

# Palliative sedation: ethical perspectives from Latin America in comparison with European recommendations

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## Purpose of review

Palliative sedation is a standard procedure used in palliative care especially for patients at the very end of their lives, who are enduring otherwise intractable suffering. It consists of the administration of sedatives and, when necessary, other drugs, usually by infusion, either subcutaneously or intravenously, at the necessary rate to achieve the patient's relief, by means of reducing the consciousness of the patient. If this administration is not discontinued, the usual outcome is the patient's death. So, the most frequent criticisms regarding the procedure are those that consider it as a form of euthanasia. The intention of the review is analyzing the *status questionis* in Europe and Latin America.

## Recent findings

Current thinking and research about this issue refers especially to the terminology, the boundaries between palliative sedation and slow euthanasia, especially in pediatric settings, the lacking of precise definition for concepts such as refractory symptoms and unbearable suffering, and the place for existential suffering in this context; the ethical positioning of Latin-American normative and authors is similar to that of Europe.

## Summary

It does not seem that solution to the conflicting points will come from better guidelines or more experts' meetings. Instead, efforts should be directed to reinforce moral, professional integrity, within the framework of an ethics of virtue, as inherent to palliative care. Such ethics can effectively be taught and infused, and then required to all healthcare professionals.

## Keywords

euthanasia, palliative sedation, professional integrity, refractory symptoms, unbearable suffering

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## Introduction

Palliative sedation is a standard procedure used in palliative care especially for patients at the very end of their lives and who are enduring otherwise intractable suffering. It consists of the administration of sedatives and, when necessary, other drugs, usually by infusion, either subcutaneously or intravenously, at the necessary rate to achieve the patient's relief. This implies in most cases reducing the consciousness of the patient. As it does not include artificial hydration/nutrition except in special situations [1], if it is not discontinued, the expected outcome is the patient's death. So, the most common criticisms from an ethical point of view are those that consider the procedure as a form of euthanasia [2].

The most frequent symptoms requiring palliative sedation are intractable pain, dyspnea, agitated confusion (delirium), terminal restlessness, existential pain, acute bleeding, nausea, and vomiting. Another use of palliative

sedation, outside of the usual scope of palliative care is, in intensive care settings, for the withdrawal of artificial breathing.

It would be interesting to explore the *status questionis* in regions as in Anglo-Saxon and French North America (USA and Canada), the East (China, Japan), and Africa. But I was commissioned specifically to compare perspectives from Latin-America and Europe.

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## Terminology

The European Association for Palliative Care (EAPC) Forum does not recommend the term 'terminal sedation' because, in many cases, the sedation can be stopped, keeping the patient alive, and also because it must never be seen as an end in itself, but a means to relieve suffering. Moreover, when palliative sedation is applied correctly, in those cases in which the patient is not facing impending death, it does not hasten death [3,4]. The

most widely names used for the procedure are ‘palliative sedation’ and ‘palliative sedation therapy’. Recently some British and French authors have recommended the term ‘sedation in palliative medicine’, avoiding qualifying it [5,6]. Other proposed names such as ‘end-of-life sedation’, ‘total sedation’, ‘sedation in the final phase’, ‘sedation in the terminal or final stages of life’ [1•], were not spread.

### Palliative sedation and euthanasia

The relationship between euthanasia and palliative sedation has been always vigorously disclaimed by the people enrolled in the Palliative Care/Hospice movement. In fact, palliative care has introduced itself as an alternative to euthanasia [7•]. What is undoubtedly true is that, when the accessibility to qualified palliative care in a particular social group is guaranteed, the requirements for euthanasia usually decrease.

The factual differences between both actions are notwithstanding very subtle [8•]. The foremost difference is the *intention* behind each one of the actions [9]: the intention of palliative sedation is the relief of unbearable suffering and, if the patient dies, this fact is seen as a secondary effect, not desired but allowed, according to the ethical/catholic theological principle of the double (or second) effect, and to the principle of proportionality; instead, euthanasia, as Wilkinson stated, ‘destroys the problem rather than solving it’ [10]; it eliminates suffering by means of killing the patient in which this suffering reigns; that is to say, the outcome pursued is the patient’s death to free him from suffering. Intentions are, notwithstanding, opaque by the sights outside the decision maker.

Euthanasia is legal only in the Benelux countries (The Netherlands, Belgium and Luxembourg), and the related practice of physician-assisted suicide, in a few other countries and in the USA states of Oregon and Washington [11]. Facts show that, outside these places, there have been very few physicians who were effectively prosecuted and sentenced for performing these practices.

For cultural and historical reasons, euthanasia is *a priori* rejected by the prevailing thinking and religious beliefs in Occident; and by professional organizations worldwide.

My personal position about this problem is as follows: euthanasia concerns me especially due to the possibility of its political implementation as a mean to easily get rid of the ‘undesirable’, as it occurred in the Nazi regimes. But it is a completely different problem when a patient enduring unbearable suffering (physical, psychological, spiritual/existential), implores me that, using my medical

### Key points

- Current research and thinking about ethical aspects of palliative sedation in Europe and Latin America refers to conflicting points as terminology, the boundaries between palliative sedation and slow euthanasia, the lacking of precise definition for concepts such as refractory symptoms and unbearable suffering, and the place for existential suffering in this context.
- Solutions might come from reinforcing moral, professional integrity, as inherent to palliative care within the framework of an ethics of virtue. Such an ethics can effectively be taught, infused and then required to all healthcare professionals.
- The ethical positioning of Latin-American normative and authors is similar to that of Europe.

expertise in palliative care, I kill him (by performing euthanasia) or help him to kill himself (be it by means of medically assisted suicide or by his voluntary refusal of foods and fluids). In cases as the aforementioned, it is my conviction that, if I am sure that this is an autonomous and exclusively self-affecting decision, I must think thoroughly whether denying this petition does not imply an act of patient abandonment. Laws, deontological norms and normative ethics will only work as a guide, but the decision that I should take will be an exclusively personal one [12,13]. I must take a side, to say either yes or no. It is the patient who interpellates me [13,14•,15•]. A tragedy like that of Ramón Sampedro is still for me a shame for all of us physicians.

### Current thinking and research about palliative sedation in Europe and Latin America

I will now try to summarize the current thinking on palliative sedation, confronting the points of view manifested through different guidelines, consensus statements and position papers from collegiate bodies, laws, and published opinions from particular authors, arising from Europe and Latin America.

#### In Europe

For instance, Juth *et al.* [16] from Stockholm discuss thoroughly the problem of palliative sedation for existential suffering, and develop a critical ethical discussion of the document of EAPC of 2009 [17] for being imprecise about what is meant by ‘refractory symptoms’ and ‘intolerable suffering’, without which EAPC qualifies deep continuous sedation as an abuse indistinguishable from slow euthanasia. The Swedish authors also criticize recurring to the principle of double effect to justify deep and continuous sedation, which is an old objection already made by Quill *et al.* [18].

It is very difficult to be so accurate about issues as 'refractory symptoms', 'intolerable suffering', and 'existential suffering', because they are subjective and, therefore, not measurable. The 2009 document was an official statement of the EAPC on palliative sedation. Instead, the 'EAPC Forum' of 2010 is a collection of studies from a group of experts, open to continuous discussion, created after 'the discussion in the group confirmed that there are still many open questions' [1\*].

It should be recognized that in the practice of medicine, there are many things that must not be analyzed as they belong to natural sciences. What must be certainly required to health workers is, within the framework of an ethics of virtue, to perform their work with professional and moral integrity [12,13,19–21], and patients and observers should be able to trust them. However, it is true that nowadays, for many reasons, medical and public health actions are under deep scrutiny.

This distrust is favored because qualified palliative care is not yet accessible for all people [22\*\*]. For example, a questionnaire sent to some Dutch physicians committed to end-of-life care showed that over 30% of them considers opioids as the favored drugs for palliative sedation, (which) 'according to Dutch guidelines for palliative sedation' (...) 'should be considered malpractice'. Moreover, in the 19% (clinical specialists) and 11% (general practitioners) of the cases, they recognized that they increased the dosage of opioids to a level above what is needed for pain and symptom control, aiming at hastening the patient's death, and 75% of the physicians assigned to elderly care, when conducting a sedative palliation, have felt frequently pressure coming from relatives 'or other persons' to hasten death. The authors suggest that this last so strikingly high number may be related to the fact that many of these patients have dementia, are incompetent, and their relatives make decisions for them [23].

As it has been said, another use of palliative sedation, for patients usually out of the scope of palliative care teams, is the removal of life support in intensive care settings [24]. Professor Kompanje [25] (Erasmus University of Rotterdam), writing about a study published with his colleagues about this issue, claims: 'Even in The Netherlands, deliberate termination of life of ICU' (ICU, Intensive Care Units) 'patients is extremely rare' (look specially to the word 'even'). The aforementioned paper affirms that 'approximately 80% of patients who die in an ICU in The Netherlands die after organ function supportive care or when organ function replacement therapy is withdrawn' [26].

Other authors assert that in The Netherlands, palliative sedation is not applied correctly. For example, the doses

recommended by Dutch guidelines are clearly higher than those from other countries or international recommendations, and the recourse to euthanasia, too expeditious [27]. As I have argued elsewhere, palliative care in The Netherlands had not been sufficiently qualified or accessible until now, and this has been improving only recently [13].

The case of The Netherlands and, in general, of the Benelux countries, is special because of the 10 years of experience since the euthanasia Dutch law was passed. The Belgian law (2002) puts more emphasis on the development of quality and accessibility to palliative care than the Dutch law does [13,28,29]. The third country in legalizing euthanasia was Luxembourg [30\*], but only a brief period of time has elapsed since then for any conclusion to be made.

As it was already noted, in some other countries of Europe, Asia, and two states of the USA, what it is legal is physician-assisted suicide. In general, the application of the corresponding laws is prudent, abuses are not reported and people are satisfied with it. The USA state of Oregon still maintains a legal dispute with the U.S. Supreme Court, which unanimously ruled in 1997 that 'there is no constitutional right to assisted suicide'.

A recent protocol from the Italian province of Bergamo considers the technical and ethical aspects of the problem in a comprehensive way [31]. They address specifically to the issue of palliative sedation at home, as do, on their own way, Mercadante *et al.* [4] also from Italy, Blanchet *et al.* [6] from France, and Alonso-Babarro *et al.* [32] from Spain.

The 'Consejo General de Colegios Oficiales de Médicos de España' published, in 2009, a statement under the title 'Ética de la sedación en la agonía' [33]. The document limits its scope to patients expecting impending death, without any comments on intermittent or reversible sedation. This point was analyzed at a conference held in Buenos Aires, Argentina, on May 2010. At the meeting, there were representatives from different disciplinary curricula, working in palliative care, from Argentina and Uruguay. They agreed with the Spanish statement and strongly recommended the implementation and spread of palliative care in the region [34].

A very specific and challenging problem is that of palliative sedation in children. French and German authors say that published information about it is very limited [35–37]. I will not address this question, because my experience is in working with adults. In this issue of 'Current Opinion', my colleague Dr Rut Kiman, who is an Argentinean pediatrician, dedicates her contribution to this matter.

## In Latin America

Latin-American guidelines are scarce, designed mostly by governments or specific scientific societies [38–40]. There are also a few federal [41\*,42,43\*] and states/provinces laws [44–47], in general devoted to patients' rights, dying with dignity or palliative care, from which indications, ethical framework, and procedures for palliative sedation can be deducted. These documents neither add to nor modify substantially what has been described above.

Published studies from this region do not differ in their approaches from those published in Europe, already commented [48\*,49\*,50–53,54\*].

## Existential suffering

Finally, the issue of existential suffering, also called existential distress, is a particularly unresolved one, beginning with the lack of a widely accepted definition of what is meant by existential suffering. The commonest point of view is the one which assimilates it to emotional or spiritual suffering (bearing in mind the concept of 'total pain' coined by Cicely Saunders) [13,32,55–57,58\*,59]. In a further exploration on this issue, it can be concluded that the term existential was spread because the word *spiritual* was restricted by many authors to religious beliefs and conflicts [57]. However, 'spiritual' was the term used, for example, by one group of the World Health Organization experts in 1990, with the following meanings: 'those aspects of human life relating to experiences that transcend sensory phenomena. This meaning is not the same as 'religious'. (...) 'It is often perceived as being concerned with meaning and purpose' (...) 'a need for forgiveness, reconciliation and affirmation of worth' [60].

## Conclusions

The problem of palliative sedation is not a solved one, at least from an ethical point of view. There are still many conflicting points without resolution. The main problems are

- (1) the diffuse boundaries between palliative sedation and slow euthanasia;
- (2) the lack of precision in defining concepts such as refractory symptoms and unbearable suffering. This would prevent bringing peace to the minds of health workers committed to such practice, recognized as a serious decision to be made;
- (3) the place for existential suffering in this context.

I do not think the solution for the remaining controversial issues will come from better guidelines or more experts meetings. Instead, I believe that efforts should be directed to reinforce moral, professional integrity as

inherent to palliative care, within the framework of an ethics of virtue. Such an ethics can be taught, infused and then required to all healthcare professionals.

It seems convenient, as some authors propose, to avoid the term 'terminal sedation' and separating palliative sedation, which may be intermittent, from sedation of patients facing impending death ('*sedación en la agonia*'), which will be usually permanent, ending with the patient's death.

The ethical positioning of Latin-American normative and authors regarding palliative sedation is similar to those of Europe.

## Acknowledgement

### Conflicts of interest

The author herein declares having no conflict of interests whatsoever, nor sponsorship or receiving any grant or subsidy for the elaboration of this study.

## References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 305).

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- It is a comprehensive review of the issue made by experts, by means of a series of papers open to discussion. Formally, they are not uniformly treated. Some are more polished and others are a mere draft. Some include references, and others mention and list the references but do not put the references itself. It is recommendable to have a panoramic view of the problem at the year 2005, when papers were submitted to the 9th Congress of the EAPC at Aachen (Germany).
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