

Chapter 2

Palliative Sedation and the Goals of Care at the End of Life

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2.1 Introduction

The term *palliative sedation* covers a range of current practices. Some have argued that the ethical boundary distinguishing palliative sedation from euthanasia is becoming blurred in a number of these practices (Ten Have and Welie 2014; Hauser and Walsh 2009). Recent policy frameworks and guidelines that have been developed by health care institutions or groups of clinicians in different countries are not consistent in terminology or the medical and ethical guidance that they provide (Taboada 2011; Claessens et al. 2008).

A shared understanding of goals of care among health care professionals, patients, their family and other caregivers is an important guide for clinical and ethical decision making regarding interventions at the end of life and an essential component of person-centred and holistic palliative care (Haberle et al. 2011). This chapter addresses various ethical controversies surrounding palliative sedation in relation to goals of care. The central argument is that, by maintaining the focus in decision making on appropriate goals of care that are informed by well-established principles of good palliative care and ethics, the distinction between palliative sedation and euthanasia can be clarified in practice and the overall good of the patient promoted. Two extremes in palliative sedation may be averted by considering and discussing goals of care: sedating inappropriately when the intention is to hasten the patient's death; not sedating appropriately or proportionately to address the patient's goals, such as to relieve or manage distressing symptoms or to prepare for death.

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My argument proceeds in three steps:

1. Appropriate goals of care are ones that are informed by well-established principles of good palliative care and ethics. Here I draw upon the definition of palliative care of the World Health Organization (WHO), canons of good health care implicit in the nature and meaning of health care, and the components of the patient's good. Examples of appropriate goals of care in decisions regarding palliative sedation are provided. Other goals of care that have generated ethical controversy are also discussed.
2. Discussing goals of care in decision making regarding palliative sedation serves to clarify the intention of health care professionals, to promote communication and a shared understanding among health care professionals, patients, family and other caregivers of the overall good of the patient, and to provide guidance for a plan of care that can be assessed and reviewed according to whether it meets the needs and goals of patients, their family and other caregivers.
3. I urge the development of education, tools and other resources for health care professionals, patients, family and other caregivers to help them understand and reflect upon appropriate goals of care at the end of life, and to facilitate communication and discussion of these goals.

2.2 Principles of Good Palliative Care

A consensus exists among providers of palliative care that “at the heart of palliative care is the affirmation of life, not the choosing of death.” (Scott 1991) Good palliative care has, as its fundamental concern, respecting the inherent dignity and worth of the person who is seriously ill or dying, and this is manifested through efforts to enhance what remains of his or her life. In euthanasia, by contrast, the emphasis is placed on the patient's death and on ‘getting it over with’. On this view, the patient's remaining life is held no longer to have much meaning or value.

The World Health Organization (WHO) has defined palliative care as care that, among other things:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor 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 counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness... (World Health Organization 2011).

These well-established principles of good palliative care are consistent with the nature and meaning of health care as a healing and comforting profession. They imply certain canons of good health care that Daniel P. Sulmasy has helpfully identified, and which I have reformulated in relation to palliative care as follows:

Restoration: Interventions should aim to restore a patient as much as possible to a state of functioning, well-being and comfort.

Proportionality: Interventions should be appropriate to the goals of care being sought, such as to extend life, restore or maintain function, relieve or manage distressing symptoms, as well as take into account the relation of expected likely benefits and risks of harm and burdens for the patient.

Parsimony: Only as much of an intervention as is needed to achieve the desired response in the patient should be used.

Totality: Decisions regarding interventions should aim at the overall good of the patient rather than only a part.

Discretion: Clinicians should recognize and observe both the limits of their own expertise and the limits of medical interventions (Sulmasy 2011).

The WHO definition of palliative care also stresses that such care “integrates the psychological and spiritual aspects of patient care.” In other words, it is holistic care and promotes the overall good of the patient.

Edmund D. Pellegrino has distinguished among four components of the overall good of the patient (Pellegrino 2006). There is the *medical good* or what the intervention of health care professionals hopes to accomplish through interventions to address a biological and/or psychological issue and to bring about as much restoration of a patient’s functioning, well-being and comfort as possible. There is also the *patient’s perception of the good*. This might include the medical good. It might also differ from the medical good depending on the patient’s beliefs, plans for life, values, and level of tolerance of interventions. Beyond the medical good and the patient’s perception of the good, there is also what Pellegrino calls the *human good*. This is the set of basic goods that all human beings require in order to live and thrive as human beings. Finally, and ultimately for Pellegrino, there is the *spiritual good* of the patient or those deep and inspiring principles that characterize the patient’s seeking of transcendent beauty, truth, goodness and authentic relationships. Good palliative care is care that aims for the overall good of the patient by taking into consideration all components of the patient’s good.

2.3 Appropriate Goals of Care in Relation to Palliative Sedation

There is a dialogue in Lewis Carroll’s *Alice’s Adventures in Wonderland* between Alice and the Cheshire Cat that is insightful:

‘Would you tell me, please, which way I ought to go from here?’

‘That depends a good deal on where you want to get to,’ said the Cat.

'I don't much care where —' said Alice.

'Then it doesn't matter which way you go,' said the Cat (Carroll and Green 1998).

Without goals, there would be no direction for decisions regarding alternatives for treatment and care. Some authors consider goals of care only in relation to promoting patient autonomy. Although the patient's perspective is fundamental to person-centred palliative care, appropriate goal-setting cannot only depend upon the patient's input but should involve their family and other caregivers and health care professionals. The patient depends upon family, other caregivers, who also are affected by decisions regarding treatment and care. Formulating appropriate goals of care is contingent upon understanding the patient's diagnosis, prognosis, the availability and limits of treatments, and the principles of good palliative care, towards which health care professionals can contribute. The practice that works best in palliative care, therefore, is communication and discussion among patients, their family, other caregivers, and health care professionals leading to a shared understanding of goals of care.

Appropriate goals of care in palliative care are those informed by well-established principles of good palliative care, such as the ones elaborated above. This point has several implications for palliative sedation. First, the distinction that is maintained in the WHO's definition of palliative care between such care and hastening death is clear and robust, and it should hold also for palliative sedation. The hastening of death is not an appropriate goal of palliative sedation. Likewise, if we consider the canons of good health care and the components of the patient's good elaborated above, the hastening of death restores nothing to the patient but rather aims to end the patient's life.

Second, the WHO definition of palliative care emphasizes holistic care that addresses the overall good of the person who is seriously ill or dying. The implication of this for palliative sedation is that the relief or management of distressing symptoms might not be the only appropriate goal of care. Considering the good for the patient or the spiritual good might entail that the patient and his or her family or other caregivers have the goal of maintaining consciousness, lucidity of thinking and communication for as long as possible in order to complete plans or prepare for death. Even when relief or management of distressing symptoms is the only or primary goal of care for the patient, decisions regarding palliative sedation must take into account the canon of proportionality, i.e., whether sedation is an appropriate measure for addressing the sort of distress experienced by the patient, and that its benefit is proportionate to the reduction or loss of the capacity for consciousness in the patient, which is a human good.

Third, the WHO definition of palliative care stresses that such care is applicable early in the course of a serious illness. Discussions of goals of care should also be held early on, but they could, and typically do, change over time for the patient, his or her family and other caregivers. Examples of ethically appropriate goals of palliative care are to conserve the function and resilience of the patient, to relieve or manage distressing symptoms temporarily until alternative interventions become available, or to provide respite for family and other caregivers. If sedatives are used, reversibility is a key consideration in relation to these goals of care.

There are, however, two other goals of care cited in the literature on palliative sedation that have generated some controversy among ethicists. I wish to review and comment on what I take to be the principal objections to them.

The first has been described by Greene and Davis as the goal to “dissociate the patient’s consciousness from the symptoms” (Greene and Davis 1991). Daniel P. Sulmasy claims that this goal of care is different from that of trying to relieve or manage the symptom itself and can generally be determined by the type and dose of sedative that is used (Sulmasy 2011). He reasons that, when the goal of palliative sedation is to dissociate the patient’s consciousness from the distressing symptoms, a continuous state of unconsciousness is not merely foreseen as a side effect but rather what is intended. According to Sulmasy, suppressing the capacity for consciousness, which is a human good, is an act that does not meet one of the conditions for the application of the Principle (or Rule, as Sulmasy prefers to call it) of Double Effect, namely that the act be neutral or good.

It could be argued, however, that, in aiming to dissociate the patient from awareness of the distressing symptom, the health care professional might not have started out intending unconsciousness. This is the argument that Timothy E. Quill et al. have recently put forward in the practice they call ‘proportionate palliative sedation’ or PPS, in which the depth of sedation is progressively increased to achieve relief of suffering (Quill et al. 2009). Sulmasy maintains that this still does not get around the requirement of the Principle of Double Effect. In PPS, the health care professional intends reducing the patient’s capacity for consciousness to dissociate the patient from his or her suffering continuously until death, only the health care professional does so by intending incremental reductions. These are not two distinct effects that follow from the same act of palliative sedation but “two degrees of the same effect.”

Sulmasy’s reasoning implies that only the goal of relieving or managing intractable and intolerable symptoms is ethically appropriate for palliative sedation, and the use of a sedative is proportionate when it is capable of doing something to relieve those *particular* symptoms, and not merely to reduce consciousness. It is *not* justified ethically for the sole goal of alleviating the distress that might arise from a patient’s *awareness* of those symptoms, such as in the experience of terminal dread.

I would argue that, although the *capacity* for consciousness is a human good, the *content* of consciousness, e.g., the distress that the patient is aware of, might not be. In that case, the health care professional may ethically intend to suppress this distress (i.e., act for the reason of alleviating something that is humanly not good). Moreover the *degree* to which a patient’s awareness and responsiveness is reduced (the degree to which dissociation of awareness of a distressing symptom is required in order for the patient to tolerate the symptom) is a relevant ethical factor in the analysis. Mild reductions in the patient’s level of consciousness, even if continuous, might actually enable patients to tolerate their symptoms better or, if time-limited, to carry out functions and activities that are humanly good (such as conversing or praying) when they are resilient. Thus dissociating the patient’s consciousness from the symptom could sometimes be an appropriate goal of palliative sedation.

Another practice of palliative sedation that has generated ethical controversy regards the goal of relieving or managing a patient's so-called 'existential suffering' (Boston et al. 2011). Part of the controversy has to do with the non-specific meaning of 'existential suffering' that has resulted in a wide range of definitions. Perhaps it would be better to clarify this term by distinction, as the Ancient and Mediaeval philosophers were accustomed to do. Existential suffering is *not* reducible to a particular 'symptom' that is due to some psychosomatic disturbance (e.g., dyspnea or delirium), although it might be influenced by and have an effect on the experience of such symptoms. Nor is existential suffering *simply* the awareness of an aversive symptom such as severe pain (such as might be prompted by a nurse asking the patient to rate pain on a scale of 1–10). It is, rather, the patient's understanding and judgment that such a symptom amounts to *a limitation or a loss* for that person in realizing his or her values, hopes, and relationships, which has a deleterious effect on the patient's overall good. Such suffering is manifested by feelings, for example, of low self-esteem, lack of purpose or meaning in life, guilt, regret, doubt, despair, loneliness, and alienation. Note that this experience is different than what might be classified as psychological symptoms or psychiatric disorders. This existential suffering relates to the patient's negative self-assessment or judgment regarding the meaning and value of his or her continued existence and future, and the meaning of death. In this sense, such suffering is a human issue that has a philosophical and spiritual origin.

The relevant ethical question here, it seems to me, is not whether the goal of relieving or managing existential suffering, as defined, is ethically appropriate within palliative care (it can be, in my opinion), but whether the use of sedatives to address it is a proportionate measure. It would not be a means that is proportionate to this goal as there is nothing in the sedative medications used that is specific to attaining that goal. Pharmacological and technical solutions are not fitting solutions for what are essentially human issues of a philosophical or spiritual nature. Holistic measures such as counselling, social support or pastoral care are better suited and have shown to be effective (Chochinov et al. 2005). I should note, however, that holistic care is not possible in every circumstance, e.g., in response to a crisis, when patients are reluctant or resistant, or when resources are not readily available. Mild to moderate levels of sedation might be ethically justified by the Principle of Double Effect, as explained above, in those instances when the patient's existential and spiritual distress is refractory. Mild to moderate palliative sedation could also play a secondary role in enabling holistic interventions for some patients (International Association of Catholic Bioethicists 2011).

2.4 Clinical and Ethical Benefits of Goals of Care Discussions

Discussing goals of care in decision making regarding palliative sedation serves to clarify the intention of health care professionals, to promote communication and a shared understanding among health care professionals, patients, family and other

caregivers of the overall good of the patient, and to provide guidance for a plan of care that can be assessed and reviewed according to whether it meets the needs and goals of patients, their family and other caregivers.

2.4.1 *Clarifying the Intentions of Health Care Professionals*

Goals of care discussions are one practical way to maintain the ethical distinction between appropriate palliative sedation and euthanasia because it requires health care professionals to reflect upon and express the reasons why they are offering and administering palliative sedation. The health care professional's intention is ethically relevant and important in the ethical analysis of the proposed use of sedatives.

Against critics who argue that it is always impossible to disengage the health care professional's intention of relieving or managing distressing symptoms from that of hastening the patient's death in those instances when this is foreseen as a likely effect, Lynn A. Jansen has urged a distinction between a narrow and a broad sense of intention: "...on one sense of intention, call it the *broad* sense, an action is intentional if it is done with self-awareness and knowledge of its consequences. But, on another sense of intention, call it the *narrow* sense, an action is intentional only if it is part of the agent's plan in acting." (Jansen 2010)

A moral agent is only responsible for what he or she intends in this narrow sense. This way of ethical reasoning is consistent with the aforementioned Principle of Double Effect, but it could be defended ethically, according to Jansen, even without appeal to this Principle if one accepts that the reason(s) *for which* an agent acts conditions the meaning of his or her action.

In the ethical analysis of palliative sedation, I believe that the health care professional can distinguish between the 'narrow' goal of relieving or managing intractable and intolerable distress in the patient, if this is his plan of care in consultation with the patient and his or her family and other caregivers, from the 'broad' foreseen effect of hastening death in some cases, and express this narrow goal in the health care professional's plan of care.

Focus on discussions regarding goals of care would also exclude the possibility of reasoning by appeal to 'ultimate' intentions. Daniel P. Sulmasy has distinguished between 'the end of the agent' (which could include an 'ultimate intention') and the 'end of the act' (which corresponds to Jansen's 'narrow intention') (Sulmasy 2011). Thus if a health care professional were to reason that he or she 'ultimately' intends the relief of a patient's suffering *by means of* hastening the patient's death, he or she would have to specify this as one of the goals in the plan of care. This would not be an indication for appropriate palliative sedation.

Furthermore, where there are explicit goals discussed regarding the plan of care for the patient, disingenuity is easier to detect in a health care professional than if there has been no such discussion. If sedatives are deliberately given in higher dosages than are necessary for the expressed goal of relieving or managing the

patient's distressing symptoms or distress, this would indicate either a medically injudicious practice or a (narrow) intention to hasten the patient's death.

On a policy level, a focus on clarifying the intentions of health care professionals through discussing goals of care would circumvent some policy decisions regarding palliative sedation that I consider to be either inefficacious, if their aim is to protect vulnerable patients, or centred more on serving the interests of health care professionals than those of patients, their family and other caregivers.

Because of an alleged uncertainty related to determining the intention of health care professionals, some policy frameworks and clinical guidelines have urged that continuous palliative sedation should only be given to patients who are imminently dying, often estimated to be within 2 weeks of death (Verkerk et al. 2007). This gives health care professionals the assurance that they did not intend to hasten the patient's death, because there is emerging evidence that there is no statistically significant difference between the survival rates of patients who received palliative sedation and those who did not, within this timeframe (Maltoni et al. 2009; Sykes and Thorns 2003). Estimates of when death is imminent are imprecise and uncertain. Such a policy provision could entail that persons who could benefit from palliative sedation to relieve or manage their distressing symptoms would not receive it on the grounds that they are assessed not to be imminently near death. Discussing and formulating goals of palliative sedation for patients who are at *any* stage of a serious and life-threatening illness is a more practical and ethically just manner of promoting clarity in the intention of the health care professional in administering palliative sedation.

A mirror problem regards policies on the withdrawal of medically-assisted nutrition and hydration with the initiation of continuous palliative sedation in some protocols and clinical pathways (e.g., the Liverpool Care Pathway in the United Kingdom). This practice is justified when death is assessed to be imminent because research shows that such withdrawals do not have a statistically significant impact on the patient's survival. This ethical justification, however, still does not address the fundamental issue of the health care professional's *intention* in withdrawing medically-assisted nutrition and hydration. A moral agent is not less responsible for omissions than actions. If the health care professional's reason for not feeding or hydrating the patient is to have the patient die, then that is what he or she intends. The withdrawal is ethically inappropriate regardless of whether the patient happens to die because of complications due to his or her disease, let's say, rather than from dehydration. (For an explication of this point, see Tollefsen 2006). A policy that stipulates generally that it is appropriate to withdraw medically-assisted nutrition and hydration with the initiation of continuous palliative sedation obscures the distinction between palliative care and euthanasia, which is based, as I have shown above, on the ethical relevance and importance of intention. Discussing and formulating goals for withdrawing medically-assisted nutrition and hydration from patients receiving continuous palliative sedation, on a case-by-case basis, is a more practical and ethically appropriate manner of promoting clarity in the intention of the health care professional. It also serves better the interests of the particular patient.

2.4.2 Promoting Communication and a Shared Understanding of the Overall Good of the Patient

Discussing and formulating goals of care enhances communication among health care professionals, patients, family and other caregivers, and contributes to a shared understanding of the patient's overall good. Research has shown the efficacy of such collaborations in end-of-life decision making in alleviating the burden experienced by many patients and their family and other caregivers, helping them to make sense of various interventions in light of identified and agreed upon goals, prioritizing multiple goals, and resolving goal conflicts (Kadjian et al. 2008). A shared understanding of the overall good of the patient provides guidance regarding whether and when to initiate palliative sedation, and its duration and depth. As noted above, sometimes the medical good that health care professionals aim for might not be the patient's perception of his or her own good. Policy frameworks and guidelines provide general guidance as to the clinical and ethical criteria for appropriate palliative sedation, but health care professionals cannot apply them to justify the appropriateness of palliative sedation for a particular patient without understanding what the patient's goals of care are. Conversely, many families and other caregivers experience significant distress over decisions regarding palliative sedation (Claessens et al. 2008). This could be mitigated by the health care professional's facilitation of discussions regarding ethically appropriate goals of palliative sedation and available alternatives, if any, to meet those goals.

2.4.3 Applying the Canons of Good Health Care Concretely

A focus on discussing and formulating goals of palliative sedation provides a practical basis for applying the canons of good health care. For example, discussing appropriate goals of care for palliative sedation helps to formulate a concrete plan of care in light of those goals. This plan can guide the proportionate administration of palliative sedation according to the patient's condition and response, and the review of those goals when circumstances change.

2.5 The Need for Education, Tools and Other Resources

While affirming the advantages of discussing and formulating appropriate goals of care for palliative sedation, I acknowledge the need for developing education, tools and other resources, to enhance the capacity of health care professionals, patients, family and other caregivers to participate knowledgeably and meaningfully in such discussions. Stone has published, for example, a tool that I have found useful for teaching family physicians to formulate and discuss goals of care at the end of life

(Stone 2001). Peereboom and Coyle have written on communication strategies to facilitate goals of care discussions (Peereboom and Coyle 2012). Other examples of education and tools that would be useful for health care professionals engaged in palliative care are those that will help them to assess distress in patients, to familiarize themselves with a range of interventions and resources possible for addressing such distress, and on the use of sedatives.

2.6 Conclusion

In this chapter, I have argued that, by maintaining the focus in decision making regarding palliative sedation on appropriate goals of care that are informed by well-established principles of good palliative care and ethics, the distinction between palliative sedation and euthanasia can be clarified in practice and the overall good of the patient promoted. I have affirmed that hastening a patient's death is not an ethically appropriate goal of care for palliative sedation. I have argued that clarity regarding the intention of health care professionals in offering and administering palliative sedation can be promoted through goals of care discussions and the formulation of a concrete plan of care in light of those goals. Focusing on appropriate goals of care for palliative sedation also complements the efforts of policy frameworks and clinical guidelines to provide ethical and legal parameters for appropriate palliative sedation on uncertain or contentious issues such as sedation for existential suffering, limiting continuous sedation to those who are imminently dying, or concomitant withdrawal of medically-assisted nutrition and hydration. Focusing on appropriate goals of care for palliative sedation also enhances person- and family-centred holistic care of persons who are seriously ill and dying. It enhances communication among health care professionals, patients, family and other caregivers and provides guidance for decision making regarding palliative sedation based on a shared understanding of the overall good of each patient. It holds health care professionals accountable to a plan of care in palliative sedation that is assessed in light of the patient's condition, response and other circumstances. It allows for flexibility in providing palliative sedation, to take into account changing goals of care over the course of the patient's illness. In summary, two extremes in palliative sedation may be averted by considering and discussing goals of care: sedating inappropriately when the intention is to hasten the patient's death; not sedating appropriately or proportionately to address the patient's goals, such as to relieve or manage distressing symptoms or to prepare for death. I urge developing education, tools and other resources, to enhance the capacity of health care professionals, patients, family and other caregivers to participate knowledgeably and meaningfully in discussions and formulations of goals of care to guide decision making regarding palliative sedation.

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