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# PERFORMANCE OF THE MULTIDISCIPLINARY TEAM REGARDING THE APPROACH TO PALLIATIVE CARE IN NEUROLOGICAL PATIENTS

## ATUAÇÃO DA EQUIPE MULTIPROFISSIONAL ACERCA DA ABORDAGEM DOS CUIDADOS PALIATIVOS EM PACIENTES NEUROLÓGICOS

## ACTUACIÓN DEL EQUIPO MULTIDISCIPLINARIO RESPECTO DEL ABORDAJE DE LOS CUIDADOS PALIATIVOS EN EL PACIENTE NEUROLÓGICO

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#### ABSTRACT

**Objective:** describe the performance of the multidisciplinary team regarding the approach to palliative care in neurological patients. Methods: descriptive, cross-sectional and quantitative study, carried out from February to April 2024 with the multidisciplinary team of a unit at the General Hospital of Fortaleza. An electronic form was used, with sociodemographic data, six objective questions, and one open question about palliative care. Results: 18 professionals participated, 83% were women, 88% were between 25 and 44 years old, and 38.8% had 6 to 10 years of experience. Regarding palliative care, 88.9% stated that it promotes the quality of life of patients and families, who face life-threatening illnesses, through the prevention and relief of physical, psycho-social, and spiritual suffering; 66.7% stated that they were initiated upon severe diagnosis; 94.4% agreed that it promotes the quality of life of the patient and family through the prevention and relief of suffering; 77.8% stat-ed that care covers the patient, family, and caregiver; 77.8% indicated care in hospitals, homes, and outpatient clinics; 55.6% believe that invasive measures should not be carried out in patients with therapeutic limitations and in active process of death. Relief from pain/suffering was the most cited finding in the open question. Conclusion: The team still has a limited understanding of palliative care, highlighting the need to expand knowledge on the topic, especially in relation to neurological patients. Considering that most neurological diseases have no cure and compromise quality of life, it is essential to strengthen this approach. Therefore, the study adds to the literature by expanding this understanding of the application of palliative care in this patient profile. Keywords: Multidisciplinary Team; Neurological disorders; Palliative care.

#### RESUMO

Objetivo: descrever a atuação da equipe multiprofissional acerca da abordagem dos cuidados paliativos em pacientes neurológicos. Métodos: estudo descritivo, transversal e quantitativo, realizado de fevereiro a abril de 2024 com a equipe multiprofissional de uma unidade do Hospital Geral de Fortaleza. Foi utilizado o formulário eletrônico, com dados sociodemográficos, seis perguntas objetivas e uma aberta sobre cuidados paliativos. Resultados: Participaram 18 profissionais, 83% eram mulheres, 88% tinham entre 25 e 44 anos e 38,8% tinham de 6 a 10 anos de experiência. Sobre cuidados paliativos, 88,9% afirmaram que promovem a qualidade de vida de pacientes e familiares, que enfrentam doenças ameaçadoras à vida, através da prevenção e alívio do sofrimento físico, psicossocial e espiritual; 66,7% afirmaram ser iniciados no diagnóstico grave; 94,4% concordaram que promove a qualidade de vida do paciente e familiares através da prevenção e alívio do sofrimento; 77,8% afirmaram que o cuidado abrange paciente, família e cuidador; 77,8% indicaram o atendimento em hospitais, domicílios e ambulatórios; 55,6% acreditam que não devem realizar medidas invasivas em pacientes com limitações terapêuticas e em processo ativo de morte. O alívio da dor/sofrimento foi o achado mais citado na pergunta aberta. Conclusão: A equipe ainda apresenta uma compreensão limitada sobre cuidados paliativos, evidenciando a necessidade de ampliar os conhecimentos sobre o tema, especialmente em relação aos pacientes neurológicos. Considerando que a maioria das doenças neurológicas não tem cura e compromete a qualidade de vida, é fundamental fortalecer essa abordagem. Portanto, o estudo acrescenta à literatura ao expandir esse entendimento sobre a aplicação dos cuidados paliativos nesse perfil de pacientes.

Palavras-chave: Equipe Multidisciplinar; Distúrbios Neurológicos; Cuidados Paliativos.

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#### RESUMEN

Objetivo: describir el desempeño del equipo multidisciplinario respecto al abordaje de los cuidados paliativos en pacientes neurológicos. Métodos: estudio descriptivo, transversal y cuantitativo, realizado de febrero a abril de 2024 con el equipo multidisciplinario de una unidad del Hospital General de Fortaleza. Se utilizó un formulario electrónico, con datos sociodemográficos, seis preguntas objetivas y una pregunta abierta sobre cuidados paliativos. Resultados: Participaron 18 profesionales, el 83% eran mujeres, el 88% tenían entre 25 y 44 años y el 38,8% tenían de 6 a 10 años de experiencia. Respecto a los cuidados paliativos, el 88,9% afirmó que promueven la calidad de vida de los pacientes y familiares, que enfrentan enfermedades potencialmente mortales, a través de la prevención y alivio del sufrimiento físico, psicosocial y espiritual; El 66,7% afirmó que se inició ante el diagnóstico grave; El 94,4% coincidió en que promueve la calidad de vida del paciente y familiares a través de la prevención y alivio del sufrimiento; El 77,8% afirmó que la atención abarca al paciente, familia y cuidador; el 77,8% indicó atención en hospitales, domicilios y ambulatorios; El 55,6% cree que no se deben realizar medidas invasivas en pacientes con limitaciones terapéuticas y en proceso activo de muerte. El alivio del dolor/sufrimiento fue el hallazgo más citado en la pregunta abierta. Conclusión: El equipo todavía tiene una comprensión limitada de los cuidados paliativos, lo que destaca la necesidad de ampliar el conoci-miento sobre el tema, especialmente en relación con los pacientes neurológicos. Considerando que la mayoría de las enfermedades neurológicas no tienen cura y comprometen la calidad de vida, es fundamental fortalecer este enfoque. Por lo tanto, el estudio se suma a la literatura al ampliar esta comprensión de la aplicación de los cui-dados paliativos en este perfil de paciente.

Palabras clave: Equipo Multidisciplinario; Trastornos Neurológicos; Cuidados Paliativos.

### **INTRODUCTION**

The World Health Organization (WHO) registers 58 million deaths a year worldwide, 34 million of which are due to disabling and incurable chronic degenerative diseases. In 2019, the second and seventh leading causes of death worldwide were cerebrovascular diseases (stroke) and dementia syndrome (Alzheimer's), respectively <sup>1-2</sup>. In Brazil, the annual average of deaths from cerebrovascular diseases is 92,540<sup>3</sup>. A study carried out in the state of Ceará identified 24,552 deaths from stroke between 2009 and 2019<sup>4</sup>.

People with neurological diseases can have uncertain or even incurable prognoses, as well as affecting essential functions related to communication, cognition, motor coordination and mobility, among others, causing greater dependence and altering life expectancy. Such impairments alter the disease progression for patients, their families and caregivers, thus increasing the demand for palliative care (PAL) specific to this profile, since traditional models, such as those used for cancer patients, do not meet the needs of neurological patients <sup>5</sup>.

According to a survey carried out in 2020, the main diseases requiring PAL in adults around the world include neoplastic diseases, which account for 28% of cases, followed by human immunodeficiency virus (HIV) with 22%, cerebrovascular diseases with 14% and dementias with 12%. In Brazil, this panorama reflects the global scenario, with a predominance of the same diseases<sup>6-7</sup>. Palliative care emerged in the 1960s in the UK and in Brazil in the late 1980s, with significant growth since 2000. The PAL approach aims to improve the quality of life of patients and families facing life-threatening illnesses by preventing and relieving pain and suffering, addressing physical, psychosocial and spiritual problems through a multi-professional team (MPT)<sup>7</sup>.

Created in 2014, the Palliative Care sector at the Fortaleza General Hospital (HGF) brings together a specialized multi-professional team made up of physiotherapists, speech therapists, doctors, nurses, psychologists, and social workers, with the support of the chaplaincy for spiritual assistance. Initially, care was focused on inpatients, but since

2020, with the opening of the palliative care outpatient clinic, care has also been extended to the outpatient unit. In 2022, the average number of monthly visits was 115 inpatients and 20 outpatients<sup>8-9</sup>.

In order to improve the quality of life of patients and their families suffering from serious and life-threatening illnesses, it is necessary to have a MPT made up of qualified professionals, based on a holistic and humanized approach to relieving pain and suffering through the actions offered by PAL. Studies show that the training of health professionals is more focused on curing, with little exploration of the finitude of life and its benefits for the patient, as well as the awareness of adequate care based on the identification of a palliative approach directed at the individual<sup>10</sup>.

Although the topic of palliative care has grown in recent years, it is important to know more about the role of MPT in caring for neurological patients, which will enable actions to be taken to improve care in the process of life and death. The study is relevant because of the need to qualify these professionals in PAL and the importance of an early approach from the moment of a serious neurological diagnosis, as well as at all stages of the illness process and not just at the end of life. In view of this, the aim of the study was to describe how the multi-professional team approaches palliative care in neurological patients.

## **METHODS**

A descriptive, cross-sectional study with a quantitative approach was carried out between February and April 2024 in the Hemorrhagic Stroke Unit at HGF, which has fifteen beds specializing in stroke, subarachnoid hemorrhage, aneurysms, and other neurological diseases.

The unit has a multi-professional team made up of 38 (thirty-eight) professionals: 3 (three) social workers, 17 (seventeen) nurses, 2 (two) pharmacists, 6 (six) physiotherapists, 2 (two) speech therapists, 2 (two) psychologists, 4 (four) doctors, and 2 (two) nutritionists. Care professionals who did not work in the unit were excluded.

The data was collected using an electronic form on *Google Forms*, which included sociodemographic information such as age, gender, profession and years of experience, and an open question about what types of approaches or care are directed at neurological patients in palliative care, and the findings answered by the participants were described and quantified.

In addition, six objective questions on Palliative Care were prepared, based on the Palliative Care Manual (2020), with adaptations: 1) the concept of palliative care, with only one correct answer; 2) what is the indication for palliative care, with more than one correct answer; 3) what is the main objective of palliative care, with only one correct answer; 4) to whom is palliative care directed, with more than one correct answer; 5) in which environment can the patient be assisted by palliative care, with more than one correct answer; 6) when it is not determined not to carry out invasive measures on a patient in palliative care, with more than one correct answer.

The form was made available through an access link sent via the *Whatsapp* messenger platform and passed on by the coordinators responsible for each professional category to the respective professionals in the unit. After collection, the data was inputted

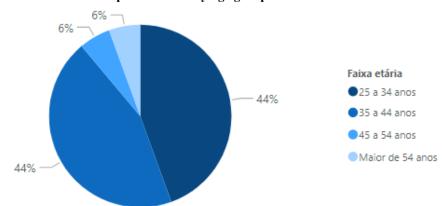
in spreadsheets, generated by the form itself, processed in the *Power Bi* program and then analyzed and compared with the reading of the Palliative Care Manual of the National Academy of Palliative Care (2023), prepared by the Sírio Libanês Hospital in partnership with the Ministry of Health (MS), which has an indispensable theoretical basis on the subject for health professionals. The results were expressed in absolute numbers and percentages.

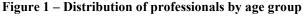
The research was approved by the Ethics Committee of the Fortaleza General Hospital (technical opinion no. 6537260), with a Free and Informed Consent Form for the participants, in accordance with resolution no. 466/12 of the National Health Council of the Ministry of Health.

## RESULTS

Eighteen (18) professionals took part in the survey, representing 47% of the AVCH unit team. Among them were 8 (eight) nurses, 3 (three) physiotherapists, 2 (two) nutritionists, 2 (two) psychologists, 1 (one) speech therapist, 1 (one) social worker and 1 (one) pharmacist. The doctors, however, chose not to take part in the survey.

Most participants were women, accounting for 83%, while men accounted for 17%. The predominant age group was young adults aged between 25 and 34, with 44%, and 35 to 44, also with 44%. Professionals aged 45 to 54 accounted for 6%, as did those aged over 54, who also accounted for 6% (figure 1). As for length of experience, 39% had between 6 and 10 years, 28% between 3 and 5 years, 22% between 11 and 20 years, and 11% had between 21 and 31 years of experience (figure 2).





Source: survey data (Feb to Apr/2024).

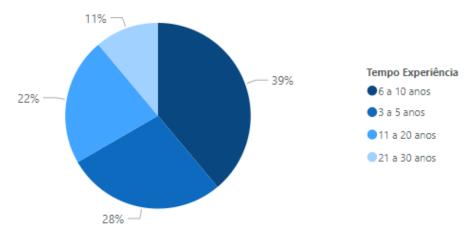


Figure 2 – Distribution of professionals by length of experience

Source: survey data (Feb to Apr/2024).

After this stage, objective questions were made about knowledge of Palliative Care. When asked about the meaning of PAL, 16 (sixteen) professionals stated that it is an approach that promotes quality of life for patients and their families facing life-threatening illnesses, by preventing and relieving physical, psychological, social and spiritual suffering. However, two professionals gave an incomplete conceptualization of PAL (Table 1).

Tabela 1 – Meaning of pallia	tive care.
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Answers	Professionals (n)	%
An approach that promotes the quality of life of patients facing life- threatening illnesses by preventing and relieving physical, psychological, social and spiritual suffering.	1	5.6%
An approach that promotes the quality of life of patients and their families facing life-threatening illnesses through the prevention and relief of pain.	1	5.6%
An approach that promotes quality of life for patients and their families facing life-threatening illnesses by prevent-ing and relieving physical, psychological, social and spir-itual suffering.	16	88.9%
Total	18	100%

Source: survey data (Feb to Apr/2024).

Regarding the indication of the palliative care approach, 12 (twelve) professionals, representing 66.7%, stated that it should start as soon as a serious illness is diagnosed. However, two (2) professionals argued that PAL should only be applied in the final phases, the end-of-life phase and during the active dying process. Another two (2) professionals believe that PAL should be indicated both from the moment of a severe diagnosis and at the end of life. In turn, two (2) professionals consider PAL to be appropriate for all stages of the course of the disease, corresponding to 11.1% for each answer (Table 2).

Answers	Professionals (n)	%
From the moment of severe diagnosis, End-of-life phase, End-of- life phase, Active dying process	2	11.1%
From severe diagnosis, end of life stage	2	11.1%
Termination of life phase, End of life phase, Active dy-ing process	2	11.1%
Since the severe diagnosis	12	66.7%
Total	18	100%

#### Table 2 – Indication of palliative care approach.

Source: survey data (Feb to Apr/2024).

The professionals were asked about the main objective of palliative care. Seventeen of them (94.4%) said that PAL aims to promote quality of life for patients and their families by preventing and relieving suffering. However, one professional (5.6%) said that PAL promotes the relief of pain and suffering, and no professional agreed that the aim of palliative care is to promote a dignified death (table 3).

### Table 3 – Main objective of palliative care.

• •	%
0	0%
1	5.6%
17	94.4%
18	100%
	1,

Source: survey data (Feb to Apr/2024).

When asked to whom PAL should be directed, 14 (fourteen) professionals, representing 77.8%, said that care should cover the patient, the family and the caregiver. On the other hand, three professionals (16.6%) stated that the focus should be on the patient and family, without including the caregiver, and one professional (5.6%) stated that care should be directed only at the patient (table 4).

#### Table 4 – To whom palliative care should be directed.

Answers	Professionals (n)	%
To the patient	1	5.6%
The patient, the Family	3	16.6%
The patient, The family, The caregiver	14	77.8%
Total	18	100%

Source: survey data (Feb to Apr/2024).

As for the environments in which palliative care patients can be cared for by the multidisciplinary team, most participants (77.8%) pointed out that this care can take place in hospitals, homes and outpatient clinics. However, two professionals (11.1%) indicated that care should only take place in the hospital and at home, one professional (5.6%) mentioned the hospital and the outpatient clinic, while another (5.6%) indicated only the hospital (table 5).

Answers	Professionals (n)	%
Hospital	1	5.6%
Hospital, Outpatient	1	5.6%
Hospital, Home	2	11.1%
Hospital, Home and Outpatient	14	77.8%
Total	18	100%

#### Table 5 – Care environments for palliative care patients.

Source: survey data (Feb to Apr/2024).

Regarding the decision not to carry out invasive measures on patients undergoing PAL, ten professionals (55.6%) believe that these interventions should not be carried out on patients with therapeutic limitations and who are actively dying. On the other hand, four professionals (22.2%) stated that invasive measures should not only be carried out on patients with limitations. Two professionals (11.1%) indicated that these measures should not be applied to patients with or without therapeutic limitations, as well as those in the active process of dying. Another two professionals (11.1%) stated that invasive measures should not be carried out on patients who are actively dying (table 6).

Answers	Professionals (n)	%
Conduct for Palliative Care in the Active Death Process	2	11.1%
Conduct for Palliative Care without Therapeutic Limitations,		
Conduct for Palliative Care with Therapeutic Limitations,	2	11.1%
Conduct for Palliative Care in the Active Death Process		
Conduct for Palliative Care with Therapeutic Limitations	4	22.2%
Conduct for Palliative Care with Therapeutic Limitations,		
Conduct for Palliative Care in the Active Death Process Conduta	10 55.	55.6%
para Cuidados Paliativos com Limitações Terapêuticas, Conduta		55.070
para Cuidados Paliativos em Processo Ativo de Morte		
Total	18	100%

#### Table 6 – Decision not to perform invasive measures on a patient in palliative care.

Source: survey data (Feb to Apr/2024).

The professionals were asked what types of approaches or care would be indicated for neurological patients in palliative care. The answers were analyzed and the main terms related to these approaches were identified, quantified and described as central ideas. The frequency of mentions was highlighted, revealing the following as the most frequently cited: relieving pain and suffering, family approach, promoting comfort, quality of life and the work of a multi-professional team (table 7).

Relieving pain and suffering were the most mentioned terms among the professionals, with ten (10) mentions, followed by family approach, with seven (7). Comfort appeared six (6) times, quality of life was mentioned in five (5) answers, and the multi-professional team only got four (4) mentions.

Central ideas	Frequency cited
Pain relief	10
Family approach	7
Comfort	6
Quality of life	5
Multiprofessional team	4

Table 7 – Central ideas of the answers on the approaches or care indicated for neurological pa-tients
in palliative care.

Source: survey data (Feb to Apr/2024).

#### DISCUSSION

Neurological patients can benefit from PAL at different stages of the disease, as in the case of stroke, which presents an acute decline followed by uncertain recovery, and dementia, which presents a rapid or prolonged decline. These phases require a more targeted view of palliative care, making it essential for the team to have adequate knowledge of the subject <sup>11</sup>.

In this sense, the study revealed that 88.9% of the professionals who responded to the survey demonstrated a complete understanding of the concept of palliative care, as shown in Table 1. This result is in line with the Manual, which defines palliative care as comprehensive assistance to patients, their families and caregivers throughout the life-threatening disease process, by relieving physical, spiritual and psychosocial pain and ensuring quality of life <sup>2</sup>.

Although palliative care is seen as complementary to curative care, it is still poorly understood by professionals and often associated only with terminality<sup>2</sup>. According to table 2, 66.7% of the professionals said that they indicate palliative care from the moment of a serious diagnosis, in line with a survey in which 70% of the health professionals interviewed also indicated the start of PAL at this stage <sup>12</sup>. However, PAL is intended for any patient at any stage of a serious illness, including neurological diseases, and can be carried out in conjunction with curative treatment <sup>13</sup>.

In view of this, there is no specific time or prognostic limit for applying PAL. It is recommended to start it from the moment of a serious diagnosis, but if this is not possible, it is indicated in the terminality, end-of-life and active dying phases, since the approach is structured in phases, based on principles and centered on the patient <sup>14</sup>. In this way, palliative care should be indicated at all stages, ensuring the necessary interventions throughout the course of the disease, especially in neurological diseases, which often have uncertain or even incurable prognoses.

The aim of palliative care, according to the Manual, is to ensure quality of life during the progression of a serious illness, offering care that includes not only the physical aspect, but also psychosocial and spiritual factors, both for patients and their families, and not just providing a dignified death <sup>2</sup>. This objective applied to neurological patients is essential, as neurological diseases are associated with neuropsychological and behavioral disorders<sup>11</sup>. As a result, 94.4% of the professionals taking part in the survey were aligned with the objective described in the Manual, as shown in Table 3.

As severe neurological disease progresses, the symptoms of communication, motor and cognitive deficits, among others, intensify and patients consequently become more dependent and need support to carry out basic activities, whether in hospital or at home<sup>11</sup>. During this process, family members and caregivers often feel more fragile and overwhelmed by the responsibility of caring for their loved ones. For this reason, the support offered by palliative care should consider both the family and the caregiver as essential parts of the care plan, implementing actions aimed at relieving the physical, spiritual and psychosocial burden <sup>15</sup>. As answered by the professionals in Table 4, 22.2% of the professionals did not answer correctly about the principle of palliative care, which advocates a holistic and humanized approach, offering support not only to the patient but also to all those involved in the illness process <sup>2</sup>.

Palliative care goes beyond the hospital and seeks outpatient and home care. According to the professionals' answers in Table 5, 22.3% did not answer according to the Manual, which emphasizes that palliative care is not restricted to a specific location or modality but should be guided by the patient's clinical needs and the goal of care. Palliative care promotes a comprehensive approach that goes beyond hospital boundaries, encompassing grief during and after the illness, and ensuring continuous support for neurological patients and their families <sup>2-6</sup>.

According to the research carried out by Lima in 2019, it was highlighted that some professionals relate PAL to the absence of investment or treatment, which demonstrates a limited view based only on curing the disease. However, according to the Palliative Care Manual, they should be started alongside other life-prolonging measures, highlighting that disease-modifying treatments, whether curative or not, can be used if they provide an improvement in the patient's quality of life, provided there are no contraindications.

The decision to maintain or suspend invasive measures must consider ethical aspects and assess whether they are beneficial to patient <sup>13</sup>. Thus, PAL should be adapted to the needs of each patient and their family, offering a flexible and personalized approach and not just based on therapeutic criteria <sup>14</sup>. Therefore, the discussion on the use of invasive measures in neurological patients under palliative care still needs to be further developed among professionals, to break the stigma that these patients no longer deserve attention or that there are no treatment options, as shown in Table 6.

Promoting the relief of pain and suffering is described as the second guiding principle of palliative care and is also established in Article 2 of Resolution No. 41 of October 31, 2018. This principle seeks not only to reduce physical pain, but also to relieve psychosocial and spiritual suffering<sup>2-18</sup>, highlighting the importance of this care for patients with dysfunctions resulting from neurological diseases. This relevance is confirmed by most of the professionals consulted, and is the most frequently cited term among them, as shown in Table 7.

In addition, including the family in the process of becoming ill with a lifethreatening neurological condition is extremely important, as mentioned by some professionals (Table 7), as it is not only part of the concept of palliative care, but also part of its guiding principles. When the family's needs are understood and included in the care plan, the benefits are significant, since awareness of end-of-life care and a positive perception of palliative care act as protective factors against depression and grief, even after the loss of a loved one <sup>2</sup>.

Comfort is integrated into the set of palliative care interventions and is achieved through the relief of symptoms, pain and suffering, which aim to improve the quality of life for patients, including those with neurological diseases. In this context, MPT is considered a key player, and it is essential to raise awareness and align the entire team with the care plan, seeking to promote comfort for these patients, but this term was mentioned by a small number of professionals (Table 7)<sup>2-16</sup>.

Although the terms quality of life and multi-professional team were barely mentioned (Table 7), it is essential to promote quality of life through the actions carried out by the MPT in palliative care, since these findings are included as benefits and guiding objectives of palliative care, in addition to Resolution No. 41 of October 31, 2018, Article 2, which emphasizes that the quality of life of the patient and family results from assistance offered by a multidisciplinary team. Thus, offering treatment that promotes quality of life is essential for patients and families facing the process of a serious neurological illness, and this must be guaranteed by a trained MPT. However, even though the promotion of quality of life is linked to the assistance of the multi-professional team, there is still a need to broaden the vision of professionals about the conduct that contributes to the well-being of neurological patients in palliative care and, consequently, to promote adequate, targeted and humanized care <sup>2-12-18</sup>.

### FINAL CONSIDERATIONS

The limitations found in the study were the low level of participation by professionals, the lack of participation by the medical team and the fact that the survey was carried out in just one unit of the institution. Despite this, the research concluded that there is still a limited understanding of palliative care, including its objectives, areas of action and indications of approach, among professionals who care for neurological patients.

It is therefore essential to provide basic training for these professionals, including the subject in educational institutions and continuing education actions in health establishments, as these professionals are responsible for assisting the patient for most of the time during health promotion, treatment or rehabilitation, given that palliative care assistance is not restricted only to the team specialized in PAL.

In addition, participation of the medical team in this context is important, since the doctor is responsible for the early identification of the diagnosis of severe neurological disease, as well as for drawing up the care plan according to the demands of the neurological patient in palliative care and their family, together with the other professionals in the multi-professional team.

It is therefore necessary to expand knowledge about palliative care for neurological patients, as most neurological diseases have no cure and compromise quality of life. The study has the potential to contribute to literature by expanding the knowledge of the multiprofessional care team about PAL, especially for neurological patients, meeting the demands of people and their families, thus promoting a comprehensive approach in all areas of the healthcare network.

## ACKNOWLEDGEMENTS

I thank my God, who with his infinite grace and mercy poured out on my life every day, renewed my strength and helped me to persevere.

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