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DEFINING TERMINAL SEDATION: ETHICAL ASSUMPTIONS AND CONCEPTUAL BOUNDARIES

Absztrakt

This article argues that definitions of sedation at the end of life are not merely descriptive but embody distinct ethical commitments. The terminology used to describe sedation in terminally ill patients reflects underlying normative assumptions that shape both the procedural criteria and the moral boundaries of clinical practice. Through a conceptual analysis of the terms "terminal sedation" and "palliative sedation," the paper shows that "palliative sedation" has become closely aligned with the philosophical framework of palliative care, while "terminal sedation" is often employed to designate practices that diverge from its core principles. The study demonstrates that definitional differences in this field cannot be fully understood without reference to the ethical worldviews that inform them.

Keywords: terminal sedation, palliative sedation, palliative care, suffering, the imminence condition, refractory symptoms, proportionality, consciousness, intended and foreseen consequences, the doctrine of double effect, euthanasia

In the context of terminally ill patients, the use of sedation forms that may potentially, or certainly, shorten life remains the subject of intense debate. Multiple terms are employed to describe these medical interventions, and the meaning of any given term may vary among interpreters (Kremling-Schildmann, 2020; Papavasiliou, 2013; Morita-Tsuneto-Shima, 2002; Morita-Tsuneto-Shima, 2001). This study aims to demonstrate that the choice of terminology can reflect not only a neutral preference but also the ethical stance toward the procedure itself. Descriptive terms that capture the objective features of the care context can implicitly define the legitimate boundaries of patient management. Accordingly, philosophical analysis serves, among other purposes, to bring these latent value orientations to light, articulate them clearly, and explain how different ethical frameworks give rise to different conceptual definitions of sedation, thereby facilitating open ethical dialogue in end-of-life care.

In the United States, the question of the legitimacy of sedation initially arose in a very narrow context, involving patients with cancer in the terminal phase who experienced physical symptoms - such as pain - that they perceived as unbearable, and for which no therapeutic options other than sedation were available to the treating physician. Sedation in these cases was administered continuously until the patient's death. The earliest studies addressing this challenging scenario emerged in the early 1990s: Ventafridda and colleagues observed 120 terminally ill patients, finding that physical suffering could only be relieved through sedation in more than half of the cases. Similarly, Greene and Davis reported that between 1975 and 1989,

17 terminally ill cancer patients received continuous intravenous barbiturates because conventional palliative care measures proved inadequate. Ventafridda and colleagues acknowledge that the uncontrollability of physical suffering during the final days or hours of a patient's life is a frequent challenge, yet one that is rarely discussed openly. They highlight the ethical implications of sedation, noting that while it may be the only means to alleviate the perception of uncontrollable suffering, it also progressively diminishes cognition, ultimately severing the patient's communication with their emotional, social, and spiritual world: "If on one hand the sedation of the patient is the only way to reduce the perception of uncontrollable suffering, on the other hand this brings about a progressive decrease in cognition until there is no communication between the patient and his emotional, social and spiritual world. [Sic!] Is this palliative approach correct?" (Ventafridda et al., 1990, p. 10) While debate continues over whether pain truly intensifies during the immediate dying phase, how frequently patients experience uncontrollable suffering, and what its underlying causes are (e.g., Mount, 1990), the discourse on care for terminally ill patients has evolved in two notable ways:

1. The term "unrelievable symptoms" has increasingly emerged to describe symptoms that cannot be managed through conventional medical interventions ("unrelievable symptoms" – Enck, 1991, p. 4; "intractable symptoms" – Latimer, 1991, p. 332; "refractory symptoms" – Cherny-Portenoy, 1994, p. 31; Billings-Block, 1996, p. 24; Morita et al., 1999, p. 20; "intolerable suffering" – Quill-Lo-Brock, 1997, p. 2099; "intractable distress" – Krakauer et al., 2000; "unendurable suffering" – Morita et al., 1999, p. 22);
2. There has been a gradual establishment of a practice involving the use of drugs to reduce the patient's level of consciousness, described with various expressions incorporating the concept of sedation ("sedation-inducing sleep" – Ventafridda et al., 1990, p. 7; "sedation to unconsciousness" – Mount, 1990, p. 5; "sedation into unconsciousness" – Roy, 1990, p. 3; "drug-induced terminal sedation" – Enck, 1991, p. 3), or interpreted as one form of sedation as a general therapeutic measure (Cherny-Portenoy, 1994).

By 1996, Billings and Block had already identified "terminal sedation" as a widely recognized term for cases in which sedative drugs, including opioids, were administered to patients in the terminal stage (Billings-Block, 1996, p. 21). The term quickly gained traction, particularly as its first recorded usage appeared in Robert E. Enck's 1991 study, which reviewed two prior studies reporting the administration of sedative drugs to terminally ill patients (Enck, 1991).

Simultaneously, controversy emerged regarding the meaning of the qualifier "terminal" in the term "terminal sedation." For some, it was unclear whether "terminal" refers solely to the patient's terminal stage - thus encompassing various

forms of sedation under the umbrella of "terminal sedation" - or whether it implies sedating the patient to death, thereby connoting the intentional hastening of death as the goal of the intervention (Chater et al., 1998, p. 256; Papavasiliou, 2013, pp. 695–696). If the latter interpretation holds, terminal sedation may be construed as a form of euthanasia, such as the so-called "slow euthanasia" (Billings-Block, 1996).

By the latter half of the 1990s, it had become increasingly recognized and accepted that, for terminally ill patients, when symptoms that are not alleviable by conventional or standard therapies - including pain - so-called unbearable symptoms - are present, the primary duty to relieve pain or suffering could be accompanied by reducing, or even eliminating, the patient's level of consciousness (Rousseau, 2005, p. 10). In discussions surrounding this medical intervention, however, the definitive boundary conditions of its application became a matter of intensifying debate:

a) the precise definition of the terminal stage, including whether the intervention should be limited to patients in the immediate dying phase or extended to those not imminently dying,
b) the definition and practical identification of unbearable symptoms,
c) the determination of which unbearable symptoms may serve as indications for terminal sedation,
d) the definition of pain and, above all, suffering,
e) the required depth of sedation, and
f) the acceptability of any potential life-shortening effect of sedative drugs, and if deemed acceptable, the justification for its legitimacy.

The 1980s and 1990s represented a particularly fertile period for both the theoretical and practical consolidation of palliative care (Clark, 2016, pp. 149–195). Within the spectrum of comfort-focused interventions, sedation gradually came to acquire the "palliative" qualifier, and the term "palliative sedation" became increasingly established (Sinclair-Stephenson, 2006, p. 33; Rousseau, 2005, p. 10; Rousseau, 2004), denoting certain forms of sedation within the context of palliative care, guided by a specific set of criteria. The choice of these criteria is closely linked to how palliative care defines itself and to the intellectual milieu - namely, the hospice movement - in which it developed. The first official WHO definition of palliative care was issued in 1990:

> „Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care
> – affirms life and regards dying as a normal process;
> - neither hastens nor postpones death;

- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement."

(WHO, 1990, p. 11)

During the early development of palliative care, the principal target population comprised terminally ill patients, primarily those with cancer, with the primary focus of care on alleviating suffering. In the context of sedation, it was almost taken as "self-evident" that sedation extending until the moment of death should only be administered during the immediate dying phase. This was based on the assumption that the dying process was a natural course, in which any intervention that would advance the timing of death beyond its natural course was considered impermissible.

The emergence of critical reflection on the "imminence condition" in sedation was greatly facilitated by subsequent developments in the scope of palliative care, particularly the expansion of its target patient population: "Early in the history of palliative care, to assume the imminence condition was an unproblematic move and went unnoticed, because palliative care dealt only with imminently dying patients. But over the past 20 years there has been a great shift in the patient populations treated by palliative care practitioners, to include patients with life-threatening or chronic or sometimes even potentially curable illness." (Cellarius, 2008, p. 70) This, of course, did not call into question within palliative care the principle that only patients in the immediate dying phase may be sedated until the moment of death. It also became widely accepted that the presence of a refractory symptom could serve as an indication for this form of sedation. Although the definition of palliative care underwent two revisions after 1990, the prohibition against life-shortening interventions remained a central ethical tenet. In 2002, palliative care was defined as follows:

„Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care
• Provides relief from pain and other distressing symptoms
• Affirms life and regards dying as a normal process
• Intends neither to hasten or postpone death
• Integrates the psychological and spiritual aspects of patient care
• Offers a support system to help patients live as actively as possible until death

• Offers a support system to help the family cope during the patient's illness and in their own bereavement
• Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
• Will enhance quality of life, and may also positively influence the course of illness
• Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications"

(Sepúlveda et al., 2002, p. 94-95)

Almost two decades later, the definition of palliative care underwent another revision, yet the ethical foundation of palliative sedation until the moment of death continues to remain an integral element of the definition's context:

„Palliative care is the active holistic care of individuals across all ages with SHS (suffering is health related when it is associated with illness or injury of any kind. Health-related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, spiritual, and/or emotional functioning. Available from http://pallipedia.org/serious-health-related-suffering-shs/) because of severe illness (severe illness is a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress. Available from http://pallipedia.org/serious-illness/) and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers. Palliative care:
• Includes, prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. Whenever possible, these interventions must be evidence based
• Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them, and their families determine goals of care
• Is applicable throughout the course of an illness, according to the patient's needs
• Is provided in conjunction with disease-modifying therapies whenever needed
• May positively influence the course of illness
• Intends neither to hasten nor to postpone death, affirms life, and recognizes dying as a natural process
• Provides support to the family and caregivers during the patients' illness, and in their own bereavement
• Is delivered recognizing and respecting the cultural values and beliefs of the patient and family

• Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary)
• Can be provided by professionals with basic PC training
• Requires specialist PC with a multiprofessional team for referral of complex cases"
(Radbruch et al., 2020, p. 761)

Considering that sedative drugs may, in some cases, have a life-shortening effect, it became necessary within palliative care to reconcile this potential outcome with the categorical prohibition against hastening death. In Catholic healthcare ethics, a perspective has been present since the late 1950s that regards the therapeutic use of analgesics and sedatives as ethically permissible even when their administration entails a risk of shortening life. It is widely recognized that the Catholic stance was most clearly articulated by Pope Pius XII in his address to anesthesiologists on February 24, 1957, which served as a response to three questions posed by Professor Piero Mazzoni during the IX National Congress of the Italian Society of Anesthesiology (Società Italiana di Anestesiologia), held from October 15–17, 1956 (Pius XII, 1957). Professor Piero Mazzoni's third question addressed the use of analgesics for dying patients:

"3. Is the use of narcotics licit for the dying or for patients in danger of death, assuming there is a clinical indication? Can they be used even if pain relief is likely to be accompanied by a shortening of life?"

In his reply, Pope Pius XII stated:

„If between the narcosis and the shortening of life there is no direct causal bond, decided by the will of the parties or by the nature of the things (what would be the case, if the suppression of pain could be obtained only by the shortening of life), and if on the contrary the administration of narcosis has by itself two distinct effects, on the one hand the relief of pain, and on the other hand the shortening of life, it is licit; however there it would remain to be seen whether there were between these two effects a reasonable proportion, and if the advantages of the one compensate for the disadvantages of the other. It is also important to ask whether the current state of science does not allow to obtain the same result, by employing other means, then, not to exceed, in the use of narcosis, the limits of what is practically necessary.

Conclusion and answer to the third question

In short, you ask Us: 'is the suppression of pain and of the consciousness by the means of narcosis (when it is demanded by a medical indication), allowed by the religion and morals to the doctor and to the patient (even with death approaching, and with the knowledge that the use of narcosis will shorten

> life)?' The answer will be: 'If there are no other means and, if, in the given circumstances, that does not prevent the fulfillment of other religious and moral duties: Yes.'"

In its 1980 Declaration on Euthanasia (*Iura et bona*), the Congregation for the Doctrine of the Faith provided the following explanation of the papal view:

> „In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine. However, painkillers that cause unconsciousness need special consideration. For a person not only has to be able to satisfy his or her moral duties and family obligations; he or she also has to prepare himself or herself with full consciousness for meeting Christ. Thus Pius XII warns: "It is not right to deprive the dying person of consciousness without a serious reason."" (Congregatio pro Doctrina Fidei, 1980)[1]

Within the *Ethical and Religious Directives for Catholic Health Facilities*, the question of the possible life-shortening effects of analgesic and sedative medications is addressed with the explicit aim of distinguishing such practices from euthanasia: "It is not euthanasia to administer sedatives and analgesics to a dying patient for the relief of pain when this intervention is deemed necessary, even if it results in a loss of consciousness or may contribute to the shortening of life." (National Conference of Catholic Bishops, 1971, pp. 13–14)

The cited passages clearly show that, within the Catholic perspective, considerations other than the protection of life were articulated at an early stage and came to serve as important points of orientation in decisions about the sedation of imminently dying patients. Among these, the value attributed to consciousness is central, as it provides the basis for fulfilling moral and familial responsibilities and for preparing to meet Christ. The diminishment or loss of consciousness is therefore framed as a potential adverse effect that may be accepted only on serious grounds; in other words, this possible harm must be balanced against the therapeutic benefits of sedation in alleviating suffering. This reasoning contributes to the emergence of a particular interpretation of the proportionality requirement governing sedation.

Within the philosophy of palliative care, the preservation of consciousness is also accorded special significance. David J. Roy noted in 1990 that there is almost unanimous agreement on the emancipatory principle of palliative care, understood as the obligation to "spare no scientific or clinical effort to free dying persons from the tormenting pain that overwhelms and constricts their consciousness, leaving

[1] The letter *Samaritanus bonus* issued by the Congregation for the Doctrine of the Faith was made public on 22 September and addresses the care of patients in critical clinical situations and at the end of life. The approximately 30-page document, approved by Pope Francis, explicitly rejects all forms of euthanasia and assisted suicide.

them without the psychological or mental space to think, speak, and act as they wish before death." (Roy, 1990, p. 3). This line of reasoning also underpins the proportionality requirement, according to which the diminishment or loss of consciousness is typically regarded as justified only if the relief of a refractory symptom necessitates it.

The apparent conflict between the obligation to protect life and the potential life-shortening effect of sedation is typically addressed in mainstream palliative care by emphasizing that sedation is always intended to relieve suffering rather than to hasten death. In certain cases, this ethical requirement is expressed through the broader framework of the doctrine of double effect (*duplex effectus*), from which the ethical legitimacy of practice is derived (Cherny–Portenoy, 1994, p. 36; Mount, 1996, pp. 34–35; Orentlicher, 1997; Krakauer et al., 2000). The principle of double effect, its scope of application, and critical discussion appear very early in the bioethical literature, including in debates on analgesic interventions that may inadvertently accelerate death (Beauchamp–Childress, 1979, p. 104; The President's Commission, 1983, pp. 78–79).

We can provide several examples of definitions for palliative sedation, a concept that has gradually gained a clear form. According to the National Hospice and Palliative Care Organization (NHPCO): "Palliative sedation (also called palliative sedation therapy) is the controlled administration of sedative medications to reduce patient consciousness to the minimum extent necessary to render intolerable and refractory suffering tolerable." (Kirk–Mahon, 2010, p. 917.) The European Association for Palliative Care (EAPC) offers the following definition:

> „1. Palliative sedation aims to relieve refractory suffering through the monitored proportional use of medications intended to reduce consciousness in patients with life-limiting disease.
>
> …
>
> 2. Symptoms or a state of existential distress are considered to be refractory when there is a lack of methods likely to provide appropriate relief within an acceptable time frame and without unacceptable adverse effects.
>
> …
>
> 5. The aim of palliative sedation is to relieve refractory suffering, not to shorten life"
>
> (Surges et al., 2024. p. 9.)

The Association applies the principle of proportionality in two respects: A. it regards sedation deeper than necessary to alleviate suffering and maintain interactive capacity as unjustified; and B. in certain circumstances - such as when the therapeutic benefit of other interventions takes time to occur (temporary sedation),

or when the patient can be momentarily relieved from the difficulties of their condition (restorative sedation) - intermittent rather than continuous sedation is considered appropriate. (Surges et al., 2024, p. 7)

Considering that for at least twenty years palliative care has consistently used the term "palliative sedation" as the standard expression for sedation therapy (Twycross, 2023; Broeckaert–Nunez Olarte, 2002), it is unsurprising that definitions of sedation deviating in one or more key criteria from the palliative care perspective frequently adopt the term "terminal sedation." A representative early example is the definition by Timothy Quill and colleagues in 1997:

> „With TS [Terminal sedation] the suffering patient is sedated to unconsciousness, usually through ongoing administration of barbiturates or benzodiazepines. The patient then dies of dehydration, starvation, or some other intervening complication, as all life-sustaining interventions are withheld." (Quill et al., 1997, p. 2100)

This definition already excludes several limiting conditions that others deem necessary for sedating a patient in the direct dying phase, such as the presence of refractory symptoms or the life-shortening impact of discontinuing life-sustaining treatments. While the authors still state that it may be argued that the patient's death in this context is not intended but only foreseen, Quill challenges the viability of this simplified understanding of intention (Quill, 1993). Additionally, in the broader discussion on sedation, the principle of double effect was questioned quite early by other commentators as well (Billings–Block, 1996, p. 22). A subsequent example of a comparable definition of terminal sedation reads:

> „By 'terminal sedation' I denote … a procedure where through heavy sedation a terminally ill patient is put into a state of coma, where the intention of the doctor is that the patient should stay comatose until he or she is dead. No extraordinary monitoring of the medical state of the patient is undertaken. Normal hydration is ignored. All this means that in some cases where patients are being sedated, death is hastened; if the disease does not kill the patient, some complication in relation to the sedation, or the withdrawal of treatment and hydration, or the combination of these, does."
>
> (Tännsjö, 2004, p. 15)

The concept of "expanded terminal sedation" has emerged in the literature, explicitly denoting sedation approaches that reflect the most frequent core criteria of the conventional palliative care perspective:

> „Terminal Sedation (TS) refers to the use of sedatives in dying patients until the point of death. The following limits are commonly applied: (1) symptoms should be refractory, (2) sedatives should be administered proportionally to symptoms and (3) the patient should be imminently dying. The term

> 'Expanded TS' (ETS) can be used to describe the use of sedation at the end of life outside one or more of these limits." (Gilbertson et al., 2023, p. 252)

For these authors, the preservation of consciousness is no longer self-evident. They differentiate between "good" and "bad" consciousness: good consciousness is that which is meaningful and valuable to the patient, while bad consciousness is that which the patient no longer wishes to endure. (Takla–Savulescu–Wilkinson, 2021; Savulescu–Radcliffe–Richards, 2019) Accordingly, the ethical justification of consciousness becomes individualized. As a result, the principle of proportionality may lose its general applicability, since, for instance, in cases of existential suffering coexisting with refractory physical symptoms, deep sedation until death may be the only therapy acceptable to the patient. When the overarching goal of medical intervention is to relieve or eliminate the patient's suffering in a manner the patient deems acceptable, the requirement of the imminent dying period may lose its relevance; for example, the terminal stage defined as spanning a longer duration may serve as the criterion. It seems that some individuals oppose euthanasia but would find immediate deep sedation acceptable if only a very short time remains. (Takla et al., 2021) Naturally, "expanded" terminal sedation should only be understood as such relative to the conventional palliative approach to sedation used as the reference point.

A variety of definitions for sedation in end-of-life care exist in the literature, and these can be categorized along several dimensions. (Jones, 2013) The foregoing analysis has sought to reconstruct the conceptual logic underlying these definitions by examining the ethical assumptions on which they rest, rather than to assess the normative merits of the competing frameworks. Nonetheless, it is clear that, because palliative care - which has gained increasing recognition over the past decades - has embedded a specific and progressively widely accepted value orientation into the definitions of palliative sedation offered by its practitioners, concepts that differ from the traditional philosophy of palliative care are more likely to have a formative impact on practice or to more explicitly reveal a perspective diverging from conventional palliative thinking, especially when they do not employ the already heavily laden adjective "palliative," even if the relief of suffering remains a core value for them.

To summarize, the elements present in a definition of "palliative sedation" or "terminal sedation" cannot be fully understood solely from the definition itself (excluding, for instance, clearly defined criteria such as the drugs suitable for sedation). It remains opaque why the immediate dying phase is deemed necessary or not, why refractory symptoms are included or omitted, and why proportionality is required in some cases but not others. Only the ethical framework underlying the authors' worldview can clarify these choices. This perspective also reveals whether the foundational ethical stance is linked to any metaphysical assumptions, and the origins of the ethical requirements themselves. Viewed in this way, definitions of sedation serve as possible responses to the question of under which conditions -

guided by our own worldview - we consider drugs appropriate for sedation to be ethically acceptable for suffering individuals at the end of life. Philosophical analysis, in turn, allows us to uncover the underlying value framework of these definitions and to engage it in critical dialogue.

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