Arguments for and against palliative sedation
- an ethical reflection

Version 2

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Abstract

Introduction: Palliative sedation is the use of sedatives to lower the alertness for symptom control, when suffering is otherwise uncontrollable. Its role in palliative care is frequently argued, with both proponents and opponents. End-of-life decisions raise many concerns, including ethical ones, regarding which ethical principle should be valued the most. Some opponents argue that palliative sedation is ethically similar to euthanasia, but there also appears to be some confusion concerning concepts and definitions.

Aim: To discuss ethical arguments for and against palliative sedation, and relevant ethical differences between palliative sedation and euthanasia. Furthermore, to try to clarify different concepts and definitions used in the discussion of the matter.

Materials and methods: This work is based on a qualitative literature study, and an argumentative- and concept analysis on hermeneutic ground. Material was gathered through a literature search, and contains official material, debate articles and scientific articles.

Results: Palliative sedation can be argued to protect the ethical values of autonomy, beneficence, dignity and integrity, but simultaneously it is argued to violate those ethical concepts. There seems to be disagreements regarding which principle should be highest valued.

Conclusion: The matter of palliative sedation is delicate, and engages a lot of people. Pro- and contra-arguments vary in strength, partly because of an inconsistency in the use of different concepts and definitions. In most of the material studied, it is argued that palliative sedation is ethically acceptable, whereas euthanasia is not.

Key words: palliative sedation, euthanasia, autonomy, beneficence, non-maleficence
1. Introduction

*How long must I continue to suffer such intolerable pain? When will I be permitted to accept "sweet peace" or even to ask for it?*

- Sigmund Freud

Sigmund Freud died in 1939, at the age of 83. He had then suffered from a malignant oral epithelioma for many years. Years before his death, he had asked his personal physician, Max Schur, that “when the time comes, you will not let me suffer unnecessarily”. By the end, he told Schur it was “nothing but torture, and makes no sense anymore.” After this, his physician gave him a dose of morphine (two centigrams), and Freud fell asleep. Morphine was given again 12 hours later, and after that, Freud never regained consciousness, and died two days after receiving the first injection[1].

Sometimes when patients are close to dying, they suffer (physically or psycho-existentially) in a way that is hard for doctors to control. In this situation, palliative sedation is an option[2]. Palliative sedation means that a patient at the end of life gets to sleep (obtundation) when suffering cannot be controlled in any other way[2,3].

When doctors and other nursing staff, in line with science and proven experience, find that curative care no longer is possible, it should end and the focus should be exclusively on palliative care[4]. Depending on the patient’s need, this can be treatment for pain, anxiety, delirium or nausea. If these interventions are not enough, palliative sedation is an alternative[4]. Important to remember is that palliative sedation is used with the purpose to provide relief from the symptoms, and not to precipitate death. The decision has to be made together with the patient, and/or with relatives if the patients are not able to speak clearly for themselves[4–6].

Doctors are required to do what they can to ease their patients suffering, as long as it is morally defendable. An ethical dilemma arises when the suffering is so great that no other medications are helpful, but palliative sedation includes the patient not being able to interact with others or express a potential change of mind, nor eat or drink (which potentially reduce survival during certain circumstances)[3]. This background will contain information about different terms and definitions used while discussing end-of-life care and methodology of
palliative sedation, as well as an overview of relevant ethical concepts that need to be taken into consideration when making a decision about palliative sedation.

1.1 Concepts and definitions
The matter of end-of-life-decisions raises many ethical questions, and in the discussion, there are mainly five different concepts used. There is a need for precision in the definition of concepts, and therefore the most central concepts will now be presented. There is not enough space to discuss all of these, so forgoing life-sustaining treatment and physician-assisted suicide will not be discussed further on. The focus hence lies on palliative sedation, and to some extent also euthanasia.

1.1.1. Sedation
Sedation is used in different parts of medicine, and always includes an impact on patient consciousness. The American Association of Anesthesiology have presented guidelines, dividing sedation into different subgroups. The first level is called minimal sedation, which is a drug-induced state where the main aim is to calm the patient and minimize anxiety, patients can respond normally to verbal commands, but cognitive function and physical coordination may be impaired. Deeper levels are moderate and deep sedation, where consciousness is depressed. Airways, reflexes and cardiovascular functions may be affected. The deepest level is general anesthesia, which is a drug-induced loss of consciousness. Sedation is a continuum, and individuals might react differently to the same dose of medication given[7]. In this text when talking about sedation, what is meant is an altered state of consciousness where the patient clearly approaches unconsciousness.

1.1.2 Palliative sedation
Many attempts have been done to try and define palliative sedation, but there is still no internationally recognized definition[8]. This has led to confusion and difficulties in comparing studies, as well as inconsistency in the use of terms[9]. In Sweden, Läkemedelsverket (the Swedish Medical Products Agency) has given out recommendations on how to use palliative sedation, and they point out the lack of an internationally recognized definition, but states that with the term ‘palliative sedation’, what is most often meant is “a treatment that includes lowered alertness, which is given to ease painful symptoms when other interventions are ineffective[8].” (my translation). This definition is broad, and can be claimed to include a number of cases that are not by intention palliative sedation. A similar definition is used by Svenska Läkaresällskapet (The Swedish Society of Medicine), stating
that palliative sedation is a treatment for patients at the end-of-life stage, a deliberate impact on a palliative patient’s consciousness, with the aim of symptom relief when other treatments are not enough” (my translation). It is also stated that the patient must have a short estimated survival time, usually one to two weeks[10]. Läkemedelsverket does not recommend to limit the use of palliative sedation to the last weeks of life, but propose that it can be used also in the early phase of palliative care[8]. In this way, the two organizations differ. As stated earlier, the inconsistency is a problem.

In this work, the focus of the arguments is on a subgroup of the patients treated with palliative sedation, which are the patients who are treated to unconsciousness/close to unconsciousness, either intermittently or continuously.

1.1.3 Terminal sedation
The definition of terminal sedation also varies within the literature[11]. In Sweden it is used as a synonym to continuous palliative sedation, which means that once sedated, the patient never regains consciousness again, but die within a few days[2,5].

1.1.4 Forgoing life-sustaining treatment
Life-sustaining treatment is a treatment given in a life threatening situation to sustain a patient’s life. For example, circulatory or respiratory help, food- and/or water supplies and some medical treatments[12]. Hälso- och sjukvårdslagen (The Swedish Health and Medical Service Act) emphasizes respect for patient self-determination, and if patients want to withhold or withdraw life-sustaining treatment, this has to be respected as long as the patients are capable to make decisions. If a patient dies after demanding to forgo life-sustaining treatment, the patient dies from the disease, and the aim with forgoing the treatment has been to meet the patient’s wish, not to hasten death[12].

1.1.5 Physician-assisted suicide
Physician-assisted suicide is defined as: “a physician intentionally helping a person to terminate his/her life by providing drugs for self-administration, at that person’s voluntary and competent request.”[13]

1.1.6 Euthanasia
Euthanasia is “a physician (or other person) intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request.”[13]
1.2 Methodology and use of palliative sedation in Sweden

_Läkemedelsverket_ in 2010 presented general treatment recommendations for palliative sedation. In this section, all information presented is consistent with their recommendations, which – to the author’s understanding - serves as a praxis for the use in Sweden. Palliative sedation is stated to be a medical treatment aiming at symptom relief, and is not considered to be illegal.

Palliative sedation can be intermittent or continuous, superficial or deep. The range of lowered alertness varies, from just a slight effect on alertness to unconsciousness. When intermittent, the medicine dose is lowered with certain time intervals, allowing the patient to wake up, enabling doctors to evaluate the need of continued sedation, and the patient can express possible changes in attitude towards the sedation[2]. This method can be used against agonizing symptoms, even if the patient is not fully at the end-of-life stage[8]. Continuous palliative sedation is primarily a deep form, and sometimes called terminal sedation. Continuous palliative sedation/terminal sedation should only come in question when a patient is estimated to have hours-days left to live, and when no other optional treatments remains[8]. It is stated that when palliative sedation begins, liquid- and food supply normally is not medically meaningful, because of the patient’s palliative state. Sometimes, it can even worsen the patient’s symptoms. Because of this, it often ends when palliative sedation begins, after consideration to the individual situation[2,4]. The nursing team should be involved and informed about the decision, and it is important that the medical record is explicit, mentioning background, interventions and how the communication with the patient and/or the relatives has been[8].

The initial treatment strives for intermittent, superficial sedation with acceptable symptom relief, unnecessarily deep sedation should be avoided. The first line of treatment is usually midazolam, a benzodiazepine[8]. If insufficient, alternatives can be used (i.e. propofol or haloperidol), or continuous palliative sedation can come in question[8,14]. To help medical staff in the course of treatment, _Läkemedelsverket_ has come up with a flowchart (Figure I).
To the author’s knowledge, only one study has been done to determine how common palliative sedation is in Sweden[14]. A cross-sectional study was done in 2009, on 2021 patients with specialized palliative care (Table 1). This study showed palliative sedation to be rarely used, and most of the patients who received the treatment were cancer patients (Table 1).
Table 1. Occurrence of palliative sedation reported in the Swedish study of 2009[14].

<table>
<thead>
<tr>
<th>Occurrence of palliative sedation</th>
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<tbody>
<tr>
<td>Registered patients, number</td>
<td>2021</td>
</tr>
<tr>
<td>Patients with a cancer diagnose, n (%)</td>
<td>1799</td>
</tr>
<tr>
<td>Patients with palliative sedation, n (%)</td>
<td>22</td>
</tr>
<tr>
<td>With a cancer diagnose, n (%)</td>
<td>20</td>
</tr>
<tr>
<td>Patients with lowered alertness, n (%)</td>
<td>12</td>
</tr>
<tr>
<td>Patients with continuous palliative sedation, n (%)</td>
<td>1 (0.5‰)</td>
</tr>
</tbody>
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The most commonly used medicine for sedation was midazolam, with an average dose of 20 mg/day[14]. The most common reason for treatment was severe anxiety[14]. In 16 of the 22 cases, the patients were highly involved in making the decision about sedation. The authors of the study state that palliative sedation is uncommon, possibly because of good possibilities to treat severe symptoms more efficiently than before[14].

1.3 The palliative register
In Sweden, 92 075 people died in 2017[15]. Of these deaths, 49 814 of these deaths were registered in the Swedish palliative register during the same year[16]. Two common reasons for palliative sedation in Sweden are anxiety and pain[14], but according to the Swedish study mentioned earlier, palliative sedation is rarely used because of efficient alternatives. However, of the patients registered, 7070 were reported to suffer from anxiety, and 7383 from pain, when they died[16].

1.4 Physician-assisted suicide and euthanasia in Sweden
To assist to suicide is not a crime in Sweden, but doctors are required to give the patient a competent and attentive care, that meets the criteria of science and proven experience[5]. A common judgement is that physician-assisted suicide would not meet those criteria, and if a doctor prescribed the medicines needed, he would be risking his medical license[5]. To deprive another person of their life is on the other hand penalizing, even if it is done out of compassion and with consent[5]. There is not enough space in this work to discuss physician-assisted suicide and euthanasia thorough, but an attempt will be made to try and distinguish if there are any ethical relevant differences between palliative sedation and euthanasia.
1.5 Relevant ethical concepts

Ethics is the reflection over human values, actions and motives for the actions[17]. The following ethical concepts have been included because of their relevance to the topic of palliative sedation.

1.5.1 Beneficence and nonmaleficence

The Hippocratic Oath is an oath historically taken by doctors, and is a number of advices, sort of promises a doctor can make if he strives to be a competent doctor[2,17]. Two important parts of this oath are nonmaleficence and beneficence[18]. Beneficence requires agents to provide benefits to others, in terms of being kind and merciful. This means that doctors shall - to the best of their abilities - do good[2]. It does not necessarily mean that a person is morally required to benefit persons at all occasions, but with patients, doctors should protect their rights, prevent them from harm and help them when disabled[18].

Nonmaleficence is an obligation to avoid harming others intentionally or unintentionally[18]. Compared to beneficence, nonmaleficence means that one should do no harm, whereas beneficence means that one should try his best to prevent or remove harm, and do or promote good. The principle of nonmaleficence is often equalized with Primum non nocere: “Above all do no harm”[18]. Closely linked to nonmaleficence is the rule of double effect, also known as the doctrine of double effect. The rule of double effect is invoked to explain that a single act can be justified, even if it has both a good effect and a harmful effect, if the harmful effect is a side effect of the good action[18]. Naturally, there has to be a balance between the size of good effect and the possible side effect.

1.5.2 Autonomy and informed consent

In biomedical ethics, the general understanding is that autonomy means self-government[2,19]. In principal, to be autonomous means that one has the capacity to decide over one’s own life and actions, and live according to one’s own values and primary wishes, as long as it does not violate someone else’s self-government[2,20]. In medicine, this means for example that an individual has the right to receive all the information about medical condition, treatments, procedures and risks, but also the right to abstain some or all of that information[20]. A patient can fully decide to say no to a treatment (if the patient still has decision-making capacity), and when it comes to receiving treatment, the patient is entitled to have a say, and the decision is made together with the medical profession[17]. Informed consent is a term closely linked to autonomy, and a way to express respect for a person’s
autonomy. It is considered being a requisite in order for a patient to make a rational and considered decision, and therefore a requisite for autonomous decision-making. A person can lack autonomy, temporarily or permanently. For example, a sedated person (which is the case once a patient is under palliative sedation), lacks autonomy[2]. Sometimes in discussion of the matter of palliative sedation for a specific patient, the question comes up if the patient still has enough decision making-capacity left. If not, it is possible for doctors and other medical staff to make a decision, in collaboration with the patients close family, based on what the patient is believed to have wanted[2,8].

1.5.3 Dignity

Hälsosjukvårdslagen states that “medical care should be given with respect for all human beings’ equal value, and for each individual’s dignity.”[21] (my translation). Dignity is a central term when it comes to treating patients[2]. “Dignity is the quality or state of being honored or valued.”[22] To treat someone with dignity, means to see them as a whole person, with unique needs and to respect them, their values, goals and privacy[22,23]. Staff attitude and approach at a hospital can potentially influence patient perceptions of dignity[24]. When people through sickness - for example when they are terminally ill, as is the case for people who might be treated with palliative sedation – are limited, they can feel they lose some of their dignity, since they need to depend on others[2]. Human dignity is also connected to integrity, and undignified acts can violate a person’s integrity.

1.5.4 Integrity

The term integrity is tied to value and worthiness, and affirms each human’s intrinsic value as a person. It can be associated with respect for a person’s opinions, values and wishes, irrespective of how capable that person is to present those[2,26]. The term can be divided into many different forms, for example physical and psychological integrity[26]. Physical integrity means for example that no one has the right to examine another person’s body without their consent, whereas psychological integrity focuses on the complex of the individual’s opinions, wishes, values and mental life, and means that a person’s opinions and values should not be violated[26]. Everybody, including people who are not able to speak for themselves, shall have their integrity respected[17], for example, a person who is sedated for palliation. Those who cannot defend their own dignity and integrity by making their own decisions, need to have their integrity ensured by the help of others, for example dependents or medical staff[17].

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2. Aim
The aim is to study palliative sedation in terms of methodology and ethics. The focus is on the ethical arguments for and against palliative sedation, and also to clarify different concepts. This will be done by answering a number of research questions:

- What are the guidelines/definitions of palliative sedation in Sweden, and how common is it?
- Which arguments can be used in favor of palliative sedation?
- Which arguments can be used against palliative sedation?
- Are there any relevant ethical differences between palliative sedation and euthanasia?

3. Material and Methods
This is a qualitative work, a literature study, with an argumentative- and concept analysis on a hermeneutic ground. Hermeneutics is about interpreting and understanding written texts, and the interpretations are used to try and bring understanding about patterns of thoughts, motive for actions and emotional reactions[27].

Qualitative research and hermeneutics are based on preconceptions and the pre-understanding from the researcher. Pre-understanding is the idea one has about a phenomenon, which has been acquired through own experiences and education. This is seen as an “objectively” given starting point for the own research project. It is impossible to free ourselves from preconceptions and pre-understanding, but important for the researcher to be aware, and critically test one’s own opinions, not only look for information that confirms them[28]. In this project, a pre-understanding that could affect the results is the ethical principle most valued from the author. It might show in the way the material is gathered, and in the analysis of the arguments.

In this work, pre-understanding is based on the ethical concepts described in the background. The author’s own pre-understanding is also based on the biomedical ethics that have been taught in medical school. To the author, the principle of beneficence and non-maleficence is important, but attempts will be made to make sure this does not affect the analysis. Yet another source of pre-understanding is a close relative who is working with palliative care and sometimes in collaboration with patients (and their relatives) decides about palliative
sedation. This is something the author must try to be aware of, in analyzing different opinions and views.

3.1 Data collection and limitations
In this work, the material includes scientific articles, official material, textbooks and debate articles, and it has been gathered through literature research done in several databases.

The databases include PubMed, Google Scholar, CINAHL and PsycINFO. Keywords used were “palliative sedation”, “definitions” and “ethics”, and also different ethical concepts such as “autonomy”, “beneficence”, “non-maleficence”, “dignity” and “integrity”. To be able to sort out different definitions regarding end of life-care, the terms “terminal sedation”, “physician-assisted suicide” and “euthanasia” were also used. All of these terms were combined differently, to ensure that as much relevant material as possible was found. In total, 13 references were chosen from the different databases. The search was limited to texts written in Swedish or English and available in full text. Complementary information was gathered from several official records (21 references), regarding laws and guidelines from i.e. Socialstyrelsen (the National Board of Health and Welfare), SMER (the Swedish National Council on Medical Ethics) and Hälso- och sjukvårdslagen. 7 references were found in the Swedish Medical Journal Läkartidningen, by searching their website with the keywords displayed in the beginning of this section. Another search was made by investigating references from chosen articles.

4. Results
4.1 Arguments for and against palliative sedation
In these following sections arguments for and against palliative sedation will be presented. The term “palliative sedation” does in these arguments mean sedation until unconsciousness/close to unconsciousness, and therefore they do not include all patients treated with palliative sedation, if using the definition from Läkemedelsverket explained earlier.

4.2.1 Beneficence and non-maleficence
4.2.1.1 Justifications of palliative sedation
One argument for palliative sedation is that the primary aim in palliative care is to retain patient freedom from dolorous symptoms, and when out of other options, palliative sedation...
is an alternative, to achieve a benefit for the patient[29]. While some people argue that medications used for sedation most likely shortens life, others mean that the sedatives rarely shortens life, and if the patient’s suffering is unbearable, it is unethical not to sedate the patient for symptom relief[30]. This is reinforced by several studies, which proposes that deeply sedated patients are not dying sooner that patients who are not sedated, and because of this, the rule of double effect is not even longer necessary to justify using palliative sedation[31]. Others argue that even if the rule of double effect is applied, the benefit of symptom relief from refractory symptoms can exceed the harm done by unconsciousness[31,32].

4.2.1.2 Against palliative sedation

Some argue that palliative sedation easily can be used for the wrong purpose, which would be to maintain complete unconsciousness until death, and not to only treat until symptoms are controlled, which is the principle for palliative sedation[31]. It is argued that research shows this is not all that uncommon, but that up to 10% of 2010’s deaths in The Netherlands were preceded by that type of sedation[31]. Furthermore, it is debated that judgement of prognosis will be unreliable if the patient is sedated for a prolonged amount of time[33]. Initiating sedation, combined with withdrawal of fluids- and food supply, is argued to most likely shorten the patient’s life, which is not the purpose of palliative sedation[33]. The rule of double effect states that alleviating treatment can be given even if fatal side effects are possible, but some argue that the rule of double effect cannot be applied on palliative sedation, since it with certainty involves that risk[33]. Another argument against palliative sedation is that if used for a prolonged time, it can cause serious medical complications, including thrombosis, muscle atrophy and gastrointestinal problems[33].

Sometimes palliative sedation is used for psychological reasons (psycho-existential suffering). An argument against sedation in that situation is that the amount of the suffering does not necessarily mean that patients are close to dying, and it is possible that the survival time would be longer if sedation was not performed, indicating that physicians cannot argue that patients’ shortened survival is only expected and not intended[32].
4.2.2 Autonomy

4.2.2.1 Justifications of palliative sedation

A common reason for people wanting to end their life is loss of capacity to exert autonomy[34]. Palliative care, including palliative sedation, is reasoned to be an alternative for these patients, since it can help them with relief from agonizing and refractory symptoms[35]. Patient autonomy must be valued at the end-of-life stage, and if the wish is to abstain from life sustaining treatment and receive end-of-life care, including palliative sedation, this should be respected[36,37]. It is nationally accepted in Sweden that palliative sedation is an option for refractory symptoms, and promoters emphasizes that only a patient can decide if his suffering is refractory or not[10,31].

To justify palliative sedation according to the autonomy principle, it requires patient wish for sedation. It is argued that unambiguous wishes for sedation could therefore justify palliative sedation[32]. Although, as stated earlier, a patient is entitled to have a say regarding treatment, but autonomy does not mean a right to decide which treatment to receive.

4.2.2.2 Against palliative sedation

Palliative sedation leads to weakening or complete loss of a patient’s capacity for interactions and communication with family and friends[31]. Sometimes the sedation can be given as family’s – or someone else’s – wishes, and not because of the patient, which may violate patient autonomy[38]. In cases where patients are not capable of decision-making, and designated decision-makers choose palliative sedation for them, the strict respect for the presented consent is argued to be compromised[39]. One doctor states that the effectiveness of sedation is hard to judge, since the patient is unable to communicate it, and without knowing if symptoms are truly controlled, how can a patient make an informed consent and autonomous choice, he wonders[40]. Another argument is that it is not a doctor’s only job to respect patient autonomy, but sometimes to protect it. A patient sedated with continuous palliative sedation “is robbed of his or her autonomy. This is not acceptable”[22]. Furthermore, it is also argued that having to give palliative sedation can violate a doctor’s autonomy[41].

4.2.2 Dignity and integrity

4.2.3.1 Justifications of palliative sedation

One argument for palliative sedation is that when caring for terminal patients, maintaining optimal quality of life (including symptom control) is one of the primary responsibilities, to
enable the patient to die with dignity. This is, even if symptom control may have an additional effect of accelerating the process of dying[37]. Furthermore, it is reasoned that reducing suffering by palliative sedation at the end of life, frees a patient from serious distress, and preserves that person’s dignity[42]. Sedation can mean that for a patient, life can be dignified and tolerable in an otherwise miserable situation[43].

It is argued that when terminally ill and suffering, parts of a person are destroyed, for example their thinking and feelings are affected, which destroys the consistency of the whole human being, and that in turn threatens a person’s integrity. For this reason, palliative sedation should be an option to dying patients who are suffering[44].

4.2.3.2 Against palliative sedation

An argument used against palliative sedation is that wrongful actions are done due to lack of knowledge, which may lead to patients not only being sedated, but die from these actions, which is incompatible with the aim of palliative care - to help people to live a dignified life until the end[45]. Some patients reject continuous palliative sedation on the grounds that they feel that their dignity would be violated, were they to be sedated for an extended time until they died[22]. It is also argued that the sedation cannot relieve all types of symptoms, for example heavy internal bleeding or difficulties in swallowing from oropharyngeal cancer, and although the patient might not be aware of it because of the sedation, families might not experience their relatives’ deaths as dignified or peaceful[22].

To some medical staff, preparing and injecting sedatives for palliative sedation can be a challenge to their professional identity and their integrity, if they fear that the potential harmful effects from sedation can be greater than the benefit[46].

5. Discussion and conclusion

5.1 Methodology and current use of palliative sedation in Sweden

The definition used by Läkemedelsverket regarding palliative sedation seems to be broad, and it can be interpreted to include a large number of patients who do not by intention receive palliative sedation, but any treatment that aims for symptom relief which includes sedatives. This is surely not the case, but it confirms what is pointed out by multiple sources, which is that an internationally recognized definition is needed. As I showed in 1.1 we have different definitions of palliative sedation, and these different definitions mirror differences in attitudes and also ethical values. Looking at the Swedish study done in 2009 regarding the use of
palliative sedation in Sweden, one wonders what kind of definition they are using[14]. The number of patients reported treated with palliative sedation was very low. Unfortunately, there was not a closer explanation on their definition of palliative sedation. The fact that only one study has been done is another limiting factor in the matter, and makes it hard to draw any conclusions about the actual use of palliative sedation in Sweden. It seems like more research is needed in the field.

As pointed out in 1.3, there seems to be a considerable number of persons in Sweden dying without sufficient palliation for their pain and anxiety. This raises the question if there is a need of palliative sedation that is not fully met. The numbers presented seem to indicate that there is a need for palliative sedation in Sweden, possibly for a larger group of patients.

5.2 Arguments for and against palliative sedation

Palliative sedation is argued to both protect a patient’s right to autonomy, at the same time as it can violate the ethical principles of beneficence and non-maleficence. The decision about whether palliative sedation can be an option or not has to be made in each individual case. By agreeing to palliative sedation, the medical staff can protect both a patient’s autonomy, dignity and integrity. At the same time, palliative sedation can be a violation of those same principles, regarding of how you choose to see them. In this discussion, an attempt will be made to analyze the major arguments for and against palliative sedation, considering the ethical principles discussed in the introduction.

5.2.1 Beneficence and non-maleficence

Regarding the ethical principle of beneficence and non-maleficence, a major argument for the use of palliative sedation concerns one of the primary aims of palliative care, which is symptom relief. It is argued that symptom relief is such a big benefit for the patient that it is ethically acceptable with palliative sedation, even though the treatment may include that the patient’s alertness is lowered[47]. Opponents argue that it would be easy to overuse palliative sedation, with the purpose of not only symptom relief, but unconsciousness until death[31].

An important and well discussed matter regarding if palliative sedation is beneficial or not, is the possible shorting of life. There seems to be a difference in opinion regarding this, when sedatives are used with the purpose of palliative sedation. Some proponents refer to research showing that deeply sedated patients are not dying sooner than unsedated patients[30,31], while others argue that sedatives most likely shortens life[2]. In the material used as foundation for this work, a majority of the articles propose that sedation does not hasten
death, which could indicate that the contra-argument is not as strong as the pro-argument in this particular case.

Another argument linked to patient benefit is that one always has to take into consideration intent and outcome of an action[48]. According to the rule of double effect, benefit of an action needs to exceed the possible harmful side effects of an action. Proponents argue that the benefit of relief from refractory and hurtful symptoms can exceed the harm done by unconsciousness[31,32], but some opponents argue that this argument is not valid, since there has to be possible side effects from an action in order for the rule of double effect to be applicable, and they state that palliative sedation with certainly involves the risk of fatal side effects[33].

5.2.2 Autonomy
Considering the principle of autonomy and self-determination, patients right to self-determination is highly valued in the medical society[41,49], and some proponents of palliative sedation argue that patient autonomy must be honored at the end-of-life-stage as well as in any other time during life[41]. Regarding receiving a treatment, the patient is entitled to have a say, but the decision has to be made together with the medical profession[50]. They mean that palliative sedation must be an alternative, and respected as a choice if that is what the patient wishes for, as long as the decision is made together with the medical staff as stated above[41]. Looking at arguments against palliative sedation, when considering the principle of autonomy, a contra-argument is that it can violate a doctor’s autonomy[41]. This argument raises the question, what is more important? The doctor’s right to self-determination, or the doctor’s responsibility to relief patients from suffering in order for their benefit? According to Läkarförbundet, the doctor should always have the patient’s health in mind, but can never take measures with the aim of hastening death[49]. As reported earlier, palliative sedation is not aiming on shortening life, but on relieving patients from symptoms when other measures have failed. This may indicate that in this matter, the argument for palliative sedation due to the patients’ benefit, might be stronger than the argument that palliative sedation can violate a doctor’s autonomy. Furthermore, the argument about the doctor’s autonomy is questionable, since doctors are not allowed to refuse treating patients based on their personal opinions or believes, unless a conscience clause exists.

While autonomy seems to be a strong argument for proponents of palliative sedation, opponents also invoke the argument of autonomy, but with a different perspective. It is argued
that sedation lessens a person’s autonomy and self-determination, since the ability to communicate is lost[40]. With a patient not being capable of decision-making, the decision is left to medical staff or relatives, which is argued to compromise the patient’s autonomy[39]. It is argued that allowing a person the treatment of palliative sedation, even if that is what the patient wishes, is not solely to honor patient autonomy, but also to rob the patients of autonomy, since they will be sedated and unable to communicate their wishes and possible concerns. Here, the opponents says that respecting patient autonomy is not always the right thing to do - but to protect it is - which cannot be done if they are treating someone by sedation[22]. When reading this, one wonders what is more important to value, the autonomy of a person capable of making decisions, once that patient makes a choice, or the possible risk that one individual might change their mind regarding the treatment after making an autonomous choice. If one was to think like presented in the section above, it would not be possible to sedate patients for any cause, because of the possible risk that they would change their mind. Therefore, this argument cannot be said to be of great strength, since it contradicts the way medicine works today.

5.2.3 Dignity and integrity

When analyzing the arguments while considering the ethical principle of dignity, it is shown that - as stated previously - the primary aim of palliative care is symptom relief, and maintaining optimal quality of life[29,37,47]. In doing this, one can allow a patient to die with dignity. It is argued that everybody deserve to live a dignified life until death, even if this includes symptom control which might be accelerating the processes of dying[37], as palliative sedation sometimes is argued to do. An argument that contradicts this is that sometimes lack of knowledge might lead to not only sedation, but an accelerated death, which is incompatible with the core of palliative care – to help people to live a dignified life until the end[45]. In Sweden there are clear guidelines regarding palliative sedation[51], so the strength of this argument can be questioned, at least from a Swedish point of view. Sedation is argued as being an option to live a dignified life in an otherwise intolerable situation due to lack of symptom control[43], but on the contrary it is also argued that it can create unpleasant situations for families to palliative patients, making the families experience the death as undignified, since not all symptoms can be relieved by sedation[22]. Here, the question of who’s experience should be more valued is raised, the dying and perhaps unconscious patient, or the families who will keep on living, maybe wondering if their relatives were still suffering despite the sedation. Läkarförbundet states in their ethical rules that “a doctor’s deed shall
always be done with the patient’s health as the primary aim” (my translation)[49], which suggests that the patient’s experience should be the most important thing.

Some opponents of palliative sedation are not only pressing on the importance of honoring the patients regarding different ethical concepts, but also the medical staff, who are the ones preparing the sedatives. It is argued that palliative sedation can harm both a doctor’s autonomy, as stated previously in the discussion, but also challenge the professional identity and integrity. This is, if the medical staff are afraid of potential harmful effects from the sedation being greater than the benefit[46]. Again, as earlier discussed, clear guidelines for the use of palliative sedation could possibly lessen this fear.

5.3 Relevant ethical differences between euthanasia and palliative sedation
In a number of countries, for example Sweden, Norway and Finland, the physicians organizations argue that euthanasia contradicts the code of ethics for doctors[52]. However, among doctors there is a considerable difference of opinion. A survey done among 1200 Swedish physicians revealed that 34% of the participants were positive towards physician-assisted suicide1[54]. The ethical rules from Läkarförbundet were mentioned earlier, and according to them, a doctor is forbidden to use interventions with the intention of hastened death[49]. In Sweden, some doctors have argued that euthanasia would change the ethical grounds for a doctor’s deed, which is, “to harm never, to cure sometimes, to relieve often, and to comfort always” (my translation)[41]. Patients’ right to self-determination is more and more valued, and should apply also at end-of-life, indicating that palliative sedation should be an option if that is what a patient wants. At the same time, its argued that autonomy and self-determination cannot be honored at any cause whatsoever, not when it violates someone else’s right to self-determination. In the case of euthanasia, another person’s responsibilities, decisions and actions are involved, and it is argued that euthanasia violates a doctor’s professional autonomy[41]. When hearing these arguments, it seems as if with palliative sedation, both the patient’s and the caregiver’s autonomy can be protected.

Besides autonomy and the right to decide over one’s life, the ethical principles of beneficence and non-maleficence are highlighted as important when it comes to distinguish between

1 Physician-assisted suicide is by some considered to be a form of euthanasia, while others would deny this, claiming that it is the ill person who takes his or her own life[53].
palliative sedation and euthanasia[48]. When considering beneficence and non-maleficence, it is important to look at intent and outcome. It is argued that palliative sedation differs from euthanasia by intent and outcome [22,31,48], in terms that palliative sedation is aiming for symptom relief, whereas the intent of euthanasia is to terminate a person’s life[48]. Regarding desired outcome, in the case of euthanasia, it is a person’s death, while for palliative sedation the desired outcome is relief from suffering through sedation (with the small potential risk of accelerating death)[48]. The aim of palliative sedation is not sedation or ending the patient’s life, but symptom relief, which is the opposite of euthanasia, where the aim is the death of a person[22,31]. Therefore, it is argued that if you add it up, palliative sedation benefits the patient[48]. Additionally, its argued that palliative sedation is ethical, whereas euthanasia is not, because of the rule of double effect[22]. It is argued that there is a clear difference between giving medication with the intention to kill a patient, and a case where medication is given to relieve a symptom, despite knowing that the treatment might contribute to hastening the patient’s death. Relieving a patient from unbearable symptoms is argued to be ethically acceptable, despite the fact that it robs a patient of possibilities for social interactions[48]. With euthanasia the intent is different but clear, and that is to deprive a person of his or her life[31]. This is stated to be unethical, not only by Läkarförbundet as mentioned earlier, but also by the worldwide organization World Medical Association[55]. However, some proponents of euthanasia argue that the intention can be to ease someone’s suffering, because symptom relief is not possible in any other way[56].

A majority of the articles studied in this work argue for a difference between palliative sedation and euthanasia[22,31,41,48], and the importance of keeping them apart. There are however, also some who argue that palliative sedation, particularly in the continuous form, is merely a way to disguise euthanasia, or that it is some sort of mercy killing in disguise[31].

This work was limited both by numbers of references allowed to use, and the words were limited as well. Would it have been larger, an interview study could have been carried out, interviewing either medical staff and/or patients/relatives. This would have added another layer to the work. Furthermore, a limitation is that pre-understanding might have affected which material that was chosen for a complete read-through, and furthermore chosen to be used in the work. Also, it would have been interesting to compare the results found about Sweden to different countries, both regarding how commonly palliative sedation is used and how it is regulated by law. A systematic literature review could have been done trying to sort this out, but due to the limited space, those questions were not examined closer, and an
argumentative- and concept analysis was chosen instead, with the primary aim to study the ethical arguments for and against palliative sedation. The strength of this study was the broad range of material that was gone through, from both researchers, patients, doctors as well as authorities, which made it possible to look at arguments from many different perspectives. Palliative sedation is an important medical treatment option that many medical professionals are not fully aware are ethically and legally acceptable. However, its matter needs to be discussed, partly because it has been suggested to be an alternative to another well-discussed topic, euthanasia.

5.4 Conclusion
When it comes to the matter of palliative sedation, some argue for a primary conflict of interest between protecting a patient’s autonomy and between the will to always do good, and to harm as little as possible. However, those who argue in favor of palliative sedation claims that this is not the case, rather that autonomy and doing good coincide in this case. The subjects discussed in this work (palliative sedation and euthanasia) are delicate matters. Both facts and values are put forward when it comes to the arguments. The strength of the arguments varies, partly because of an inconsistency regarding terms and definitions, which sometimes makes it hard to compare different arguments, if they are based on different definitions. Also, there are different opinions regarding the well-used argument that palliative sedation accelerates death, and there does not seem to be a clear understanding if this is the case or not, but for many of those involved in this question it is despite this accepted with palliative sedation.

To conclude, it seems like the ethical values discussed can be both protected and violated by the use of palliative sedation. Many strong arguments promoting the use are put forward, regarding both autonomy, beneficence and dignity. A very important thing in medicine is to have the patient’s best in interest. After carefully scrutinizing all the arguments, it seems to the author that the weight of the arguments is in favor of palliative sedation, and that it could be an ethically acceptable way of treating remaining symptoms, when caring for palliative patients at the end-of-life-stage.
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To the editor-in-chief  
Medical Ethics Journal

Dear Editor,

We have written a paper titled “An ethical reflection on palliative sedation”, enclosed is the manuscript and we would kindly ask you to consider publishing our work in your journal.

The work encompasses an ethical argumentative analysis regarding palliative sedation, with the arguments allocated by the ethical principles of autonomy, beneficence/non-maleficence, dignity and integrity. Palliative sedation is an important question and its matter needs to be discussed, partly because it has been suggested to be an alternative to another well-discussed topic, euthanasia.

In this paper, arguments have been gathered from various debate articles and scientific articles, and carefully scrutinized. Many strong arguments promoting the use are put forward in the materials, regarding both autonomy, beneficence and dignity. We believe our findings would appeal to the readers of Medical Ethics Journal, since the matter is delicate and repeatedly debated in end-of-life-discussions.

We confirm that this manuscript has not been published elsewhere and is not under consideration by another journal. All authors have approved the manuscript and agree with its submission to Medical Ethics Journal.

We look forward to hearing from you at your earliest convenience.

Sincerely,

Tove Åström, MB.  
School of Medicine, Faculty of Science and Health  
Örebro University
Populärvetenskaplig sammanfattning

Medvetandesänkning möjlig symtomlindring i livets slutskede


Etik innebär reflektion över mänskligt värde, agerande och motiv för människans agerande. Några viktiga principer är;

- autonomi – rätt till självbestämmande
- syftet att agera för att göra gott/inte skada
- värdighet
- integritet – ett begrepp knutet till värde och värdighet som person

Det finns både människor som förespråkar palliativ sedering, och människor som motsätter sig detta, utifrån de etiska principerna nämnda ovan. Vi har i vårt arbete analyserat för- och motargument, och sammanfattat dessa för att ge en överblick av de argument som finns. De vanligaste argumenten som används handlar om människans rätt till självbestämmande, samt det krav som sjukvården har att alltid försöka göra gott och inte skada. Argumenten är hämtade både från sjukvårdspersonal, anhöriga och patienter.

De allra flesta argumenterar för att palliativ sedering är en behandling som går i linje med de etiska principerna, och att det kan vara ett gott alternativ när annan behandling är otillräcklig. Vår uppfattning efter att ha gått igenom argumenten är att palliativ sedering tycks vara ett etiskt acceptabelt behandlingsalternativ i livets slutskede.
Etiskt öervägande

Det primära syftet med den här studien var att studera etiska argument för och emot palliativ sederings, samt att klargöra begrepp som används i diskussionen. Vid litteraturstudier som denna påverkas inga människor direkt ur ett etiskt perspektiv, men det finns ändå viktiga etiska frågor gällande forskningsområdet.

Palliativ sederings innefattar medvetandesänkning i symtomlindrande syfte, och frågan i sig väcker etiska frågeställningar gällande bland annat autonomi, göra gott/inte skada-principen, värdighet och integritet. En granskning av argument för och emot området palliativ sederings kan vara av nytta på samhällsnivå, då palliativ sederings är ett behandlingsalternativ som kan hjälpa patienter i livets slutskede.

Palliativ sederings är en fråga som inte diskuteras så mycket i samhället, och det är fördelaktigt att den lyfts fram. Autonomi och informerat samtycke är två viktiga etiska principer, och en förutsättning för informerat samtycke är att man har vetskap om den kunskap som finns, vilket studier likt denna kan bidra med. En förutsättning för att behandling ska ges med största möjliga hänsyn till de etiska principer som finns är att information om vilka etiska dilemman som kan uppstå är lättillgänglig.

Man kan vidare argumentera att det är viktigt på samhällsnivå att belysa denna behandlingsform, och att granska argumenten som finns. Genom att göra detta kan man öka förståelsen för behandlingen, och vårdpersonal kan bli mer positivt inställda till att använda den, vilket är i linje med en annan etisk princip, nämligen göra gott-principen.