

# Palliative Sedation and Nursing: The Place of Palliative Sedation Within Palliative Nursing Care

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## Abstract and Introduction

### Abstract

Despite the fact that palliative sedation can be considered a gradually accepted form of therapy within palliative care, it still remains a much debated issue in palliative nursing. Moreover, research shows that palliative sedation often involves an emotional burden for care providers and, more specifically, for nurses. This article focuses on clarifying how palliative sedation as a therapy fits into the care perspective of palliative nursing. It describes the way in which decisions can be made about sedation and how the practical procedure may be carried out, and it illustrates the role the nurse can play. It becomes clear that nurses, alongside other care providers, play a crucial role in the process of palliative sedation. By using this step-by-step plan for palliative sedation, however, the decision-making process becomes multidisciplinary and diminishes the emotional burden for nurses. Moreover, it brings about clarity among care providers on when palliative sedation is and is not an issue.

### Introduction

An essential element in palliative care is striving for the best possible quality of life for each terminally ill patient and his or her family. To accomplish this goal, it is important to relieve the patient as much as possible of unpleasant physical, psychological, social, or spiritual problems.<sup>[1,2]</sup> In recent years, a positive evolution has been noticed regarding the treatment of such physical symptoms as pain.<sup>[3]</sup> Research shows that on the whole, palliative care succeeds in adequately treating a number of symptoms, mainly physical,<sup>[4-6]</sup> but at the same time it is evident that many symptoms, although treated, are not accounted for sufficiently. Sometimes these symptoms concern physical problems but increasingly they include spiritual and existential problems.<sup>[7]</sup> These inadequately manageable symptoms are also called "refractory symptoms" and can be distinguished from other symptoms that are difficult to treat because contrary to the advice of many clinical experts, they cannot be treated without compromising the patient's consciousness.<sup>[7,8]</sup> These refractory symptoms often can have a significant adverse effect on the functioning and well-being of a patient<sup>[8,9]</sup> and increase in intensity as the patient approaches death.<sup>[10]</sup> Since 1990, some have begun to consider palliative sedation as the final therapeutic possibility.<sup>[11]</sup>

Despite the fact that palliative sedation can be considered a gradually accepted form of therapy within palliative care, research has shown that palliative sedation often involves a heavy emotional burden for care providers and, more specifically, for nurses.<sup>[12]</sup> It is chiefly the nurse who, after the palliative sedation has been initiated, is assigned the largest share of the subsequent follow-up and care of the sedated patient and his or her family. Morita et al<sup>[12]</sup> surveyed 3,187 nurses with the objective of identifying the extent of the emotional burden when confronted with the care of a patient who is undergoing palliative sedation. This research group also identified which factors possibly influence the emotional burden experienced. The study shows that 12% of the nurses experience palliative sedation as an additional burden, 12% feel helpless when a case of palliative sedation occurs, 11% try to avoid situations in which palliative sedation occurs, and 4% consider palliative sedation to be pointless.<sup>[12]</sup>

Factors such as a patient's unclear wishes as to palliative sedation, difficult-to-diagnose refractory

symptoms, insufficient knowledge of palliative sedation, insufficient skills to deal with sedated patients and their families, differences in opinion between doctors and nurses, and conflicts between patient and family, and ethical uncertainties contribute to causing the extra burdens that the nurses experience in these situations and give rise to a certain form of incomprehension or distrust of the method of treatment.

For these reasons, we wish to explain in this article the way in which palliative sedation as a therapy fits into the care perspective of palliative nursing care, the way in which decision-making and the practical procedure of palliative sedation may be carried out (based on a step-by-step plan), and, concretely, the role the nurse can play.

## **Does Palliative Sedation Constitute Good Nursing Care?**

A question often raised when nurses discuss palliative sedation is whether this therapy fits in with "good nursing care," more specifically, good palliative nursing care. Opinions on this vary greatly among palliative nurses. These differences are mainly a consequence of the many misapprehensions that still exist about palliative sedation which, in turn, lead to practices that equally cannot always be distinguished from euthanasia or other forms of end-of-life decisions (ie, improperly increasing certain medication).<sup>[13]</sup> Consequently, nurses occasionally raise serious ethical questions about this form of symptom treatment. A great deal of work has been carried out recently regarding the interpretation and the meaning of the concept of palliative sedation, however.<sup>[13]</sup>

Although there is no national or international consensus on the definition of palliative sedation, several essential points appear in the many definitions. The most important elements of most of the definitions are terms such as "proportionality," "refractory symptoms and consciousness," and "terminal condition of the patient." Proportionality refers to the fact that the extent of sedation (as a side-effect of the treatment) must be in proportion to the severity of the symptoms the patient is exhibiting. This rules out considering as palliative sedation the increased use of opioids, among other pain relievers, without taking account of the severity of the symptoms. Practice has shown that high dosages of opioids may result in drowsiness, but this effect can never manifest itself to such an extent that it offers a solution for refractory symptoms. In fact, the symptoms that are treated with palliative sedation are strictly refractory symptoms. In other words, palliative sedation is never used to suppress difficult-to-treat symptoms but is used when a patient is confronted with physical and psychological forms of untreatable suffering. This clearly shows that it is related to controlling symptoms and not euthanasia or any other form of end-of-life decisions under which circumstances the intention is to end life rather than treat refractory suffering.<sup>[14]</sup>

The implementation of palliative sedation is a moral duty in the exceptional cases of untreatable symptoms and cannot be a source of concern to nurses. Denying this therapy to a small group of patients who suffer unnecessarily from refractory symptoms would be immoral if the nurse, in such situation, were not to take into account the ethical foundation of good medical care, namely, patient-oriented care and therapy with respect for the person and, as its most important goal, the patient's comfort.<sup>[15-17]</sup> This does not mean that palliative sedation is to be considered an ideal. On the contrary, this form of therapy may be used only when the care provider has no other possibilities and regular palliative care seems to be insufficient for the patient. In other words, it is important that the nurse, working with the multidisciplinary team, establishes that it concerns a case of refractory suffering and not symptoms that are difficult to treat. Palliative sedation, then, becomes a moral duty in accordance with the values and standards of good medical palliative care (eg, comfort, patient-oriented care, respect).

In the context of the University Hospitals Leuven, Belgium, we elaborate on the nurse's role in coming to a decision on palliative sedation, carrying out palliative sedation, caring further for the patient, and counseling the family. In doing so, the focus is on the multidisciplinary character of the decision-making process and how the emotional burden of the several care providers can be diminished in this way.

## **Procedure for Palliative Sedation and the Role of the Nurse**

### **History and Development of the Protocol**

In 1999, a palliative care unit was opened in the University Hospitals of Leuven, Belgium. The physician in charge, who was medical director of the palliative support team since 1992, brought his considerable experience with regard to palliative sedation to the unit, and palliative sedation was elaborately discussed and applied where indicated in concrete circumstances of refractory symptoms. However, this application resulted in many questions from nurses and other care providers, and soon it became clear that there was a need for a more refined procedure concerning the decision-making process and the initiation and execution of palliative sedation. Based on multidisciplinary consultation and ethical reflection (continuous evaluation of the protocol was carried out by the ethics committee of the hospital), they managed to refine the procedure, and the definition, indications, and procedure were drafted into a protocol for the department.<sup>[18-20]</sup> After a patient received palliative sedation, there was an extensive evaluation, and certain adaptations to the protocol were implemented. For instance, after a concrete request for palliative sedation, there was a waiting period of 24 hours initiated between the request and the start of the procedure. The possibility of a parting moment also was incorporated, because a particular patient had not clearly understood the information provided about palliative sedation and as a result the patient had not been able to say farewell to his friends. Because all questions of palliative sedation were discussed in the multidisciplinary team, the team's consensus and experience in palliative sedation and symptom control grew. Communication with and counseling of the patient and family were more profound and better founded, and spiritual suffering was better recognized and identified. The quality of palliative care increased and requests for palliative care were dealt with transparently. The protocol was progressively adjusted and a flowchart now clarifies the different steps that are to be observed in the decision-making process. The team had grown and was convinced that when a decision for palliative sedation had to be made according to this protocol, this was the only correct solution to treat the refractory symptoms. This certainty creates an undeniable peace of mind for the nurse and the other care providers and supports the nurse and doctor in carrying out palliative sedation.

### **Definition of the Concept of Palliative Sedation**

Palliative sedation in this unit was defined as "inducing a terminally ill palliative patient's full loss of consciousness through intermittent or continuous application of medication at the patient's request because there was no other way to gain control over one or more refractory symptoms. The untreatable illness continues evolving naturally during the palliative sedation and the patient will spontaneously and almost always die within a few days. The palliative sedation, carried out *lege artis*, does not seek to nor shall it cause death and it is not the intention to speed up or slow down the process of dying."<sup>[7]</sup>

Acute sedation of the patient in case of an acute life-threatening hemorrhage or acute respiratory distress does not fall under this definition but is included in essential symptom control and is part of "good clinical practice." There are specific standard procedures, a standing order, for these acute situations. Palliative sedation, as defined in this unit, is always carried out at the request of the terminally ill palliative patient who is suffering from one or more refractory symptoms for which all therapeutic possibilities for physical, psychological, spiritual, and social comfort have been exhausted. A patient also must have been adequately informed and have understood what this treatment involves.

It must be emphasized that palliative sedation is and hopefully will remain an exceptional measure. Therefore, it is also important to incorporate enough steps, conditions, and controls to prevent mistakes, pitfalls, and abuses.

### **The Procedure**

Nurses, alongside other care providers, play a crucial role because they, as the only ones of the multidisciplinary team, are there with the patient and his or her family 24 hours a day.

**Phase 1. Prevention of Palliative Sedation: Optimizing Palliative Care.** Because palliative sedation is an exceptional measure that is only appropriate in cases in which suffering is refractory in form, the first and foremost element of palliative care is the prevention of palliative sedation. The nurses must quickly recognize and acknowledge the needs of the patient (ie, physical, social, psychological, and spiritual) and communicate them to the appropriate care provider (ie, doctor, nurse, psychologist, physiotherapist, pastor, moral counselor). This way, timely intervention is ensured and the suffering of the patient is reduced to a minimum. In this context it is essential that nurses are unconditionally heard by the other care providers of the team. Practice has shown that when there is a quick reaction to symptoms, they often can be kept under control and the need for palliative sedation often disappears.

For other patients who exhibit refractory suffering, discussing palliative sedation as a possible therapy is a reassurance in itself. The patient realizes that help is available if the suffering is effectively no longer bearable for him or her. The certainty of a possible solution relaxes the patient and creates a feeling of control. The patient contributes to the decision of his or her further treatment. The nurse plays more of an informing, reflecting, communicating, and explaining role with the patient.

**Phase 2. When Refractory Symptoms Persists and Cannot be borne by the Patient.** In some rare circumstances, the patient's treatment no longer suffices and signs of continued refractory symptoms remain or the patient explicitly requests palliative sedation. When the nurse or another care provider is asked this question (sometimes the question is also put to a nonmedical team member because he or she is viewed as less intimidating), it first must be heard and thoroughly explored. Why does the patient request this now? What does this question mean and what needs are behind it (is this a real request for palliative sedation or is there another question behind it)? Are there perhaps other answers to this question? After the request is heard, it is passed on to the medical team and all aspects of it are discussed by the members of the multidisciplinary team, who gather weekly. If there is an urgent matter, an *ad hoc* interdisciplinary team can be called together. The most important element of this discussion is whether the patient is effectively exhibiting refractory symptoms and whether there are any other possible solutions to these symptoms. Only when the team (including every discipline) is satisfied that all other solutions have failed can they further consider the request for palliative sedation. Every decision that is made by the multidisciplinary team must be well reasoned and clearly communicated to the patient and his and her family and must be included in the patient's file.

There is always a nurse present during the discussions between the doctors and patients on palliative sedation so that the nurse can come back to it at any time and give further explanations when necessary. The family also receives necessary information from the doctor. Afterward, the nurse ensures that the explanation was clear and well understood by both the patient and the family and determines whether there were any misunderstandings or further questions.

Sometimes the family makes the request for palliative sedation without such request being formulated by the patient, sometimes even without the patient being aware of the request. This question also must be heard and reported to the multidisciplinary team. It is more likely an indication of the family's loss of spirit and a plea for extra support from the whole team. A request made uniquely by the family can never be a reason to initiate palliative sedation with a patient.

**Phase 3. Preparing the Patient and the Family.** The decision to initiate palliative sedation is always taken at a multidisciplinary level. It can never be an individual decision taken by one member of the team alone. The patient and the entire team must agree once all attempts to treat the refractory symptom have been made. The family must be closely involved or at least be fully informed of the decision process.

The doctor or doctors communicate the decision and the procedure to the patient and family in the presence of a nurse. It is also necessary to clearly communicate to the patient a decision not to resort to palliative sedation. The goal of the sedation and the consequences of such are explained clearly, and the team confirms whether the patient wishes to be sedated intermittently or continuously. The nurse also evaluates whether anything is unclear, or the patient or family has any questions. Clear communication

with the patient and family is essential. Terminology such as "putting to sleep" can cause confusion and be an unwitting reference to euthanasia. It is important to use clear and simple language, repeat certain elements regularly, and explain them thoroughly. It is also crucial to ask the patient to repeat in his or her own words what he or she has understood from the explanations.

There is a 24-hour period between the request for palliative sedation and its final execution. This period gives the patient and family the opportunity to consider fully the treatment, perhaps make certain arrangements, and part from loved ones. The nurse might, with the patient and the family, verify whether there are any financial, notarial, or other practical issues that need arranging. Does the patient wish to phone or see certain people, such as family, friends, doctors, psychologist, pastor, social worker, or notary? Is there a need for a parting moment or ritual? Does the patient wish to make certain arrangements concerning his or her funeral?

Once the decision is taken to proceed to palliative sedation, the patient often experiences a certain feeling of calmness. The end of the suffering is nearing; there is the prospect that it will all end.

**Phase 4. Initiating Palliative Sedation.** When palliative sedation is initiated, it must be well organized and well structured. The doctor must be accessible at all times. In consultation with the patient, the nurse inquires who of the family wishes to be present at the start of the sedation and possibly who wants to "keep watch." What can be expected from the initiation and the course of the palliative sedation is always discussed with the patient and the family beforehand. It is explained that the palliative sedation is initiated through a continuous subcutaneous (under the skin) drip with Midazolam. At the same time a single injection of Midazolam is given that, on average, induces sleep after about 10 minutes. We explain to the patient and family that this is an initial dose that might still have to be adjusted if the patient's sleep is not adequately deep (observable through handling or nursing) but that appropriate action will be taken immediately at every such episode so that the patient's wish is respected to the greatest extent possible. The nurse continues to be responsible for the patient's comfort and monitors all possible symptoms. Until the moment of death and beyond, the patient is cared for with respect and dignity. A doctor sees the patient daily or more frequently when necessary. The family is followed and supported during the whole process by the multidisciplinary team so that this last phase remains bearable for them, too. Not infrequently the family indicates that this phase is draining because their patience is often put to the test.

The initiation of the sedation itself is an emotional moment during which deep and genuine emotions often surface with the patient and the family. The nurse ensures that this time remains a moment of serenity in the memory of the surviving relatives. Allowing the patient and the family to determine the right time to start is sometimes emotionally difficult, and making the decision is often assumed by the team. Having the sedation initiated by two nurses may ensure that it is a shared experience. The nurse, at that moment, is aware that he or she is carrying out an important turning point, both for the patient and relatives. Nurses must support each other in this undertaking but also must feel supported by the decision the team has taken. When necessary, nurses must not hesitate to ask for the supporting presence of doctors; doctors must be able to provide this support by inducing the sleep themselves if necessary. This kind of delicate treatment requires the meticulousness that is typical of any medical treatment. A well-developed and implemented protocol provides emotional and ethical support, peace of mind for nurses, and prevents improvisation. The initiation of the palliative sedation is often experienced as liberating, not only by the patient but also by the nurse and the family; the patient's suffering is finally over. This sentiment is regularly communicated to the nurses by the family. As a result, the nurses and the team feel supported in the decision they have made and experience a feeling of contentment. This liberating effect and the resulting satisfaction not infrequently wash away any possible uncertainties or even negative feelings that the nurses may have. This way, there is often compensation for the emotional burden experienced by nurses directly before or during the initiation of the palliative sedation.

**Phase 5. Care for the Patient and Support for the Family During the Sedation.** During the phase in which the patient is in sedated sleep, meticulous medical observation is of the utmost importance to track and report any possible disrupting symptoms in time. The medical care can be adjusted proactively to the

anticipated needs of the patient. A bladder catheter can be placed, an antidecubitus mattress provided, and the repositioning schedule adjusted. The nurse checks whether the patient is lying quietly, comfortably, and safely. Mouth care is performed regularly and sometimes can be taught, partly or wholly, to the family keeping watch, which often makes them feel that their presence has more use. In doing so, the mouth is moistened to prevent dehydration and a suitable salve is applied to the lips. If the eyes are open, eye drops or salve prevents local discomfort.

During nursing and handling, the nurse carefully observes the patient's reactions. What is the facial expression? Does the patient moan? Does he or she attempt to resist? Do the eyes open? The level of consciousness must be keenly observed. Is the patient always asleep, does he or she react to external stimuli such as sound, touch, or repositioning? These reactions require immediate (remedial) attention so that the dose required for the optimal treatment of the refractory symptoms is found quickly.

During the course of palliative sedation, the nurse must involve and support the family but also ensure that the patient's room is peaceful and quiet. The family may, if they wish and feel it is appropriate, be involved in caring for the patient. The importance of being present here and now can be emphasized if the family considers it pointless. The nurse also should point out that it is equally important to leave the room, and this request should not be accompanied by feelings of guilt. A question that is often asked and should be approached with the necessary empathy and perspective is: "How much longer is this going to carry on?" This question can be an expression of the heavy burden the family is experiencing and must be received properly by the care providers. Only then can the family retain a positive feeling from the patient's final but important stage of life.

**Phase 6. Aftercare of Family and Nurse.** After the patient has died, there is an assessment conversation with the family members involved. All possible needs are addressed and a further follow-up by a psychologist can be organized. Homecare and the family physician are notified so that they can take over and further assist the surviving relatives. The role of the nurse is fairly limited in this phase. Within the team, the course of the sedation is also assessed. How was it for the patient and the family? How have the nurses experienced this period? What are the positive and less positive aspects and what lessons can be drawn? If necessary, a debriefing is organized and a protocol adjustment is discussed.

### Evaluation of the Prevalence of Palliative Sedation and the Effect of Using a Protocol

Since the palliative unit opened (1999) and the protocol was entered into use (2001), there has been a clear decrease in prevalence of palliative sedations on the palliative care unit. Whereas palliative sedation was carried out with approximately 7% of the patients in 1999, this percentage fell to 2.5% in 2005. This decrease can be attributed to an increased expertise concerning the symptom treatment of terminally ill palliative patients. The expertise has evolved to such an extent that most patients are not or are rarely confronted with physical refractory suffering. As a result, the demand for sedation against physical refractory suffering has declined sharply. Furthermore, there is clarity among all care providers on how requests for palliative sedation are dealt with in the palliative care unit. This way, the patient receives the same information from all disciplines, which has a positive influence on a patient's trust because everybody is speaking the same language. As a result, fewer patients are inclined to proactively request palliative sedation, even before the symptomatology becomes a heavy burden, and they wait until they are confronted with refractory suffering.

The development of this step-by-step plan and the precise definition of palliative sedation have made it clear when palliative sedation is and is not an issue. The narrow definition of palliative sedation that is used in this article is partly the cause of the low prevalence compared to some other reported statistics in the international literature.<sup>[21,22]</sup>

### Conclusion

It should be made clear that nurses play a pivotal role in the prevention of palliative sedation, the decision-making process, the execution and follow-up during the palliative sedation, and the aftercare of the family and the team. They are, as it were, the hub between the patient and the family on the one hand and several disciplines on the other because they are available to the patient 24 hours a day. In that capacity they are often the first to be confronted with the many problems and questions inherent. It is logical and necessary that the nurse receives professional training regarding palliative sedation and an opportunity to gain professional experience and that he or she feels supported by the entire team. Only when these conditions are met will the nurse be able to function optimally for the patient and family. In other words, the nurse is able to ensure, with dignity and respect, that the patient is provided the necessary comfort in the final stage of life.

Unfortunately, there are many medical and ethical misconceptions concerning the indications, procedure, and course of palliative sedation. These misconceptions explain why nurses experience this form of treatment as emotionally draining. It is essential that more attention be paid to being more explicit in the role that palliative sedation can play and removing any misconceptions concerning palliative sedation.

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#### **Disclaimer**

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