PALLIATIVE CARE IN AMYOTROPHIC LATERAL SCLEROSIS: STRATEGIES FOR THE RELIEF OF PHYSICAL AND EMOTIONAL SUFFERING

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Abstract

Amyotrophic lateral sclerosis (ALS) is a progressive, incurable neurodegenerative disease with a high biopsychosocial impact, characterized by the gradual loss of voluntary motor functions and partial or complete preservation of cognitive abilities. In this context, palliative care emerges as an essential approach for relieving physical and emotional suffering and promoting quality of life. This study aimed to analyze the scientific evidence on palliative care strategies in amyotrophic lateral sclerosis, with emphasis on symptom control and coping with emotional distress. This is an integrative literature review conducted through the analysis of national and international studies published in scientific databases, selected according to previously defined inclusion and exclusion criteria. The results showed that ALS causes profound repercussions in the physical, psychological, and social dimensions, requiring an integral and multidisciplinary care approach. Symptom control, especially pain, dyspnea, dysphagia, and spasticity, proved to be fundamental for reducing physical suffering, while psychological and psychosocial support was indispensable for coping with anxiety, depression, and existential distress. Furthermore, the literature highlights the importance of therapeutic communication, advance care planning, and the inclusion of the family as a unit of care. It is concluded that the early implementation of palliative care in amyotrophic lateral sclerosis significantly contributes to the preservation of dignity, reduction of overall suffering, and improvement of quality of life throughout the course of the disease.

Keywords: Amyotrophic lateral sclerosis, Mental health, Palliative care, Quality of life, Suffering.

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a progressive, rare, and fatal neurodegenerative disease, characterized by the selective degeneration of upper and lower motor neurons, leading to progressive loss of muscle strength, atrophy, speech and swallowing impairments, and, in advanced stages, respiratory failure (Feldman et al., 2022; Younger; Brown, 2023). It is a complex clinical condition whose course imposes significant functional limitations and a high degree of dependence, substantially affecting the

quality of life of affected individuals and their families. Despite scientific advances in the field of neurology, ALS remains incurable, with therapeutic options still limited in terms of modifying the course of the disease (Chavda et al., 2022; Corcia et al., 2023).

ALS progression is heterogeneous, varying among individuals, but it invariably culminates in progressive functional loss and increasing care demands. Studies indicate that the average survival after diagnosis ranges from three to five years and may be influenced by factors such as age, type of disease onset, access to specialized care, and multiprofessional follow-up (Diniz; Passos, 2022; Rizea et al., 2024). In this context, coping with the disease is not limited to physical manifestations; it also involves intense emotional, psychological, social, and ethical challenges.

The psychosocial impact of ALS is profound, as many patients maintain preserved cognitive functions while experiencing a progressive loss of physical autonomy. This dissociation contributes to emotional suffering, feelings of helplessness, anxiety, depression, and existential anguish, especially in view of a guarded prognosis and increasing dependence on caregivers (Lira; Firmino de Sá; Pachú, 2024; Costa et al., 2024). In addition, communication changes such as dysarthria and functional anacusis may intensify social isolation and further compromise quality of life (Nunes et al., 2023).

From a clinical standpoint, ALS is accompanied by a broad range of symptoms that intensify over the course of the disease. Dyspnea, pain, fatigue, spasticity, sialorrhea, dysphagia, sleep disturbances, and respiratory discomfort are frequent manifestations and are responsible for substantial physical suffering (Tozani; Siqueira, 2023; Tolochko et al., 2025). Although there are pharmacological and non-pharmacological therapies aimed at controlling these symptoms, management is often challenging and requires continuous, individualized, and integrated interventions.

Given this reality, palliative care assumes a central role in the follow-up of individuals with ALS. According to the literature, this approach should be initiated early, concurrently with disease-modifying treatment, with the aim of preventing and alleviating suffering in all its dimensions (Mercadante; Al-Husinat, 2023). Unlike the mistaken conception that associates palliative care exclusively with end-of-life

care, this approach proposes active, person-centered care oriented toward promoting quality of life from diagnosis to advanced stages of the disease (Silva et al., 2022; Andrade et al., 2025).

Palliative care in ALS encompasses strategies directed toward rigorous control of physical symptoms, emotional and psychological support, strengthening patient autonomy, and continuous support for family members and caregivers. Evidence indicates that appropriate palliative interventions contribute to reducing suffering, improving communication among the team, the patient, and relatives, and facilitating decision-making that is more aligned with the values and preferences of the ill person (Queiroz et al., 2023; Meira et al., 2022). In this sense, practices such as pain and dyspnea management, nutritional and ventilatory support, adapted functional rehabilitation, and psychological follow-up become fundamental elements of care.

The role of multiprofessional teams is widely recognized as one of the pillars of palliative care in neuromuscular diseases, including ALS. Integration among different areas of knowledge enables a comprehensive and continuous approach capable of responding to the multiple needs imposed by disease progression (Davico et al., 2024; Matamala et al., 2022). Recent studies demonstrate that multidisciplinary follow-up is associated with improved quality of life, reduced avoidable hospitalizations, and greater satisfaction of patients and family members with the care received (The Lancet Neurology, 2024).

In addition to clinical management, palliative care is also grounded in essential ethical principles such as respect for autonomy, dignity, and the patient’s choices. In ALS, decisions related to life-support technologies such as invasive mechanical ventilation, gastrostomy, and tracheostomy require sensitive, clear discussions based on shared information (Costa et al., 2024; Santana et al., 2025). Anticipating these discussions through advance directives has been identified as a fundamental strategy to ensure that care aligns with the patient’s wishes, reducing conflict and suffering throughout the course of the disease.

Emotional suffering associated with ALS also demands special attention within palliative care. The high prevalence of depressive and anxious symptoms reinforces the need for ongoing psychosocial

interventions based on qualified listening, welcoming, and strengthening bonds (Lira; Firmino de Sá; Pachú, 2024). Approaches such as dignity therapy have shown promise in fostering the re-signification of the illness experience, valuing life history, and preserving existential meaning, even in the face of a progressive and incurable disease (Meira et al., 2022).

Although scientific advances have expanded understanding of the pathophysiological mechanisms of ALS and driven the development of new experimental therapies (Chavda et al., 2022; Rizea et al., 2024), it remains evident that care centered on relieving suffering must occupy a prominent position in the follow-up of these patients. In this scenario, palliative care does not represent the absence of treatment, but rather an active, ethical, and humanized strategy of comprehensive care oriented toward promoting comfort, dignity, and quality of life throughout the course of the disease (Mercadante; Al-Husinat, 2023; Santos et al., 2024).

Figure 1

Multidimensional approach to palliative care in amyotrophic lateral sclerosis, encompassing the physical, emotional, social, and spiritual domains.

Source: Gemini – Google (2026)

Given the clinical, emotional, social, and ethical complexity that characterizes amyotrophic lateral sclerosis, it is essential to deepen the discussion about the role of palliative care as a structuring axis of

comprehensive care. Thus, the objective of this study is to analyze the main palliative care strategies applied to amyotrophic lateral sclerosis, with emphasis on relieving physical and emotional suffering, in light of current scientific evidence, contributing to the qualification of care and to the promotion of dignity for people affected by this condition.

METHODOLOGY

This is a qualitative study with a descriptive design and an integrative literature review approach, developed with the objective of analyzing palliative care strategies applied to amyotrophic lateral sclerosis, with emphasis on relieving physical and emotional suffering. The choice of this method is justified by its ability to gather, analyze, and synthesize results from relevant scientific research, enabling an expanded understanding of the current state of knowledge on the topic and the identification of gaps that may support care practices and future investigations.

The integrative review was conducted in a systematized manner, following the steps proposed in the scientific literature: definition of the guiding question, establishment of inclusion and exclusion criteria, database searching, study selection, critical appraisal of content, data extraction, and synthesis of results. The guiding question of the study was elaborated using the PICo strategy (Population, Interest, and Context), and was defined as: which palliative care strategies have been described in the scientific literature for alleviating physical and emotional suffering in people with amyotrophic lateral sclerosis?

The search for studies was carried out in national and international databases recognized for relevance in the health field, including PubMed/MEDLINE, Scopus, Web of Science, Scientific Electronic Library Online (SciELO), and Latin American and Caribbean Health Sciences Literature (LILACS). These databases were selected because they encompass extensive scientific production in the areas of neurology, palliative care, and multiprofessional health.

To identify studies, controlled and uncontrolled descriptors were used, extracted from the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH), combined through the Boolean

operators AND and OR. The main descriptors employed were: "*esclerose lateral amiotrófica*", "amyotrophic lateral sclerosis", "*cuidados paliativos*", "palliative care", "*qualidade de vida*", "*sofrimento*", "*dor*", and "*saúde mental*". The search strategies were adapted according to the specificities of each database, aiming to increase search sensitivity and reduce the loss of relevant studies.

Figure 2

Search descriptors used in the integrative review.

Source: Authors 2026)

The inclusion criteria adopted were: original scientific articles, integrative or systematic reviews, case studies, and clinical guidelines addressing palliative care in amyotrophic lateral sclerosis; full-text availability; studies published in Portuguese, English, or Spanish; and works published between 2021 and 2025, considering the updating and relevance of scientific evidence. Studies that discussed physical, emotional, psychosocial, or ethical aspects related to palliative care in patients with ALS were also included.

The sample excluded duplicate studies across databases, editorials, letters to the editor, conference abstracts, reports without scientific grounding, and publications that did not directly address palliative care in ALS or that dealt exclusively with molecular and experimental aspects without correlation to care practice. Studies whose full text was not available were also excluded.

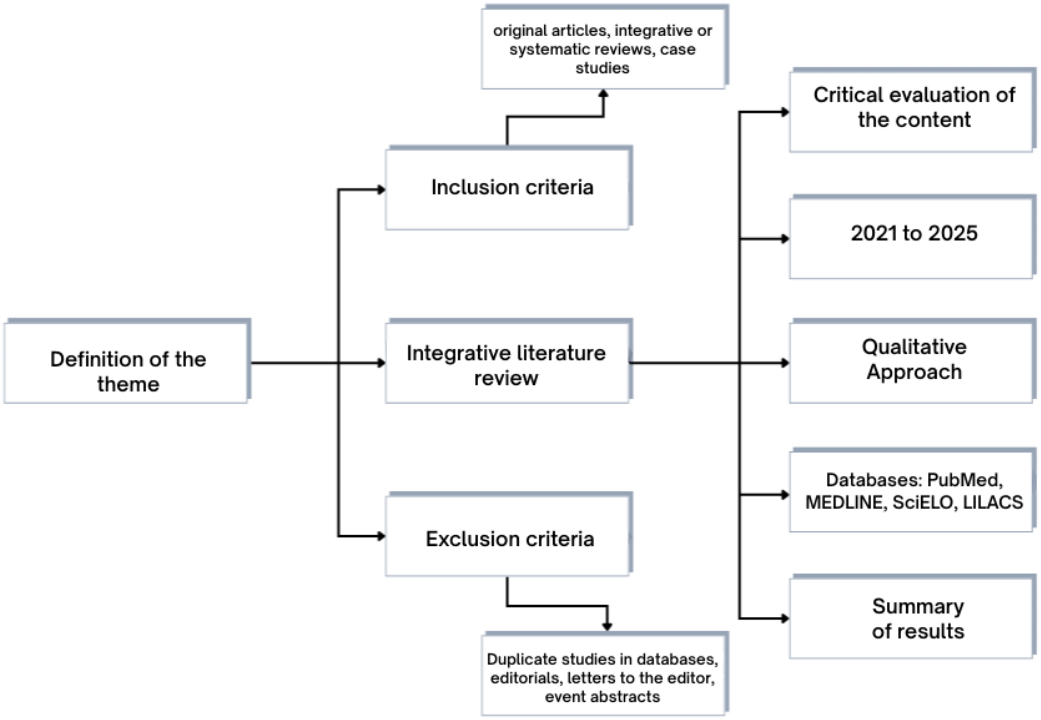
Article selection occurred in two stages. In the first, titles and abstracts were read to verify adequacy to the previously established inclusion criteria. In the second stage, potentially eligible studies were read in full to confirm their pertinence and relevance to the study's objective. The selection process was carried out independently, with subsequent consensus regarding inclusion of articles, aiming to minimize selection biases.

Data extraction was performed using an instrument developed by the researchers, encompassing the following information: authors, year of publication, country of origin, type of study, objectives, main palliative care strategies described, dimensions of suffering addressed (physical and emotional), and main results. The data obtained were organized into tables and thematic categories, facilitating comparative analysis and synthesis of evidence.

Data analysis was conducted descriptively and interpretively, based on exhaustive reading of the included studies. Findings were grouped into analytical categories defined according to the recurrence and relevance of emerging themes, such as management of physical symptoms, emotional and psychological support, multiprofessional care, communication and shared decision-making, and ethical aspects in palliative care. This strategy enabled the construction of an integrated view of practices and recommendations present in the scientific literature.

Figure 3

Scheme for developing and synthesizing the included studies, highlighting the stages of selection, analysis, and thematic categorization



Source: Authors (2026)

Because this is an integrative literature review study, there was no need for submission to a Research Ethics Committee, as provided by Resolution No. 466/2012 of the National Health Council. However, the ethical principles of scientific research were respected, with rigor in citing sources, fidelity to the authors' ideas, and commitment to academic integrity.

RESULTS AND DISCUSSION

The results of this integrative review made it possible to systematically identify and analyze the main scientific evidence related to palliative care in amyotrophic lateral sclerosis, with emphasis on relieving physical and emotional suffering. The synthesis of studies revealed that ALS constitutes a condition of high clinical and care complexity, whose repercussions transcend neuromuscular impairment and significantly affect the psychological, social, and existential dimensions of the patient and their

family. Accordingly, the discussion of findings was organized into thematic subchapters, covering the biopsychosocial repercussions of the disease in the palliative context, scientific evidence on symptom control, and emotional suffering and patients' mental health, in order to foster an integrated and in-depth understanding of palliative care in amyotrophic lateral sclerosis.

BIOPSYCHOSOCIAL REPERCUSSIONS OF AMYOTROPHIC LATERAL SCLEROSIS IN THE PALLIATIVE CONTEXT

The results of this integrative review demonstrate that amyotrophic lateral sclerosis produces profound, progressive, and interdependent repercussions in the biological, psychological, and social dimensions of the patient's life, configuring a complex suffering framework that requires comprehensive and continuous palliative care. According to Feldman et al. (2022), ALS is marked by progressive degeneration of motor neurons, which irreversibly compromises voluntary motor functions and imposes increasing functional limitations. From the perspective of Younger and Brown (2023), this inexorable progression results in significant loss of autonomy, making the patient increasingly dependent on specialized care.

In the biological domain, the analyzed studies indicate that progressive physical decline constitutes one of the main sources of suffering in the palliative context. According to Diniz and Passos (2022), generalized muscle weakness associated with atrophy and spasticity compromises the performance of basic activities of daily living, such as walking, feeding oneself, and communicating, directly impacting quality of life. According to Oliveira et al. (2023), as the disease advances, symptoms such as dyspnea, dysphagia, and pain become more frequent and intense, requiring constant reassessments of the care plan and early palliative interventions.

According to Tozani and Siqueira (2023), the presence of respiratory symptoms, especially dyspnea, represents an important milestone in ALS progression and is often associated with intense physical and emotional distress. In Mercadante and Al-Husinat's analysis (2023), inadequate management

of these symptoms may intensify the patient's overall suffering, reinforcing the need for structured palliative care from the early stages of the disease. As Rodrigues and collaborators (2019) state, insufficient control of physical symptoms tends to negatively affect other dimensions of human suffering.

Regarding psychological repercussions, the literature evidences a high emotional impact from the moment of diagnosis. According to Costa et al. (2024), awareness of ALS's progressive and incurable nature triggers feelings of fear, sadness, anguish, and anticipatory suffering, frequently associated with the perception of the gradual loss of autonomy and functional identity. In Martins' view (2018), living with chronic and disabling illness causes an ongoing process of grief in which the patient faces successive losses over the course of the disease.

According to the findings of Lira, Firmino de Sá, and Pachú (2024), partial or total preservation of cognitive functions in many ALS patients intensifies psychological suffering, since the individual consciously witnesses the progression of physical limitations imposed by the disease. As noted by Ferreira and Silva (2020), this dissociation between cognitive lucidity and motor incapacity may favor the emergence of depressive and anxious symptoms, especially when there is no adequate psychological support.

In the social domain, the results indicate that ALS produces significant changes in family dynamics and interpersonal relationships. According to Andrade et al. (2025), the growing need for continuous care redefines family roles, often transferring responsibility for care to close relatives who then experience physical, emotional, and financial overload. As argued by Nogueira and Almeida (2019), chronic and progressive illness affects not only the patient but the entire family nucleus, which also comes to require support and guidance.

According to Araújo (2017), withdrawal from work activities and reduced social participation are frequent consequences of ALS progression, contributing to social isolation and loss of the individual's social role. According to Nunes et al. (2023), speech and communication impairments such as dysarthria

exacerbate this isolation by hindering the expression of needs, feelings, and wishes, which may intensify emotional suffering and further compromise social interaction.

The literature indicates that these biopsychosocial repercussions do not manifest in isolation, but rather interact dynamically, potentiating the patient's overall suffering. In Castro's analysis (2021), uncontrolled physical suffering tends to aggravate psychological suffering, while the absence of adequate social support may intensify both emotional symptoms and the perception of pain and physical discomfort. In agreement with Gomes (2018), palliative care must consider this interrelationship among dimensions, adopting a comprehensive, person-centered approach.

In this context, palliative care emerges as a fundamental strategy for coping with the biopsychosocial repercussions of ALS. According to Queiroz et al. (2023), this approach recognizes the patient in their entirety, considering not only clinical manifestations of the disease but also emotional, social, spiritual, and family needs. For Santos (2019), including the family as a unit of care is a central element of palliative care, especially in neurodegenerative diseases with prolonged trajectories.

The analyzed studies emphasize that the work of multiprofessional teams is essential to mitigate the biopsychosocial impact of ALS. According to Davico et al. (2024), integration among professionals in medicine, nursing, physiotherapy, speech-language pathology, nutrition, psychology, and social work enables more comprehensive interventions tailored to the patient's individual needs. As highlighted by Almeida and Costa (2020), teamwork fosters continuity of care, communication among professionals, and the construction of more effective therapeutic plans.

Another widely discussed aspect concerns the importance of therapeutic communication in the palliative context. According to Silva et al. (2022), qualified listening, welcoming, and providing clear and honest information about disease progression help reduce anxiety, strengthen the bond between the team and the patient, and support shared decisions. From Carvalho's perspective (2022), effective communication is a fundamental instrument for humanizing care and preserving patient dignity.

Thus, the results of this review reinforce that palliative care in amyotrophic lateral sclerosis must be understood as a longitudinal process initiated early and maintained throughout the entire course of the disease. As Pereira and Souza (2021) indicate, this approach makes it possible to reduce suffering, promote better adaptation to illness, and preserve, as much as possible, the patient's autonomy and dignity. Therefore, it becomes evident that understanding and addressing the biopsychosocial repercussions of ALS are fundamental to qualifying care and promoting truly comprehensive assistance.

Table 1

Immediately after this subchapter – Synthesis of the main biopsychosocial repercussions of ALS and associated palliative interventions.

Dimension	Main repercussions identified	Palliative strategies described in the literature	Contributions to care
Biological	Progressive muscle weakness, loss of mobility, dysphagia, dyspnea, pain, fatigue, and spasticity	Pharmacological symptom management, noninvasive ventilatory support, nutritional adaptation, palliative physiotherapy	Reduction of physical suffering, promotion of comfort, and maintenance of residual functionality
Psychological	Anxiety, depression, anticipatory suffering, anguish regarding disease progression	Psychological follow-up, qualified listening, dignity therapy, therapeutic communication	Emotional strengthening, preservation of autonomy, and existential meaning
Social	Functional dependence, social isolation, changes in family dynamics, caregiver burden	Psychosocial support for the family, guidance for caregivers, inclusion of the family as a unit of care	Reduction of family overload and strengthening of the support network
Ethical	Decisional conflicts, doubts about invasive interventions, fear of loss of autonomy	Advance care planning, advance directives, shared decision-making	Promotion of dignity, respect for patient preferences, and person-centered care

Source: Authors 2026)

SCIENTIFIC EVIDENCE ON SYMPTOM CONTROL IN AMYOTROPHIC LATERAL SCLEROSIS

The results of this integrative review show that symptom control constitutes one of the central pillars of palliative care in amyotrophic lateral sclerosis and is widely recognized in the literature as a fundamental strategy for relieving physical suffering and promoting quality of life. According to Silva

(2022), ALS is characterized by a set of multiple, progressive, and often refractory symptoms, which requires continuous, individualized clinical management centered on patient comfort. In Castro's analysis (2021), inadequate management of these symptoms contributes to intensification of overall suffering and significant worsening of the illness experience.

Among the most frequently described symptoms, pain occupies a prominent place, although it has historically been undervalued in the ALS context. According to Pereira and Souza (2021), pain manifests especially in more advanced stages of the disease and is associated with prolonged immobility, muscle contractures, spasticity, and postural changes. As Ferreira and Silva (2020) point out, systematic pain assessment using validated scales is essential for implementing effective therapeutic strategies, which include both pharmacological and non-pharmacological interventions such as postural changes, physiotherapy, and comfort measures.

Dyspnea is described in the literature as one of the most distressing symptoms for ALS patients due to progressive respiratory failure. According to Oliveira et al. (2020), impairment of respiratory musculature leads to a persistent sensation of shortness of breath, often accompanied by anxiety and fear. From Carvalho's perspective (2022), noninvasive ventilation represents one of the main strategies for managing dyspnea and is associated with improved respiratory comfort, sleep quality, and survival. As Rodrigues and collaborators (2019) state, the judicious use of low-dose opioids also proves effective in relieving respiratory discomfort, especially in advanced stages of the disease.

Fatigue and spasticity also rank among recurrent and impactful symptoms. According to Santos (2019), fatigue in ALS is multifactorial, related both to muscular effort and to respiratory changes and the emotional impact of illness. In agreement with Gomes (2018), appropriate management of these symptoms involves combining pharmacological therapies, such as muscle relaxants, with non-pharmacological interventions, including physiotherapy, energy conservation guidance, and adaptation of daily activities. As argued by Nogueira and Almeida (2019), these strategies contribute to preserving residual functionality and reducing physical discomfort.

Dysphagia and sialorrhea were widely discussed in the analyzed studies and are recognized as significant sources of physical and emotional suffering. According to Lima et al. (2021), swallowing difficulty increases the risk of aspiration, malnutrition, and dehydration, requiring continuous speech-language and nutritional follow-up. According to Oliveira et al. (2020), adapting food consistency, using thickeners, and, when indicated, performing gastrostomy are effective measures to minimize complications and promote greater feeding safety. According to Araújo (2017), such decisions should be conducted in a shared manner, respecting the patient's values, beliefs, and preferences.

Sleep disturbances and excessive sialorrhea are also frequently reported in the literature. According to Silva (2022), these symptoms directly interfere with rest, comfort, and the patient's social interaction. As Almeida and Costa (2020) highlight, management of sialorrhea may include pharmacological measures such as anticholinergics, and non-pharmacological interventions, in addition to speech-language support. In Martins' view (2018), adequate control of these symptoms contributes to reducing social embarrassment and improving patient self-esteem.

The results show that effective symptom control strongly depends on multiprofessional action. According to Pereira and Souza (2021), integration among medicine, nursing, physiotherapy, speech-language pathology, nutrition, and psychology enables more comprehensive interventions tailored to individual needs. In Castro's analysis (2021), isolated professional practice limits the effectiveness of palliative care, whereas teamwork fosters continuity of care and rapid responses to clinical changes.

Another relevant aspect concerns aligning symptom control with the patient's goals of care. According to Ferreira and Silva (2020), early discussions about expectations, therapeutic limits, and advance directives help avoid disproportionate interventions and ensure care is centered on comfort and dignity. From Carvalho's perspective (2022), respect for patient autonomy is an essential element of palliative care and should guide all clinical decisions.

Overall, the analyzed studies reinforce that symptom control in amyotrophic lateral sclerosis must be understood as a dynamic process that accompanies disease progression and continuously adapts to the

patient's needs. According to Santos (2019), the palliative approach, by integrating scientific evidence, multiprofessional practice, and person-centered care, is fundamental for relieving physical suffering and promoting quality of life throughout the entire course of ALS.

Table 2

Immediately after this subchapter – Main ALS symptoms, symptom-control strategies, and associated scientific evidence.

Predominant symptom	Impact on quality of life	Symptom-control strategies	Associated scientific evidence
Pain	Functional limitation, physical and emotional suffering	Analgesics, opioids, physiotherapy, appropriate positioning	Relief of suffering and improvement of overall comfort
Dyspnea	Intense anxiety, sensation of suffocation	Noninvasive ventilation, low-dose opioids, emotional support	Reduction of anxiety and improvement of quality of life
Dysphagia	Risk of aspiration, malnutrition, discomfort	Diet adaptation, speech-language therapy, gastrostomy when indicated	Prevention of complications and greater feeding safety
Sialorrhea	Social embarrassment, risk of aspiration	Anticholinergics, botulinum toxin, nursing care	Improved comfort and social interaction
Spasticity and fatigue	Pain, limited mobility, exhaustion	Muscle relaxants, palliative physiotherapy	Improved mobility and reduced discomfort
Sleep disturbances	Tiredness, worsening mood and cognition	Sleep hygiene, management of nocturnal dyspnea, medication support	Positive impact on physical and emotional well-being

Source: Authors (2026)

EMOTIONAL SUFFERING AND MENTAL HEALTH IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

The results of this review show that emotional suffering and mental health impairments are central dimensions of the illness experience in amyotrophic lateral sclerosis, constituting inseparable elements of palliative care. According to Silva (2022), ALS imposes on the individual not only progressive functional losses but also profound emotional ruptures related to awareness of the disease's irreversibility and

anticipation of future limitations. In Castro's analysis (2021), the psychological impact of ALS tends to intensify over time, accompanying clinical progression and increasing functional dependence.

Depression is widely described in the literature as one of the most prevalent mental disorders among ALS patients. According to Pereira and Souza (2021), depression is often underdiagnosed due to overlap between physical symptoms of the disease—such as fatigue, motor slowing, and sleep changes—and emotional manifestations. For Santos (2019), the gradual loss of autonomy, associated with the inability to perform previously meaningful daily activities, is a determining factor for psychological illness, contributing to persistent feelings of sadness, hopelessness, and personal devaluation.

Anxiety also emerges as an expressive component of emotional suffering in ALS. According to Oliveira et al. (2020), fear of disease progression, loss of verbal communication, and respiratory failure generates a constant state of apprehension, often accompanied by anticipatory suffering. In Martins' view (2018), preservation of cognitive functions in a large portion of patients aggravates this condition, as the individual lucidly and continuously follows the evolution of functional losses, which intensifies feelings of anguish and vulnerability.

Figure 4

Dimensions of emotional suffering in Amyotrophic Lateral Sclerosis in the palliative context

Source: Gemini – Google (2026)

Communication changes such as dysarthria and anarthria are identified as factors that intensify emotional suffering. As Almeida and Costa (2020) highlight, difficulty expressing thoughts, wishes, and emotions compromises social interaction and favors progressive isolation. According to Araújo (2017), restriction of verbal communication affects not only functionality but directly impacts the subject's identity, negatively influencing self-esteem and sense of social belonging.

The analyzed studies demonstrate that emotional suffering in ALS is not restricted to the patient but extends significantly to relatives and caregivers. According to Lima et al. (2021), living with a progressive and incurable disease triggers processes of anticipatory grief, chronic stress, and emotional overload in informal caregivers. As Rodrigues and collaborators (2019) state, the absence of adequate psychological support for family members may result in mental illness, compromising both caregiver well-being and the quality of care offered to the patient.

In this context, palliative care plays a fundamental role in promoting mental health and coping with emotional suffering. From Carvalho's perspective (2022), the palliative approach broadens the focus of care by recognizing psychological, social, and spiritual dimensions as essential components of assistance. As Ferreira and Silva (2020) point out, interventions based on active listening, welcoming, and continuous psychological follow-up contribute to reducing depressive and anxious symptoms and fostering adaptation to the illness process.

Structured psychosocial approaches such as support groups and psychotherapeutic follow-up are described as effective strategies in the palliative context. In agreement with Gomes (2018), these spaces enable the expression of emotions, sharing of experiences, and strengthening of bonds, reducing the feeling of isolation. As argued by Nogueira and Almeida (2019), including the family in these interventions favors the construction of collective coping strategies and promotes greater emotional balance within the family nucleus.

Among the innovative interventions highlighted in the literature, dignity therapy occupies a relevant position. According to Silva (2022), this approach seeks to restore the patient's existential

meaning by valuing life history, affective bonds, and legacy. In Castro's analysis (2021), dignity therapy contributes to preserving self-esteem and reducing existential suffering, even in the face of ALS's inexorable progression, strengthening the perception of the value and meaning of one's own life.

Another widely discussed aspect concerns advance care planning and advance directives. According to Oliveira et al. (2020), patients who actively participate in these discussions report a greater sense of control, autonomy, and tranquility regarding the future. For Santos (2019), early addressing of these issues reduces anxiety related to decision-making in advanced stages of the disease and promotes care aligned with the patient's values and wishes.

Taken together, the results of this review reinforce that emotional suffering and mental health impairments in patients with amyotrophic lateral sclerosis require continuous, specialized, and sensitive attention. According to Silva (2022), palliative care, by recognizing these dimensions as constitutive of comprehensive care, contributes significantly to reducing suffering, promoting emotional well-being, and preserving dignity throughout the entire course of the disease.

Table 3

Main mental health impairments in ALS patients and associated palliative interventions.

Mental health impairments	Triggering factors in ALS	Repercussions for patient and family	Recommended palliative interventions
Depression	Progressive loss of autonomy, functional dependence, awareness of disease irreversibility	Persistent sadness, hopelessness, reduced motivation, impaired quality of life	Continuous psychological follow-up, qualified listening, individualized emotional support, judicious use of psychotropic medications when indicated
Anxiety	Uncertainty about disease progression, fear of respiratory failure and loss of communication	Constant anguish, anticipatory suffering, sleep and concentration changes	Supportive psychotherapy, psychoeducational interventions, clear communication about the care plan, pharmacological management when necessary
Existential suffering	Confrontation with finitude, changes in identity and social role	Feelings of emptiness, loss of meaning in life, spiritual suffering	Dignity therapy, spiritual support according to patient beliefs, valuing life history and affective bonds
Social isolation	Dysarthria, motor limitations, and reduced social participation	Loneliness, social withdrawal, worsening emotional suffering	Alternative communication strategies, encouragement of family participation, support groups, and psychosocial support
Family emotional overload	Continuous responsibility for care, anticipatory grief, lack of institutional support	Stress, anxiety, depression, and physical and emotional exhaustion of caregivers	Inclusion of the family in palliative care, psychological support for caregivers, guidance and distribution of responsibilities
Suffering related to decision-making	Difficulty discussing therapeutic limits and end-of-life issues	Anguish, sense of loss of control, and insecurity	Advance care planning, advance directives, shared decision-making

Source: Author's own (2026)

The analysis of studies showed that amyotrophic lateral sclerosis imposes profound repercussions on the physical, emotional, and social dimensions of patients' lives, configuring a complex suffering scenario that demands comprehensive and continuous palliative care. The inexorable progression of the disease compromises functional autonomy, communication, and social participation, directly impacting

quality of life and requiring a person-centered care approach grounded in the individual's support network.

In the physical domain, symptom control emerges as one of the central pillars of palliative care in ALS. The literature highlights the high prevalence of symptoms such as pain, dyspnea, dysphagia, spasticity, and fatigue, which require systematic assessment and individualized interventions. Pharmacological and non-pharmacological strategies, when conducted by multiprofessional teams, prove effective in reducing physical suffering and promoting comfort, especially when aligned with goals of care and patient preferences.

The findings also emphasize that emotional suffering and mental health impairments are inseparable dimensions of the illness experience in ALS. Depressive symptoms, anxiety, and existential suffering are frequently reported and are aggravated by awareness of disease progression, gradual loss of autonomy, and communication changes. Moreover, the emotional impact extends to family members and caregivers, who experience burden, ongoing stress, and anticipatory grief, reinforcing the need to include the family as a unit of care in the palliative context.

In this scenario, palliative care stands out as an essential strategy for coping with the overall suffering associated with ALS. The work of multiprofessional teams, combined with clear communication, continuous psychological support, and advance care planning, contributes to reducing suffering, preserving dignity, and improving quality of life throughout the entire course of the disease. Thus, the literature reinforces that early implementation of palliative care should be understood as an indispensable component of comprehensive care for the person with amyotrophic lateral sclerosis.

CONCLUSION

This review showed that amyotrophic lateral sclerosis constitutes a progressive neurological condition with high biopsychosocial impact, whose clinical course imposes complex challenges for patients, family members, and health professionals. Throughout the analysis, it was possible to understand

that suffering associated with ALS goes beyond the limits of physical impairment, reaching emotional, social, and existential dimensions, which reinforces the need for a comprehensive and humanized care approach.

The results demonstrated that palliative care plays a central role in coping with ALS repercussions by prioritizing suffering relief, comfort promotion, and preservation of dignity. Early implementation of this approach proved fundamental to respond effectively to the patient's multiple needs, enabling continuous interventions adjusted to disease progression, focusing on quality of life rather than solely on survival.

Regarding symptom control, the analyzed literature highlighted the importance of systematic assessment and appropriate management of symptoms such as pain, dyspnea, dysphagia, spasticity, and fatigue. Integration of pharmacological and non-pharmacological strategies conducted by multiprofessional teams proved essential to minimize physical suffering and promote comfort throughout the disease course, especially when aligned with patient values and preferences.

The discussion on emotional suffering and mental health revealed a high prevalence of depressive symptoms, anxiety, and existential suffering among ALS patients, as well as significant impact on relatives and caregivers. These findings reinforce the need to include psychological and psychosocial support as structuring components of palliative care, recognizing the family as a unit of care and promoting strategies that foster emotional coping and adaptation to the illness process.

In addition, the studies emphasized the relevance of therapeutic communication, advance care planning, and advance directives as fundamental instruments for shared decision-making. These practices contribute to strengthening autonomy, reducing anxiety related to the future, and ensuring care aligned with patient wishes and values, consolidating ethics and humanization as central axes of palliative assistance.

Finally, it is concluded that palliative care in amyotrophic lateral sclerosis should be understood as a continuous and integrated care model to be initiated from diagnosis. As a suggestion for future research,

the need for empirical studies evaluating the effectiveness of specific palliative interventions—such as dignity therapy and structured caregiver support programs—in the ALS context is highlighted, especially within public health services, contributing to the improvement of care practices and the formulation of health policies more sensitive to the needs of this population.

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