

Meditation intervention in a person with amyotrophic lateral sclerosis

*Intervenção de meditação
em uma pessoa com esclerose
lateral amiotrófica*

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Abstract

Introduction: Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease affecting motor neurons in the motor cortex, brainstem, and spinal cord, resulting in muscle weakness, atrophy, and stiffness. These symptoms severely compromise motor function, sleep quality, and overall quality of life. Meditation is a complementary practice that may enhance rehabilitation outcomes and overall quality of life for individuals with ALS by improving sleep quality and reducing anxiety, depression, and negative emotions. **Objective:** To describe changes in quality of life, sleep quality, and functional capacity following a guided meditation intervention in a patient with ALS. **Methods:** This study involved 25 guided meditation sessions with one individual diagnosed with ALS. Quality of life, sleep, and functional capacity were assessed pre and post-intervention using the WHOQOL-100, Pittsburgh Sleep Quality Index, and Amyotrophic Lateral Sclerosis Functional Rating Scale, respectively. **Results:** The participant showed decreases across all variables. However, a positive change suggesting improvement was observed only for quality of life. She exhibited declines in the independence level and environment domains, but improvements were noted in the physical, psychological, and personal relationships domains. Although sleep quality and functional capacity worsened, these changes were not clinically significant. **Conclusion:** The meditation intervention positively influenced quality of life in the physical, psychological, and personal relationships domains, despite declines in sleep quality and functional capacity.

Keywords: Amyotrophic lateral sclerosis. Quality of life. Sleep quality. Functional status. Meditation.

Resumo

Introdução: A esclerose lateral amiotrófica (ELA) é uma doença degenerativa progressiva dos neurônios motores no córtex motor, tronco cerebral e medula espinhal, resultando em fraqueza muscular, atrofia e rigidez, com grave comprometimento da função motora, qualidade do sono e qualidade de vida. A meditação é uma prática complementar aos programas de reabilitação para pessoas com ELA e pode promover benefícios para qualidade do sono, ansiedade, depressão e sentimentos negativos, consequentemente promovendo melhor qualidade de vida. **Objetivo:** Descrever qualidade de vida, qualidade do sono e capacidade funcional após intervenção de meditação em uma paciente com ELA. **Métodos:** Foram realizadas 25 sessões de meditação guiada com uma pessoa com diagnóstico de ELA. A qualidade de vida, o sono e a capacidade funcional foram avaliados pré e pós-intervenção pelos instrumentos WHOQOL-100, Pittsburgh Sleep Quality Index e Amyotrophic Lateral Sclerosis Functional Rating Scale, respectivamente. **Resultados:** A participante apresentou diminuição em todas as variáveis, no entanto, apresentou uma mudança que sugere melhora apenas no âmbito da qualidade de vida. Ela teve perdas nos domínios de nível de independência e meio ambiente, mas incrementos nos domínios físico, psicológico e de relações pessoais. Embora tenha sido observada uma piora na qualidade do sono e na capacidade funcional, não houve mudança clinicamente significativa. **Conclusão:** A meditação teve impactos positivos na qualidade de vida nos domínios físico, psicológico e relações pessoais, mesmo com a piora na qualidade do sono e capacidade funcional.

Palavras-chave: Esclerose lateral amiotrófica. Qualidade de vida. Qualidade do sono. Estado funcional. Meditação.

Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive degenerative disease that affects motor neurons in the motor cortex, brainstem, and spinal cord, leading to muscle weakness, atrophy, and stiffness, with severe impairment of motor function and quality of life.¹ The median survival is approximately three years, with respiratory failure being the leading cause of death.¹ In addition to motor symptoms, 50% of patients experience extramotor manifestations such as cognitive and behavioral changes, due to the involvement of the frontal and

temporal lobes.² Approximately 10% of cases progress to frontotemporal dementia (FTD), which requires specific therapeutic approaches, although evidence regarding its management remains limited.^{3,4}

The etiology of ALS is idiopathic in 80% of cases, while 20% of patients have identifiable genetic mutations.¹ In addition to the evident decline in functional capacity, sleep may also be impaired due to progressive diaphragm muscle weakness resulting from reduced pulmonary function.⁵ However, muscle weakness is not the only cause of sleep disturbances. Structures such as the hypothalamus, thalamus, hippocampus, and brainstem, key regulators of the sleep-wake cycle, may also undergo pathological changes.⁶ Research has indicated that individuals with ALS experience difficulty initiating and maintaining sleep, reduced sleep efficiency, prolonged time in stage one sleep, and disrupted REM and non-REM sleep cycles.⁶

These sleep disorders tend to intensify as motor impairment progresses. However, in the early stages of ALS, poor sleep quality and daytime sleepiness adversely affect both quality of life and daily functioning.⁶ Improving quality of life and survival in individuals with ALS is closely linked to adequate multidisciplinary care that addresses the complex interplay of respiratory, nutritional, orthopedic, neuropsychiatric, and communication-related challenges.⁷ However, complementary interventions, such as meditation, may also be beneficial in addressing behavioral factors associated with poor sleep quality,⁸ anxiety, depression, and negative emotions.^{9,10}

Meditation practices can promote self-awareness, emotional self-regulation, and better social skills.¹¹ Rooted in Eastern spiritual philosophies, it is a valuable tool for coping with the demands of daily life and emphasizes training in focused attention and present moment awareness.^{12,13} Among the various forms of meditation – concentrative, mindfulness, and contemplative – mindfulness has the most research supporting its use in individuals with ALS.^{9,14,15}

Given this context, meditation may serve as an important adjunct to multidisciplinary ALS care by promoting physical and emotional well-being, even in the face of disease progression and functional decline. Therefore, the aim of this case report was to describe changes in quality of life, sleep quality, and functional capacity in an individual with ALS following a meditation intervention.

Case report

This is a case report of a 36-year-old female patient, a professional pastry chef, diagnosed with familial ALS exhibiting an autosomal recessive inheritance pattern. The diagnosis was confirmed through whole exome sequencing, which identified the c.358G>C variant in the SOD1 gene. The patient also met the El Escorial diagnostic criteria.

This study was approved by the Universidade Paulista (UNIP) Research Ethics Committee under protocol CAAE 24842019.2.0000.5512. The participant provided written informed consent to participate in the study, which was conducted at the UNIP Health Clinic, Alpha-ville Campus. However, due to the COVID-19 pandemic, the intervention program, originally in-person, was changed to a remote telehealth model. Five sessions were held in person, and 20 remotely. During this period, the patient also discontinued all other in-person therapies.

Initial, data collection was based on the patient's medical records available at the clinic, including her current age, age of symptom onset, age at diagnosis, and medical diagnosis. At the baseline assessment, the patient was asked about her main complaint, co-existing conditions, other ongoing therapies, and use of non-invasive ventilation and gait devices.

The patient began experiencing global muscle weakness and excessive fatigue at 28 years old. At 30, her symptoms worsened, and she received a clinical diagnosis of ALS. However, genetic confirmation was only obtained at age 36. She exhibited no comorbidities and was taking Riluzole. She was also receiving neuro-functional and aquatic physical therapy three times a week, but was not undergoing respiratory physiotherapy or using non-invasive ventilation. At the beginning of her participation in this study, she used Canadian crutches for independent ambulation but was dependent for sit-to-stand transfers. She reported difficulties with transfers and writing, which persisted throughout and after the intervention.

Three measurement instruments were applied by a blinded assessor before and after the intervention to evaluate quality of life, sleep quality, and functional capacity: the World Health Organization Quality Of Life Assessment Instrument (WHOQOL-100), the Pittsburgh Sleep Quality Index (PSQI), and the Amyotrophic Lateral Sclerosis Functional Rating Scale - Revised (ALSFRS-R), respectively.

Measurement instruments

The WHOQOL-100, a questionnaire developed by the World Health Organization, consists of 100 items that assess quality of life across six primary domains: physical health, psychological well-being, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. It also includes two general questions on overall quality of life and health, and two additional questions on satisfaction with life and health. Each item is scored on a five-point Likert scale, ranging from "very dissatisfied" to "very satisfied" for positive questions, and "not at all" to "extremely" for negative questions. Domain scores are summed and multiplied by four to obtain a total score ranging from 0 to 100, where higher scores indicate better quality of life.^{17,18}

PSQI was developed in 1989 to assess sleep quality over a one-month period. It evaluates subjective sleep quality, sleep latency, duration, habitual efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction. The instrument contains 19 self-rated items and 5 questions for a bed partner or roommate. In this case, the patient's husband completed the latter. The total PSQI score ranges from 0 to 21, with higher scores reflecting poorer sleep quality.^{19,20}

ALSFRS-R is a disease-specific functional assessment tool, considered clinically significant and predictive of survival time. It contains 12 items, scored from 0 to 4, with a maximum total score of 48 points. Higher scores reflect greater functionality. The scale evaluates speech, salivation, swallowing, handwriting, cutting food and handling utensils (with or without gastrostomy), dressing and hygiene (fine motor function), bed mobility, walking and stair climbing, breathing, orthopnea; and respiratory failure.²¹

Intervention

The intervention was adapted from Sharma et al.²² The intervention phases, patient instructions, and verbal commands from the therapist were the same for both in-person and remote sessions. Initially, the patient was instructed to complete 10 breathing cycles, following the verbal command: "breathe in for four seconds, hold for 2 seconds, and exhale for 4 seconds." To accommodate the patient's condition and prevent fatigue, the breathing cycles were adjusted from the original protocol.

Next, the therapist guided the meditation, directing the patient to focus on breath awareness and non-judgmental acceptance of thoughts and sensations, observing her breathing cycles. The verbal command was: "observe the temperature of the air as you inhale through your nose, expanding your chest. During exhalation, observe the temperature of the air as it passes through your lips."²²

In-person sessions were conducted in a quiet, private room, with the patient sat on a cushioned chair, her back supported, eyes slightly closed, and gaze directed at the floor at a 45-degree angle. For remote sessions, the patient remained in a supine position on her bed wearing headphones, with the lights off and door, curtains, and windows closed to minimize noise and distractions. The therapist guided the patient via a WhatsApp video call. Each twice-weekly session lasted an average of 10 to 20 minutes.

Results

Following the meditation intervention, the patient obtained improved scores on the WHOQOL-100 in the physical (increase of 8.33 points), psychological (1.25 points), and personal relationships (6.25 points) domains, with no change in the spirituality domain (Tables 1 and 2).

Table 1 - Scores on quality of life, sleep quality, and functional capacity questionnaires pre- and post-meditation

Questionnaires	Pre	Post
WHOQOL-100		
Physical domain	47.92	56.25
Psychological domain	57.50	58.75
Independence level	42.19	37.50
Social relationships	47.92	54.17
Environment	47.66	42.97
Spiritual aspects	75.00	75.00
Total	49.75	48.75
PSQI	4	7
ALSFRS	34	32

Note: WHOQOL-100 = World Health Organization Quality of Life Assessment Instrument; PSQI = Pittsburgh Sleep Quality Index; ALSFRS-R = Amyotrophic Lateral Sclerosis Functional Rating Scale.

Declines were noted in the level of independence (4.69 points) and environment domains (4.69 points), resulting in a net decrease of less than one point in the overall WHOQOL-100 score (Tables 1 and 2).

Table 2 - Scores for World Health Organization Quality of Life Assessment Instrument (WHOQOL-100) facets pre- and post-meditation

Domain/Facets	Pre	Post
Physical		
Pain and discomfort	43.75	50.00
Energy and fatigue	31.25	50.00
Sleep and rest	56.25	68.75
Psychological		
Positive feelings	56.25	62.50
Thinking, learning, memory and concentration	68.75	75.00
Self-esteem	56.25	56.25
Body image and appearance	43.75	31.25
Negative feelings	37.50	31.25
Independence level		
Mobility	12.50	0.00
Activities of daily living	31.25	25.00
Dependence on medication or treatments	6.25	12.50
Work capacity	31.25	37.50
Social relationships		
Personal relationships	56.25	56.25
Social support	43.75	43.75
Sexual activity	43.75	62.50
Environment		
Physical safety and protection	50.00	37.50
Home environment	56.25	43.75
Financial resources	43.75	50.00
Health and social care: availability and quality	31.25	31.25
Opportunities for acquiring new information and skills	75.00	62.50
Participation in and opportunities for recreation/leisure	43.75	43.75
Physical environment (pollution/noise/traffic/climate)	56.25	25.00
Spiritual aspects/religion/personal/ beliefs		
Spirituality/religion/personal beliefs	75.00	75.00
Self-rated quality of life	43.75	25.00
Transport	25.00	50.00

The patient's sleep quality worsened from good to poor in relation to habitual sleep efficiency, latency and daytime dysfunction after the intervention program (Tables 1 and 3). On the ALSFRS-R scale (Tables 1 and 4), the patient's score declined from 34 to 32 points in speech and handwriting functions after the intervention.

Table 3 - Pre- and post-meditation Pittsburgh Sleep Quality Index (PSQI) item scores

Components	Pre	Post
1 - Subjective quality of life	1	0
2 - Sleep latency	1	2
3 - Sleep duration	0	0
4 - Habitual sleep efficiency	0	2
5 - Sleep disturbances	2	2
6 - Use of sleep medication	0	0
7- Daytime dysfunction	0	1

Table 4 - Pre- and post-meditation Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS) item scores

Functions	Pre	Post
Speech	4	3
Salivating	4	4
Swallowing	4	4
Writing	3	2
Handling food and utensils	3	3
Dressing and hygiene	2	2
Turning in bed and adjusting bed clothes	1	1
Walking	1	1
Stair climbing	0	0
Dyspnea	4	4
Orthopnea	4	4
Respiratory failure	4	4
Total	34	32

Discussion

ALS is a severe neurodegenerative disease that leads to a loss of functional abilities and compromises sleep quality and overall quality of life. This study demonstrated that, after 25 sessions of guided meditation, the patient with ALS experienced gains in specific quality

of life domains, namely, physical, psychological, and personal relationships, despite declines in sleep quality and functional capacity. The observed functional decline, including reduced speech and writing ability as measured by the ALSFRS-R,²³ aligns with the expected clinical course of ALS.

With respect to sleep quality, a decrease in sleep latency, habitual sleep efficiency, and daytime dysfunction was observed, albeit with no clinically significant difference.²⁴ Several factors may have contributed to this decline, including disease progression and the context of the COVID-19 pandemic. Diaz-Abad et al.²⁵ assessed sleep in 43 individuals with ALS and 43 controls and found that at diagnosis, people with ALS exhibited sleep disturbances linked to depression symptoms and limited bed mobility. Excessive daytime sleepiness was associated with respiratory muscle weakness. Altered sleep could also be attributed to disease progression, with a worsening of nocturnal hypoventilation.²⁵ Another contributing factor might be the COVID-19 pandemic, as social isolation intensified feelings of loneliness and anxiety in people with ALS, negatively impacting sleep quality during confinement.²⁶

The physical domain of the WHOQOL-100 scale¹⁸ showed a post-intervention increase from 56.25 to 68.75 points. Although decreases in the independence level and environment domains influenced the instrument's total score (declining from 49.75 to 48.75), the possible influence of meditation is underscored by the improvement in the psychological domain score from 57.50 pre-meditation to 58.75 post-meditation. Regular mindfulness may be linked to positive changes in brain structure and function, including increased grey matter density in the prefrontal cortex. This area plays a crucial role in decision-making, emotional regulation, attention, and the reduction of anxiety, depression, and stress.²⁷

Despite pandemic-related social restrictions, a change in the social relationships domain score was observed (pre-intervention: 47.92; post-intervention: 54.17). This finding corroborates the study by Fogel et al.,²⁸ which showed that pandemic-related confinement intensified intrafamilial bonds, which emerged as adaptive mechanisms, fostering relational cohesion and mutual support, thereby optimizing coping strategies for daily life challenges and favoring psychosocial resilience.²⁸

The shift from in-person to remote intervention was a limitation in our study; however, it was an effective strategy for ensuring continuity and adapting to the

COVID-19 pandemic. Studies suggest that remote care may reduce travel-related costs, provide support in resource-limited areas, and improve adherence to interventions.^{26,29}

Furthermore, this approach is a valuable and effective strategy even beyond the pandemic.^{26,29} In a randomized clinical trial, Pagnini et al.¹⁴ investigated a non-meditative mindfulness intervention in individuals with ALS and their caregivers. They found reductions in depression, anxiety, and negative emotions among the patients, while caregivers reported decreased caregiver burden, lower depression and anxiety scores, and improved energy and well-being over time. Thus, remote care is a feasible and low-cost alternative for individuals facing transportation challenges to rehabilitation centers.

Conclusion

The findings of this research suggest that meditation positively impacted the patient's quality of life in the physical, psychological, and personal relationships domains, even amid declines in sleep quality and functional abilities.

Authors' contributions

VMG and TBCO contributed to the study's conception and design, data analysis and interpretation, manuscript drafting and revision, and approval of the final version.

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