

Profile of patients with indication of palliative care and admitted at the Júlia Kubitschek Hospital – FHEMIG

Perfil dos pacientes com indicação de cuidados paliativos internados no Hospital Júlia Kubitschek – FHEMIG

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ABSTRACT

Introduction: Technological and therapeutic progress associated with improvements in general life conditions of the population led to the increased life expectancy of Brazilians. Aging is related to the emergence of chronic and disabling illnesses in which monitoring and care constitute the main goal to be accomplished. **Objectives:** To evaluate the profile of patients with indication of palliative care admitted in the internal medicine wards of the Júlia Kubitschek Hospital (HJK); to identify the characteristics of these patients in relation to gender, age, illnesses, and general clinical picture. **Methods:** This was a cross-sectional study with data collection from reviewed medical records and questionnaire with information about clinical conditions during hospitalization. **Results:** 261 admissions were recorded between June 27 and September 27 of 2012. The percentages of 41% (96) and 44% (101) of patients had and did not have an indication of palliative care, respectively. **Discussion:** The indication of palliative care reaches expressive numbers observed in the current study and the literature used. **Conclusions:** There is a significant number of patients admitted in the internal medicine wards of HJK who need palliative care, which is also described in the literature, showing the needed for better assistance to these patients, which requires training a multidisciplinary team for the improvement of this service.

Key words: Palliative Care; Hospice Care; Inpatients; Hospitalization; Critical Illness.

RESUMO

Introdução: progressos tecnológicos e terapêuticos associados a melhorias das condições gerais de vida da população levaram ao aumento da expectativa de vida do brasileiro. O envelhecimento está relacionado ao surgimento de doenças crônicas e incapacitantes, nas quais o acompanhamento e o cuidado constituem a principal meta a ser cumprida. **Objetivos:** avaliar o perfil dos pacientes com indicação de cuidados paliativos admitidos nas enfermarias de clínica médica do Hospital Júlia Kubitschek (HJK); identificar características desses pacientes em relação a sexo, idade, doenças prevalentes e quadro clínico geral. **Métodos:** realizado estudo transversal com coleta de dados a partir de revisão dos prontuários, preenchimento do questionário com informações sobre as condições clínicas durante a internação. **Resultados:** foram contabilizadas 261 admissões no período de 27 de junho a 27 de setembro de 2012. Obteve-se que 41% (96) e 44% (101) dos pacientes tiveram e não tiveram indicação de cuidados paliativos, respectivamente. **Discussão:** a indicação de cuidados paliativos atinge números expressivos, observado tanto no estudo vigente quanto na literatura utilizada. **Conclusões:** há significativo número de pacientes que se internam nas enfermarias da clínica médica do HJK que precisam de cuidados paliativos, o que também é descrito na literatura, mostrando-se necessária melhor assistência a esses pacientes, o que requer treinamento de equipe multidisciplinar para o aperfeiçoamento desse atendimento.

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Palavras-chave: Cuidados Paliativos; Cuidados Paliativos na Terminalidade da Vida; Pacientes Internados; Hospitalização; Estado Terminal.

INTRODUCTION

Technological advances and associated therapeutic improvements in the general conditions of life of Brazilian populations led life expectancy at birth to change from 45.5 years old in 1940 to 72.7 years in 2008. According to the projection of the Brazilian Institute of Geography and Statistics (IBGE), it will reach 81.29 years in 2050.^{1,2} In 2008, the contingent of 65 years old and older represented 6.53%; in 2050, it is estimated that the elderly population will exceed 22.71% of the total population.²

Aging is accompanied by the involvement of organic functions, leading to greater likelihood of emergence of chronic and disabling diseases.³ In these cases, clinical follow-up and care are key measures for aging with less impact on quality of life, and a multidisciplinary assistance is essential to alleviate potential discomforts and sufferings.⁴

Thus, the World Health Organization (WHO) recommends palliative care, which consists of promoting multidisciplinary team assistance aimed at improving the quality of life of patients and their families facing life-threatening illnesses, through the prevention and relief of suffering, early identification, comprehensive evaluation, and treatment of pain and other physical, social, psychological, and spiritual symptoms.⁵

Palliative care was traditionally seen as exclusively applicable in the moment when death was imminent. Currently, they are offered in the early stages of progressive, advanced, and incurable diseases.⁶⁻⁸

Palliative care should be started early, associated with other measures such as chemo and radiotherapy, and include all the necessary investigations to understand better and control clinical situations. The transition from treatment to modify the disease to palliative treatment is gradually made, which is determined by clinical alterations that depend on medical judgment and evaluation of the disease's natural history. In addition, data on the clinical therapeutic response, comorbidities, psychosocial factors, and level of functional decline must be considered. An early approach allows the prevention of symptoms and complications inherent in the underlying disease and provides appropriate diagnosis and treatment of comorbidities that may develop in parallel with the main disease.⁹

This type of assistance may be needed at any time, as low-complexity measures, and even in situations when they become fundamental.⁷

Although the importance of this type of care is well-defined, there are few establishments in Brazil with well-structured service for this purpose.⁸ The most important aspect of planning the palliative care service are the local characteristics of each institution, which are variable in reality. The local needs for assistance must be primarily known, and the evaluation of the number of potential patients, ages, and those who are carriers of certain diseases that could benefit from palliative care is of paramount importance.^{10,11}

This study is justified by the need to discuss the difficulties and adjustments needed in the hospital environment for the adaptation of infrastructure and professional training in order to meet this new reality.

MATERIAL AND METHODS

This was a cross-sectional study of patients admitted to the wards of the Júlia Kubitschek Hospital (HJK), located in Belo Horizonte-MG and coordinated by the Hospital Foundation of the State of Minas Gerais (FHEMIG). The institution has 238 beds, being 54 in the Internal Medicine wards (33 males and 21 females).

The study evaluated the need for palliative care in patients admitted to the Internal Medicine wards from June 27 to September 27, 2012.

The data collection included the reviewing of medical records, filling out the questionnaire (Table 1), and obtaining the clinical opinion of the attending physician about the evaluated patient. The applied questionnaire was compiled from the "Supportive and palliative care indications tool" based on clinical and laboratory characteristics that indicate chronic and irreversible diseases in advanced stages, and the Palliative Care Handbook of the National Academy of Palliative Care, which evaluates indicators of terminal illnesses in patients with AIDS.^{9,10}

Patients admitted to the Internal Medicine wards, over the age of 18 years, and of both genders were included in the study. The exclusion criteria were: being under 18 years old, with medical records not available and/or with insufficient information, and lack of cooperation from the attending physician in filling out the questionnaire. To avoid data collection bias, patients admitted in beds from the researcher, responsible for this project, were excluded.

Table 1 - Questionnaire

Date: _____ Date of admission: _____ Age: _____ Sex: _____	
<p>1. Question to the doctor: 1.1 "Would you be surprised if this patient dies over the next 12 months?" <input type="checkbox"/> No <input type="checkbox"/> Yes</p>	
<p>2. General clinical condition: <input type="checkbox"/> 2.1 Bad or deteriorating functional status (limited self-care/restricted to bed or chair in more than 50% of the time in a day) <input type="checkbox"/> 2.2 Progressive weight loss in the last 6 months (> 10%) <input type="checkbox"/> 2.3 2 or more unplanned hospitalizations in the last 6 months <input type="checkbox"/> 2.4 Patient and from home care or institutionalized</p>	
<p>3. Two or more indicators related to diseases:</p>	
<p>3.1 Cardiopathy: <input type="checkbox"/> 3.1.1 Class IV heart failure, severe valvular disease or extensive coronary artery disease <input type="checkbox"/> 3.1.2 Dyspnea or precordialgia at resting or minimal efforts <input type="checkbox"/> 3.1.3 Persistent symptoms when using optimized tolerated therapy <input type="checkbox"/> 3.1.4 Kidney insufficiency (< clearance 30 mL/min) <input type="checkbox"/> 3.1.5 PAS < 100 mhg and/or FC > 100 <input type="checkbox"/> 3.1.6 Cardiac cachexia <input type="checkbox"/> 3.1.7 2 or more acute episodes requiring intravenous treatment in the last 6 months</p>	<p>3.2 Kidney disease: <input type="checkbox"/> 3.2.1 Chronic kidney disease stage V (clearance < 15 ml) <input type="checkbox"/> 3.2.2 Kidney conservative management due to multimorbidity <input type="checkbox"/> 3.2.3 Failing on dialysis; persistent symptoms and/or increasing in dependency <input type="checkbox"/> 3.2.4 Dialysis not started after failure following kidney transplant <input type="checkbox"/> 3.2.5 New life-threatening condition or kidney failure as a complication of another condition or treatment</p>
<p>3.3 Respiratory disease: <input type="checkbox"/> 3.3.1 Severe airway obstruction (VEF1 < 30%) or restrictive deficit (vital capacity < 60%) <input type="checkbox"/> 3.3.2 Criterion for continual oxygen therapy <input type="checkbox"/> 3.3.3 Dyspnea at rest or at minimal efforts between exacerbations <input type="checkbox"/> 3.3.4 Severe symptoms persisted despite appropriate therapy <input type="checkbox"/> 3.3.5 Symptomatic heart failure <input type="checkbox"/> 3.3.6 IMC < 21 <input type="checkbox"/> 3.3.7 Frequent admissions in PA due to exacerbations and/or respiratory failure</p>	<p>3.4 Liver disease: <input type="checkbox"/> 3.4.1 Advanced cirrhosis with 1 or more complications: refractory ascites, hepatic encephalopathy, hepatorenal syndrome, bacterial peritonitis, recurrent varices bleeding <input type="checkbox"/> 3.4.2 Serum Albumin < 2, 5 g/l and prothrombin time or extended RNI <input type="checkbox"/> 3.4.3 Hepato cellular carcinoma</p>
<p>3.5 Cancer: <input type="checkbox"/> 3.5.1 Deteriorating functional status due to metastatic cancer and/or comorbidities <input type="checkbox"/> 3.5.2 Persistent symptoms despite appropriate oncological palliative treatment or patient is too fragile for the oncological treatment</p>	<p>3.6 Neurological disease: <input type="checkbox"/> 3.6.1 Progressive physical and/or cognitive deterioration despite appropriate therapy <input type="checkbox"/> 3.6.2 Complex symptoms and difficult to control <input type="checkbox"/> 3.6.3 Language disorders and progressive dysphagia <input type="checkbox"/> 3.6.4 Recurrent aspiration pneumonia; dyspnea or respiratory insufficiency</p>
<p>3.7 Dementia: <input type="checkbox"/> 3.7.1 Unable to dress, walk, or eat without help; unable to communicate significantly <input type="checkbox"/> 3.7.2 Receiving liquid diet or supplements or enteral diet <input type="checkbox"/> 3.7.3 Recurrent febrile episodes; aspiration pneumonia <input type="checkbox"/> 3.7.4 Fecal and/or urinary incontinence</p>	<p>3.8 Patients with AIDS: <input type="checkbox"/> 3.8.1 CD4 < 25 cells/ mcl <input type="checkbox"/> 3.8.2 Persistent viral load > 100,000 copies/ml <input type="checkbox"/> 3.8.3 Association to any of the situations below: • CNS Lymphoma • 33% loss of lean body mass • Bacteremia by mycobacterium avium (not treated, which is not responding the treatment or refuse) • Progressive multifocal leukoencephalopathy • Systemic lymphoma, partial response to chemotherapy • Visceral Kaposi's Sarcoma not responsive to therapy • Renal Insufficiency not eligible or not wanting dialysis • Infection with Cryptosporidium • Toxoplasmosis that does not respond to therapy <input type="checkbox"/> 3.8.4 persistent diarrhea for one year <input type="checkbox"/> 3.8.5 serum albumin less than 2.5 <input type="checkbox"/> 3.8.6 advanced dementia by AIDS <input type="checkbox"/> 3.8.7 toxoplasmosis and symptomatic ICC at rest</p>

The patients were classified in:

- with an indication for palliative care, with two or more indicators marked on the questionnaire and/or compromised general clinical condition (section 2 of the questionnaire);

- no indication for palliative care in which patients had none, or one indicator marked.

A waiver for the Voluntary Informed Consent Form was requested to the Ethics Committee from

FHEMIG. The research project was evaluated and approved by the Center for Study and Research (NEP) from FHEMIG and registered in the Brazil Platform.

RESULTS

A total of 261 admissions in the Internal Medicine wards were accounted for in this study, and 30 admissions were not included due to failure in completing the questionnaire. Out of the admitted patients, 231 medical records fit the inclusion criteria.

Palliative care was indicated to 41% (96) of the patients, and 44% (101) did not receive this indication. The exclusion criteria were applied in 15% (34) of the patients (Figure 1).

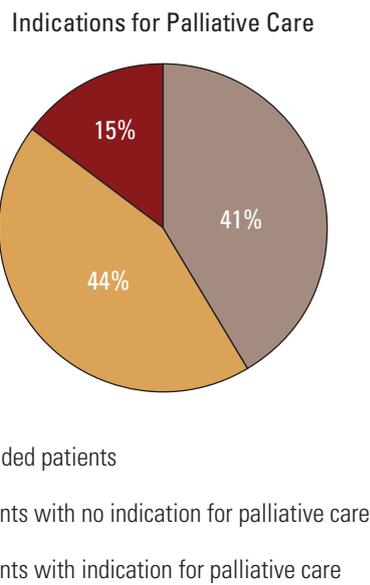


Figure 1 - Distribution of hospitalized patients in the Internal Medicine wards of the Júlia Kubitschek Hospital from June 27 to September 27, 2012, according to indication for palliative care.

Among patients with an indication for palliative care, 60.5% were male. These patients were distributed in 76, 63.5, 39.5, and 16.6% with compromised general clinical condition; bad or decayed functional state defined as limited self-care and/or restricted to bed or chair for longer than 50% of the time in a day; two or more unplanned hospitalizations in the last six months; and progressive weight loss reported in the past six months, respectively. The following received indication for palliative care and were distributed as 32.3, 27, 25, 19.7, 9.3, 7.3, and 7.3% due to cardiac, neu-

rological, respiratory, psychological, hepatic, neoplastic, and renal diseases, respectively.

Out of all patients who had palliative care indications, 28.1% presented diseases related to two or more different systems.

The average age of patients was 62 years and median of 63 years, with a standard deviation of 16.59. The maximum documented age was 100 years, and the minimum was 20 years.

About the question to the attending physician: "Would you be surprised if this patient dies over the next 12 months?" The answer was "No" in 80.2% (77) of the cases out of 96 patients with an indication for palliative care. As for the patients without an indication for palliative care (101 patients), the physician answered "Yes" in 71.3% (72) of the cases.

DISCUSSION

Among patients who were admitted to the Internal Medicine wards, 41% (96) received an indication for palliative care based on the indicators published by Murray and Boyd. The rate of indication for palliative care was higher than expected compared to the literature data that refers to an occurrence of approximately 25% of hospitalized patients.¹²

The relative prevalence of males (60.5%) in indications for palliative care was against expectations because the prevalence of chronic diseases in the elderly amounts to 75.5% (69.3% in men and 80.2% in women). In addition, life expectancy for men in relation to women is 7.6 years shorter, and the incidence of palliative care is directly proportional to age.¹³

There are three different trajectories to the various chronic and progressive diseases.^{9,14} The first one is characterized by a rapid decline in weeks or months and often in a terminal phase, which usually happens and almost always in cases of cancer. The second one is with a slow and prolonged decline, with sparse episodes of exacerbation, being typical in older frail and demented patients. Moreover, finally, there is a trajectory of gradual decline, episodes of acute deterioration, and partial functional recovery, typically seen in coronary artery, chronic lung, or late-stage liver diseases.

Thus, cardiovascular diseases (32.3%) stood out as the main cause for palliative care, which is consistent with the high rates of mortality by heart diseases - 52.4 (deaths per 100,000 inhabitants).¹⁵

The question prompted to the attending physicians is variable and difficult to be evaluated, particularly by the degree of subjectivity in the answers offered. The answer may vary with the prior experience of the doctor, preexisting doctor-patient relationship, and how the doctor deals with the process of illness and death of patients.

CONCLUSION

The ageing of a population is a reflection of increased life expectancy due to the advancement in the field of health. The same can be accompanied by the emergence of chronic and disabling diseases and, in these cases, the clinical follow-up and care are key measures for aging to be accompanied by increased quality of life requiring the promotion of palliative care with the goal of minimizing suffering, including that of family members.

A high incidence of hospitalized patients with an indication for palliative care in the Internal Medicine wards of the HJK was observed, which creates a demand for trained professionals and adequate infrastructure.

The home monitoring of these patients is also important to provide deinstitutionalization and avoid complications and unnecessary hospitalizations.

Faced with the need to organize a model of appropriate assistance to patients with advanced and terminal diseases, physicians should be encouraged to address this aspect, questioning patients about their prospects. Therefore, it would be interesting to conduct further research, in this environment, about the various aspects that involve care at the end of life.

REFERENCES

1. Matsumoto DY. Cuidados paliativos: conceito, fundamentos e princípios. In: Academia Nacional de Cuidados Paliativos. Manual de cuidados paliativos. Rio de Janeiro: Diagraphic; 2009. p.14-9.
2. Instituto Brasileiro de Geografia e Estatística. População brasileira envelhece em ritmo acelerado [Internet]. 2008. [Cited 2012 Apr 10]. Available from: <http://www.ibge.gov.br>
3. Burlá C. Cuidados paliativos: afinal, do que se trata? In: Duarte Moritz R, organizadora. Conflitos bioéticos do viver e do morrer. Brasília: CFM; 2011. 188p.
4. Feio AGO. Responsabilidade e tecnologia: a questão da distanásia. *Rev Bioét.* 2011; 19(3): 615-30.
5. World Health Organization. WHO definition of palliative care [internet]. Geneva; 2010. [Cited 2012 Apr 10.] Available from: <http://who.int/cancer/palliative/definition>.
6. Pessini L. Cuidados paliativos: alguns aspectos conceituais, biográficos e éticos. *Prát Hosp.* 2005 set/out; 7(41):107-12.
7. Lynn J, Adamson DN. Living well at the end of life: adapting health care to serious chronic illness in old age. Arlington, VA: Rand Health; 2003.
8. Georgia AMC. Os cuidados paliativos no Brasil. *Rev Bras Cuidados Paliativos.* 2008;1(1):5-8.
9. Boyd K, Murray SA. Recognising and managing key transitions in end of life care. *BMJ.* 2010; 341:649-52.
10. Arantes AC. Indicações de cuidados paliativos. In: Academia Nacional de Cuidados Paliativos. Manual de cuidados paliativos. Rio de Janeiro: Diagraphic; 2009. p. 20-36.
11. International Association for Hospice and Palliative Care. Promoting Hospice and Palliative Care Worldwide. The IAHPIC Manual of palliative care. 2ª ed. [Cited 2012 July 15]. Available from: <http://www.hospicecare.com/iahpc-manual/iahpc-manual-08.pdf>.
12. Currow DC, Wheeler JL, Glare PA, Kaasa S, Abernethy APA. Framework for generalizability in palliative care. *J Pain Symptom Manage.* 2009 Mar; 37(3):373-86.
13. Instituto Brasileiro de Geografia e Estatística. Indicadores Socio-demográficos e de Saúde no Brasil [Internet]. 2009 [Cited 2013 Sep 06]. Available from: <http://www.ibge.gov.br>.
14. Kendall M, Murray SA, Boyd K. Illness trajectories and palliative care. *BMJ.* 2005; 330: 1007-11.
15. Departamento de Informática do Sistema Único de Saúde (DATASUS). Indicadores e Dados Básicos – Brasil [internet] [Cited 2013 Sep. 06]. Available from: <http://www.datasus.gov.br>.