

## Sociodemographic and clinical profile of patients admitted under palliative care

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### ABSTRACT

**Objective:** To identify the sociodemographic and clinical profile of patients admitted under palliative care. **Methods:** This is a descriptive study with a quantitative approach. Data collection was performed through research in electronic medical records. A structured form was used to collect the information of interest. Descriptive statistics were used for data analysis. **Results:** Most patients were female (53.8%), with a mean age of 69 years. The main reason for admission was dyspnea (24.4%) and the most recurrent diagnosis was head and neck cancer (24.4%; n=98). Regarding the outcome, 53.1% of the patients were discharged from the hospital and the mean number of days of admission was 9.6. **Conclusion:** The data obtained allowed to know the sociodemographic and clinical profile of patients, in order to favor the planning of care and, with the incorporation of palliative care, promote better quality of life.

**Descriptors:** Palliative Care; Hospital care; Inpatients.

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## INTRODUCTION

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New challenges have been emerging daily due to increased life expectancy, not only in Brazil, but also in the world, resulting in a significant increase in elderly people <sup>(1)</sup>. According to the World Health Organization (WHO), it is expected that by 2025, in the world population, the number of people considered elderly (over 60 years) will reach approximately 1.2 billion. Brazil will be the sixth country with the highest number of elderly people. For 2050, an increase of almost 67% is estimated, reaching 2 billion people, of which 80% will be from developing countries <sup>(2)</sup>.

The aging process of the population is related to the improvement in their living condition, which is a multidirectional process, in which the individual will undergo physiological, psychological and social changes. Such changes in addition to the possible impacts of external factors can lead to a greater or lesser disability <sup>(3)</sup>.

Population aging increases health problems which in turn put pressure on healthcare and social security systems. Getting older does not necessarily mean becoming sick. Unless there are associated illnesses, aging is associated with a good

level of health. Moreover, advances in the fields of health and technology allow people with access to adequate public or private services to have a better quality of life at this stage of life. With this, it is essential to invest in prevention actions throughout the life course of individuals <sup>(4)</sup>.

Numerous factors present in the process of senility can affect elderly people, such as chronic-degenerative diseases, especially cancer. This clinical condition represents the second leading cause of death in Brazil and worldwide, being an important public health issue, due to its impact on the service network and the care that cancer patients demand <sup>(5)</sup>.

Considering that the increase in the prevalence of chronic-degenerative diseases is related to the population's longer survival, recommendation of palliative care will be increasingly frequent. Palliative care (PC) is active holistic care offered to people of all ages who are in intense suffering related to their health, resulting from serious diseases, especially those who are at the end of life. The goal of PC is, therefore, to improve the quality of life of patients, their families and their caregivers <sup>(6)</sup>.

PC can be complex and requires

integrated work, i.e., performed by a multidisciplinary team. Thus, it is real the need for improvement of professionals in this context, not only for the proper management of symptoms presented by patients experiencing a serious disease, but also to assist them in coping with death, identifying the negative and positive aspects relevant to the evolution of each case <sup>(7)</sup>.

Thus, professionals should be tools to optimize care at their different levels, considering the needs of each individual, which should be fully assisted. Professionals involved in PC need constant updating of knowledge and sharing of responsibilities <sup>(7)</sup>.

Knowing the profile of patients who have been admitted under PC will allow not only the planning of a health care that contemplates all dimensions of individuals, promoting the control and relief of symptoms and better quality of life, but also the identification of the need for team training and improvement on such care. In view of the above, the present study aimed to identify the sociodemographic and clinical profile of patients who were admitted under PC.

## METHOD

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This is a descriptive, cross-sectional, quantitative study conducted in a university hospital.

Data were collected from September 2018 to February 2019 and 403 medical records were consulted. This number corresponds to the total number of patients admitted under PC from 2015 to 2018. The period of three years, chosen for this study, corresponds to the period in which the referred hospital began to care for patients under PC, and 10 exclusive beds were allocated for the admission of such patients.

The identification of medical records was performed with the help of the Information technology team of this service, which, from the International Statistical Classification of Diseases and Health-Related Problems (ICD) Z51.5, related to PC, obtained a list of patients admitted in the proposed period. From there, access to the electronic medical records was performed and, using a structured form, the information of interest was collected.

The study included medical records of patients admitted to medical clinic wards

from January 2015 to December 2018, aged over 18 years, of both sexes, with the record of ICD Z51.5 among the diagnoses listed.

The research project was prepared according to the precepts of CNS Resolution 466/12 <sup>(8)</sup>, submitted and approved by the Institutional Review Board (IRB) of *Escola de Enfermagem de Ribeirão Preto* at *Universidade de São Paulo*, under number 2,921,617, and access to a large number of participants due to probable death would not be waived due to the application of the Informed Consent Form (ICF), since, due to the clinical and epidemiological profile of pathologies presented by patients under PC, it would not be possible to access a high number of participants due to probable death.

The structured form was constructed by the researchers and validated by three nurses working in PC. For sociodemographic characterization, the following data were collected: date of birth, date of admission, gender, marital status, time of study (in complete years of formal study), main caregiver and their degree of kinship with patients. For clinical characterization, the following were collected: number of

previous admissions for symptom control, number of days of admission, reason for admission; underlying disease; date of recommendation of exclusive PC; disease-modifying treatment to which patients were previously submitted; dates of beginning and end of modifier treatment; medications in use during admission, patient functional status, evaluated through the Karnofsky Performance Scale (KPS) <sup>(9)</sup> and the Palliative Performance Scale (PPS).

The KPS is a general measure of independence and has been widely used for the evaluation of cancer patients. The KPS classifies individuals according to the degree of functional impairment presented and is composed of 10 descriptions associated with a percentage graduation ranging from 10 to 100, in which 10% represents a dying individual and 100% represents an individual without evidence of disease and with complete functional independence <sup>(10)</sup>. No cut-off points and higher scores indicate better functionality, while lower scores represent worse prognosis and lower expectation of recovery or return to normal activities. The scale has been widely used in patients also affected by diseases other than oncologic diseases.

The KPS scale has been commonly used for the overall evaluation of cancer patients in order to identify their functional status since its development in 1948. It is a scale consecrated by its clinical use, however, there are limited data documenting its reliability and validity for use in research <sup>(11)</sup>.

PPS is an adaptation of KPS for PC; it has 11 performance levels, ranging from 0 to 100 and should be used daily, in order to provide decision-making in PC, since it seems to have prognostic value when associated with the evaluation of other symptoms presented by patients (edema, delirium, dyspnea and low food intake) <sup>(12)</sup>.

The data were structured in microsoft excel spreadsheets being double-typed and going through a validation step to minimize transcription errors. For sociodemographic and clinical characterization, descriptive statistics were used in order to summarize the information of interest. The qualitative variables were described in terms of absolute frequency and percentage and the quantitative variables were described using measures of central tendency (mean) and dispersion (standard deviation).

## RESULTS

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Of the total number of patients who were admitted under PC, 217 (53.8%) were female and 186 (46.2%) males; regarding marital status, 157 (39%) patients were married or had a consensual union, 116 (28.8%) were widowed, 43 (10.7%) were separated or divorced, 36 (8.9%) were single and in 51 (12.6%) medical records did not contain this information.

The mean age of patients at the time of first admission was 69 years (SD= 14.1). Regarding the time of formal study, it was possible to identify this information in only 136 medical records (33.7%), and the mean was 7.13 years (SD=4.2).

In 203 (50.4%) medical records, it was identified that the main caregiver was the child, followed by 99 (24.6%) whose caregivers were a wife, husband or spouse. It was not possible to obtain information about caregivers' age in most medical records (87.1%; n=351); among the remaining 12.9%, the mean age was 53.1 years (SD= 17.3).

Table 1 presents data related to sociodemographic profile.

**Table 1- Sociodemographic data obtained from the medical records of patients admitted under palliative care from 2015 to 2018 (n=403). São Paulo, Brazil, 2018**

Variables	n	%
Sex		
Female	217	53.8
Male	186	46.2
Marital status		
Married	157	39.0
Widowed	116	28.8
Separated/divorced	43	10.7
Single	36	8.9
No information in the medical records	51	12.6
Principal caregiver		
Child	203	50.4
Spouse	99	24.6
Another family caregiver	59	14.6
Non-family caregiver	31	7.7
Parent	7	1.7
No information in the medical records	4	1.0

Regarding the clinical aspects, the results of the 403 medical records analyzed are presented in Table 2.

In 297 medical records, the record of at least one comorbidity was observed, and the most frequent was hypertension (205; 69%), followed by diabetes mellitus (95; 32%). A total of 55 (18.5%) patients had dyslipidemia and 36 (12.1%) had hypothyroidism.

Regarding the date of

recommendation for PC, it was observed that 238 patients (59.2%) received exclusive PC recommendation in their first admission in the said service. The exact dates of diagnosis indicative of PC were not obtained, as it would be possible to identify after how long the PC were indicated, which was a limitation.

Among the drugs most used during the first admission are dipyrone (90.6%; n=365), bromopride (78.2%, n=315),

morphine (66.7%; n=269), omeprazole (40.7%; n=164), enoxaparin (38.2%; n=154), and ondansetron (35.7%; n=144).

In only 47.1% (190) of the medical records, functional evaluation was recorded.

Through the use of KPS. Regarding the PPS, it was possible to obtain the measurements in only 17.6% (71) of the medical records, as highlighted in Table 3 below.

**Table 2 - Reasons for admission and diagnosis obtained from the medical records of patients admitted under palliative care from 2015 to 2018 (n=403). São Paulo, Brazil, 2018**

Variables	n	%
Reason for admission		
Dyspnea	98	24.3
Cough and sputum	55	13.6
Fever	51	12.6
Palliative care	49	12.1
Others	150	37.2
Diagnosis		
Head and neck cancer	98	22.4
Cervix cancer	73	16.7
Colorectal cancer	57	13.0
Dementia	51	11.7
Stomach cancer	49	11.2
Others	109	24.9

**Table 3 - Functional evaluation obtained from the medical records of patients admitted under palliative care from 2015 to 2018. São Paulo, Brazil, 2018**

Variables	n (%)	Variables	n (%)
KPS (190)		PPS (71)	
100%	1 (0,5)	100%	0
90%	12 (6,3)	90%	1 (1,4)
80%	18 (9,5)	80%	0
70%	23 (12,1)	70%	4 (5,6)
60%	23 (12,1)	60%	5 (7,0)
50%	41 (21,6)	50%	5 (7,0)
40%	30 (15,8)	40%	14 (19,7)
30%	14 (7,4)	30%	10 (14,1)
20%	22 (11,6)	20%	15 (21,1)
10%	6 (3,2)	10%	17 (23,9)

Regarding the outcome of the first admission, 214 patients (53.1%) were discharged from the hospital, 176 (43.7%) died and 13 (3.2%) transferred to another service. The mean number of days of admission was 9.7 (SD=15).

Of the total number of patients admitted under PC during the study period, 153 were readmitted. In readmission, there was a record of functional evaluation in only 30 and 20 medical records, evaluated through KPS and PPS, respectively. Among these records, there was a prevalence of KPS=40% (8; 26.7%), followed by 30 and 20 (5; 16.7%). Of the 20 medical records that had the PPS record, 7 (35%) patients had 30% functionality.

Of the readmitted patients, 77 (50.3%) died, 73 (47.7%) were discharged and three (2%) transferred to another service. The mean time between the date of discharge (at the first admission) and the date of readmission was 34 days.

## DISCUSSION

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Based on the information contained in the 403 medical records evaluated, the

present study outlined a profile of patients admitted under PC. There was a predominance of female sex, different from that found in another study, which aimed to identify the profile of admitted patients, with recommendation of PC in Minas Gerais, whose participants were mostly male (60.5%). The same study corroborated our findings by identifying a high number of elderly people, whose mean age was similar in both <sup>(13)</sup>.

Another study with cancer patients under PC obtained a higher percentage of women in their sample, however the mean age was lower than that obtained in the present study, whose age range ranged from 30 to 59 years <sup>(14)</sup>.

The advanced mean age identified among patients who were admitted under PC in this study is consistent with the current increase in longevity observed and, therefore, an increase in chronic health conditions <sup>(15)</sup>.

Regarding the formal time of study in full years, the present study identified that the majority of patients who had such information recorded in their medical records had incomplete elementary school, i.e., low education. This result differed from the



findings of a study that evaluated the quality of life of cancer patients admitted under PC, in which more than half of participants had complete elementary education <sup>(14)</sup>.

In the present study, the main caregiver was represented by the children, as well as in a study that aimed to determine the clinical-epidemiological profile and functionality of patients admitted under PC in a general teaching hospital (58.8%) <sup>(16)</sup>. The results found in the present study follow a normative line and reaffirm the existence of a sociocultural norm that children have the role of caring for elderly parents and many feel satisfaction, transforming the feeling of duty into motivation and inspiration for this care <sup>(17)</sup> and spouses to care for the care of their partners as a matter of respect responsibility and solidarity.

The active participation of the family in this PC process is fundamental. For this reason, this type of care also extends to patients' family network, also extending to the mourning phases before and after patients' death. It provides better coping with death, acceptance and also minimizing physical and psychological suffering, mainly

through spirituality, which represents a good influence on patients' lives and their relatives, alleviating tiredness and resuming emotional well-being <sup>(18)</sup>.

Regarding the main reasons for admission, recorded in the medical records evaluated in this study, dyspnea had a higher prevalence, followed by cough/sputum and fever. In other words, the main reasons for admission were related to symptom control, as well as, in a study conducted in Portugal, whose objective was to characterize the referral of patients to PC admission units in an Internal Medicine service, in which 49% of the participants were admitted for symptomatic control. <sup>(19)</sup>.

There was a predominance of oncological diseases among participants. The main diagnoses indicative of the need for PC were head and neck cancer, cervical cancer and colorectal cancer. The findings of this study differed from the results presented in another study, whose main diagnoses were represented by breast cancer (36.8%), colorectal cancer (17.5%) and ovarian cancer (7.0%) <sup>(20)</sup>. Also, in silva's study <sup>(14)</sup>, the prevalent diagnoses differed from those obtained in the present study, prevailing prevalent, gynecological (23.8%),

gastrointestinal system (19.1%) and breast (14.3%) cancers.

Evidence indicates that PC is more commonly offered to cancer patients than to those with other diseases of progressive character and without the possibility of cure. Studies indicate that one of the barriers may be related to lack of institutional guidelines to better identify patients who require PC and refer them in a timely manner to specialized services <sup>(21)</sup>.

Observing the comorbidities described in the study, the high prevalence of hypertension (HP) was identified (69%) among patients, which is one of the most dominant health problems today and is one of the important risk factors for the development of chronic cerebrovascular, cardiovascular and oral diseases. Despite committing a large number of old people of both sexes, negative outcomes or sequel of HP should not be seen as a normal consequence of aging <sup>(22)</sup>.

Chronic conditions mainly affect the older age segment, as seen in vigitel data, the Ministry of Health's Surveillance of Risk Factors for Chronic Noncommunicable Diseases (CNCDS). There is a higher prevalence of HP among people over 65

years (59.3%), affecting women more (27.3%) than men (21.2%), having a medical diagnosis frequency of 24.5%, this between 2010 and 2018 <sup>(23)</sup>.

In the case of eligibility for PC, it should be taken into account that it is difficult to assess and care for suffering, for this reason criteria were established to assist in this recommendation, given that patients have exhausted all possibilities of maintenance treatment or prolongation of life and that they present moderate to intense suffering, opting to maintain comfort and dignity of life <sup>(12)</sup>.

However, it is important to emphasize that PC cannot be limited to terminal care and should be offered during the course of the disease, with the purpose of optimizing the benefits. It is estimated that, worldwide, 40 million people require PC at some point, of which most of these patients have some progressive non-malignant disease, followed by the diagnosis of cancer <sup>(24)</sup>.

Relating all these issues described above, due to the decline in the organic functions of the elderly population, there is this involvement by chronic health conditions without the possibility of cure, which leads to

the context of end of life and requires PC. However, in addition to physical condition, psychological, social and spiritual aspects are present; thus, the humanization of care is sought, since this model is interdisciplinary and proposes active and integral care, especially to the elderly population that is affected by physiological and health changes that makes them dependent on this care <sup>(25)</sup>.

Considering the main reason for admission of patients in this study, medications for symptom relief were identified as the most frequent in use during admission. Most patients in our sample, as they already have varied diagnoses and associated diseases, used polypharmacy, i.e., pharmacological treatment was multiple, with five or more medications, which act together to assist in treatment and reduce symptoms. This high level of polypharmacy can be explained by the high rate of patients with chronic diseases, since they end up requiring a more rigorous drug therapy.

One of the principles of PC is to promote the relief of pain and other symptoms that worsen the quality of life of terminally ill patients. Therefore, adequate

pain control and evaluation of pharmacotherapy applied to treatment is one of the indicators of quality of life and good care and one of the objectives of this care <sup>(26)</sup>.

However, symptom control in PC requires an integrated and multidisciplinary team, which should think of the best alternatives for each case with caution, since there are adequate techniques to relieve suffering refractory to medications, such as palliative sedation. This depends on continuous reassessments of dose and type of medication, monitoring and continuous patient evaluation <sup>(26)</sup>.

Regarding the functional evaluation of patients, the KPS and PPS scales, used in the service in question, are important instruments for monitoring the evolution curve of the disease and have been used for decision-making in PC, in addition to predicting prognosis and diagnosis of terminality <sup>(12)</sup>.

The results identified that there was a scarcity of patient functionality records in the medical records, assessed by PPS. Among those medical records in which the information was recorded, most were with PPS < 20%, indicating considerably impaired

functionality, requiring assistance in personal care, thus requiring family support. Regarding the use of KPS, the most recorded functional status was 50% (indicating the need for considerable care and frequent medical care). Assessing a patient's functionality measured by both PPS and KPS showed an important degree of dependence of these patients.

A study aimed at evaluating the quality of life of cancer patients under PC identified that almost half of participants (47.6%) had a KPS of 50% <sup>(14)</sup>. A study suggests that PPS should be applied daily, as it is an auxiliary element in prognostic estimation and decision-making <sup>(27)</sup>. Nevertheless, considering the scarcity of records on functional evaluation in the medical records evaluated, it becomes unfeasible to infer any type of comparison between the findings of this study and the current literature on the subject.

In general, the lack of adequate record was observed in the medical records, and many important information was lost. The medical records are instruments that help in the evaluation of quality of care provided to patients <sup>(28)</sup>, presenting the evolution of each case and, thus, allowing

the better direction of care, enabling the adoption of the best therapy and measures to be taken in each case.

Besides being a tool for patients and multidisciplinary teams, medical records are an indispensable element for hospital management, adequate patient care, research and identification of the need for permanent education. It also presents itself as a document that conducts actions, ethical and professional defense <sup>(28)</sup>. The lack of information contained in it makes communication flawed or at least outdated, making the entire process for which it is intended difficult.

The scarcity of relevant information observed during data collection, related to the absence or incompleteness of records in the medical records, was an important limitation of this study.

## CONCLUSION

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The profile of patients admitted under PC between 2015 and 2018 was characterized by a majority of women, elderly, with low level of education, married or in consensual union and whose main

caregiver was the child. Regarding clinical characterization, the main underlying diseases were oncological diseases, followed by dementia; the reasons for admission were related to symptom control and the most used medications were dipyrone, bromopride, ondansetron and morphine.

The results reaffirm the aging of the population and, thus, the emergence of chronic-degenerative diseases, such as cancer, which in its course will point to the early need for PC in order to promote a better quality of life for patients. Therefore, it is necessary a directed view of the team, adding the foundations and principles of PC in order to promote actions capable of benefiting patients, families and caregivers, considering their physical, psychosocial and spiritual dimensions.

Despite the limitations imposed by the absence of relevant records in medical records, the present study allows the identification of important information about the profile of patients who need PC in the hospital context, enabling team training to make decisions capable of promoting the best care to be offered to this population.

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