

# Evaluation of overloading on caregivers of people with Amyotrophic Lateral Sclerosis (ALS)<sup>1</sup>

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**Abstract:** Introduction: Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disorder that results in the selective death of motor neurons, with weakness and generalized muscle atrophy as primary symptoms. With cure yet to be found, the patients in treatment need assistance in mobility and daily activities. Taking care of a patient with ALS results in varying degrees of burden and time, demanding stress reduction strategies and an increase in the quality of life of caregivers. In this sense, support groups emerge as alternatives. Objective: The aim of this study was to assess whether caregivers of patients with ALS exhibit burden and the possible benefits from participating in a support group specifically designed for them. Method: This is a cross-sectional descriptive study that applied the Zarit Caregiver Burden Scale and Interview regarding participation in the “Hope for ALS” support group, at a public hospital in Recife, Brazil. Seven families’ caregivers and one professional caregiver were assessed. Results: Data analysis showed that most caregivers exhibit moderate burden and nearly all live with the patient, which may contribute to limitations in their lifestyle. Participation in the group is recognized by all as a source of exchange and learning about the disease, also an opportunity to discuss emotional issues and caregiving difficulties. Conclusion: It is concluded that these caregivers display moderate burden and that they benefit from the support received from the Hope for ALS group. However, other strategies may be needed to minimize this burden and improve patient care safety.

**Keywords:** *Amyotrophic Lateral Sclerosis, Caregivers, Cost of Illness, Needs Assessment.*

## Avaliação da sobrecarga dos cuidadores de pessoas com Esclerose Lateral Amiotrófica (ELA)

**Resumo:** Introdução: Esclerose lateral amiotrófica (ELA) é uma desordem neurodegenerativa que resulta na morte seletiva de neurônios motores, causando fraqueza e atrofia muscular generalizada como principais sintomas. Ainda sem cura, o doente em tratamento requer assistência na mobilidade e atividades diárias. Cuidar de um paciente com ELA implica maior ou menor sobrecarga e tempo, demandando estratégias de redução do estresse e ampliação da qualidade de vida dos cuidadores. Nesse sentido, os grupos de apoio surgem como alternativas. Objetivo: O objetivo deste estudo é avaliar se há sobrecarga dos cuidadores de pacientes com ELA e os possíveis benefícios relacionados à participação no grupo de apoio específico a cuidadores. Método: Trata-se de um estudo descritivo e transversal, com aplicação da Escala de Sobrecarga do Cuidador - Zarit e entrevista sobre a participação no Grupo de Apoio Esperança para ELA, realizado em um hospital público do Recife. Foram avaliados sete cuidadores familiares e um profissional. Resultados: Após análise dos dados, verificou-se que a maioria dos cuidadores apresenta sobrecarga moderada e quase todos residem com o doente, o que pode contribuir para limitações e modificações no estilo de vida destes. A participação no grupo é reconhecida por todos como fonte de trocas e aprendizado sobre a doença, além de acolhedora de questões emocionais e dificuldades no cuidado. Conclusão: Conclui-se que esses cuidadores evidenciam sobrecarga moderada e se beneficiam do apoio recebido no Grupo Esperança para ELA. No entanto, outras estratégias podem ser necessárias para minimização dessa sobrecarga e segurança no cuidado ao doente.

**Palavras-chave:** *Esclerose Amiotrófica Lateral, Cuidadores, Efeitos Psicossociais da Doença, Determinação de Necessidades de Cuidados de Saúde.*

## 1 Introduction

Motor neuron diseases (MND) are a group of neurodegenerative clinical syndromes characterized by neuronal death in the motor cortex, brain stem and anterior horn of the spinal cord. Amyotrophic lateral sclerosis (ALS) is the most common of the MND, defined by progressive degeneration of the upper and lower motor neurons, causing atrophy, fasciculation, weakness, and spasticity. Single clinical signs and symptoms and progression patterns, not shared by other diseases cause considerable changes in the individual with ALS and his family. The physical limitations that the disease establishes to the individual make it incapable of remaining in their professional life, further reducing their social participation and, gradually, can no longer be responsible for their self-care (SALVIONI et al., 2014).

Other symptoms also referred to dysarthria and dysphagia due to impairment of bulbar muscles. Dysphagia will cause difficulties in swallowing food, which causes successive episodes of choking. Also, there may be a weakness of the respiratory muscles, causing respiratory insufficiency, typically leading to the death of the patient. Most cases after receiving the diagnosis have two to five years of life, on average. To date, there is still no curative treatment (PICHON et al., 2013; MATOS et al., 2011).

Studies have shown that men are more affected than women, in a ratio of 1:1.8. The initial symptoms usually appear between 55 and 65 years old, with an average age of 64 years old. The onset before 30 years old, called sporadic juvenile onset is only found in 5% of the cases (CALVO et al., 2014; LIMA; NUCCI, 2011).

The patient's muscle weakness causes him/her to require mobility assistance and most activities of daily living (ADL), depending on the progression of the disease. This requires that professionals propose different therapeutic goals, which will differ according to the functional status of the patient (LIMA et al., 2009; OLIVEIRA; PEREIRA, 2009).

The assistance of the multidisciplinary team has been a strategy to give better quality and extend the life of the patient. The composition of the team is variable and usually social workers, nurses, physiotherapist, speech therapist, neurologist, psychologist and occupational therapist are part of it. The action of these professionals can benefit and give comfort to the patient and the family in several aspects and stages of the disease (LIMA et al., 2009; OLIVEIRA; PEREIRA, 2009).

By highlighting the interaction of the occupational therapists that make up the team, the meetings that were conducted by them enable new ways of thinking about care: a broader and more comprehensive care, understanding the complexities not only physical but contextual, personal and singular ones of each, since the occupational therapeutic action seeks to emphasize the holistic and subjective issues in the attention to the individuals (JOAQUIM; SILVESTRINI; MARINI, 2014).

The fast progression of the disease makes the patient more and more dependent on a caregiver. More than an act, caring is an attitude because it involves a moment of attention and zeal and constitutes an act of occupation, responsibility and affective involvement with the other. The limiting situation represented by caring for a patient with ALS during the time of disease manifestation makes us think of ways of reducing stress and reducing the overload that can be caused by caring for the other (FALLER et al., 2012).

For Mello et al. (2009), care activities will have a direct relationship with patient autonomy and emotional issues, such as loss of self-esteem. For the caregiver, these may require more or less physical overload and time. The care to the patient with functional dependency makes the task even more exhaustive and stressful, since the individual when dependent will need more demanding and indefinite care (OLIVEIRA et al., 2012; SCHNAIDER; SILVA; PEREIRA, 2009).

The idea of overhead is quite broad. The term caregiver burden refers to stress and it is characterized as an acute negative reaction to caregiving. It emerges when new demands for care are introduced or intensified and caregivers present difficulties to adapt or modify their strategy to meet them, experiencing the overload (MANUEL et al., 2013; TOLEDO; BALLARIN, 2013).

Caregivers of people with some limitations such as Alzheimer's disease, cancer treatment and bed rest due to severe disability, experience changes in lifestyle, such as reduced time to care for themselves, changes in health and social limitation (FALLER et al., 2012; YAMASHITA et al., 2013). These changes negatively impact the quality of life and personal satisfaction in the caregiver's family life and are also perceived as overload (SEQUEIRA, 2010).

The professionals and health services recognize the burden for the caregiver. Thus, strategies are developed to support them, in the form of physical activity and leisure programs; training courses; support groups and alternatives to minimize the

negative impact on caregivers (BATISTA et al., 2012; MANUEL et al., 2013; SAMPAIO, 2011). These aspects related to the caregiver's overload and care to justify the interest in carrying out this study.

## 2 Objective

To identify the overload of caregivers of people diagnosed with ALS.

## 3 Method

This is a cross-sectional descriptive study that seeks to describe the characteristics of a given population or phenomenon (GIL, 2010). The study population is composed of caregivers of patients with ALS, older than 18 years old and participants of the Support Group called Hope for ALS, which is a service offered at a university hospital in Recife (PE), already working for a year. It is an open group, with approximately 15 caregivers, of the total of 20 patients attended by the hospital's interdisciplinary team.

The meetings are held monthly and lasting 1h30m, taking place in the Rehabilitation Sector and conducted by one of the seven professionals who make up the team, according to the theme to be discussed (two occupational therapists, two physiotherapists, a speech therapist, a psychologist and a neurologist). In these meetings, pre-established topics by the participants and the doubts that arise during the meetings are discussed.

For data collection, a sociodemographic questionnaire was applied that identified age, gender, kinship, living conditions with the patient, education level, personal income and frequency in the group. It also contained two open questions, in which respondents expressed their views on the group and the possible benefits of participation.

The Caretaker Overload Scale - Zarit (SCAZUFCA, 2002) was applied to assess the presence of overload. This is a standardized and validated evaluation for Brazil by Scazufca (2002), who verifies how care activities impact on social life, physical and emotional well-being, and caregiver finances. It is composed of 22 affirmative questions that reflect how people can feel when they take care of another, indicating the frequency (never, rarely, sometimes or always) of the feeling, according to the question. Each response has a score between 0 and 4 points and the total can vary between 0 (zero) and 88 points, in which the higher scores indicate greater overload. Some studies adopt the classification of the score described in Table 1 and this parameter will be

**Table 1.** Zarit Scale Classification.

Zarit Scale Score	Overload level
0-20	No overload
21-40	Moderate overload
41-60	Moderate to severe overload
≥ 61	Severe overload

Source: Wachholz, Santos, Wolf (2013). Recognizing the overload and quality of life of family caregivers of fragile elderly people.

used in this study to attribute the level of stress verified among the Hope Group's caregivers for ALS (MANUEL et al., 2013; OLIVEIRA et al., 2012; SCAZUFCA, 2002; WACHHOLZ; SANTOS; WOLF, 2013).

Simple descriptive statistics were used for the analysis of the data, considering the results and frequencies of the Zarit Scale and the general score with the respective classification. As to the possible benefits of participation in a support group, investigated based on open questions, the contents of the discourses were analyzed to group them into thematic categories, considering the established objectives and the similarities and differences between them, following the references of Bardin's content analysis (2009).

## 4 Results and Discussion

The study population consisted of eight caregivers of patients with ALS, older than 18 years old and present in at least two meetings of the Hope Caregiver Support Group for ALS, during the research period between November and December 2014. There was a loss of participation of two caregivers who fit the inclusion criteria, but no contact was possible during the referred period.

The reduced number of participants in the study is a reflection of the group's recent constitution. Another aspect is the difficulty of attending caregivers since many cannot be substituted in their function before the patient, to be present at the group's monthly meetings.

The sociodemographic characterization of the study participants is presented in Table 2. When analyzing it, it was verified that the study population is made up of women. Regarding the kinship, more of the caregivers are the patient's spouses, followed by daughters and daughters-in-law.

The findings of this study corroborate with the studies of Batista et al. (2013), Borghi et al. (2013), Marques et al. (2011) and Wegner and Pedro (2010), who say that women are most of the caregivers,

**Table 2.** Sociodemographic characterization of the eight caregivers participating in the Hope Group for ALS (Recife/PE), from November to December 2014.

Variables	Frequency
<b>GENDER</b>	
Male	1
Female	7
<b>AGE</b>	
18 to 30 years old	3
48 to 60 years old	4
More than 60	1
<b>KINDSHIP</b>	
Spouse	3
Daughter/son	2
Daughter in law	2
Formal caregiver	1
<b>EDUCATION LEVEL</b>	
Incomplete Elementary School	1
Complete High School	3
Complete Higher Education	3
Post-graduation	1
<b>FAMILY INCOME</b>	
Caregiver: income generator	1
Patient: income generator	2
Caregiver with independent income	4
<b>LIVING WITH THE PATIENT</b>	
Yes	5
No	3

and the wives and daughters are the informal or family caregivers. For women, the caregiver role is historically and culturally evidenced among the various roles played. When it comes to caring for the health or who has some disability, especially those who are part of the family circle, it is the woman who is implicitly associated as the main caregiver of the family. The role covers issues related to maternal instinct and the difficulties of some men to perform care, which makes the majority to be a woman, even among the formal (FC), who are paid professionals to perform the care activity.

Although the family is generally also affected by the disease, the care of the patient relies most of the time on a single member, who has to take responsibility for the provision of physical, emotional, and in some cases financial care, without the help of other family members or professionals (MELLO et al., 2009; YAMASHITA et al., 2013).

This coincides with the reality of the interviewees. Only one of the families has more than one caregiver involved, but the main one is clearly identified. In the last years, the family caregiver became the

target of investigations in Brazil and in the world, confirming the impact of the care act on their living and health conditions (BATISTA et al., 2012; BORGHI et al., 2013; MELLO et al., 2009).

Only one interview is in the category of the formal caregiver (FC). In this way, he does not reside with the patient and, at the end of his shift, returns home. Two other caregivers, though family members also do not reside with the patient. Therefore, five of the eight interviewees live with the patients, being negative because of the great exposure to the effects of the care process experienced daily and, generating high levels of tension.

Studies point out that this still contributes to the emergence of limitations and modifications in their lifestyle and to the increase of their daily activities, as well as the caregiver to leave aside his private life, to take care of the life of the other, and sometimes to be responsible also for the other members of the family (ANDRADE et al., 2009; GRATÃO et al., 2013; MARQUES et al., 2011).

As for the personal income, only one caregiver is the only generator of all family income, keeping the patient and his/her daughter a caregiver who participates in the research; two caregivers do not have any income, having financial support for the patient's income, and four have independent income from the patient.

Half of the eight participants interviewed had training in Higher Education, three had completed High School and the only one did not finish the Elementary School. One of the questions in the Zarit Scale investigates the frequency of caregiver when giving care to patients. Six of them responded it affirmative. Of them, two responded that they always have doubts and four are in doubt sometimes. Although some studies report that low education level may negatively interfere with care, according to the results, we did not verify the relationship between the education level and the doubts in patient care (LOPES; MASSINELLI, 2013; PAULINO et al., 2009)

It was also not possible to establish a pattern between the time or frequency of the support group and the doubts about caring for the patient. Participation in the group was at least two meetings, the criterion for inclusion in the study. The average participation was 4.5 meetings. However, among the interviewees, neither the level of education nor the amount of participation in the meetings of the support group seemed to influence safety in their task and care provided.

When analyzing the question in the Zarit Scale that directly assess whether caregivers feel generally burdened when caring for the patient (Table 3), we find that only one (C8) assumed to be overloaded, two of them denied any overload (C2 and C7) and five felt moderate or a little overwhelmed.

By relating the response of this specific question to the total score of the assessment by the Zarit Scale, there is a concordance between the evaluation of self-reported personal overload and that attributed by the full-scale score for moderately or poorly overloaded caregivers and for the two who do not feel overwhelmed. These participants do not score on the scale sufficiently to indicate the presence of overload, perhaps because one of them does not have the affective burden of the imminent loss of the relative caused by the illness by being a formal caregiver and the other case is a recent diagnosis, so the family is still doing the first contacts with the disease and care are being shared with other relatives.

We also noted that the caregiver who feels overloaded is the one with the lowest score among those who are moderately overloaded according to the scale score. That is, there is a more evident personal sensation that is not informed in the other scale issues. This perception of extreme overload can be attributed to the fact that this is the only man/husband interviewed, and he is currently the sole responsibility for the whole family's support, without the support of the wife who previously assisted him in the company, and today, the symptoms prevent their collaboration.

Studies that identify the man and the husband as a caregiver (EUZÉBIO; RABINOVICH, 2006; BORGES, 2003) point out that when a woman becomes ill, a husband and children only assume the role of caregiver if there is no woman to take on this role, usually a daughter. The authors call the man, in this case, as "neglect care," indicating that

it was not an option. This condition is explained culturally by the central role attributed to the woman in the care and also because culturally man assumes the role of provider and he is the one who assumes extra domiciliary tasks, like buying medicines, transporting to the health service, paying bills, covenants, among others.

Another important aspect highlighted in the study by Borges (2003) with caregivers of patients with ALS and for whom professionals should be aware is the previous quality of affective and family ties. The author warns that even in the face of a serious and incapacitating illness such as ALS, the solidarity of care is not always spontaneous and it can be difficult to recover commitments and affections for care.

Another important dimension in the relationship of care is to consider the totality of the human being who cares, his/her affective needs and even the technological adaptations in the home care space, since the caregivers' concern goes beyond the corporal care and mobilizes feelings (BRONDANI et al., 2010).

This is what we evaluate in the answers when asking about the caregiver's fear of the future of the patient. Among those who respond "always" and "frequently", five of the eight respondents are caregivers of patients with definite ALS and one of possible ALS, but all of them already present well-advanced symptoms, with impaired mobility and constant gagging. The two caregivers who respond to feel this fear only "sometimes" are those who care for patients who have "lighter" symptoms than the others and both still do not have impaired mobility.

The study by Lillo et al. (2012) reports that there is no difference in the overload of caregivers of ALS patients who started the symptoms by limbs or bulbar muscles. The caregiver goes through anxiety and stress processes according to the impacts and

**Table 3.** Information on the intensity of the overload reported by the participant caregiver of the Hope Group for ALS (Recife / PE) and score on the Zarit Scale (Recife / PE) from November to December 2014.

Caregiver	Intensity of the informed overload	Zarit Scale	
		Total score	Total score
C1	Moderately	18	No overload
C2	Not even a little	12	No overload
C3	Moderately	46	Moderate to severe
C4	A little	27	Moderate
C5	A little	33	Moderate
C6	Moderately	31	Moderate
C7	Not even a little	10	No overload
C8	A lot	26	Moderate

hardships that the symptoms that arise in the patient cause. With emotional tension, caring for the patient with ALS requires high physical effort, particularly during the advanced stages of the disease. The severity of the disease is directly related to the overload, anxiety and somatic expression of depression in the caregiver (PAGNINI et al., 2010).

When we relate the severity of the stage at which each patient encounters the answers given to question 8 (do you feel that "S" [the patient] depends on you?), We find that the two who use "always" and one that uses "frequently" as an answer are the caregivers of the most affected patients. Among the others, four responded "sometimes" and only one refers "rarely." As the disease progresses, patients request more help from their caregivers and become more dependent.

The stress of reconciling care activities with others is assessed by asking questions directly (question 3) or by questioning whether the patient's presence is a cause of irritation (question 5) and tension (question 9) for the caregiver. Regarding stress, three caregivers say "never" and two of them responded "rarely" feel that way, while three reported that "sometimes" they feel stressed when they reconcile tasks. As for irritation or tension, six affirm absence of both feelings and two participants assumed that "sometimes" or "rarely" feel tense or irritated. This refers to the emphasis given by Mello et al. (2009), in which before proposing any support or intervention program for caregivers, it is necessary to know their characteristics and needs, as well as the stress and impacts produced by the act of caring.

Caregivers usually report some type of health impairment, such as spine pain, migraine, hypertension, depression, among others. However, most of them "rarely" seek medical help because they do not have someone to leave the patient (MARQUES et al., 2011). From the data obtained from the interviews, only one caregiver replies that "often" feels that they do not have time for themselves because of the time is taken to care for the patient and their health is affected because of their involvement in care. The remaining seven had responses ranging from "sometimes", "rarely" and "never".

The findings of this research suggest other aspects of the literature, such as the feeling of guilt of the family caregiver in assuming that the need for care is cause of interference in their own lives, difficult to leave the place of primary caregiver, feeling emotionally rewarded to take care and see the improvement or gratitude of the person they take care (MANUEL et al., 2013; MARQUES et al., 2011; MENDES; MIRANDA; BORGES, 2010).

When we analyze the question in which the caregiver evaluates whether the patient expects him to be the only person responsible for his or her care, which represents the centralization of care in the caregiver, we find that three caregivers reported that "always" there is patient's expectation, but those same caregivers are those who respond that they "never" or "rarely" feel their health affected or do not have time for themselves because of the care they have taken. With this, it seems that they have already been able to reconcile the patient's expectation, the centrality as a caregiver and their personal needs. This condition is little reported in the literature.

Finally, when analyzing the opinion of the interviewees about the group, most of them have a positive evaluation, feeling welcome and valuing the service as an important space for personal comfort, learning and facilitation in care, as evidenced below:

*[...] only we, who need this support, can testify to what the donation of each of the members really means (C8).*

*It meets all our expectations. Welcoming and guiding (C2).*

*We learn from them (professionals) and they learn from us (C4).*

*I come with a heavy head and here I unload everything (C7).*

Manuel et al. (2013) and Gonçalves et al. (2011) point out that activities directed to caregivers, usually the specific groups, are usually evaluated as important and that support the caregiver from an emotional point of view, listening to their complaints and receiving the anxieties and stress generated by care. The importance of actions directed at the caregiver is also recognized for its instrumental value, since there are possibilities for professionals and other participants to learn techniques that facilitate the daily management of situations or specific acts of care, as the disease requires or progresses (SAMPAIO, 2011; MELLO et al., 2009).

The analysis of the benefits of participation in the group for themselves and also in their own care activities resulted in five categories grouped according to the most frequent responses of the interviewees, in which all recognize benefits in their participation: A) orientation and adequacy to deal with the disease/patient; B) security in the assistance procedures; C) confidence in diagnosis; D) exchange of experience and benefits for the patient; E) benefits for the caregiver, which are portrayed in the following fragments:

*I argued with him and here I was learning how to handle it (C4) - Category A.*

*I feel safe and oriented, to guide the family, which is who lives with it (C2) - Category B.*

*I could be sure of the diagnosis when I heard the other caregivers talking about the symptoms, which I also noticed in her (C6) - Category C.*

*I learned how to act with the symptoms, gagging mainly (C7) - Category D.*

*I learned to take time for myself too, the group teaches us to take care of ourselves and have leisure time (C5) - Category E.*

The topics cited by caregivers, grouped in the previous categories, were discussed during the meetings. Besides the guidelines for their doubts or insecurities (categories A and B), caregivers also received support and encouragement to take care of their health, to take care of themselves during the care of the other and moments for themselves, without feeling guilty about it (categories D and E). One of the difficult aspects for the attending caregivers was this disengagement of care, even for a moment, and to be quiet about it, even if the sick person shows disapproval.

With this, we understand that the meetings are used to identify relevant aspects in the life of the caregiver, which can guide the search for strategies that balance the altered aspects and favor the routine of care with more quality. Such a balance helps to minimize the association between exposure to care and illness and assists the family in their organization to avoid overloading only one person (DAHDAHA; CARVALHO, 2014).

## 5 Conclusion

Even with limitations due to the small number of participants in the study, we understood the complexity of the task of caring for a person with ALS, and the need to assess the condition of the caregiver. Thus, when assisting the patient with ALS, health professionals can extend measures also to caregivers, paying attention to their physical and mental health, as well as ways that they can or do not cope with the burden of caring for others and facilitating care to the patient when instrumentalizing the caregiver.

The participants of this research show a moderate overload, although this perception is contradictory in some more personal aspects. The application of

the Zarit Scale allowed evaluating the overload and how it is expressed in relation to the time spent, the apprehension with the future or the expectation of the patient. Through the study, we also identified that caregivers benefit from the support received at Hope Group for ALS. However, other strategies may be necessary to minimize such overload and safety in patient care.

It is expected that the knowledge from this study can be added to others and contribute to better care for caregivers and people with ALS.

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### **Author's Contributions**

All authors were responsible for the design of the text, analysis, and organization of sources, writing and review to the text. The data collection was the responsibility of the lead author. All authors approved the final version of the text.

### **Notes**

<sup>1</sup> The study was approved by the Research Ethics Committee of Universidade Federal de Pernambuco, CAAE number 38045914.0.0000.5208.