paramount. This information allows health professionals to better anticipate and recognize depression and burden symptoms. The identification of stressors allows for the implementation of intervention services. Preventative measures should help reduce caregiver depression symptoms and burden, leading to an overall better quality of life for these individuals throughout the caregiving process. While some contributory factors cannot be changed, such as age or gender, knowing these risk factors allows for different counseling and the offering of more appropriate services. Knowing someone's age or religious denomination, for example, could help anticipate his/her likelihood of developing depression symptoms or burden. With more information, healthcare providers can focus on various aspects of care that may be lacking – adequate social support networks, financial resources, and support group options. Many of these factors are more malleable.

Which factors can be targeted for intervention and future study? Interventions could be appropriately

formulated to modify the abovementioned malleable factors, especially in those at highest risk for depression symptoms and increased burden, and their effects can be examined. For example, interventions can consist of education to enhance caregiver understanding of insurance, community, agency, and governmental financial support. Although relevant information may already be conveyed in multidisciplinary clinics to some degree, its dissemination can likely be expanded and enhanced. The role of support groups specifically for caregivers could be assessed. The exact protective role of various religious denominations could be explored more deeply.

Overall, our findings should be interpreted with consideration of several study limitations. All caregivers were recruited from a single multidisciplinary ALS center. Sample size was limited, but most eligible subjects participated. It was cross-sectional rather than longitudinal. A longitudinal approach could also be advantageous even though depression symptoms and burden do not appear to correlate with disease severity. It would be valuable to record and compare caregivers' responses over time and to track changes in the caregivers' emotional and mental health statuses.

Caregiver burden and the development of depression symptoms are a significant problem, especially among caregivers of those with fatal and progressive neurodegenerative conditions, like ALS. Our study provides specific information regarding which aspects of the caregivers' lives produced the most stress and anxiety (burden), with the hope that interventions and preventative services could be implemented to lessen burden and reduce the risk of depression symptoms. Both risk and protective factors were established. Better understanding of these risk factors can facilitate caregiver support and ultimately help healthcare professionals preserve and protect the caregiver's quality of life.

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