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Epidemiological profile and clinical stage of patients in palliative care at a university hospital

Perfil epidemiológico e desfecho clínico de óbito de pacientes em cuidados paliativos num hospital universitário

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ABSTRACT

Introduction: Palliative Care aims to promote the quality of life of patients and their families in the face of illnesses that threaten the continuity of life. It is the responsibility of the multidisciplinary team, in the case of incurable and/or terminal illnesses, to offer all available palliative care without undertaking unnecessary diagnostic or therapeutic actions. Therefore, understanding the epidemiological profile of these patients and the correct therapeutic management becomes urgent.

Objective: To analyze the epidemiological profile, clinical outcome and the profile of resident doctors responsible for the care of patients in palliative care admitted to the University Hospital of Aracaju/SE.

Method: Longitudinal study lasting one year, in which medical records were analyzed and questionnaires were applied to evaluate patients and the resident doctors who were responsible for their care.

Result: 40 patients and 17 resident doctors were studied. Significance was observed for the presence of neoplasia with metastasis (p=0.02), use of antiemetics (p=0.0003) and the indication of full palliative care (0.08). Most patients had a Charlson Comorbidity Index > 5, Eastern Cooperative Oncology Group Performance Status ≥ 3, Karnofsky Performance Status < 70% and Palliative Performance Scale ≤ 50%; both showed a certain tendency towards association, which could possibly be resolved with a larger sample "n". Around 17.64% of resident doctors reported insufficient teaching on palliative care during their undergraduate studies, while 29.41% reported the same insufficiency during medical residency. Despite this, 85.71% of the answers to the surprise question were compatible with reality. The majority of the patients (75%) died during the one-year research.

Conclusion: The large percentage of patient deaths and correct answers to the surprise question may signal a late indication for palliative care in HU-Aju, probably due to the mistaken understanding that palliative care is a therapeutic approach necessary only in the terminality and end-of-life process.

Keywords: Palliative Care, Epidemiological Profile; Public health.

RESUMO

Introdução: *Os cuidados paliativos visam a uma abordagem em prol da promoção da qualidade de vida de pacientes e de seus familiares perante doenças que ameaçam a continuidade da vida. É de responsabilidade da equipe multidisciplinar, em caso de doenças incuráveis e/ou terminais, oferecer todos os cuidados paliativos disponíveis sem empreender ações diagnósticas ou terapêuticas desnecessárias. Assim, compreender o perfil epidemiológico desses pacientes e o correto manejo terapêutico se torna urgente.*

Objetivo: *Este estudo teve como objetivo analisar o perfil epidemiológico, o desfecho clínico e o perfil dos médicos residentes responsáveis pelos cuidados destinados aos pacientes em cuidados paliativos internados no Hospital Universitário de Aracaju (HU-Aju), em Sergipe.*

Método: *Trata-se de um estudo longitudinal com duração de um ano, em que se realizaram a análise de prontuários e a aplicação de questionários para a avaliação de pacientes e dos médicos residentes que estiveram responsáveis pelos seus cuidados.*

Resultado: *Foram estudados 40 pacientes e 17 médicos residentes. Houve significância para a presença de neoplasia com metástase (p = 0,02), o uso de antieméticos (p = 0,0003) e a indicação de cuidados paliativos plenos (p = 0,08). A maioria dos pacientes obteve Índice de Comorbidades de Charlson > 5, Performance Status do Eastern Cooperative Oncology Group ≥ 3, Karnofsky Performance Status < 70% e Palliative Performance Scale ≤ 50%, e todos apresentaram certa tendência à associação, o que poderia possivelmente ser resolvido com um "n" amostral maior. Cerca de 17,64% dos médicos residentes referiram ensino insuficiente de cuidado paliativo durante a graduação, enquanto 29,41% referiram a mesma insuficiência durante a residência médica. Apesar disso, 85,71% das respostas à pergunta-surpresa foram compatíveis com a realidade. A maioria dos pacientes (75%) evoluiu a óbito durante um ano de pesquisa.*

Conclusão: *O grande percentual de óbitos de pacientes e de acertos à pergunta-surpresa pode sinalizar uma indicação tardia dos cuidados paliativos no HU-Aju, provavelmente pelo entendimento equivocado de estes serem uma abordagem terapêutica necessária apenas no processo de terminalidade e fim de vida.*

Palavras-chave: *Cuidados Paliativos; Perfil Epidemiológico; Saúde Pública.*

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INTRODUCTION

According to definitions of the World Health Organization (WHO), the Palliative Care approach is related to the promotion of the quality of life of patients and their families in the face of diseases that threaten the continuity of life, both through prevention and relief of suffering. For this purpose, it is essential to identify pain at an early stage, assess and treat pain impeccably, as well as other physical, psychosocial and spiritual problems[1].

In the same sense, the Code of Medical Ethics reinforces the physician's responsibility to offer, in cases of incurable and terminal diseases, all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, in order to take into account the patient's expressed will[2]. Thus, clinical actions must be considered together with the team that assists and cares for the patient integrally aiming to maintain health in all spheres.

According to the WHO, all patients with severe, progressive and incurable diseases that threaten the continuity of life should receive the palliative care approach from the moment of their diagnosis[1]. As a result, some recommendation criteria[3] are established for the palliative approach, namely:

1. Patient not a candidate for curative therapy;
2. Patient has a severe illness and prefers not to be submitted to life-prolonging treatment;
3. Unacceptable level of pain for more than 24 hours;
4. Uncontrolled symptoms;
5. Uncontrolled psychosocial and/or spiritual suffering;
6. Frequent visits to emergency care;
7. More than one hospital admission for the same diagnosis in the last 30 days;
8. Prolonged ICU stay and/or no evidence of improvement;
9. Guarded prognosis documented by the medical team.

It is important to highlight that the palliative approach does not exclude curative treatment in any way, nor vice versa. Thus, in the same way as at the beginning of the diagnosis, actions aimed at modifying the disease are usually a priority, as the life-threatening disease progresses, curative treatment loses space and palliative care increases in effectiveness, reaching a level of absolute necessity when the disease reaches the incurable phase[4].

In addition, these competencies, when included early, provide not only an improvement in quality of life, but also an important economic impact and, precisely for this reason, the WHO recommends that national palliative care policies be promoted, aiming to fully strengthen the health system at all levels[5].

Despite this, it is known how difficult it is to correctly implement palliative care in the health system, both because of the lack of knowledge of the topic by patients and their families, and because of health professionals' inadequate training, resulting from a sometimes scarce professional training, which culminates in the view of death as a technical failure. instead of a possible and natural episode, which substantially compromises the care of terminally-ill patients[6].

Moreover, the effective implementation of palliative care places quality of life as a priority in the health-illness process, emerging as a form of health care humanization[3]. In this context, the use of unnecessary therapeutic measures that aim only at prolonging life is not justified – usually also accompanied by the prolongation of the patient's suffering.

Therefore, the present study aimed to analyze the epidemiological profile and therapeutic management of patients in palliative care admitted in the wards of the Hospital Universitário de Aracaju (HU-Aju), aiming to understand the quality of this care and improve its understanding and application in this hospital. Based on the analyzed data, the aim is to enable the improvement of palliative care and the better training of medical students, resident physicians and the entire interdisciplinary team of the HU-Aju.

METHOD

The present study consisted of a longitudinal analysis lasting one year, from January to December 2023, carried out in the city of Aracaju, state of Sergipe, Brazil. At Hu-Aju, patients in palliative care are monitored through outpatient clinics and, when necessary, are admitted to the specific wards of their underlying comorbidity: 1) Pulmonology; 2) Infectious diseases; 3) Onco-Hematology; 4) Internal Medicine; and 5) Surgical Clinic. In all these wards, there is a multidisciplinary team involved, consisting of physicians (day laborers, on-call physicians and residents), medical students, nurses, nursing technicians, nutritionists, physical therapists, speech therapists, dentists, psychologists and social workers. The service is part of Universidade Federal de Sergipe and is part of the Unified Health System network and is, therefore, fully public.

The process of recruiting the participants was carried out through the daily investigation of patients over 18 years of age, hospitalized in the wards of the HU-Aju and who had an indication for palliative care – comprising group 1 – and the resident physicians responsible for their care – comprising group 2. Data were collected through interviews with both groups and analysis of medical records.

All participants or their legal guardians were approached about their interest in participating in the research and, when they agreed, they signed the Informed

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Consent Form. The project was submitted to and approved by the Ethics Committee for Research involving Human Beings of Universidade Federal de Sergipe.

The data obtained were stored in a database, which allowed the anonymization of the data by replacing the name with a number during the analysis. The Student's t-test was used as the statistical test, and the values of $p < 0.05$ were considered significant.

Group 1 was analyzed in relation to the epidemiological profile, including the analysis of age, religious belief, gender, sexuality, marital status, number of children, level of education, underlying comorbidities, ward in which they are admitted, degree of palliative care under management and how this indication was made. From the review of the patient's medical record, the therapeutic management was also analyzed, in addition to evaluating the functional capacities considering validated palliative care scales, namely: 1) Karnofsky Performance Status (KPS), a tool that objectively documents the patients' clinical decline; 2) Palliative Performance Scale (PPS), a scale that includes the assessment of ambulation, disease activity, self-care, food intake and level of consciousness; 3) Performance Status of the Eastern Cooperative Oncology Group (PS-ECOG), an instrument that is more simplified and easier to apply, in addition to being routinely applied in the wards of the HU-Aju; 4) Edmonton Symptom Assessment System (ESAS), useful in stratifying symptom intensity; 5) Charlson Comorbidity Index (CHF), as it is an important predictor of short-term mortality; and 6) Supportive and Palliative Care Indicators Tool (SPICT-BR™), an excellent tool used to indicate patients who deserve this type of care.

Concomitantly, group 2 was studied in terms of age, gender, years since graduation, current specialty (medical residency) and years since the beginning of this postgraduate course. The teaching of palliative care in relation to the undergraduate course and medical residency was questioned, in addition to investigating the intentions of each one about complementing (or not) their training with specialization courses. In addition, the surprise question was asked, that is: whether the resident physician would be surprised if the respective patient assisted by them died in one year, and consequently the answers were analyzed in the face of what really happened.

RESULT

Forty patients were considered eligible for the present study, with a mean age of 60.7 years. About 47.5% of the participants were female and 52.5% were male. The vast majority of the sample considers themselves to be heterosexual (97.5%) – only 01 participant reported being homosexual (2.5%) and there were no reports of other sexual orientations. The most common religious belief was Catholicism (65%), followed by evangelical religion (27.5%). Regarding the number of children, 24 participants (60%) had three or more children. Most of the sample was single (40%). Regarding the level of schooling, most of the sample fell into "incomplete elementary school" (55%).

Considering the underlying comorbidity, neoplasm with metastasis was the most common disease among the group of hospitalized participants (67.5%), with an association with the death outcome within 01 year after hospital admission (p=0.02), while neoplasm without metastasis was present in 20% of the sample (Table 1). A minority of the participants (27.5%) were diagnosed with some psychiatric disorder, especially anxiety disorders (12.5%) and depressive disorders (10%).

Among the medications used during hospitalization, the most commonly used, in decreasing order of frequency, were: opioid analgesics (92.5%), non-opioid analgesics (87.5%), proton-pump inhibitors (72.5%), antiemetics (70%), antibiotics (60%) and laxatives (40%). In this study, the use of antiemetics (n=28) was associated with the clinical outcome of death (p=0.0003) (Table 2).

Regarding the assessment of comorbidities according to the Charlson Comorbidity Index, the majority (65%) of the participants had a score above 5 (p=0.19), which is associated with higher mortality rates. In relation to the Karnofsky Performance Status, the vast majority of participants (90%) showed a result lower than 70% (p=0.22), commonly associated with the early indication of palliative care. In *the* Performance Status scale of the Eastern Cooperative Oncology Group, it was evidenced that the majority (82.5%) of the participants showed a result greater than or equal to "3" (p=0.14), which correlates to patients who are more dependent on others for

Table 1. Distribution of patients according to baseline comorbidity.

Baseline comorbidity	Frequency	%	p
Neoplasm with metastasis *	27	67.5	0.02
Systemic arterial hypertension	11	27.5	
Neoplasm without metastasis	08	20.0	
Diabetes mellitus	07	17.5	
Smoking	06	15.0	
Stroke/cerebrovascular disease	03	7.5	
Alcoholism	02	5.0	
Chronic kidney disease	02	5.0	

Source: prepared by the author.
*p<0.05 Pearson's chi-square test.

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basic self-care. Considering the Palliative Performance Scale, it was evidenced that the majority of the sample (87.5%) showed values equal to or less than 50% (p=0.14), a value also related to loss of functionality. Despite the reduced performance status assessed by these scales, in this sample none of them showed an association with the clinical outcome of death; however, all of them showed a certain tendency towards significance, which could be possibly resolved with a larger sample.

By analyzing the symptoms through the Edmonton Symptom Assessment System, 13 participants (32.5%) were not able to effectively answer about their symptoms during the interview due to disorientation and incommunicability. Among those who answered, it was observed that the most objective symptoms – pain, fatigue, drowsiness, nausea and appetite – scored higher values than the more subjective symptoms – depression, anxiety and well-being.

Regarding the assessment tool 'Supportive and Palliative Care Indicators Tool', it was found that 100% of the sample had at least two general indicators of clinical deterioration, with 80% of the participants having a history of unscheduled hospital admissions, 97.5% had poor or declining functional capacity with limited reversibility, 92.5% depended on others for their personal care – these caregivers were usually offspring or other close relatives –, 55% had significant weight loss in the last 3 to 6 months and/or a low body mass index, 90% had persistent symptoms despite optimal treatment, and 15% of patients or their families requested palliative care, interruption or limitation of treatment, or focus on quality of life. In the evaluation of specific severity indicators, about 39 participants (97.5%) showed the presence of at least 01 indicator. Thus, using the tool SPICT-BR,™ palliative care was indicated in 97.5% of the patients, with a significant association with the clinical outcome of death (p = 0.01) (Table 3).

When assessing the level of care by the attending medical team, 50% of the participants received Palliative Support, while 50% received full/exclusive palliative care. Significance was observed between the level of exclusive palliative care and the clinical outcome of death (p=0.008) (Table 4). Among the 40 eligible participants, 75% died during the one-year evaluation.

The present study had the participation of 17 resident physicians from the HU-Aju, with a mean age of 27.7 years. Most had obtained their medical degree less than 03 years before (88.23%), in the first year of post-graduation, that is: medical residency (76.47%); and in the internal medicine specialty (76.47%). None of the patients included, and consequently none of the resident physicians responsible for their care, came from the surgical clinic wards of the HU-Aju.

When asked about learning palliative care during graduation, 17.64% of the resident physicians reported having sufficient training, while during medical residency this number rose to 29.41%. Regarding the specialization or postgraduate course in palliative care, only 11.76% stated that they had attended or were attending it, while the majority (88.23%) stated they had not had any specific training on the subject.

When asked the surprise question, there was only one "yes" answer per resident physician for all 40 patients analyzed (2.5%) - that is: only one physician reported that he would be surprised if the patient he assisted died within 01 year. Of the

Table 2. Distribution of patients according to the used drugs.

Medications used during hospitalization	Frequency	%	p
Opioid analgesics	37	92.5	
Non-opioid analgesics	35	87.5	
Proton-pump inhibitors	29	72.5	
Antiemetics*	28	70.0	0.0003
Antibiotics	24	60.0	
Laxatives	16	40.0	
Corticosteroids	14	35.0	
Antihypertensives	12	30.0	
Anticonvulsants	12	30.0	
Tricyclic antidepressants	12	30.0	

Source: prepared by the author.
*p<0.05 Pearson's chi-square test.

Table 3. Distribution of patients evaluated by SPICT-BR.™

SPICT-BR™ Assessment Tool	Score	Frequency	%	p
Number of general indicators of clinical deterioration				
	0 - 1	00	0.0	
	≥ 2	40	100.0	
Number of specific severity indicators *				
	0	01	2.5	
	≥ 1	39	97.5	0.01

Source: prepared by the author.
*p<0.05 Pearson's chi-square test.

Table 4. Distribution of patients according to the level of palliative care.

Level of palliative care of inpatients	Frequency	%	p
Full/exclusive palliative care *	20	50.0	0.008
Palliative support	20	50.0	

Source: prepared by the author.
*p<0.05 Pearson's chi-square test.

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39 patients of whom the resident physicians in charge reported they would not be surprised if there was a death within 01 year, 30 actually died within 01 year (Table 5).

The vast majority of the participating patients (92.5%) had an indication for palliative care based on a decision by the attending medical team in which the resident physicians worked, while the rest (7.5%) was indicated by request for interconsultation. None of the patients were referred at the request of the patient themselves or their family member.

Table 5. Distribution of patients according to the association between death and the response of resident physicians to the surprise question.

Association between death and surprise question	Frequency	%
Surprise question "no" in case of death	30	85.7
Surprise question "no" in case of non-death	05	14.2

Source: prepared by the author.

DISCUSSION

In the scientific literature, there is a certain variation regarding the epidemiological profile of patients in palliative care hospitalized in a hospital unit. The present article found a higher frequency of males and chronic non-communicable diseases, similar to that found in a retrospective cohort study, which included the analysis of 572 admissions of critically-ill patients[7]. In addition, although the hospital in this study is a public one, the higher frequency of elderly patients, with multiple comorbidities and with total dependence for activities of daily living are also characteristics found in a quantitative descriptive study that analyzes the epidemiological profile of patients in a private hospital[8].

Regarding the evaluation of therapeutic management, it is expected that the most routinely prescribed drugs in a sample of patients under palliative approach will be symptomatic ones, especially analgesics. This information is corroborated in this study, considering the presence of opioid analgesics in the prescriptions of 92.5% of the patients, and was higher than that found in the analysis by Simone et al., who analyzed a sample of 399 cancer patients hospitalized at a Palliative Care Reference Center in Brazil and found good pain control[9].

Although the efficacy of palliative care in the approach to patients and their families has already been attested, in addition to the efficiency in providing care, access to the palliative care approach remains limited, both in Brazil and worldwide[10]. And, although in recent decades there has been an exponential increase in the number of medical schools, medical residencies that incorporate palliative care into their programs vary drastically in terms of the degree and manner of implementation[11]. Concomitantly, medical team members still have insufficient knowledge about palliative care and should pay close attention to their knowledge, attitude, and behavior in relation to this form of approach[12]. Moreover, the focus on the professional relationship between physician and patient has shifted from physician paternalism to shared decision-making, although widespread discomfort regarding discussions about terminality and palliative approach remains[12, 13].

Regarding this aspect, despite the advance in patient autonomy, the importance of developing communication skills, person-centered medicine and reflection on bioethical aspects is perceived, both for physicians and medical students, as reported by a systematic review that analyzed 22 articles on medical teaching of palliative care[14]. In the present study, the resident physicians' lack of confidence was notable when asked about learning palliative care during medical education, when only 17.64% reported having had sufficient training during the undergraduate course and only 29.41% reported having had sufficient training during medical residency.

It is questionable, therefore, whether medical education in the country is efficiently contemplating the palliative approach. It is already known that, although most medical schools offer some formal teaching on this approach, there is considerable evidence that the current training is still inadequate[15,16]. It is plausible, therefore, to analyze that the lack of interest of the resident physicians participating in this research in specialization or postgraduate courses in the area (88.23%) may be linked precisely to the inefficient and unattractive training in the palliative approach and the absence of encouragement to perform such practice.

In an editorial published in the important Journal of Palliative Medicine, it is lamented that the link between palliative care and end-of-life care is a marked impediment to the adoption of the basic knowledge of this service[17]. When analyzed in relation to this study sample, this fact may be directly related to the large number of deaths in 01 year of research (75%), which may signal a late indication of palliative care, precisely because of the mistaken understanding that it is a therapeutic approach necessary only in the process of terminality/end of life and not in the entire process of illness from a life-threatening disease.

In a meta-analysis carried out in 2017, it was observed that, when applying PS, physicians are better at predicting death within 12 months (sensitivity of 73% and specificity of 74%) compared to nurses (sensitivity of 45% and specificity of 82%)[18]. Another interesting piece of information points to the fact that the greater the specialization in internal medicine, the greater the

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ability to get a right answer when asked the surprise question. This can be considered due to the fact that its association with clinical parameters allows achieving more accurate and objective results in establishing the disease prognosis[19].

However, despite this insufficiency, a high percentage of correct answers was observed related to the patients' prognosis. The scientific literature indicates that the greater the medical specialization, the greater the ability to get the right answer to the surprise question, given that such evaluation is not subjective and includes specific clinical parameters. Thus, it would be expected that the resident physicians participating in this study would not have the answer to the surprise question compatible with the patient's clinical outcome, mainly due to the fact that most of them had graduated less than three years before and were in the first year of specialization. However, there is a positive association between the clinical outcome of death and the resident physicians' answer, with a number of correct answers of 87.5%.

This difference in reality in relation to the literature may indicate that the indication of palliative care in the HU-Aju service is made in such late phases of disease progression that it would be difficult to find incompatibility of the responses with the outcome of the studied patient, since the clinical outcome of death would be a more expected and probable event. This may also be suggested by the high percentage of patients who actually died in 01 year of research. All of this culminates in a great possibility that there is still an inadequate understanding that palliative care is a therapeutic approach that is only necessary in the process of terminality and end of life.

Another fact to be pointed out is the absence of patients – and their respective residents – from the surgical clinic wards of the HU-Aju, which may correspond to an important gap in the content of palliative care in the training of residents in the surgical areas of this hospital, given that most of the indications (92.5%) for this service were made precisely through the decision of the attending medical team, in which resident physicians are included.

The study has several strengths, such as the use of a longitudinal approach that allowed the detailed follow-up of patients in palliative care and medical residents over the course of one year, offering a comprehensive and temporal view of the care processes. The inclusion of a multidisciplinary team and the collection of data through interviews and analysis of medical records also constitute strengths, allowing a rich understanding of the clinical and social aspects of care.

However, some weaknesses may include possible biases related to the sample restricted to a single hospital and with a reduced sample size, which may limit the generalization of the results to other regions or realities of the SUS. Additionally, the use of validated scales, although robust, may be subject to variable interpretations among evaluators, and recruitment based on hospital admission may have excluded patients in hospice care at home or in other units.

CONCLUSION

The participants in group I of the study were mostly elderly, male, heterosexual, with incomplete elementary education, single marital status, had Catholic religious belief, and had three or more children. The clinical characteristics most often found in the analyzed sample were: presence of neoplasm with metastasis, systemic arterial hypertension, neoplasm without metastasis and type 2 Diabetes Mellitus, high score on the Charlson Comorbidities Index and the Performance Status of the Eastern Cooperative Oncology Group, in addition to Karnofsky Performance Status < 70% and Palliative Performance Scale ≤ 50%. Palliative care was present sometimes as palliative support, and sometimes as full palliative care. Most patients died within one year of the study.

The resident physicians participating in group II of the study were mostly young, female, with at least three years of medical training, in the first year of medical residency and in the Internal Medicine specialty. Most resident physicians reported having had insufficient palliative care training during their undergraduate and residency courses. Most physicians stated they did not have any specific training in palliative care and most also stated that they had no desire to complement their training in the area. Most of the answers to the surprise question achieved an answer that was compatible with the clinical outcome of death in 01 year.

AUTHORS' CONTRIBUTIONS

Sarah Souza Marques was responsible for the bibliographic review, data collection, statistical analysis and writing of the manuscript.

Rivia Siqueira Amorim responsible for the conception and design of the study and for the critical and final review of the article.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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