Original article

Nursing diagnoses formulated in outpatient care for people with amyotrophic lateral sclerosis

Diagnósticos de enfermagem formulados em atendimento ambulatorial para as pessoas com esclerose lateral amiotrófica

Gerson Trinchão Ferreira Júnior[1]
Luana Carvalho do Rosário[2]
Marilaine Matos de Menezes Ferreira[3]

[1]Corresponding author. Escola Bahiana de Medicina e Saúde Pública (Salvador). Bahia, Brazil. gersonjunior3237@gmail.com
[2,3]Escola Bahiana de Medicina e Saúde Pública (Salvador). Bahia, Brazil.

ABSTRACT | OBJECTIVE: To identify the Nursing Diagnoses (NDs) formulated by nurses when assisting people with Amyotrophic Lateral Sclerosis (ALS), in a specialized outpatient clinic. **METHODOLOGY:** This is a documentary analysis study, being descriptive and exploratory with quantitative analysis; with ambispective data collection (retrospective from 2022 to August 2023 and prospective, from September to December 2023) carried out in an outpatient clinic specializing in Neuromuscular Diseases - Salvador, Bahia. The study population consists of individuals with ALS undergoing outpatient care. The data were analyzed using descriptive statistics (absolute and relative frequency) and collected from medical records of people with a medical diagnosis of ALS who have been monitored at the outpatient clinic. Clinical data were obtained to evaluate and validate the NDs found. **RESULTS:** Data obtained from 25 medical records with sporadic ALS; higher frequency in males (64%); age between 34 and 80 years, with an average age of 61.2 years; mean age of 53.3 years when the medical diagnosis was confirmed. 11 NDs were identified, the most prevalent being Risk of Skin Injury (60%) and Risk of Fall (44%). **CONCLUSION:** The elaboration of accurate and appropriate NDs to the patient's condition allows nurses to reflect and make decisions, and consequently, more assertive and complete assistance.

KEYWORDS: Nursing Diagnosis. Amyotrophic Lateral Sclerosis. Nursing Process.

RESUMO | OBJETIVO: Identificar os Diagnósticos de Enfermagem (DEs) formulados pelo enfermeiro na assistência às pessoas com Esclerose Lateral Amiotrófica (ELA), em um ambulatório especializado. **METODOLOGIA:** Trata-se de um estudo de análise documental, sendo descritivo e exploratório com análise quantitativa; com coleta de dados ambispectivos (retrospectiva de 2022 a agosto de 2023 e prospectivo, de setembro a dezembro de 2023) realizado em um ambulatório especializado em Doenças Neuromusculares - Salvador, Bahia. A população do estudo constitui-se de indivíduos com ELA em acompanhamento ambulatorial. Os dados foram analisados pela estatística descritiva (frequência absoluta e relativa) e coletados em prontuários de pessoas com diagnóstico médico de ELA que vem sendo acompanhados no ambulatório. Foram obtidos dados clínicos para avaliação e validação dos DEs encontrados. **RESULTADOS:** Os dados obtidos em 25 prontuários com ELA esporádica; maior frequência no sexo masculino (64%); idade entre 34 e 80 anos, com média de idade de 61,2 anos; média de idade de 53,3 anos quando confirmaram o diagnóstico médico. Foram identificados 11 DEs, sendo os mais prevalentes o Risco de Lesão de Pele (60%) e Risco de Queda (44%). **CONCLUSÃO:** A elaboração de DEs precisos e adequados à condição do paciente possibilitam a reflexão e tomada de decisão pelos enfermeiros, e consequentemente, uma assistência mais assertiva e completa.

PALAVRAS-CHAVE: Diagnóstico de Enfermagem. Esclerose Lateral Amiotrófica. Processo de Enfermagem.

Submitted Sept. 27th, 2024, Accepted Jan. 30th, 2025,
Published Feb. 21st, 2025
J. Contemp. Nurs., Salvador, 2025;14:e5941
http://dx.doi.org/10.17267/2317-3378rec.2025.e5941 | ISSN: 2317-3378
Assigned editors: Cátia Palmeira, Tássia Macêdo

How to cite this article: Ferreira Junior GT, Rosário LC, Ferreira MMM. Nursing diagnoses formulated in outpatient care for people with amyotrophic lateral sclerosis. J Contemp Nurs., 2025;14:e5941. http://dx.doi.org/10.17267/2317-3378rec.2025.e5941

1. Introduction

The Nursing Process (NP) is a method that guides the critical thinking and clinical judgment of the nurse directing the nursing team to care for the person, family, community and special groups. It also provides the structuring of systematic actions and guides professional nursing care, being guided by ethics, moral values and beliefs and technical-scientific knowledge.[1,2] The Resolution n. 736/2024 of the Federal Council of Nursing, establishes that the Nursing Process must be carried out, in a deliberate and systematic manner, in any socio-environmental context in which nursing care occurs. It is composed of five interdependent, recurrent and cyclical stages: nursing assessment, nursing diagnosis, nursing planning, nursing implementation and nursing evolution.[2]

Nursing diagnoses are the clinical focus of nursing science, a form of expression of care needs that professionals identify through reflective clinical judgment in those they care for.[3] Thus, the identification and classification of diagnoses are essential for the development of patient evolution, because it serves as a basis for the proper construction of the planning and implementation of the interventions that will be offered to patients through the conditions of the process health and disease of the individual. It is essential that the steps of the nursing process are worked together so that the professional service becomes more organized.[3,4]

The Taxonomies of Nursing Diagnoses are used to universalize and standardize the professional language of nursing. In addition to the Taxonomy of the North American Association of Nursing Diagnostics (NANDA-I), we have the taxonomy called "International Classification for Nursing Practice" (ICNP). Through the Brazilian Nursing Association (ABEN), it was approved the inclusion of ICNP in the scope of Primary Care – International Classification for Nursing Practices in Collective Health (CINPSC), after an analysis of the nursing work process in Brazil using terms that direct the systematization of care.[5]

According to the World Health Organization (WHO), Rare Diseases (RRs) are defined as those that affect 1.3 out of every 2,000 individuals, being characterized by a diversity of clinical manifestations that can vary from person to person, as well from illness to disease. Most of these diseases are part of the group of neuromuscular diseases (NMD).[6]

Amyotrophic Lateral Sclerosis (ALS) is a rare disease that is diagnosed in 1 to 2 individuals per 100,000 inhabitants each year in most countries. There are few epidemiological studies on ALS in Brazil, but a national study estimated the prevalence and incidence of 0.9 to 1.5 per 100,000 and 0.4 per 100,000 inhabitants per year, respectively. In addition, the only state with a state management perspective focused on implementing the epidemiological control of ALS is Rio Grande do Norte (RN), where it published law N. 10.924 of 2021 that implements the database "Registration of Amyotrophic Lateral Sclerosis" in order to record information on the incidence of cases of this disease in the state, epidemiologically.[7]

ALS is one of the main neurodegenerative and progressive diseases, along with Parkinson's and Alzheimer's diseases, of unknown cause that affects mainly the motor neurons in the cortex, spinal cord and brainstem.[8] The term "sclerosis" means stiffness and healing, resulting from the involvement of the upper motor neurons; "lateral" corresponds to the hardening of the body's lateral (spinal cord), and "amyotrophic" is due to muscle atrophy, resulting in weakness. Therefore, the main signs and symptoms that characterize ALS include: muscle weakness and cramps in the limbs, spontaneous muscular activities, hardening of the limbs, difficulty speaking (dysarthria) and swallowing (dysphagia).[9,10]

The diagnosis of ALS is evaluated based on its clinical signs and motor neuron involvement, and attention should be paid to the differentiation of its forms: Progressive Muscular Atrophy (AMP), Primary Lateral Sclerosis (PLS), Progressive Bulbar Palsy (PBP) and Bulbospinal Muscular Atrophy (Kennedy's disease). For this, it is necessary to perform the physical examination, laboratory tests, magnetic resonance imaging of the brain and craniocervical junction and eletroneuromyography of four members to have a more definitive diagnosis, since there are clinical manifestations similar to other diseases.[11]

The assistance directed to the patient affected by ALS is considered complex and requires a humanized work involving the family members and the multiprofessional team. Considered an incurable disease, the therapeutic plan should involve palliative care seeking to preserve functional performance, reduce the progress of the disease and consequently improve quality of life. The nursing professional has a fundamental role in the patient care process, taking into account biopsychosocial issues.[12]

Since 2009, the Ministry of Health through the Unified Health System (SUS) offers assistance and provides free medicines to people with ALS in full considering the Clinical Protocol and Therapeutic Guidelines for Amyotrophic Lateral Sclerosis (AML), which is based on proven scientific evidence. In 2014, extended care to people with rare diseases by establishing the National Policy for Comprehensive Care for People with Rare Diseases, including ALS.[7]

The elaboration of accurate and condition-based nursing diagnoses will support a care plan that is more targeted to the needs of the person with ALS, resulting in qualified and individualized assistance.

Moreover, with the importance of Nursing Diagnostics, together with quality care focused on patients with ALS, the choice of the guiding question arose: "What are the main nursing diagnoses formulated to patients affected by ALS in the Bahiana Saúde Neuromuscular Disease Outpatient Clinic?".

Given the above, this study aims to identify nursing diagnoses formulated by nurses in the assistance to people with Amyotrophic Lateral Sclerosis (ALS), in a specialized outpatient clinic.

2. Methodology

This is a documentary analysis study, being descriptive and exploratory with quantitative analysis, and collection of ambispective data (retrospective from January 2022 to August 2023; and prospective in 2023, in the period of September to December).

The research was carried out in the Bahiana Saúde Outpatient Center, located on the Brotas campus, where it offers care for the diagnosis, treatment and follow-up of people with neuromuscular diseases and, especially, with ALS.

The Bahiana Saúde is a reference in community-oriented assistance and provides students of the Educational Institution with interprofessional experiences, educational actions and development in research activities. Among the services available is the DNM outpatient clinic. It is a service of specialized care in rare diseases, which offers assistance for the diagnosis and treatment of some neuromuscular diseases, such as Amyotrophic Lateral Sclerosis (ALS), through specialized assistance involving multiprofessional team, led by neurologist and neuropediatrics.

The nursing students involved in the care of patients with NMD are extensionists of the program called Nursing Caring Does Well, which promotes the insertion of the course students in outpatient settings with assistance activities, research and health education. With the insertion of the extension program in Bahiana Saúde, it was verified that there was implementation of the nursing process in the care of patients accompanied in the service.

Data were collected from medical records of people with a medical diagnosis of ALS who have been followed by multiprofessional team in the outpatient clinic and who agreed to participate in the study. For the selection of participants, the following inclusion criteria were adopted: people over 18 years with diagnoses of ALS in outpatient follow-up between January 2022 and December 2023. The exclusion criteria were: incomplete records related to the information of the variables studied and people who had a fatal outcome. The collection was started in September 2023 and completed in December 2023.

The researchers had access to information about individuals in follow-up since January 2022 and consultations scheduled for the period from September to November 2023. With this, two forms of recruitment were established: 1. Face-to-face approach: the researchers made the invitation to

participate in the research in the consultations scheduled in the period from September to December 2023 and obtained the signature of the Informed Consent Form (ICF); 2. Virtual approach: Telephone contact with the people and/or their responsible persons of the retrospective phase to explain the research. Then, the ICF was sent through WhatsApp for prior reading and scheduled a video call to resolve doubts and obtain consent, which was obtained through audio or video recording. As participants with ALS maintain the cognitive preserved, they consented to participate in the research. However, some responsible persons (spouses or children) signed the ICF in case of participants with impaired fine motor functions in hands and speech.

The collection was initiated after the release of the Research Ethics Committee (REC) of the institution. Data collection was based on electronic records and used an Excel spreadsheet composed of the variables: medical diagnosis and typology of ALS, sex, age, age that was diagnosed with the disease, clinical data (evaluation of motor strength, respiratory capacity, mobility, skin condition, communication and swallowing) for the characterization of the studied population and identification of nursing diagnoses formulated by nurses of the service.

Regarding the taxonomy adopted by the nursing service of the study site, the nomenclature used is CINPSC, since it is more suitable for the scenario and dynamics of the outpatient clinic being similar to primary care. In the absence of a nursing diagnosis in CINPSC terminology, nurses also use nursing diagnoses from the NANDA-I taxonomy version 2018-2020 to fill some gaps and subsidize nursing planning. The nursing forms of the electronic chart were developed in 2017, thus the version used is from 2015-2017.

The data related to this characterization were analyzed in a quantitative way (absolute and relative frequency) consisting of: preparation and organization of the data obtained in the chart; reduction of the data into themes through a process of creation and condensation of codes, and representation of data in table or tables. In relation to the variables age and age that was diagnosed with the disease, the means were also calculated.

The study met the standards of resolution 466/2012 and 510/2016 of the National Health Council and the Circular Office n. 1/2021 and had REC approval with Opinion Number: 6.297.022.[13-15] In addition, the autonomy of eligible participants for the research is respected and confidentiality, secrecy, anonymity and the right to refuse or withdraw from participating in the research are guaranteed.

3. Results

From 57 people with ALS who are part of the outpatient follow-up (in the period specified as inclusion criteria), a sample of 25 medical records was obtained, representing a sample of 43.8% of the total. Given the severity of the disease, there was a record of deaths of people with ALS accompanied in service, loss of medical records and difficulty in returning some people and/or responsible in the retrospective phase, which contributed to the reduction of the sample.

From the analysis of the 25 medical records of participants, it was found that the highest prevalence of ALS affects men, corresponding to 16 (64%). The participants were between 34 and 80 years old, with an average age of 61.2 (Table 1). Considering the age of the patients, the participants were between 26 and 79 years old, with an average age of 53.3 years.

Table 1. Characterization of participants affected by ALS, followed in a neuromuscular disease outpatient clinic Salvador, 2023 (N=25)

Variables	N	%
Sex		
Male	16	64
Female	09	36
Age Group		
30 – 34	01	04
35 – 39	02	08
40 – 44	01	04
45 – 49	00	00
50 – 54	02	08
55 – 59	06	24
60 – 64	03	12
65 – 69	06	24
70 – 74	03	12
75 – 79	00	00
80 – 84	01	04
Age group when diagnosed*		
15 – 64	19	76
65 or more	06	24

Note: (*) big IBGE age groups.
Source: the authors (2023).

Regarding the classification of ALS, all were identified as sporadic ALS. However, regarding the typology, only 12 medical records had the identification of being bulbar (06), spinal (05) or juvenile (01) ALS. In addition, of the 25 participants, 3 are restricted to the bed with comprehensive care developed by formal or informal caregivers.

Table 2 identifies the nursing diagnoses of each participant that were formulated by the nurse at the last nursing appointment. The data was in a specific form of electronic record.

Table 2. Characterization of participants affected by ALS, followed in a neuromuscular disease outpatient clinic. Salvador, 2023 (N=25) (to be continued)

Participants	Nursing Diagnosis *
P1	Risk of skin injury; Decreased body movement.
P2	Inadequate sleep; Risk of falls; Risk of choking*; Altered food intake.
P3	Inadequate sleep; Risk of choking; Risk of skin injury; Altered food intake; Decreased body movement; Absent motor coordination.
P4	Risk of skin injury; Decreased body movement; Absent motor coordination.
P5	Inadequate sleep; Risk of choking; Risk of skin injury; Decreased body movement.
P6	Risk of skin injury.
P7	Risk of choking; Risk of skin injury; Altered food intake; Decreased body movement.
P8	Risk of falls*.
P9	Risk of skin injury;
P10	Risk of choking.
P11	Weight loss; Inadequate sleep; Risk of skin injury; Altered food intake; Decreased body movement.
P12	Weight loss; Inadequate sleep; Risk of skin injury.
P13	Risk of falls*; Weight loss; Risk of skin injury; Altered food intake.

Table 2. Characterization of participants affected by ALS, followed in a neuromuscular disease outpatient clinic. Salvador, 2023 (N=25) (conclusion)

Participants	Nursing Diagnosis *
P14	Risk of choking*; Altered food intake; Decreased body movement; Absent motor coordination.
P15	Risk of falls*; Inadequate sleep; Weight loss; Risk of skin injury; Altered food intake; Decreased body movement.
P16	Risk of choking *; Risk of falls *; Overweight.
P17	Risk of falls*; Inadequate sleep; Risk of skin injury.
P18	Weight loss; Risk of skin injury.
P19	Weight loss; Risk of falls*.
P20	Weight loss; Anxiety; Inadequate sleep; Risk of choking*; Risk of falls*; Altered food intake.
P21	Risk of skin injury.
P22	Weight loss; Risk of falls *.
P23	Risk of skin injury.
P24	Pain; Overweight; Risk of falls*.
P25	Risk of falls*

Note: *2015-2017 NANDA Taxonomy.
Source: the authors (2023).

Table 3 shows the absolute and relative frequency of nursing diagnoses identified in participants' medical records, with the most frequent being the Risk of skin injury (60%) and Risk of falling (44%). Some nursing diagnoses that had a frequency of 32% should also be considered: risk of choking, decreased body movement, Inadequate sleep, altered food intake and weight loss.

Table 3. Absolute and relative frequency of Nursing Diagnoses formulated during care for people with ALS. Salvador, 2023. (N=25)

Nursing Diagnoses	N	%
Risk of skin injury	15	60
Risk of falls	11	44
Risk of choking	08	32
Decreased body movement	08	32
Inadequate sleep	08	32
Altered food intake	08	32
Weight loss	08	32
Lack of motor coordination	03	12
Overweight	02	8
Anxiety	01	4
Pain	01	4

Source: the authors (2023).

In relation to the variables "clinical data" obtained in nursing evaluations, complemented with evaluation of the multidisciplinary team (neurologist, physiotherapy and speech therapy), we have:

Motor strength – lower limb involvement (LL) was higher than in upper limbs (UL), since 79% had significant reduction of LL strength (grade 0 to 3). The Motor Force Evaluation Scale used is Medical Research Council (MRC).

Respiratory Capacity – 18 (72%) participants use air stacking with manual reanimation and two-level positive airway pressure, using BI-level positive airway pressure (BiPAP) as respiratory support, 04 (16%) participants have indication of ventilator assistance without adherence to treatment, only 03 (12%) participants still do not have indication of ventilator assistance;

Skin condition – the prevalence is of whole skin, corresponding to 19 (76%) participants, and 05 (20%) with slimming and decreased elasticity and 01 (04%) has slight signs of elbow injury (note the record that it is restricted to wheelchair and injury may be due to continued pressure on the chair);

Mobility – 11 (44%) participants have impaired locomotion requiring support from family members as well as the use of walking and wheelchair to promote mobility, 10 (40%) participants are restricted to wheelchairs, using it continuously during the day, while 03 (12%) participants are restricted to bed, being dependent on full care of caregivers. Only 01 (04%) participant present preserved mobility.

Communication – 19 (76%) participants have oral and intelligible communication, however there are participants with a nasal voice and/ or dysarthria present; and 06 (24%) participants are aphasic, use alternative communication as tablet, board or cell phone.

Swallowing – 16 (64%) participants present dysphagia (mild, moderate to severe), and 08 (32%) participants present preserved swallowing. It is worth mentioning that only 02 (08%) participants use gastrostomy (GTT) for feeding (Table 4).

Table 4. Clinical data identified in the medical records of people with ALS followed in a neuromuscular disease outpatient clinic. Salvador, 2023 (N=25)
(to be continued)

	Clinical Data (Evaluation)					
Patients	**Motor Strength**	**Respiratory Capacity**	**Skin Condition**	**Mobility**	**Communication**	**Swallowing**
P1	Degree 1 UL and LL.	Manual resuscitator 1x a day; BiPAP at night.	Whole	Wheelchair restricted	Preserved	Preserved
P2	Degree 4 - UL Degrees 1 and 2 LL.	Indication of BiPAP – however, it is not used.	Whole	Limitation in UL; Impaired Locomotion.	Oral and Intelligible	Moderate Dysphagia
P3	Degrees 1 - UL Degree 0 - LL.	Nighttime BiPAP.	Whole; emaciated	Bedridden	Intelligible with Attention; Dysarthria	Severe Dysphagia
P4	Degree 0 UL and LL	Manual resuscitator 3x a day and BiPAP 24 hours.	Whole	Bedridden	Aphasic	GTT
P5	Degree 2 – UL Degree 3 - LL	Nighttime BiPAP.	Whole	Walks with aid – use of wheelchair	Mild dysarthria	Preserved
P6	Degree 5 - UL Degree 1 - LL	Dyspnea with minimal exertion.	Whole	Restricted to wheelchair	Preserved	Preserved
P7	Degree 1 – UL Degree 3 - LL.	Dyspnea when lying down – Indication of respiratory devices – not used.	Decreased elasticity and mild signs of elbow injury.	Restricted to wheelchair	Oral – impaired speech intelligibility	Oropharyngeal Dysphagia
P8	Degree 1 - UL Degree 3 - LL	Manual resuscitator 3x a day and nocturnal BiPAP	Whole	Restricted to wheelchair	Oral and Intelligible	Preserved
P9	Degree 3 UL and LL	BiPAP	Whole	Restricted to wheelchair	Oral and Intelligible	Dysphagia
P10	Degree 4 UL and Degree 3 LL	Preserved	Decreased Elasticity	Generalized weakness in LL	Intelligible and Dysarthria	Dysphagia
P11	Degree 2 - UL Degree 3 - LL	Indication of ventilator support – but does not use it	Whole	Impaired Mobility – Use of a wheelchair on certain occasions.	Oral and Intelligible	Severe Dysphagia – Indication of GTT.

Table 4. Clinical data identified in the medical records of people with ALS followed in a neuromuscular disease outpatient clinic. Salvador, 2023 (N=25) (conclusion)

	Clinical Data (Evaluation)					
Patients	**Motor Strength**	**Respiratory Capacity**	**Skin Condition**	**Mobility**	**Communication**	**Swallowing**
P12	Degree 0 - UL Degree 0 - LL	Nighttime BIPAP and Ambu 3x a day.	Whole	Bedridden	Oral and Intelligible	Severe Dysphagia – Indication of GTT.
P13	Degree 4 - UL and LL	Nighttime BIPAP and Ambu 3x a day.	Whole	Impaired Locomotion – Use of wheelchair/walker	Total Aphonic – Use of alternative communication (tablet)	Severe Dysphagia – Indication of GTT
P14	Degree 1 - UL Degree 3 - LL	Nighttime BIPAP	Whole	Restricted to wheelchair	Oral and Intelligible – Dysarthria	Severe Dysphagia – Indication of GTT
P15	Degree 3 - UL and LL	Nighttime BIPAP and Ambu only in physiotherapy (3x a week).	Whole	Impaired Locomotion – Use of a Wheelchair	Total Aphonic – Use of communication board	Severe dysphagia - Indication of GTT.
P16	Degree 4 – UL and LL	Irregular BIPAP and Ambu twice a day.	Whole	Impaired Locomotion – Use of crutches	Oral and Intelligible - Mild Dysarthria	Mild Dysphagia
P17	Degree 3 – UL Degree 4 - LL	Nighttime BIPAP and Ambu.	Whole	Impaired Locomotion – Use of a Wheelchair	Oral and Intelligible with attention	Mild Dysphagia
P18	Degree 3 - UL Degree 1 - LL	Nighttime BIPAP.	Whole	Restricted to wheelchair	Total Aphonic – Use of alternative communication (cell phone)	Moderate to Severe Dysphagia
P19	Degree 3 - UL Degree 1 - LL	Nighttime BIPAP	Decreased Elasticity	Restricted to wheelchair	Aphonic	Severe Dysphagia – Use of GTT.
P20	Degree 5 - UL Degree 3 - LL	Indication of Ambu and BIPAP - but does not use	Decreased Elasticity	Impaired Locomotion	Aphonic	Severe Dysphagia – Indication of GTT.
P21	Degree 3 - UL and LL	Afternoon and nighttime BIPAP	Whole	Restricted to wheelchair	Oral and Intelligible	Preserved
P22	Degree 1 - UL Degree 5 - LL	Preserved	Whole	Preserved	Oral and Intelligible	Preserved
P23	Degree 2 - UL Degree 4 - LL	Nighttime BIPAP	Decreased Elasticity	Restricted to wheelchair	Oral and Intelligible	Moderate Dysphagia
P24	Degree 4 - UL Degree 3 - LL	Daytime and nighttime BIPAP	Whole	Impaired Locomotion – Use of crutches	Oral and Intelligible	Mild Dysphagia
P25	*	Use of Ambu	Whole	Impaired Locomotion	Oral and Intelligible	Preserved

(*) Information not found.
Source: the authors (2023).

4. Discussion

Amyotrophic Lateral Sclerosis is a chronic neurodegenerative disease that affects some motor neurons irreversibly, presenting clinical manifestations in the upper and lower limbs, and later in the other regions of the chest and neck.[16] According to these authors, as the disease and symptoms evolve, there is focal asymmetric limb weakness, evidenced by difficulty walking, falls or difficulty keeping the grip, or bulbar findings such as dysarthria, dysphagia, sialorrhea, weakness in the facial muscles, neck, among others, in order to affect basic body functions such as breathing capacity, mobility and swallowing.

In the present study, a predominance of risk of skin injury and risk of falls was observed in nursing diagnoses. risk of choking, decreased body movement, inadequate sleep, altered food intake and slimming were formulated.

There is a shortage of original studies discussing nursing diagnoses in the care of people with ALS. In an integrative review study, which aimed to raise the contents about the contributions of nursing in the care of the individual affected by ALS, the main diagnoses and related nursing interventions were identified: impaired swallowing, Impaired walking, impaired mobility in bed, ineffective respiratory pattern, deficit of self-care to dress, deficit of self-care for bathing and hygiene, deficit of self-care for food, impaired verbal communication, impaired tissue integrity, Risk of damaged skin integrity and acute pain.[17] It is worth noting that the authors use the NANDA I taxonomy, while this study addresses the CINPSC taxonomy.

It was noticeable to identify, in the analyzed medical records, more significant motor deficit in lower limb motor strength (LL) than in upper limbs (UL), since 79% had significant reduction of LL force (grade 0 to 3). This reflects on the mobility of participants, since 44% have impaired locomotion that need support to move as canes and walkers, 40% are restricted to wheelchairs, and 12% are bedridden because the disease stage is more advanced.

The decreased body movement and absent motor coordination are characteristic nursing diagnoses of the disease, related to muscle weakness and atrophy that limit the movements of the upper and/or lower limbs, making difficult to perform daily tasks, due to the degeneration of motor neurons responsible for control and communication between the nervous system and voluntary muscles.[18]

These clinical manifestations are factors that influence the postural instability of the individual, who, at the same time, depends on third parties (formal or informal caregivers) to perform daily life activities and require transfer from the bed to a bath chair and/or wheelchair, which are considered actions contributing to increase the risk of falls.[19]

In this study, it was possible to identify that all presented motor force impairment, some are restricted to bed requiring care for hygiene and position change and many use accessories to support locomotion and mobility. These conditions are described as risk factors for the fall risk diagnosis (NANDA 2015-2017). However, it is verified that in the sample studied, 11 (44%) patients presented a nursing diagnosis of risk of falling. It can be inferred that the lack of registration of this nursing diagnosis in the analyzed records is due to the dynamics of the care. During the process of recruitment of participants, we can observe the operation of the outpatient clinic and the dynamics of the consultations. Many individuals need immediate and short-term consultation, prioritizing a multiprofessional consultation in order to optimize the time spent away from home. Consequently, this process directly influences the accuracy of nursing diagnoses formulated during the consultation.

With the advance of the disease, movement limitation may worsen leading to the patient remain confined to the bed, making it impossible for him to perform any movement independently. In this case, it is essential to prioritize attention regarding decubitus changes, since the individual has a risk of skin lesions in certain areas of the body, mainly where there are bone prominences.[19] Nursing diagnosis Risk for skin injury is prevalent in the sample analyzed, however, there is a predominance of participants with intact skin (76%), which indicates good care provided by the caregivers through the guidelines provided by the service nurse.

Among the changes related to the bulbar region, there is the impairment of the musculature responsible for oral function, respiratory and swallowing, generating the main symptoms such as dysarthria and dysphagia. Such signs can bring important complications and it is up to the multiprofessional team to define strategies to minimize the risks.[20]

With the advance of the disease, there is a communication difficulty. Dysarthria affects about 80% of individuals with ALS, due to atrophy and weakness of the tongue, lips, facial muscles, pharynx and larynx; manifesting initially with hoarseness, weak voice, lack of vocalization, resulting in anarthria. Therefore, individuals with ALS and their caregivers should be advised on communication strategies (use of communication boards) as early as possible and, when possible, assistive technologies such as optical mouse and voice synthesizers should be implemented.[10] these changes should be considered for the formulation of nursing diagnosis Impaired verbal communication (NANDA 2015-2017). It was found that this nursing diagnosis was not formulated for the participants of the study, and 09 (36%) had dysarthria or aphasia.

Regarding swallowing, 12 (48%) study participants manifest dysphagia (mild, moderate to severe), which is considered one of the most common initial symptoms of ALS. It was found, in the sample studied, that the diagnosis of altered food intake and choking risk were formulated for participants with dysphagia.

Dysphagia affects about 60% of individuals with ELA, and occurs due to changes in the motor activity of the tongue, by increasing the duration of the voluntary swallowing phase, and by the involvement of the glossopharyngeal, vagus, accessory and hypoglossus nerves. With the progression of the disease, some complications may arise such as: aspiration of salivary secretions by sialorrhea, choking on food or liquids, respiratory difficulty, pneumonia, inability to swallow and speak.[10,16] Thus, there are significant weight loss, dehydration, recurrent pulmonary infections and worsening of the respiratory capacity.[10] The impaired nutritional status occurs rapidly and progressively and, therefore, it is necessary to use a nasogastric tube or gastrostomy catheter for supplementation, avoid aspiration and, consequently, aspirative pneumonia.[16] For the treatment of dysphagia, there is a need for multidisciplinary action (speech therapist, nutritionist, gastroenterologist) rapid and coordinated.[10]

It is still possible to highlight that 32% of the participants in the analyzed sample have a diagnosis of inadequate sleep. This is due to respiratory discomfort during the night or at bedtime/rest. This factor is due to the presence of apnea during sleep, which, many times, ends up interrupting it because of the lack of adequate cerebral oxygenation.[19] The deterioration of muscle groups affects the inspiratory muscles, resulting in alveolar hypoventilation and increasing hypercapnia, which is manifested by sleep fragmentation, lived dreams, morning headaches, daytime drowsiness and cognitive deterioration.18 If the introduction of ventilator assistance with the limit of the fall of 50% of the Forced Vital Capacity (FVC). However, it is known that before this value occurs nocturnal hypoxemia and decrease in maximum respiratory pressure.[10]

There are techniques used in respiratory physiotherapy that promote lung clearance and expansion, optimizing coughing and eliminating bronchial secretions, which can reduce respiratory complications, improve the quality of life and prolong the survival of individuals with ALS. These actions can also delay or avoid the need for more complex interventions, such as invasive ventilator support.[16] However, when the individual has difficulty maintaining adequate ventilation, with a decrease in FVC close to 50% of the predicted value, early introduction of ventilator assistance using a mask with a positive pressure device (BI-level Positive Airway Pressure - BiPAP) should be indicated.[10,20]

The multidisciplinary team should guide people with ALS and their caregivers on the use of non-invasive therapeutic techniques and recommend adherence to this therapeutic proposal. Non-invasive ventilator support, in its various forms, is the one that most increases the survival and quality of life of patients with ALS.[20] Treatment depends heavily on the participation and involvement of the person as an active subject of their treatment. It is responsibility of the nurse to assess the understanding of the person and their caregivers on the importance of ventilator support, as well as adherence to treatment.

With this in mind, it is noted that the majority of study participants (72%) use respiratory devices such as BiPAP at night and the manual resuscitator (AMBU) to perform air stacking 2 to 3 times a day, with the aim of assisting respiratory capacity and, consequently, improving sleep quality.

In the sample studied, it was also observed that the participant with an advanced stage of the disease (P4) already uses ventilator assistance (BiPAP) 24 hours a day; and 4 (16%) participants (P2, P7, P11 and P20) have indications for the devices, but do not use them. The combination of non-pharmacological therapies and drug treatment proposed by the multidisciplinary team will favor improvements in vital functions, increasing survival and quality of life.[20] Another important point is that, in progressive diseases, the autonomy of the person to make decisions regarding their life must be respected. To this end, communication with the person with ALS must be as frank as possible. The basic principles of care are: well-informed patient, respect for autonomy, attention from a specialized team, and appropriate time for special decisions.[20]

The role of nursing in caring for people with ALS goes far beyond technical procedures and therapeutic approaches. It is important to promote comfort and the best possible adaptation of the patient to the reality of a chronic and disabling disease. The individual and family need support from the team to better cope with the conditions imposed by the disease, and, at the same time, to promote greater integration, participation and accountability of all involved.

It is worth emphasizing the extreme need for attention and care for people with ALS, who find themselves in a process of vulnerability and dependence on all caregivers, viewing them in an integral way, intervening correctly for a better adaptation to the new reality that the disease has imposed on their lifestyles.

A limitation of the study is that the number of participants included in the study (25) is lower than the number of people with ALS treated during the study period (57). This is due to the fact that this is a progressive, debilitating disease that results in death, and that deaths were recorded in patients treated at the service (retrospective phase). Another limitation of the present study is the incomplete data in medical records related to information on the variables studied.

5. Conclusion

The present study allowed the identification of nursing diagnoses formulated by nurses in outpatient care of people diagnosed with ALS. The most frequent were Risk of skin injury and Risk of fall. Other nursing diagnoses that are relevant were also identified: Risk of choking, decreased body movement, Inadequate sleep, altered food intake and weight loss.

Based on critical reflection and clinical reasoning of the clinical data of the study participants, the researchers propose the diagnosis verbal communication altered, which was not formulated by the nurse in the service. It is assumed that the absence of this nursing diagnosis is due to the high demand for work combined with the dynamics of consultations, which were observed in the prospective collection.

The use of the nursing process by the nurse makes the look more humanized and complete in front of the problems faced by the person with ALS, and consequently subsidizes the elaboration of accurate nursing diagnoses and adequate to the individual's condition, enabling reflection and decision-making to establish the most assertive nursing interventions. The medical record of the service of care specialized in rare diseases of the Institution has the nursing process in a computerized system (electronic medical record), which facilitates the formulation of nursing diagnoses during the nursing consultation.

ALS, being a rare disease and difficult to diagnose, brings few studies and effective treatments to delay its immutable repercussions, there is need for greater preparation of the health team to deal with the reality that complex care to this disease brings with it, necessarily including the nursing team, since it is this that establishes continuous and direct care to individuals. In this condition, research and studies in the nursing environment should be carried out with the objective of enabling nurses to deal with the reality of the person with ALS and their families.

Authors' contributions

The authors stated that they made substantial contributions to the work in terms of research design or design; data acquisition, analysis or interpretation for the work; and writing or critical review of relevant intellectual content. All authors approved the final version to be published and agreed to take public responsibility for all aspects of the study.

Competing interests

No financial, legal or political conflict involving third parties (government, companies and private foundations, etc.) has been declared for any aspect of the submitted work (including but not limited to grants and funding, participation in advisory board, study design, manuscript preparation, statistical analysis, etc.).

Indexers

The Journal of Contemporary Nursing is indexed by DOAJ and EBSCO.

References

1. Cedraz J. Processo de Enfermagem: o que preciso saber? [Internet]. Sanar; 2020. Available from: https://www.sanarsaude.com/portal/carreiras/artigos-noticias/colunista-enfermagem-processo-de-o-que-preciso-saber

2. Conselho Federal de Enfermagem – COFEN. Resolução COFEN-736/2024 - Dispõe sobre a implementação do Processo de Enfermagem em todo contexto socioambiental onde ocorre o cuidado de enfermagem [Internet]. Cofen – Conselho Federal de Enfermagem; 2024. Available from: https://www.cofen.gov.br/resolucao-cofen-no-736-de-17-de-janeiro-de-2024/

3. Moreira LHD, Hong MV, Silva DA, Silva RG. The important nursing diagnosis: vision of nurses. Res Soc Dev. 2021;10(2):6-1. http://dx.doi.org/10.33448/rsd-v10i2.12508

4. Braga CG, Cruz DALM. Open-access The Taxonomy II proposed by the North American Nursing Diagnosis Association (NANDA). Revista Latino-Am. Enfermagem. 2003;11(2). https://doi.org/10.1590/S0104-11692003000200016

5. Cavalcante MDMA. A Classificação Internacional para as Práticas de Enfermagem em Saúde Coletiva (CIPESC) como instrumento do processo de trabalho do enfermeiro em saúde coletiva [Internet] [master's thesis]. Curitiba: Universidade Federal do Paraná; 2014. Available from: https://acervodigital.ufpr.br/xmlui/bitstream/handle/1884/37159/R%20-%20D%20%20MARILIA%20DANIELLA%20MACHADO%20ARAUJO%20CAVALCANTE.pdf?sequence=3&isAllowed=y

6. Oliveira ASB, Pereira RDB. Amyotrophic lateral sclerosis (ALS): three letters that change the people's life. For ever. Arq. Neuro-Psiquiatr. 2009;67(3a):750–82. https://doi.org/10.1590/S0004-282X2009000400040

7. Dourado Júnior MET. Estudo epidemiológico da Esclerose Lateral Amiotrófica no Brasil [Internet]. Natal: UFRN; 2021. Available from: https://revelanos.lais.ufrn.br/media/Estudo_Epidemiol%C3%B3gico_da_ELA_no_Brasil.pdf

8. Pallotta R, Andrade A, Bispo OCM. The Sporadic Amyotrophic Lateral Sclerosis as Autoimmune. Revista Neurociência. 2001;20(1):144–52. https://doi.org/10.34024/rnc.2012.v20.8309

9. Ministério da Saúde (Brasil). Esclerose Lateral Amiotrófica (ELA) [Internet]. Ministério da Saúde. [cited 2023 Aug. 23]. Available from: https://www.gov.br/saude/pt-br/assuntos/saude-de-a-a-z/e/ela

10. AbrELA. ELA - Esclerose Lateral Amiotrófica [Internet]. São Paulo: Associação Brasileira de Esclerose Lateral Amiotrófica; 2013. Available from: https://www.abrela.org.br/wp-content/uploads/2018/05/AbrELA_LIVRETO_web.pdf

11. Portaria Conjunta nº 13, de 13 de agosto de 2020 (Brasil). Aprova o Protocolo Clínico e Diretrizes Terapêuticas da Esclerose Lateral Amiotrófica [Internet]. Diário Oficial da União. 2020 Aug 13. Available from: https://bvsms.saude.gov.br/bvs/saudelegis/saes/2020/poc0013_19_08_2020.html

12. Diniz ABR, Passos MAN. Amyotrophic lateral sclerosis -ALS: progression of the disease in diagnosed patients. Revista JRG. Zenodo. 2022;5(11):160–80. https://doi.org/10.5281/zenodo.7199354

13. Resolução Nº466 de 12 de dezembro de 2012 (Brasil). Aprova as seguintes diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos [Internet]. Diário Oficial da União. 2013 Jun. 13. Available from: https://www.gov.br/conselho-nacional-de-saude/pt-br/acesso-a-informacao/legislacao/resolucoes/2012/resolucao-no-466.pdf/view

14. Resolução Nº 510, de 07 de abril de 2016 (Brasil). Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais cujos procedimentos metodológicos envolvam a utilização de dados diretamente obtidos com os participantes ou de informações identificáveis ou que possam acarretar riscos maiores do que os existentes na vida cotidiana. Ministério da Saúde; Conselho Nacional de Saúde; 2016. Available from: https://bvsms.saude.gov.br/bvs/saudelegis/cns/2016/res0510_07_04_2016.html

15. Ministério da Saúde (Brasil). Carta Circular nº 1/2021-CONEP/SECNS/MS. Comissão Nacional de Ética em Pesquisa, Secretaria-Executiva do Conselho Nacional de Saúde e Ministério da Saúde [Internet]. Brasília: Ministério da Saúde; 2021. Available from: https://www.foar.unesp.br/Home/ComissoeseComites/CEP/carta_circular_01.2021.pdf

16. Santos RC, Silva RA, Matias GC, Vieira ACF, Cavichio AFCS, Carvalho MR, et al. The complications and symptoms of amyotrophic lateral sclerosis (ALS): A literature review. Brazilian Journal of Health Review. 2021;4(6):2192-2189. https://doi.org/10.34119/bjhrv4n6-369

17. Araújo JS, Abreu WO, Silva JLL, Santos DA. Assistência de enfermagem no cuidado ao paciente portador de esclerose lateral amiotrófica. Revista Pró-UniverSUS. 2022;13(3):44-51. https://doi.org/10.21727/rpu.v13i2.3314

18. Guimarães VS, Silva CH, Neves YF, Dutra TL. Complicações Respiratórias na Esclerose Lateral Amiotrófica e Métodos de Reabilitação [Internet]. Revista Interdisciplinar do Pensamento Científico. 2017;3(2):277-269. Available from: https://reinpec.cc/index.php/reinpec/article/view/175

19. Ribeiro ACS, Santana DA, Silva SG, Aoyama EA, Lima RN. Diagnósticos e Intervenções de Enfermagem ao Adulto acometido por Esclerose Lateral Amiotrófica [Internet]. Revista Brasileira Interdisciplinar de Saúde. 2019;1(4):23-17. Available from: https://revistarebis.rebis.com.br/index.php/rebis/article/download/46/42/108

20. Ministério da Saúde (Brasil). Protocolo Clínico e Diretrizes Terapêuticas da Esclerose Lateral Amiotrófica [Internet]. Brasília: Ministério da Saúde, Secretaria de Ciência, Tecnologia, Inovação e Insumos Estratégicos em Saúde, Departamento de Gestão e Incorporação de Tecnologias e Inovação em Saúde; 2021. Available from: https://www.gov.br/conitec/pt-br/midias/protocolos/publicacoes_ms/20210713_publicacao_ela.pdf