

NURSING CARE FOR A PERSON WITH AMYOTROPHIC LATERAL SCLEROSIS: AN EXPERIENCE REPORT

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Abstract: Amyotrophic lateral sclerosis is a progressive neurodegenerative disease of complex and multifactorial etiology. The median survival of patients is 3-5 years after diagnosis, and death is usually caused by respiratory muscle failure. In this context, the attention provided by a multidisciplinary team is necessary, in which the nurse actively participates in decisions and nursing care. This is a descriptive study with a qualitative approach, of the experience report type on nursing care for people with Alzheimer's, hospitalized in a Medical Clinic Unit of a Federal University Hospital located in the city of João Pessoa, state of Paraíba. Amyotrophic lateral sclerosis is an irreversible and, so far, incurable disease, leading those affected to become dependent. In the multidisciplinary team, the nurse identifies the health/disease situations and plans care actions based on the Nursing Process. The main nursing diagnoses were: Impaired swallowing; Impaired bed mobility; Impaired spontaneous ventilation; Deficit in self-care; Risk of impaired skin integrity; Risk of infection; Pain; Impaired verbal communication; Hopelessness / Sadness / Depression. Excellent nursing care becomes extremely important as it promotes the necessary comfort, prevents complications, improves quality of life, helps in the patient's adaptation process in the various stages of pathology advancement and in the support to family members throughout the course of the disease.

Keywords: Amyotrophic Lateral Sclerosis, Nursing Process, Nursing care, Nursing Diagnosis, Quality of life.

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease characterized by loss of motor neurons in the spinal cord, brainstem and motor cortex that drastically reduces the patient's life

expectancy. The degenerative process has a complex and multifactorial etiology, current hypotheses about the underlying pathological mechanisms of this entity suggest that there is a complex interaction between the various mechanisms, including genetic factors, oxidative damage, accumulation of intracellular aggregates, mitochondrial dysfunction, axonal transport defects, glial cell pathology and excitotoxicity (Bertazzi et al., 2017).

The physical findings depend on the location where the degeneration of the motor neurons will occur, and may be: cervical, bulbar or lumbar. Only 25% of patients with A.L.S. have the bulbar onset form, defined by degeneration of the upper motor neuron (pseudobulbar palsy), the lower motor neuron (bulbar palsy), or both. This affects the nerves that perform respiratory, swallowing and speech functions, initially generating dysarthrophonia, followed by dysphagia, atrophy, weakness and lingual myofasciculation, and later there is paralysis of the upper and lower limbs. The median survival of patients is 3-5 years after diagnosis, and death is usually caused by respiratory muscle failure (Ribeiro et al., 2020).

According to the Brazilian Association of Amyotrophic Lateral Sclerosis, the population prevalence of ALS is from 3 to 8/100,000 inhabitants, corroborated by the latest American studies that reported a prevalence of 5/100,000 inhabitants. The most frequent age of onset in women is 75-79 years and in men the range is 70-74 years. In some Brazilian studies, an incidence of 0.6 to 2.6 per 100,000 inhabitants was observed. Males are the most affected, in a ratio of 2:1 and present with an average age of onset of symptoms at 57 years, earlier in men, although recent studies indicate that the number of cases is closer. equality between men and women (Braga, 2019).

In view of the involvement by the pathology, palliative care is almost always essential in order to offer quality of life for the individual and family/caregiver. In this context, the attention provided by a multidisciplinary team is necessary, in which the nurse actively participates in decisions and nursing care. The role of nurses stands out in the prior identification of possible complications arising from the disease, in care actions that contribute to the promotion, prevention, recovery and rehabilitation of the health of the individual, family and community, ensuring comfort and longer survival time with less suffering. to the affected individual (Silva et al., 2018).

Thus, this study aims to describe, through experiences lived by the team, the nursing care provided to patients with A.L.S. in a medical clinic unit.

METHODOLOGY

This is a descriptive study with a qualitative approach, of the experience report type on nursing care for people with ALS, hospitalized in a Medical Clinic Unit of a Federal University Hospital located in the city of João Pessoa, state of Paraíba.

RESULTS AND DISCUSSION

This experience report portrays the experience of nurses in providing nursing care to patients affected by ALS in a Medical Clinic Unit of a Public Hospital in the city of João Pessoa. The clinic has 30 beds for the care of patients involving various clinical pathologies such as liver, kidney, neurological, skin, rheumatological diseases, among others.

ALS is an irreversible neurodegenerative disease and, so far, incurable, leading those affected to become dependent on modern life support technology. Due to the great difficulty in offering the home-care service

in the SUS network, hospital admissions become quite prolonged, representing a high cost and demanding multiprofessional specialized assistance. In addition, this longer period favors an increase in the emergence of complications related to bacterial exposure in the hospital environment.

In the multiprofessional team, the nurse as an active member, there is the importance of a qualified and qualified nursing care to implement the Nursing Process. It consists of a methodological work instrument used for care actions, organizing and allowing for an improvement in the quality of care provided.

The nurse identifies the health/disease situations and plans care actions that contribute to the promotion, prevention, recovery and rehabilitation of the health of the individual, family and community. This Process is composed of steps that are interrelated and interdependent, namely: history, nursing diagnosis, planning, implementation and evaluation.

Nursing care is based on the Nursing Process and requires nurses to develop creative strategies that involve their engagement in an attempt to provide the best comfort, symptom relief, and prevention of disease complications. Such assistance goes well beyond technical operations such as administering medication and knowing how to handle hospital equipment such as an infusion pump, aspirator or mechanical ventilator. Professionals work with dedication and seek to create intelligent alternatives that can promote well-being, associated with other members of a multidisciplinary team.

All care planning must be unique and individualized. However, due to the circumstances of the pathology, the main nursing diagnoses (NANDA-I, 2021) associated with patients affected by ALS and the main interventions applied in our daily lives will be described below:

- Impaired swallowing: Administration of diet via gastrostomy, with drip controlled by an infusion pump to prevent gastric complications; Maintain elevated decubitus at 300; pause diet during patient mobilization in bed.

- Impaired bed mobility: For this diagnosis, we adopted interventions to provide the best comfort to the patient, with the help of correctly positioned pillows and cushions and the change of decubitus always taking place with scheduled intervals for every two hours.

- Impaired spontaneous ventilation: Use of invasive mechanical ventilation, paying attention to the need for aspiration whenever necessary, following aseptic techniques; Communicate and record the characteristics of the aspirated content in the medical record, so that tracheal aspirate collection for cultures is requested whenever necessary; Adequate positioning of the tracheas so that they are not pulling the tracheostomy; Change the fan circuit every 7 days according to the sector's routine; Change bacteriostatic filter whenever necessary; Be aware of changes in the ventilator charts to act in cases of complications, always in conjunction with medical professionals and physical therapists.

-Deficit in self-care: Offer strict body hygiene, leaving patients always clean, free from moisture and prolonged contact with urine and feces; Hydrate the skin; Keep bed sheets clean and wrinkle-free;

-Risk of impaired skin integrity: It consists of the same care mentioned for the self-care deficit, also including careful inspection of the skin and use of pressure relievers in the sacral and calcaneal region; Keep patients using a pneumatic mattress available at the service for bedridden.

-Risk of infection: Check vital signs

every 6 hours; Be alert for any signs of inflammation; use aseptic techniques in every procedure performed.

-Pain: Administer analgesics as prescribed; observe and record if there was pain relief; Promote positions that aim to reduce the sensation of pain.

- Impaired verbal communication: Be aware of non-verbal communication through facial expressions and lip articulation of words. In addition, our patients were able to purchase the Tobii Dynavox PCEYe Mini through a donation campaign. This consists of an eye tracker that connects to a notebook allowing you to use your eyes as if it were a mouse or keyboard, allowing you to type what you want and control the mouse cursor with eye movement. We can say that it has been a very important instrument in the communication of these patients, bringing a better quality of life.

-Hopelessness/Sadness/Depression: Our strategies consist of strengthening the bond with the patient and their families, maintaining an empathic posture, being attentive to their complaints; Therapeutic touch; Incentive to music therapy, entertainment with movies, series, games and soap operas; Promotion of a welcoming environment in the patient's ward with personalized decoration; Spiritual support enabling visits by the Chaplaincy or other religious; Sporadic visits by patients to the hospital's roof so that they can contemplate the view of the sea and all the natural beauty of the Atlantic Forest located near the hospital. They can also count on the monitoring of service psychologists.

Our main focus is the patient, however, due to the patient's need to have a companion, it is essential that there is a harmonious bond

between the nursing team and the patient. It is necessary to always exercise health education to train the caregiver as a collaborator within the hospital care and prepare them for home care, in case they ever get access to the home-care service. The team needs to be willing to listen to the companion's complaints, being attentive to signs of wear and tear caused by the fatigue that care causes and any sign of illness.

CONCLUSION

Because it is a progressive neuro-degenerative disease and, until the present day, without a cure, excellent nursing care becomes extremely important as it acts to promote necessary comfort, prevent complications, and improve quality of life, helping in the patient's adaptation process in the various stages of pathology advancement and in supporting family members throughout the course of the disease.

The Nursing Process constituted our main tool for offering organized, planned care and in constant pursuit of achieving the best possible results. It is worth mentioning once again that no technology applied to health would have meaning if it were not carried out with love and empathy, in the construction of an affective bond that represents the total commitment and engagement of the professional in offering the best possible care, providing a better quality of life within of the limitations that ALS imposes.

Although we do not always obtain the expected results, the achievement of positive results is rewarding and drives us to continue motivated in the attempt to practice Nursing, always seeking better professional training through continuing education offered by our service, as we are open to associating in our practical activities that seek to promote well-being, raise self-esteem, provide physical and spiritual comfort and assist those affected by ALS in this process of finitude of life.

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