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Effectiveness of the Mindfulness-Based Interventions for Caregivers of Patients with Amyotrophic Lateral Sclerosis: A Scoping Review

Amyotrofik Lateral Skleroz Hastalarının Bakım Verenlerine Yönelik Farkındalık Temelli Müdahalelerin Etkinliği: Kapsam Derlemesi

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ABSTRACT

Objective: This study aimed to evaluate and summarize the literature on the effectiveness of mindfulness-based interventions for informal caregivers of the patients with ALS.
Methods: A scoping review was conducted using electronic databases such as EBSCO, Scopus, PubMed and Web of Science. Total of 475 studies were identified by searching through databases and other sources. After screening the titles and abstracts, 19 studies remained for full text review. Questions such as 'What is the effect of awareness based interventions on caregiver burden for caregivers of ALS patients?' were sought to be answered. The PRISMA flowchart was adhered to throughout the process.
Results: 6 studies were included in this scoping review; one RCT, two pre-post design studies, one qualitative study and two cohort study. The fact that studies on Mindfulness-Based Interventions for caregivers of patients with ALS have only been available since 2016, and the number of them is small, and demonstrates the lack and novelty of trials on this topic. The findings of this scoping review suggest that mindfulness-based interventions can significantly alleviate caregiver burden, enhance quality of life, and improve psychological well-being, including reductions in anxiety and depression, among caregivers of patients with ALS.
Conclusion: Despite the limited number of studies, the evidence supports the potential effectiveness of mindfulness-based approaches as a valuable support strategy for this population. It is believed that further research is required on this topic.

Keywords: Amyotrophic lateral sclerosis, motor neuron disease, caregiver burden, mindfulness

ÖZ

Amaç: Bu çalışmanın amacı, ALS hastalarının bakım verenlerine yönelik farkındalık temelli müdahalelerin etkinliğine ilişkin literatürü değerlendirmek ve özetlemektir.
Yöntemler: EBSCO, Scopus, PubMed ve Web of Science gibi elektronik veri tabanları kullanılarak literatür taraması gerçekleştirildi. Toplam 475 çalışmaya erişildi. Başlıklar ve özetler incelendikten sonra tam metin incelemesi için 19 çalışma dahil edildi. "ALS hastalarının bakım verenleri için farkındalık temelli müdahalelerin bakım veren yükü üzerindeki etkisi nedir?" gibi sorulara yanıt arandı. PRISMA akış şemasına uygun hareket edildi.
Bulgular: Bu kapsam derlemesine bir tane randomize kontrollü, iki tane ön test-son test tasarımlı, bir tane nitel, iki tane kohort çalışma olmak üzere 6 çalışma dahil edildi. ALS hastalarının bakım verenlerine yönelik farkındalık temelli müdahaleler üzerine yapılan çalışmaların 2016'dan beri devam etmesi, bu konunun güncelliğini koruduğunu gösterirken, çalışmaların sayısının yetersizliği de alandaki araştırma eksikliğini vurgulamaktadır. Araştırmalar, farkındalık temelli müdahalelerin ALS hastalarının bakım verenlerinin bakım yükü, anksiyete ve depresyon düzeylerini azaltma, yaşam kalitesi düzeyini artırma, psikolojik refahı iyileştirme potansiyelini vurguladığı görülmektedir.
Sonuç: Sınırlı sayıda çalışmaya rağmen, kanıtlar farkındalık temelli yaklaşımların bu popülasyon için değerli bir müdahale olarak potansiyel etkinliğini desteklemektedir. Konuyla ilgili daha fazla çalışmaya ihtiyaç olduğu düşünülmektedir.

Anahtar Kelimeler: Amyotrofik lateral skleroz, motor nöron hastalığı, bakıcı yükü, farkındalık

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INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is an adult-onset neurodegenerative condition of both upper and lower motor neurons in the brain and spinal cord resulting in dysfunction of the voluntary muscles.[1] Clinical presentation of ALS is varied, but primary symptoms are associated with motor dysfunction, such as muscle weakness, cramping, fasciculations, limb palsy, dysarthria, and dysphagia, and approximately 50% of patients reported cognitive and behavioral abnormalities. There is no known treatment, and death from respiratory compromise typically occurs within 3 to 5 years.[2,3]

The progressive nature of disease leads to a rising need for care in activities of daily living. It is known that they spend about 11 hours per day in caregiving, even while they have been receiving no professional caregiver assistanc.[4,5] The caregivers of the patients with ALS, commonly informal caregivers such as a member of the family, are adversely affected by clinical impairments of the disease. Although ALS is a rare disease, it results in an increased social, economic, and personal burden for both patients and their primary caregivers.[6,7]

Caregiver burden is the impact of the caregiving role to the patients with progressive chronic disease on the physical and emotional health of caregivers.[6,8] Both the caregiver and patient related factors affect the caregiver burden. In a systematic review, it was reported that "behavioral impairments" and "physical functioning" of the patient and "feeling of depression" of the caregiver affect the caregiver burden with moderate to high-quality evidence.[6] Moreover, studies have shown that reduced caregiver well-being impacts patient well-being negatively.[9,10]

Currently, supportive interventions for caregivers are available and to be developed. One of the new interventions is a mindfulness-based intervention that may help manage the caregiver burden. Mindfulness is defined as paying attention in a specific way on purpose, in the present moment, and non-judgmentally and based on Buddhist philosophies.[11] Mindfulness is a simple way of relating to all experiences that have the potential to reduce suffering and pave the way for positive personal transformation. It is a fundamental psychological process that can change how the person responds to the unavoidable challenge of life, including suicidal ideation, chronic depression, and psychotic delusions.[12,13] Mindfulness is also defined as both a skill and practice: The practice of mindfulness breeds the ability to be mindful. The stronger individual's ability to adopt a mindful state in the constant ups and downs of life, the less pain one will suffer.[14]

In recent years, researchers have focused on mindfulness as a protective factor against the effects of challenging life events[15] and increasing evidence supports that mindfulness-based interventions reduce caregiver burden.[12]

Those who provide care for individuals with severe chronic conditions, such as amyotrophic lateral sclerosis (ALS) , are at an elevated risk of developing depressive and anxiety disorders, as well as a diminished quality of life.[16] There are limited studies compiling information about interventions for caregivers of patients with ALS.[16-19] The results of a study demonstrated a positive correlation between mindfulness and quality of life, as well as a negative correlation between mindfulness and the level of caregiver burden. Those acting in a caring capacity who demonstrate high levels of mindfulness tend to perceive themselves as experiencing lower levels of burden. Those who possess this quality experience reduced levels of anxiety and depression and exhibit a superior quality of life in comparison to individuals who lack this attribute. The study indicates that mindfulness may serve as a preventive factor against the adverse effects associated with caregiving. It can be posited that an enhancement in the level of mindfulness may serve as a protective factor against the onset of caregiver burden. Consequently, the implementation of mindfulness-based interventions may prove an efficacious strategy for the enhancement of the quality of life of the caregiver.[16] A study was conducted to investigate the feasibility and acceptability of a therapeutic group intervention promoting self-care, problem solving and mindfulness to informal caregivers of individuals with ALS. The findings indicated that the intervention was both feasible and acceptable for this population.[19]

However, a general view of mindfulness-based interventions for caregivers of the patients with ALS and their impact on care burden is lacking. This issue is regarded as significant due to the pivotal role that caregivers play in the management of ALS disease. It is therefore vital that interventions are provided to support the psychological state and care-related needs of these individuals.[20] It has been demonstrated that anxiety and depression are significant predictors of caregiver burden in ALS. It has been demonstrated that those acting as caregivers exhibit considerable apprehension regarding the future and become increasingly critical of their role as the disease progresses.[21] Mindfulness-based interventions can make it easier to cope with these challenges.

AIM

This scoping review aimed to evaluate and summarize the current scientific literature on the effectiveness of mindfulness-based interventions for informal caregivers of patients with ALS. It also aimed to assess the quality of evidence.

Research Questions

For this review, 5 research questions were asked:

- *"What is the effect of mindfulness-based interventions for caregivers of the patients with ALS on caregiver burden?"*
- *"What are the studies in the current literature on the subject?"*
- *"What is known about the use of mindfulness-based interventions for caregivers of the patients with ALS?"*
- *"What types of mindfulness-based interventions are used?"*
- *"What evidence is there for the acceptability and effectiveness of mindfulness-based interventions for caregivers of the patients with ALS?"*

METHODS

Study Design

A scoping review was utilized, incorporating summaries, explanations and interpretations from available quantitative, and qualitative studies to address review questions. This method allows a review to extract different data, and develop them in a way that is meaningful, transparent and systematic.[22] Scoping reviews are a useful tool in the ever increasing arsenal of evidence synthesis approaches. Researchers may preference the conduct of a scoping review over a systematic review where the purpose of the review is to identify knowledge gaps, scope a body of literature, clarify concepts, investigate research conduct, or to inform a systematic review. Although conducted for different purposes compared to systematic reviews, scoping reviews still require rigorous and transparent methods in their conduct to ensure that the results are trustworthy.[23] This scoping review adhered to the PRISMA-ScR guidelines to ensure a systematic and comprehensive approach, in addition to the utilization of a scoping review methodology that was guided by the methodological framework developed by Arksey and O'Malley.[24]

This scoping review was conducted in four steps as suggested by Arksey and O'Malley.[24]

1. *Examining the extent, range, and nature of research activity.*
2. *Determining the value of undertaking a full systematic review.*
3. *Summarizing and disseminating research findings.*
4. *Identifying research gaps in the existing literature.*

Types of Sources

Our search strategy primarily relied on electronic databases. Web of Science, Scopus, EBSCO, and PubMed were searched for relevant articles published by 2024. We also searched various gray literature sources, including Google Scholar, Open Grey, and PROQUEST, to capture all relevant information.

Search Strategy

Before identifying relevant articles, the authors determined keywords based on the research questions. Search terms were developed by one of the authors (L. İ.) via an iterative process, and keywords relating to ALS, mindfulness, interventions, and family caregivers. And "amyotrophic lateral sclerosis", "ALS", "motor neuron disease", "mindfulness-based stress reduction", "mindfulness", "MBSR", "mindfulness-based intervention", "caregiver burden", "caregiver stress", "caregiver fatigue", "caregiver burnout", "caregiver strain", "caregiver overload" keywords were used. In detail, the following search was conducted on Web of Science, Scopus, EBSCO, and PubMed with the following terms, as depicted in Table 1.

Table 1. In Detail the Research Conducted on Web of Science, Scopus, EBSCO, Pubmed in 2024

Electronic Databases	Search Terms
Web of Science	ALL= ((mindfulness* OR MBSR* OR "mindfulness intervention" OR "mindfulness-based stress reduction") AND ("Amyotrophic lateral sclerosis" OR " ALS" OR "motor neuron disease") AND ("caregiver burden" OR "caregiver stress"))
Scopus	"Mindfulness" AND [{amyotrophic lateral sclerosis} OR "ALS" OR {motor neuron disease}] AND [{caregiver burden} OR {caregiver stress} OR {caregiver fatigue} OR {caregiver burnout} OR {caregiver strain}]
EBSCO	- Mindfulness Based Stress Reduction OR Mindfulness OR MBSR OR Mindfulness Intervention - Motor Neuron Disease OR ALS OR MND OR Amyotrophic Lateral Sclerosis - Caregiver Burden OR Caregiver Stress OR Caregiver Fatigue OR Caregiver Burnout OR Caregiver Strain
PubMed	"mindfulness" [All Fields] AND ("amyotrophic lateral sclerosis" [MeSH Terms] OR "amyotrophic lateral sclerosis" [All Fields] OR "motor neuron disease" [All Fields]) AND "caregiver" [All Fields]

Eligibility Criteria

The inclusion and exclusion criteria were discussed among the team and established. The population, concept, and context (PCC) pneumonic for scoping reviews was used to structure the eligibility criteria.[25] (Table 2). The inclusion criteria for papers in this scoping review were as follows: Written in English; published in a peer-reviewed journal; employed quantitative, qualitative, or mixed-method research designs; and described a mindfulness-based intervention for caregivers of ALS patients. Data from included studies were charted and descriptively analyzed concerning the research questions. No date limitations were applied. Excluded articles that did not include mindfulness-based interventions for caregivers of the patients with ALS.

Table 2. Inclusion and Exclusion Criteria

PCC Category	Inclusion Criteria	Exclusion Criteria
Population: Informal Caregivers of ALS patients.	English articles Published in a peer-reviewed journal	Paid carers Not empirical research, such as case studies, editorials, or opinion pieces
Concept: Mindfulness Based Interventions	Employed quantitative, qualitative, or mixed-method research designs	Other types of psychological interventions, such as cognitive-behavioral therapy or relaxation techniques.
Context: Care of ALS patients	Mindfulness-based intervention for caregivers of ALS patients Include studies that report on outcomes relevant to caregiver well-being, such as stress, anxiety, depression, quality of life, or caregiver burden.	

Source of Evidence Selection

Firstly, the authors screened titles and abstracts, and the papers that all authors agreed on met the inclusion criteria. Each of the selected full-text papers was read thoroughly, several times by the four authors to capture all relevant information and to ensure that nothing important was missed. The dataset for the paper was constructed by extracting findings that were relevant to the research questions. The study selection process, including the number of studies identified, screened, assessed for eligibility, and included in the final analysis, is illustrated in the PRISMA flow diagram (Figure 1).

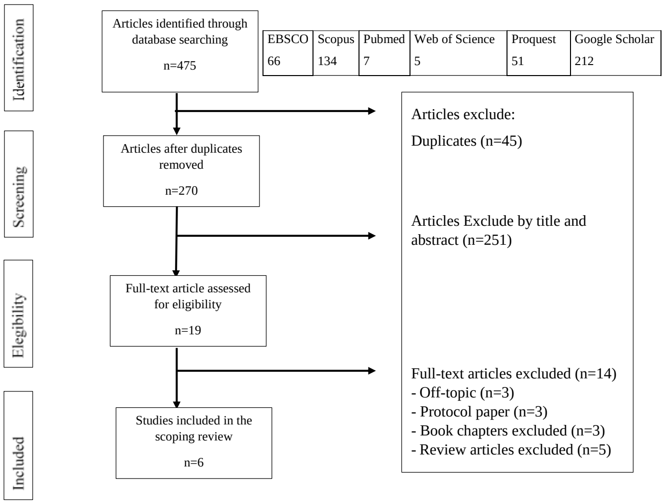

Figure 1. PRISMA Flow Diagram for Identification, Screening, Eligibility, and Inclusion

Assessment of Methodological Quality

The Downs and Black quality analysis tool was used to evaluate the quality of included studies. This tool has been shown a good intra-rater (p=0.88) and inter-rater (0.75) reliability and consists of 27 questions under 4 main titles: (1) unbiased reporting, (2) external validity, (3) internal validity measuring bias and confounding, and (4) power of value assessing the possibility of chance influencing the findings.[26] The 'power' item examines the power of the results; if there was no sample size calculation, it was scored with '0'. Contrary there was a reported sample size calculation, it was scored with '1'. Therefore, the maximum score for the randomized studies could be 28 and for the non-randomized studies could be 25.[27] The total score between 26 to 28 is reported as excellent; between 20 to 25 is reported as good; between 15 to 19 is reported as fair, and 14 or less is reported as poor quality.[28]

Data Extraction

Data extraction protocols involved the following 6 stages:

- *Two researchers completed the search of various sources of literature.*
- *Search results were screened on title/abstract by 4 researchers.*
- *Four researchers discussed any discrepancies and agreed.*
- *The selected articles were screened in full text.*
- *Four researchers discussed any discrepancies and agreed.*
- *Four researchers extracted the data.*

RESULTS

As illustrated in the PRISMA flow diagram (Figure 1), a total of 475 studies were yielded by searching through databases and other sources. After screening the titles and abstracts, 19 studies remained for full-text review. Of these, 6 met the inclusion criteria and were included in the final analysis. The summaries and general information of the studies are given in Table 3 and Table 4.

The included studies were conducted in the USA (n=2)[16,30], Australia (n=1)[19], Italy (n=1)[31], Türkiye (n=1)[29] and the Netherlands (n=1).[32]

The included study designs were a randomized controlled trial (RCT),[30] two cohort study,[16,29] two longitudinal studies; a single group in the pre-and post-test design,[19,31] and a qualitative study; semi-structured interviews with open-ended questionnaires (Table 3). [32]

Four of the 6 studies had sample sizes of less than 30 participants. The achieved largest study sample was 114 but it was reported that decreased to 55 participants at follow-up (Table 4). No sample size limitation was set in any of included studies in this review. The participants in three of the included studies[16,30,31] consisted of only ALS patients and their caregivers. In one of the included studies,[19] the diagnosis of the patients was reported as motor neuron disease (MND) and it was mentioned that it was also known as ALS. In remaining one of the included studies consisted of only caregivers of the patients with ALS or progressive muscular atrophy (PMA) patients.[32] The inclusion and exclusion criteria for each study were summarized in Table 4.

Quality of life was investigated in two studies with 36-Item Short Form Survey (SF-36),[29,30] McGill Quality of Life Single-Item Scale (MQOL-SIS),[16] and Hospital Anxiety and Depression Scale (HADS).[16,30] The HADS was also used for assessing anxiety and depression in another study.[16] Two studies assessed the caregiver burden as an outcome measure with the Zarit Burden Interview (ZBI)[16,29,30] and one with Caregiver Reaction Assessment Scale (CRA).[19] Mindfulness was assessed with Langer Mindfulness Scale (LMS) in one study,[16] the Cognitive and Affective Mindfulness Scale- Revised (CAMS-R) in another study,[19] and the Mindful Attention Awareness Scale in a third study.[29] Other outcome measures were reported as somatization, preparedness, problem-solving confidence, approach-avoidance style, and personal control.

Semi-structured interviews were conducted in two studies.[31,32] The acceptance of intervention was assessed in one study with a specifically designed questionnaire consisting of open-ended questions asking comments from participants on sessions and benefits.[19] Both caregivers and patients participated in only one study.[30] In another study, the severity of physical impairment and disability related to patients were evaluated by caregivers (Table 3). [32]

Four of all included studies have been focused on mindfulness-based interventions. One study has only reported assessment results without any intervention.[16] One study was a RCT and compared a group of a customized online ALS Langerian mindfulness-based program (consisting of active learning, online and website-supported video, and written content about mindfulness) and wait-list controls.[30] One study investigated the effects of an online psychosocial support program that includes mindfulness.[32] Two studies investigated face-to-face sessions of programs including mindfulness (Table 3). [19,31]

The results of the study, which is the only RCT of all included studies, reported that the mindfulness-based program showed significant improvement in both patients and caregivers, especially in the quality of life.[33] As a result of the semi-structured interviews, the supportive meditation programs increased the awareness of caregivers and were reported effective.[22,30] According to one study, the intervention, which focuses on caregiver self-care, problem-solving, and mindfulness and is presented in a group setting, had no significant difference in pre- and postintervention assessments. However, it has also been reported that caregivers benefit from their psychological well-being.[16] However, the authors also reported that the intervention appeared to be feasible and acceptable (Table 3). [19] Mindfulness was shown to be negatively correlated with burden, depression, and anxiety, and positively correlated with quality of life in a study that reported the relationship between mindfulness and health-related outcomes (Table 4). [15]

Table 5 presents the consensus of all four authors about the scores of the Downs&Black Analysis Tool. The quality of the included articles varied in a range of 10-20, with a total mean (standard deviation) score was 14 (3.52) (Table 5).

DISCUSSION

This paper is the first scoping review on the effects of Mindfulness-Based Interventions on caregivers of the patients with ALS and aims to provide an overall summary of the studies to collect its effect on caregivers. It was not possible to conduct a systematic review due to the limited number of published RCTs on this topic. This paper primarily discusses the effect of a mindfulness-based intervention on caregiver burden, quality of life, and psychological well-being such as anxiety and depression in caregivers of patients with ALS. Six studies were included

Table 3. Summary of Study Characteristics

Study design	Author, Year, Country	Data collection and analysis (for qualitative studies)	Intervention Sessions	Outcome Measures and Measurement times	Results, Conclusion	Feasibility and acceptability of the intervention
Longitudinal, uncontrolled, single treatment group, pre-test, post-test	**Marconi, 2016, Italy[31]**	Grounded theory approach.	Adapted to ALS, the meditation program was based on the original Mindfulness-based Stress Reduction protocol. Meditation sessions were held weekly and lasted 8 weeks.	**<u>Caregivers</u>** Semi-structured interview were audio-recorded and transcribed verbatim. **Main identified domains**. 1. Improvement in well-being 2. Relaxation 3. Emotional self-regulation 4. Acceptance 5. Consciousness 6. Breathing issues 7. Sleep cycle 8. Relationships Participants attended an interview at the end of training.	Both caregivers and ALS patients reported a positive impact on their psychological well-being, promoted by an increase in acceptance and non-judgmental attitude. Furthermore, coping strategies seem to improve, with a positive effect on resilience skills. Participants also showed improvements in coping with anxiety and depression Meditation training could be improved QoL, favored consciousness and acceptance of the disease, improved breathing and sleep quality, and favored relationships within the family and with the caregiver.	No data
Cohort study	**Pagnini, 2016, Italy [16]**	Online Questionnaire (Qualtics survey software).	No intervention	**<u>Caregivers:</u>** ***-Mindfulness:*** LMS ***-Caregiver burden:*** ZBI ***-Quality of life****:* MQOL-SIS ***-Anxiety&Depression:*** HADS. Participants were assessed 2 times: 1st; recruitment, 2nd; 4 months after recruitment.	Mindfulness correlated negatively with burden, depression, and anxiety and positively with quality of life, and maintaining stability through time. People with a mindful attitude experience lower levels of burden, anxiety, and depression and report better scores of QOL compared with people with a mindless attitude Developing a mindful attitude could well have a protective effect against burden. For that reason, interventions that promote mindfulness could increase caregivers' well-being and quality of life.	No data
	Ipek, 2024, Türkiye[29]	The data were collected during these face-to-face ALS-MND Association (Antalya) visits using paper-based forms for patients and primary caregivers.	No intervention	**<u>Caregivers:</u>** ***-Mindfulness:*** MAAS ***-Caregiver burden:*** ZBI ***-Quality of life:*** SF-36 **<u>Patients:</u>** **-Physical Impairment:** ALSFRS-R	This study was conducted to evaluate the caregiver burden, mindfulness, and quality of life of caregivers of ALS patients. It also examined the patient's functional level and explored the relationship between these factors. In this study, the increase in the mindfulness level of the caregivers was associated with a decrease in the caregiver burden. A negative correlation was found between the caregiver burden of caregivers of ALS patients and mindfulness level and quality of life (except physical function).	No data

Table 3. Summary of Study Characteristics (Continued)

Study design	Author, Year, Country	Data collection and analysis (for qualitative studies)	Intervention Sessions	Outcome Measures and Measurement times	Results, Conclusion	Feasibility and acceptability of the intervention
A pilot study with one-arm pre- & post-test.	**Ugalde, 2017, Australia**[19]	No relevant information could be found in the analysed study.	Single, 2.5-h group session including mindfulness, self-care, and problem-solving. 2 sessions with a 20-minute break scheduled at convenient times in 3 weeks (each participant attended once).	**Caregivers:** **-Burden:** CRA **-Depression, anxiety, and somatization:** BSI-18 **-Preparedness:** PCS **-Problem-solving confidence, approach-avoidance style, and personal control:** PSI **-Mindfulness:** CAMS-R **-Acceptance of intervention:** A questionnaire designed specifically for this study. Participants were assessed 3 times for acceptability (at baseline; 2-week post-intervention and 6-week post-intervention) and assessed for other outcomes 2 times (at baseline and 6-week post-intervention)	There was no significant change in outcome (distress, burden, problem-solving, mindfulness, preparedness) between pre-intervention and 6 weeks post intervention. Despite the positive feedback about the intervention in the acceptability questionnaire, this did not translate to improvements across caregiver measures.	Intervention is reported to be feasible and acceptable
Qualitative study	**De Wit, 2019, Netherlands**[32]	Semi-structured interviews were conducted by telephone using an interview guideline and audio-taped. The interview guideline was developed with open-ended questions related to caregivers' experiences with the support program in general and the specific components of the program.	A blended psychosocial support program includes mindfulness exercises The program was scheduled to be completed within 8 weeks. However, if caregivers needed more time, this could be extended to 12 weeks. The interview ranged from 38 to 82 min (m= 57 min)	**Caregivers:** **-Severity of the patient's disability**: ALSFRS-R. **-Physical Impairment:** SA-ALSFRS-R **Behavioral changes in patients:** ALS-FTD-Q Interviews were transcribed verbatim and analyzed thematically. 3 measurements completed by caregivers	The support program increased the awareness of caregivers and was evaluated effectively. Caregivers reported that the program contained all the crucial and disease-tailored themes and information. Most of the participants found the interface of the program user-friendly, the timing of the program appropriate, and flexibility in pacing themselves. The home visits of the counselor and psycho-educational information were found useful. However, caregivers reported that they did not perceive the mindfulness exercises as beneficial and did not feel the need to get in touch with peers.	No data

Table 3. Summary of Study Characteristics (Continued)

Study design	Author, Year, Country	Data collection and analysis (for qualitative studies)	Intervention Sessions	Outcome Measures and Measurement times	Results, Conclusion	Feasibility and acceptability of the intervention
A randomized controlled trial with two arms	**Pagnini, 2021, Italy[30]**	Participants received a link to a survey to be completed within 5 days via e-mail. Online using Qualtrics suite (Qualtrics, Provo,UT).	Experimental group, which participated in a **customized online ALS Langerian mindfulness-based program.** Two versions of the program were conducted and customized according to their physical limitations and roles for patients and caregivers. Online website including video and written mindfulness content and two daily exercises, (2–10 min to complete) for 5 weeks.	**Caregivers:** ***-Quality of life****:* SF-36, HADS. ***-Caregiver burden:*** ZBI. **Patients:** ***-Quality of life****:* ALSSQOL-R, HADS. ***-Physical Impairment:*** SA-ALSFRS-R Participants were assessed 4 times: 1st; recruitment, 2nd; after completing intervention or 5 weeks after the recruitment, 3rd; 3 months after recruitment, 4th; 6 months after recruitment.	**Caregivers:** There was a significant time group effect for **care burden**, **depression, anxiety**, same subgroups of quality of life (role limitation due to personal or emotional problems, energy/fatigue, and emotional well-being) in the mindfulness caregiver group. No differences between groups for some subgroups of quality of life (general health perceptions, physical functioning, role limitations due to physical health problems, social functioning, and bodily pain). **Patients:** There was a significant group by time effect for **ALSSQOL-R**, **HADS** Depression and Anxiety scores.	Intervention is reported to be feasible and acceptable based on recruitment and anecdotal feedback from the participant.

Abbreviations: ALS: Amyotrophic Lateral Sclerosis; QoL: Quality of Life; LMS: Langer Mindfulness Scale; ZBI: Zarit Burden Interview; MQOL-SIS: McGill Quality of Life Single-Item Scale; HADS: Hospital Anxiety and Depression Scale; CRA: Caregiver Reaction Assessment; BSI-18: Brief Symptom Inventory; PCS: The Preparedness for Caregiving Scale; PSI: Problem-Solving Inventory; CAMS-R: Cognitive and Affective Mindfulness Scale-Revised; ALSFRS-R: Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised; ALS-FTD-Q: Amyotrophic Lateral Sclerosis-Frontotemporal Dementia-Questionnaire; SA-ALSFRS-R: Self-Administered ALS Functional Rating Scale-Revised; SF-36: Short Form 36; MAAS: Mindful Attention Awareness Scale

Table 4. Characteristics of the Participants and Sampling in the Included Studies

First author, year	Inclusion & Exclusion Criteria	Sample size (n=baseline to the end) & drop-out rate (%)
Pagnini, 2021[30]	*** Caregivers:** ***Inclusion criteria*** • Able to use a computer, and access the Internet. ***Exclusion criteria*** • Unsuitable for the study (determined by the clinical staff). *** Patients:** ***Inclusion criteria*** • Having the physical ability, with or without adaptive devices. • Able to use a computer and having to access Internet. • Being ≥18 years old. ***Exclusion criteria*** • Having frontotemporal dementia according to the Edinburgh Cognitive and Behavioral ALS Screen within 90 days of study entry. • Having significant cognitive impairment or significant uncontrolled psychiatric disease (determined by the clinical staff)	**Caregivers:** n=27 to 13 & 51.85% **Patients:** n=47 to 25 & 46.8%
Pagnini, 2016[16]	• One caregiver for each ALS patient was recruited. • The diagnosis was self-reported by subjects. • Being ≥18 years old.	**Caregivers:** n=114 to 55 & 51.75% **Patients:** n=187 to 100 & 46.52%
Ugalde, 2017[19]	• Being a caregiver of people with a diagnosis of MND within the past 12 months. • Being ≥18 years old. • Able to speak, read and write in English • Attending the neurology clinic was eligible.	**Caregivers:** n=15 to 13 & 13.33%
Marconi,2016[31]	• Probable or defined ALS diagnosis • Diagnosis communication within 6 months of the recruitment. • Ability of the patient to speak and comprehend • Having no secondary severe comorbidity. *(all criteria reported only for the patients)*	**Caregivers:** n=18 & NA. **Patients:** n=26 & NA.
De Wit, 2019[32]	• Being a partner of the ALS or PMA patient. • Being ≥18 years old. • Being proficient in Dutch. • Having internet access. • Having consent of the patient to participate. • Caregivers in the RCT who completed or dropped out of the support program and who finished the third measurement (approximately 6 months after baseline), were selected.	**Caregivers:** n=40 to 23, n=23 to 17 & 57.5% and 26.08%
Ipek, 2024[29]	• Patients diagnosed with ALS and their primary caregivers. • Being ≥18 years old. • Able to communicate. • Unfamiliar with the concept of mindfulness. • Not participating in mindful meditation on their own or formal mindful meditation with a group • Not having a paid employee helping the primary caregiver.	**Caregivers:** n=57 & NA. **Patients:** n=57 & NA.

Table 5. Downs & Black Quality Analysis Tool [26]

Study Design	Author Country	Year	Reporting										External Validity			Internal Validity													Power	Total Score
																Bias							Confounding							
	Items		**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	**23**	**24**	**25**	**26**	**27**	**28**
Non-randomized trial	**Pagnini, Italy[16]**	**2016**	1	1	1	0	0	1	1	0	0	1	1	1	0*	0*	0*	1	1	1	0*	1	0*	0*	0*	0*	1	0	0	13
	Marconi, Italy[31]	**2016**	1	1	1	1	0	1	0	0	0	0	1	0*	0	0*	0*	1	1	1	0	1	0*	0*	0*	0	0	0*	0	10
	De Wit, Netherlands[32]	**2019**	1	1	1	1	0	1	1	0	1	0	0*	1	0	0	0	1	0	1	0*	1	0*	0*	0*	0	0	0	1	12
	Ugalde, Australia [19]	**2017**	1	1	1	1	0	1	1	0	1	0	1	1	0	0	0	0	1	1	0*	1	0*	0*	0	0	0	1	0	16
	Ipek, Türkiye [29]	**2024**	1	1	1	0	0	1	1	0	0	1	1	1	0*	0	0	1	1	1	0*	1	0*	0*	0*	0*	1	0	0	13
Randomize controlled trial	**Pagnini, Italy[30]**	**2021**	1	1	1	1	0	1	1	0	1	1	1	1	0	0	0	1	1	1	1	1	1	1	1	0	1	1	1	20

Reporting: 1; Yes, 0; No. **Only for the item 5:** 2; Yes, 1; Partially, 0; No. **External Validity and Internal validity (Bias and Confounding):** 1; Yes, 0; No, 0*; Unable to determine. Power: 1; Yes, 0; No.

in this scoping review; one RCT,[30] two pre-post design studies,[19,31] one qualitative study[32] and two cohort study.[16,29] The fact that studies on Mindfulness-Based Interventions for caregivers of patients with ALS have only been available since 2016, and the number of them is small, and demonstrates the lack and novelty of trials on this topic.

A review of the six included studies according to their quality levels reveals a considerable range in scores, from 10 to 20. The maximum score can be 28 for randomised trials and 25 for non-randomised trials. One study has a good quality score.[30] One study has an average quality score.[19] The other four trials have a low quality score. It is seen that the distributions of principal confounders in each group of subjects to be compared clearly described is not performed in all studies. Not all studies reported all important adverse events that may be a consequence of the intervention. In all studies it was clear that no attempt was made to blind participants to the intervention they received. In all studies, no attempt was made to blind those measuring the main outcomes of the intervention. In all studies, the question 'Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?' was unanswered. In addition, there are very few intervention trials on the subject and very few randomised controlled trials. Therefore, the trials may not have used randomisation and blinding. This may have led to a lower quality of the trials.

The rapid progress of ALS disease makes the patient dependent on the caregiver day and night, which increases the physical and psychological burden on the caregiver, unlike other progressive chronic diseases. It is known that both the patient and the caregiver are emotionally affected by ALS. [6,34,35] Studies are emphasizing the negative psychological effects of caregiving in ALS patients.[36,37] It is known that negative psychological factors also increase the perceived caregiver burden[38] and caregivers of ALS patients need supportive interventions. One of these supportive interventions is mindfulness-based interventions, and this approach has recently been used by adapting caregivers of patients with ALS. [39] There is evidence that mindfulness-based interventions are feasible and acceptable for caregivers of patients with ALS.[19,30,31]

Recently, there has been a growing interest in mindfulness-based interventions. Mindfullnes-based intervention can be implemented in a variety of ways. The most known and most widely used form is the MBSR program.[11,30] In the studies we included, the MBSR method was not used directly, but mindfulness-based programs adapted to ALS based on the original MBSR,[30,31] and mixed psychosocial support programs including mindfulness exercises. [19,32] In one of the included studies, the mindfulness status of ALS caregivers was evaluated without any intervention.[16]

The mindfulness-based interventions have a reducing effect on the caregiver burden in various chronic diseases.[12,33,40] Considering the positive effects of mindfulness-based interventions on caregiver burden, the number of studies that examined the effect of mindfulness-based interventions on caregivers burden in caregivers of patients with ALS in the literature was limited.[30,31] It was reported that mindfulness-based interventions had a reducing effect on the caregiver burden[30,31] and people with a mindful attitude had a lower level of caregiver burden than those who did not receive the mindfulness-based interventions.[16] On the other hand, Ugalde et al. reported that there was no additional significant effect on caregiver burden for caregivers of patients with ALS.[19] But also, developing a mindful attitude can have a protective effect against the caregiver burden,[16] it is thought that mindfulness-based interventions may be important in the development of effective, efficient, sustainable, applicable, accessible and low-cost service models that reduce the caregiver burden.

Important studies emphasizing the psychological effects of caregiving in ALS patients.[36,37] It is known that psychological factors also increase the perceived caregiver burden.[21,38,41] There is evidence that mindfulness-based studies show significant improvement in psychological well-being.[40] Pagnini et al. assessed depression and anxiety using the HADS and they reported that the mindfulness-based intervention provides benefits for the psychological well-being of caregivers of patients with ALS. Caregivers who are more mindful will show higher psychological well-being over time.[16] In a qualitative study, caregivers reported a positive impact of the mindfulness-based intervention on their psychological well-being, promoted by an increase in acceptance and non-judgmental attitude.[31] The positive effects of mindfulness-based interventions on caregiver anxiety and depression have been demonstrated in studies conducted with various chronic patients.[12,40,42-44] In a RCT, Pagnini et al. reported that the caregivers of patients with ALS had lower depression, anxiety, and better emotional well-being after an online non-meditative mindfulness intervention compared to the control group.[30] As a safe, simple, accessible and transportable approach, mindfulness-based interventions seem to improve psychological functioning and facilitate long-term self-care of caregivers.[12]

The caregivers of patients with ALS endure significant caring pressure as a result of caring for patients with chronic illnesses, which can negatively impact their health-related quality of life.[45] There are different available non-pharmacological interventions were used for improving caregivers' health related quality of life.[46] Mindfulness based interventions seem to be an effective method in improving health-related quality of life for caregivers with different chronic diseases.[16,30,44] Pagnini et al. examined the relationship between mindfulness and health-related quality of life in caregivers of patients with ALS, and they reported that the mindfulness-based intervention was positively related with quality of life.[16] In a RCT Pagnini et al. indicated that the mindfulness-based interventions were improved the quality of life for caregivers of patients with ALS compared to control. According to current literature mindfulness-based interventions can be a beneficial approach for caregivers to have a good quality of life.

There is also a study reporting that most of the caregivers do not find mindfulness-based interventions helpful. It is to be expected that most caregivers in the study did not perceive the mindfulness exercises as helpful, reporting unpleasant reactions during the exercises, such as agitation, discomfort, or confusion. These reactions are seen as part of the psychological process. Another point to note in this study is that the caregivers who perceived the mindfulness exercises as helpful were those with previous meditation experience.[32]

The findings of this scoping review revealed that the mindfulness-based interventions had a positive effect on the caregiver burden, quality of life, and psychological well-being such as anxiety and depression in caregivers of patients with ALS with limited studies. The insight of the knowledge gained through this review will add to the knowledge of interventions to reduce the burden of care for caregivers of patients with ALS.

Few studies have demonstrated the benefits of mindfulness-based interventions for caregivers of patients with ALS. Studies have significant methodological problems that render the overall evidence base low. High-quality and carefully designed research is essential for the effective implementation and testing of mindfulness-based interventions aimed at reducing the caregiver burden. Especially since the caregivers of patients with ALS are neglected and the consequences of caregiver burden can be serious, more attention should be paid to this area.

Physicians, nurses, physiotherapists, social workers, gerontologists, and all specialists who may form other members of the multidisciplinary team can suggest structured exercises that improve a mindful attitude for caregivers.

Limitations

It is known that studies on mindfulness-based interventions are gradually increasing, and the main strength of this study is that it is the first study to examine the studies on this population and draw attention to the subject. Another one strength and contribution to the field of this study is the methodological and critical evaluation of the studies in the literature on the subject and determining the methodological development areas of future studies. We believe that this scoping review identified areas for future methodological improvement as the studies included did not meet all the criteria of the 'assessment tool we used'.

A significant limitation encountered in this scoping review was the difficulty in comparing and synthesizing the findings, given the availability of studies employing disparate methodologies and outcome measures on the topic. Notwithstanding this limitation, it is proposed that mindfulness-based practices may be an easily accessible and feasible intervention for this population, with the potential to reduce caregiver burden.

Etik Komite Onayı: Kapsam derlemesi insan denekleri, insan materyali, insan dokuları veya insan verilerini içermez. Bu nedenle etik kurul onayına gerek duyulmadı.
Hasta Onamı: Kapsam derlemesi insan denekleri, insan materyali, insan dokuları veya insan verilerini içermez. Bu nedenle hasta onamına gerek duyulmadı.
Hakem Değerlendirmesi: Dış bağımsız.
Yazar Katkıları: Fikir- Lİ; Tasarım- Lİ, GYGG; Denetleme- GYGG; Kaynaklar- Lİ; Materyaller- Lİ, PK, SBB ; Veri Toplanması ve/veya İşlemesi Lİ, SBB; Analiz ve/ veya Yorum- Lİ, GGYG, PK, SBB; Literatür Taraması- Lİ, SBB; Yazıyı Yazan- Lİ, GYGG, PK, SBB; Eleştirel İnceleme- GGYG;
Çıkar Çatışması: Yazarlar, çıkar çatışması olmadığını beyan etmiştir.
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Ethics Committee Approval: A scoping review not involves human subjects, human material, human tissues, or human data. Therefore, the approval of an ethics committee was not necessary.
Informed Consent: A scoping review not involves human subjects, human material, human tissues, or human data. Therefore, the approval of an Informed Consent was not necessary.
Peer-review: Externally peer-reviewed.
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REFERENCES

1. Zarei S, Carr K, Reiley L, et al. A comprehensive review of amyotrophic lateral sclerosis. *Surg Neurol Int.* 2015;6:171. https://doi.org/10.4103/2152-7806.169561
2. Hardiman O, Al-Chalabi A, Chio A, et al. Amyotrophic lateral sclerosis. *Nat Rev Dis Primers.* 2017;3:17071. http://dx.doi.org/10.1038/nrdp.2017.71
3. Kiernan MC, Vucic S, Cheah BC, et al. Amyotrophic lateral sclerosis. *Lancet.* 2011;377(9769):942-955. https://doi.org/10.1016/S0140-6736(10)61156-7
4. Chiò A, Gauthier A, Vignola A, et al. Caregiver time use in ALS. *Neurology.* 2006;67(5):902-904. https://doi.org/10.1212/01.wnl.0000233840.41688.df
5. Rabkin JG, Wagner GJ, Del Bene M. Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosom Med.* 2000;62(2):271-279. https://journals.lww.com/bsam/abstract/2000/03000/resilience_and_distress_among_amyotrophic_lateral.20.aspx
6. de Wit J, Bakker LA, van Groenestijn AC, et al. Caregiver burden in amyotrophic lateral sclerosis: A systematic review. *Palliat Med.* 2018;32(1):231-245. https://doi.org/10.1177/0269216317709965
7. López-Bastida J, Perestelo-Pérez L, Montón-Alvarez F, Serrano-Aguilar P, Alfonso-Sanchez JL. Social economic costs and health-related quality of life in patients with amyotrophic lateral sclerosis in Spain. *Amyotroph Lateral Scler.* 2009;10(4):237-243. https://doi.org/10.1080/17482960802430781
8. Creemers H, de Morée S, Veldink JH, Nollet F, van den Berg LH, Beelen A. Factors related to caregiver strain in ALS: a longitudinal study. *J Neurol Neurosurg Psychiatry.* 2016;87(7):775-781. https://doi.org/10.1136/jnnp-2015-311651
9. Boerner K, Mock SE. Impact of patient suffering on caregiver well-being: the case of amyotrophic lateral sclerosis patients and their caregivers. *Psychol Health Med.* 2012;17(4):457-466. https://doi.org/10.1080/13548506.2011.613942
10. Chiò A, Gauthier A, Calvo A, Ghiglione P, Mutani R. Caregiver burden and patients' perception of being a burden in ALS. *Neurology.* 2005;64(10):1780-1782. https://doi.org/10.1212/01.WNL.0000162034.06268.37
11. Kabat-Zinn J. Mindfulness-based interventions in context: past, present, and future. *Clin Psychol Sci Pract.* 2003; 10(2): 144-156. https://doi.org/10.1093/clipsy.bpg016
12. Li G, Yuan H, Zhang W. The Effects of Mindfulness-Based Stress Reduction for Family Caregivers: Systematic Review. *Arch Psychiatr Nurs.* 2016;30(2):292-299. https://doi.org/10.1016/j.apnu.2015.08.014
13. Siegel RD, Germer CK, Olendzki A. Mindfulness: What is it? Where did it come from? In F. Didonna (Ed.), Clinical handbook of mindfulness. Springer Science + Business Media; 2009: 17–35. https://doi.org/10.1007/978-0-387-09593-6_2
14. Bodhi B. What does mindfulness really mean? A canonical perspective. *Mindfulness.* 2013; 12(1): 19–39. https://doi.org/10.1080/14639947.2011.564813
15. Weinstein, N, Brown KW, Ryan, RM. A multi-method examination of the effects of mindfulness on stress attribution, coping, and emotional well-being. *J Res Pers*. 2009; 43(3): 374-385. https://doi.org/10.1016/j.jrp.2008.12.008
16. Pagnini F, Phillips D, Bosma CM, Reece A, Langer E. Mindfulness as a Protective Factor for the Burden of Caregivers of Amyotrophic Lateral Sclerosis Patients. *J Clin Psychol.* 2016;72(1):101-111. https://doi.org/10.1002/jclp.22235
17. Burke T, Wilson O'Raghallaigh J, Maguire S, et al. Group interventions for amyotrophic lateral sclerosis caregivers in Ireland: a randomised controlled trial protocol. *BMJ Open.* 2019;9(9):e030684. https://doi.org/10.1136/bmjopen-2019-030684
18. Murfield J, Moyle W, O'Donovan A. Mindfulness- and compassion-based interventions for family carers of older adults: A scoping review. *Int J Nurs Stud.* 2021;116:103495. https://doi.org/10.1016/j.ijnurstu.2019.103495
19. Ugalde A, Mathers S, Hennessy Anderson N, Hudson P, Orellana L, Gluyas C. A self-care, problem-solving and mindfulness intervention for informal caregivers of people with motor neurone disease: A pilot study. *Palliat Med.* 2018;32(4):726-732. https://doi.org/10.1177/0269216317743434
20. Bruletti G, Comini L, Scalvini S, et al. A two-year longitudinal study on strain and needs in caregivers of advanced ALS patients. *Amyotroph Lateral Scler Frontotemporal Degener.* 2015;16(3-4):187-195. https://doi.org/10.3109/21678421.2014.974616
21. Burke T, Hardiman O, Pinto-Grau M, et al. Longitudinal predictors of caregiver burden in amyotrophic lateral sclerosis: a population-based cohort of patient-caregiver dyads. *J Neurol.* 2018;265(4):793-808. https://doi.org/10.1007/s00415-018-8770-6
22. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J.* 2009;26(2):91-108. https://doi.org/10.1111/j.1471-1842.2009.00848.x
23. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol.* 2018;18(1):143. https://doi.org/10.1186/s12874-018-0611-x
24. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol.* 2005;8(1):19-32. https://doi.org/10.1080/1364557032000119616
25. Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil, H. Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z (Editors). 2020;169(7):467-473. https://doi.org/10.46658/JBIMES-20-12
26. Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care

interventions. *J Epidemiol Community Health.* 1998;52(6):377-384. https://jech.bmj.com/content/52/6/377

27. Huffer D, Hing W, Newton R, Clair M. Strength training for plantar fasciitis and the intrinsic foot musculature: A systematic review. *Phys Ther Sport.* 2017;24:44-52. https://doi.org/10.1016/j.ptsp.2016.08.008
28. Samoocha D, Bruinvels DJ, Elbers NA, Anema JR, van der Beek AJ. Effectiveness of web-based interventions on patient empowerment: a systematic review and meta-analysis. *J Med Internet Res.* 2010;12(2):e23. Published 2010 Jun 24. https://doi.org/10.2196/jmir.1286
29. Ipek L, Güneş Gencer GY. Is caregiver burden of patients with amyotrophic lateral sclerosis related to caregivers' mindfulness, quality of life, and patients' functional level. *J Clin Neurosci.* 2024;126:95-100. https://doi.org/10.1016/j.jocn.2024.06.007
30. Pagnini F, Phillips D, Haulman A, Bankert M, Simmons Z, Langer E. An online non-meditative mindfulness intervention for people with ALS and their caregivers: a randomized controlled trial. *Amyotroph Lateral Scler Frontotemporal Degener.* 2022;23(1-2):116-127. https://doi.org/10.1080/21678421.2021.1928707
31. Marconi A, Gragnano G, Lunetta C, et al. The experience of meditation for people with amyotrophic lateral sclerosis and their caregivers - a qualitative analysis. *Psychol Health Med.* 2016;21(6):762-768. https://doi.org/10.1080/13548506.2015.1115110
32. de Wit J, Vervoort SCJM, van Eerden E, et al. User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: a qualitative study. *BMC Psychol.* 2019;7(1):35. https://doi.org/10.1186/s40359-019-0308-x
33. Shim M, Tilley JL, Im S, Price K, Gonzalez A. A Systematic Review of Mindfulness-Based Interventions for Patients with Mild Cognitive Impairment or Dementia and Caregivers. *J Geriatr Psychiatry Neurol.* 2021;34(6):528-554. https://doi.org/10.1177/0891988720957104
34. Oh J, An JW, Oh KW, et al. Depression and caregiving burden in families of patients with amyotrophic lateral sclerosis. *J Korean Acad Nurs.* 2015;45(2):202-210. https://doi.org/10.4040/jkan.2015.45.2.202
35. Tramonti F, Bongioanni P, Leotta R, Puppi I, Rossi B. Age, gender, kinship and caregiver burden in amyotrophic lateral sclerosis. *Psychol Health Med.* 2015;20(1):41-46. https://doi.org/10.1080/13548506.2014.892627
36. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA.* 2014;311(10):1052-1060. https://doi.org/10.1001/jama.2014.304
37. Gauthier A, Vignola A, Calvo A, et al. A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology.* 2007;68(12):923-926. https://doi.org/10.1212/01.wnl.0000257093.53430.a8
38. Lillo P, Mioshi E, Hodges JR. Caregiver burden in amyotrophic lateral sclerosis is more dependent on patients' behavioral changes than physical disability: a comparative study. *BMC Neurol.* 2012;12:156. https://doi.org/10.1186/1471-2377-12-156
39. Pagnini F, Di Credico C, Gatto R, et al. Meditation training for people with amyotrophic lateral sclerosis and their caregivers. *J Altern Complement Med.* 2014;20(4):272-275. https://doi.org/10.1089/acm.2013.0268
40. Tkatch R, Bazarko D, Musich S, et al. A Pilot Online Mindfulness Intervention to Decrease Caregiver Burden and Improve Psychological Well-Being. *J Evid Based Complementary Altern Med.* 2017;22(4):736-743. https://doi.org/10.1177/2156587217737204
41. Parks SM, Novielli KD. A practical guide to caring for caregivers. *Am Fam Physician.* 2000;62(12):2613-2622. https://www.aafp.org/pubs/afp/issues/2000/1215/p2613.html
42. Brown KW, Coogle CL, Wegelin J. A pilot randomized controlled trial of mindfulness-based stress reduction for caregivers of family members with dementia. *Aging Ment Health.* 2016;20(11):1157-1166. https://doi.org/10.1080/13607863.2015.1065790
43. Whitebird RR, Kreitzer M, Crain AL, Lewis BA, Hanson LR, Enstad CJ. Mindfulness-based stress reduction for family caregivers: a randomized controlled trial. *Gerontologist.* 2013;53(4):676-686. https://doi.org/10.1093/geront/gns126
44. Sun Y, Ji M, Leng M, Li X, Zhang X, Wang Z. Comparative efficacy of 11 non-pharmacological interventions on depression, anxiety, quality of life, and caregiver burden for informal caregivers of people with dementia: A systematic review and network meta-analysis. *Int J Nurs Stud.* 2022;129:104204. https://doi.org/10.1016/j.ijnurstu.2022.104204
45. Roach AR, Averill AJ, Segerstrom SC, Kasarskis EJ. The dynamics of quality of life in ALS patients and caregivers. *Ann Behav Med.* 2009;37(2):197-206. https://doi.org/10.1007/s12160-009-9092-9
46. Lulé D, Ludolph AC, Kübler A. Psychological morbidity in amyotrophic lateral sclerosis: Depression, anxiety, hopelessness. In: Pagnini F, Simmons Z, eds. Amyotrophic Lateral Sclerosis: Understanding and Optimizing Quality of Life and Psychological Well-Being. Oxford Academic. 2018:33. https://doi.org/10.1093/med/9780198757726.003.0003