End-of-Life Care on Oncohematological Disease: Challenges and Management Strategies

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Cuidados ao Fim de Vida na Doença Onco-Hematológica: Desafios e Estratégias para o Manejo

Atención al Final de la Vida en Enfermedad Oncohematológica: Desafíos y Estrategias para el Manejo

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ABSTRACT

Introduction: End-of-life care is part of exclusive palliative care, consisting of actions conducted by a multidisciplinary team aimed at patients in the active dying process. For oncohematological patients, such care is essential to ensure quality of life throughout the course of the disease and in its terminal phase. **Objective:** To discuss the criteria for identifying oncohematological patients in end-of-life care. **Method:** A qualitative and descriptive study conducted between August and October 2024 in a federal oncology hospital. Two focus groups were held with 15 professionals working in oncohematology. **Results:** Two categories emerged: "Barriers to identifying patients in the active dying process/end-of-life care" and "Criteria for characterizing patients in end-of-life care." A lack of consensus was observed among participants regarding exclusive palliative care and end-of-life care. Professionals reported limited knowledge on the subject, insufficient human resources, and a lack of preparation to provide end-of-life care. Clinical and laboratory criteria were identified for characterizing patients in this stage. The creation of an algorithm was suggested to support shared decision-making. **Conclusion:** Healthcare teams face structural, political, and personal barriers in implementing end-of-life care for oncohematological patients, resulting in prolonged suffering due to the lack of early identification and integration of palliative care. Prognostic evaluation in hematology is challenging, and tools such as algorithms may assist in decision-making. Further studies are needed to validate these criteria and expand the discussion, aiming for comprehensive care that promotes quality of life and death.

Key words: Hematological Neoplasms; Palliative Care; Patient Care Team; Terminal Care.

RESUMO

Introdução: Os cuidados de fim de vida fazem parte dos cuidados paliativos exclusivos, sendo ações da equipe multiprofissional voltadas a pacientes em processo ativo de morte. Para pacientes onco-hematológicos, esses cuidados são essenciais para garantir qualidade de vida durante a doença e em sua fase terminal. **Objetivo:** Discutir critérios para identificar pacientes onco-hematológicos em cuidados ao fim de vida. **Método:** Pesquisa qualitativa e descritiva, realizada entre agosto e outubro de 2024 em um hospital federal oncológico. Foram conduzidos dois grupos focais com 15 profissionais da onco-hematologia. **Resultados:** Emergiram duas categorias: "Barreiras para a identificação de pacientes em processo ativo de morte/cuidados ao fim de vida" e "Critérios para a caracterização de pacientes em cuidados ao fim de vida". Observou-se falta de consenso sobre cuidados paliativos exclusivos e cuidados de fim de vida. Os profissionais relataram desconhecimento sobre o tema, escassez de recursos humanos e despreparo para oferecer cuidados ao fim de vida. Foram identificados critérios clínicos e laboratoriais para caracterização desses pacientes. Sugeriu-se a criação de um algoritmo para apoiar decisões compartilhadas. **Conclusão:** As equipes enfrentam barreiras estruturais, políticas e pessoais na implementação dos cuidados ao fim de vida em pacientes onco-hematológicos, o que prolonga o sofrimento pela ausência de identificação precoce e integração dos cuidados paliativos. A avaliação prognóstica na hematologia é complexa, e ferramentas como o algoritmo podem auxiliar na tomada de decisão. São necessários mais estudos para validar os critérios e ampliar a discussão, visando uma assistência integral que promova qualidade de vida e de morte.

Palavras-chave: Neoplasias Hematológicas; Cuidados Paliativos; Equipe de Assistência ao Paciente; Assistência Terminal.

RESUMEN

Introducción: Los cuidados al final de la vida forman parte de los cuidados paliativos exclusivos, consistiendo en acciones del equipo multidisciplinario dirigidas a pacientes en proceso activo de muerte. Para los pacientes oncohematológicos, estos cuidados son esenciales para garantizar calidad de vida durante el curso de la enfermedad y en su fase terminal. **Objetivo:** Discutir criterios para identificar pacientes oncohematológicos en cuidados al final de la vida. **Método:** Estudio cualitativo y descriptivo realizado entre agosto y octubre de 2024 en un hospital oncológico federal. Se llevaron a cabo dos grupos focales con 15 profesionales que trabajan en oncohematología. **Resultados:** Surgieron dos categorías: "Barreras para la identificación de pacientes en proceso activo de muerte/cuidados al final de la vida" y "Criterios para la caracterización de pacientes en cuidados al final de la vida". Se observó falta de consenso entre los participantes sobre los cuidados paliativos exclusivos y los cuidados al final de la vida. Los profesionales informaron desconocimiento sobre el tema, escasez de recursos humanos y falta de preparación para ofrecer cuidados al final de la vida. Se identificaron criterios clínicos y de laboratorio para caracterizar a estos pacientes. Se sugirió la creación de un algoritmo para apoyar la toma de decisiones compartidas. **Conclusión:** Los equipos de salud enfrentan barreras estructurales, políticas y personales en la implementación de cuidados al final de la vida para pacientes oncohematológicos, lo que prolonga el sufrimiento debido a la falta de identificación precoz e integración de los cuidados paliativos. La evaluación pronóstica en hematología es compleja, y herramientas como el algoritmo pueden ayudar en la toma de decisiones. Se necesitan más estudios para validar los criterios y ampliar el debate, buscando una atención integral que promueva calidad de vida y de muerte.

Palabras clave: Neoplasias Hematológicas; Cuidados Paliativos; Grupo de Atención al Paciente; Cuidado Terminal.

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INTRODUCTION

Cancer represents a considerable global public health issue, affecting individuals of all age groups and ethnicities. In Brazil, projections for each year of the 2023-2025 triennium indicate there will be approximately 704 thousand new cases of the disease, not considering non-melanoma skin cancer[1]. Of the several neoplastic typologies, this research emphasizes those of hematological nature: leukemias, lymphomas, and myeloma.

Excluding non-melanoma skin cancer, leukemia is the tenth most frequent, presenting 12 distinct subtypes. Lymphomas, on the other hand, are classified into two main groups: Hodgkin (HL) and non-Hodgkin (NHL). There is a greater prevalence in men, with 2,040 new cases of NHL and 3,080 cases of HL estimated[1]. Risk factors associated with the development of hematological neoplasms are many and often caused by multiple factors. The treatment can include chemotherapy, radiotherapy, immunotherapy, and/or bone marrow transplant (BMT).

Hematological neoplasms are significantly challenging due to their heterogeneity, specific markers, and clinical frailty profile of patients, which spans not only from the disease itself, but also from the inherent aggressiveness of the usual treatments[2]. In this context, considering the intensity of oncohematological treatments and the refractoriness of malignancies, early and appropriate implementation of palliative care alongside standard treatment is pertinent.

However, several barriers are identified in the applicability of the palliative approach, including deficits in interpersonal relationships, mistaken perceptions of what constitutes palliative care, belated discussions about the end of life, conflicting feelings that care should be predominantly about healing, among others. These barriers can result in invasive interventions that are often not necessary[3,4]. Limited access to early palliative care can lead to outcomes of intense suffering for patients and their families, particularly when the baseline disease progresses and healing or control therapeutic resources are consumed. And yet, health teams need to be prepared for the most critical period of the progressive disease, the active process of death.

To simplify, the terms "active process of death" and "end-of-life care" (ELC) will be used interchangeably in this text. ELC is a set of actions developed by the multiprofessional team for patients in the active process of death[5-7]. This care must be timely applied to everyone, notably to patients with hematological diseases, given the elevated load of symptoms that permeate these individuals' journey, aiming to mitigate their suffering and alleviate pain and other anguishing symptoms without hastening or accelerating death, but implementing ELC appropriately[7].

To identify the active process of death, it is necessary to perform a prognostic assessment to plan palliative care more effectively during the patients' final days, acknowledging characteristic laboratory factors and clinical signs and symptoms that compose these prognostic indicators. Some signs and symptoms include: changes in the respiratory pattern, reduced oral intake, build-up of secretions in the upper airways, reduced interaction and response to verbal and visual stimuli, numbed or comatose behavior, tachycardia, low blood pressure, cold and cyanotic extremities, loss of sphincter control, inability to close the eyes, and nasolabial folds' descent[8]. Laboratory factors include systemic inflammatory response markers, such as leucocytosis with lymphopenia, increased C-reactive protein (CRP), and hypoalbuminemia[8].

However, this assessment is commonly used for solid tumors, and the instruments that help define ELC for oncohematological patients are still poorly discussed, in the sense of ensuring a good death, with appropriate symptom control, and sharing decisions between teams, patients, and families, avoiding disproportionate care that prolongs suffering[8].

The clinical-laboratory profile of oncohematological patients presents yet another barrier in relation to the prognostic estimate tools for clinical prediction of survival, like the palliative prognostic index (PPI) and the palliative prognostic score (PAP-Score). Those tools, especially PAP-Score, utilize lab results, which, in hematological patients, can reveal significant alterations due to compromised bone marrow, infections, and chemotherapy treatment[8].

However, there is a scarcity of discussions on ELC in the scope of multiprofessional teams, which hinders its provision to these patients. In the face of uncertainties regarding early interventions and ELC, it can be inferred that a thorough analysis and the subsequent definition of criteria for the delimitation of ELC could standardize the conduct towards these patients, while preserving the individuality of care for each patient[3].

This research has, however, the objective of exploring the experience, perceptions, and needs of the multiprofessional team in managing oncohematological patients in ELC.

METHOD

Descriptive qualitative study that used the Consolidated Criteria for Reporting Qualitative Research (COREQ)[9] checklist to ensure better validity of the methodological aspects.

The study setting was the oncohematological neoplasm clinic of an oncology-specialized federal institute located in Rio de Janeiro (RJ), Brazil.

The study included: doctors, nurses, nursing technicians, social workers, and nutritionists who provide direct care to adult oncohematological patients for at least a year. Professionals who were on leave for any reason or on vacation during the data collection period were unable to participate in the study. No exclusion criteria were defined.

The chosen data collection technique was the focus group (FG). The participants were recruited through a direct approach despite the availability to compose the group, and when reaching a consensus, the participants were informed by email of the date, time, and place. This direct approach to the participants was facilitated by the main researcher, a resident in the Oncology Multiprofessional Residency program of the institute, who was working in the oncohematological clinic at the time of data collection.

Two FG meetings were held, the first in person and the second online via Google Meet, due to the difficulty of gathering participants in person. Both FG tried to meet the criteria of having at least one member of each professional category for a purposive and heterogeneous sampling[10]; however, due to the lack of routine social workers, psychologists, and physiotherapists, it was not possible to rely on the collaboration of these categories. The researchers opted for two meetings aimed at reaching a consensus between the data collected in the first FG.

The first FG happened in a meeting room, inside the study setting, which ensured easy access to participants in addition to privacy during data collection. The study was conducted by the main researcher with the support of the assistant researcher, a nurse in the proponent institution who is a specialist in Oncology and has a master's in Nursing. The second FG was conducted by the main researcher with the support of an assistant researcher, a nurse in the proponent institution who is a specialist in Oncology and has a doctorate in Nursing.

Participants who were present in the first focus group were also observed in the second FG. However, this repetition did not follow a specific criterion, simply occurring due to the availability of participants on the previously defined dates.

The FG guiding questions were: "What do you understand is a patient in end-of-life care?"; "To you, are there signs and symptoms associated with that phase? If yes, what are they?"; "Do you know how to provide or have you ever provided end-of-life care to an oncohematological patient?"; "What are the greatest difficulties in identifying an oncohematological patient in end-of-life care?"; "What are the greatest difficulties for implementing end-of-life care to an oncohematological patient?"; "Do you find it important to define criteria for identifying patients in end-of-life care?"; and "What would these criteria be?". As the group progressed, circular questions were raised beyond the script.

The first FG recording totaled 43 minutes transcribed in 11 pages. In turn, the second FG recording had 1 hour and 13 minutes, transcribed in 16 pages. In the first group, the transition to the next question happened when responses to the inquiries reached a consensus among participants, which was considered data saturation. In the second FG, the questions and respective answers of the first FG were recalled deepening the discussion, solidifying the consensus around the addressed topics.

Before the FG, the participants filled out a sociodemographic variable's identification instrument, including sex, age, education, and specialization.

To maintain anonymity, the term "participant" was used, followed by the corresponding number to the FG in which they participated. For instance: Participant 01 – participant who took part in FG 1. Thus, each one's privacy was kept, not creating an association with any specific category, but with a general context.

All the discussions were recorded and transcribed in full and, after wording, returned to the participants individually for validation.

The first FG took place on August 8th, 2024, with ten professionals who work in the oncohematology ward. The second FG took place on October 29th, 2024, remotely via the Google Meet platform, with nine professionals, four of whom had already participated in the first group, and the other five were new participants.

The data analysis used the thematic content analysis methodology proposed by Bardin[11], which is structured on three sequential steps. The first step, called pre-analysis, consists of fluctuating and exhaustive reading of the collected material. The second step consists of exploration of the material, codification of the units of register and context, followed by thematic categorization of indexers. In this phase, the codes are grouped by similarity to proceed to category analysis. Finally, on the third step, which includes results and interpretation, the collected data are interpreted and inferred upon, with discussion based on literature review and a conceptual framework related to the theme, as well as the author's critical perspective.

This research has been approved by the Research Ethics Committee, report number 7154979 (CAAE (submission for ethical review): 80302924.6.0000.5274). All the ethical aspects were respected, and the participants signed an Informed Consent Form following the National Health Council Resolution N. 466/12[12] on research with human beings.

RESULTS AND DISCUSSION

Most of the interviewees were women, predominantly in the 30-40-year age group. Regarding professional training, six were nurses, five were nursing technicians, three were doctors, and one was a nutritionist. Most of them had some specialization and/or master's degree (Supplementary material – Table 1). From the data analysis emerge two categories (Supplementary material – Chart 1).

CATEGORY 1: BARRIERS TO IDENTIFYING PATIENTS IN THE ACTIVE DYING PROCESS/END-OF-LIFE CARE

When asked about what they understand to be a patient in ELC, the participants demonstrated a lack of consensus in their responses and often confused ELC with exclusive palliative care. The imprecision is directly associated with a care that is often fragmented, and the automatic definition of concepts[13].

> A patient who has reached a stage in which they no longer have any therapeutic possibility and their disease is worsening, and at that time, there is no other... No other resource to help them (Participant 01).

> When the patient has a chance of dying soon (Participant 01).

Exclusive palliative care is characterized by not being associated with futile treatments or diagnostic procedures, but rather by accepting the natural progression of the disease, prioritizing quality of life, and symptom control[5].

Whereas ELC are defined as a set of actions instituted by the multiprofessional care team for a patient who is in their last days of life or in the active process of death[8].

According to the National Academy of Palliative Care (*Academia Nacional de Cuidados Paliativos*)[14], a six-month lifetime prognosis can be used to indicate exclusive palliative care. The active process of death can take from hours – 48h on average – to days, including some assessment criteria.

In this context, defining care goals for the patient in the active process of death is essential to the quality of death and the process of communication between the team, patient, and families. Therefore, the definition of ELC must be understood by professionals, which can be challenging in the face of an education targeted at healing care and often misguided on palliative care[14].

Falling ill is a complex experience that encompasses varied dimensions of suffering and care, including physical, psychic, social, and spiritual. Thus, dignity and comfort for who is dying should be prioritized, including the participation of the family and caregivers in this process. Knowing the time of their death is approaching facilitates understanding and definition of the necessary care in that particular period, such as medication review to see which are necessary and which are not, prioritization of hygiene and comfort measures, and others[14].

Likewise, for patient quality of death, the team must be prepared not only to identify this phase, but also to manage the symptoms that may arise or exacerbate. And the reports demonstrate that the team fears they are not ready for this.

> I think the challenge is the clinical part, the part of... The difficulty, a hard-to-define prognosis, and the part of our own competencies, really, of our professional and personal limitations as well. Of having time, of being able to touch this subject [...]. It is a complex patient, and we can't assist them, all that (Participant 01).

> I think the greatest difficulty, one of the greatest difficulties we face in defining this patient, is the lack of a multidisciplinary round (Participant 02).

> And I, just one more thing, so I can conclude, the matter of the professional team, for instance, psychology... It is nonexistent here (Participant 01).

It was possible to grasp that the team does not feel prepared to offer end-of-life care to hematological patients and their families, partly due to the lack of training in the field, but also due to the insufficient human resources, notably the lack of indispensable multiprofessional teams in this process, such as, for instance, the psychologist[8].

Care from the perspective of a multidisciplinary team promotes better assistance practice in the last moments of life, operationalizing palliative care and more precise interventions that can be discussed together, favoring interdisciplinary communication. ELC relies on the management of a team composed of different professionals to provide care in all its dimensions. Thus, through meetings and knowledge exchange, and science-based discussions from each professional class, proposing singular therapies for the individual, care becomes harmonious and convergent to the patient, determining that the active process of death is managed as appropriately as possible[13].

Another issue highlighted was work overload, related to the lack of members in the interdisciplinary team and the demand of the ward and patients in ELC.

> The care, the patient in end-of-life care is not [done] just here, it's [done] outside, [by] the family, so we can't manage [all] this, we have a giant prescription to follow now, 18 baths, you can't possibly do 18 baths in an infirmary, 4 technicians, and be aware of so many things related to the needs of this patient (Participant 01).

The lack of professionals to compose the multiprofessional team is seen as a difficulty factor in designing a care plan targeted at ELC, compromising the quality and humanization of care. The qualification of care includes sharing decisions and knowledge, which is compromised when there are not enough professionals for a suitable plan[15].

> I feel that we do not have the availability to put ourselves up for a talk, to create a bond (Participant 01).

Beyond the technical care performed by each category, there is still the need to understand death as a natural process. Historically, death has become taboo and, despite its inevitability, many professionals fear verbalizing about it. Within the context of oncohematology, there is dysfunctional coping with the terminal phases, leading to resistance to changes and non-acceptance of finitude, which directly impacts the patient and their families[16].

The unpredictability of the prognosis in the context of hematology is associated with greater depression and anxiety levels for patients and their families. More precise prognostic information allows the professional to know when to honestly introduce this discussion on death with the individual and their family members. Ideally, these conversations should happen throughout the course of disease, precisely in periods of clinical stability. Thus, discussions would allow for review of care goals in agreement with the patient's and their family's will[17].

Knowing how to identify the futility of aggressive measures and the absence of benefits to patients with hematological neoplasms is the health team's responsibility, but it must be shared with the individual and their family[17].

> There are expectations for a patient who is usually young, and... It's hard to deal with this... This finitude, with terminality, so it's... They often express the wish to have a light at the end of it all, of having one last card to play, then how do you do it? How is the team's decision to retreat completely? (Participant 01).

> In hematology, this line is really fine between a patient who is down bad and sometimes a treatment that... A second line, anyway, that can recover that guy who was on the verge of death (Participant 02).

> Because it really depends on the expectation the patient has on their life, I believe this decision, which is a medical one, must be very hard when you decide to stop palliation to provide end-of-life care... Because what is the perception the patient has of their life? Sometimes the guy just wants to try, bro. This guy wants to go, you see? Sometimes, the guy, we see this patient profile, the defeated and the fighter (Participant 01).

Health professionals found communication barriers about ELC with patients, their families, and their peers. In this context, many fear the information can destroy the patients' feeling of hope, and consequently, increase their suffering[15].

By offering assistance to people in the active process of death, we note that technical preparedness is required; however, it must be done along with the other members of the team, so the emotional and physical overload is decreased. With a multidisciplinary approach, the management of physical, spiritual, and psychosocial symptoms is better executed, helping the patient face a dignified death[15,16].

> In our service, when we think of palliating a patient, we have very big divergences, so, within the staff discussions, we always seem to have staff who think this is very new, who don't think of something like that, that we're always following orders (Participant 02).

Thus, the team must be coordinated and share information and knowledge, setting objectives and plans to be followed together, so quality care can be provided. Therefore, horizontal professional relationships must be prioritized so that knowledge does not overlap but complements each other[8].

It is perceived that there are no defined criteria to identify a patient in ELC.

> This patient can last an undetermined time, even without the maneuvers that will prolong their suffering; this is something inherent to the person, then comes in a more spiritualized view and a professionalized view... (Participant 02).

> In clinical oncology, it becomes easier to reach this agreement, understand this scenario. In hematology, undoubtedly, the thing is much more subjective, it is not as clear as in solid tumors (Participant 01).

To assess the end-of-life prognosis, clinical indicators are used, such as functionality and lab parameters, signs and symptoms, and prognostic scales. However, the oncohematological patient naturally has lab alterations, impairing a quicker assessment and definition of criteria to establish the active process of death, since prognostic scales are targeted at patients with solid tumors[8].

> It's just that... Sometimes, there are some diseases, especially hematological diseases, which are very chemosensitive, so even if we know the patient will not survive the disease, even in their end-of-life, perhaps a treatment [can be applied] to try and stretch their quality of life (Participant 01).

> So, these are diseases that have particularities that sometimes respond well to chemotherapy, as well as providing some quality of life, you can't [determine]... It's hard... (Participant 01).

> Because you have this complexity in hematology, it is much more complex to draw a prognosis because the patient often benefits from palliative chemotherapy (Participant 01).

Given these reports, we can notice that the effectiveness of palliative chemotherapy in increasing survival of oncohematological patients influences the decision to suspend or maintain the treatment. However, survival increase is not necessarily tied to quality of life and, contradicting the principles of palliative care on the concept of death, it can prolong physical and psychic suffering, and generate a higher financial cost to the patient and the health system[18]. In this scenario, care that integrates the hematology specialist team and the palliative care specialist team can be greatly beneficial.

Studies have proved that chemotherapy in hematology, when prescribed in the last 30 or 15 days of life, has been related to increasing visits to the emergency department, hospitalization, use of the ICU, and death in the hospital. The costs for the institution are boosted by the performed interventions, which often yield no benefits. It is important to monitor the use of these resources to enable the identification of gaps in the care and costs of healthcare service in Brazil, since countries with limited resources should review the excessive use of end-of-life interventions such as prolonged hospitalizations, systemic therapies with no gain or benefit, and imaging exams, which considerably increase healthcare costs[19].

There is still the understanding of the shared decision between team, patients, and families; however, with the service overload, there is a difficulty in creating a bond and establishing assertive communication. Communication is an instrument to delineate tasks, conduct, and bonds, promoting better practice of palliative care[15].

> This patient is not being prepared for this, the family is not in agreement, when you remove the bond of care, the patients, they are all with us at some point and with you all the time (Participant 01).

Communication with the patient and their family is often hindered by the fragmentation of knowledge and not sharing decisions. The process of death involves, beyond the physical dimension, the mourning family and health professionals[16].

The family can be used as a communication channel between the team and the patient, facilitating the understanding of relayed information, clearing doubts, and the sharing and planning of therapeutic decisions to be adopted from then on, being an important coping and care tool. Interpersonal communication establishes bonds of trust, compassionate presence, and is an attribute of palliative care[8,15].

To have palliative care, interdiscipline must be interdependent and complementary, and in this sense, all team members must be connected and articulated between themselves[15].

> Within nutrition, I'll speak a little bit since the question was related to signs and symptoms, they are all classic, but much more expressive in the end-of-life (Participant 02).

For that, you need to have a clinical body present that will manage each symptom, either physical, social, psychological, or even spiritual, on its terms. Therefore, we understand that only one or two perspectives of care under the disciplinary lens are not enough to contemplate the human being in the active process of death in all its dimensions[8,15].

CATEGORY 2: CRITERIA FOR CHARACTERIZING PATIENTS IN END-OF-LIFE CARE

During the FGs, it was suggested to design an instrument that could have the shape of an algorithm to help identify patients in ELC. This tool can structure processes and behaviors to illustrate, in a more simplified way, the identification of a patient in ELC[20].

> I think it's of utmost importance to have a protocol like this that would be very helpful for us to guide our decisions and challenges, it's what we have already been through, it's taking this protocol that already exists in oncology and trying to adjust it to the peculiarities of hematology, mainly this clinical issue... (Participant 02).

The participants were capable of identifying clinical and laboratory situations that contribute to the identification of patients at the end-of-life.

> Diuresis decrease, heart rate alteration… (Participant 01).

> Lower consciousness level, tachypnea… (Participant 01).

> I wouldn't go into this issue of neutropenia, I'd focus more on the biochemistry, I believe, not the hemogram part, but it's more of the biochemical issue, and blood gas analysis, and electrolytes… (Participant 01).

We highlight the need for an individualized look at each patient, even when following an algorithm. ELC actions must be permeated by the precepts of palliative care and by the understanding of finitude. Technicality must be reconsidered so care is not bound only by protocols but also considers the whole human dimension[20].

> A protocol... It can be a very complex protocol, it must be very practical, within reality (Participant 01).

It must be noted how important it is to consider the expectations of patients in relation to their prognosis. The psychological aspects of the disease must be considered in humanized care; emotional and psychosocial factors are strongly present in end-of-life care. The team must know how to cruise and align their conduct according to the patient's wishes[21].

> But, you see, it could be less aggressive and could have the patient's wish involved in this care planning (...) and also have the family's feelings and values preserved in this moment, may the patient have the right to decide what they want to do in these last days they have… (Participant 02).

There is a cultural barrier around exclusive palliative care that transposes into the professional relationship with the oncohematological patient. According to studies, these professionals believe that, mostly, ELC is seen as a hope-reducing factor for their patients; therefore, they are not even mentioned by them[22].

From this perspective, demands arise for the humanization of the multidisciplinary team and specialization for the care of this patient profile. There are still major limitations among teams when treating patients in ELC, with few practices based on scientific and quality criteria. It is necessary to invest in cohesive and constant clinical practices that foster communication between teams[23].

> I think for hematology it's harder to palliate a patient, right? Hematology doesn't aim much for palliation, they want to fight until the end (Participant 02).

> And I've heard many colleagues say "oh, I don't want to refer this patient to palliative care because I don't want to lose this bond with them", and the patient also wants to keep this bond, you see, because breaking it would be bad (Participant 02).

In this context, elaborating an algorithm helps practically and directly guide actions that still need perfecting, and the service cannot offer at the moment, without restricting clinical decisions. Discordance between therapies, lack of experience within exclusive palliative care, and work overload reinforce how a standard instrument could favor actions towards the patient in their final days of life, by identifying them early[23,24].

The participants have suggested several criteria in their speeches, such as signs, symptoms, and lab results that can help identify patients in ELC:

> Things that guide in a practical way: age, comorbidity, if the patient has a treatment and healing proposition (Participant 01).

> Loss-to-follow-up (LF) before hospitalization, LF after hospitalization (Participant 01).

> Vital signs, consciousness level, skin coloration, perfusion, diuresis, I think all of these could compose a protocol (Participant 02).

> Things I would like to see in a protocol, first: communication, two: signs, signs, symptoms, and if you must include any lab parameter, I think it should be albumin (Participant 02).

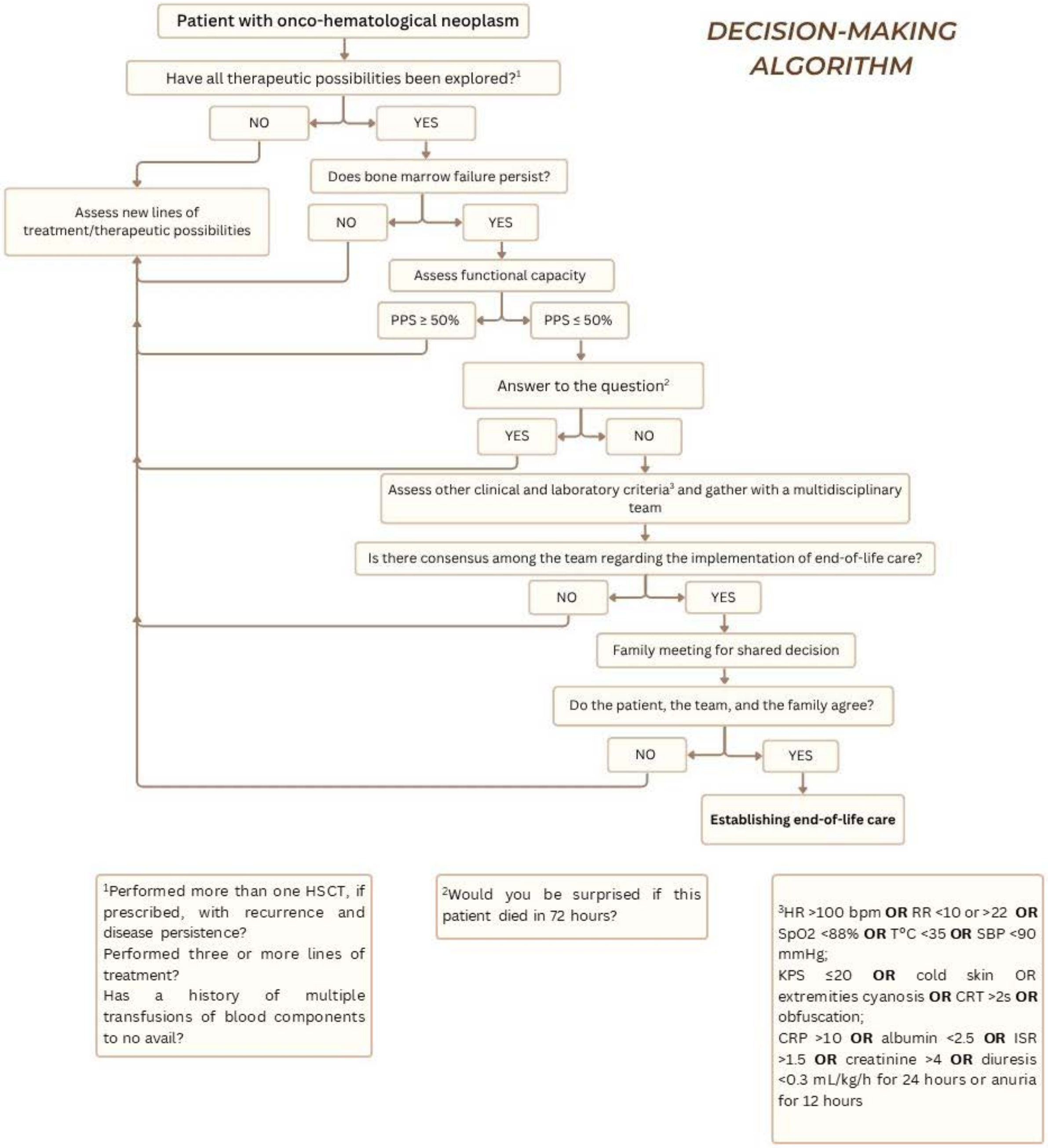
> CRP over 10 (Participant 02).

> At the end of life, they are much more expressive, that sporadic nausea that becomes intense, the sporadic vomiting that becomes uncontrollable, the malignant intestinal obstruction, right... It becomes a much more common finding... (Participant 02).

> I think the criteria for us to assess organic dysfunction, like kidney, hepatic dysfunction, which is getting worse, I think the most important thing is not only to see that it's bad, but that it's gradually worsening. So... worsening criteria (Participant 02).

> Suddenly, vital signs, consciousness level, skin coloration, perfusion, diuresis, I think all of these could compose a protocol. I think it should be on our day-to-day, besides, it goes through better defining the status of a patient's disease... Whether we're going to invest [in healing] or not, you see? (Participant 02).

Based on the standardization needs identified from the speeches, we have created an algorithm as a suggestion to guide future research in identifying patients in ELC, to qualify care and decrease individuals' level of suffering. Clinical criteria and some laboratory criteria were used, in addition to perceptions from the study's participants (Figure 1)[8,25-28].



[1] Performed more than one HSCT, if prescribed, with recurrence and disease persistence?
Performed three or more lines of treatment?
Has a history of multiple transfusions of blood components to no avail?

[2] Would you be surprised if this patient died in 72 hours?

[3] HR >100 bpm **OR** RR <10 or >22 **OR** SpO2 <88% **OR** T°C <35 **OR** SBP <90 mmHg;
KPS ≤20 **OR** cold skin OR extremities cyanosis **OR** CRT >2s **OR** obfuscation;
CRP >10 **OR** albumin <2.5 **OR** ISR >1.5 **OR** creatinine >4 **OR** diuresis <0.3 mL/kg/h for 24 hours or anuria for 12 hours

Figure 1. Proposal for a decision-making algorithm. Rio de Janeiro, 2024
Captions: HSCT: hematopoietic stem cell transplant; PPS: Palliative Performance Scale; HR: heart rate; RR: respiratory rate; SpO2: blood oxygen saturation; T°C: temperature; BP: blood pressure; KPS: Karnosfky Performance Status; CRT: capillary refill time; CRP: C-reactive protein; and ISR: international standardized relationship (assesses liver function).

CONCLUSION

In general, the team finds structural, political, social, and personal barriers to implementing care for patients at the end of life. Although the importance of identifying this moment is acknowledged, it does not happen in an early and integrated manner, which may prolong suffering in the active process of death of patients with hematological neoplasms.

The need for advancements in this area must be highlighted, given that palliative care must be simultaneously integrated into clinical practice. Lack of knowledge can hinder integral assistance to patients, since it interferes with the management of symptoms, which, in addition to physical, includes psychosocial aspects notably in the active process of death.

Prognostic assessment in hematology is a challenge, and producing tools to help in this process and with decision-making is a demand perceived in both practice and scientific literature. The creation of an algorithm can contribute to discussing terminality criteria in oncohematology and guide actions to institute ELC.

It must be highlighted that further clinical trials are needed to assess these and other criteria and that this discussion be amplified, thinking not only from the perspective of patients and their families on palliative care, but also that it fosters data for the provision of more directed care aimed at a better quality of life and death.

A limitation for this study that must be noted is the non-validation of the algorithm; however, a further study may propose its evaluation by a group of specialists in hematology and palliative care to validate it and apply it in the future. Other limitations refer to the fact that the study was conducted in a single setting and did not have the participation of a psychologist or a social worker.

CONTRIBUTIONS

Cintia de Carvalho da Silva contributed to the study concept; analysis of research data; and wording. Audrei Castro Telles contributed to the study design; analysis of research data; and wording. Renata Carla Nencetti Pereira contributed to the study wording; research data acquisition; and review. Vanessa Gomes da Silva and Marcelle Miranda da Silva contributed to revising the work. Marlise Barros de Medeiros contributed to data acquisition and revising the work. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

All the contents associated with the article are included in the manuscript.

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