Development of a risk classification protocol for cancer patients in Home-based Palliative Care

Elaboração de um protocolo de classificação de risco para pacientes oncológicos em Cuidados Paliativos Domiciliares

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ABSTRACT Home-based Palliative Care services specialized in the treatment of cancer patients aim to identify and control physical, psychosocial, and spiritual symptoms at home. Some challenges encountered are the complexity of symptoms, reduced survival of patients with advanced cancer, and limitations of the health care system. To stratify the priority of care for patients with advanced cancer in home Palliative Care, a risk classification protocol was developed. This article is an experience report on the process of creating a risk classification protocol for patients with advanced cancer treated at a home Palliative Care service in Rio de Janeiro. The initial stage involved meetings of the home care team at an oncology hospital and structured searches in the literature. Afterwards, the clinical situations of more complex management at home were listed and named as warning signs and symptoms: pain, shortness of breath, nausea/vomiting, bleeding, and acute mental confusion. An assessment and triage protocol was developed with five categories/colors to determine the priority of patient care. The developed triage system has easy applicability and requires a brief training of the health professional so that it can be used during home visits.

KEYWORDS Palliative Care. Neoplasms. Home care services. Triage. Signs and symptoms.

RESUMO *Os serviços de Cuidados Paliativos Domiciliares especializados no tratamento de pacientes oncológicos têm como objetivo identificar e controlar sintomas físicos, psicossociais e espirituais em domicílio. Alguns desafios encontrados são a complexidade de sintomas, a sobrevida reduzida dos pacientes com câncer avançado e limitações do sistema de saúde. Para estratificar a prioridade de atendimento dos pacientes com câncer avançado em Cuidados Paliativos Domiciliares, foi elaborado um protocolo de classificação de risco. Este artigo é um relato de experiência sobre o processo de elaboração de um protocolo de classificação de risco para pacientes com câncer avançado atendidos em um serviço de Cuidados Paliativos Domiciliares no Rio de Janeiro. A etapa inicial envolveu reuniões da equipe da Assistência Domiciliar de um hospital oncológico e buscas estruturadas na literatura. Depois, foram listadas as situações clínicas de manejo mais complexo no domicílio, chamadas de sinais e sintomas de alerta: dor, falta de ar, náuseas/vômitos, sangramento e confusão mental aguda. Elaborou-se um protocolo de avaliação e classificação de risco com cinco categorias/cores, para determinar a prioridade de atendimento dos pacientes. O sistema de triagem desenvolvido possui fácil aplicabilidade e requer um treinamento breve do profissional de saúde para que possa ser utilizado durante os atendimentos domiciliares.*

PALAVRAS-CHAVE *Cuidados Paliativos. Neoplasias. Serviços de assistência domiciliar. Triagem. Sinais e sintomas.*

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Introduction

Cancer is the leading disease requiring Palliative Care (PC) worldwide since many cases of this disease are diagnosed at an advanced stage and with little chance of cure[1,2].

PC is applicable from the beginning of the cancer course, in conjunction with disease-modifying therapies. As the disease worsens, there is a progressive reduction in disease-modifying therapies (such as chemotherapy) and an increase in PC measures. PC includes investigations to control the patient's clinical complications and offer support to help the family in coping with the patient's disease and in the grieving[3].

The provision of home-based PC is associated with the reduction of emergency room visits, even in the final stage of life, allowing patients to stay at home, with their families, for as long as possible[4].

Patients with advanced cancer often have multiple symptoms, which need to be routinely checked by health care providers[5].

Oncology patients treated by Home-based Palliative Care (HPC) services are characterized by low functional capacity and low survival expectancy[6,7]. Considering this profile of patients and the resource limitations of health services, it is desirable that Home Care (HC) teams are able to define which patients have the highest priority of care.

Several emergency services in the world have already demonstrated the great importance of using the triage system (also called risk classification) to define the prioritization of care for patients with more severe cases[8]. The Manchester Triage System (MTS), created in the United Kingdom in 1997 to establish clinical priority of medical care for users of urgent and emergency units, and which is currently used in several countries worldwide, is an example[8-10].

The use of a triage system is a fundamental step in the management of clinical risk in any service where clinical demand exceeds the supply of resources for care[10].

Despite the benefits evidenced in emergency services, the triage system is still not a strategy frequently used in HPC services. The study conducted by Dhiliwal et al.[11] evaluated the use of a triage system for patients in HPC, based on the evaluation of clinical symptoms. This study showed that triage facilitated early intervention by the HPC team, improved control of patients' symptoms, and reduced the number of deaths in hospital[11].

Based on the growing demand for PC, reduced survival of patients with advanced cancer, and the need to optimize the use of health service resources, a risk classification protocol for patients treated by the HC service of an oncology PC unit in the city of Rio de Janeiro, Brazil, was developed. The objective of this article is to describe the process of preparing the HPC risk classification protocol, which was based on the assessment of warning signs and symptoms (pain, shortness of breath, nausea/vomiting, bleeding, and acute mental confusion).

Material and methods

This study consists of an experience report on the preparation of a risk classification protocol for patients with advanced cancer treated in an HCP service.

The description of this report was based on the process of systematization of experience proposed by Holliday[12]. According to Eckert[13], the systematization of experience is a methodological proposal that consists of the critical reflection of a concrete experience, aiming at producing learning processes[13].

The present article aimed to describe the process of creating the risk classification protocol for patients in HPC, stimulate a reflection on the results developed, and share practical experiences with other health professionals and/or researchers.

Contextualization

This study was developed between the years 2018 and 2022. The first version of the risk classification protocol was devised by two researchers from an HPC oncology service. Its origin occurred in 2018, based on a practical need to define the priority of care for patients assisted by the HC service linked to an oncological hospital of Exclusive Palliative Care, in the city of Rio de Janeiro (Brazil).

The daily experience of face-to-face care at home and in telecare with HPC patients, added to the challenges discussed among the HC team, helped the researchers formulate some hypotheses about the circumstances that interfered with the probability of patients staying at home.

Between 2020 and 2022, the study received the participation of an external researcher, who contributed to guiding and improving the final version of the protocol as a technological product developed during a professional master's degree course. The following describes different steps taken by the researchers – from the idealization of the first version of the protocol to the current version.

Bibliographical research

A search was carried out in the literature, with the description and analysis of the data collected for the purpose of developing a technological product in health[14]. First, an Integrative Review (IR) was elaborated on the factors associated with the visit to the emergency room or hospitalization of cancer patients in HPC, in order to understand which situations caused the interruption of HPC[15]. Through IR, the main causes, risk factors, and protective factors were identified in relation to the search for emergency or hospitalization[15].

Next, the researchers elaborated an IR on the methods used to screen the care of cancer patients in HPC. The data obtained in this IR were systematized and will be detailed in a scientific article to be published. The scarcity of studies on HCP triage motivated the researchers to develop a proposal for a care triage protocol for oncology patients in HPC in Brazil, based on the evaluation of signs and symptoms.

Preparation of a proposal for the evaluation of signs and symptoms

Based on data from literature reviews and successive clinical discussions between the HC team, the prototype of an instrument for the evaluation of signs and symptoms was developed.

This instrument included the parameters of the Edmonton Symptom Assessment Scale (ESAS), plus other signs and symptoms prevalent in patients with advanced cancer (bleeding, diarrhea, constipation, dysphagia, and acute mental confusion).

Originally, the clinical information of home care was written in the medical records on paper standardized by the institution. The quality and type of information recorded varied according to the criteria and understanding of each professional.

The first prototype of the instrument arose from the need to better structure the information of home care. A set of stamps was prepared to be used in the evolution sheets of the medical records on paper. These stamps contained specific fields to fill in information about the presence and intensity of the patients' signs and symptoms. There was also room to detail such clinical manifestations, describe the physical examination, and therapeutic conduct. The implementation of the prototype was accompanied by daily meetings of the HC service, in order to clarify some doubts regarding the information in the forms, and the most complex cases were discussed.

As of 2020, the information contained in the stamps was submitted to a new review and standardization by the HC, being recorded by the professionals directly in the institution's computerized medical record.

Definition of warning signs and symptoms in HC

To determine the priority of home care, the clinical situations of more complex management at home were defined. These risk situations were called warning signs and symptoms.

In the first version of the prototype, the choice of warning signs and symptoms was based on empirical aspects from the practical experience of HC professionals, complemented by a non-structured bibliographic search, using references obtained predominantly from grey literature.

Subsequently, a structured literature search was carried out, based on scientific evidence, through an IR on the determining factors of emergency room visits or hospitalization of cancer patients in HPC[15]. The results of this IR were important to consolidate the warning signs and symptoms. In addition, the process of choosing these parameters considered aspects resulting from new meetings between researchers from the HC management group, the structure of the institution's HC at the time of the research, as well as the profile of patients treated by the service.

The following was selected as warning signs and symptoms in the risk triage: pain, shortness of breath, nausea or vomiting, acute mental confusion (delirium) and bleeding.

Although identified in IR as factors associated with emergency room visit or hospitalization, fatigue and fever/infection were not included as warning signs/symptoms in the HC[15] risk classification prototype.

Fatigue is a very prevalent symptom in cancer patients, especially in the final stage of life, and has a multifactorial origin. However, it can be managed at home, through care and guidance of the team to patients and family members. Pharmacological and non-pharmacological measures (such as energy optimization) can be performed to minimize the effects of fatigue and so that the patient can remain comfortably at home. For this reason, it was understood that, for most patients treated by the institution's HC service, fatigue would not require visiting the emergency room or being hospitalized.

Fever/infection was also not selected as a warning criterion in the risk classification. Fever in cancer patients in HPC can occur both due to infectious conditions and tumors.

The most commonly diagnosed infections in cancer patients are those of the respiratory, urinary, and abdominal tracts[16]. Depending on the suspected infection, the HC team should assess the need for antibiotic use and/or other therapeutic measures, aiming to offer comfort to the patient at home. Hospital referral usually occurs in cases of severe infections and/or refractory disease to initial treatment.

The infectious disease caused by the SARS-CoV-2 virus (COVID-19) is another example of an infection that, since 2020, has started to impact the possibility of cancer patients treated by HC staying at home[17,18]. In cases of COVID-19 without signs of severity, the possibility of monitoring the patient remotely is offered, with guidance from the HC team through telecare[17]. Hospitalization is usually reserved for severe cases of COVID-19 and/or other situations of greater complexity, considering the desire of the patient/family regarding where care should be provided.

Development of a risk classification protocol for cancer patients in Home-based Palliative Care, based on warning signs and symptoms

Screening for home care priority was based on the presence and intensity of warning signs and symptoms (pain, shortness of breath, nausea/vomiting, bleeding, and acute mental confusion). In this prototype, the screening of care priority was called risk classification.

The first version of the risk classification protocol had three categories: red, yellow, and green. The red category consisted of the presence of one or more warning signs/symptoms of strong or moderate intensity (signs/symptoms with scores between 4 and 10 points). The yellow category corresponded to the presence of one or more warning signs and symptoms of only mild intensity (score between 1 and 3). The green category was used for patients without any warning signs and symptoms.

Based on the field analysis of the risk classification prototype and the discussions made as a team in the last four years, the risk classification protocol was reformulated in May 2022.

The final version of the risk classification protocol was based on the MTS[8-10], with five categories/colors: red, orange, yellow, green, and blue. The warning signs and symptoms used in the first version of the HC protocol were maintained and consolidated after RI.

Those with warning signs/symptoms of strong intensity (score greater than or equal to 7) began to characterize the red category (with higher priority of care), while those of moderate intensity (score between 4 and 6) were classified in the orange category.

The yellow category represents patients with mild warning signs/symptoms (score between 1 and 3). The green classification is used to designate people without any warning signs/symptoms and without other urgent reason for team case discussion and/or priority in the appointment. Green category patients are cared for within the ordinary schedule planning of the service.

Another change in the current version of the protocol was the creation of the blue category to designate patients without warning signs/symptoms, but who have another critical situation with priority of attention by the HC team. Some examples included in the blue category would be situations of social vulnerability, caregiver overload, intense emotional/spiritual suffering, or the presence of other potentially serious clinical conditions (such as infectious conditions or decompensation of comorbidities). The creation of the blue category arose from the observation that, in the first version of the prototype, some patients were purposely classified by professionals as red, even in the absence of warning signs/symptoms, so that they had priority in the discussion of cases and/or in the subsequent appointment.

Documentation in the unit

In July 2022, an official Technical Activity Procedure documentation was formulated describing the updated version of the protocol for assessment of signs and symptoms and risk classification of HC patients from an oncology unit with PC.

Results and discussion

An instrument to assess the signs and symptoms of cancer patients in HPC was developed and is described in *table 1*.

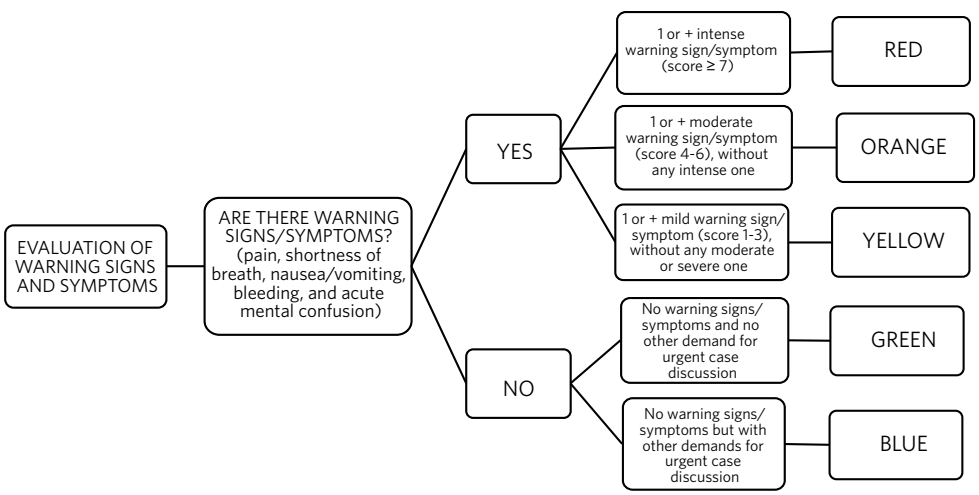
Table 1. Instrument for assessing signs and symptoms of cancer patients in Home-based Palliative Care

Symptoms of the Edmonton Scale (ESAS)	Intensity (0-10)
Pain*	
Fatigue	
Nauseas*	
Shortness of breath*	
Lack of well-being	
Drowsiness	
Anxiety	
Sadness	
Lack of appetite	
Others	
Additional signs and symptoms	Intensity (0-10)
Constipation	
Diarrhea	
Acute mental confusion*	
Bleeding*	
Dysphagia	
Source of information: ( ) patient ( ) caregiver ( ) professional	
*warning signs/symptoms used in patient risk classification	

Source: Prepared by the authors.

The instrument uses data from the Symptom Assessment Scale associated with other signs and symptoms frequently reported by patients with advanced cancer. Based on the presence and intensity of warning signs and symptoms, the patient's risk classification is defined, according to the Flowchart prepared by the researchers and presented in *figure 1*.

Figure 1. Flowchart for risk classification of oncology patients in Home-based Palliative Care, based on warning signs and symptoms



Source: Prepared by the authors.

The manifestations defined in this protocol as warning signs and symptoms correspond to more complex management situations at home and represent an increased risk of being admitted to the emergency room and/or to hospital[15]. As many patients wish to remain at home, including in the final stage of life, the HPC team must be able to identify and control factors that may impair the patient's stay at home.

The choice of these warning signs and symptoms (defined on the basis of an IR) is reinforced by the results of a study conducted by Mercadante et al.[19], which evaluated the main causes of emergency calls made by oncology patients treated by home-based PC service. According to the study, the five main causes for emergency calls were, in descending order of prevalence: dyspnea, pain, delirium, loss of consciousness, and bleeding.

In addition, shortness of breath (dyspnea) and delirium (represented by acute mental confusion) are multidimensional symptoms associated with a worse prognosis and can cause intense suffering for patients and their families[20,21].

According to the model described by Hui and Bruera[6], patients with advanced cancer have four categories of personal needs: acute, chronic, psychosocial, and spiritual/existential problems. The initial approach of health professionals should be directed to acute problems, which involve physical symptoms (such as pain, shortness of breath, nausea), delirium, and depression with risk of suicide[22].

It is important to highlight that, in addition to warning signs and symptoms, other factors related to the disease, both individual and environmental, interfere in the choice of the patient's place of death and, therefore, may contribute to the interruption or continuity of patient care at home. A systematic review by Gomes and Higginson[21] showed that the factors associated with the highest probability of death at home are: patient preference, good social conditions, access to HC services, intensity of home care, long evolution of the disease, low functional capacity, rural environment, social support network and socio-historical moment[21].

As mentioned, the protocol for risk classification of cancer patients in HPC described in this article was based on the MTS. Both screenings use clinical criteria to determine the priority of care of patients and classify them into one of five categories, which are represented by colors. However, *table 2*, lists some of the main differences between these two triage systems.

Table 2. Key differences between the Manchester Triage System (MTS) and the oncology Home-based Palliative Care (HPC) risk classification

Triage System Model	**Manchester TriageSystem[8-10]**	**Risk classification in oncological HPCs (Source: the authors)**
Scenario	• Emergency Services	• HPC Services
In charge of the triage	• Nurses	• Nurses and medical doctors
Patients profile	• Patients with different health problems	• Patients with advanced cancer in HPC
Objective	• To determine the priority of medical care	• To determine the priority of subsequent home care, telecare and/or team case discussion
Other features	Optimal maximum time until medical care is defined according to the patient's risk category;	Time limit for subsequent care depends on the patient's risk category, but may also vary depending on the availability of human resources in the HC service;

Table 2. Key differences between the Manchester Triage System (MTS) and the oncology Home-based Palliative Care (HPC) risk classification

Triage System Model	Manchester TriageSystem[8–10]	Risk classification in oncological HPCs (Source: the authors)
Other features	Blue category means 'not urgent' and is the one that can wait longer for service provision	Blue category represents patients without warning signs/symptoms, but with another reason for team discussion; green category is the lowest priority of care

Source: Prepared by the authors.

In the current version of the risk classification developed for patients in HPC, the blue category has a higher priority of care than the green one. The reason for this is that, in the previous version of the protocol (that used three colors: red, yellow, and green), the green category was already well consolidated as a group of patients without any warning signs/symptoms, which meant they would have an appointment scheduled according to the ordinary operation of the service. By adding two more categories to the risk classification (orange and blue), the researchers decided that the green category would retain its original meaning, while the blue category would represent patients without any warning signs/symptoms, but with another demand for urgent team discussion.

Final considerations

This experience report described the process of preparing the risk classification protocol for cancer patients treated by an HPC service. This research started when the researchers had to define the priority of patient care in the service in which the protocol was developed.

This protocol seeks to identify and facilitate the control of signs/symptoms of patients with advanced cancer treated in HC, with the ultimate objective of improving the quality of life and favoring patients staying at home with their families. It can be easily applied by health care providers, requiring only a brief training so that it can be used in home-based appointments.

Since its first version, the protocol has been undergoing adaptations aimed at improving the evaluation process of cancer patients in HPC and, thus, assisting the HC team's care planning. Although the latest version of the HPC risk classification protocol was completed in 2022, the process of evaluating the results of its application and the validation of this instrument will be the focus of further studies.

Through this article, the authors intend to share a practical and innovative triage strategy used to guide the allocation of resources, in the face of a scenario of great demand (in number of patients and/or complexity of symptoms) and limitation of human, and material resources of the health system.

Collaborators

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References

1. Worldwide Hospice Palliative Care Alliance. Global Atlas of Palliative Care. 2. ed. 2020. [acesso em 2022 set 5]. Disponível em: https://www.thewhpca.org/resources/global-atlas-on-end-of-life-care.

2. Atty ATM, Tomazelli JG. Cuidados paliativos na atenção domiciliar para pacientes oncológicos no Brasil. Saúde debate. 2018 [acesso em 2022 set 5]; 42(116):225-236. Disponível em: https://doi.org/10.1590/0103-1104201811618.

3. World Health Organization. Definition of Palliative Care. 2020. [acesso em 2022 set 5]. Disponível em: https://www.who.int/cancer/palliative/definition/en/.

4. Mracek J, Earp M, Sinnarajah A. Palliative home care and emergency department visits in the last 30 and 90 days of life: A retrospective cohort study of patients with cancer. BMJ support. palliat. care. 2021 [acesso em 2022 set 5]; (1):1-10. Disponível em: https://doi.org/10.1136/bmjspcare-2021-002889.

5. Hui D, Bruera E. The Edmonton Symptom Assessment System 25 Years Later: Past, Present, and Future Developments. J. pain symptom man. 2017; 53(3):630-643.

6. Hui D, Bruera E. Models of palliative care delivery for patients with cancer. J. clin. oncol. 2020; 38(9):852-865.

7. Mercadante S, Adil C, Caruselli A, et al. The palliative-supportive care unit in a comprehensive cancer center as crossroad for patients' oncological pathway. PLos ONE. 2016 [acesso em 2022 set 5]; 11(6):e0157300. Disponível em: https://doi.org/10.1371/journal.pone.0157300.

8. Jesus APS, Okuno MFP, Campanharo CRV, et al. Manchester Triage System: assessment in an emergency hospital service. Rev. bras. enferm. 2021 [acesso em 2022 jun 1]; 74(3):e20201361. Disponível em: https://doi.org/10.1590/0034-7167-2020-1361.

9. Santos Filho LAM. Revisão sistemática do Sistema de Triagem de Manchester na estratificação de risco. [monografia]. Salvador: Faculdade de Medicina da Bahia, Universidade Federal da Bahia; 2013. 28 p.

10. Mackway-Jones K, Marsden J, Windle J, editores. Emergency triage: Manchester Triage Group. 3. ed. Chichester (UK): John Wiley & Sons; 2014. [acesso em 2022 set 5]. Disponível em: https://onlinelibrary.wiley.com/doi/book/10.1002/9781118299029.

11. Dhiliwal S, Salins N, Deodhar J, et al. Pilot testing of triage coding system in home-based palliative care using Edmonton Symptom Assessment Scale. Indian J Palliat Care. 2016 [acesso em 2022 set 5]; 22(19). Disponível em: https://doi.org/10.4103/0973-1075.173943.

12. Holliday OJ. Para sistematizar experiências. 2. ed. Brasília, DF: MMA; 2006. p. 128.

13. Eckert C. Orientações para elaboração de sistematização de experiências. Porto Alegre: EMATER/RS-ASCAR; 2009. p. 9-18.

14. Fontenelles MJ, Simões MG, Frias SH, et al. Metodologia da pesquisa científica: diretrizes para a elaboração de um protocolo de pesquisa. Rev. para. med. Belém. 2009; 23(3):25-37.

15. Souza FN, Silva VG, Silva AS. Fatores associados à visita à emergência ou hospitalização em cuidados paliativos oncológicos domiciliares: uma revisão integrativa. Rev. Pesqui. (Univ. Fed. Estado Rio J.). 2023 [acesso em 2023 abr 15]; (15):e12000. Disponível em: https://doi.org/10.9789/2175-5361.rpcfo.v15.12000.

16. Instituto Nacional de Câncer José Alencar Gomes da Silva. Capitulo 18 – Infecções. In: Instituto Nacional de Câncer José Alencar Gomes da Silva. Cuidados paliativos: vivências e aplicações práticas do Hospital do Câncer IV. Rio de Janeiro: INCA; 2021. p. 167-174.

17. Silva VG, Telles AC, Guimarães NPA, et al. A propulsão do teleatendimento no cuidado paliativo oncológico domiciliar durante a pandemia de CO-

VID-19. Res Soc Dev. 2022 [acesso em 2022 set 5]; 11(5):e35711528300. Disponível em: http://dx.doi.org/10.33448/rsd-v11i5.28300.

18. Porzio G, Cortellini A, Bruera E, et al. Home Care for Cancer Patients During COVID-19 Pandemic: The Double Triage Protocol. J. pain symptom manage. 2020 [acesso em 2022 set 5]; 60(1):e5-e7. Disponível em: https://doi.org/10.1016/j.jpainsymman.2020.03.021.

19. Mercadante S, Porzio G, Valle A, et al. Emergencies in patients with advanced cancer followed at home. J. pain symptom manage. 2012 [acesso em 2022 jan 1]; 44(2). Disponível em: http://dx.doi.org/10.1016/j.jpainsymman.2011.07.016.

20. Verhoef MJ, Nijs E, Horeweg N, et al. Palliative care needs of advanced cancer patients in the emergency department at the end of life: an observational cohort study. Support. care cancer. 2020 [acesso em 2022 set 5]; 28(3). Disponível em: https://doi.org/10.1007/s00520-019-04906-x.

21. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: Systematic review. BMJ, Br. med. j. (Clin. res. ed.). 2006 [acesso em 2022 set 5]; 332(7540). Disponível em: https://doi.org/10.1136/bmj.38740.614954.55.

22. Hui D, Bruera E. Integrating palliative care into the trajectory of cancer care. Nat. rev., Clin. oncol. (Online). 2016 [acesso em 2022 jun 1]; 13(3):159-171. Disponível em: https://doi.org/10.1038/nrclinonc.2015.201.

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