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PALLIATIVE CARE IN HOME CARE: INDICATION FOR PALLIATION

CUIDADOS PALIATIVOS EM ATENÇÃO DOMICILIAR: INDICAÇÃO DA PALIAÇÃO

CUIDADOS PALIATIVOS EN LA ATENCIÓN DOMICILIARIA: INDICACIÓN DE PALIACIÓN

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ABSTRACT

Objective: To investigate the conditions of patients monitored by the "Programa Melhor em Casa" considering the criteria for indicating palliative care. **Method:** Cross-sectional study carried out in São Luís, Maranhão, with a sample of 71 patients. An instrument containing socioeconomic variables and the Palliative Care Screening Tool Scale was used to indicate palliation. **Results:** Most patients were female (56,34%), single (46,48%), complete primary education (43,66%), out of the workforce (36,63%), family income between 1 to 2 minimum wages (78,87%), aged between 70-86 years (32,40%). As for the underlying disease, 45,07% have stroke sequelae, 54,93% have associated diseases, cardiovascular and metabolic ones being frequent (37,90%), 59,15% need help and 69,10% have a degree of dependence 4. **Conclusion:** The palliation criteria indicated that most patients were considered eligible for Palliative Care, which contributes to the implementation of qualified interventions by the multidisciplinary team.

Descriptors: Palliative Care; Home Nursing; Chronic Disease.

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RESUMO

Objetivo: Investigar as condições dos pacientes acompanhados pelo "Programa Melhor em Casa" considerando os critérios de indicação de cuidados paliativos. **Método:** Estudo transversal realizado em São Luís, Maranhão, com amostra de 71 pacientes. Utilizou-se um instrumento contendo variáveis socioeconômicas e a Escala Palliative Care Screening Tool para indicação de paliação. **Resultados:** A maioria dos pacientes eram do sexo feminino (56,34%), solteiros (46,48%), ensino fundamental completo (43,66%), fora da força de trabalho (36,63%), renda familiar entre 1 a 2 salários mínimos (78,87%), faixa etária entre 70-86 anos (32,40%). Quanto a doença de base, 45,07% apresentam sequelas de Acidente Vascular Cerebral, 54,93% doenças associadas sendo as cardiovasculares e metabólicas frequentes (37,90%), 59,15% necessitam de ajuda e 69,10% têm grau de dependência 4. **Conclusão:** Os critérios de paliação indicaram que a maioria dos pacientes foram considerados elegíveis para os Cuidados Paliativos, o que contribui na implementação de intervenções qualificadas pela equipe multiprofissional.

Descritores: Cuidados Paliativos; Assistência Domiciliar; Doença crônica.

RESUMEN

Objetivo: Investigar las condiciones de los pacientes acompañados por el "Programa Mejor en Casa" considerando los criterios para la indicación de cuidados paliativos. **Método:** Estudio transversal realizado en São Luís, Maranhão, con una muestra de 71 pacientes. Se utilizó un instrumento que contenía variables socioeconómicas y la Palliative Care Screening Tool Scale para indicar la paliación. **Resultados:** La mayoría de los pacientes eran del sexo femenino (56,34%), solteros (46,48%), primaria completa (43,66%), fuera de la fuerza laboral (36,63 %), ingreso familiar entre 1 a 2 salarios mínimos (78,87 %), con edad entre 70 -86 años (32,40%). En cuanto a la enfermedad de base, el 45,07% tiene secuelas de ictus, el 54,93% tiene enfermedades asociadas, siendo frecuentes las cardiovasculares y metabólicas (37,90%), el 59,15% necesita ayuda y el 69,10% tiene grado de dependencia 4. **Conclusión:** Los criterios de paliación indicaron que la mayoría de los pacientes fueron considerados elegibles para Cuidados Paliativos, lo que contribuye a la implementación de intervenciones calificadas por el equipo multidisciplinario.

Descriptores: Cuidados Paliativos; Atención Domiciliaria de Salud; Enfermedad Crónica.

INTRODUCTION

Palliative Care (PC) is defined by the World Health Organization (WHO)[1] as a set of actions promoted by a multidisciplinary team with the aim of improving the quality of life of patients with no prospect of cure due to certain health conditions. PC emerged in the care of terminally ill cancer patients, but over time it was incorporated into the care of patients with other chronic non-communicable diseases (NCDs).—such as Alzheimer's, stroke, Parkinson's and others.

Over the last decade, palliative care has been expanding in Brazil, albeit incipiently. Some research on palliative care indicates the importance of disseminating this line of care, which is so necessary in view of the aging population and the epidemiological changes in the country.[2] These two phenomena of demographic transition and epidemiological transition, in developing countries such as Brazil, have led to a sharp increase in the number of elderly people and, consequently, an

increase in the number of chronic noncommunicable diseases that are responsible for generating the need for palliative care.[3]

According to the WHO, it is estimated that in Brazil there are between 521,000 and 536,000 people who require palliative care, but these patients are only eligible for such care at the end of their lives, restricting the work of specialized teams in this area.[2] Half of the palliative care services in Brazil are concentrated in the state of São Paulo, highlighting the predominance of outpatient care in the public network, with oncological and non-oncological patients, adults and the elderly.[4] Thus, the scarcity of this home care in primary health care is noticeable, even with a survey carried out in 2017 by the Kaiser Family Foundation in partnership with the newspaper The Economist indicating that death at home is preferential for patients and family members.[2]

In primary care, as studies have progressed, patients with disabling sequelae and a decline in physical functions as a result of one or more NCDs are observed to be eligible to receive palliative care.[5] NCDs lead the patient to a progressive functional decline, incapacitating the person until death. This relationship between population aging and the incidence of NCDs fosters the need to expand PC in the country, thus being a great challenge for Public Health managers in Brazil, given the levels of care.[6]

Care for patients with chronic diseases, in accordance with the theory of Palliative Care, is based on the perspective of offering well-being and comfort in the continuity of life, whether through prevention, adequate treatment and family guidance. Thus, for better care and promotion of PC, the work of a multidisciplinary team is necessary, which aims to meet the biopsychosocial and spiritual needs of the patient and their family members.[7]

Providing care to those in the final stages of life represents a major challenge for the multidisciplinary team. The nursing team stands out in this care by remaining by the patient's side, offering comprehensive care, not only through professional technique and scientific knowledge, but also through the ability to listen and understand the situation experienced by them and their families.[7]

Palliative Care, within the context of the Unified Health System (SUS), is provided at home by professionals linked to Primary Health Care (ABS) or Home Care Service (SAD), and by the caregiver. Through the ABS, this service is provided in the Basic Health Units (UBS), Family Health Strategy Teams (ESF) and in the SAD, through the Multidisciplinary Home Care Teams and Multidisciplinary Support Team. The caregiver is the person who directly provides care on a continuous or regular basis, and is most often a close

family member.In recent years, home care has been focused on patients who require palliative care. The “Better at Home Program” of the Ministry of Health established guidelines for organizing home care for this population.[8]

It is expected that this study will contribute to the improvement of public health care policies and encourage the implementation of strategies that promote a better quality of life for patients in Palliative Care and their family caregivers. In this perspective, based on home care provided by the “Better at Home Program” in palliative care for clients with advanced chronic diseases, this study aims to investigate the conditions of patients followed by the “Better at Home Program” considering the criteria for indicating palliative care.

METHOD

This is a cross-sectional study, with an approach in Palliative Care in Home Care, carried out in the city of São Luís, capital of the state of Maranhão, where health institutions direct patients in palliative care for home monitoring through the Better at Home Program (PMC).

This study complies with the ethical aspects of Resolution 466/2012 2012 of the National Health Council and was submitted to the Plataforma Brasil directed to the Research Ethics Committee (CEP), assessed and approved under no. 3,643,591 and by the Research Ethics Committee of the Federal University of Maranhão, under protocol CAAE–11424619200005087. The published data correspond to a partial analysis of a larger research entitled “Family-Centered Palliative Care”.

The study population consisted of 156 people registered in the Melhor em Casa Program, aged 18 or over, with compensated/controlled health problems classified as Noncommunicable Chronic Diseases and who consented to participate in the study or had their participation authorized by their guardian/caregiver by signing the Free and Informed Consent Form (FICF). However, only 71 people participated in the study due to data collection difficulties caused by the COVID-19 pandemic.

Among the exclusion criteria, all and any cases of patients with a need for continuous monitoring, need for continuous nursing care, need for complementary propaedeutics, with potential demand for carrying out several diagnostic procedures, in sequence, urgently; need for urgent surgical treatment; or need for use of continuous invasive mechanical ventilation were considered.

From December 2020 to February 2021, data were collected from some of the patients registered and treated by the PMC. The PMC operates in four teams based in

the Municipal Emergency Hospitals, providing multidisciplinary assistance from doctors, nurses, social workers, nursing technicians, physiotherapists, speech therapists and occupational therapists.

For data collection, a systematized instrument was used with socioeconomic and demographic data, as well as the criteria for indicating palliative care according to the Palliative Care Screening Tool – PCST – scale provided by the Center to Advance Palliative Care (TABLE 1). The instrument included variables such as age, sex, race, education, marital status, work/occupation, family income, housing conditions, number of residents, number of rooms, underlying and/or associated diseases, contact of family member and/or guardian.

The PCST scale indicates whether or not palliative care is required based on the sum of the items and is characterized as follows: up to two points, no indication of palliative care; up to three points, the patient should be kept under clinical observation; four points or more are considered an indication of palliative care. The data collection procedure was performed by telephone contact available in the patients' medical records, by interviewers who are nursing undergraduates from a public university in the state of Maranhão, duly trained and under the supervision of the supervising professor responsible for the research.

Chart 1 – Palliative Care Screening Tool (PSCT) Scale

Scale: Palliative Care Screening Tool[8]

Criterion number 1

Baseline diseases - Two points for each sub-item:

1. Cancer - metastasis or recurrences
2. Advanced chronic obstructive pulmonary disease (COPD) - repeated exacerbations
3. Cerebrovascular accident (CVA) sequela - decrease in motor function ≥ 50%
4. Severe renal failure - creatinine clearance < 10 ml/min
5. Severe heart disease - congestive heart failure (CHF) with left ventricular ejection fraction (EF) EF < 25%, myocardiopathy and significant coronary insufficiency
6. Other life-limiting diseases

Criterion number 2

Associated diseases - one point for each sub-item:
Liver disease
Moderate kidney disease - creatinine clearance < 60 ml/min
Moderate COPD - stable clinical picture
Moderate CHF - stable clinical picture
Other associated diseases - all together worth 1 point

Criterion number 3

Patient's functional condition - This criterion assesses the patient's degree of dependence, taking into account the ability to carry out normal activities of daily living, acts of personal care and the number of hours a day confined to bed or a wheelchair. Scores range from 0 (totally independent, active patient with no restrictions) to 4 (completely dependent, needs full-time help, confined to bed or wheelchair).

The sum of the sub-items will justify whether or not palliative care is indicated:
Up to two points - no indication for care
Up to three points - clinical observation
Four points or more - consider palliative care

Criterion number 4

Patient's personal conditions - one point for each sub-item:

7. Need for help with complex treatment decisions and undefined psychological or spiritual issues
8. History of recent admissions to emergency departments
9. Frequent hospitalizations due to decompensation of the underlying disease
10. Prolonged stays in Intensive Care Units (ICU) or patient already in ICU with poor prognosis

Source: Center to Advance Palliative Care. Crosswalk of JCAHO Standards and Palliative Care – Policies, procedures and assessment tools; 2007. p. 66. Available at: http://www.capc.org/supportfrom-capc/capc_publications/JCAHO-crosswalk-new.pdf.Accesson April 10, 2021.

Data analysis was performed using descriptive measures for quantitative variables and absolute and relative frequencies with the construction of a contingency table for qualitative variables. The SPSS 25.0 program was used for analysis.

RESULTS

The participants were 71 patients in palliative care with the socioeconomic characteristics described in Table 1. There was a higher percentage of females (56.34%), mixed race (47.89%), singles (46.48 %), completed elementary education (43.66%), out of the workforce (36.63%), family income between 1 and 2 minimum wages (78.87%). In the age group, the highest frequency was between 70-86 years (32.40%), with an average age of 67.20 years and a standard deviation of 20.74.

The most prevalent housing situation among patients treated by the Melhor em Casa program was own housing (88.73%), with 4 to 6 rooms predominating (67.61%). The records showed that the number of residents varies from 4 to 5 (43.66%), with an average of 4 people per residence.

Table 1- Socioeconomic and demographic characteristics of patients treated by the Melhor em Casa program. São Luís, Maranhão, Brazil, 2021.

Variables	n	%	Average	Standard deviation
Age			67.20	20.74
18-35	6	8.45		
36-52	11	15.49		
53-69	18	25.35		
70-86	23	32.40		
87 or more	13	18.31		
Gender				
Female	40	56.34		
Male	31	43.66		
Race/Color				
White	24	33.80		
Black	13	18.31		
Brown	34	47.89		
Education				
No schooling	18	25.35		
Elementary education	31	43.66		
High school	20	28.17		
In superior	2	2.82		
Marital status				
Single	33	46.48		
Married	17	23.94		
Divorced	4	5.63		
Widower	17	23.94		
Occupation				
Out of the workforce	26	36.63		
Own account	13	18.31		
Employee with card	13	18.31		
Housework	8	11.27		

Unpaid domestic work	7	9.85		
Ignored	4	5.63		
Income in minimum wage			1.83	0.97
1 to 2	56	78.87		
3 to 4	14	19.72		
5 or more	1	1.41		
Housing				
Rented	4	5.63		
Given	4	5.63		
Own	63	88.73		
Number of rooms			5.44	1.7
1 to 3	9	12.68		
4 to 6	48	67.61		
7 or more	14	19.72		
Number of residents			4.29	1.78
2 to 3	27	38.03		
4 to 5	31	43.66		
6 or more	13	18.31		
Total	71	100.00		

The palliative care indicators according to the PCST scale allowed an assessment regarding the indication of PC (Table 2), through defined criteria of underlying diseases (criterion 1), associated diseases (criterion 2), functionality (criterion 3) and personal aspects of the patient (criterion 4).

Table 2- Palliative care indicators according to the Palliative Care Screening Tool (PCST) scale. São Luís, Maranhão, 2021.

Indicators	**n**	**%**
Underlying disease		
Cancer	2	2.82
Stroke Sequelae*	32	45.07
Serious heart disease	3	4.23
Other limiting diseases	34	47.89
Other neurosequelae	11	15.49
Degenerative disease	14	19.72
Neurological disease	4	5.63
Orthopedic trauma	2	2.82
Pseudobulbar syndrome	1	1.41
Spondylodiscitis	1	1.41
Special needs	1	1.41
Associated diseases	1	1.41
Moderate COPD**		
Moderate CHF*** and other associated diseases	4	5.63
Other associated diseases	39	54.93
No associated diseases	27	38.03
Degree of dependence		

0	1	1.41
1	1	1.41
2	8	11.27
3	12	16.90
4	49	69.01
Personal conditions		
None	3	4.23
Need help	42	59.15
Need for help and history of hospitalization	19	26.76
Need for help and history of hospitalization and frequent hospitalizations	6	8.45
Need for help and history of hospitalization and frequent hospitalizations and prolonged ICU stays****	1	1.41
PCST		
Up to 2 points	0	0.00
Up to 3 points	2	2.82
Greater than or equal to 4 points	69	97.18
Total	**71**	**100.00**

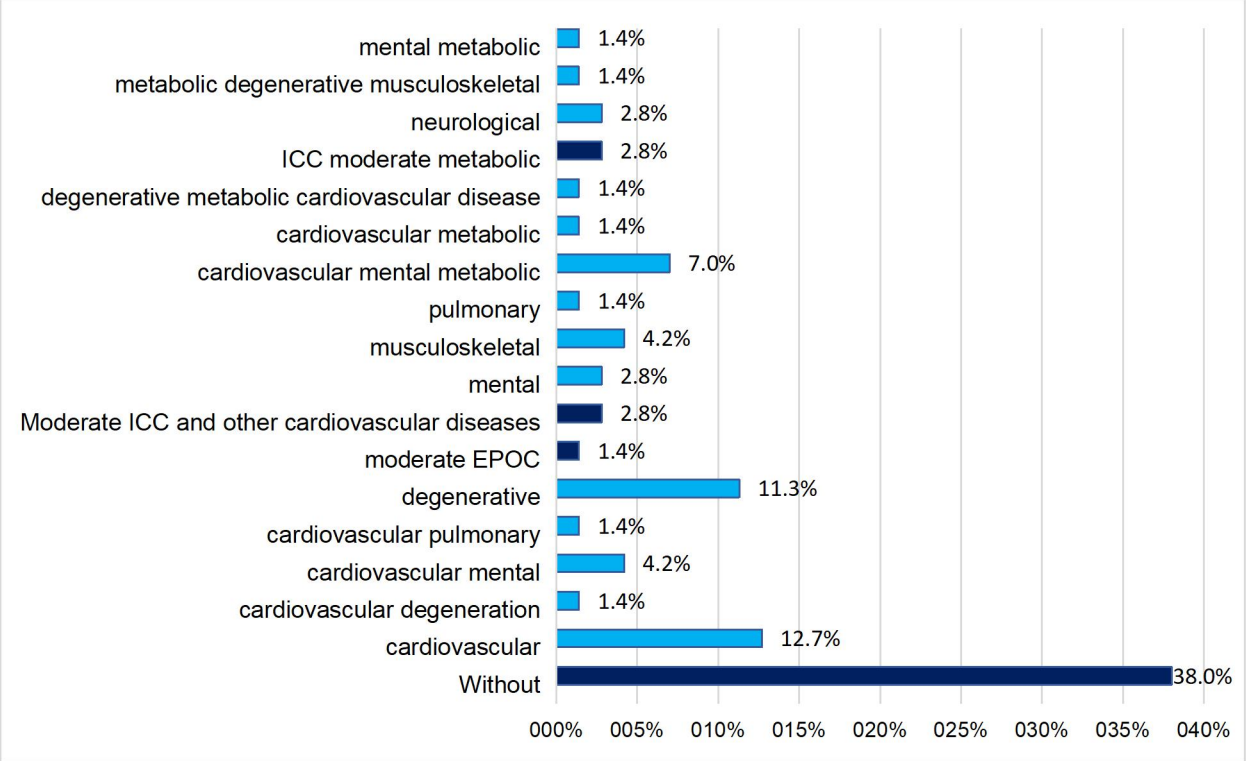
*Stroke; **Chronic Obstructive Pulmonary Disease; ***Congestive Heart Failure; ****Intensive Care Unit

It was observed that the most relevant underlying diseases are stroke sequelae (45.07%) and other limiting diseases (47.89%), followed by serious heart disease (4.23%) and cancer (2.82%).

Regarding associated diseases, more than half of the patients studied had other associated diseases (54.93%), followed by moderate Congestive Heart Failure (5.63%) and moderate Chronic Obstructive Pulmonary Disease (1.41%) which had a low percentage detected in the collected sample.

In this study, the highest percentages of associated diseases diagnosed in palliative patients treated in home care are from the cardiovascular and metabolic classes, which together account for 37.9%, followed by the degenerative class, which has a percentage of 15.5%. Associated diseases come in various forms, from mental disorders (9.8%, such as Alzheimer's, dementia syndromes, and Parkinson's), to neurological disorders and moderate CHF, which also account for 2.8% of the total surveyed. Diseases that affect the respiratory system are classified as pulmonary, with 2.8%, and moderate COPD, with 1.4%. In addition, there are other classes that were identified with a lower incidence, such as musculoskeletal diseases, with 5.6% of representation in the survey.

Graph 1- Class of associated diseases of patients treated by the Better at Home program.



It was identified that most patients had a level of dependence of 4 (69.01%), followed by level of dependence of 3 (16.09%), level of dependence of 2 (11.27%), level of dependence of 1 (1.41%) and no dependence (1.41%). Regarding the patient's personal conditions, more than half needed help for some decision-making (59.15%), followed by recent hospitalizations (26.76%).

The results of the scores regarding the criteria presented on the PCST scale were that 69 patients (97.18%) were considered eligible for Palliative Care, and two 2 patients (2.82%) remained under clinical observation.

DISCUSSION

The results of this study demonstrate the great importance eligibility for palliative care. It was possible to analyze that not only cancer patients, but also those with other chronic-degenerative diseases, need this care, since the high degree of physical and social dependence reflects on the quality of life of patients.[9]

Advances in health technology encourage the prolongation of life, causing more suffering to patients with chronic and advanced-stage diseases. Early diagnosis of palliative care has been a major challenge for health institutions, as there are a number

of institutional obstacles, such as the lack of sufficient beds for palliative patients, uneven training of health professionals on the subject, and few PC programs in health institutions.[10] It is essential to think of more appropriate strategies for implementing health services and policies that provide safe care for these people until the end of their lives.

According to data from the Global Atlas of Palliative Care, it is estimated that more than 20 million people worldwide require end-of-life palliative care each year.[11] Resolution No. 41/2018, published by the Ministry of Health, was a decisive step forward for the practice of palliative care in Brazil, as it regulated this practice as a health policy. This resolution determines that any person with a life-threatening disease, whether acute or chronic, will be offered this care after the diagnosis of their condition.[12]

It was found that the female sex was predominant in the sample studied, with a slightly higher percentage being found in relation to a study carried out in Minas Gerais with 131 patients that aimed to identify the epidemiological and clinical characteristics of patients attended by a public home care program in the city of Montes Claros, in this study the majority were also women (55%).[9] Given these results, the gender differences in relation to health are highlighted, although women live longer than men, they present greater morbidity, as they are more concerned about health, use services and have access to diagnoses and treatments.[13]

Regarding age, the elderly population predominated, with a higher frequency in the age range of 70-86 years. A study carried out in the city of Maceió, Alagoas, found that 80% are elderly and that the most prevalent age range (44%) was 79 years or older.[14] A study evaluated medical records of home patients from private institutions in the United States and found an average age of 62 years. A study in Spain, carried out in the cities of Málaga, Costa del Sol, Almeria and Granada, found an average age of 75.49 years. This age range profile can be justified by the demographic transition process that has been occurring in Brazil and worldwide, with an increase in the number of elderly people and especially in the female population, due to the greater life expectancy of women compared to men.

It is important to emphasize that advanced age leads to a reduction in functional reserve and the body's ability to maintain energy balance. As a result, the mechanisms necessary to perform activities may be compromised, thus increasing the prevalence of diseases and injuries, making the elderly more susceptible to developing frailty and, consequently, the need for palliative care.[15] The aging process demands greater care, specifically in relation to

chronic degenerative diseases, whether cardiovascular, musculoskeletal or others.[16]

In this study, the main chronic diseases found were cardiovascular diseases, indicating the sequelae of stroke and other limiting diseases, followed by serious heart disease and cancer in smaller proportions. Global estimates from the World Health Organization show that the main diseases that generate the need for palliative care are cardiovascular (38.5%), neoplasms (34.0%) and chronic obstructive disease (10.3%).[17] A study carried out in Alice Springs, Australia, revealed that the second largest group of patients in PC were diagnosed with cardiovascular and respiratory diseases, both with 8% of cases.[18] Research carried out in Southeast Brazil portrays the same situation regarding the situational diagnosis of the patients investigated, with the highest frequency being cancer (48.0%), cardiovascular disease (10.6%) and pulmonary disease (9.1%).[6]

Stroke is the leading cause of hospitalization in Brazil. It is characterized as a disabling disease that can lead to death and result in physical and mental sequelae, restricting the individual's functionality, especially in activities of daily living (ADLs).[19] In this study, in addition to stroke, other disabling diseases were identified, especially Alzheimer's, dementia syndromes and Parkinson's. However, a low number of individuals who only had diagnoses of mental disorders as underlying diseases were found.

PC is a response applied to imbalances resulting from progressive diseases that have no possibility of cure, with the aim of preventing the suffering caused by them, providing quality of life to patients and their families. Thus, the characterization of patients diagnosed with NCDs, eligible for PC in home treatment, can generate evidence for the need to introduce this care in all health services.[20]

It is important to implement PC screening scales that meet the needs of not only cancer patients, but all patients with chronic diseases, taking into account other assessment criteria in addition to functional capacity. In this sense, the PCST scale has been shown to be viable for eligibility of patients for PC.[20]

Thus, it was possible to verify that the majority of individuals assessed, affected by NCDs, were indicated as eligible for PC by the PCST scale. A study carried out at the State Hospital in Espírito Santo, Brazil, in 2017, states that 47% of the opinions that could benefit from the practice of palliative care were effectively requested, this fact highlights the high sensitivity of the scale and reinforces the understanding about the possibility of using it as an assessment of palliative care.[16]

In this study, it is possible to observe that a significant percentage of patients do

not have associated diseases, but more than half of those surveyed have some associated disease. According to a survey conducted in 2017 with 286 patients in Espírito Santo, 55.9% of patients were hospitalized due to decompensation of associated diseases. Such clinical conditions gradually affect the patient's daily activities and increase the degree of dependence.16 In this study, cardiac patients with mental disorders account for a small number of the individuals surveyed, as do those who have more than one diagnosis with cardiovascular manifestations. In addition, it was identified that the class of cardiovascular diagnoses and degenerative diseases have a similar percentage, and patients with moderate COPD studied in the sample have an insignificant number.

Regarding the patient's functional condition, the degree of dependence considers the ability to perform daily activities, acts of personal care and the number of hours confined to bed or wheelchair. More than half of the patients were completely dependent, required full-time assistance, were confined to bed or wheelchair users with bed restrictions. This was found in a study conducted in the city of Maceió, Alagoas, where 72.5% were bed-ridden.[17] Regarding degree 3 of dependence, the study indicates the equivalent of 16.90%, degree 2 of dependence a total of 11.27% of those surveyed and 1.41% of the patients were completely independent, active, and had no restrictions.

Patients' personal conditions are also relevant for palliative care indications. It was observed that just over half of the patients needed help with complex treatment decisions and psychological or spiritual issues, and a quarter had a history of previous hospitalizations in emergency services, followed by less than 10% with some frequent hospitalization due to decompensation of the underlying disease. This result is lower than that identified in a 2019 study that researched the sociodemographic and clinical characterization of 44 patients admitted to a university hospital in the city of João Pessoa, Paraíba, in which it was shown that 88.6% of the participants reported previous hospitalizations.[11]

This research contributes to the expansion of scientific knowledge among health professionals, as well as to the improvement of the Home Care process, such as palliative care services. One of the limitations of the study was due to errors in completing the telephone call, whether non-existent numbers or outside the operator's coverage area, which resulted in data loss. The telephone interview did not allow for a true understanding of the clinical situation of the patients to score on the scale, requiring a detailed interview with the caregiver, which resulted in moments of emotional

exhaustion for the interviewee, who often became emotional when reporting the palliative condition of their loved one. Therefore, new studies with larger samples should be carried out to confirm or not the results identified in this study.

CONCLUSION

The results of the research allowed us to identify that most patients were elderly, female, bedridden, with cardiovascular disease, with the most common diagnosis being sequelae of stroke. In addition to objectively and concisely characterizing real and potential difficulties of the patient in palliative care, as well as contributing to the qualification of palliative care, impacting the planning and implementation of appropriate interventions. It is recommended to investigate the factors associated with palliative care, in addition to the need for research to determine which care is most appropriate for the conditions of palliative patients treated at home.

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