

PALLIATIVE CARE TO PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS: EXPERIENCES OF PHYSIOTHERAPISTS IN A HOSPITAL SETTING

Cuidados paliativos ao paciente com esclerose lateral amiotrófica: vivência de fisioterapeutas no âmbito hospitalar

Cuidados paliativos al paciente con esclerosis lateral amiotrófica: vivencia de fisioterapeutas en el ámbito hospitalario

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ABSTRACT

Objective: The study's main purpose has been to investigate the experiences of physiotherapists caring for patients with Amyotrophic Lateral Sclerosis (ALS) undergoing palliative care in a hospital setting. **Methods:** It is a descriptive-exploratory study with a qualitative approach, which was performed with physiotherapy professionals from the internal medicine and surgical wards of a public hospital in João Pessoa city, Paraíba State, Brazil, using a semi-structured interview and empirical material subjected to the content analysis technique. **Results:** After interviewing eight physiotherapists and based on data analysis, the following four thematic categories were elaborated: I- Physical therapists' understanding in regard to palliative care; II- Strategies used by physical therapists to promote palliative care for ALS patients; III- Interaction of physical therapists with the patient care team promoting palliative care for ALS patients; IV- Experience of physical therapists when assisting the patient with ALS undergoing PC. **Conclusion:** The physiotherapists based their arguments on their professional experience, underlining the need for further discussions and a better understanding of the subject amongst these professionals aiming to align theory with practice.

Descriptors: Amyotrophic lateral sclerosis, Palliative care, Physiotherapy, Hospital care, Patient care team.

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RESUMO

Objetivo: Investigar a vivência de fisioterapeutas na atenção a pacientes com esclerose lateral amiotrófica (ELA) sob cuidados paliativos no âmbito hospitalar. **Métodos:** Estudo descritivo, exploratório, com abordagem qualitativa, realizado com fisioterapeutas das enfermarias clínica médica e cirúrgica de um hospital público do município de João Pessoa-Paraíba-Brasil, mediante entrevista semiestruturada e material empírico submetido à técnica de análise de conteúdo. **Resultados:** Foram entrevistados oito fisioterapeutas e, da análise dos dados, emergiram quatro categorias temáticas: I- Compreensão dos cuidados paliativos; II- Estratégias dos fisioterapeutas na promoção dos cuidados paliativos a esses pacientes; III- Interação dos fisioterapeutas com a equipe multiprofissional promovendo os cuidados paliativos na ELA; IV- Vivência dos fisioterapeutas ao assistir esses pacientes. **Conclusão:** Os fisioterapeutas discorreram seus argumentos com base em sua vivência profissional, destacando-se a necessidade de maiores discussões e aprofundamentos sobre a temática entre esses profissionais para articular a teoria e a prática.

Descritores: Esclerose amiotrófica lateral, Cuidados paliativos, Fisioterapia, Assistência hospitalar, Equipe interdisciplinar de saúde.

RESUMEN

Objetivo: Investigar la vivencia de fisioterapeutas en atención a los pacientes con esclerosis lateral amiotrófica (ELA) en cuidados paliativos en ámbito hospitalario. **Métodos:** Estudio descriptivo, exploratorio, con abordaje cualitativo, realizado con fisioterapeutas de las enfermerías clínica médica y quirúrgica de un hospital público de la ciudad de João Pessoa-Paraíba-Brasil, por medio de entrevista semiestructurada y material empírico sometido a la técnica de análisis de contenido. **Resultados:** Fueron entrevistados ocho fisioterapeutas y, del análisis de los datos, emergieron cuatro categorías temáticas: I- Comprensión de cuidados paliativos; II- Estrategias de fisioterapeutas en la promoción de cuidados paliativos para esos pacientes; III- Interacción de los fisioterapeutas con el equipo multiprofesional promoviendo los cuidados paliativos en ELA; IV- Vivencia de los fisioterapeutas al asistir esos pacientes. **Conclusión:** los fisioterapeutas hablaron sus argumentos con base en su vivencia profesional, se destacando la necesidad de mayores discusiones y profundizaciones sobre la temática entre esos profesionales para articular teoría y práctica.

Descriptor: Esclerosis lateral amiotrófica, Cuidados paliativos, Fisioterapia, Atención hospitalaria, Grupo de atención al paciente.

INTRODUCTION

Palliative Care (PC) is an approach that improves the quality of life of adult patients and children and their families in the face of life-threatening diseases. Prevent and relieve suffering with the early identification, evaluation and treatment of pain and other physical, psychosocial or spiritual problems.¹ This care was initially intended for cancer patients, but this type of care should extend to other chronic diseases.

Nowadays, it is estimated that 40 million people need PC each year, of which 78% live in low- and middle-income countries. Given this framework, around the world, only about 14% of people who need this care receive it.¹

Accordingly, it is considered that PC can be useful at any time after the diagnosis of complex or life-limiting chronic diseases, nevertheless, there are usually more effective at the onset of the disease.² Among them, stands

out the Amyotrophic Lateral Sclerosis (ALS), a devastating neurodegenerative disorder that results in the selective death of motor neurons in the central nervous system. This progressive degeneration leads to a prognosis of terminality for most individuals only two to three years after the onset of the disease,³ constituting respiratory failure as the common cause of death, often associated with infection.⁴

Studies consider that people diagnosed with ALS might benefit from palliative care.³⁻⁵ The PC team is part of the broader multidisciplinary care approach that covers the different care sectors involved in providing services to patients with ALS and their families.⁴

Hence, the need to include several health professionals in the provision of care in ALS is highlighted in view of its multiplicity of physical problems such as loss of mobility, difficulties in speech and swallowing, respiratory failure, and psychosocial problems caused by loss, depression, grief and family suffering.⁴

The physical therapist professional, as part of the patient care team, plays an important role to complement the treatment, since physiotherapy adapted to the needs and objectives of the individual, focused on the treatment of symptoms and on maximizing function and participation, allows the individual with ALS to live his life to the maximum and with quality.⁶

Furthermore, in PC, the physiotherapist helps patients to preserve their dignity so that they can live as actively as possible in comfort, in addition to guiding and supporting family members, including when facing illness and grief.⁷

Bearing the aforesaid in mind, addressing physical therapists who assist patients with ALS under PC in the hospital setting, in order to know their conceptions and the development of care, will contribute to qualify care in this context. Hence, this work meant to investigate the experiences of physiotherapists caring for patients with amyotrophic lateral sclerosis undergoing palliative care in a hospital setting.

METHODS

It is a descriptive-exploratory study with a qualitative approach, which was performed with physiotherapy professionals who assisted people with ALS undergoing PC. This work took place in October 2018 at a public hospital in *João Pessoa* city, which is considered an outstanding health structure throughout the *Paraíba* State, Brazil.

The study sample consisted of eight physiotherapists who are part of the patient care team working in the internal medicine and surgical wards of the public hospital and who provide assistance to patients with ALS. The selection of this sample was performed for convenience, meeting the following inclusion criteria: being active during data collection and having at least one year of experience in the place selected for the investigation. Physical therapists who were away from the service were excluded due to vacations,

work leave, among others.

Data collection took place through a semi-structured interview script with guiding questions, so that the empirical material was obtained from a digital voice recording system.

The analysis was performed based on the thematic content analysis technique,⁸ which uses careful and objective procedures to describe the content of a given document, starting from the word production.

Thus, the procedures proposed by the author were followed, which consists of three phases: pre-analysis with speed reading; material exploration with the codification of the data through the registration units, creating the thematic categories; processing and interpretation of the results obtained according to the literature. The physical therapists were named by the letter PT followed by ordinal numbering according to the sequence of the interviews (PT1, PT2, PT3...), thus ensuring the anonymity of the participants.

The study was approved by the Research Ethics Committee of the Center for Health Sciences from the *Universidade Federal Paraíba (UFPB)*, with the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appraisal] No. 96121518.2.0000.5183 on September 11th, 2018, which is in line with the ethical observances of research with human beings, recommended by the Resolution No. 466/12 from the National Health Council, in force in the country, mainly regarding the informed consent form.⁹

RESULTS AND DISCUSSION

Considering the participants' characteristics and the eight physical therapists interviewed, five (62.5%) were male, within the age group from 29 to 40 years old (35.8±4.8 years old), having a professional training time ranging from 7 to 18 years. The period of work in the hospital ranged from 1 year to 3 years and 8 months; three (37.5%) physiotherapists have already performed training in the area of palliative care and one of them was attending a *Lato Sensu* postgraduate program in PC.

Following, four thematic categories elaborated from the analysis of the empirical material of the study will be presented, which express the studied phenomenon:

Category I- Physical therapists' understanding in regard to palliative care

Herein, physical therapists express their understanding of palliative care, referring to care that aims to provide comfort and better quality of life, aiming to alleviate the suffering and pain of patients who have life-threatening diseases, according to the following discourses:

[...] you have gotten to seek a dignified treatment, seeking to provide the greatest comfort for the patient to naturally

progress. (PT1)

[...] these are interventions performed to alleviate suffering, pain in patients who have life-threatening diseases. (PT3)

[...] a patient has a diagnosis that he no longer has a treatment, a specific approach that can lead to healing, so this patient is accompanied with all the care from a patient care team so that he has a comfort, diminished pain, comfort to breathing [...]. (PT4)

Category II - Strategies used by physical therapists to promote palliative care for ALS patients

The discourses emphasize the strategies of physical therapy intervention in PC patients with ALS, which is described as a progressive and chronic neuromuscular disease that triggers generalized muscle weakness and consequently respiratory symptoms, motor deficits and pain processes.

All physical therapists spoke about respiratory impairment of ALS and described corresponding respiratory management, as can be seen in the following excerpts:

[...] we try to focus on what is vital that is the respiratory part, so we act to relieve dyspnea, give a better condition from the respiratory point of view until the patient's progression. (PT1)

[...] ALS is a neuromuscular disease, so these patients have difficulty breathing, so much so that sometimes they are tracheostomized, and we participate in this line of bronchial hygiene, letting the patient breathe well, without respiratory discomfort, maintaining the patient's airway. (PT2)

[...] Patients with ALS usually has decreased respiratory muscle strength leading to respiratory failure and dependence on mechanical ventilation, so physiotherapy promotes palliative care by doing this follow-up, leading the patient in relation to ventilation, ventilator parameters and care for pulmonary hygiene and expandability [...]. (PT4)

[...] the great differential of the physiotherapist in the patient in palliative care with ALS is to reduce the suffering from dyspnea [...]. (PT5)

[...] if he/she is already tracheostomized and needs bronchial hygiene, we do it to improve the respiratory pattern. (PT6)

With regard to the motor deficits characteristic of the disease, physical therapists approach conducts aimed at the

functionality of the individual:

[...] mobilization if needed, being active, assisted or passive [...]. (PT4)

[...] depending on the stage of the disease, if the patient still has functionality present, has ambulation, bedside sedation, we maintain the activities he can do and if he is already bedridden, we mobilize to prevent deformities [...]. (PT6)

[...] We act by giving the best conditions to the patient [...] preventing the consequent contractures, the deficit of muscle strength that is progressive [...]. (PT7)

Another strategy mentioned are the conducts that can be performed for comfort and relief of pains that affect people with ALS. Here are some reports:

[...] to mitigate pain processes, [...] to reduce discomforts related to postures due to long time of bed restriction [...]. (PT3)

[...] the comfort and positioning of the patient in bed [...]. (PT4)

[...] In patients with ALS, we generally avoid motionlessness, we provide mobility to give them comfort [...]. (PT8)

Category III - Interaction of physical therapists with the patient care team promoting palliative care for ALS patients

Here, physical therapists report the difficulties of interaction with the other professionals of the palliative care team, exposing the reality of their work environment, as evidenced in the following reports:

[...] here, in the hospital, we are a little restricted, usually, what is there for interaction is when we know that this patient, through medical records or through nursing communication, has entered this process of palliative care [...]. (PT1)

[...] I still understand these contacts and interactions as very fast, restricted. We do not have multidisciplinary meetings to discuss the patient's health condition, for each case, so they are isolated interactions [...]. (PT3)

[...] usually, the experiences I had were not with the patient care team, [...] kind of each one went and did his part and if he had any complications, [...] we communicated, but I never got to sit with the team to trace a treatment of the patient, I think this is still missing. (PT6)

[...] Physiotherapy works integrated following the actions, the proposal for the patient, and the reality here is that we do not have a formal interaction, there are no multidisciplinary protocols [...]. (PT8)

Given some reported weaknesses, the professionals also propose measures that can improve knowledge about palliative care, as can be seen in the following excerpts:

[...] I have little knowledge on the subject, but I would love to have, for instance, here in the hospital, more lectures, qualification talking about palliative care [...]. (PT2)

[...] these themes need to be discussed further, mainly in relation to patients with ALS and other patients with neuromuscular disease [...]. (PT4)

Category IV - Experience of physical therapists when assisting the patient with ALS undergoing PC

In this Category, they talked about their professional practice, the importance of physiotherapy in the care of these individuals, as can be seen in the following discourses:

[...] Assisting patients with ALS [...] it has the very good side that we can see our contribution to this pathology so threatening, we see how much the patient progresses along with the physiotherapy care. (PT3)

[...] we try to [...] make the patient feel able to perform what they can, their activity, always as independently as possible and when the limitations occur [...] see another way to perform such activity. (PT7)

[...] We had some patients who spent long periods and work precisely in this part [...] to maintain his comfort and also to prepare the family to continue treatment at home. (PT8)

In addition to professional involvement, some mention emotional connection with the life stories of people with ALS assisted by them, as observed in the following reports:

[...] at the same time, there is the emotional side in which we have to prepare a lot to deal with the patient's ups and downs of the pathology; I understand that our performance is very limited since it is a disease that has no cure, so we have to be prepared and prepare the patient for this prognosis so reserved. (PT3)

[...] The experience is that it is difficult to see the human being in the situation in which they themselves know how the destination will be [...] it is a difficult experience. (PT7)

Additionally, in this Category, it was possible to observe the difficulty of experiencing palliative care in their clinical practice, according to the following reports:

[...] when speaking of palliative care, usually still there is that idea of doing as little as possible, it is what I perceive in a team as a whole [...] many people take this situation as a way of saying "Look, I cannot do anything else for this patient" [...] there is a great distance between theory and practice. (PT1)

[...] Patients with sclerosis, I am experienced on that [...] but I did not identify if these patients were defined as palliative care, because they were followed, dependent on ventilation and sometimes were hospitalized, tracheostomized [...] but if, for instance, this patient went through a cardiac arrest, a hemodynamic instability, we did frequent examinations. (PT4)

PC provides pain relief and other distressing symptoms; affirm life and consider dying as a normal process; do not intend to accelerate or postpone death; offer a team support system to help patients live as actively as possible to death, increasing quality of life and positively influencing the course of the disease, and meeting the needs of families.¹⁰

Thus, it was possible to observe that although most study participants do not have training in PC, they understand aspects of this approach, such as the search for comfort, quality of life, alleviation of pain and suffering.

Authors of a study,¹¹ when analyzing the experience of a team that provides PC, at the hospital level, including physiotherapist, also observed that the professionals understood it as a care provided to the patient out of the possibility of cure, aiming at the control of symptoms.

ALS presents a relentless progression capable of triggering numerous symptoms and absolute motor disability of the carrier. In a national survey¹² with 567 patients from five major ALS clinical care centers in the United States of America, the prevalence of symptoms of the disease were identified, as follows: fatigue (90%); muscle stiffness (84%); muscle cramps (74%); shortness of breath (66%); pain (59%); among others. Shortness of breath was one of the three most reported symptoms and the most uncomfortable symptoms; nevertheless, it is the most effectively treated.

Physiotherapy, when introduced early, will preserve cardiopulmonary function and muscle integrity, which are necessary components to maximize functional capacity, however, the patient will benefit even when his endurance is low, and the end of life is near.¹³

Accordingly, physical therapists agree with the literature when describing, in Category II, respiratory impairment in ALS and their approaches to address these symptoms, because a study⁵ shows that respiratory deficiencies in

the disease are related to respiratory muscle weakness that impairs the ability to clean secretions in the airways. So, some physiotherapeutic interventions that benefit are the recruitment of lung volume and airway clearance techniques.⁶

The participants of this study also refer to tracheostomy and ventilatory support to these individuals, whose roles generate increasing discussion. Patients who have severe secretion problems or do not tolerate noninvasive ventilation consider tracheostomy as an elective procedure, although this type of ventilation demonstrates efficacy in reducing symptoms, improving quality of life and prolonging it.³

Moreover, in Category II, exercises within the physical therapy approaches to address motor deficits are reported as dependent on the stage of the disease. Due to the limited evidence regarding the benefits and risks of exercise in the patient with ALS, the physiotherapist needs to carefully monitor and adjust the mode and intensity of the exercise, respecting the stages of disease progression, avoiding excessive fatigue and possible damage.⁶

Regarding the pain, physical therapists make interventions for their control and highlight the importance of avoiding immobility and positioning in bed according to reports of Category II. Corroborating this, study⁶ reveals that, depending on the cause of pain, physiotherapy interventions may include Range of Motion (ROM) exercises, passive stretching, joint mobilizations and guidance regarding adequate joint support and protection. Although ALS does not primarily affect the pathways of pain, other factors may cause it, such as musculoskeletal impairments, ROM loss, immobility, muscle weakness, difficulty positioning, edema, and acute injuries such as sprains, strains, and falls.⁶

According to the reports referring to Category III that address the interaction of physical therapists with the patient care team of PC, one of the weaknesses highlighted was communication and interaction between professionals. Therefore, health professionals need to improve their communication skills, since in palliative care, the team works collaboratively to coordinate all aspects of care.²

In the aforementioned study,¹¹ communication is understood by the interviewees as strategies to overcome the difficulties and limitations found in multiprofessional teamwork.

It can be affirmed that multiprofessional work in PC is important, however, interdisciplinarity is necessary for patient and family care to be effective. Consequently, in order to achieve excellence in this care, there must be a team of interdisciplinary and interprofessional scope, whose dedications will be quantified according to the concrete needs of care.¹⁴

Considering the fact that professionals try to propose measures that improve knowledge about PC, in Category III, it can be seen that it is considered relevant, because some

obstacles are related to the lack of training and training of professionals to identify and initiate a comprehensive palliative approach such as the lack of resources that meet the needs and resistance stems from changes in the organization of services due to lack of information about the process.¹⁵

The Category IV discourses, about the experiences of physical therapists when assisting people with ALS under PC, ratify what other authors have recommended,⁷ since it is the role of the physiotherapist to establish a plan of conducts that facilitates the adaptation of the patient to progressive physical decline and its emotional, spiritual and social implications, until death. In addition, physiotherapists in palliative care help patients and families to fill the gap between real and ideal daily life, with the aim of maximizing safety, autonomy and well-being.¹⁶

In Category IV, emotional involvement and difficulty in accompanying patients diagnosed with a progressive disease without a cure prognosis were also reported in Category IV. Thus, it is necessary to develop support and education systems that help health professionals in controlling the emotional and moral suffering they encounter in the practice of ALS.¹⁷

Therefore, it is essential that the professional knows how to manage their emotions, because this is reflected in the interdisciplinary work in PC, resuming further discussions on this subject. A review study⁴ identified that developing best practice guidelines and protocols to improve communication between health professionals can alleviate the emotional burden and suffering that ALS patients and their families face.

It is also known the need for a collaborative approach to ALS involving many services and thus, it is important to ensure that these services offer coordinated care to patients,³ even in view of the possibility of there being limitations within and between care teams by different modes of care.

Concerning the difficulty of experiencing PC in clinical practice reported by some physical therapists still in Category IV, it is possible to affirm that this difficulty can start from the little experience in this area of PC aimed at people with ALS or even limitations in understanding the principles of PC. In the past, this approach was considered only in the later stages of the progression of ALS, close to the terminality, but, currently, it is considered appropriate since diagnosis,¹⁸ particularly due to the reserved prognosis, nonetheless, there is a challenge in explaining the antecedent role of PC to all involved.³

As ALS progresses, individuals become unable to move, communicate, live independently and with less autonomy, so that they may have reduced feelings of their own value.¹⁸ Still, researchers consider the assumption that there is nothing more to be done for these patients, if there is life, then providing care is also needed. Hence, the interdisciplinary team must act to help an individual to seek quality of life, and when it is no longer possible to

add quantity, one can strengthen its essence and dignity as a human being.¹⁹

CONCLUSIONS

The physical therapists expressed their arguments based on their professional experience and highlighted the role of the physiotherapist in the patient care team of PC towards ALS patients, describing the conducts according to the clinical commitments of the disease.

It is necessary to highlight the difficulties that some professionals presented in understanding palliative care. So, it is necessary that this study allows the opening of spaces for discussion on the theme among physical therapists who work directly in this area, allowing them to articulate theory and practice in order to seek new possibilities of thinking and acting.

Concerning the limitations of this research, it is not possible to make generalizations because it is qualitative in nature, given the small number of professionals who participated in the study, and the fact that the scenario involves medical and surgical clinic units. Hence, this study can be expanded to other health professionals working in palliative care and other hospital practice scenarios, such as intensive care units and ambulatories.

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