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SOCIODEMOGRAPHIC AND CLINICAL PROFILE OF PATIENTS REFERRED TO THE PALLIATIVE CARE TEAM

Perfil sociodemográfico e clínico de pacientes encaminhados para a equipe de cuidados paliativos

Perfil sociodemográfico y clínico de los pacientes remitidos al equipo de cuidados paliativos

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ABSTRACT:

Objective: to identify the sociodemographic and clinical profile of patients in the first consultation with the Palliative Care team. **Method:** a cross-sectional study, developed with patients who attended their first consultation with the Palliative Care team. A form with sociodemographic and clinical variables and the Brazilian version of the Palliative Performance Scale and the Edmonton Symptom Assessment Scale were used. Non-parametric Mann-Whitney and Kruskal-Wallis tests were adopted. **Results:** the majority of participants were female, with an average age of 66.6 years, with an oncological diagnosis, who had metastases and low functional performance, and who had previously undergone chemotherapy, radiotherapy, and/or surgery. **Conclusion:** patients referred for the first consultation with the outpatient Palliative Care team were characterized by low functional capacity.

DESCRIPTORS: Palliative care; Forwarding; Multidisciplinary team.

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RESUMO:

Objetivo: identificar o perfil sociodemográfico e clínico de pacientes na primeira consulta com a equipe de Cuidados Paliativos. **Método:** estudo transversal, desenvolvido com pacientes que compareceram à primeira consulta com a equipe de Cuidados Paliativos. Utilizou-se formulário com variáveis sociodemográficas e clínicas, a Escala de Desempenho em Cuidados Paliativos versão 2 e a Escala de Avaliação de Sintomas de Edmonton. Adotaram-se testes não paramétricos de Man-Whitney e Kruskal-Wallis. **Resultados:** a maioria dos participantes foi do sexo feminino, com idade média de 66,6 anos, com diagnóstico oncológico, que apresentavam metástases e baixo desempenho funcional e que foram submetidos, previamente, a quimioterapia, radioterapia e/ou cirurgia. **Conclusão:** os pacientes encaminhados para a primeira consulta com a equipe ambulatorial de Cuidados Paliativos caracterizaram-se pela baixa capacidade funcional.

DESCRITORES: Cuidados paliativos; Encaminhamento; Equipe multiprofissional.

RESUMEN

Objetivo: identificar el perfil sociodemográfico y clínico de los pacientes en la primera consulta con el equipo de Cuidados Paliativos. **Método:** estudio transversal, desarrollado con pacientes que acudieron a su primera consulta con el equipo de Cuidados Paliativos. Se utilizó un formulario con variables sociodemográficas y clínicas y la versión brasileña de la Escala de Desempeño Paliativo y la Escala de Evaluación de Síntomas de Edmonton. Se adoptaron las pruebas no paramétricas de Man-Whitney y Kruskal-Wallis. **Resultados:** la mayoría de los participantes fueron del sexo femenino, con edad promedio de 66,6 años, con diagnóstico oncológico, que presentaban metástasis y bajo rendimiento funcional y que habían sido sometidos previamente a quimioterapia, radioterapia y/o cirugía. **Conclusión:** los pacientes remitidos para la primera consulta al equipo de Cuidados Paliativos ambulatorios

INTRODUCTION

Advances in living and working conditions, in the context of the epidemiological transition, have reduced the effect of infectious diseases on the process of individuals becoming ill and dying, leading to a gradual increase in life expectancy.1 However, there has been an increase in chronic non-communicable diseases. In addition, the process of population aging and the adoption of unhealthy lifestyle habits by the population corroborate the worsening of health conditions and the consequent need for Palliative Care (PC).[2]

PC consists of a therapeutic approach that aims to improve the quality of life of patients whose health condition is life-threatening and their families. This approach includes the prevention and relief of suffering in the physical, psychosocial and spiritual spheres, offering health care to treat pain and other symptoms experienced by these individuals.[3]

There are various health conditions that require a PC approach. The majority of adults who require PC have chronic health conditions such as cancer, cardiovascular, pulmonary, neurological, hepatic and cerebrovascular diseases. Worldwide, it is estimated that approximately 56.8 million individuals need this health approach every year, 25.7 million of whom are nearing the end of their lives.[4]

Studies show that when PC is started early, there is an improvement in quality of life, mood, symptoms and greater satisfaction with the treatment.[5,6] It should be noted that, in the outpatient setting, the actions of the PC team have significant benefits for patients.[7] However, referral to the PC team usually occurs late, considering the progression of the disease.[8]

In this way, identifying the sociodemographic and clinical profile of patients referred to the PC outpatient team is essential for planning strategies and establishing criteria for early referral, so that these individuals can benefit from a comprehensive PC approach. In addition, there is a lack of national studies on this subject.

The aim of this study was to identify the sociodemographic and clinical profile of patients during their first consultation with the Palliative Care team.

METHOD

This is a cross-sectional, descriptive study with a quantitative approach. The study was carried out at the PC outpatient clinic of the Hospital das Clínicas of the Ribeirão Preto Medical School of the University of São Paulo (HCFMRP-USP). A consecutive, non-probabilistic sample consisted of patients of both sexes aged over 18 who had been referred for their first consultation with the PC outpatient team at HCFMRP-USP.

For data collection, an instrument was drawn up with the sociodemographic and clinical variables of interest to the study. This instrument was validated by three PC specialists. In addition, the Palliative Care Performance Scale version 2 (EDCP v2)[9] and the Edmonton Symptom Assessment Scale (ESAS-Br) were used.[10]

The Palliative Care Performance Scale version 2 (EDCP v2) is the Brazilian translation of the Palliative Performance Scale version 211 and consists of an instrument that makes it possible to assess the functional performance of patients in PC, considering aspects such as ambulation, activity and evidence of the disease, self-care, eating and level of consciousness. This scale ranges from 100%, which indicates maximum functional activity, to 0%, indicating death.[11]

The Edmonton Symptom Assessment Scale (ESAS-Br) was validated for Brazil[11] based on the Edmonton Symptom Assessment System.[12] The ESAS is a scale that assesses the patient's perception of the intensity of physical and psychological symptoms. It is made up of a list of nine symptoms that are frequently experienced by cancer patients: pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, sadness, anxiety and well-being.

The intensity of each of the symptoms listed is measured using a numerical scale ranging from zero to 10 on which the patient marks the value corresponding to their perception of the intensity of the symptoms. Zero represents the absence of the symptom and 10 represents the symptom in its strongest manifestation.[11]

Patients were also asked if they knew what PC was and if they had been advised about referral to the PC team by the doctors at their clinic of origin.

Data collection took place between June 2022 and July 2023. The data collected was structured in Microsoft Excel® 2019 spreadsheets and double typed to minimize transcription errors. The qualitative variables were described in terms of absolute frequency and percentage, while the quantitative variables were described using measures of central tendency (mean) and dispersion (standard deviation).

In addition, the Kruskal-Wallis and Mann-Whitney13 non-parametric statistical tests were carried out to compare the scores of some variables. In these cases, these variables were described using median values. A significance level of 0.05 was adopted. The statistical program IBM Statistical Package for Social Science (SPSS) version 24.0 for Windows was used. The research project was drawn up in accordance with the precepts of CNS Resolution 466/1214 and was approved by the Research Ethics Committee of the Ribeirão Preto School of Nursing under No. 3.895.877 and CAAE 25880919.0.0000.5393.

RESULTS

Seventy patients who were waiting for their first appointment with the PC outpatient team took part in the study. Table 1 shows the participants' sociodemographic data.

Table 1 - Sociodemographic data of participants at their first appointment with the PC outpatient team*. Ribeirão Preto, SP, Brazil, 2023.

Variables	n	%	Median (SD)
Gender			
Female	37	52,9	
Male	33	47,1	
Age (in years)			66,6 (12,1)
Schooling (in years of study)			5,8 (4,9)
Marital status			
Married or in a stable union	31	44,3	
Separated or divorced	13	18,6	
Single	13	18,6	
Widowed	13	18,6	
Origin			
Administrative region of Ribeirão Preto	29	41,4	
Ribeirão Preto	30	42,9	
Other cities in the state of São Paulo	11	15,7	
Religion			
Catholic	43	61,4	
Evangelical	21	30,0	
Other religions or report of belief in God	6	8,5	

*PC = Palliative Care

Table 2 shows the caregivers' sociodemographic data.

Table 2 - Sociodemographic data of patients' caregivers at the first appointment with the PC outpatient team*. Ribeirão Preto, SP, Brazil, 2023.

Variables	n	%	Median (SD)
Main caregiver			
Children	33	47,1	
Wife, husband or spouse	13	18,6	
Other relative	10	14,3	
No caregiver	9	12,9	
Formal caregiver	3	4,3	
Long-stay institution (ILP)	2	2,9	
Age of main caregiver (in years)			49,7 (14,1)
Caregiver lives with participant			
Yes	45	76,3	
No	14	23,7	
The caregiver carries out domestic activities			
Yes	51	87,9	
No	7	12,1	

*PC = Palliative Care

The participants' clinical data is shown in Table 3. Of the medical diagnoses that led to referral to the PC team, 56 (80%) were oncological diagnoses and 14 (20%) were non-oncological. Of the patients with cancer diagnoses, 29 (51.8%) had metastases. With regard to continuous medication, 31 (44.3%) participants used dipyrone, 22 (31.4%) morphine and 16 (22.8%) gabapentin. In addition, with regard to comorbidities, 37 (52.8%) had systemic arterial hypertension, 11 (15.7%) dia-

betes mellitus and 11 (15.7%) other cardiovascular conditions.

Table 3 - Participants' clinical data at the first appointment with the PC outpatient team*. Ribeirão Preto, SP, Brazil, 2023.

Variáveis	n	%
First appointment with the PC team		
PC outpatient clinic	51	72,9
Internal Medicine Outpatient Clinic	5	7,1
Clinical Oncology Outpatient Clinic	5	7,1
Infirmary	6	8,5
Baseline disease that led to referral to the PC team		
Primary tumor site - Head and neck neoplasm	11	15,7
Neurological diseases	8	11,4
Hematological tumors	6	8,6
Primary tumor site - Breast neoplasm	6	8,6
Primary tumor site undetermined	5	7,1
Primary tumor site - Colon and rectum neoplasm	5	7,1
Non-oncological diseases	6	8,6
Other neoplasms	23	32,9
Amount of metastasis		
Metastasis to one site	9	31
Metastasis to two sites	7	24,1
Metastasis to three sites	7	24,1
Metastasis to four sites or more	4	13,8
Types of metastasis		
Liver metastasis	11	37,9
Metastasis to lymph nodes	11	37,9
Metastasis to CNS**	10	34,5
Lung metastasis	10	34,5
Disease-modifying treatment		
Chemotherapy, radiotherapy and surgery	12	21,4
Chemotherapy	10	17,9
Treatment-naive	8	14,3
Chemotherapy and surgery	8	14,3
Chemotherapy and radiotherapy	7	12,5
Radiotherapy	4	7,1
Radiotherapy and surgery	4	7,1
Surgery	2	3,6
Radiotherapy and hormone therapy	1	1,8
Reason for referral to the outpatient PC team		
Symptom control	55	78,6
Disease progression	15	21,4

*PC = Palliative Care. **CNS = Central Nervous System.

Table 4 shows the comparisons between the symptom scores reported by participants with cancer and non-cancer diagnoses, taking into account the symptom intensity data of 66 participants for sleepiness and 67 for the other symptoms. There was no significant difference between the scores. The median score on the Palliative Care Performance Scale (version 2) for participants with an oncology diagnosis was 55 and the median score for participants with a non-oncology diagnosis was 50. The result of the Kruskal-Wallis test was 0.776 and the Mann-Whitney test was 0.264. Therefore, no significant difference was identified between the two groups, considering the symptoms reported and the functional capacity between the groups.

Table 4 - Comparison of symptom intensity scores presented by patients with an oncological and non-oncological diagnosis at the first consultation with the PC outpatient team* using the ESAS-Br**. Ribeirão Preto, SP, Brazil, 2023.

Variables	Cancer diagnosis Median	Non-oncological diagnosis Median	Kruskal-Wallis test	Mann-Whitney test
Pain	3	1	0,450	0,767
Tiredness	5	1	0,391	0,742
Drowsiness	0	0	0,767	0,965
Nausea	0	0	0,369	0,451
Lack of appetite	5	1	0,464	0,193
Shortness of breath	0	0	0,582	0,110
Depression	4	2	0,488	0,471
Anxiety	4	4	0,759	0,955
Well-being	5	6,5	0,778	0,548

*CP = Palliative Care. **ESAS-Br = Edmonton Symptom Assessment Scale.

With regard to the time between diagnosis and the first appointment with the PC outpatient team, data was obtained from only 55 individuals (the missing data refers to those patients who were unable to provide information and whose information was not obtained from medical records). Participants with an oncological diagnosis had a median of 0 years, with a minimum of 0 years and a maximum of 8 years, while participants with a non-oncological diagnosis had a median of 5 years, with a minimum of 0 years and a maximum of 27 years (the numeral zero indicates a referral of less than 12 months between diagnosis and the first consultation). The result of the Kruskal-Wallis test was 0.004 and the Mann-Whitney test was 0.016, indicating that patients with a non-oncological diagnosis were referred to the PC team later than patients with an oncological diagnosis.

Table 5 - Shows the data on the functional capacity of the participants at their first appointment with the outpatient PC team.

Variables	n	%
PC Performance Scale version 2		
10%	1	1,4
20%	2	2,9
30%	6	8,6
40%	11	15,7
50%	17	24,3
60%	12	17,1
70%	12	17,1
80%	6	8,6
90%	3	4,3

*PC = Palliative Care.

In addition to the sociodemographic and clinical data collected, the participants were asked about the meaning of PC and information on referral to the first appointment with the PC outpatient team. It is worth noting that 56 (78.6%) participants did not know what PC was and 37 (52.9%) said they had not received any information about referral to the PC team from the doctors at their clinic of origin.

DISCUSSION

This study did not show any significant difference in terms of the sex of the participants, which is similar to what was found in another study which aimed to define the clinical-epidemiological profile of cancer patients treated at a public outpatient clinic specializing in PC, in which there was also no significant difference.[15] In this study, the participation of women was slightly higher than that of men. However, the literature shows that the adjusted cancer incidence rate was 19% higher in males (222.0 per 100,000) compared to females (186.0 per 100,000), with differences between different regions of the world.[16]

Worldwide, the majority of people who need PC every year are adults aged over 50, as seen in this study.[4] It should be noted that the advanced average age identified is related to the increased longevity of the Brazilian population, a consequence of Brazil's demographic transition process, in which the population has aged.[17]

The average years of schooling of the participants in this study corresponded to incomplete primary education, which is in line with another study, in which 31.3% of the participants had no formal schooling and 38.9% had studied up to primary education.[15] It should be noted that low levels of schooling can be an obstacle for individuals to access the Unified Health System (SUS), to understand the instructions given by health professionals and in the process of self-care.[18]

In a study that aimed to identify the burden among caregivers of adult patients undergoing PC, 42.5% of the caregivers were children, with a mean age of 56.7 years and 77.5% lived with the patients,[19] data similar to that found in this study.

This study found that all the participants reported a connection with spirituality, either through religion or just belief in God, as analyzed in another study,[20] which found that spirituality provides meaning and comfort in addition to conventional treatment. However, it should be noted that the demands made by patients in relation to spirituality are often disregarded, minimized or not identified by health professionals.[21]

Among the participants with an oncological diagnosis, considering solid tumors, the most frequent primary site in this study was the head and neck region, as identified in another study.[22] However, this data differs from another study in which the most prevalent primary sites were the prostate and breast.[15] In another study on PC patients,[23] the majority of participants did not have an underlying oncological disease and among those who had an oncological diagnosis, the most frequent primary tumor site was the prostate, data that differs from this study.

Head and neck cancer corresponds to neoplasms that originate in the pharynx, larynx, trachea, oral cavity, neck lymphomas, salivary glands, ear, paranasal sinuses, skull base, paragangliomas found in this region, with the exception of the thyroid gland. These neoplasms may be related to alcohol and tobacco consumption, papillomavirus (HPV) infection, unhealthy diet, family history and lack of physical activity.[24]

The most common treatments for head and neck cancer are radiotherapy, surgery and chemotherapy and, depending on the stage of the disease, different types of therapy may be combined. It should be noted that for the treatment of more advanced tumors, there is usually a combination of multimodal and more aggressive treatments.[25]

As identified in this study, another finding in the literature indicates that more than half of the patients had metastases on admission to PC.[15] Another study found that the most prevalent sites of metastasis were liver, lung, bone and lymph nodes.19 In this study, liver, lymph node and lung metastases were also among the most significant results. However, the occurrence of CNS metastasis was also observed, diverging from the aforementioned study. It should be noted that metastasis is an aggressive condition which limits a favorable prognosis and the positive evolution of antineoplastic treatment.[26]

Authors have identified symptom control and disease progression as the main reasons for referral to PC,[15] as in this study. With regard to disease-modifying treatment, in a study which aimed to characterize cancer patients hospitalized under PC undergoing peripheral venous puncture and hypodermoclysis, more than 60% of the participants had undergone chemotherapy, radiotherapy and/or surgery,[27] a figure lower than that identified in this study, in which more than 80% of the individuals underwent one or more of these procedures.

Communication, in the context of the transition to PC, is a

complex process for health professionals, which leads to the development of barriers between the multidisciplinary team, patients and families.[28] In the present study, there were problems in the communication process between the patient who was referred to PC and the doctor responsible for the referral, considering that more than half of the participants did not receive guidance on the reason for the referral to the PC team, nor did they know the meaning of PC.

According to the results of this study, more than half of the participants had a score of 50% or less on the Palliative Care Performance Scale version 2. Another study identified an average of 56.77 in relation to the functionality of the participants using the same scale.15 It should be noted that values of 50% or less on this scale represent individuals with significantly impaired functional capacity, indicating the need for full-time care and, as a consequence, family restructuring to deal with this new context.[12]

CONCLUSION

The sociodemographic and clinical profile of the patients referred for their first outpatient consultation with the PC team comprised females, aged over 65, married or in a stable union, with a low level of education and from Ribeirão Preto - SP. The main reason for referral was symptom control and disease progression. Oncological diagnosis was predominant, most of the participants had metastases and had previously undergone chemotherapy, radiotherapy and/or surgery, and had low functional capacity.

The intensity of symptoms did not differ between oncological and non-oncological participants, nor did functional status. The participant with a non-oncological diagnosis took longer to be referred for a consultation with the outpatient PC team. In addition, the majority of patients had not received prior guidance on referral to the PC team and did not know what PC is.

It should be noted that the results of this study indicate a late referral to the PC team, making it impossible for patients to benefit fully from PC.

LIMITATIONS

One of the limitations of the study is the number of participants, since a larger sample would allow for a better definition of this population. However, it should be noted that during the data collection period, there was low patient adherence to follow-up with the PC outpatient team, with many missed appointments.

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