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Original Article

Profile of patients in need of palliative care in a public tertiary hospital ward in Northeastern Brazil

Perfil de pacientes com necessidade de cuidados paliativos em enfermaria de hospital público terciário no Nordeste do Brasil

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ABSTRACT

Introduction: Palliative care (PC) is an approach that improves the quality of life of patients facing problems associated with life-threatening illnesses.

Objective: To investigate the prevalence, clinical, and epidemiological profile of hospitalized patients and those referred for PC in a tertiary hospital ward in a capital city in the Northeast of Brazil.

Methods: This was an observational, descriptive, and cross-sectional study. The modified SPICT (Support & Palliative Care Indicators Tool) and sociodemographic profile forms were applied to patients of legal age admitted to the ward between July and August 2022, after consent was obtained and signed. The data was obtained through percentage analyses of the sample.

Results: The profile was composed of men approximately 55 years old, black or mixed race, with incomplete primary education, monthly family income of 1 to 3 minimum wages, with comorbidities. The majority (64%) scored on the SPICT, with an indication for PC, but only 10.5% received such care.

Conclusion: Of the patients taking part in the study, 64% of them scored two or more general indicators of worsening and at least one specific indicator of advanced disease, suggesting the indication for palliative care. However, only 10.5% of the sample who needed palliative care actually received it.

Keywords: Palliative Care; Health Profile; Internal Medicine; Brazil.

RESUMO

Introdução: Os cuidados paliativos (CP) são uma abordagem que melhora a qualidade de vida dos pacientes que enfrentam problemas associados a doenças que ameaçam a vida.

Objetivo: Investigar a prevalência e o perfil clínico e epidemiológico de pacientes internados e daqueles com indicação para CP em uma enfermaria de clínica médica de um hospital terciário em uma capital do Nordeste do Brasil.

Métodos: Estudo observacional, descritivo e transversal. Foram aplicados os formulários SPICT (*Support & Palliative Care Indicators Tool*) modificado e de perfil sociodemográfico a pacientes maiores de idade internados na enfermaria entre julho e agosto de 2022, após anuência e assinatura de termo de consentimento. Os dados foram obtidos através de análises percentuais da amostra.

Resultados: O perfil foi composto por homens de aproximadamente 55 anos, pretos ou pardos, com ensino fundamental incompleto, renda familiar mensal de 1 a 3 salários-mínimos e portadores de comorbidades. A maioria (64%) pontuou no SPICT, com indicação para CP, mas apenas 10,5% recebiam este cuidado.

Conclusão: Dos pacientes que participaram do estudo, 64% deles pontuaram dois ou mais indicadores gerais de piora e ao menos um indicador específico de doença avançada, sugerindo a indicação de cuidados paliativos, entretanto, apenas 10,5% da amostra que necessitava de cuidados paliativos os recebia.

Descritores: Cuidados Paliativos; Perfil de Saúde; Medicina Interna; Brasil.

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INTRODUCTION

According to the World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illnesses, and that prevents and alleviates suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual[1,2].

Most patients who need palliative care (76%) live in poor or developing countries[1]. Each year, around 56.8 million people, including 25.7 million in the last year of life, need palliative care. Worldwide, only around 14% of people who need palliative care currently receive it[1].

In Brazil, the inadequate training of professionals and restrictions on the use of medication, as well as the limited hospital structure and health care network are factors that make it difficult to include patients in palliative care, especially in the public service and in poor regions of the country. Moreover, retrospective studies show that even experienced clinicians are inaccurate when prognosticating patients, which can delay the indication of palliative care in patients who need it[3].

Thus, understanding the profile of a health service, and whether palliative care is being provided adequately among patients can have an impact on the creation of actions such as hospital protocols and team training, which can reduce dysthanasia and improve care[2,3].

Considering the need to investigate the profile of patients with an indication for palliative care within the health system, this study aims to provide data to promote improvements in the implementation of this type of care, as well as suggesting social determinants that can have a direct impact on assistance. Carrying out this study in a tertiary hospital located in a capital of the Brazilian Northeast, one of the poorest regions in Brazil, aims to assess the picture of palliative care in one of the region's medical centers, in the internal medicine sector, the focus of this study. Its objective was to investigate the prevalence, clinical and epidemiological profile of inpatients and those referred for PC in a medical ward in a tertiary hospital in a capital city in the Northeast of Brazil.

METHODS

This was an observational, descriptive and cross-sectional study. The population analyzed was those who had been admitted to hospital during the proposed period; no sample calculation was carried out to select candidates. In this context, patients admitted to the internal medicine ward of a tertiary hospital located in a capital city in the Northeast of Brazil between June and August 2022 were interviewed. All patients over the age of 18 admitted in the unit in the three months during which the survey was carried out were considered eligible for participation. Thus, 100% of the patients admitted to the medical ward during the proposed period were included in the study.

Patients were asked to answer a questionnaire after the aim, risks and benefits of the research had been explained. The modified Support & Palliative Care Indicators Tool (SPICT) tool was then applied. SPICT is an instrument developed at the University of Edinburgh in 2010 and widely used in the UK National Health System. The tool was developed with the aim of assessing patients in deteriorating clinical condition, as a method of aiding holistic and future planning[4,5]. It is currently a highly widespread tool in palliative care and hospice services to support therapeutic decisions and has even been translated and validated in Portuguese language[5]. The instrument has two types of indicators, general indicators of worsening and specific indicators of advanced disease. Among those interviewed, those with two or more general indicators of worsening and at least one specific indicator of advanced disease were considered suitable for palliative care. SPICT is not a quantitative analysis tool, but a qualitative one. According to the tool, if there are two positive criteria for general indicators of worsening health and one for a specific marker of advanced disease, palliative care is required.

All the participants were given a sociodemographic profile questionnaire, which asked about marital status, ethnicity, origin, religion, monthly family income (in minimum wages), previous comorbidities, smoking habits, drinking habits and whether they had received medical care in the previous year. The questionnaires were administered in person, after the participant or their guardian had signed the informed consent form, and the researcher verbally asked the questions on the questionnaires and registered the answers.

Medical records were analyzed on the same day as the interviews to determine whether or not the patients had already been referred for palliative care.

Statistical analysis of the data was carried out with percentage evaluations of the characteristics of the group analyzed: gender, religion, ethnicity, monthly family income, percentage of smokers and drinkers and how many had received regular medical care in the previous year. An arithmetic mean analysis assessed the age of the participants.

This study was approved by the Research Ethics Committee (CAAE nº 61720122 4 0000 5197). Those who agreed to take part in the study signed the proposed informed consent form.

RESULTS

The study included the entire population treated at the service between June and August 2022, totaling 88 patients admitted to the internal medicine ward. It was noticed that 64.7% of the sample (n = 57) scored high on the SPICT tool and were considered to have an indication for palliative care. Among the most prevalent pathologies, 12 patients (13%) were admitted to the ward with a diagnosis of leptospirosis and eight (9%) with anemia. Another eight (9%) were diagnosed with a urinary tract infection. These three pathologies alone accounted for 31% of all admissions to the ward during the period.

In the group of patients who scored in the SPICT, the majority were men. We analyzed 33 men who had an indication for palliative care according to SPICT, compared to 24 women. Despite the difference in absolute numbers, proportionally, 72.7% of women scored in the SPICT, compared to 60% of men (Table 1).

Among the group of patients with an indication for palliative care, only six (10.5% of the patients who scored in the SPICT) had palliative care instituted by the medical team when they were interviewed by the survey, three men and three women.

As for the sociodemographic profile of the sample analyzed, it was found that the majority of the population was made up of 33 middle-aged men (62.5%), with a mean age of 54.8 years, with the mean age of women being 58.75 years and men 52.54 years. The oldest patient in the sample was 92 years old and the youngest, 20 years old.

Most of the sample was made up of black and mixed-race people (a total of 70% of the sample, 47% self-declared brown and 23% self-declared black), married (43%), from the metropolitan region of Recife (63%), with incomplete primary education (15%), with a monthly family income of between 1 and 3 minimum wages (77%). Just over half of the sample had been seen by a doctor in the previous year (54%), the majority did not drink (56%), did not smoke (72%) and had comorbidities (63%). Hypertensive patients accounted for 31% of the sample and diabetics for 26%. The other 43% reported more than 30 previous comorbidities, which were not calculated individually.

The group of patients indicated for palliative care were mostly men, making up 33 of the 57 patients who scored in the SPICT (57.8% of the sample). Although the absolute majority of indications for palliation were among the male population, proportionally, women were indicated for palliative care in 72.7% of cases, compared to 60% of men.

The mean age of female inpatients with an indication for palliative care was also higher than that of women in general. Among those who scored in the SPICT, 62.5 years was the mean age, compared to 58.75 years in the general group and 48.7 years in the group of women who did not score in the SPICT (Table 1). The prevalence of comorbidities among all the women was also higher among the general sample, with 76% of them having some pre-existing comorbidity, compared to 55% of the men and 63% of the general sample. The majority of the female sample was illiterate (24%), married (39%), black or brown (73%, with 21% self-declared black and 52% self-declared brown), and had a monthly family income of between 1 and 3 minimum wages (88%). Around 55% have received regular medical care in the previous year. Around a third were alcoholics (30%), another 24% were smokers and had comorbidities (76%) (Table 2).

In the male group, the mean age was 52.54 years in the general group, 59 years in the group with an indication for palliative care and 42.5 years in the group with no indication for palliative care (Table 2). Of the total sample, 45% were married, 70% black or brown (25% self-declared black and 45% self-declared brown), 33% evangelical, 73% from the Metropolitan Region of Recife (RMR, in the Portuguese acronym), 20% with incomplete primary education, the majority with a family income of between 1 and 3 minimum monthly wages (69%), who had been followed up by a doctor in the previous year (55%), alcoholics (47%) and smokers (31%), a further 55% had comorbidities (Table 2). Of the total sample, 20% had systemic arterial hypertension and another 15% had diabetes.

Among all the patients who scored in the SPICT, the mean age was 60.47 years, compared to 54.8 years for the total sample. Among these, 57.8% were men and 42% women, 45.6% married, 67% black or brown, 44% evangelical, 82% from the RMR, 19% with incomplete primary education, around 79% with an average family income of 1 to 3 minimum monthly wages, with 58% of the sample having been followed up by a doctor in the previous year, 48% alcoholics, 30% smokers and 70% with comorbidities (Table 3).

As for the sociodemographic profile, the patients with an indication for palliative care had a similar profile to the general sample. The majority of the sample was made up of men, married, evangelical, with a family income of between 1 and 3 minimum wages, non-alcoholics, non-smokers and most of whom had comorbidities. Thus, despite inferring the possibility that greater social vulnerability factors, lower socioeconomic status and more comorbidities could contribute to a greater need for palliative care, in this study the samples seemed to be relatively homogeneous.

Table 1. Patients who scored or not on the SPICT, age of the groups.

	Women	Men	General
	(N = 33; 37.5%)	(N= 55; 42.5%)	(N = 88; 100%)
Scored on the SPICT	24 (72.7%)	33 (60%)	57 (64%)
Mean age (years old)	62.5	59.0	59.71
Did not score on the SPICT	11 (27.3%)	22 (40%)	33 (37.5%)
Mean age (years old)	48.7	42.95	44.8

Abbreviation: SPICT - Support & Palliative Care Indicators Tool.

Table 2. Sociodemographic profile of the general population and by gender.

	Women	Men	General
	(N = 33; 37.5%)	(N= 55; 42.5%)	(N = 88; 100%)
Mean age (years old)	58.75	52.54	54.8
Marital status			
Married	13 (39%)	25 (81%)	38 (44%)
Single	9 (27%)	25 (45%)	34 (39%)
Widowed	8 (24%)	6 (11%)	14 (16%)
Divorced	3 (9%)	4 (7%)	7 (%)
Ethnicity			
Mixed race	17 (52%)	25 (45%)	42 (47%)
Black	7 (21%)	14 (25%)	21 (23%)
White	6 (18%)	10 (18%)	16 (18%)
Yellow	1 (3%)	3 (5%)	4 (4.5%)
Not declared	2 (6%)	3 (5%)	5 (6%)
Religion			
Not religious	1 (3%)	17 (31%)	18 (20.5%)
Evangelical	16 (48%)	18 (33%)	34 (39%)
Catholic	10 (30%)	15 (27%)	26 (29%)
Spiritist	1 (3%)	1 (2%)	2 (2%)
Christian	5 (15%)	4 (7%)	9 (10%)
Origin			
Metropolitan Region of Recife	25 (78%)	40 (73%)	65 (73%)
Another municipality in Pernambuco	8 (22%)	11 (20%)	19 (21%)
Municipality in another state	0	4 (7%)	4 (4.5%)
Education			
Not declared	14 (45%)	24 (44%)	38 (43%)
Complete university degree	0	1 (1%)	1 (1%)
High school completed	4 (12%)	5 (9%)	9 (10%)
High school incomplete	1 (3%)	2 (4%)	3 (3%)
Elementary school completed	3 (9%)	7 (13%)	10 (11%)
Elementary school incomplete	3 (9%)	11 (20%)	14 (16%)
Illiterate	8 (24%)	5 (9%)	13 (14%)

Table 2. Cont.

	Women	Men	General
	(N = 33; 37.5%)	(N= 55; 42.5%)	(N = 88; 100%)
Monthly Family Income			
Less than 1 minimum wage	4 (12%)	12 (22%)	16 (18%)
1 to 3 minimum wages	29 (88%)	38 (69%)	67 (76%)
4 to 10 minimum wages	0	4 (5%)	4 (4.5%)
More than 10 minimum wages	0	1 (1%)	1 (1%)
Medical follow-up in the previous year			
Yes	18 (55%)	30 (55%)	48 (54%)
No	15 (45%)	25 (45%)	40 (46%)
Alcoholic			
Yes	10 (30%)	26 (47%)	36 (41%)
No	23 (70%)	29 (53%)	52 (59%)
Smoker			
Yes	10 (30%)	17 (31%)	27 (30%)
No	23 (70%)	38 (43%)	61 (70%)
Previous Comorbidities			
Yes	25 (75%)	30 (55%)	55 (63%)
No	8 (24%)	25 (45%)	33 (37.5%)

Table 3. Sociodemographic profile of the general population and the population that scored in the SPICT.

	Population that scored in the SPICT	General population
	(N= 68, 77.2%)	(N = 88, 100%)
Gender		
Men	33 (57.8%)	55 (62.5%)
Women	24 (42%)	33 (37.5%)
Mean age (years old)	60.47	54.8
Marital status		
Married	26 (45.6%)	38 (43%)
Single	15 (26.3%)	30 (34%)
Widowed	14 (24.5%)	14 (16%)
Divorced	2 (3.5%)	6 (7%)
Ethnicity		
Mixed-race	24 (42%)	42 (47%)
Black	14 (25%)	21 (23%)
White	14 (25%)	16 (18%)
Yellow	2 (3.5%)	4 (4.5%)
Not declared	2 (3.5%)	5 (6%)
Religion		
Not religious	9 (18%)	18 (20.5%)
Evangelical	25 (44%)	34 (39%)
Catholic	18 (32%)	26 (29%)

Table 3. Cont.

	Population that scored in the SPICT (N= 68, 77.2%)	General population (N = 88, 100%)
Spiritist	1 (1%)	2 (2%)
Christian	4 (7%)	9 (10%)
Origin		
Metropolitan Region of Recife	47 (82%)	65 (73%)
Another municipality in Pernambuco	8 (14%)	19 (21%)
Municipality in another state	3 (5%)	4 (4.5%)
Education		
Not declared	26 (45%)	38 (43%)
Complete university degree	0	1 (1%)
High school completed	1 (2%)	9 (10%)
High school incomplete	2 (4%)	3 (3%)
Elementary school completed	8 (14%)	10 (11%)
Elementary school incomplete	11 (19.)	14 (16%)
Illiterate	10 (15%)	13 (14%)
Monthly Family Income		
Less than 1 minimum wage	10 (18%)	15 (17%)
1 to 3 minimum wages	45 (79%)	68 (77%)
4 to 10 minimum wages	2 (4%)	4 (4.5%)
More than 10 minimum wages	0	1 (1%)
Medical follow-up in the previous year		
Yes	33 (58%)	48 (54%)
No	24 (42%)	40 (46%)
Alcoholic		
Yes	24 (42%)	39 (44%)
No	22 (58%)	49 (56%)
Smoker		
Yes	17 (30%)	25 (28%)
No	40 (70%)	63 (72%)
Previous Comorbidities		
Yes	40 (70%)	55 (63%)
No	17 (30%)	33 (37.5%)

Abbreviation: SPICT - Support & Palliative Care Indicators Tool.

DISCUSSION

Most of the patients analyzed were black and brown men. According to data from the National Household Sample Survey (Continuous PNAD, in the Portuguese acronym) 2021, 43.0% of Brazilians declared themselves as white, 47.0% as brown and 9.1% as black, which suggests that in the sample analyzed there was a greater presence of black and brown patients compared to the Brazilian population[6]. An interesting fact is that, although most of the sample was made up of men who needed palliative care at the time of the interview, the literature suggests that it is more difficult to implement this type of care for men.

Men are often taught that expressing emotions is "unmanly" and that vulnerability is a weakness[7]. This can discourage them from seeking support at the end of life or communicating their feelings and symptoms to health professionals. Men find it more difficult to communicate needs, fears or perceived weaknesses, while women, in general, are more encouraged to talk about their subjectivity and fragil-

ity, even at the end of life. The fact that the sample had low implementation of care may be related to the fact that, in this study, a large part of the sample was made up of men.

Another significant fact is that the majority of patients were evangelicals, as opposed to the national majority, i.e., Catholics. According to the 2010 census, evangelicals made up 22.2% of the population, an increase of around 16 million compared to the 2000 census[8]. The fact that most of the patients interviewed had a religion is a favorable aspect when considering the role of spirituality in palliative care. Religion helps to find comfort in religious/spiritual beliefs, leading to the construction of meaning and sense, which are important in the end-of-life process.[9]

The latest National Health Survey (PNS, in its Portuguese acronym) carried out in 2019 found that 12.7% of Brazilians were smokers, with an average of 10.8% in the Northeast. Among women, the average was 9.6% among Brazilians and 7.7% in the Northeast, while among men, the average was 15.9% nationally and 14.2% in the Northeast[10]. In the 2021 evaluation of the Surveillance System for Risk and Protective Factors for Chronic Diseases by Telephone Survey (VIGITEL, in its Portuguese acronym), the frequency of adult smokers was higher in males (11.8%) than in females (6.7%)[11]. The incidence of smokers in this survey was higher than that reported in epidemiological data, but this difference may also reflect the fact that the survey considered previous or current smoking, while the information collected by the PNS and Vigitel only showed current and active smoking[10,11]. Another point is that, according to Vigitel, higher smoking rates were reported among populations with lower socioeconomic status and among black or brown people[11], a profile compatible with that of the population analyzed. Thus, socioeconomic fragility and less access to public health prevention policies may be related to the number of smokers in the sample.

Regarding alcohol consumption, more than 40% of all interviewees reported using alcohol. In the Vigitel 2021 evaluation, the frequency of alcohol abuse in the last 30 days was higher in men (25.0%) than in women (12.7%)[11]. In both genders, this frequency decreased with age and increased with education level. The fact that the sample selected had a low monthly family income contradicts the literature, but again, it may reflect the social conditions of the region, where it is difficult to access public policies such as those to prevent the abuse of alcohol and drugs, for example.

Throughout the analysis, in terms of social and demographic profile, men and women did not appear to differ in terms of education level, income, religion, alcohol and tobacco consumption or previous medical follow-up. However, in terms of age and comorbidities, women were older and more comorbid. When it comes to health care, the common-sense view has historically been that men are strong beings who hardly ever get ill, which is why women predominate in seeking health services[12]. A previous study found that women seek health services 1.9 times more often than men[11], which is possibly related to greater prior knowledge of comorbidities.

Overall, what was most striking was that only 6 patients, 10.5% of the total, had a palliative care discussion implemented by the medical team at the time of the study.

It could be questioned whether the high incidence of cases requiring palliative care found in the study was related to the high sensitivity of the instrument used. SPICT is widely used in the UK National Health System (NHS) to help detect patients who need palliative care[4]. Initially, the tool was used to assess patients in primary and secondary care, however, studies have been carried out with the tool used in-hospital, demonstrating good results with the use of the tool[13].

SPICT has six general markers of advanced functional decline and another six markers of advanced disease. A score of two general markers or one for advanced disease already characterizes the patient as eligible for palliative care, which suggests referral to a specialized team or long-term care planning[4]. Although there is no gold standard method or instrument to indicate the implementation of palliative care, a retrospective study showed that SPICT was able to predict 62% of deaths associated with chronic liver disease within 12 months[13]. The same study even assessed a sensitivity of 83% for 12-month mortality. Another study compared SPICT and the so-called "surprise question", a validated method that consists of assessing the prognosis of sick patients by asking the following question "Would you be surprised if this patient died in the next 12 months?". The study found that between the surprise question and the SPICT, there was a sensitivity of 50% for the surprise question and 57% for the SPICT. Specificity was 99% and 98%, respectively. Both instruments have been considered when assessing patients who could benefit from palliative care[12]. Even so, there seemed to be greater reliability when using SPICT.

Considering the reliability of the SPICT, the majority of the individuals in the sample evaluated in this study do not appear to have received adequate palliative care. However, there are limitations to this analysis, the study method, a cross-sectional study, makes it impossible to assess the final outcome of patients in terms of mortality and the institution of palliative care, which may have occurred at a different time to that analyzed. Other elements should also be evaluated when instituting palliative care for a patient, besides SPICT – clinical assessment and other factors should be evaluated when planning care for palliative care prospects[4,14].

Around the world, significant barriers must be overcome to meet the need for palliative care, such as national health policies and systems, which often do not include palliative care; palliative care training for health professionals, which is often limited or non-existent; and the population's access to opioid analgesics, which is often inadequate[2]. In Brazil, other factors that hinder the implementation of palliative care are the difficulty of providing death certificates at home; the "basic package" of medicines, which is very expensive; and limitations in storage, distribution, and disposal of opioid medicines[16]. The fact that this study was carried out in a hospital located in one of the poorest regions of the country may also be an indication of the high incidence of patients with advanced illnesses, since the precariousness of primary care in the region results in patients arriving at tertiary services at an advanced stage of illness. Other local studies have found similar data: a 2018 study carried out at the *Santa Casa de Misericórdia* Hospital in Recife[16] indicated that 77% of those admitted to the internal medicine ward required palliative care. At the Agamenon Magalhães Hospital, in 2016, also in Recife, among the patients included in the study, 43% had an indication for palliative care in the internal medicine ward, and only 9% of the sample underwent this type of care throughout the study[17].

CONCLUSION

Most of the patients assessed in the proposed service were men (62.5%), aged around 55. The vast majority of patients seen at the unit were black and brown, with incomplete primary education, with an average family income of between 1 and 3 minimum monthly wages, with comorbidities, non-smokers and non-alcoholics. The sociodemographic profile of the groups of patients who were or were not indicated for palliative care according to the SPICT tool appeared to be similar.

Of all the patients analyzed, 64% scored well on the SPICT tool and were candidates for receiving palliative care. However, only 10.5% of the sample was receiving this type of assistance at the time of the study. Although palliative care is still a neglected topic in the school training of most health professionals, the use of hospital protocols or tools (such as SPICT) can help to implement this type of care, promoting better treatment and limiting dysthanasia.

Learning about the profile of patients in a tertiary hospital in northeastern Brazil is important for elucidating the health needs of the region, contributing to the planning and implementation of public policies geared towards regional demands, such as training and capacity-building for healthcare teams. In the service investigated, the results of the study shed light on the need to review institutional practices and train teams to ensure better care for patients and their families, especially regarding palliative care.

As a limitation, the fact that the sample was not selected based on a statistical calculation may represent a bias in the analysis of the group presented.

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