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Health status of patients under palliative care attended by a multiprofessional home care team: an epidemiological analysis

Estado de saúde de pacientes em cuidados paliativos atendidos por equipe multiprofissional de atenção domiciliar: uma análise epidemiológica

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Abstract

Introduction: Palliative care comprises a set of measures aimed at improving the quality of life of patients and family members who are faced with issues related to a disease that threatens the continuity of life. This care encompasses the prevention and relief of suffering, made possible through early identification, efficient assessment, and treatment of pain, as well as attention to other physical, psychological, and spiritual symptoms. **Objectives:** To identify the health status and actions of patients under palliative care assisted by a multidisciplinary home care team (MHCT). **Materials and Methods:** Retrospective research through the analysis of medical records of patients in palliative care assisted by an MHCT in Ceara, Brazil, between January and June 2022, to identify the epidemiological profile and compare the variables analyzed between sexes. **Results:** In total, 52 participants were included, 21 female and 31 male, with median ages of 80 and 73 years, respectively, without differences between the two groups. The majority of patients were classified as complementary palliation in both the male (64.5%) and female (61.9%) groups. There were no differences between the two groups when comparing the stratification of palliative care ($p=0.38$) and monthly income ($p=0.98$). There was a higher percentage of the presence of a partner in the group of men (74.2%; $p= 0.03$). Concerning comorbidities, there was a higher percentage of hypertensive women ($p=0.02$), without differences for other comorbidities. **Conclusion:** The data presented in this study highlight the importance of the multidisciplinary home care team in attending patients in palliative care.

Keywords: Integrative palliative care. Patient care team. Home care

Resumo

Introdução: Os cuidados paliativos compreendem um conjunto de medidas que visam melhorar a qualidade de vida dos doentes e familiares que se deparam com questões relacionadas com uma doença que ameaça a continuidade da vida. Esse cuidado abrange a prevenção e o alívio do sofrimento, possibilitados pela identificação precoce, avaliação eficiente e tratamento da dor, além da atenção a outros sintomas físicos, psicológicos e espirituais. Objetivos: Identificar o estado de saúde e as ações de pacientes em cuidados paliativos atendidos por uma equipe multiprofissional de atenção domiciliar (MHCT). Materiais e Métodos: Pesquisa retrospectiva por meio da análise de prontuários de pacientes em cuidados paliativos atendidos por um MHCT no Ceará, Brasil, entre janeiro e junho de 2022, para identificar o perfil epidemiológico e comparar as variáveis analisadas entre os sexos. Resultados: No total, foram incluídos 52 participantes, 21 do sexo feminino e 31 do sexo masculino, com idade mediana de 80 e 73 anos, respetivamente, sem diferenças entre os dois grupos. A maioria dos pacientes foi classificada como paliação complementar tanto no grupo masculino (64,5%) quanto no feminino (61,9%). Não houve diferenças entre os dois grupos ao comparar a estratificação dos cuidados paliativos ($p=0,38$) e renda mensal ($p=0,98$). Houve maior percentual de presença de companheira no grupo de homens (74,2%; $p= 0,03$). Em relação às comorbidades, houve maior percentual de hipertensas ($p=0,02$), sem diferenças para as demais comorbidades. Conclusão: Os dados apresentados neste estudo destacam a importância da equipe multiprofissional de assistência domiciliar no atendimento a pacientes em cuidados paliativos.

Palavras-chave: Cuidados paliativos integrativos. Equipe de assistência ao paciente. Visitadores domiciliares.

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Introduction

Palliative care is based on principles that aim to counter the idea that “there is nothing more we can do”, that is, to promote better quality of life for patients in a state of health that makes it impossible to modify the disease, as well as giving importance to spirituality. These principles are made up of an interdisciplinary set of techniques and knowledge from the most diverse areas, resulting in nine principles, namely:[1,2]

1. Promote the relief of pain and other symptoms through pharmacological and non-pharmacological approaches, in addition to psychosocial aspects;[2]

2. Affirm life and consider death as a normal process of life, bringing death to light as an object of discussion and elucidation; [2]

3. Do not anticipate or postpone death, but monitor the patient and the natural history of the disease, considering the techniques that can be used; [2]

4. Integrate psychological and spiritual aspects into patient care to help them deal with the losses that occur in the illness process; [2]

5. Offer a support system that allows the patient to live as actively as possible until the moment of death; [2]

6. Offer a support system to help family members during the patient's illness and in coping with grief, considering that the human being's identity cell is the family (biological and acquired); [2]

7. Include a multidisciplinary approach focused on the needs of the patient and their family, including grief monitoring, taking into account the polymorphism of the health-disease process; [2]

8. Improve quality of life and positively influence the course of the disease through a holistic approach; [2]

9. Care should be initiated as early as possible, along with other life-prolonging measures, including all necessary investigations to better understand and manage stressful clinical situations. [2]

Therefore, palliative care is not a protocol, but a set of principles that guide medical interventions, always aiming to improve the patient's quality of life, guaranteeing active survival when possible, and weighing the cost-benefit within the natural history of the disease. Palliative care requires a multidisciplinary team, since the disease profile of the Brazilian population is multifactorial, with a predominance of chronic diseases. The presence of a multidisciplinary team covers not only the basic needs of the patient, but also the family unit itself.[2,3]

In this sense, the Home Care Service (HCS) is a type of health care that complements or replaces existing services, characterized as a set of health promotion, disease prevention, and treatment and rehabilitation actions at home, with guarantee of continuity of care and integrated into the health care network.[3,4]

From this perspective, home care can be considered a practice that concerns the very existence of the family as a unit of social organization. There are several situations of dependency that are chronically assumed by families, which were not included in the health actions organized by the health system.[5,6]

The HCS should be organized into three modalities, defined based on the patient's characterization, type of care, and procedures used to care for them. Namely, these modalities are classified as:[7]

1) HCS1: intended for users with controlled/compensated health problems and who have physical difficulties or are unable to travel to a health unit, who require less frequent care, and who have less need for health resources. Providing assistance in this modality is the responsibility of primary care teams, including teams from the Family Health Strategy and Family Health Support Centers (NASF), through regular home visits, at least once a month;[7]

2) HCS2: Intended for users with health problems and difficulty or physical impossibility of traveling to a health unit and who require more frequent care, health resources, and continuous monitoring, which can come from different services in the health care network. The provision of healthcare in this modality is the responsibility of a multidisciplinary home care team (EMCD) and a multidisciplinary support team (EMA);[7]

3) HCS3: This modality is intended for users with health problems and physical difficulties or inability to travel to a health unit, who need more frequent care, health resources, continuous monitoring, and use of equipment, which can be from different services.[7]

The current study aims to compare male and female palliative care patients treated by an EMCD, to evaluate their habits and prevalent diseases, compare biological sexes in relation to their sociodemographic profile, and categorize patients according to the types of treatment.

Materials and Methods

Sample and type of study

This is a retrospective study, through the analysis of medical records of patients in palliative care treated by a Municipal Health Service (MHS) in Iguatu/CE. The EMCD is part of the home care service, that attends patients with a palliation profile. The choice for this health service was based on the following arguments: it is a reference for home care in the municipality, due to the diversity of comorbidities and complexity of users, and it covers the different health territories of the studied municipalities.

Inclusion and exclusion criteria

The study included patients in palliative care assisted by an EMCD, in the AD2 and AD3 modalities.

To select the sample, the following inclusive parameters were adopted: all medical records of patients in palliative care treated by an EMCD, in the AD2 and AD3 modalities, treated between the period from January to June 2022. Volunteers with incomplete medical records and patients under 18 years of age were excluded.

Data collection procedures

Data collection took place using a form prepared by the researcher, containing information from the date of the patient's initial care by the MHS, as well as age, biological sex, whether they have a partner, education, profession, income, diagnoses, functionality, stratification (early, complementary, predominant, or exclusive), comorbidities (diabetes, hypertension, neoplasms), as well as risk factors (not practicing physical activity, smoking) for Chronic Non-Communicable Diseases (NCDs).

Ethical aspects

The study was approved by the Research Ethics Committee (CEP) of UNISA (Santo Amaro University) - number 5,597,958, and followed the principles described in the Declaration of Helsinki.

Statistical analysis

SPSS version 18.0 was used for data analysis. Sample normality analysis was performed using the Kolmogorov-Smirnov test. Comparisons between groups were obtained using Pearson's chi-square test. Significance was considered p<0.05.

Results

In total, 52 participants were considered, 21 female and 31 male, with median ages of 80 and 73 years, respectively, with no differences between the two groups.

Table 1 presents the percentages of the female and male groups according to the stratification of care.

Table 1 presents the stratification of palliative care (attachment). It can be observed that in the male group the vast majority of patients were classified as complementary palliation (64.5%), followed by predominant palliation (25.8%) and exclusive palliation, which is at the end of life (9.7%). There were no male patients in early palliative care. In the female group, as in the male group, there was a higher proportion of complementary care (61.9%), followed by predominant (33.3%) and early (4.8%) care. Pearson's chi-square test showed no significant differences between female and male patients in relation to palliative care stratification (p=0.38).

Table 1. Palliative care stratification

Stratification	**Group 1, male**		**Group 2, female**	
	n	%	n	%
Early			1	4.8
Complementary	20	64.5	13	61.9
Predominant	8	25.8	7	33.3
Exclusive	3	9.7		
Total	31	100	21	100

*p=0.38, Kolmogorov-Smirnov test

The results regarding monthly income are presented in Table 2. There were no differences between the two groups.

Table 2. Monthly income

Groups		**No income**	**Up to R$ 1320.00**	**Up to R$ 2640.00**	**Total**
Female	Frequency %	1 4.76	18 85.72	2 9.52	21
Male	Frequency %	3 9.68	27 87.09	1 3.23	31

*p=0.98, Kolmogorov-Smirnov test

Table 3 presents the percentages of female and male individuals with partners.

Table 3. Presence of a partner

Biological sex	Partner			
	Yes	No	Total	% Yes
Female	9	12	21	42.9
Male	23	8	31	74.2
Total	32	20	52	61.5

*p=0.03, Pearson's chi-square test

The data point to a higher frequency/percentage of the presence of a partner in the male group (74.2%) than in the female group (42.8%), p= 0.03, which is expected to impact palliative care regarding psychological and family problems.

Table 4 presents the percentages of participants, according to the presence or absence of comorbidities or habits. A higher percentage of hypertensive women was observed (p=0.02), with no differences for other comorbidities.

Table 4. Presence or absence of comorbidities or habits

Comorbidity/habit	Group 1, male		Group 2, female		p*
	n	%	n	%	
Diabetes	10	32.2	8	38.1	0.66
Smoking	7	22.5	5	23.8	0.92
Hypertension	17	54.8	18	85.7	**0.02**
Obesity	11	35.5	8	38.1	0.59
Physical activity	29	93.5	21	100	0.23
Acute myocardial infarction	4	12.9	5	23.8	0.31
Respiratory depression	11	35.5	3	14.3	0.09
Neoplasm	3	9.7	3	14.3	0.61

* Pearson's chi-square test

Discussion

Palliative Care (PC) is a holistic approach that integrates physical, psychological, social, and spiritual aspects to prevent, identify, and treat pain and suffering associated with the health-disease process at an early stage. Epidemiologically, recent statistical surveys estimate that 48 million individuals will have a serious health condition by 2060, representing an increase of 87% in relation to the 26 million reported in 2016. These data suggest that, within the period of 44 years, the need for PC will be approximately twice as high as the current need, rising most rapidly in low-income individuals, people over 70, and those with neurological conditions.[6,8]

In view of the aforementioned, we will discuss the findings regarding the profile of age, biological sex, education, profession, income, and having or not having a partner of PC patients treated by a multidisciplinary team in the city of Iguatu-Ceará, in relation to data from the scientific literature.

The main objective of palliative care is to offer quality of life to patients who are in an advanced stage of chronic and progressive diseases, seeking symptom relief and emotional support. A multidisciplinary team of health professionals is needed, involving nurses, physiotherapists, nutritionists, among others, perform home care, which is a type of palliative care that provides patients with adequate care in the comfort of their own home. With the aging of the population associated with the increased prevalence of chronic diseases, such as cancer, and cardiovascular and neurological diseases, the demand for palliative care at home has become an increasingly relevant option in assisting patients at an advanced stage of disease.[8-10]

The clinical situation and health actions of patients under palliative care, assisted by a multidisciplinary home care team, are still little explored in the literature. It is essential to know the epidemiology of these patients, as well as the interventions carried out by the multidisciplinary team and the health outcomes achieved, in order to support clinical decision-making and improve the quality of care offered.[9,10]

One of the main advantages of home care is the possibility of offering individualized and personalized care to patients. Health professionals who work in home care have the opportunity to establish a closer and more trusting relationship with patients and their families, which allows deeper understanding of their needs and desires in relation to health care. In this way, it is possible to offer truly patient-centered care, taking into account their life history, beliefs, and preferences, and adapting the care plan according to their specific needs.[11,12]

In addition, home care also enables a more comprehensive approach by health professionals who work in home care as a team, generally made up of doctors, nurses, social workers, psychologists, and other health professionals, who collaborate in an integrated way to offer comprehensive care and multidisciplinary care to patients. This collaborative approach allows for the appropriate management of physical symptoms, such as pain, dyspnea, nausea, and vomiting, as well as emotional and psychosocial support for patients and their families, helping them to face the emotional and spiritual challenges which often accompany advanced patients or those undergoing terminal illnesses.[13,14]

Another advantage of home care as a form of palliative care is the possibility of offering more accessible and sustainable care. A hospital stay can be expensive and often uncomfortable for patients, especially those with advanced chronic conditions. Home care can offer a more viable and economical alternative, allowing patients to receive quality care in their own home, and avoiding the need for prolonged hospitalization. Additionally, home care can also be a more environmentally sustainable option, as hospitalization often involves high consumption of resources, such as energy, water and medical materials, in addition to generating hospital waste.[15,16]

Regarding the comorbidities listed by patients, chronic non-communicable diseases (NCDs) were associated with PC, without significant differences between biological sexes, as only arterial hypertension was significantly more prevalent in females. For risk factors, not practicing physical activity, which leads to a sedentary lifestyle, appears as the main factor in both sexes. Estimates from the World Health Organization (WHO) on the availability of PC for patients with chronic non-communicable diseases point to 39% of developed countries globally, with inclusion of PC in the national NCD policy of 50% and specific financing of 68%. Palliative care is generally available to patients in need of primary health care (PHC) facilities, where funding is specifically allocated, in 50% of countries, compared to 15% of countries where there is no dedicated funding for palliative care.[7,8]

There is growing evidence that palliative care is effective and cost-effective in high-, low-, and middle-income countries. For this reason, the 2014 World Health Assembly resolution called on all governments to integrate palliative care into their health plans. However, it is estimated that among people living in hospitals in high per capita income countries, only 14% of people needing palliative care receive it. Only 30 of 198 countries surveyed in 2017 presented advanced integration of palliative care services, and the development of palliative care services outside the "Global North" has been slow. Barriers to palliative care are found in low- and middle-income countries, where there is a lack of human resources (as is the case in the city of Iguatu/Ce, where MHSM is the only support service in palliative care, with a team composed of a doctor, nurse, physiotherapist, and nursing technician), financial constraints, limited political commitment, restrictive pharmacovigilance regulations, challenges in medication import processes, and fragmentation of the healthcare system.[8,17]

With regard to pathological diagnoses (underlying diseases), according to the International Classification of Diseases established in the aforementioned data, it was found that neurological disorders - cerebrovascular diseases and dementias (64.5% and 61.9%), other liver diseases and frailty syndrome (19.4% and 19%), and oncology (9.7% and 4.8%) were associated with men and women undergoing PC, respectively. Likewise, the conditions that most commonly contribute to health distress are malignant neoplasms, cerebrovascular diseases, lung diseases, and dementia, respectively. It is estimated that the conditions with the greatest contributions to severe health-related suffering between 2016 and 2060 will continue to be malignant neoplasms (7.8 million to 16.3 million), while the condition with the greatest estimated proportional increase will be dementia (1.5 million to 6 million). In low-income countries, the relative increase is expected to be greater, as the absolute burden associated with malignant neoplasms is expected to increase fivefold (300,000 to 1.6 million).[7,18]

Pathological diagnoses are an important tool for understanding the prevalence and distribution of different health conditions in different populations. Based on the aforementioned data, it was observed that neurological disorders were the most common in patients receiving palliative care, with a proportion of 64.5% for men and 61.9% for women. Other conditions were also significant, corresponding to 19.4% for men and 19% for women, while oncological diagnoses represented 9.7% for men and 4.8% for women.

Considering aspects of social and economic vulnerability, the predominance of individuals with income of up to 1 minimum wage among men (87%) and women (85.7%) is highlighted. Furthermore, the occupations reported were mainly farming among men (41.9%) and cleaning assistant among women (47.6%). In turn, according to the identification of education levels, men reported mainly having primary education (51.6%) and women were mainly illiterate (80.9%). Between the years 2016 and 2060, for low-income countries, data perspectives point to an increase in health-related suffering from 41% to 42% in lower-middle income countries, 50% to 52% in upper-middle income countries, and 51% to 53% in high-income countries. All WHO regions are likely to experience an increase in the burden of severe health-related suffering, with the largest proportional increases in the Eastern Mediterranean (170% increase) and African regions (126% increase). For the group of low-income countries, an absolute increase of 155% is estimated in the same period, reaching 3 million people in 2060.

Regarding the biopsychosocial profile, there was inclusion of PC for a wide age range (21-98 years), as well as the spectrum of biological sex, with no statistical difference between men and women. At the international level, health-related suffering is expected to increase in older age groups, especially in people in their 70s, with 22 million more older adults in 2060 than in 2016, with the increase being most pronounced in low-income countries, where rates will increase by more than 400% in the period described. On the other hand, a decrease in suffering is expected in younger age groups (0 to 4 years, 5 to 14 years, 15 to 29 years, and 30 to 49 years), except in low-income countries. Severe health-related distress among infants (0-4 years) is expected to decline in all regions.[7,18]

The epidemiological findings of PC patients treated by a multidisciplinary team show a wide spectrum of age (21-98 years) and biological sex. The relationships established for PC patients were related to previous comorbidities, such as diabetes mellitus, high blood pressure, and obesity, and a sedentary lifestyle was a relevant risk factor. Neurological and oncological disorders were pathological diagnoses associated with PC patients, in a convergent manner with international epidemiological data.[7,18]

Another relevant aspect is the need for health policies aimed at promoting palliative care, especially in countries with an aging population and a shortage of services in this area. It is essential to invest in training health professionals in palliative care, structuring specialized services and promoting health education programs for the population, aiming to raise awareness about the importance of palliative care and the prevention of risk factors.[18-20]

Another important measure is to invest in the training and qualification of health professionals in palliative care, ensuring that they are adequately prepared to offer this type of care in a comprehensive and holistic way. This includes doctors, nurses, psychologists, social workers, therapists, and other professionals who make up the palliative care team, who need to work in an interdisciplinary way to provide the best possible care to patients and their families.[19]

Conclusion

Among the results found, there was a higher frequency/percentage of partner presence in the male group compared to the female group, which is expected to impact palliative care with regard to psychological and family problems.

The epidemiological analysis of the data presented in this study highlights the importance of the multidisciplinary home care team in approaching patients in palliative care, as well as the need for integrated management of comorbidities and associated chronic conditions. Home care can be an effective strategy in promoting a comprehensive and holistic approach to palliative care, aiming to improve quality of life and reduce suffering related to the health conditions of patients and their families. It is essential that managers, health professionals, and other professionals involved in palliative care work in an integrated manner, continually seeking to improve the care offered and ensure that patients in palliative care receive the appropriate and humanized care they deserve.

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