

Nursing care in palliative care for patients with amyotrophic lateral sclerosis

Cuidados de enfermagem em cuidados paliativos al paciente con esclerosis lateral amiotrófica

Assistência de enfermagem no cuidado paliativo aos portadores de esclerose lateral amiotrófica

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Abstract

This study focuses on nursing care in palliative care for patients with amyotrophic lateral sclerosis (ALS). ALS is a disease that causes the death and degeneration of motor neurons, leading to muscle atrophy in the upper and lower limbs. It is an incurable disease that progresses rapidly, but care is available to improve the quality of life of those affected. The first objective is to characterize palliative care, which aims to alleviate pain and improve quality of life. The second objective describes the pathophysiology of the disease and how it affects patients as it progresses. The third objective clarifies how palliative care and a multidisciplinary team contribute to a longer life with improved quality of life. This study was conducted as an integrative review, with an exploratory character, given the patient's familiarity with the subject. The study concludes that patients are affected daily by the disease and gradually lose essential mobility. In the acute phase, they tend to require ventilatory support due to muscle atrophy affecting the muscles responsible for breathing.

Descriptors: Amyotrophic Lateral Sclerosis; Palliative Care; Nursing; Quality of Life; Neurodegenerative Disease.

Resumen

Este estudio se centra en la atención de enfermería en cuidados paliativos para pacientes con esclerosis lateral amiotrófica (ELA). La ELA es una enfermedad que causa la muerte y degeneración de las neuronas motoras, lo que provoca atrofia muscular en las extremidades superiores e inferiores. Es una enfermedad incurable que progresa rápidamente, pero existen tratamientos disponibles para mejorar la calidad de vida de los afectados. El primer objetivo es caracterizar los cuidados paliativos, cuyo objetivo es aliviar el dolor y mejorar la calidad de vida. El segundo objetivo describe la fisiopatología de la enfermedad y cómo afecta a los pacientes a medida que progresa. El tercer objetivo aclara cómo los cuidados paliativos y un equipo multidisciplinario contribuyen a una vida más larga y una mejor calidad de vida. Este estudio se realizó como una revisión integrativa, con carácter exploratorio, dada la familiaridad del paciente con el tema. El estudio concluye que los pacientes se ven afectados diariamente por la enfermedad y pierden gradualmente la movilidad esencial. En la fase aguda, tienden a requerir soporte ventilatorio debido a la atrofia muscular que afecta a los músculos responsables de la respiración.

Descriptoros: Esclerosis Lateral Amiotrófica; Cuidados Paliativos; Enfermería; Calidad de Vida; Enfermedad Neurodegenerativa.

Resumo

O presente trabalho tem como tema a assistência da enfermagem nos cuidados paliativos aos portadores da esclerose lateral amiotrófica. É uma doença que causa a morte e degeneração dos neurônios motores, causando atrofia muscular em membros superiores e inferiores. É uma doença que não possui cura e avança progressivamente, porém possui cuidados voltados a melhorar a qualidade de vida de seus portadores. O primeiro objetivo caracteriza os cuidados paliativos que buscam aliviar a dor de seus pacientes melhorando a qualidade de vida. O segundo objetivo descreve a fisiopatologia da doença e como ela afeta seus portadores no avançar da doença. O terceiro objetivo esclarece como os cuidados paliativos e uma equipe multidisciplinar fazem com que seus pacientes tenham uma sobrevida com mais qualidade. Este estudo foi realizado através de uma revisão integrativa, com caráter exploratório, pois possui maior familiaridade com o assunto. Conclui-se com esse estudo que os portadores são afetados diariamente pela doença e aos poucos vão perdendo movimentos essenciais para a locomoção. Na fase aguda tende a necessitar de suporte ventilatório devido à atrofia muscular que atinge os músculos responsáveis pela respiração.

Descritores: Esclerose Lateral Amiotrófica; Cuidados Paliativos; Enfermagem; Qualidade de Vida; Doença Neurodegenerativa.



Introduction

Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease that involves the loss of motor neurons in the spinal cord, brainstem, and motor cortex, reducing the life expectancy of those affected. The clinical picture of ALS directly reflects the loss of neurons in the motor system from the cortex to the anterior horn of the spinal cord. The physical signs of this disorder involve findings in the upper and lower motor neurons. This sensory dysfunction is incompatible with the diagnosis of ALS. Therefore, the physical findings correlate with the different topographies of degeneration of the motor nuclei: bulbar, cervical, or lumbar. Patients with bulbar-onset ALS present with dysarthria, dysphagia, or both^{1,2}.

Diagnosis is made through neurological examinations and symptoms reported by patients. Initially, the limbs tend to progressively lose muscle mass, movement, and strength. As the disease progresses, patients experience cramps, muscle stiffness, involuntary reflexes, changes in speech and swallowing, coughing, and loss of control of their muscles, including the respiratory system³.

Currently, there is no cure for ALS, nor are there therapeutic options to slow its progression. Therefore, efforts and investments have focused on improving survival and quality of life through palliative measures⁴.

The interventions aim to relieve and control symptoms, manage pain, combat complications, and attempt to control the progression of symptoms. This is achieved through a multidisciplinary team (doctors, physiotherapists, speech therapists, nurses, psychologists, social workers, nutritionists, occupational therapists), with care provided in Intensive Care Units (ICUs) in hospital or in home care settings⁵.

As highlighted in the previous paragraphs, the diagnosis of ALS affects motor neurons, meaning that the patient retains their consciousness, reasoning, hearing, and touch until the very end of their life⁴.

Palliative care is the care provided to patients whose illness is terminal or incurable. Its main objective is to improve the quality of life of patients and their families. Palliative care goes beyond just pain relief; it also addresses psychological, physiological, and spiritual problems⁶.

The pathophysiology of ALS is a set of cellular and biochemical alterations that deteriorate motor neurons. Some cellular alterations are in the genetic modification of the SOD1 protein, which causes oxidative stress that, through the accumulation of free radicals, leads to the deterioration of motor neurons. Elevated glutamate over a prolonged period also causes neuronal death; glutamate is present in both plasma and cerebrospinal fluid (CSF), causing excitotoxicity⁷.

The presence of ubiquitin in motor neurons is responsible for maintaining protein levels and excreting damaged and mutant cells. The activation of microglia, astrocytes, and T lymphocytes, in turn, leads to an increase in cytokine levels, originating from the constitutive catalytic subunits and the corresponding inducible homologous subunits $i\beta 1$, $i\beta 2$, and $i\beta 5$, forming the immunoproteasome.

These cytokines can then exacerbate the formation of damaged proteins, which tend to aggregate and accumulate at the site⁷.

To provide better care, family and nurses need to work together. When the nurse understands the complexity of the patient, they develop skills that facilitate communication, whether verbal or non-verbal. Since there is no cure or way to stop the disease, the care provided by the nurse will be neurological with palliative purposes. Care is much more than gestures and technical procedures; it is necessary to promote comfort and the best possible adaptation of the patient to the disease and of the family members to the sick patient⁸.

Given the research question, "How can palliative care influence the therapy of patients with Amyotrophic Lateral Sclerosis?", the hypothesis is that palliative care can provide comfort to the patient in the most acute phase of the disease, considering that ALS is a neurodegenerative disease that gradually affects the patient's muscles, causing them to lose body movement and some vital physiological functions necessary for maintaining life.

The objective was to evaluate how palliative care can emerge in the therapeutic process of patients with Amyotrophic Lateral Sclerosis, as well as to describe what palliative care is and its applicability, characterize the pathophysiology of Amyotrophic Lateral Sclerosis; and identify in the literature improvements related to palliative care in patients with Amyotrophic Lateral Sclerosis.

Methodology

This study will employ an integrative literature review methodology, a method that aims to synthesize research findings on a topic in a systematic, organized, and comprehensive manner. Furthermore, the study will be exploratory in nature, as it generally provides greater familiarity with the problem, that is, it aims to make it explicit^{9,10}.

A source is what puts the researcher in direct contact with the problem, being the material with which human society is examined or analyzed in its time and space. This implies that, for this study, the sources of this investigation will be scientific works published in the form of articles, and the authors who will be used as a theoretical reference will be called supporting literature, which will provide a foundation for and engage in dialogue with the text¹¹.

The study will use the years 1997 to 2021 as a time frame, due to the creation of the Brazilian Association of Amyotrophic Lateral Sclerosis (ABRELA)¹². The selection will be based on articles and books. The following filters will be used to select articles: being within the Web of Science repository of the CAPES/MEC periodicals portal using the keywords "Amyotrophic Lateral Sclerosis" and "Palliative Care," and having been published between 1997 and 2021, in Portuguese, in peer-reviewed journals. The following aspects were delimited as exclusion criteria: duplicate articles, preprints, and incomplete texts.

To collect and analyze the data, the documentary observation technique will be used; this analysis will be



applied to the study of documents to obtain measurable observations of reality. The document analysis stage aims to produce or rework knowledge and create new ways of understanding phenomena. It will be necessary for the facts to be mentioned, as they do not explain anything by themselves. Therefore, the researcher must interpret them, synthesize the information, determine trends, and, as far as possible, make inferences^{13,14}.

Results and Discussion

Palliative care and its applications

Palliative care is the care provided to patients whose illness is terminal or incurable, aiming to improve the quality of life for both patients and their families. Palliative care goes beyond simply relieving pain, also addressing psychological, physiological, and spiritual problems. During palliative care, various needs must be met, and one of the most important is spirituality. Spirituality seeks the meaning of life and may or may not be linked to God, nor may it involve religion. Each person connects with spirituality in their own way, some through music, art, or nature. This helps people find their true calling, become more confident, and have more courage to express their feelings throughout the process⁶.

"Spirituality refers to the personal quest for understanding the ultimate questions about life and its relationship with the sacred and the transcendent, which may or may not lead to the development of religious practices. Religion, on the other hand, corresponds to an organized system of beliefs, practices, rituals, and symbols designed to facilitate an individual's connection with the sacred or the transcendent. Religiosity, in turn, is the most basic level of religion; it concerns the extent to which an individual believes in, follows, and practices a particular religion"^{6:582}.

In 1960, palliative care emerged as a healthcare practice in the United Kingdom, pioneered by Cicely Saunders. This care was aimed at patients with chronic, incurable illnesses. In 1967, she created a care center for these patients, St. Christopher's Hospice (a clinic for terminally ill patients). Then, in 1970, psychiatrist Elisabeth Kübler-Ross brought the palliative care movement to America. Combining their work, in 1974 and 1975, they founded a hospice in the USA. From that moment on, palliative care grew significantly and spread to various countries, integrating treatments for patients with no possibility of cure^{15,16}.

Studies published by the Brazilian Institute of Geography and Statistics (IBGE) show that between 1901 and 2000, the Brazilian population increased from 17.4 to 169.6 million people; the life expectancy of a Brazilian man rose from 33.4 years in 1910 to 64.8 years in 2000. With the increase in life expectancy, healthcare professionals began to understand that even without a cure, care would be probable, with emphasis on quality of life and patient care, through interdisciplinary assistance and close involvement with family members who share this stage and the terminal phase of life, along with the care provided¹⁷.

In 1990, the World Health Organization (WHO) first defined palliative care as care for terminally ill patients

whose disease is incurable, attempting to improve their quality of life through such care. Then, in 2002, a new publication changed the term from "care for patients whose disease is incurable" to "care for patients whose disease is life-threatening," broadening the scope of care to include not only the patient but also their family members, given that the patient often does not go through this period alone¹⁸.

With a more humanized approach, the patient is seen not only as a biological being, but also treated holistically, respecting their wishes, desires, and needs, thereby improving the disease process and implementing palliative care, controlling their symptoms, bringing comfort in terms of pain that arises during the course of the disease, thus having their needs met and still being able to participate in daily activities with their family, catching up on pending issues, trying to prolong the patient's survival, and making death a natural process of their illness¹⁹.

According to the WHO, palliative care aims to improve the quality of life of patients and their families by alleviating suffering. This is achieved through the early identification of pain, physical, psychosocial, and spiritual problems. The WHO highlights several principles for palliative care: death is a natural process of illness, part of life, and the main objective is to maintain the patient's quality of life. Care is not provided to prolong the dying process (no means are used to prolong life), nor is it intended to hasten death. Patients and families have the right to know all information inherent to the case, such as health status, evolution, and treatment, respecting their ethical and cultural values. Palliative care is offered by a multidisciplinary team (doctors, nurses, physiotherapists, speech therapists, psychologists, etc.). Assistance does not end with the patient's death; it continues with support for the bereaved family for as long as necessary^{20,21}.

The Brazilian National Academy of Palliative Care (ANCP) published in 2006 that there are approximately 40 active teams and 300 hospital beds dedicated to palliative care in Brazil. As this information was still quite outdated, two meetings marked the first publications on palliative care in the country. The first was held in 2013 in the capital of the Czech Republic, at the 13th Congress of the European Association for Palliative Care, and the second was held in the capital of Denmark in 2015, at the 14th Congress of the European Association for Palliative Care. The study published in 2015 identified that more than half of the palliative care services offered were in the state of São Paulo, predominantly outpatient care, sought by both cancer patients and patients with neurodegenerative diseases, with adults and the elderly being the most affected population, and the most common treatment being found in the Public Health Network²².

The assistance provided by palliative care included: controlling pain and its symptoms, bringing comfort and well-being to the patient, preventing and avoiding complications and reducing the patient's disability, promoting the patient's self-confidence, autonomy and independence, maintaining activities and relationships that are meaningful to the patient, helping the patient



Characterization of the pathophysiology of ALS disease from the perspective of nursing professionals

According to the study²⁸, in 2025, the Brazilian population is expected to grow, thus occupying sixth place in the world in the number of elderly people. With an older population, the health service tends to have a greater demand, requiring medical and nursing care. ALS presents a series of clinical definitions, usually prevailing among people aged 55 to 75 years. It shows continuous growth in Brazil and worldwide, considering that life expectancy has increased. Data from the Ministry of Health indicate that for every 100,000 inhabitants, about 2.5 individuals develop the disease per year; age is an essential factor for this occurrence, with 20% of cases prevailing in men rather than women.

The family plays a special role in the care of elderly individuals with ALS, as they provide the greatest support the elderly person needs at this time. The nurse often takes on the role of the family, caring for and attending to the elderly person with the disease in their home, making them feel safe and secure in the nurse's presence. The nurse provides confidence, security, and the necessary technical tools to assist ALS patients. In Brazil, there is a specific program for elderly people with the disease where nurses provide home care, assisting families who are often overburdened. With their experience, nurses care for the elderly with appropriate benefits and accurate knowledge^{28,29}.

Nursing, as a science and discipline, can fill knowledge gaps by developing standards that encompass the complexity and diversity of phenomena of common interest to ALS. Through nursing care, the nurse seeks to integrate into the multidimensional realm of the human being, who needs specific attention to be cared for in their process of becoming healthy, so that the nurse can create paradigmatic methods and pathways in nursing care for the elderly²⁸.

There are several types of care provided by nurses to elderly ALS patients: Primary caregiver - the person who has total or the greatest responsibility for the elderly person; Secondary caregiver - family members and professional nurses; Formal caregiver - hired; Informal caregiver - close family members²⁹.

According to the IBGE (Brazilian Institute of Geography and Statistics), modern societies are facing a progressive aging of the elderly population due to the increasing number of senior citizens. Healthcare professionals and nurses are bringing their practical experience to the care of these patients with ALS³⁰.

Nurses study for five years, seeking specialization in a field that often faces many challenges and difficulties. Upon graduation, they become qualified to work for the government or in the private sector; there are many areas in which nurses work professionally. Nurses must fit into society as professionals who assist patients or as individuals who provide services in the healthcare field. It is known that in Brazil, healthcare is one of the most affected areas; there is a lack of financial resources to maintain well-equipped hospitals, and there is a shortage of professionals, leaving

understand their condition using emotional and social tools, and supporting not only the patient but also their family²².

Palliative care programs vary internationally. Each location has its own different model of care, considering differences in its socioeconomic status, health policies, and the needs of patients and their families. According to the author, in developing patients, the programs so far are poorly connected to local health policies, and care is centered on end-of-life care. Economic limitations and a low composition of human resources are the two main reasons cited in her study²³.

Palliative care means recognizing the patient's needs early on and supporting their closest relatives so they can handle the end of life with authority and greater quality, assisting them in coping with death, which is a natural consequence. The topics of death and the dying process, although part of the reality for healthcare professionals, still cause discomfort, as some professionals are still unprepared for this event. For these professionals, especially nurses, the most comfortable and appropriate way to deal with this end-of-life process is to consider it as biological and natural, necessary for all human beings. Patients desire professionals with technical expertise but also want improvements in healthcare relationships. This healthcare condition, as focused on here, increases the safety and cooperation of the patient and their family in the therapeutic processes²⁴.

Although nursing professionals present a positive view, there is an understanding of how much palliative care is related to death and that these tasks generate a feeling of insensitivity in the face of the client's poor prognosis. They describe the indispensability of interpersonal relationships between professionals in interdisciplinary teams to level the multidisciplinary nature of care. Furthermore, the complexity of having good coordination with the medical team is evident to avoid errors in effective communication with the family, which would compromise the humanization and quality of care necessary for patients with no prospect of cure²⁵.

The basic requirements for palliative nursing practice consist of knowledge of the pathophysiology of degenerative malignant diseases, human anatomy and physiology, pharmacology of medications used in symptom management, health relief techniques, and the ability to establish good communication²⁶.

Furthermore, nursing is one of the professions that experiences the most emotional strain due to constant interaction with sick patients, frequent hospitalizations, and often witnessing their suffering, pain, illness, and death. To improve the quality of life of terminally ill patients, nurses strive to provide comfort, going beyond basic and pathophysiological tasks, fulfilling their needs and desires whenever possible. Therefore, nursing professionals are fundamental to palliative care, as their training is based on the art of caring. The importance of this type of work has been evident since the early days of the ideology, stemming from the knowledge of a nurse, Cicely Saunders, who later studied medicine and social work²⁷.



more people in society at the mercy of inadequate care in public hospitals³¹.

In neuromuscular diseases, the progressive loss of strength in the respiratory muscles is most often the cause of respiratory failure. However, it can occur for several reasons: muscle weakness, alterations in the mechanical properties of the respiratory system, muscle fatigue, alterations in the central regulation of ventilation, and/or dysfunctions of the upper airways and sleep-disordered breathing³².

Nursing professionals, in their daily work, encounter many situations involving the theme of health and work, not only related to their own work, but also to the individuals and the community they serve. In these cases, they are always attentive to the breathing of patients with ALS, who require a differentiated approach³¹.

"ALS is a progressive disorder that leads to generalized weakness. Because there is still no cure for the disease, treatment is primarily symptomatic. Among the various causes of death in these patients, respiratory failure is the main one. For this reason, close attention must be paid to the progression of respiratory dysfunction, and ventilatory support must be instituted rapidly as needed"^{32,38}.

Given this diagnosis, the patient needs someone who is more familiar with nursing care and specialties. Non-specialist professionals often believe they have no responsibility in this matter, which is incorrect, considering the need for a holistic approach to the patient/service user. It is the responsibility of all nursing professionals, regardless of their professional category, to be sensitive to the health issues of patients with ALS and committed to improving the patient's quality of life and maintaining their physical and mental well-being. Mental health can be one of the sciences that will contribute to a comprehensive and reflective understanding of these phenomena, which are permeated by human actions and reactions present in the many scenarios of the ALS patient's world³¹.

Therefore, this aims to demonstrate and structure some concepts that will help in this understanding/reflection, permeated by studies and research that focus on the problem in ALS patients and those who work in the Health and Nursing sectors³¹.

Research^{33,5} states that "to improve quality of life, physiotherapy, speech therapy, medication, and nutritional and psychological assistance are employed." The multidisciplinary team can help build new alternatives for relationships, interaction, and social participation. Dependent patients are those who "need assistance to perform most activities of daily living," as they have great difficulty with all movements, eating, dressing, and moving around. At this stage, the difficulty in communicating verbally is accentuated, and the caregiver or interlocutor must assume responsibility for communication; thus, their responsibilities are intense.

The degenerative nature of the disease predicts the final outcome; however, even so, functional therapies help stabilize the condition, preventing unnecessary complications in many cases²³.

Individuals with moderate or severe bulbar deterioration benefit little or not at all from ventilatory support due to poor adaptation to the modality. Patients tend to discontinue its use and choose whether to opt for invasive mechanical ventilation from the moment they report "being short of breath," a moment that coincides with the progression of bulbar dysfunction. Atrophy of both upper and lower limbs compromises movement, and patients have difficulty grasping objects and are unable to move around, initially requiring the use of canes and, later, wheelchairs and even bed rest. This pathology leads to a total loss of functional independence; the patient is unable to perform any activity involving the use of the body's musculature, becomes a prisoner of their own body, and vulnerable to developing depression and anxiety³⁴.

As ALS progresses, individuals become increasingly unable to move, communicate, live independently, and experience reduced autonomy, potentially leading to diminished self-worth. ALS is a multifactorial disease. Contributing factors include oxidative stress, glutamate-mediated excitotoxicity, superoxide dismutase mutation, specific protein aggregation, intermediate neurofilament disruption, altered anterograde and retrograde axonal transport, microglial activation, inflammation, and growth factor disorders³⁵.

Weakness of the respiratory muscles (intercostals, diaphragm, abdominals) is the most serious problem during the progression of the disease. The patient begins to experience shortness of breath and difficulty coughing. The accumulation of secretions in the bronchial tree precipitates respiratory irritation and infection, justifying the more frequent pneumonia in these patients, especially when dysphagia (aspiration) is present. Morning headaches and interrupted sleep are already signs of compromised respiratory function, related to a gradual increase in CO₂. A greater increase in this gas causes fear, anxiety, panic, and even mental confusion³⁶.

Palliative care for improved quality of life for ALS patients

Physical therapy is fundamental for good health and provides the body and mind with greater serenity and tranquility. A person who undergoes physical therapy has a more fulfilling and stress-free life. ALS - also called Lou Gehrig's disease and Charcot's disease - is a degenerative disease that affects the central nervous system. The pathophysiological mechanism of ALS can be distinguished according to the causal hypotheses^{37,38}.

Nowadays, physiotherapy is considered the best option to mitigate functional decline and promote a better quality of life for people diagnosed with ALS. Studies describe physiotherapy as the main factor in maintaining bone mass; during regular exercise, the activity of the cells responsible for bone matrix formation and bone mineralization is stimulated by the mechanical force provided during the execution of the exercises³⁹.

It is described that most elderly people report being in good health; therefore, preventive methods are of paramount importance in this context. According to the aforementioned authors, research results reveal the practice



of regular and systematic physiotherapy as the main factor in longevity, contextualizing it as both a prophylactic and curative strategy for the factors and dysfunctions resulting from aging⁴⁰.

"Considering that most elderly people have been sedentary for some time, choosing the right physical activity requires careful consideration. The best physical activity for the elderly is always low to medium intensity and, above all, low impact. Exercise is the best method, with its main objective being the strengthening and stretching of muscles. Activities such as walking and water aerobics are also options, and these are considered the most efficient methods today"^{37,98}.

According to the authors, it can be inferred that exercise provides greater motor and sensory performance, in addition to being a beneficial form of physical exercise in terms of balance, especially when it comes to elderly people. In old age, the main factor in the process of prevention and rehabilitation of health is still the regular and guided practice of physiotherapy. Each individual ages differently, and this process is influenced by genetics and especially by lifestyle; healthy habits such as eating correctly, sleeping well, controlling stress, and practicing physical exercise contribute to a better quality of life. People today are concerned with the best possible quality of life and therefore seek various activities that bring them benefits and well-being. It is good to remember that the elderly should seek various ways to live better, improving their social and emotional aspects and especially their health, as this is essential^{37,41}.

ALS deserves close attention regarding physiotherapy activities, as everything must be done through specialized and safe monitoring, with the support of a medical report, and in the best possible way to avoid serious health damage. Other triggering factors of the pathology under study are the relationship between immune imbalance and neurovascular changes that cause neuronal damage, increasing the progression and symptomatology of the disease^{37,42,43}.

ALS affects the upper motor neuron, triggering clonus, which are involuntary contractions caused by muscle stretching, and the lower motor neuron, where there is atrophy, that is, muscle weakness, as well as decreased muscle volume and fasciculations. As the disease progresses, there is involvement of the respiratory muscles and the bulbar region. Physiotherapy plays an important role in the palliative treatment of patients diagnosed with ALS. A large part of the research articles portrays the importance of using non-invasive mechanical ventilation (NIMV). This represents an advance in intensive therapeutic care for these patients^{2,26,38}.

ALS requires greater care, and this care comes through nurses, who use various resources to improve the quality of life of patients with ALS. Professional help, not only from nurses but also from doctors, psychologists, neurologists, and others, provides greater support in the treatment of this disease, which has no cure, but prevention is key to a better life with improved health⁴⁴.

According to the study⁴⁵, which conducted a qualitative analysis of the physiotherapy strategy in

respiratory failure resulting from ALS. It was noted that non-invasive ventilation significantly increased survival time in patients due to improved respiratory function and delayed the need for tracheostomy. Specifically, in physiotherapy treatment, respiratory resistance exercises are not effective, but moderate resistance exercises are beneficial; however, non-invasive ventilation remains the most used approach in this pathology. Even knowing the benefits of the approaches and palliative treatment, there is a need for further studies to investigate the best mechanism of action of adjuvant therapy in this pathology to discover new treatments and even theoretically establish a cure for the disease⁴⁶.

Nursing can contribute greatly to the well-being of elderly ALS patients, as nurses have experience and knowledge in the field, thus helping to provide patients with a more peaceful and secure life in relation to this disease. The nurse is simultaneously an executor, counselor, therapist, supervisor, educator, friend, partner, and confidant of the patient with dementia, spending most of their time with their patient, creating a very strong bond^{44,45}.

Final Considerations

Brazilian nursing needs to position itself in relation to current trends in scientific knowledge and suggest new paths, as nurses aim for comprehensive care with adequate support for those with ALS, since it is a disease that requires specific and professional care because it affects the patient's cognitive abilities and causes significant loss of movement, disabling the individual from performing motor, physical, and social functions, leading to a loss of autonomy and independence, thus requiring comprehensive care.

During this work, it was found that nutrition is an essential factor for the health of people with ALS; food provides vitamins to improve the body's immunity, thus improving the patient's health. Physiotherapy is also essential for better muscle maintenance and body movements, promoting greater strengthening of the human body. It is observed that as the disease progresses, the patient develops progressive asthenia of all muscles, including the respiratory muscles, which, when affected, cause the patient to present with hyperventilation, the most common cause of discomfort and death in these patients. Breathing becomes very weak and, in most cases, the patient needs specific breathing equipment; these situations leave the patient very weak, even emotionally, causing discomfort and thus requiring a professional most of the time. With advances in technology and medicine, this disease has brought about changes for the population, which has sought resources that promote a healthy life for those affected. Medications are more advanced, and there are several techniques that offer the patient a good prognosis.

In conclusion, this work contributes to providing information about ALS to healthcare professionals and even to those living with the disease, describing possible care options so that those affected can have a better quality of life as the disease progresses, thus confirming the hypothesis and answering the research problem.



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