

# Palliative sedation in Brazil: an integrative literature review

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## Abstract

Palliative sedation integrates the broad spectrum of practices and approaches in palliative care. Its main objective is not to anticipate the end of life, but to provide comfort and symptom relief for terminal conditions; however, opinions in academic, professional, social, and religious contexts differ about its application. This integrative literature review gathers relevant discussions and research in the Brazilian context to contribute to a more updated and appropriate understanding of palliative sedation. Discussions on palliative sedation bring issues regarding its emergence, the opinions of physicians and students, bioethical factors, and challenges. However, the available literature on this topic is scarce, encompassing social, ethical, religious, and professional aspects that require individual interpretations and consensus among social spheres.

**Keywords:** Hospice care. Terminal ill. Bioethics.

## Resumo

### Sedação paliativa terminal no Brasil: revisão integrativa da literatura

A sedação paliativa está inserida no amplo espectro de práticas e condutas dos cuidados paliativos. Seu objetivo principal não é adiantar o fim da vida, mas sim prover conforto e alívio dos sintomas em uma condição de vida terminal. A prática diverge opiniões tanto no ambiente acadêmico e profissional quanto no social e religioso. Como objetivo, esta revisão integrativa da literatura buscou discussões e pesquisas mais pertinentes no cenário brasileiro, a fim de contribuir para a construção de uma noção mais atualizada e adequada ao contexto contemporâneo quanto à sedação paliativa. Questões como surgimento, opinião de médicos e estudantes, fatores bioéticos e desafios quanto à aplicação compõem a discussão da sedação paliativa na terminalidade. Todavia, a literatura disponível sobre a temática ainda é escassa, permeada de aspectos sociais, éticos, religiosos e de profissionais que demandam interpretações individuais e consenso entre as esferas sociais.

**Palavras-chave:** Cuidados paliativos na terminalidade da vida. Doente terminal. Bioética.

## Resumen

### Sedación paliativa terminal en Brasil: revisión integradora de la literatura

La sedación paliativa integra el amplio conjunto de prácticas y acciones de los cuidados paliativos. Su objetivo principal no es acelerar el final de la vida, sino proporcionar confort y alivio de los síntomas de los pacientes terminales. Esta práctica genera opiniones divergentes tanto en el ámbito académico y profesional como en el social y religioso. Esta revisión integradora de la literatura busca levantar las discusiones e investigaciones más pertinentes en el escenario brasileño para contribuir a la construcción de una noción más actualizada y adecuada contemporáneamente sobre sedación paliativa. El surgimiento, la opinión de médicos y estudiantes, los factores bioéticos y los desafíos en la aplicación constituyen temas de discusión sobre la sedación paliativa en el final de la vida. Sin embargo, la literatura disponible sobre este tema sigue siendo escasa, permeada de cuestiones sociales, éticas, religiosas y profesionales que requieren interpretaciones individuales y consenso entre las esferas sociales.

**Palabras clave:** Cuidados paliativos al final de la vida. Enfermo terminal. Bioética.

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Palliative sedation is part of the broad spectrum of palliative care practices and procedures. It consists of the deliberate administration of drugs capable of reducing the level of consciousness, with the consent of the patient or their guardian, to mitigate the refractory symptoms of an advanced terminal illness. Its main objective is not to bring about the end of life, but to provide comfort and relief to individuals suffering from symptoms that no longer respond to other treatments<sup>1</sup>.

However, opinions differ on this practice. Often, the major discussions and ethical controversies on the subject stem from misinformation and the mistaken association of palliative sedation with euthanasia and assisted suicide, whether by the lay population or health professionals<sup>1</sup>. Therefore, knowing the basic differences from the perspective of palliative care is the starting point for delving deeper into the issue and building an evidence-based discussion.

According to the National Academy of Palliative Care of Brazil (ANCP), palliative sedation is administered to relieve refractory symptoms/suffering by lowering the patient's level of consciousness with a dosage of sedative drugs adjusted to their response, with the ultimate aim of relieving suffering, in principle, in a reversible manner<sup>1</sup>. Thus, death would occur naturally and only at the end of life. Euthanasia, on the other hand, involves the intention to cause death in order to end suffering, that is, to end life quickly by lethal drugs with a rapid increment. This procedure is essentially irreversible because it brings forward the end of life for extrinsic reasons.

This study aimed to collect data, facts, reports, and perspectives on the subject of palliative sedation in terminally ill patients from the national scientific literature. Afterwards, the most relevant aspects involving this content were reviewed, from the perspective of Brazilian health professionals. The discussion addressed aspects such as misconceptions, ethical dilemmas about the anticipation of death, the involvement of psychological issues and misinformation, which are detailed below.

## Method

This is an integrative literature review, and the PICO strategy is its starting point. The research

question was: what are the main issues related to palliative sedation in terminally ill patients in the Brazilian health system? The search was carried out in the Virtual Health Library (VHL) and Google Scholar databases. The descriptors used were “deep sedation,” “palliative care,” and “terminally ill” in Portuguese, with the Boolean operator AND. Only papers available in Portuguese and published from 2010 onwards were considered, excluding literature reviews. Based on these criteria, the search yielded 2,150 results in Google Scholar and one in the VHL, five of which were selected for this literature review.

## Results and discussion

The work by Girond and Waterkemper<sup>2</sup> presents a summary of all terms and guidelines on palliative care. These authors carried out an extensive search in the literature via manuals, articles with high levels of evidence, published books, and others. Therefore, only the best and most reliable data were analyzed and compared, providing a solid base for the fundamentals of palliative care discussed in this article. Furthermore, we aimed to reflect on the emergence of this practice and its relationship with the human imagination about death, as well as to relate this care to its main philosophy: provide quality of life<sup>2</sup>. Another remarkable factor is that all these aspects are addressed within oncology, but are applicable to various pathologies.

From Costa's perspective, palliative sedation is defined as *the deliberate administration of drugs in doses and combinations necessary to reduce the level of consciousness, with the consent of the patient or their guardian*<sup>3</sup>. There is an active search for pain relief when the symptoms can no longer be cured by the latest treatments.

In this way, it is explained that this practice is carried out by a multi-professional team made up of physicians (who choose the best drug and dosage to use), nurses and nursing technicians (who maintain and care for the patient's vital needs and comfort), psychologists (who can help by talking to the patient before sedation and supporting their family), social workers (who provide new ways for the family to

understand the main implications during and after palliative care), and spiritual workers (especially if the family is affiliated with a religion, as faith provides a broad view of death and can offer support at this time). The place where sedation is administered is usually the hospital itself, but in some countries this procedure can be done on an outpatient basis and the patient can receive care at home, with professional help.

Furthermore, adaptations are necessary for each patient, since an intervention may work at the acute phase but not be applicable to the terminal phase. In other words, cardiopulmonary resuscitation, artificial respiration, intravenous infusions and other measures are primary support techniques used for general recovery, but should not be carried out on patients with no prospect of improvement, as they prolong suffering.

Girond and Waterkemper<sup>2</sup> indicated that the Brazilian Ministry of Health (MS) defines sedatives as any drug that calms or tranquilizes. These drugs are mainly used in cases of abnormal agitation or excitement. By administering them, it is possible to reduce the patient's psychomotricity, relaxing their body—and consequently alleviating pain—as well as their mind, dispelling anxiety and other undesirable sensations.

On the other hand, to promote a better understanding of this article, it is crucial to clarify the difference between palliative sedation and euthanasia. Euthanasia can be described as the procedure of indirectly speeding up death via medical actions, which are carried out to relieve pain and suffering. There are various types of death and this article discusses the most relevant, namely: voluntary euthanasia (in which the patient consents to death); involuntary euthanasia (which happens without the patient's consent); dysthanasia (also called futile treatment; in which death is postponed); orthothanasia or therapeutic euthanasia (in which no means are used to terminate life, only to relieve symptoms); and assisted suicide (in which the patient receives professional help to carry out self-extermination).

In the medical field, mostly, health professionals do not think about how their daily practice is linked to death, only to life and its maintenance. For this reason, many of these professionals suffer when they have to start

thinking about the death of a patient and about caring for that patient's family. This is because they feel inadequate in terms of their work potential; but it is precisely at this moment that they begin to value life even more, even in its final moments.

Lastly, by relating these two terms to bioethics, it is possible to observe that they have very different proposals. According to health ethics, the intention of palliative sedation is to give patients quality of life (beneficence), and not seek to hasten their death (maleficence). Therefore, palliative care concerns the patient as a whole, their life, death, way of dying, family, dignity, and well-being.

Eich and collaborators<sup>4</sup> carried out an exploratory and descriptive study with a qualitative approach based on the testimonies of various professionals regarding the administration of palliative sedation to patients. The authors sought to understand, in a scientific and bioethical way, what these professionals understood about the implications of this act in their work environment.

The vast majority of these professionals supported palliative sedation, since its main objective was to provide patients with relief. Furthermore, these professionals emphasized that they only supported this practice as the last resort, that is, when it was no longer possible to control the pain and suffering felt by the patient or when the standard treatment was more harmful than beneficial to their quality of life, due to severe side effects<sup>4</sup>. It was also specified that the suffering did not necessarily have to be physical: it could also be psychological or social.

The professionals also cited the literature to ground their arguments about palliative sedation, considering that several types of palliative sedation are practiced and each one is employed in a different scenario. Some of the variations of palliative sedation are: primary or secondary; continuous or intermittent; and deep or proportional. Such variations are applied based on the history of the patient and their illness and on the classification of symptoms as difficult or intolerable. Thus, professionals are able to employ the optimal technique that the patient needs, in a safe and bioethical way. Patients who have a chance of getting better are

given lighter palliative sedation, while those who are in more vulnerable and severe situations are given stronger, more permanent sedation.

The professionals in the study also made it clear that it is extremely important to contact the patient's relatives and get their approval, as it is necessary to help them understand that palliative sedation is not a way of hastening death, but just another form of care that can be offered in terminal stages. This makes it possible to differentiate this technique from euthanasia, which seeks to bring about immediate death, and to ease the concern that these professionals have about explaining this subject to families, who are often confused about the topic. It was also mentioned that patients and family members who refuse palliative sedation usually have religious reasons. They believe that the moment of suffering at the end of life is a form of "purification" for the departing soul. The professionals also reported suffering for this, given that they could not ease their patient's pain. For Eichand collaborators<sup>4</sup>, the importance of dialoguing with the patient's family about palliative sedation and clarifying this issue is thus evident. It is necessary to take a cautious approach to these cases in order to prevent patients from suffering and make their families comfortable with their departure.

Regarding medical perspectives, Piedade, Cardoso and Priolli<sup>5</sup> applied a 23-items questionnaire to physicians in the city of São Paulo in order to assess their knowledge of palliative sedation. In this analysis, 99% of physicians stated supporting palliative sedation and did not believe it was comparable to euthanasia. Moreover, 68% of them reported having used the technique at some point in their practice, but only 26% said they had training in palliative care. As a result, it became clear that most professionals feel comfortable using the technique and that it is very common in their work. However, the relatively low level of training of these professionals is concerning (as the vast majority of them had no specific training in the area), since it is necessary to make the right choices about the drug to be used, to talk to families, to have knowledge about legal implications, and to be psychologically prepared to deal with the case.

Still from the perspective of medical ethics, but focused on academia and professional training,

Lima and collaborators<sup>6</sup> carried out a study with 146 medical students from the Universidade de Medicina de Presidente Prudente, who were completing the 11th or 12th semester of the course, assessing their theoretical and ethical knowledge of euthanasia and palliative sedation. Eight questions were asked about the differences and implications of this medical practice, bearing in mind that these students will become professionals and will eventually have to deal with the death of their patients.

Based on the results, it can be inferred that the total number of correct answers was generally satisfactory, with most students showing a good performance. However, concern arises when analyzing the students' errors: only 38% of them were able to correctly differentiate between palliative sedation, euthanasia, dysthanasia, and orthothanasia; and just over 55% of them could differentiate euthanasia from palliative sedation<sup>6</sup>.

In this way, it can be observed flaws in the Brazilian medical education model, since these students, who were about to graduate, did not yet have extensive knowledge of the procedures and, therefore, would not know the correct course of action when facing more delicate cases. This reveals a lot about the current state of medicine, in which many professionals support palliative sedation, but are unable to carry it out efficiently, especially when considering the emotional exhaustion suffered by families and fellow workers.

Lastly, Santos and collaborators<sup>7</sup> carried out a retrospective observational study including 919 medical records of patients who died in palliative care at the Hospital de Câncer Brasileiro. In total, 21.5% of these patients received palliative sedation: mostly women (55%); the main oncological cause was a tumor in the digestive system; and the most recurrent symptom was dyspnea, followed by pain. In addition, continuous sedation was the most commonly used technique, applied to 75% of patients. Another relevant factor was the stage of the pathology. Only 3.5% of those who had stage I cancer received sedation, while 56% of those with stage IV cancer (more advanced) did. Continuous sedation was used in cases of unbearable pain, as well as psychiatric damage (such as cases of

delirium) and psychological damage (when the patient was unable to achieve a state of well-being because no medication satisfactorily eased their pain), since quality of life goes beyond the proper functioning of the body: it is also related to maintaining social integrity.

## Final considerations

Palliative sedation remains constricted between misinformation and the limits of bioethics. Even after various debates, opinions, and discussions, the biggest challenge in relation to this issue is to create a clearer and more specific definition, based on the values of contemporary society, which is still very permeated by religious beliefs, which often assume that suffering is part of the process of living. However, the suffering present in death goes beyond the multiple


philosophical and religious interpretations, being a part of an individual's will and right to experience their own passing how they wish.

Therefore, since there is little understanding of the issue—especially from a professional and academic point of view—it is reasonable to consider an in-depth discussion of the topic. Universities, hospitals, and health facilities have sufficient conditions to provide training in this area, be it during classes, meetings or discussion panels. For the general population, building a basic understanding of this concept is still a challenge, given the heterogeneity of the Brazilian people, whose customs and beliefs are diverse. However, this fact does not exempt health professionals from their duty to raise awareness in society. To this end, the production of up-to-date material and bibliography is needed, as it can promote a better interpretation of palliative sedation in the Brazilian context.


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#### Participation of the authors

João Carlos Halfeld revised the article and was responsible for writing the introduction and conclusion, as well as formatting the work according to the required standards and searching for material in indexed databases. Together with him, Jaqueline Caldana took part in and prepared the written part of the discussion. She also developed the methodology and selected the literature by criteria of relevance.

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