

Palliative sedation for refractory psychological distress management: a flowchart

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Abstract

There is little consensus in the literature on how refractory psychological distress, a serious clinical challenge that may occur at end of life, should be managed. This case report focuses on a patient hospitalized at the Hospital de Apoio in Brasília, who required palliative sedation for refractory psychological distress relief and obtained satisfactory symptom control. A flowchart was elaborated based on bibliographic review which included the European guidelines for palliative sedation, a useful tool for clinical cases in palliative care.

Keywords: Palliative medicine. Hospice care. Personal autonomy. Psychological distress. Deep sedation. Case reports.

Resumo

Sedação paliativa para controle de sofrimento existencial refratário: um fluxograma

Há pouco consenso na literatura sobre como deve ocorrer o manejo do sofrimento existencial refratário, um desafio clínico dramático que pode ocorrer no contexto da terminalidade. Este artigo apresenta um relato de caso de uma paciente internada no Hospital de Apoio de Brasília que necessitou de sedação paliativa para alívio de sofrimento existencial refratário e obteve controle satisfatório de sintomas. Também foi elaborado fluxograma decisório, embasado em revisão que inclui as diretrizes europeias de sedação paliativa, uma ferramenta útil para clínicos em cenários de cuidados paliativos.

Palavras-chave: Medicina paliativa. Cuidados paliativos na terminalidade da vida. Autonomia pessoal. Angústia psicológica. Sedação profunda. Relatos de casos.

Resumen

Sedación paliativa para controlar el sufrimiento existencial refractario: diagrama de flujo

Existe poco consenso en la literatura sobre cómo manejar el sufrimiento existencial refractario, un desafío clínico que puede ocurrir en el contexto del fin de la vida. Este artículo presenta el reporte de caso de un paciente ingresado en el Hospital de Apoio de Brasília, quien requirió sedación paliativa para aliviar el sufrimiento existencial refractario y obtuvo un control satisfactorio de los síntomas. También se elaboró un diagrama de flujo para la toma de decisiones, basado en una revisión que incluye las directrices europeas para la sedación paliativa, una herramienta útil para los clínicos en el contexto de cuidados paliativos.

Palabras clave: Medicina paliativa. Cuidados paliativos al final de la vida. Autonomía personal. Distrés psicológico. Sedación profunda. Informes de casos.

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Palliative care is an interdisciplinary medical specialty that focuses on preventing and alleviating suffering and providing the best possible quality of life for patients facing serious illnesses and their families. Besides being appropriate at any age and at any stage of a potentially life-threatening disease, it can be provided alongside curative care^{1,2}.

Despite the famous phrase by the honorable Cicely Saunders—*suffering is only intolerable when nobody cares*³—suffering continues to be a major challenge in palliative care. This is still the case not only because of its multidimensional character, but because it sometimes remains intolerable and sometimes refractory, even after the limits of care, treatment and compassion have been reached.

Often, despite pharmacological, non-pharmacological and multidisciplinary approaches, suffering from being affected by a life-threatening disease prevails, influenced by factors such as awareness of the end of one's life and distress caused by the perception of death. Also to be considered are cases in which there is loss of functionality or worsening of physical and psychological symptoms, such as sadness, anxiety, panic, fear and a sense of dejection. Such factors may generate unbearable suffering and coping with it is a challenge for staff in charge of the patient's care⁴.

In this condition of refractoriness—whether physical, with symptoms such as dyspnea, pain and uncontrollable bleeding, or psychosocial, such as existential suffering—palliative sedation emerges as a therapeutic alternative. When control of symptoms is beyond therapeutic reach, one solution is to control the effects of disease awareness that are manifested both somatically and emotionally.

It should be noted that sedation—which can be light, moderate or deep—should be as mild as possible to achieve satisfactory symptom management and can be administered intermittently or continuously until death⁵. Studies show that the percentage of sedated patients varies greatly between populations (14.6% to 66.7%)⁶.

In the context of existential suffering, its application is still controversial⁷ and much less common⁸, as there is no consensus on the

appropriateness of its use⁹⁻¹¹. According to the literature, around 13% to 18% of patients with progressive disease may progress to clinically significant existential suffering⁶. In a systematic review, Arantzamendi and collaborators¹² found a prevalence of refractoriness of around 16% to 59% in cases in which psychological and existential suffering was reported.

This issue is still controversial due to reasons or explanations that differ from those addressed in discussions about the use of palliative sedation in other situations of physical refractoriness, among them^{11,13,14}:

1. The nature of the symptoms addressed, which makes it much more difficult to identify which are truly refractory;
2. The dynamism and idiosyncrasy inherent to the severity of the distress of certain symptoms, making them difficult to predict (in these cases, psychological adaptation and coping are common);
3. Standard treatment approaches for dealing with severe psychological symptoms or existential suffering, such as the use of psychotherapy, religious counseling and spiritual support, are not life-threatening; and
4. Unlike physical symptoms, such as pain or dyspnea, the presence of severe psychological symptoms or existential suffering does not necessarily indicate a very advanced state of physiological deterioration.

It is essential to reiterate that palliative care is not intended to speed up or delay the dying process¹⁵. This applies to palliative sedation, which aims to manage symptoms and guarantee respect for human dignity^{16,17}—the cornerstone of its indication.

The goal of this case report is to assist in identifying suitable cases and discuss ethical and practical issues in palliative sedation. The main issue among them is: decision-making through shared deliberation in the face of refractory and intolerable existential suffering experienced by terminally ill patients.

Method

This is a case report that covers events that occurred in the inpatient unit of Hospital de

Apoio de Brasília (HAB) between April and June 2022. Facts and reports from the patient, family and care team are detailed and analyzed. Data were collected in September 2022, after the patient's death, by reading the electronic medical record.

The project was submitted for consideration to the Research Ethics Committee of Fundação de Ensino e Pesquisa em Ciências da Saúde, being accepted on December 3, 2022. The informed consent form was deemed unnecessary and the paper was written following CARE guidelines¹⁸ for disclosing case reports in scientific journals.

Results

The patient J. L. E.—female, 43 years old, born in Brasília/DF, brown, single, retired—was of evangelical faith and had three brothers and a daughter, whom she venerated. In 2012, she was diagnosed with a malignant neoplasm of the central nervous system, a gemistocytic astrocytoma with an expanding lesion on the right, and shortly afterwards underwent surgical resection of 98% of the tumor in the frontal region, in addition to 27 sessions of adjuvant radiotherapy. In 2015, a new surgical intervention was performed—right frontal craniotomy with subtotal resection of the tumor—and new radiotherapy sessions were performed in 2016.

However, in April 2021, worsening headache and seizure episodes evidenced the progression of the disease. New surgical approaches were contraindicated due to possible motor sequelae, and palliative radiotherapy and chemotherapy were adopted until July 2021. Associated with these interventions, there was progressive worsening of right-sided hemiparesis, cognitive decline, difficult-to-manage epilepsy and depression. Nevertheless, the patient preserved a relative degree of functionality, scoring 60% on the palliative performance scale (PPS), as well as autonomy and independence for basic everyday activities until the beginning of 2022.

On April 1, 2022, the patient was admitted to HAB following referral from Hospital de Base do Distrito Federal (HBDF), due to repeated seizures without the possibility of disease-modifying

treatment. At the time, she had a PPS of 40%, reported generalized pain, prevalent in the left lower limb (6 out of 10 on a verbal numerical scale) and fatigue. Additionally, non-physical symptoms were noted, such as sadness, emotional lability, anxiety and fear. She was taking dexamethasone (8 mg/day), clonazepam (2 mg/day), levetiracetam (1,500 mg/day), and escitalopram (20 mg/day).

During hospitalization, her condition improved, with partial improvement in physical symptoms, both according to self-reporting and the perception of the care team. Pharmacological and non-pharmacological measures were optimized and support by an interdisciplinary team was provided, with occupational therapy, physiotherapy, integrative practices, acupuncture, chromotherapy and psychology. However, despite these efforts, the non-physical symptoms progressively worsened.

The patient presented demoralization syndrome, which led, in her own words, to refractory and intolerable existential suffering, in addition to behavior alterations, including hypobulic and severe hypoactive signs, similar to a catatonic depression. Once the indication for application was identified, palliative sedation was initiated, in accordance with a joint decision made the patient, her daughter and the entire multidisciplinary team.

Respite and superficial sedation were performed on May 27, 2023, with midazolam in continuous infusion at a flow rate of 2 mg/h; however, under the respite and superficial regimen, the patient continued to show signs and symptoms of intolerability, particularly in the absence of her daughter. It was then opted to progress to continuous and deep palliative sedation in the last five days of life. The patient died on June 20, 2023, with no signs of pain or discomfort and in the presence of her daughter.

Discussion

It should be noted that the patient had already been asking to “sleep” for some days, and when asked about the pain she felt, would refer to pain in her soul and cry profusely, once again requesting her daughter's presence. Even after

several approaches by the multidisciplinary team and the optimization of pharmacological and non-pharmacological measures, as well as associated integrative practices, existential suffering remained intolerable for her. The patient only responded to palliative sedation, initially superficial and intermittent, and then deep and continuous.

In addition to existential suffering, the patient also had headache that was difficult to manage, despite the numerous pharmacological and non-pharmacological therapies used. Nevertheless, the symptom was not classified by the team as refractory nor deemed intolerable by the patient.

In this context, it is essential to bring up the discussion about multidimensionality through the concept of total pain. Proposed in 1967 by Cicely Saunders³, the concept refers to pain that must be interpreted not only as a physical phenomenon, but as a symptom imbued with emotional, social and spiritual dimensions, which contribute to the generation of pain and the manifestation of suffering.

It is worth mentioning the difference between a difficult-to-manage symptom and a refractory symptom¹⁹: the former requires specific intervention, whether pharmacological or not, while the latter is characterized by the intensity of the attempts at treatment, their management failures or evidence of toxicity—such as impaired consciousness due to medication.

Although the difference may seem trivial, it helps illustrate the importance of recognizing the symptom and its nature. Failure to recognize a difficult-to-manage symptom may result in early progression to palliative sedation; failure to recognize a refractory symptom may lead to preventable uncontrolled symptoms and suffering.

Between a quarter and a third of all terminal patients in palliative care undergo palliative sedation, and up to a quarter of them require continuous deep sedation²⁰. As already described in the literature^{6,21}, family support in this context is very important.

In the clinical case analyzed, one of the points of greatest impact was the absence of family members, especially the daughter, who was rarely present during the hospitalization period. She explained that she was busy at work, also mentioning previous conflicts with her

mother. In the daughter's presence, the patient's peace of mind was manifest and reported; however, when the daughter was absent, the symptom burden increased exponentially and was even described by the patient as intolerable.

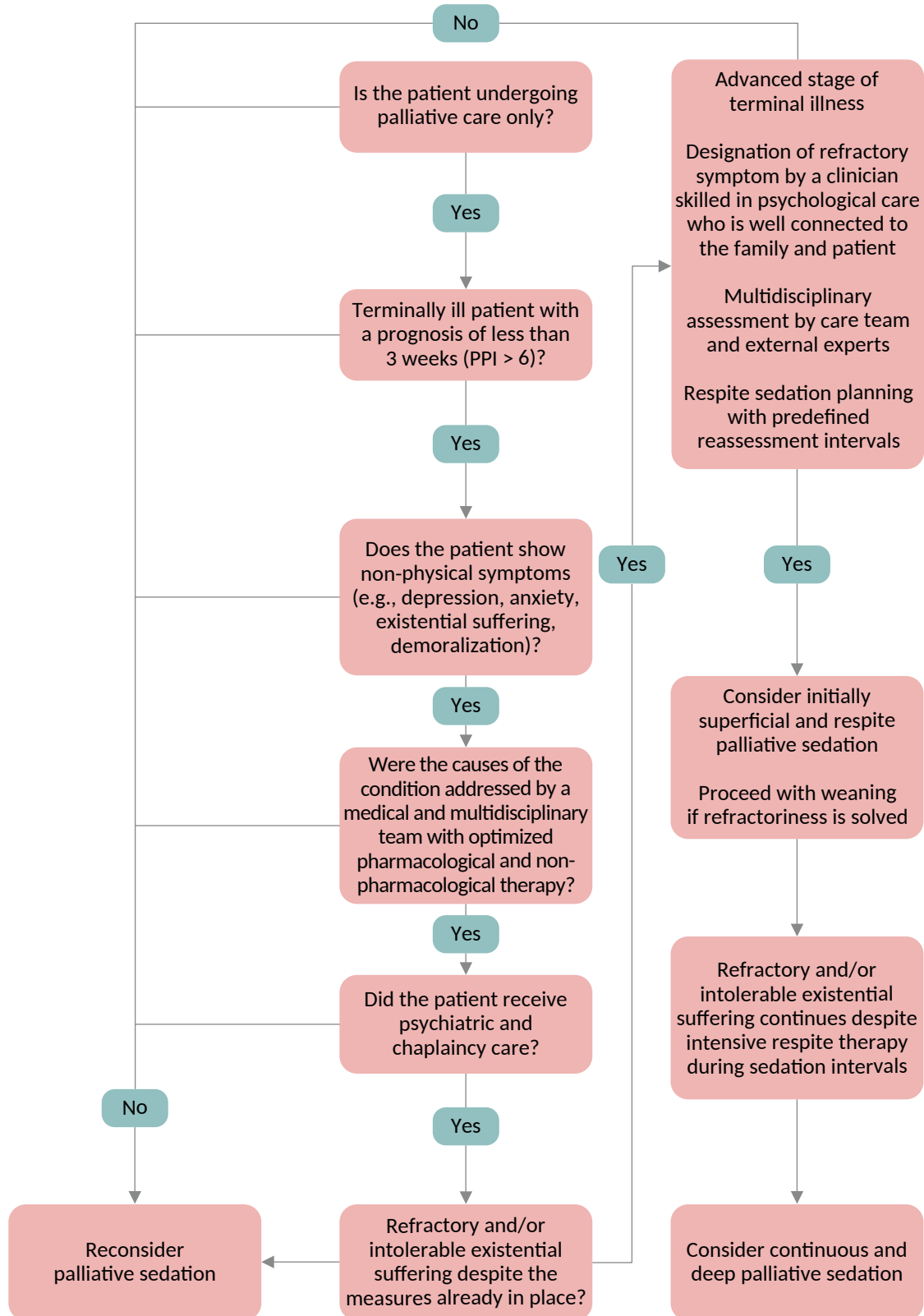
There are additional important data that may cause confusion. Not only a previous psychiatric condition—depressive episodes during life—may have added to the symptom burden, but also metastasis in the central nervous system, a possible organic factor that contributed to the evolution of previously established depression. It is likely that such factors posed an even greater challenge to the mitigation of suffering in its multiple dimensions.

In a narrative literature review on the use of palliative sedation in cases of refractory psychological and/or existential suffering, Reich and collaborators⁸ show that alternative diagnoses may obscure or be obscured by psycho-existential suffering. In these cases, correct diagnosis and appropriate management become more difficult. It must be emphasized that, until her death, the patient described in this study was also evaluated by a psychiatrist, who adjusted the medication with little therapeutic success, and that the only kind of care not offered by the multidisciplinary team was chaplaincy.

Given the difficulties cited in managing similar cases, it is important to create care models—protocols, flowcharts and other tools to support clinical decision-making—that serve as guidance. Thus, it would be possible to define such a diagnosis more assertively and implement more effective measures to address such a sensitive subject, which involves complex ethical and moral issues.

The flowchart featured in Figure 1 aims to facilitate and assist in decision-making on palliative sedation in the context of existential suffering and was designed based on the literature reviews referenced in this work, being in line with the criteria of the European Association for Palliative Care (EAPC)¹⁶. These criteria address the main clinical issues to be considered when formulating institutional guidelines and protocols for palliative sedation in managing refractory symptoms related to existential suffering at end of life. The adequacy to these criteria was included in the formulation of the flowchart proposed in this article.

Figure 1. Flowchart for palliative sedation in the context of existential suffering



PPI: palliative prognostic index

Research

General instructions regarding medical performance in palliative sedation in any context are beyond the scope of this article and available in various references^{6,16,17,19-22}. EAPC¹⁶ guidelines aimed at the context of existential suffering include:

1. Palliative sedation for the treatment of refractory existential suffering should be reserved for patients in advanced stages of terminal illness;
2. The designation of refractoriness of existential suffering should be made by a team skilled in psychological and spiritual care who have established a relationship with the patient and their family and exhausted therapeutic possibilities;
3. The decision for palliative sedation should be made in the context of a multidisciplinary case conference, ideally including a psychiatrist, a bioethicist and a chaplain;
4. Once the decision to sedate has been made, treatment should start with light, respite sedation, with predefined reassessment intervals to readjust frequency and depth of sedation; and
5. Deep and continuous sedation should only be considered after repeated reevaluations of

respite sedation that confirm its insufficiency for symptom management.

Final considerations

Determining when psychological or existential suffering is refractory and unbearable remains a complex and controversial issue. With such a degree of human subjectivity and multidimensionality, it is essential to seek standardized instruments that facilitate and assist in decision-making in relation to refractoriness and intolerability.

It should be stressed that, given the subjective nature of existential suffering, team assessment and construction offer different perspectives on ethical dilemmas that may provide a protective element. Nevertheless, the paucity of evidence-based resources limits the ability of the current literature to inform clinical policy and practice.

Therefore, the use of solid guidelines in the decision-making, documentation and assessment process is very valuable. Qualitative and quantitative multicenter research is required to help healthcare providers and institutions enhance their capacity for deliberation and implementation of more appropriate action.

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Participation of the authors

Arthur Amaral de Souza designed the scientific project and took part in the care team assisting the patient, and contributed to the literature review and writing of the paper. Gabriel Souza Borges contributed to the literature review, writing and review of the paper, and flowchart design. Erika Renata Nascimento Cavalcanti de Oliveira contributed to designing the scientific project and reviewing the manuscript. Luiza Alvarenga Lima Bretones contributed to designing the scientific project and reviewing the manuscript.

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