

Review Article

Palliative Sedation for Existential Suffering: A Systematic Review of Argument-Based Ethics Literature



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Abstract

Context. Although unanimity exists on using palliative sedation (PS) for controlling refractory physical suffering in end-of-life situations, using it for controlling refractory existential suffering (PS-ES) is controversial. Complicating the debate is that definitions and terminology for existential suffering are unclear, ambiguous, and imprecise, leading to a lack of consensus for clinical practice.

Objectives. To systematically identify, describe, analyze, and discuss ethical arguments and concepts underpinning the argument-based bioethics literature on PS-ES.

Methods. We conducted a systematic search of the argument-based bioethics literature in PubMed, CINAHL, Embase®, The Philosopher's Index, PsycINFO®, PsycARTICLES®, Scopus, ScienceDirect, Web of Science, Pascal-Francis, and Cairn. We included articles published in peer-reviewed journals till December 31, 2016, written in English or French, which focused on ethical arguments related to PS-ES. We used *Peer Review of Electronic Search Strategies* protocol, *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*, and *The Qualitative Analysis Guide of Leuven* for data extraction and synthesis of themes.

Results. We identified 18 articles that met the inclusion criteria. Our analysis revealed mind-body dualism, existential suffering, refractoriness, terminal condition, and imminent death as relevant concepts in the ethical debate on PS-ES. The ethical principles of double effect, proportionality, and the four principles of biomedical ethics were used in argumentations in the PS-ES debate.

Conclusion. There is a clear need to better define the terminology used in discussions of PS-ES and to ground ethical arguments in a more effective way. Anthropological presuppositions such as mind-body dualism underpin the debate and need to be more clearly elucidated using an interdisciplinary approach. *J Pain Symptom Manage* 2018;55:1577–1590. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Systematic review, deep sedation, ethics, palliative sedation, end-of-life care, existential suffering

Introduction

Palliative sedation (PS) is considered a treatment of last resort in end-of-life care for the management of intolerable and refractory symptoms in the final stages of life. The terminology used for sedation in end-of-life situations is confusing and needs clarification and systematization.^{1–7} Systematic reviews to date have covered the main findings related to specific issues in

PS, such as its definition^{8–10} and distinction from euthanasia, physician-assisted suicide and lethal injection,¹¹ indications¹² and decision making regarding its initiation and continuation,^{13–15} medication and monitoring during application,^{16–19} survival time once it has begun,^{20,21} guidelines to use,^{22,23} recommendations for standards,²⁴ perspectives of relatives²⁵ and caregivers,^{26,27} and ethical issues related to its use.^{28–32}

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Because PS is used to alleviate refractory symptoms at the end of life,³³ it is important to distinguish PS from minimal sedation (anxiolysis), moderate sedation (conscious sedation), and general anesthesia. This distinction becomes clearer when refractory symptoms and PS are precisely defined. As Cherny³⁴(p. 143) proposed, “refractory symptoms” refer to “symptoms that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.” Broeckaert³⁵(p. 246) defined PS as “the intentional administration of sedatives in such dosages and combinations as required to reduce the terminal patient’s consciousness as much as needed to adequately control one or more refractory symptoms.”

PS has been used to deal with not only physical refractory symptoms (e.g., dyspnea, nausea, vomiting) but also nonphysiological refractory symptoms, such as psychological distress (anxiety, anguish, depression, delirium, etc.)³⁶ and existential suffering (e.g., hopelessness, meaninglessness, fear, panic, etc.).^{37,38} Applications of PS for nonphysiological refractory symptoms have provoked much debate because the nature of suffering (e.g., physical, psychological, social, existential, spiritual) is still controversial.³⁹ As existential suffering requires subjective assessment by a health professional and because a clear conceptual framework for understanding the full range of suffering and pain is still lacking, there are great differences in how physicians choose to control nonphysiological refractory symptoms at a patient’s end of life.⁴⁰

Indeed, the lack of a clear conceptual framework that includes the full range of suffering adds to the incoherence surrounding PS in the end of life. Murata⁴¹(p. 17) proposed a conceptual philosophical framework for spiritual suffering, defining it as “pain caused by extinction of the being and the meaning of the self.” He later assumed the broader expression psychoexistential or spiritual suffering⁴² for spiritual suffering. This definition drift well demonstrates how difficult it is to clearly establish terminology and to distinguish these kinds of suffering.

From a psychiatric perspective, Schuman-Olivier et al.³⁶ established a theoretical framework that differentiates existential suffering from existential distress. This framework acknowledges existential suffering as a special case that applies to persons with terminal illness or who are at the end of life.³⁶ Some typologies^{43–45} permit concepts included in existential suffering, such as loss of meaning and purpose of life, fear of death, despair, loss of dignity, hopelessness, helplessness, and others. Kirk and Mahon⁴⁶(p. 916) assume that “existential suffering is suffering that arises from a loss or interruption of meaning, purpose, or hope in life” and is not restricted to persons with terminal illness.

Two studies originating from The Netherlands^{47,48} revealed that existential suffering was the indication in 16%–26.4% of cases in which PS was applied. Another study⁴⁹ reported that patients require PS for refractory existential suffering (PS-ES) in a wide range of situations, such as having a feeling of meaninglessness and worthlessness, being a burden on others, dependency, inability to care for oneself, death anxiety, fear, panic, desire to control one’s time of death, isolation, and lack of social support. This indicates that a wider range of the kinds of patient distress is included in PS-ES applications.

This diversity in conceptual frameworks and clinical experience has produced uneasiness in health care professionals. Empirical studies indicate that clinicians still feel ambivalent about using PS-ES in their practice,^{50,51} and a consensus for PS-ES is far from being reached.^{27,52–54}

Although use of PS-ES lacks a clear consensus, competing conceptual frameworks have not matured, and definitions vary about what constitutes suffering. Still, PS has been continued to be recommended by clinical practice guidelines to relieve patients of refractory existential symptoms.^{55,56} However, an international panel of palliative care experts states that PS-ES is admissible only under exceptional circumstances and after consultation with palliative care experts.²⁴ Clearly, then, guidelines have not reached a consensus on PS-ES,^{46,57} and others even consider PS-ES to be inappropriate,⁵⁸ as other kind of interventions can indeed treat existential suffering in patients in advanced stages of illness.⁵⁹

To the best of our knowledge, no clear overview of the underlying concepts and arguments used in the ethical debate on PS-ES has been made available in the literature. Thus, to address this, we undertook a systematic review of argument-based bioethics literature on PS-ES.

Methods

Several models of systematic^{60,61} and nonsystematic⁶² literature reviews have been developed in the field of bioethics. We conducted a systematic review of argument-based bioethics literature that identifies ethical arguments and underlying concepts.^{63,64} We followed the *Peer Review of Electronic Search Strategies* (PRESS) guideline⁶⁵ for our literature search, and we used the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) statement^{66,67} for reporting our search process.

Research Question

We formulated the following research question to frame our article selections and analysis:

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