Palliative Medicine & Care International Journal
ISSN: 2688-3821

Juniper Publishers
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Case Report
Volume 4 Issue 4 - February 2025
DOI: 10.19080/PMCIJ.2025.04.555645

Palliat Med Care Int J

Continuous Deep Sedation in Palliative Care Patient's Refractory with Existential Suffering at The End of Life: Case Report

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Submission: February 11, 2025; **Published:** February 25, 2025

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Abstract

Currently, the issue of refractory existential suffering has taken on greater importance as it is recognized by health personnel. However, by not distinguishing between pain and suffering, the latter can go unnoticed and without treatment that can alleviate it. It becomes a complex issue to address due to the lack of medical consensus. This article presents a case report of a patient admitted to the Oncology Hospital of the National Medical Centre Siglo XIX in Mexico, who by identifying the condition and offering treatment, managed to give the patient quality of life in her final days.

Keywords: Refractory Existential Suffering; Palliative Sedation; Palliative Care

Abbreviations: EAPC: European Association for Palliative Care; NHPCO: National Hospice and Palliative Care Organization; ESAS: Edmonton Assessment Scale; BSI: Brief Symptom Inventory; MSAS: Memorial Symptom Assessment Scale; ECOG: Eastern Cooperative Oncology Group; IK: Karnofsky Index; PPS: Palliative Performance Scale; PPI: Palliative Prognostic Index; PAP SCORE: Palliative Survival Prognostic Score; BP: blood pressure; mmHg:millimeters of mercury; HR: heart rate; bpm: beats per minute; RR: respiratory rate; rpm: breaths per minute; Temp: temperature; SAT O2:oxygen saturation; ml: millilitres; hrs: hour; cm: centimetres; CPR3: no cardiopulmonary resuscitation order; mg:milligrams; RAMSAY: RAMSAY Sedation Scale

Introduction

The patient with terminal criteria who is in the final stage of life presents a wide variety of physical, psychological, emotional, spiritual and social symptoms. Therefore, palliative medicine provides holistic care with the aim of improving the quality of life and providing a good death.1 One of the most controversial symptoms to address is existential suffering, due to the various definitions that exist. Currently, the European Association for Palliative Care (EAPC) defines it as "those feelings of hopelessness, helplessness, fear of death, disappointment, loss of self-esteem, remorse, loss of meaning and purpose in life, interruption of personal identity or loss of dignity." Which, unlike the definition of the National Hospice and Palliative Care Organization (NHPCO), adds the aspect of temporality when it occurs at the end of life.2

In palliative care clinical practices, an essential guideline is the definition of the term refractory, which is related to a symptom of an intractable nature (by health professionals) and intolerable (by the patient). Refractory existential suffering occurs when there are no methods that can provide adequate relief, in an acceptable time frame and without intolerable adverse effects.3 Currently, there are no exact statistics on refractory existential suffering, however, Gabl C et al. [1] reports that existential suffering ranges between 13-35 %, 30.5 % on average,4 and Arantzamendi et al. [2] reports that it was present in 48 % correlated with another symptom in the administration of palliative sedation. In another study, 5 % of patients only presented refractory existential suffering as an indicator of palliative sedation.5

For practical purposes, it is assumed that existential suffering is anguish due to the loss of meaning, purpose or hope in a person's life. Its objective and subjective evaluation is complex since various authors refer to it as a loss of dignity, demoralization, panic over death, hopelessness, personal and social isolation, and even loss of control.6 All of these definitions have two characteristics: the sense of future time and personal meaning that, when threatened in terms of functionality, the person's central purpose, that of

being or building themselves, is lost.7 For this reason, diagnosis and assessment can be difficult. In many cases, health personnel may suspect it, however, it is addressed when the patient openly manifests it.

The assessment process consists of a clinical interrogation, including asking questions such as: Are you suffering? Are there things worse than pain? or What is the worst thing about all this?7 and the use of tools that assess suffering indirectly, since there is no instrument that assesses it specifically. The most commonly used indirect instruments in Palliative Care that help to analyze information, symptoms or aspects of the patient in the evaluation process are: Bayés' perception of the passage of time, the distress thermometer, the Edmonton Assessment Scale (ESAS), the Brief Symptom Inventory (BSI) and the Memorial Symptom Assessment Scale (MSAS).8 Which guide us over time whether the symptom decreases, exacerbates or persists.

In addition to symptom refractoriness, the patient's deteriorating clinical status and poor short-term prognosis must be considered. Therefore, in the absence of improvement and the presence of suffering at the end of life, it is the physician's responsibility to make an appropriate judgment to provide clinically appropriate treatment options to control suffering, such as palliative sedation.9 It differs from euthanasia and assisted suicide in the aspects of intention and desired outcome.10 Palliative sedation refers to the reduction of the patient's consciousness through the administration of sedative medications to relieve intractable suffering that does not respond to treatment when the patient's life expectancy is weeks to days.11

It is distinguished by depth (superficial, intermediate and deep) and duration (intermittent or continuous), Beauverd et al. [3] mention that palliative sedation should be as superficial and intermittent as possible to alleviate the suffering of patients, except in palliative emergencies or if its cessation is harmful due to a high probability of increasing suffering during weaning.12 To implement it, an adequate doctor-patient relationship, effective communication and shared decision-making between the patient, primary caregiver and interdisciplinary medical team are essential. In addition, three talks are carried out in the process of shared decision-making, the team talk, the options talk and the decision talk during family and multidisciplinary meetings to reach a decision on the use of the procedure, after obtaining signed informed consent. 11,13 The onset of sedation may be intermittent for existential suffering or continuous until death,13 almost all patients with this diagnosis receive intermittent sedation before deep sedation,14 related to situations of dependency, loss of autonomy and hopelessness.14 The indication to offer deep sedation is linked to an intention to offer a dignified death.15

Case Report

A 37-year-old female patient was admitted to the hospital in the Gynaecological Tumours department, where she was diagnosed with moderately differentiated intestinal adenocarcinoma with metastasis to the ovary, bladder and cervix. After a month of hospital stay, she was referred to the Pain Clinic and Palliative Care department due to difficult-to-control pain, and treatment with Morphine was started with rescue doses in case of severe pain for daily titration. Relevant history: Postoperative of 5 exploratory laparotomies secondary to intestinal obstruction and postoperative complications (perforation and bleeding) / ileostomy / high output fistula / abthera system status / grade 1 anaemia / sepsis: secondary peritonitis / nosocomial pneumonia. Non-pathological personal history: Religion: Christian. Psycho-family assessment with a simple, traditional, integrated, service-based, urban nuclear family in the Duvall IV family life cycle. Para normative crisis of illness type. Primary caregivers: father and husband. With an adequate support network. Advanced guidelines addressed through consultation with the service. After a month of continued close monitoring by the Palliative Care Service and by psycho-oncology, the patient repeatedly expressed total pain and suffering. Therefore, the doctors reported the algological diagnosis of difficult-to-control breakthrough pain and the palliative diagnoses of failure to recover/total pain/refractory suffering of an existential type. Clinical manifestations: moderate to severe pain after healing. She reports physical, emotional, functional, spiritual and social pain. Her father reaffirms what the patient expresses.

Current pain: Severe

Edmonton 24-hour scale: pain 10/10, fatigue 10/10, nausea/vomiting 0/10, depression 10/10, anxiety 6/10, drowsiness 8/10, appetite 0/10, malaise 10/10, shortness of breath 0/10, difficulty sleeping 0/10. **Cardinal symptoms:** pain, fatigue, depression, and maximum malaise.

Functionality: ECOG 4. IK 20, PPS 20, PPI: 7.5 PTS, PAP SCORE: C.

Physical examination: BP: 80/44 mmHg, HR: 80 bpm, RR: 19 rpm, Temp: 36 ° C, SAT O2: 96%, Nephrostomies 400 ml/24 hrs. Ileostomy 20 ml/24 hrs. Bedridden, neurologically intact with response to verbal stimuli, normocephaly, icteric tinge to the skin, regular hydration status, normoreactive pupils, hypoventilated lung fields at baseline, rhythmic heart sounds, abdomen with pain on palpation, with functional nephrostomies. Back with pressure lesion 10x15 cm, no signs of infection, moisture-associated lesions in the vulvar and bilateral inguinal area with erythematous and phlyctenous characteristics. Hypotrophic extremities, muscle strength 3/5, delayed capillary refill.

Laboratory and Cabinet Tests: None New

Oncology plan: requests reassessment for palliative care for treatment of intensive symptoms, patient with failure to recover. Futile treatment is avoided, therapeutic adaptation is performed and CPR3 is signed. Therefore, palliative care specialists hold

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a private meeting with the patient and then with the primary caregiver. They discuss the procedure, advantages, side effects, administrative requirements and differences between palliative sedation and euthanasia (a procedure prohibited in México). After verifying the patient's wishes and autonomy, she expressly requests not to be awakened, and family members reinforce this wish because of the suffering and helplessness that could occur during weaning. A fourth meeting is held with the medical team, oncologic surgeons, palliative care specialists, department heads, attending physicians, resident physicians, social worker, primary caregiver and family, where the start of continuous deep sedation is jointly decided.

Informed consent forms for continuous deep palliative sedation were provided, signed by the patient, her husband and her father. With the help of social work, the patient's children were admitted to the hospital for cycle closure, as well as other family members. Following this, in the presence of the primary caregiver, general recommendations were made regarding care of the environment and comfort control. When doubts were resolved, continuous deep sedation was started with an induction dose of Midazolam 5 mg IV single dose and a base solution of Midazolam 30 mg plus Morphine 50 mg plus butylhyoscine 60 mg measured in 100 ml of 0.9% IV physiological solution for 24 hours, with a rescue dose of Midazolam. After 24 hours, a reassessment was performed, finding the patient with IV RAMSAY and physical signs of pain, for which a 50% increase in benzodiazepine and opiate was made, with a base dose of Midazolam 60 mg plus Morphine 100 mg plus butylhyoscine 60 mg measured in 100 ml of 0.9% IV physiological solution for 24 hours, for later assessment with a RAMSAY V during follow-up. The patient died five days later without any physical signs of pain, accompanied by family members. Family members were grateful for the Pain Clinic and Palliative Care services.

Results

We were able to observe that the patient undergoes a very rapid transition from the diagnosis of malignancy to what is known as the terminal phase when she is no longer susceptible to a specific therapeutic approach. With a clinical condition that deteriorated due to associated complications that led to her not being a candidate for other treatments. Therefore, she was limited to being bedridden with an ECOG 4, not doing basic or instrumental activities of daily living due to pain and associated symptoms, which were initially controlled with drugs such as analgesics, opiates and benzodiazepines, however they were exacerbated to the point that the opiates did not relieve the pain even though she had daily opioid titrations, this reported through the ESAS (maximum discomfort 10/10) and a medical note. The patient expressed on multiple occasions "I want to sleep and not wake up and suffer" (Sic. Pac.), in addition to the great impact on the primary caregiver in this case her father when he expressed "his pain hurts me so much that I have thought about giving him the full dose so that he does not suffer anymore" (sic. Fam.); During her time in hospital, the patient received care from a psycho-oncologist as well as spiritual care since she had spirituality as a protective factor (as she professes a religion and her father is a pastor), a support system for the patient, caregiver and family during the illness and grief from palliative care physicians; that when identifying the refractoriness of the symptom in the psychoexistential field, the alterations of the biological constants, the decrease in the functionality indices ECOG (Eastern Cooperative Oncology Group) 4, Karfnosky Index (IK) 20, Palliative Performance Scale (PPS) 20), the poor short-term prognosis Palliative Prognostic Index (PPI) of 7.5 points were evaluated, which translates to a survival of less than 3 weeks with a sensitivity and specificity of 80 and 85% respectively. Another relevant point is the intolerability of the symptom mentioned by the patient, with great impact on the primary caregiver and family.

Discussion

All the aspects mentioned were the criteria for palliative care specialists to present sedation as a therapeutic alternative when making a clinical judgment, always respecting the patient's autonomy, dignifying her life and based on the principalist method. In the literature, the double effect, the proportionality of the symptom and autonomy are the main ethical principles for the use of palliative sedation as a therapy.12 The acceptance of the treatment by the patient and family was that at all times it was made clear that the objective of palliative sedation is not to accelerate or delay the process of death but to continue with the course of the disease, control the symptoms and guarantee quality of life,14 due to this situation there was no confusion between assisted suicide or euthanasia, they even requested the state of greatest well-being. When analysing the case, we found data of confusion, since cancer patients have a great emotional burden due to the evolution of the disease. In this case, anxiety and depression can be confused with the diagnosis. However, the psycho-oncologist's evaluation reported them as maladaptive emotional reactions to a Para normative crisis of the disease type, coexisting with suffering and preventing psycho-emotional relief. After the consensual assessment, the medical group decided to individualize the patient's therapy by omitting superficial and intermittent sedation due to the adverse effect of exacerbation of the symptom upon weaning and causing destabilization of the situation, compared to authors such as Miccinesi G et al. [4] who propose multiple respite sedations to later perform deep sedation, and others consider its use controversial. We believe that the use of palliative sedation should be proportional to the situation, therefore, in cases where the patient presents a terminal illness, with refractory existential suffering and a limited vital prognosis, the use of palliative sedation is justifiable [5-10]. For the Palliative Care team, the approach to this case was hard work in which an interdisciplinary team was involved, with constant meetings, assessments, assertive communication, and medical [11-15] consensus due to the lack of support tools, protocols, and specific

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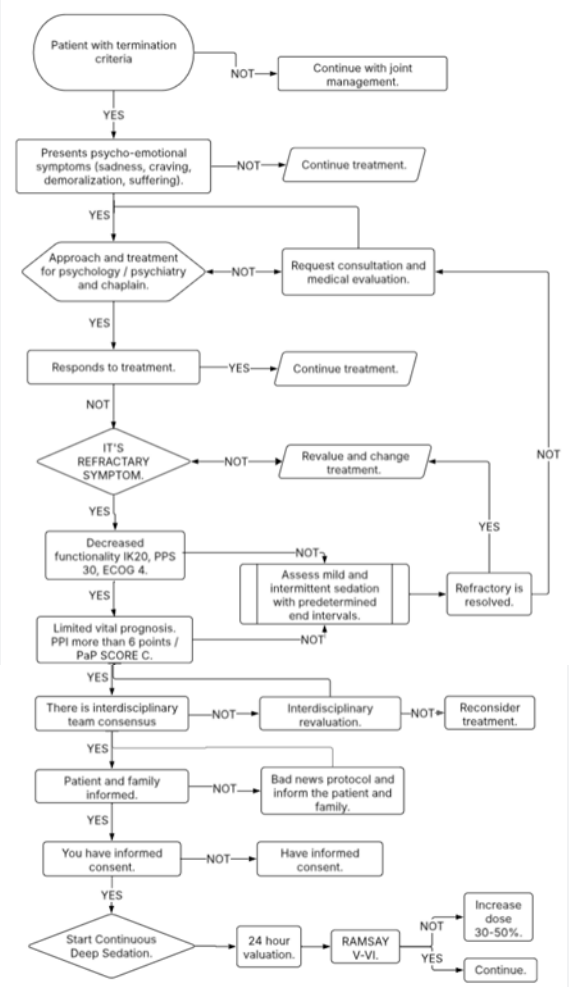
criteria that help in viable treatment strategies for refractory existential suffering.14 Below we show [Figure1], which is a modification of the flow chart of palliative sedation in existential suffering of De Souza et al [16].



Flowchart for existential suffering

ECOG: Eastern Cooperative Oncology Group; IK: Karfnosky Index; PPS: Palliative Performance Scale; PPI: Palliative Prognostic Index; PAP SCORE: Palliative Survival Prognostic Score; RAMSAY: RAMSAY Sedation Scale. ***Source:*** *Modified from Palliative Sedação para controle de sofrimento existential refratário: um fluxograma. De Souza et al. [16].*

Conclusion

Currently, existential suffering is a symptom that generates controversy in the medical field and although there is no universal definition, the evaluation of a multidisciplinary team, the use of indirect tools and the consensus of the team can be the main steps for its early diagnosis and treatment, to prevent patient complications and require a more aggressive intervention. Addressing suffering as a refractory symptom is a challenge for health professionals trained in the area of palliative care, since the lack of standardized protocols can cause ethical dilemmas. Therefore, it is considered that studies and research are needed to generate new knowledge to develop intervention strategies and continue with one of the objectives of Palliative Care, which is to provide a better quality of life for the patient and their family.

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