

Palliative sedation in patients with non-oncological terminal illnesses: ethical and practical considerations in the management of suffering*

La sedación paliativa en pacientes con enfermedades terminales no oncológicas: consideraciones éticas y prácticas en la gestión del sufrimiento

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<https://doi.org/10.36105/mye.2026v37n4.03>

* An artificial intelligence tool (NotebookLM) was used as an editorial aid to improve the manuscript's writing, grammar, and clarity. The content was reviewed, modified, and fully validated, and the author assumes full responsibility for the text.

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Received:
01.06.2026

Sent for review:
02.11.2026

Accepted:
02.28.2026

Published:
10.01.2026

CÓMO CITAR: Reyes Martínez, M. F. (2026). Palliative sedation in patients with non-oncological terminal illnesses: ethical and practical considerations in the management of suffering. *Medicina y ética*, vol. 37, núm. 4. DOI: <https://doi.org/10.36105/mye.2026v37n4.03>



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Abstract

This research examines palliative sedation as a clinical and ethical practice aimed at alleviating refractory suffering in patients with non-oncological terminal illnesses. Through an interdisciplinary literature review, it explores the ethical foundations, clinical challenges, and bioethical dilemmas associated with its application. The study emphasizes that palliative sedation, far from seeking to hasten death, is grounded in the principles of therapeutic proportionality and patient autonomy, thereby ensuring a dignified and humanized end-of-life process. It also highlights the importance of informing society about this practice, which is often mistakenly associated with death, to promote an ethical and compassionate understanding of suffering relief. The study concludes that the implementation of unified protocols and regulatory frameworks is crucial to ensuring a transparent, equitable practice centered on human dignity.

Keywords: palliative care, dignity, autonomy.

Methodology

A narrative literature review was conducted using an interdisciplinary approach in bioethics, palliative care, and health sciences, focusing on palliative sedation in adult patients with terminal non-oncological illnesses. An electronic search was conducted in PubMed/MEDLINE, SciELO, and Cochrane, supplemented by Google Scholar and a manual search of reference lists, to identify relevant articles published between 1998 and 2025 in Spanish, English, and Portuguese. Combinations of terms such as palliative sedation, terminal sedation, non-cancer / non-oncologic, end-of-life care, heart failure, chronic obstructive pulmonary disease, neurodegenerative diseases, chronic liver disease, existential suffering and their equivalents in Spanish, English, and Portuguese were used.

We included observational studies, systematic reviews, clinical practice guidelines, consensus documents, and bioethical reflection

articles that addressed palliative sedation in the context of advanced chronic non-oncologic diseases or in mixed populations where it was possible to extract considerations applicable to this group. We excluded studies focused exclusively on oncology patients, pediatric sedation, and sedation for procedures. In addition, regulatory documents and national and international guidelines on palliative care and palliative sedation were specifically included due to their relevance to the analysis of ethical and regulatory frameworks.

The information was organized around six main themes: the definition and ethical foundations of palliative sedation; characteristics of suffering in advanced chronic non-oncological disease; ethical considerations; regulations and international guidelines on palliative care; clinical and psychosocial aspects; and, finally, challenges and proposals for standardization and training; given the heterogeneity of the concepts, a critical narrative synthesis was chosen, without applying standardized risk-of-bias scales typical of systematic reviews.

Introduction

Population growth, coupled with the rise in progressive chronic diseases, has generated an ever-increasing demand for palliative care (PC) globally (1–2). The top five causes of death nationwide in Mexico in 2024 were heart disease, diabetes mellitus, malignant tumors, liver disease, and accidents (3). Although palliative care has traditionally been associated with oncology, clinical reality shows a significant prevalence of patients with chronic non-oncological conditions —such as cardiovascular, respiratory, or neurodegenerative diseases— who require advanced support, and for whom the prognosis is often difficult to predict with accuracy (1,4).

The concept of Palliative Sedation (PS) has evolved in parallel with the development of palliative care centers (PCCs). This interdisciplinary field is recognized by international organizations as a comprehensive and active approach whose primary objective is the

prevention and relief of suffering, by creating a supportive psychosocial care environment that improves the quality of life for patients and their families as they face challenges arising from life-threatening illnesses. Its application is centered on the patient's dignity and can raise bioethical dilemmas for physicians and families (1,5–7,8). This model of care is indispensable because it integrates physical, psychological, social, and spiritual aspects, and is considered an ethical responsibility of health care systems; access to it is a fundamental human right (5–6,9).

As the disease progresses to the terminal stage, refractory symptoms may arise—defined as those that persist and cause intolerable suffering despite the exhaustive application of specific treatments by expert physicians, or when available therapy entails unacceptable adverse effects (1–2,5,10). In this scenario, SP is instituted as a therapeutic option. Palliative sedation (PS) is the deliberate and intentional administration of medications to reduce the patient's level of consciousness, in the necessary dose and combination, in order to adequately alleviate one or more refractory symptoms (5–6, 10–11).

It is important to note that, among patients with non-oncological terminal illnesses, empirical evidence and available knowledge are limited, and there remains significant heterogeneity in criteria and a lack of international consensus regarding its application and definition (4,10). SP represents a fundamental clinical and humane tool for ensuring the patient's comfort, quality of life, and dignity at the end of life (5,12). Ethically, its legitimacy is grounded in the intent behind the act: the goal is the relief of suffering, not the causing of death or the deliberate shortening of life, a distinction that sets it apart from practices such as euthanasia (4–5,9,13). The decision to resort to palliative care is highly complex and has profound anthropological, psychological, and emotional implications for both the patient and their immediate family (5). Therefore, its implementation requires careful shared reflection and a rigorous interdisciplinary evaluation, following protocols that ensure transparency, therapeutic proportionality, and absolute respect for the patient's autonomy and dignity (11).

Given the various challenges —such as clinical complexity, the growing prevalence of non-oncological terminal illnesses (NOTIs), the need to ensure a dignified and humane end-of-life for patients, the lack of unified guidelines, and the ethical controversies associated with the application of SP in NOTIs— there is a clear need for a rigorous analysis of the ethical foundations and clinical guidelines applicable to these patients. The overall objective of this article is to analyze the ethical and practical implications of palliative sedation in patients with terminal non-oncological diseases, evaluating the challenges it poses in clinical practice through a comprehensive approach that includes its ethical implications, clinical aspects, and international regulatory frameworks guiding its use as a last resort for the management of intractable suffering.

1. Definition and ethical foundations of palliative sedation

palliative Sedation (PS) is a last-resort therapeutic measure in palliative care (PC), reserved for the management of symptoms that become refractory to conventional treatment, that is, those that persist and cause intolerable suffering despite the expert application of all available therapeutic options (5,10).

Historically, the procedure was known as “terminal sedation” (11,14), a term that, due to its potential ambiguity and the erroneous implication that the goal was to “end” life, has evolved into the preferred designation of Palliative Sedation (10,13). Palliative Sedation (PS) is therefore defined as the intentional administration of medications to reduce the patient’s level of consciousness, in the necessary dose and combination, with the sole aim of alleviating intractable suffering (6,10–11). This intentionality marks the fundamental ethical distinction from euthanasia and assisted suicide (5,6,13).

The Palliative Sedation Guidelines of the General Council of Official Medical Associations, in accordance with the Spanish Society of Palliative Care (SECPAL), objectively state that palliative

sedation is used exclusively to alleviate intolerable suffering caused by refractory symptoms; furthermore, they provide a comprehensive analysis of its indications and emphasize its importance as a good medical practice that is both ethically and deontologically mandatory and necessary (15).

While euthanasia directly aims to bring about the patient's death to end suffering, palliative care seeks symptomatic relief and accepts death as a consequence of the natural course of the disease (12–13). Ethically, palliative care is grounded in the principle of therapeutic proportionality, which requires using the minimum effective dose to achieve a level of unconsciousness sufficient for symptom control (9,11). Through therapeutic analysis, patients should be offered treatments that have a reasonable probability of benefit in terms of preserving and/or restoring health; that is, inappropriate treatments that yield no benefit should not be prolonged (16).

The principle of therapeutic proportionality dictates that only those interventions and treatments that maintain a proper balance between the means employed and the foreseeable outcome are morally obligatory; when this proportion is not met, the measure is considered disproportionate and not obligatory; therefore, prudent judgment is always required on the part of the palliative care team, combining quantitative elements—that is, the prognosis or probability of benefit—with qualitative elements: physical, psychological, and spiritual burdens, while respecting the patient's dignity, in order to make an informed decision (17).

The term “early palliative care” is used inconsistently in the literature, with no universal definition. A practical classification is proposed to standardize its identification and measurement in research and to facilitate its clinical implementation for patients so that they can receive care early on without obstacles or setbacks (18).

Reymond (19) proposes a model of home-based palliative care that professionals can systematize through three key processes: early identification of at-risk patients; a medical plan outlining care goals and end-of-life care; supported by three operational elements essential for high quality: a compassionate clinician, a coordinated team,

and practical resources. The team is responsible for the patient, not just the medical specialists, and managing the patient's care is the duty of each team member (20).

2. Characteristics of suffering in non-cancer terminal illness

The implementation of palliative care is particularly complex in patients with non-cancer terminal illnesses (NCTI) involving very advanced chronic-degenerative diseases such as heart failure (9), advanced respiratory failure (COPD), neurodegenerative diseases (ALS or dementia) (2,4), or kidney or liver diseases (2). Unlike the course of cancer, which often has a more predictable prognosis, the clinical course of NTDs is characterized by fluctuations and frequent crises of need that can lead to temporary recoveries before death (1,4). This nature makes it difficult to formulate a precise prognosis of life expectancy limited to days or a few weeks (14,4), which, in turn, complicates the early identification of truly refractory symptoms and the appropriate timing for palliative care (4).

In these conditions, total pain manifests as multidimensional suffering that includes physical pain —such as dyspnea or fatigue, which are prevalent in ETNO (2,14)— as well as psychological and existential suffering (5,7,21). In the non-oncological context, particularly in diseases such as Amyotrophic Lateral Sclerosis (ALS), the patient may remain conscious but with a marked loss of functionality (4), intensifying existential suffering (loss of meaning in life, hopelessness, or fear of death) (7,21). Given this complex set of symptoms within the context of an uncertain disease progression, comprehensive support for the patient and family is crucial and must be provided by a multidisciplinary team (including psychologists, social workers, and spiritual counselors) (5,47). This holistic approach is essential to exhaust all options for relief that go beyond pharmacological management before considering palliative care, thereby ensuring respect for the patient's dignity and autonomy in their final hours of life (4,11).

The available evidence suggests that an integrated palliative care approach can improve quality of life and reduce the burden of symptoms in patients with heart disease; however, the field is still in its early stages, so the authors propose strengthening primary palliative care competencies in cardiology and primary care and integrating this care according to the patient's needs (22).

With regard to chronic neurological diseases such as Parkinson's, there are concerns regarding the spiritual dimension, as it is often underserved despite its relationship to well-being, non-motor symptoms, and quality of life (23).

In advanced chronic liver disease, palliative care remains insufficiently integrated, even though it is a major cause of death worldwide and has a relatively earlier impact than other serious illnesses (24).

Furthermore, although care guidelines are emerging, they often do not sufficiently incorporate the patient's perspective. Throughout the clinical management of patients with terminal illness, demoralization may occur; it is described as a psychosocial-existential syndrome characterized by hopelessness, helplessness, and a loss of meaning or purpose, which can arise even when the patient does not meet the criteria for depression (25). This reinforces the need for comprehensive patient management that can protect their mental health.

3. Ethical considerations

The use of palliative sedation (PS) takes place within a context of high clinical complexity and extreme human sensitivity and is inevitably governed by the fundamental principles of bioethics: autonomy, beneficence, non-maleficence, and justice (5). The principle of beneficence guides the provision of maximum comfort and relief from suffering, while non-maleficence prohibits harm, requiring that the futile prolongation of biological life without a minimum quality of life—known as futile medical treatment—be avoided (5,9). Respect for autonomy is crucial, requiring that interventions

align with the values and guidelines of the patient or, failing that, of their legal representatives (5,9,14). Furthermore, Justice requires that access to Palliative Care (PC) and SP be universal and equitable, considering them an ethical responsibility of health care systems and a basic human right (5,13). The ethical justification for SP is grounded in its strictly therapeutic intent: the goal is the relief of refractory suffering, not the shortening of life (5,12–13).

It is essential that this intervention be a last resort, indicated only when the symptom has been confirmed as refractory by the expert team (11). The decision-making process must be the result of careful shared reflection and must culminate in obtaining informed consent from the competent patient or their representative (5). Accurate documentation of the indication, the procedures already exhausted, the desired level of sedation, and the record of consent (often verbal but always documented in the medical record) are essential to ensure transparency and the appropriateness of the practice (2,14). The deepest foundation of palliative care lies in the unconditional respect for the patient's dignity and in the commitment to alleviate all suffering (physical, psychological, social, and spiritual) that accompanies the terminal phase (5,13).

4. International regulations and guidelines on palliative care

Within the Latin American regulatory context, countries such as Mexico explicitly recognize access to palliative care and end-of-life support as basic human rights, backed by the Constitution and various health regulations (5). Currently in effect is the Official Mexican Standard NOM-011-SSA3-2014, which establishes the criteria for the care of terminally ill patients through palliative care. This standard stipulates that all health services must provide palliative care to terminally ill patients, ensuring dignified treatment, quality of life, and respect for autonomy (26).

In Mexico, IMSS-440-11 clinical practice guideline on palliative care for adults defines palliative care as a comprehensive approach (addressing physical, psychological, and spiritual symptoms, as well as decision-making); it also emphasizes the need to extend care to people with non-oncological illnesses and supports a care model focused on alleviating suffering and avoiding disproportionate interventions (27).

Globally, organizations such as the European Association for Palliative Care (EAPC) have promoted frameworks to ensure the rigor of palliative care. However, the prevalence of palliative care varies greatly among centers—ranging from less than 10% to more than 50% of terminally ill patients—which highlights the lack of uniformity in the clinical criteria applied internationally (10).

U.S. best-practice guidelines for primary palliative care in emergency departments organize patient care into four phases: screening and needs assessment, management of patients with palliative care needs in the emergency department, consultation with palliative care specialists, and safe transition of eligible patients to palliative care or hospice, which provides a clear operational framework from the patient's arrival through referral and continuity of care (28).

Palliative care is a fundamental human right grounded in health, dignity, and therapeutic self-determination. In Italy, despite Law 38/2010, regional inequalities in access and barriers related to funding and training persist, underscoring the need for effective protocols and policies to ensure equitable end-of-life care (29).

Kontro (30) describes the persistence of regional inequalities in access in Finland and a risk of overreliance on family caregivers; therefore, policies must prioritize equity for people living alone and strengthen communication and professional roles to better coordinate care.

The October 2025 review by the Parliamentary Technical Advisory Service of the Chilean National Congress Library details the palliative care models of the United Kingdom, Germany, and Taiwan, highlighting that all three countries have integrated palliative and end-of-life care as a legal obligation of the health system, with

robust frameworks for funding, regional governance, and instruments for advance autonomy (advance directives and advance decisions) (31).

The updated Swiss recommendations on palliative sedation not only reaffirm its ethical legitimacy but also establish it as a high-quality procedure: they emphasize standardized documentation of the indication, clinical comfort goals, periodic reassessment, and the involvement of an interdisciplinary team, and even propose that centers systematically review these cases for training and continuous improvement purposes (32).

5. Clinical and psychosocial aspects

Palliative Sedation (PS) is indicated as a last-line therapeutic intervention, strictly reserved for the management of refractory symptoms in patients with advanced, end-stage disease (5,10). A symptom is defined as refractory when, despite the exhaustion of all available treatments provided by experts, it persists and causes suffering that is perceived as intolerable by the patient, or when the available therapy entails unacceptable adverse effects that outweigh the benefit (6,10,33). The main physical symptoms that necessitate palliative sedation are agitated delirium, dyspnea, and pain (5,10). In the context of non-oncological terminal illnesses (ETNO), dyspnea has been reported as the most prevalent refractory symptom warranting sedation, followed by pain and delirium (2).

The assessment of refractory suffering requires a high degree of clinical and ethical rigor, since intolerability is a largely subjective criterion that must be confirmed by a conscious patient (33). To define a symptom as refractory, the following conditions must be met:

- 1) Conventional means of symptomatic treatment have failed.
- 2) The effect of standard therapies is not achieved quickly enough.
- 3) Standard treatments are accompanied by unacceptable adverse effects (10).

The assessment must be comprehensive, considering the patient's overall suffering, including the physical, psychological, and existential dimensions (5). Although sedation for psycho-existential suffering is more controversial, it is recognized that a loss of meaning in life, hopelessness, existential anguish, or fear of death can become refractory, justifying intervention in cases of very advanced disease and imminent death (7,16). It is vital that the clinical team avoid labeling a difficult-to-manage symptom as refractory simply due to a lack of knowledge or experience with alternative therapies, which underscores the need to seek specialized consultations before proceeding with palliative sedation (11).

The drugs of first choice are benzodiazepines, with midazolam being the most widely used globally due to its pharmacokinetic properties, such as the rapid onset and short duration of action, and its suitability for subcutaneous administration (2,5,17). For the treatment of agitated delirium or agitation, combination therapy with neuroleptics (such as haloperidol or levomepromazine) is frequently recommended (2,5,33). It is important to note that opioids (e.g., morphine) are used to treat dyspnea or pain, but they are not the primary sedatives, and their exclusive use to induce sedation is not recommended (5,10). Monitoring during palliative sedation, which should be continuous until the optimal level of sedation (providing symptom relief) is achieved, is primarily limited to observing comfort, symptom relief, and the detection of adverse effects (12).

A recent study in 2025 brought together a group of palliative care specialists to reach a consensus on doses and threshold levels for 11 potentially sedative drugs (lorazepam, midazolam, haloperidol, levomepromazine, propofol). Based on this consensus, they proposed threshold levels that serve as tools for determining reasonable doses for mild or deep sedation. These thresholds allow for better identification of unintentional sedation, support clinical judgment regarding the cause of decreased level of consciousness, and promote compliance with palliative sedation guidelines (34). Hence

the importance of following a methodology for the application of palliative sedation.

The role of the palliative care (PC) team is indispensable, as the decision to administer PC requires shared decision-making and a rigorous interdisciplinary assessment (5,11). The team, which should include trained professionals such as physicians, nurses, psychologists, and spiritual counselors, plays a key role in effective and transparent communication with the patient and their family (11). It is necessary to explain the therapeutic goals, the types of sedation (continuous or intermittent), and the possible consequences—such as the patient's “social death”—so that the family can prepare themselves (11,20). A critical issue in practice, especially in home care provided by non-specialized staff, is the lack of adequate follow-up and support for the patient and caregiver once sedation has begun—an area that must be improved to ensure ongoing comfort and emotional support for the family (2,11).

The IMSS Clinical Practice Guideline on the Detection and Management of Caregiver Burnout (IMSS-781-15) formally recognizes the risk of physical and -emotional distress among those caring for people with advanced chronic diseases and proposes a structured approach that includes systematic screening, identification of risk factors, medical, psychological, and social work interventions, as well as specific nursing support. In the context of palliative sedation for non-oncological conditions, this guideline notes that the quality of end-of-life decision-making and support also depends on the system's ability to prevent and treat caregiver burnout, and not solely on pharmacological protocols (35).

Riaño Zalbidea (36) emphasizes that, in the context of an aging population and an increase in chronic diseases involving renal or cardiovascular failure, palliative care for non-oncology patients is not only a necessity but a duty, grounded in principles of justice, equality, and equity that require offering the same standard of palliative care to all conditions with similar needs.

6. Challenges and proposals

Palliative Sedation (PS) faces significant challenges regarding standardization stemming from ambiguity in clinical criteria and the need for ongoing ethical deliberation. The literature reveals a wide variation in the prevalence of PS internationally, suggesting a notable lack of uniformity in the criteria applied for its indication (10).

A fundamental challenge is the difficulty in objectively establishing refractory suffering, since the degree of intolerability is a subjective criterion determined by the patient (33). Furthermore, a lack of experience or insufficient knowledge on the part of non-specialized staff can lead to the inappropriate labeling of a difficult-to-manage symptom as refractory (10–11). The debate intensifies in cases of emotional or existential suffering, for which the assessment and criteria for application are not universally defined (5). Persistent misinformation in society and among some professionals requires a continuous effort to clearly differentiate palliative care from euthanasia, a practice with which it is often mistakenly conflated (6,13,37).

These challenges are magnified by the lack of specific clinical guidelines and disparities in training, particularly in the management of patients with non-oncological terminal illnesses (NOTI) and in non-specialized settings. There is a significant knowledge gap regarding palliative sedation administered at home by personnel who are not part of specialized units (2).

At the same time, Cochrane reviews of “hospital-at-home” models for end-of-life care indicate that they increase the likelihood of dying at home, underscoring that decisions regarding palliative sedation must also be considered in home settings and not just in hospitals, a further challenge for healthcare professionals (38).

This practice among the ETNO population has been observed in emergency departments and primary care settings, revealing shortcomings such as a lack of awareness regarding the level of sedation achieved and a lack of adequate follow-up and support for the patient and caregiver once the intervention begins (2). In general,

the lack of institutionalized protocols means that the procedure is often managed on an individual basis, without the support of collegial deliberation (4). The absence of standardized guidelines also hinders the proper documentation of decision-making and clinical processes, compromising the transparency and quality of end-of-life care (14).

To ensure the quality and ethical soundness of palliative care, various courses of action are proposed. It is essential that healthcare institutions develop and implement rigorous decision-making and care pathways for palliative care (11). These tools must standardize the criteria for confirming symptomatic refractoriness (including a holistic assessment of psycho-existential suffering) and specify the pharmacology and proportionality of the procedure (10). It is vital to strengthen advanced and continuing education for non-specialist healthcare personnel to improve the early identification of palliative care needs (2,5). In addition, documentation in medical records must be improved (14), ensuring the transparency of the process and the recording of informed consent. Implementing clinical ethics consultation within palliative care teams is a valuable resource for guiding deliberation in the most complex cases, promoting shared decision-making that respects the patient's autonomy and dignity until the end of their life (11).

Conclusion

Palliative Sedation (PS) is reaffirmed as a deeply ethical and compassionate practice, serving as the last therapeutic resort for managing refractory and multidimensional suffering in patients with terminal illnesses, including non-oncological conditions (5). Its legitimacy is based on the unwavering intention to alleviate suffering and ensure dignity, without any intention to hasten the process of dying (6,12–13).

Clinical application highlights the urgent need to standardize criteria for defining refractory symptoms (10), especially in the non-on-

cologic population, whose disease course is uncertain (11). It is essential to strengthen advanced and continuing education for healthcare personnel in palliative care and bioethics (5,2,4), as well as to improve clinical documentation of the deliberative process and informed consent to ensure transparency in practice (14).

A crucial aspect of non-oncological end-of-life care is decision-making; cognitive decline or the inability to express one's wishes in the terminal phase requires a robust, multidisciplinary deliberative process. This process must ensure the active participation of the palliative care team, bioethicists, and —fundamentally— the family and legal representatives, while always respecting the patient's advance directives. It is this collaboration that allows for the application of the principles of proportionality and autonomy in situations where the prognosis is uncertain and communication is limited (8–12).

Finally, the importance is emphasized for society and governments to promote a culture of palliative care as a fundamental human right (5,6), overcoming the misinformation and myths that erroneously associate it with euthanasia (37), so that palliative care is understood for its value as an ethical and humane means of ensuring quality of life and the relief of all suffering —physical, psychological, and existential— during the final stage of life.

Conflict of interest

The author declares that she has no conflicts of interest.

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