

FUNCTIONAL CAPACITY OF PATIENTS INDICATED FOR PALLIATIVE CARE IN PRIMARY CARE

Capacidade funcional de pacientes com indicação de cuidados paliativos na atenção primária

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ABSTRACT

INTRODUCTION: Patients indicated for palliative care may have losses in functional capacity and quality of life, but there is little information about these conditions in primary health care. **OBJECTIVE:** To characterize the functional and symptomatic aspects of individuals indicated for palliative care in primary care. **METHODS:** This cross-sectional descriptive study involved six family health teams from three basic health units in Londrina, Paraná, Brazil that indicated patients with palliative care needs. The patients were assessed with the Karnofsky Performance Scale (KPS), the Edmonton Symptom Assessment Scale (ESAS) and a sociodemographic and clinical questionnaire. **RESULTS:** 73 patients (30 men and 43 women) whose mean age was 77.2 ± 12.1 years were included. Dementia and cerebrovascular diseases were the most frequent conditions, with 20 (27%) and 19 (26%) patients, respectively. The mean KPS score was 47.9 ± 13.9 points (44 ± 11.3 points for men and 51 ± 11.3 for women), with a significant difference between the sexes ($p = 0.023$). Cancer patients had better functionality than those with neurological diseases. The ESAS, whose mean score was below 3 points (mild intensity), indicated that the most frequent symptoms were impaired well-being, pain, fatigue and drowsiness. Patients without caregivers had better functional status, but greater pain and fatigue intensity. **CONCLUSION:** All patients had some functional limitations, and those with neurological diseases were the most affected. The symptoms were generally mild. The presence of caregivers may positively influence symptom control. **KEYWORDS:** primary health care; palliative care; frail elderly; disabled persons; quality of life.

RESUMO

INTRODUÇÃO: Pacientes com indicação de cuidados paliativos podem ter perda da capacidade funcional e da qualidade de vida, mas há pouca informação sobre essas condições na atenção primária à saúde. **OBJETIVO:** Caracterizar os aspectos funcionais e sintomáticos dos indivíduos com indicação de cuidados paliativos na atenção primária. **MÉTODOS:** Estudo transversal e descritivo com seis equipes de saúde da família de três unidades básicas de saúde de Londrina, Paraná, que indicaram pacientes com necessidade de cuidados paliativos. Os pacientes foram avaliados pela Escala de Performance de Karnofsky (EPK), pela Escala de Avaliação de Sintomas de Edmonton (ESAS) e por questionário sociodemográfico e clínico. **RESULTADOS:** 73 pacientes (30 homens e 43 mulheres) foram incluídos, com idade média de $77,2 \pm 12,1$ anos. Demências e doenças cerebrovasculares foram as condições mais frequentes com 20 (27%) e 19 (26%) pacientes, respectivamente. A média na EPK foi de $47,9 \pm 13,9$ pontos, sendo $44 \pm 11,3$ pontos para homens e $51 \pm 11,3$ para mulheres, com diferença significativa entre os sexos ($p = 0,023$). Pacientes com câncer tiveram um melhor grau de funcionalidade em comparação àqueles com doenças neurológicas. A ESAS indicou que os sintomas mais frequentes foram o comprometimento do bem-estar, dor, cansaço e sonolência, todos com escore médio abaixo de 3 pontos (intensidade leve). Pacientes sem cuidadores tiveram melhor *status* funcional, mas apresentaram maior intensidade para dor e cansaço. **CONCLUSÃO:** Todos os pacientes tinham alguma limitação da funcionalidade, sendo aqueles com doença neurológica os mais acometidos. Os sintomas tiveram, no geral, uma intensidade leve. A presença de cuidadores pode ter influência num melhor controle dos sintomas. **PALAVRAS-CHAVE:** atenção primária à saúde; cuidados paliativos; idoso fragilizado; pessoas com deficiência; qualidade de vida.

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INTRODUCTION

Incurable and non-communicable chronic diseases are associated with a progressive deterioration of quality of life in the affected individuals, often for prolonged periods, and affect several aspects of the patient's life trajectory, such as physical and psychological repercussions that are reflected in their social, family and spiritual relations.^{1,2} In offering support for these problems, palliative care (PC) aims to encourage patient autonomy and independence by preventing complications, controlling physical, psychological and social symptoms, and by comprehensive care planning until the occurrence of death.^{1,3}

There is a progressive loss of functional capacity in the evolution of incurable conditions, which affects autonomy and independence in activities of daily living. Loss of functionality is one of the main signs used in disease prognosis and can be assessed with a number of clinical tools.⁴⁻⁶

Researchers have suggested assessing functional capacity and disability as criteria for indicating PC, for example, the Karnofsky Performance Scale (KPS) or the Palliative Performance Scale, which is derived from it, in which scores of 70 points or less indicate eligibility for early PC and scores of 50 points or less are considered an objective indication for PC due to the greater short and mid-term mortality risk.^{4,7,8}

Currently, access to PC is limited in Brazil, and there is little information on the clinical and functional condition of PC patients in different health system contexts, such as primary health care.^{1,9,10} Thus, the objectives of the present study were:

- to characterize the functional aspects and symptoms of patients treated at basic health units who required PC due to advanced incurable diseases;
- to compare functionality between different diseases and genders and between patients with and without caregivers.

METHODS

A cross-sectional descriptive study was conducted with patients treated through the Family Health Strategy (*Estratégia Saúde da Família*) in Londrina, Paraná, Brazil. Three primary healthcare units were selected from the central region of the municipality, with two Family Health Strategy teams in each unit. These six teams were instructed to indicate patients with pre-defined conditions associated with the need for PC. Patients indicated by the teams were screened with the Palliative Care Screening Tool (PCST) for confirmation.

Adult patients (over 18 years of age) scoring 4 points or higher on the PCST were included in the research protocol. Written informed consent was provided by all participants or their caregivers. We excluded individuals who did not meet the inclusion criteria, who refused to participate in the study, or who died or could not be found prior to assessment.

A sociodemographic and clinical questionnaire was administered to the included individuals (age in years, gender, presence of caregiver, ability to provide personal information, main life-threatening disease).

The KPS was used to assess the participants' degree of functionality. This instrument's scale is from 10 to 100, in which 100 represents no limitations and 10 represents individuals at high risk of death. According to the literature, patients scoring 70 or less (i.e., capable of self-care but with reduced mobility and unable to perform household tasks) may be eligible for early PC, while PC is strongly recommended for those scoring 50 or less (i.e., who spend up to 50% of the day sitting or lying down and require considerable assistance and frequent medical care).^{4,7,8}

The presence and intensity of symptoms were determined with the Edmonton Symptom Assessment Scale, which uses a visual analogue scale of 0 to 10 points to assess the main symptoms associated with patients who require PC.^{4,8}

The results were analyzed with descriptive and analytical statistics in SPSS version 20 and Microsoft Excel 2016. The following descriptive data were analyzed: frequency, central tendency (mean), percentage, standard deviation (SD) and confidence interval (95%CI).

To compare scores between genders and between groups of patients with and without caregivers, Student's *t*-test or a non-parametric equivalent was used. For comparison between different types of main disease, one-way analysis of variance, or a non-parametric equivalent for non-normal distribution, along with associated tests, were used to locate the differences. All tests were preceded by a Kolmogorov-Smirnov test for normal distribution. A significance level of 5% ($p \leq 0.05$) was used for all analyses.

The research, approved by the Institutional Research Ethics Committee (CAAE: 17573113.8.0000.5231) and the Municipal Department of Health, was conducted between January and July 2015.

RESULTS

A total of 73 patients were included, of whom 43 (59%) were women and 30 (41%) were men. The mean age was 77.2 (SD = 12.1) years and the majority, 63 (86%) patients, had

a caregiver present more than 50% of the time. Dementia syndromes and stroke sequelae were the most frequent clinical conditions, with 20 (27%) and 19 (26%) patients, respectively. These were followed by osteoarticular disorders, with 9 (12%) patients, other neurological diseases, with 8 (11%) patients, heart disease, with 7 (10%) patients, and cancer, with 6 (8%) patients.

The mean KPS score for all participants was 47.9 (SD = 3.9) points, with a mean of 44 (SD = 11.3) for men and 51 (SD = 11.3) for women. There was a significant difference between the sexes ($p = 0.023$), i.e., women had a slightly higher degree of functionality than men (Figure 1).

When comparing the distribution of KPS scores according to main disease, statistically significant differences were observed between groups ($p = 0.01$). Individuals with cancer had better functional scores than those with cerebrovascular disease ($p = 0.04$), dementia ($p = 0.04$) or other neurological diseases ($p = 0.02$): the mean of the latter three was under 50 points. Cardiac patients also had significantly higher scores than dementia patients ($p = 0.04$) (Figure 2).

In the interviews, approximately 30 (41%) patients could provide all of the personal information required in the questionnaire, approximately 20 (27%) could answer basic or personal questions, such as the presence and intensity of

symptoms, but needed caregiver assistance for additional information, while 23 (32%) could not provide any information about themselves.

According to the Edmonton Symptom Assessment Scale results, the most frequent symptoms were: impaired well-being (40 patients; 55%), pain (33 patients; 45%), and fatigue and drowsiness (32 patients; 44%). The overall mean symptom intensity was mild (< 3 points on a scale of 0 to 10). The symptom intensity in cancer was moderate (between 3 and 6 points) for pain, fatigue, depression, anxiety and impaired well-being. In osteoarticular disease, the mean was over 3 for pain. Other types of organ failure (two cases of renal failure, one of pulmonary disease and one of liver disease) involved more symptoms with a moderate mean intensity (score between 3 and 7). The mean age of those with ($n = 63$) and without caregivers ($n = 10$) was 78 (SD = 15.5) and 72 (SD = 13.9) years, respectively, but this difference was not statistically significant ($p = 0.09$).

According to the KPS scores, functional independence was significantly higher (i.e., by approximately 20 points) in the group without caregivers ($p < 0.01$), although participants without caregivers scored higher for most symptoms than those with caregivers. Pain, tiredness, depression, anxiety and well-being were of moderate intensity in

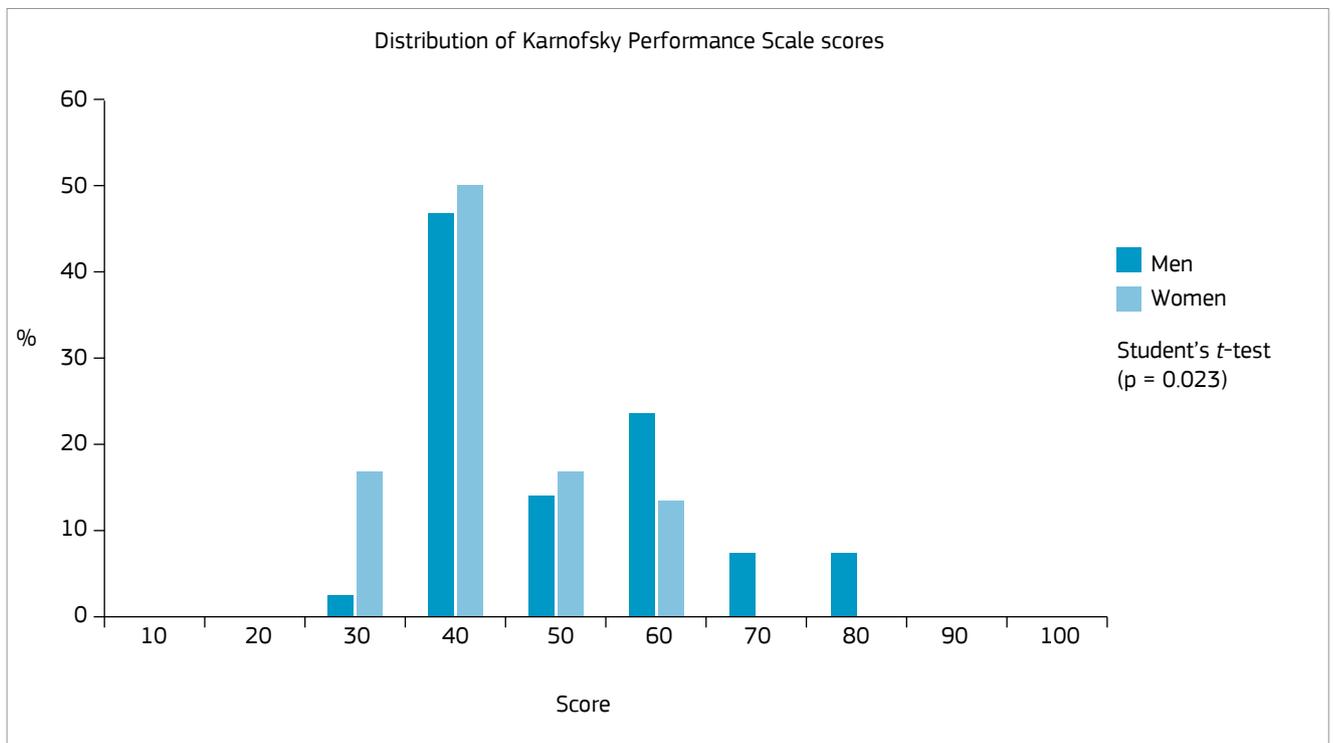


Figure 1 Distribution of functionality (Karnofsky Performance Scale) according to sex in patients indicated for palliative care through basic health units in Londrina, Paraná, Brazil (2015).

the group without caregivers (greater than 3 points), while in the caregiver group with their means were less than 3 points. However, the only statistically significant differences between groups were for pain ($p = 0.04$) and fatigue ($p = 0.03$) (Table 1).

DISCUSSION

In this study, it was found that functionality was affected in all cases. Most of these patients, whose PC needs were treated through primary healthcare units, presented important limitations in daily activities and required caregivers.

Although PC is more frequently associated with oncology cases, in this primary care context, neurological diseases (e.g., cerebrovascular diseases), dementia syndromes (e.g., Alzheimer's disease and related conditions) and other neurological diseases (e.g., medullary lesions, peripheral nerve injury, etc.) were more frequent. These conditions have also been identified by other researchers.⁹⁻¹³

A previous study by Lucchetti et al.¹² in a long-term institution for the elderly also found that PC was predominantly required by those with cerebrovascular diseases and dementia syndromes. A Spanish population study by Gómez-Batiste et al.¹³ also found a higher prevalence of frailty and dementia in the primary care context. The chronic nature of these neurological diseases, involving long periods of impairment prior to death, could be responsible for the high frequency of these conditions found in these studies.

In a study of 14 primary healthcare units in the city of São Paulo, Paz⁹ identified individuals indicated for PC based on a program that distributed supplies for urinary and fecal incontinence. Again, a predominance of chronic neurological and neurodegenerative diseases, such as cerebrovascular disease, Alzheimer's disease, Parkinson's disease and other dementias was found in a sample of 160 enrollees in the program. A total of 141 of these individuals were assessed with the KPS, with 90% scoring 50 points or less. This degree of functionality also predominated in the present study.

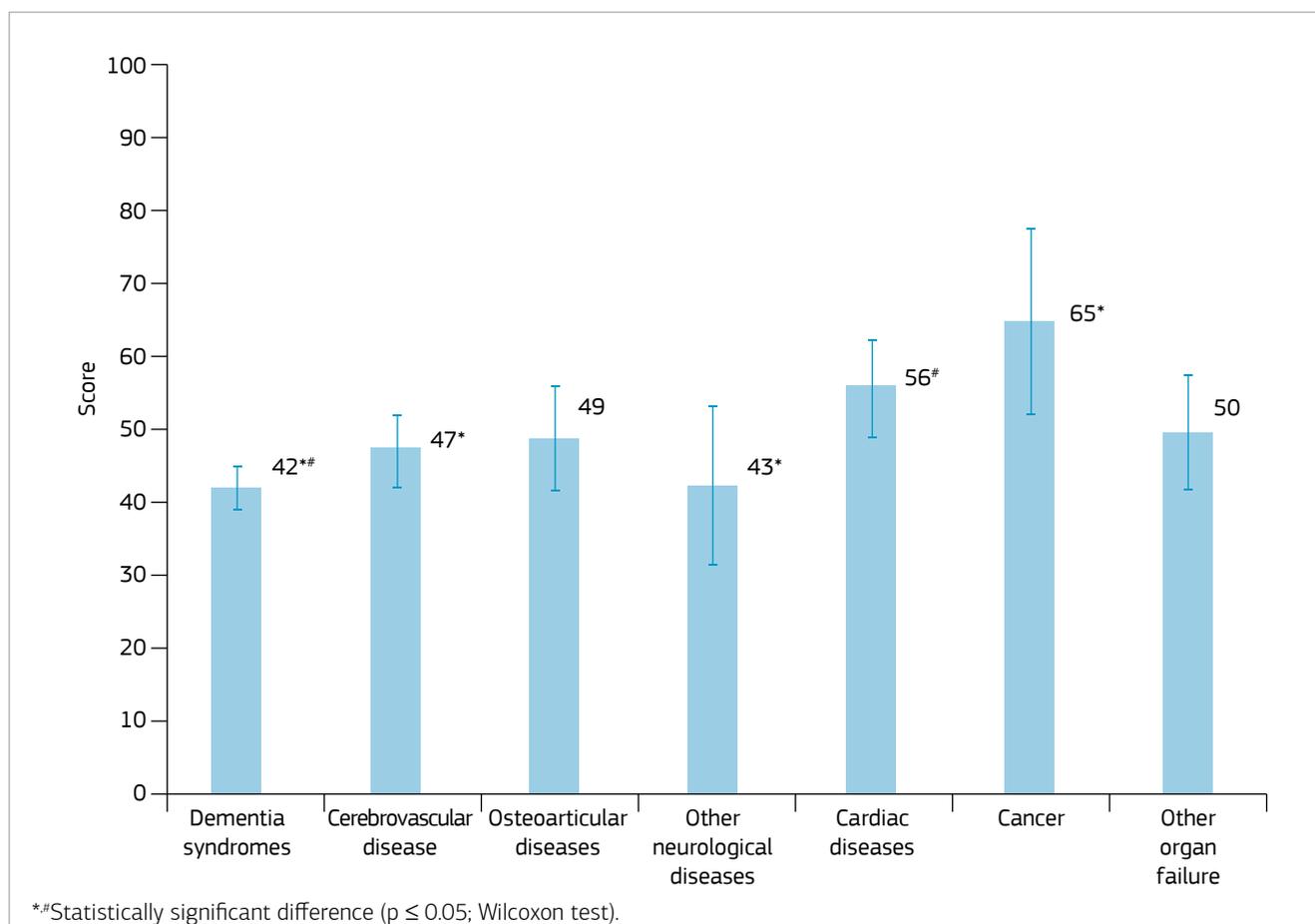


Figure 2 Degree of functionality on the Karnofsky Performance Scale (mean and 95% confidence interval) according to disease in patients indicated for palliative care through basic health units in Londrina, Paraná, Brazil (2015).

Neurological diseases are often associated with cognitive and motor impairment, which leads to limitations in functionality and, consequently, greater dependence on caregivers.^{1,14-16} Cancer patients may present less functional impairment, even in more advanced stages, which was observed in this study and agrees with other authors.^{6,17}

Since functionality is directly related to mortality risk, assessments of it are frequently used to indicate patients for PC support.^{1,4,5} Nevertheless, the prognosis for dementia is difficult, since progression varies: patients can continue on for several years or die early from pulmonary complications, nutritional deficiencies or other comorbidities.¹⁵ Although cerebrovascular disease is the leading cause of disability and one of the leading causes of death in a number of countries, PC approaches to it are still limited. When these patients are included in PC, it is often only in the final stages of the disease.¹⁶

Patients with a high degree of functional dependence are less able to describe their needs, which makes it difficult to identify, evaluate and control physical, psychological and spiritual symptoms, and also limits referral for PC.¹⁶ Although caregivers are an important part of care planning, they are also vulnerable to the development of physical symptoms, emotional distress, depression, and anxiety, and they need support to deal with overload from the day-to-day tasks and care required by their dependent patients.^{18,19}

When the symptoms of the present sample were classified according to disease type, it was found that pain,

fatigue, depression, anxiety and impaired well-being were of moderate intensity (between 3 and 7 points) in cancer patients. In osteoarticular diseases, pain was of moderate intensity, usually associated with advanced arthritis, fractures and amputations. In the few cases of organ failure (pulmonary, hepatic and renal), various symptoms were also of moderate intensity.

Although pain is frequently associated with PC patients, fatigue should be highlighted, since it has been cited by researches as very common in several types of advanced disease.¹⁹ It should also be considered that symptoms are usually interrelated, which makes control difficult and increases the need for correct assessment. In a study on the last year of life of elderly residents of São Paulo, an average of seven symptoms were found in each individual.²⁰

This study found that patients with a caregiver had a lower functional capacity (by a mean of 20 points) than those without one. However, despite the limited number of patients without caregivers (10 individuals), it is noteworthy that the mean intensity of their pain and fatigue symptoms was greater than that of the caregiver group. That is, despite having greater functional capacity, they did not necessarily have better control of some symptoms.

Both the primary health care approach and PC presuppose holistic care for the individual and focus attention on personal and family contexts in an effort to positively influence patient health and quality of life, offering guidance, treatment

Table 1 Comparison of clinical scales according to the presence of a caregiver in patients indicated for palliative care through basic health units in Londrina, Paraná, Brazil (2015).

Karnofsky Performance Scale*	With caregiver (n = 63)			Without caregiver (n = 10)			p-value
	Mean	95%CI	Number of responses N/A	Mean	95%CI	Number of responses N/A	
	45.4	± 3.1			64.0		± 12.6
ESAS symptom	Intensity		Number of responses N/A	Intensity		Number of responses N/A	p-value
	Mean	95%CI		Mean	95%CI		
Pain*	2.0	± 0.7	0	3.8	± 1.8	0	0.046
Fatigue*	1.9	± 0.7	0	4.0	± 1.9	0	0.035
Nausea	0.2	± 0.2	0	0.0	± 0.0	0	0.064
Depression	1.7	± 0.6	13	3.7	± 2.0	0	0.051
Anxiety	1.7	± 0.7	5	3.7	± 2.4	0	0.078
Drowsiness	2.0	± 0.7	0	2.4	± 1.7	0	0.358
Lack of appetite	1.4	± 0.6	0	2.7	± 1.9	0	0.123
Shortness of breath	0.9	± 0.5	0	2.3	± 2.0	0	0.120
Impaired well-being	2.6	± 0.6	15	3.7	± 1.5	0	0.105

95%CI: 95% confidence interval; ESAS: Edmonton Symptom Assessment Scale; N/A: not applicable; *p ≤ 0.05 (Student's t-test).

and care even in cases where there is no possibility of cure.^{21,22} Professional support in the community has a number of advantages for health care, including greater proximity to the patients and their families and involvement for longer periods, which engenders trust and familiarity between staff and patients.^{22,23}

Although most participants in this study had chronic conditions and were relatively stable, considering that they have an incurable disease and many are at the end of life, they may require frequent and sometimes more complex therapeutic interventions. Thus, it is essential that primary healthcare unit staff are prepared to deal with these conditions, and an integrated health care network is needed to accelerate the transition between primary care and specialized hospitals or services.²²⁻²⁵

The number of cases evaluated in this study limited its ability to identify differences between subgroups, particularly between patients with and without caregivers. Thus, the data are too limited to be generalized and further studies are required. It is recommended that future studies identify which functions in patients indicated for PC are the most limited or have the greatest influence on quality of life so more specific therapeutic interventions can be recommended.

CONCLUSIONS

It was determined that, in the context of the primary care, incurable chronic diseases have important effects on functionality and impact the independence and autonomy of those in need of PC. Neurological patients are the most affected due to their difficulties with locomotion and providing personal information. The patients presented a number of symptoms, usually with mild-to-moderate intensity.

Caregivers play an important role in the PC of individuals who are treated through basic health units. Despite their generally lower functional capacity, the mean scores for several symptoms in patients with caregivers were lower than those without caregivers. Primary care can provide PC support in a non-specialized way, promoting quality of life, symptom control and care planning for individuals facing incurable conditions.

CONFLICT OF INTERESTS

The authors declare no conflict of interests.

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