Neuropalliative care in a tertiary-level hospital

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ABSTRACT

Objectives Palliative care in neurology is a recent specialty to improve the quality of life of patients with severe neurological diseases. This study aims to determine the frequency of neurological inpatients who had indication of palliative care, and evaluate the symptomatology, demographic profile, the need for supportive measures, advance directives for life and medical history of patients in a tertiary hospital in Brazil.

Methods This cross-sectional analytical study evaluated all patients admitted to the neurological semi-intensive care unit (ICU) at Hospital Israelita Albert Einstein with neurological conditions from February through August 2022. The Palliative Performance Scale (weight loss greater than 5% associated with body changes and a negative response to the question: 'Would you be surprised if the patient died within 1 year?') was used to indicate palliative care. Patients were divided into three groups: patients with palliative care needs ($group_{indication}$), patients without palliative care needs ($group_{without\ indication}$) and patients who received at least one assessment of a palliative care team ($group_{palliative}$). Demographic data were analysed using the X^2 test for qualitative and Kruskal-Wallis test for quantitative variables.

Results Of the 198 patients included in the study, 115 (58%) had palliative care needs. Only 6.9% received assessment by the palliative care team, and 9.56% had advance directives in their medical records. Patients in $group_{indication}$ had a higher prevalence of symptoms, such as fatigue, depression, shortness of breath and lack of appetite, and required more supportive measures, such as oxygen therapy, enteral/parenteral nutrition, admissions at ICU and days in hospital.

Conclusion Despite the high demand for palliative care in neurology, few patients receive this treatment, resulting in decreased quality of care. Therefore, greater integration and discussion of palliative care in neurology are needed.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Palliative care in neurology is a recent specialty in the USA, but is still limited in the area despite the extensive need for this practice.

WHAT THIS STUDY ADDS

⇒ Our study shows the number of patients who would benefit from palliative care, representing the demographic profile of this group as well as their needs.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Our study shows the current scenario of palliative care in neurology in Brazil, bringing to debate the need to discuss the integration of this specialty in neurology. In addition, it encourages debate to carry out clinical trials on the topic.

INTRODUCTION

Palliative care (PC) is an interdisciplinary medical specialty that aims to prevent and reduce suffering in order to improve the quality of life of patients facing a serious or potentially fatal illness. PC is not limited to end-of-life context but has a significant indication for symptom control, alignment of healthcare with patient preferences and values, communication in care, psychosocial support, as well as working with families to alleviate suffering and grief. Therefore, patients facing a serious illness should receive PC aligned with curative or life-prolonging treatments.[1]

In a systematic review of patients with cancer and those without cancer (heart failure, chronic obstructive pulmonary disease, advanced kidney disease, dementia, AIDS, multiple sclerosis, Parkinson's disease and motor neuron disease (MND)), 11 most prevalent symptoms were defined: pain, depression, anxiety, confusion, fatigue, shortness of breath, insomnia, nausea, constipation, diarrhoea and anorexia. Additionally,

the study highlights the importance of expanding PC beyond patients with cancer.[2]

In neurology, since 1996, the Ethics and Humanities Subcommittee of the American Academy of Neurology has recommended PC in their specialty.[3] PC in neurology is a recent specialty in the USA with increasing development, aiming to improve the quality of life of patients with severe neurological diseases. Patients with neurological diseases have important particularities compared with patients with oncological diseases, such as loss of communication ability, cognitive decline, changes in behaviour, impulsivity, apathy, loss of empathy and depersonalisation.[4] For example, patients with MND have reported demoralisation, loss of hope and higher suicidal ideation compared with patients with oncological disease.[5] It is estimated that 35% of patients with Parkinson's disease have depression,[6] and patients with multiple sclerosis[7 8] and post-stroke[9] have a higher risk of developing depression. 71% of patients in developed countries die in institutions, but prefer to die at home.[10]

Patients with advanced dementia in nursing homes have fewer advance directives, have higher rates of hospitalisation and are more likely to be subjected to laboratory tests and tube feeding at the end of life compared with patients with oncological diseases in the same condition.[11] Regarding patients with acute stroke, only 39% of those who died during hospitalisation had documented treatment preferences in their medical records.[12] Despite high evidence of benefit of PC in various neurological conditions,[13] less than 52% of residency programmes formally include PC in their curriculum,[14] and in a questionnaire administered to neurology residents in the USA in 2009, they demonstrated little knowledge of PC topics.[15] Family members of patients with multiple sclerosis, on the other hand, believe that doctors who discuss end-of-life care are more empathetic,[16] and family members of patients with post-stroke wanted to discuss issues related to the patient's potential for death, as well as dysfunctions.[17]

Neurological diseases are estimated to affect 1 billion people worldwide and are the cause of 1 in 10 deaths. In Brazil, they are responsible for approximately 14% of clinical admissions to intensive care units (ICUs). Many of these conditions are incurable, result in reduced life expectancy and quality of life and increased dependence, and are associated with symptoms that are likely to cause suffering. Despite clear evidence of the benefit of PC in neurological patients, this practice is still not routine in the care of patients with serious neurological diseases, with few studies with a palliative focus on neurology.[18]

There is limited information about the role of neuropalliative care in Brazil and the PC criteria specifically for neurological disorders. The main goal of this study is to describe, in a tertiary referral hospital in Brazil, the frequency of neurological patients with palliative care needs (group$_{palliative}$), how many were receiving care from this specialty and had advance directives for end-of-life care. Our hypothesis is that there should be many cases with an indication for PC given the severity of the patients, but that few would actually be receiving this care, due to the lack of knowledge about the subject among the majority of professionals and the patients themselves.

METHODS

Study design and participants

In this cross-sectional analytical study, patients over 18 years of age who were hospitalised in the neurological semi-ICU at Hospital Israelita Albert Einstein during the months of February through August 2022 were included. Data collection was done by convenience sampling, according to the availability of the researchers. However, on the days selected for data collection, efforts were made to evaluate all patients in the neurological semi-ICU who were hospitalised. Hospital Israelita Albert Einstein's neurological semi-ICU has 21 beds, accommodating an average of 130 patients per month.

Eligibility criteria

The inclusion criteria for the research were patients with a neurological reason for hospitalisation or patients with a neurological diagnosis who were hospitalised due to complications associated with the neurological condition. Patients under 18 years old, non-neurological patients, patients admitted at times incompatible with those of the researchers and patients who refused to participate in the study were excluded.

Palliative criteria

In 2011, the Advance Palliative Care Center established a consensus in order to evaluate, at the time of admission, which patients would have an indication for PC (Box 1).[19] One of the primary criteria was a question for the medical team: 'would you be surprised if the patient were to die in the next 12 months or before

Box 1 Major criteria of the palliative care centre

Primary criteria

⇒ Question: Would you be surprised if the patient were to die within 12 months or before reaching legal age?
⇒ Frequent admissions for the same condition in recent months.
⇒ Difficulty in managing physical or psychological conditions.
⇒ Need for advanced care (functional dependence; home ventilatory/antibiotic/nutritional support).
⇒ Decline in functionality (Palliative Performance Scale, Karnofsky Performance Scale, Eastern Cooperative Oncology Group), nutritional intolerance, unintentional weight loss.

From Weissman and Meier.[19]

reaching adulthood?', with a negative response being the best predictor for indication of PC.[20–22] The use of the question was used in studies on patients with cancer, in emergency services and in patients with advanced chronic kidney disease, being a useful tool to identify patients with the highest risk of mortality within 1 year. Therefore, a negative answer to the question was used as a criterion to identify neurological patients in need of PC. Given that only patients over 18 years of age were included, the second part of the question was excluded.

The second criterion used was in relation to the patient's functionality, using the Palliative Performance Scale (PPS)—based on three domains (ambulation/activity level, evidence of disease and self-care),[23] with 11 levels, ranging from 100 (normal) to 0 (death). The Karnofsky Performance Scale (KPS)[24] is based on aspects such as ability to perform daily activities, self-care, need for care and hospitalisation, with score that ranges from 100 (normal patient, without complaints or evidence of illness) to 0 (death) with 11 levels. The Eastern Cooperative Oncology Group (ECOG)[25] score was also used based on activity level and bed restriction; the score has six grades, ranging from 0 (fully active patient) to 5 (death). However, the latter was used only for analysis, and not a major criterion for indicating the need for PC. The scales were validated for use in Portuguese.[26–28] Finally, weight loss greater than 5% associated with body changes based on the impression of the patient or family members was also used as a major criterion in the study.

Characteristics of the subjects

The patients were given a questionnaire that analysed demographic factors (age, sex, ethnicity, religion, body mass index (BMI), clinical and neurological diagnoses, time of neurological diagnosis, knowledge about PC, reason for hospitalisation under PC, presence of advance directives for life, perception of health, presence of comorbidities (hypertension and diabetes), and evaluation of functionality by the PPS, KPS and ECOG). Symptom analysis was conducted using the Edmonton Symptom Assessment Scale (ESAS),[29] including weight loss, dependence on oxgen/mecanical ventilation (VM) and presence of parenteral nutrition. Additionally, the number of days the patients were hospitalised in the neurological semi-ICU and the number of days they were hospitalised in the ICU in the last year were recorded.

The patients were divided into three groups: patients with PC needs ($group_{indication}$), patients without PC needs ($group_{without\ indication}$) and patients who received at least one evaluation of a PC team ($group_{palliative}$). The criteria used to indicate PC were: the researcher's negative response to the question 'would you be surprised if the patient died within 12 months or before reaching adulthood?', PPS <70%[30–33] or weight loss >5% associated with a change in appearance noted by the patient or family members. The criterion for inclusion in the $group_{palliative}$ was that the PC team had assessed the patient at least once during hospitalisation.

Outcomes

The primary outcome was the frequency of hospitalised neurological patients with PC needs. The secondary outcome was the frequency of PC evaluation in neurological patients with PC needs. Our study evaluated the frequency of advance living directives documented in medical records.

The $group_{indication}$ and the $group_{without\ indication}$ were compared in terms of epidemiology (age, underlying diseases, demographic profile, hypertension, diabetes, obesity, time since diagnosis), ESAS, the frequency of the need for oxygen therapy, the frequency of the need for enteral/parenteral nutrition, the number of days the patients were hospitalised in the last year and the number of ICU admissions in the last year.

Statistical analysis

For the sample size, we considered the survival results, comparing survival between patients in the 'no' and 'yes' groups in the response to the question 'Would you be surprised if the patient died within 12 months?', which is considered a predictor for PC.

A sample calculation was performed using the log-rank test and HR data for the question. Assuming a power of 80%, a significance level of 5% and a 5% loss to follow-up in each group, and using the proportions found in the study (16% 'no' group and 84% 'yes' group), we were able to detect an HR of 7.787 with 32 in the $group_{indication}$, for a total sample size of 198 patients. The calculations were performed using the PASS program. For 198 individuals, if the observed rate in Moss is maintained in our study, we expect to observe 31 palliative cases, which would allow for the adjustment of a multiple logistic model with up to three explanatory variables. The collected data were attached to an Excel platform, and R Commander platform was used for statistical analysis of the data. The sample was characterised by mean, SD, minimum and maximum, median and quartiles for quantitative variables, and absolute and relative frequencies for qualitative variables.

The data were illustrated in tables and graphs. In addition, the baseline conditions of the patients were attached in groups based on whether they received PC and presence or absence of indication of PC.

The demographic and clinical characteristics were compared between groups using the X^2 test and non-parametric Kruskal-Wallis test. Normality of the data was assessed using the Shapiro-Wilk test, box plots, histograms and quantile–quantile plots. A p value of <0.05 was considered statistically significant in the statistical analysis.

The analyses were performed using SPSS, V.24.0 (IBM Corp, 2016) and a significance level of 5% was

adopted. In case of missing data, the researchers tried to access the data through the electronic medical record; in case of the absence of data, they were excluded from the analysis.

RESULTS

Throughout the study, 247 neurological patients were admitted to the semi-ICU, with 198 patients included, corresponding to 80% of the sample. The study had 5 refusals and 42 patients were not included due to incompatibility of the admission date with the researchers' collection schedule. Data on 10 patients had been collected through call/medical record with missing data regarding weight, race, symptoms on the ESAS and health perception.

Of the 198 patients in the study, 115 met the criteria for $group_{indication}$, corresponding to 58% of the sample. 88 patients had a PPS <70% and 57 patients had a negative response from the researchers (30% of the sample), corresponding to 49.5% of the $group_{indication}$. Finally, 51 patients had weight loss greater than 5%, with 40 associated with a change in body appearance noted by family members (20% of the sample). Of the 197 patients included in the study, 43 patients had a PPS <40%, 70 patients had a PPS <80% and 84 patients had a PPS greater than 80%.

Regarding the ECOG scale, patients in the $group_{indication}$ had worse scores (p<0.01). 83 patients in the $group_{indication}$ had a score of 3 and 4 (41%), while only 8 had scores between 0 and 1. In $group_{without\ indication}$, 68 patients had scores between 0 and 1 (34%), and only 3 had scores between 3 and 4. Regarding the KPS, 38 patients in $group_{indication}$ had a score <40% with no patient in $group_{without\ indication}$ having a score <40% (p<0.01). Regarding score >70%, only 8 patients from $group_{indication}$ had this score and 75 patients from $group_{without\ indication}$.

68 interviewed patients had never heard of PC (34.34%), while 117 patients had heard of the medical specialty (59.09%), and 13 patients did not respond. Out of 198 patients, 8 patients had been under the care of the PC team ($group_{palliative}$), with progress in the system, corresponding to 6.9% of patients in $group_{indication}$. 11 patients had advance directives in their medical records, equivalent to 9.56% of patients in $group_{indication}$.

In $group_{palliative}$, five patients were women and three were men. The mean age of the patients in $group_{palliative}$ was 80 years. Six patients (75%) had advance life directives in the system, against only 6 of the 107 patients in the $group_{indication}$ who were not followed up, indicating 5.6% of the sample. In $group_{palliative}$, three had a diagnosis of stroke, one brain metastasis, two dementia, one Parkinson's disease and one Guillain-Barré. Eight patients (100%) in $group_{palliative}$ were using a nasogastric tube, and five patients (62.5%) needed oxygen therapy.

The care for patients in $group_{indication}$ and $group_{without\ indication}$ was compared regarding demographic factors and general characteristics. The mean age of the patients in $group_{indication}$ was 72.77 years compared with 53.59 years in the $group_{without\ indication}$. Regarding gender, 54% of patients in $group_{without\ indication}$ were men against 47% in $group_{indication}$. Of the total sample, 94% consisted of patients who declared themselves to be white. 60% of the sample had Catholicism as their religion. When evaluated in terms of gender, ethnicity, religion, the groups showed no differences, as indicated in table 1.

Regarding comorbidities, the presence of hypertension indicated a higher prevalence among patients in $group_{indication}$, with 66% of patients with hypertension being in this group (OR 1.73; 95% CI 0.97 to 3.09; p=0.059). For diabetes, 75% of patients were diabetic (OR 2.63; 95% CI 1.242 to 5.589; p=0.0099) in $group_{indication}$. The patients in $group_{indication}$ had a lower BMI compared with those in $group_{without\ indication}$, with a statistically significant difference.

In terms of neurological diagnosis, there was a higher prevalence of dementia, neurological diseases and trauma among those in $group_{indication}$, but these diagnoses also represent the most prevalent ones. 35% of the total sample (198 patients) corresponds to patients with neurovascular disease, 15% corresponds to patients with dementia, 7.5% with epilepsy, 7.5% with primary brain tumour, 11% with traumatic brain injury, 4% with neuroinfectious diseases and 20% with other pathologies, representing a diverse neurological sample.

The personal assessment of the patient's health and that of their family members was highly correlated in $group_{indication}$, indicating that family members have a good perception of the patient's condition. This highlights the importance of the patient and their family members' participation in decisions regarding the patient's care, as well as the importance of discussing end-of-life care, advance directives and patient preferences, given the good perception of the patient's condition.

Patients in $group_{indication}$ had a higher need for oxygen therapy; 24 of them required oxygen therapy (20.8%), while those in $group_{without\ indication}$ did not require it (OR 21.89; 95% CI 2.89 to 165; p=9e-6). Regarding enteral/parenteral nutrition, 45 patients in $group_{indication}$ required it, corresponding to 39.13% of the sample, while those in $group_{without\ indication}$ did not require nutritional support (OR 53.35; 95% CI 7.17 to 395; p=8.985e-11).

Patients in $group_{indication}$ had a higher rate of ICU admissions in the last year, with 66% of the patients having at least one ICU admission, compared with $group_{without\ indication}$ where 46% of patients had ICU admission (OR 2.31; 95% CI 1.28 to 4.16; p=0.0046). On average, the patients in $group_{indication}$ had 8.43 days of ICU admission compared with 1.72 days in $group_{without}$

Table 1 Comparison of demographic and epidemiological characteristics between the group with indication for palliative care and the group without indication for palliative care

Characteristic	$Group_{without\ indication}$ (83)	$Group_{indication}$ (115)	P value
Age (years)	53.59±16.65	72.77±17.20	2.64e-12*
Male sex (%)	45	55	0.31†
Diabetes (%)	13.25	28.94	9.9e-3†
Arterial hypertension (%)	37.34	50.87	0.059†
IMC	26.25±5.97	24.99±5.34	0.012*
Ethnicity (%)			
White	90.36	89.47	0.67†
Brown	2.4	0.8	
Yellow	3.6	2.6	
Black	0	0.8	
Religion (%)			
Catholic	54.2	60.52	0.56†
Evangelical	6	2.6	
Spiritualistic	7.2	3.5	
Jewish	7.2	9.6	
Atheist	10.84	7.8	
Others	9.6	11.4	
Neurological diagnoses (%)			
Neurovascular diseases	38.5	29.8	0.08†
Neurodegenerative diseases	2.4	0	
Syndrome of dementia	7.2	21.05	
Parkinson's disease	0	3.5	
Epilepsy	7.2	7	
Anoxic brain injury after cardiac arrest	0	0.8	
Primary neural cancer	6	7.8	
Brain metastasis	1.2	1.6	
Autoimmune diseases	1.2	2.5	
Neuroinfectious diseases	7.2	1.6	
Primary headaches	4.8	0.8	
Trauma	10.8	11.4	
Dysautonomia/syncope	2.4	0	
Neural surgery	2.4	0.8	
Coma/altered level of consciousness	0	0	
Performance status (%)			
Really bad	1.2	7	4.1e-4†
Bad	6	18.42	
Regular	28.91	35.96	
Good	34.9	27.19	
Really good	20.48	5.12	
Primary attending doctor specialty (%)			
Cardiologist	12.04	14.91	0.031†
Neurologist	61.44	44.73	
Geriatrician	0	5.2	
Neurosurgeon	15.66	12.28	
Oncologist	2.4	2.6	
Others	4.8	15.78	

Means and SDs are given.
*X^2 test.
†Kruskal-Wallis test.
IMC, index of body mass.

Table 2 Comparison of Edmonton Symptom Assessment Scale in the group with indication of palliative care and the group without

	$Group_{indication}$ (mean/SD)	$Group_{without\ indication}$ (mean/SD)	
	104	77	P value
Pain	2.84/3.26	2.67/3.27	0.8135
Tiredness	5.18/3.59	2.80/3.07	1.37e-5
Well-being	5.27/3.07	3.60/2.87	2.8e-4
Anxiety	4.99/3.46	4.10/3.46	0.109
Depression	5.11/3.95	2.15/2.81	3.9e-7
Shortness of breath	1.50/2.88	0.45/1.40	0.014
Nausea	1.14/2.58	1.96/3.06	0.02
Poor sleep quality	4.31/3.41	3.28/2.91	0.05
Drowsiness	5.63/3.47	3.19/3.22	8.4e-6
Lack of appetite	4.84/4.13	3.48/3.49	0.03

From Bruera *et al*.[29]
Means and SDs are given; Kruskal-Wallis test used.

$_{indication}$. When compared regarding medical admissions in the last year, both were statistically similar, but when comparing the number of days hospitalised in the last year, the patients in $group_{indication}$ had an average of 48 days of hospitalisation (95% CI 23.83 to 52.79), while those in $group_{without\ indication}$ had an average of 10.59 days of hospitalisation (p=4.71e-7).

When comparing the groups regarding symptoms (table 2), the patients in $group_{indication}$ presented with more symptoms of fatigue, less overall well-being, depression, shortness of breath, poorer quality of sleep, lack of appetite and daytime sleepiness, as indicated in table 2. The variables of pain and anxiety were not statistically significant. Meanwhile, patients in $group_{without\ indication}$ presented with more nausea.

DISCUSSION

Despite the high demand for PC in neurology, few patients receive this treatment, resulting in decreased quality of care. In our study, patients in $group_{indication}$ had more symptoms and a greater need for supportive measures. The expansion of the discussion on PC in neurology is necessary to improve the quality of care of patients with serious or potentially fatal neurological conditions.

In our study, in a semi-ICU, 58% of the patients had an indication for PC. In comparison with other studies in the field, in a retrospective observational study with 1124 patients admitted to the ICU in Santa Catarina, 40% of the patients were found to have a terminal disease.[34] In a descriptive study, researchers evaluated the demand for PC in clinical wards using the National Academy of Palliative Care's terminality criteria, finding a proportion of 33.3% of patients.[35] The higher rate of PC in our study may be due to it being in a tertiary hospital where neurological patients were concentrated, which may indicate greater severity.

Despite the broad benefit, the indication for PC is still not objective, especially when extended to neurological patients, an area that still needs further studies.[36 37] Therefore, a difficulty in our study was to determine which patients had an indication for PC in a more objective way. Among the main criteria of the PC centre, the ESAS was used to assess the symptoms of patients, showing a tendency for worsening in patients with indication for PC, demonstrating that these patients may lack specialised care in symptom control.

In the literature, symptomatology can be adopted to indicate PC in the presence of diseases with a limited prognosis. There is still no clear definition of cut-offs for symptom management. In a validation study of ESAS in Japan, for moderate to severe symptoms, the cut-off according to the receiver operating characteristic curve was 5 for four symptoms (pain, fatigue, loss of appetite, depression), 6 for two symptoms (well-being and anxiety) and 7 for drowsiness. Regarding nausea and shortness of breath, the sample size was considered insufficient for a good correlation. The sensitivity and specificity with these cut-offs were: pain (0.94/0.91), fatigue (0.89/0.79), loss of appetite (0.95/0.82), depression (0.86/0.86), well-being (0.82/0.83), anxiety (0.93/0.92) and confusion (0.86/0.88).[38] Regarding insomnia, a value above 4 was found in a study.[39] In a systematic review of studies in the oncology population, a cut-off of 7 was suggested for severe pain and fatigue, while for moderate pain and fatigue, the cut-offs were 5 and 4, respectively.[40]

In our study, $group_{indication}$ presented the cut-offs from the previous study for fatigue (adjusted mean 5.18; 95% CI 4.56 to 5.79; p=1.3e-5), depression (adjusted mean 5.11; 95% CI 4.35 to 5.86; p=3.9e-7), loss of appetite (adjusted mean 4.84; 95% CI 4.04 to 5.63, p=0.034) and insomnia (adjusted mean 4.31; 95% CI 3.65 to 4.96, p=8.4e-6), showing similarity with previous literature. These data reinforce the indication of PC in these patients and therefore the need for a specialised look at the management of these symptoms. Furthermore, the use of the ESAS for PC indication in neurological patients should also be integrated.

In a 2018 systematic review,[30] studies were grouped that evaluated the correlation of PPS with survival curve, with patients with PPS <80% showing a high probability of death within 1 year. Furthermore, the study showed a strong association, with patients with a PPS of 10% having a 3-day survival rate compared with 5–36 days in patients with a PPS of 30%. The studies[31–33] also recommended the use of the scale for defining PC patients in hospitalised care. In a study comparing survival in patients with coronavirus, a cut-off of 70% was established, with low PPS (<80%) and high PPS (80%, 90%, 100%) patients, and the score independently predicted mortality, with the low PPS group having a mean mortality rate of 2.89 (OR 2.89; 95% CI 1.42 to 5.85).[41] Thus, cut-off values were defined for indicating PC, with patients with PPS <80% and KPS <80%,[42] corresponding to an ECOG >1.[43]

In this sense, our study shows that the PPS criteria, the answer 'no' to the question and weight loss associated with body changes proved to be good indicators for PC in neurology. These patients are more symptomatic, have a higher indication for enteral/parenteral nutrition, have a greater need for oxygen therapy, have a longer hospital stay, as well as a higher need for ICU care.

The $group_{palliative}$ had only eight patients (4%) showing the low integration of the PC specialty in neurology. Despite this, the number of patients with advance life directives in $group_{palliative}$ was much higher, illustrating that even with a small sample, the integration of the PC team tends to direct treatment according to the patient's directives written in the medical record.

This study has some limitations. It has limited power for the comparison of demographic characteristics, symptoms, number of days in hospital, and diagnoses between $group_{palliative}$ and other groups. A multicentre study would be advisable to include a greater number of subjects for this comparison. Moreover, our study evaluated the panorama of PC in neurology in a reference hospital in Latin America, with the data not being extrapolated to the national scenario. However, the low integration of PC even in a reference centre indicates that the national scenario tends to be very deficient.

Despite clear evidence of the benefits of PC in neurological patients, this is still not routine practice in patients with serious neurological diseases. Understanding the prevalence of neurological diseases in a tertiary hospital is important to elevate the debate on PC in neurology, as well as integrate this specialty into the management of neurological patients.

Our study aims to improve access to PC and update the PC criteria for neurological disorders, increase access to education in neuropalliative care for all professionals, and understand the particularities and needs of this group. Therefore, we aim to add these data for the development of high-impact research such as randomised clinical trials on the topic, stimulating debate on the introduction of this specialty in Brazil.

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REFERENCES

1 Sepúlveda C, Marlin A, Yoshida T, *et al*. Palliative care: the world health organization's global perspective. *J Pain Symptom Manage* 2002;24:91–6.
2 Moens K, Higginson IJ, Harding R, *et al*. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *J Pain Symptom Manage* 2014;48:660–77.
3 Palliative care in neurology. The American Academy of neurology ethics and humanities subcommittee. *Neurology* 1996;46:870–2.
4 Laforce R. Behavioral and language variants of Frontotemporal dementia: A review of key symptoms. *Clin Neurol Neurosurg* 2013;115:2405–10. 10.1016/j.clineuro.2013.09.031 Available: http://dx.doi.org/10.1016/j.clineuro.2013.09.031
5 Clarke DM, McLeod JE, Smith GC, *et al*. A comparison of Psychosocial and physical functioning in patients with motor Neurone disease and metastatic cancer. *J Palliat Care* 2005;21:173–9.
6 Ahn S, Lee J, Chu SH, *et al*. Uncertainty and depression in people with Parkinson's disease: A cross-sectional study. *Nurs Health Sci* 2017;19:220–7.

7 Lynch SG, Kroencke DC, Denney DR. The relationship between disability and depression in multiple sclerosis: the role of uncertainty, coping, and hope. *Mult Scler* 2001;7:411–6.
8 Kroencke DC, Denney DR, Lynch SG. Depression during exacerbations in multiple sclerosis: the importance of uncertainty. *Mult Scler* 2001;7:237–42.
9 Hackett ML, Anderson CS. Predictors of depression after stroke: a systematic review of observational studies. *Stroke* 2005;36:2296–301.
10 Guerrero Lira M. Cuidados Paliativos. *ARS Med* 2018;23. 10.11565/arsmed.v23i3.1048 Available: https://173.236.243.65/index.php/MED/issue/view/23-3-1994
11 Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004;164:321–6.
12 Robinson MT, Vickrey BG, Holloway RG, *et al*. The lack of documentation of preferences in a cohort of adults who died after ischemic stroke. *Neurology* 2016;86:2056–62.
13 Hussain J, Adams D, Campbell C. End-of-life care in neurodegenerative conditions: outcomes of a specialist palliative neurology service. *Int J Palliat Nurs* 2013;19:162–9.
14 Schuh LA, Adair JC, Drogan O, *et al*. Education research: neurology Residency training in the new millennium. *Neurology* 2009;72:e15–20.
15 Creutzfeldt CJ, Gooley T, Walker M. Are neurology residents prepared to deal with dying patients *Arch Neurol* 2009;66:1427–8.
16 Buecken R, Galushko M, Golla H, *et al*. Patients feeling severely affected by multiple sclerosis: how do patients want to communicate about end-of-life issues? patient Educ Couns *Patient Educ Couns* 2012;88:318–24.
17 Kendall M, Cowey E, Mead G, *et al*. Outcomes, experiences and palliative care in major stroke: a Multicentre, mixed-method, longitudinal study. *CMAJ* 2018;190:E238–46.
18 Sady ERR, Silva L, Veiga VC, *et al*. Neuropalliative care: new perspectives of intensive care. *Rev Bras Ter Intensiva* 2021;33:146–53.
19 Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the center to advance palliative care. *J Palliat Med* 2011;14:17–23.
20 Javier AD, Figueroa R, Siew ED, *et al*. Reliability and utility of the surprise question in CKD stages 4 to 5. *Am J Kidney Dis* 2017;70:93–101.
21 Ouchi K, Jambaulikar G, George NR, *et al*. "The "surprise question" asked of emergency physicians may predict 12-month mortality among older emergency Department patients". *J Palliat Med* 2018;21:236–40.
22 Moss AH, Lunney JR, Culp S, *et al*. "Prognostic significance of the "surprise" question in cancer patients". *J Palliat Med* 2010;13:837–40.
23 Anderson F, Downing GM, Hill J, *et al*. Palliative performance scale (PPS): a new tool. *J Palliat Care* 1996;12:5–11.
24 Karnofsky A, Abelmann H, Craver F. *The use of the nitrogen mustards in the*.
25 Oken MM, Creech RH, Tormey DC, *et al*. Toxicity and response criteria of the Eastern cooperative oncology group. *Am J Clin Oncol* 1982;5:649–55.
26 Maciel MGS, de CR. A Escala de Desempenho em Cuidados Paliativos Versão 2 (EDCP V2). *Victoria Hosp* 2019;2:1–3. Available: https://victoriahospice.org/wp-content/uploads/2019/07/pps_-_portuguese_brazilian_-_sample.pdf
27 Monteiro D da R, Almeida M de A, Kruse MHL. Tradução E Adaptação transcultural do Instrumento Edmonton symptom assessment system para USO em Cuidados Paliativos. *Rev Gaúcha Enferm* 2013;34:163–71.
28 Correia FR. Tradução, Adaptação cultural E Validação Inicial no Brasil DA palliative outcome scale (POS). *Univ SÃO PAULO* 2012;146.
29 Bruera E, Kuehn N, Miller MJ, *et al*. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7:6–9.
30 Baik D, Russell D, Jordan L, *et al*. Using the palliative performance scale to estimate survival for patients at the end of life: A systematic review of the literature. *J Palliat Med* 2018;21:1651–61.
31 Harris PS, Stalam T, Ache KA, *et al*. Can Hospices predict which patients will die within six months *J Palliat Med* 2014;17:894–8.
32 Lau F, Downing M, Lesperance M, *et al*. Using the palliative performance scale to provide meaningful survival estimates. *J Pain Symptom Manage* 2009;38:134–44.
33 Lau F, Maida V, Downing M, *et al*. Use of the palliative performance scale (PPS) for end-of-life prognostication in a palliative medicine consultation service. *J Pain Symptom Manage* 2009;37:965–72.
34 Moritz RD, Machado FO, Heerdt M, *et al*. Evaluation of medical decisions at the end-of-life process. *Rev Bras Ter Intensiva* 2009;21:141–7.
35 Vieira RC, De MM, Maria L, *et al*. n.d. ENFERMARIAS DEMAND FOR PALLIATIVE CARE IN GENERAL CLINICAL WARDS A Organização Mundial de Saúde Considera os Cuidados Paliativos Como Uma Prioridade DA Política de Saúde, Recomendando a Sua Abordagem Programada E. :2017.
36 Brizzi K, Creutzfeldt CJ. Neuropalliative care: A practical guide for the neurologist. *Semin Neurol* 2018;38:569–75.
37 Creutzfeldt CJ, Kluger B, Kelly AG, *et al*. Neuropalliative care: priorities to move the field forward. *Neurology* 2018;91:217–26.
38 Yamaguchi T, Morita T, Nitto A, *et al*. Establishing cutoff points for defining symptom severity using the Edmonton symptom assessment system-revised Japanese version. *J Pain Symptom Manage* 2016;51:292–7.
39 Yennurajalingam S, Balachandran D, Pedraza Cardozo SL, *et al*. Patient-reported sleep disturbance in advanced cancer: frequency, predictors and screening performance of the Edmonton symptom assessment system sleep item. *BMJ Support Palliat Care* 2017;7:274–80.
40 Oldenmenger WH, de Raaf PJ, de Klerk C, *et al*. Cut points on 0-10 Numeric rating scales for symptoms included in the Edmonton symptom assessment scale in cancer patients: a systematic review. *J Pain Symptom Manage* 2013;45:1083–93.
41 Fiorentino M, Pentakota SR, Mosenthal AC, *et al*. The palliative performance scale predicts mortality in hospitalized patients with COVID-19. *Palliat Med* 2020;34:1228–34.
42 Sheshadri A, Cullaro G, Johansen KL, *et al*. Association of Karnofsky performance status with Waitlist mortality among older and younger adults awaiting kidney transplantation. *Clin Transplant* 2020;34:e13848.
43 Buccheri G, Ferrigno D, Tamburini M. Original paper Karnofsky and ECOG performance status scoring in lung cancer: A prospective, longitudinal study of 536 patients from a single institution. *Eur J Cancer* 1996;32A:1135–41.

Supplementary Table: Palliative Performance Scale (PPS)

%	Ambulation	Activity and evidence of disease	Self-care	Intake	Level of consciousness
100	Ambulation	Normal, no evidence of disease	Complete	Normal	Complete
90	Ambulation	Normal, some evidence of disease	Complete	Normal	Complete
80	Ambulation	With effort, some evidence of disease	Complete	Normal	Complete
70	Ambulation	Unable to work, some evidence of disease	Complete	Normal or reduced	Complete
60	Ambulation	Unable to perform hobbies, significant disease	Occasional assistance	Normal or reduced	Fully alert or with periods of confusion
50	Ambulation	Incapable of any work, extensive disease	Considerable assistance	Normal or reduced	Fully alert or with periods of confusion
40	Ambulation	Incapable of any work, extensive disease	Almost complete assistance	Normal or reduced	Fully alert or with periods of confusion
30	Ambulation	Incapable of any work, extensive disease	Complete dependence	Reduced	Fully alert or with periods of confusion
20	Ambulation	Incapable of any work, extensive disease	Complete dependence	Limited intake to spoonfuls	Fully alert or with periods of confusion
10	Ambulation	Incapable of any work, extensive disease	Complete dependence	Mouth care	Confused or comatose
0	Death	-	-	-	

Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative performance scale (PPS): a new tool. J Palliat Care. 1996;12(1):5–11.

Supplementary Table: Karnofsky Performance Scale	
100%	No signs or symptoms, no evidence of disease
90%	Minor signs and symptoms, able to perform activities with effort
80%	Major signs and symptoms, able to perform activities with effort
70%	Self-care, unable to work
60%	Occasional assistance needed, able to work
50%	Considerable assistance needed and frequent medical care
40%	Special medical care needed
30%	Extremely disabled, requires hospitalization but not dying
20%	Very sick, requires support
10%	Dying, imminent death

Karnofsky, Abelmann, Craver & Burchenal, 1948.

Supplementary Table: ECOG - PS (Eastern Cooperative Oncology Group Performance Status Scale)	
0	Normal activity
1	Symptoms of illness, but able to ambulate and perform activities normally
2	Out of bed more than 50% of the time
3	Bedridden more than 50% of the time, in need of palliative care
4	Bedridden

Oken MM, Creech RH, Tormey DC, Horton J, Davis TE, McFadden ET, Carbone PP. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol.* 1982 Dec;5(6):649-655. PMID: 7165009

Supplementary Table: Edmonton Symptom Assessment Scale

Date:	Filled by:										
	0	1	2	3	4	5	6	7	8	9	10
Pain	○	○	○	○	○	○	○	○	○	○	○
Fatigue	○	○	○	○	○	○	○	○	○	○	○
Nausea	○	○	○	○	○	○	○	○	○	○	○
Depression	○	○	○	○	○	○	○	○	○	○	○
Anxiety	○	○	○	○	○	○	○	○	○	○	○
Drowsiness	○	○	○	○	○	○	○	○	○	○	○
Appetite	○	○	○	○	○	○	○	○	○	○	○
Shortness of breath	○	○	○	○	○	○	○	○	○	○	○
Sense of well-being	○	○	○	○	○	○	○	○	○	○	○
0 - no symptoms / 10 - worst possible symptoms											

Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care. 1991;7(2):6–9.