CHAPTER 5
Determining sedation depth during continuous palliative sedation: associated factors as viewed by Dutch nurses

Tijn Brinkkemper
Judith A.C. Rietjens
Siebe J. Swart
Miel Ribbe
Luc Deliens
Stephan A. Loer
Wouter W.A Zuurmond
Roberto S.G.M. Perez

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ABSTRACT

Background Palliative sedation, is considered to be a balanced approach for symptom relief by lowering the patients’ consciousness at the end of life. In that respect, consciousness should be lowered to such a degree that sufficient symptom relief is achieved. However, factors and perspectives underlying the choice for the intended sedation depth have received little attention. Therefore, the aim of this study is to investigate nurses views on important factors determining the depth of sedation during palliative sedation.

Methods A qualitative study was performed in which 35 nurses from different settings (hospital, home care, hospice and nursing homes) underwent a semi-structured interview focusing on their views of determining the depth of sedation. After the audio tapes were transcribed verbatim and coded for striking themes, a constant comparative method was used for analysis.

Results Nurses mentioned three distinct goals with respect to palliative sedation: deep sedation, superficial sedation and symptom control. The majority of nurses in the home care and hospital settings reported to aim at achieving deep sedation. Symptom relief as the primary goal of sedation was only mentioned in the hospice and hospital setting. In all settings the largest group of nurses felt that the importance of communication during sedation was dependent on patients’ wishes. Problems in reaching the goal of sedation were mentioned by home-care nurses in a substantial portion of cases (n=5). Most frequently, the reported problems were the long duration to achieve the intended level of sedation, or that the required level of sedation was not reached at all.

Conclusions Nurses consider a deeper form of sedation as the only true form of palliative sedation, although some mention symptom relief as the most important goal when considering the value of maintaining consciousness for a patient. They seem to differ in their opinions concerning the required depth of sedation that is sufficient to reach deep sedation.
5.1 Introduction

When a patient nearing the end of life is exposed to suffering that cannot be managed with conventional treatment, palliative sedation (PS) can be considered to relieve the patients’ suffering. This care path is aimed at the intentional lowering of consciousness of a patient in the last phase of life, without shortening or protracting life.\textsuperscript{1,2}

PS can be administered intermittently or continuously, and the depth of palliative sedation can range from mild to deep. In intermittent sedation, the sedation is applied to temporarily sedate the patient, who subsequently wakes up. In continuous sedation, the sedation will be maintained until death occurs and is often a deep form of sedation.\textsuperscript{1}

In 2001, 5.6\% of all patients in the Netherlands who died received continuous deep sedation therapy until death while life-protracting treatment was discontinued. In 2005 this percentage had risen to 7.1\%.\textsuperscript{3} This may suggest that continuous deep sedation is being applied more often.

The Royal Dutch Medical Association (RDMA) acknowledged the importance of a professionally established national guideline addressing palliative sedation and issued one in 2005.\textsuperscript{2} In 2009 a revision took place to further specify aspects such as indications for palliative sedation, fluid and drug management during sedation, the presence of a physician at the start of sedation and monitoring of the comfort of the patient during sedation. A proportional approach is advocated in the guidelines, describing the administration of sedatives as a process of titration in order to adjust the depth of sedation to the amount of symptom relief required. However, whether this is the case in current practice remains to be determined.

Preconception, viewpoints with regard to the manner in which PS should be applied and circumstances under which PS is performed will presumably provide a direction with regard to the chosen depth of sedation. In the Netherlands, in the majority of cases of continuous palliative sedation deep sedation is used rather than superficial sedation\textsuperscript{4} and in the majority of studies superficially sedated patients were excluded, most likely due to the difficulties of inclusion in research and development of prospective research for this group. This means that the issue of proportional sedation remains an underdeveloped area in current research.\textsuperscript{5} The idea that deep sedation is the norm in continuous form of palliative sedation rather than superficial can have a direct effect on sedation depth and the amount of sedation health care professionals consider adequate. This may also influence the results nurses look for when monitoring the depth of sedation during palliative sedation.

Another factor that can influence depth of sedation is the importance nurses adhere to preservation of communication with the patient during palliative sedation. Even though this has not been studied yet, it seems likely that nurses with a preference for preservation of communication tend to opt for a lighter degree of sedation in comparison with those nurses who attach less importance to preservation of communication.
Another important issue is the role of monitoring sedation depth in current practice. The guideline does not provide specific recommendations concerning the manner and frequency of evaluation of sedation depth and symptom control during palliative sedation. The RDMA guideline recommends that a physician stays present until the intended sedation depth is reached. However, recent studies showed that physicians often do not stay with the patient until the intended sedation depth is reached. This can influence sedation depth when medication has to be adjusted. Nurses are usually not allowed to change medication without an order by a physician, if a physician is not present this can cause delays in necessary adjustment of medication and can cause problems when communication between nurse and physician is not good. We expect more problems regarding this factor in the home setting than in the other settings because a physician is usually present 24-hours a day in hospital or hospice while this is not the case in the home setting.

In 85-95% of cases studied the aim of continuous sedation is reached according to physicians. So in 5-15% of these cases the aim was not reached. Several reasons (such as an insufficient depth or to profound sedation depth, or insufficient symptom control) why the intended aim is not always reached needs further exploring as they might provide indications with regard to factors influencing sedation depth.

The WHO states that palliative care (and thus palliative sedation) should be characterized by a multi-disciplinary approach. Nurses play a vital role in decision-making, practical execution and monitoring during palliative sedation. Although views and beliefs of nurses concerning palliative sedation have been the subject of several studies, nurses viewpoints with regard to sedation depth have not been de focus of scientific investigation.

Therefore, the aim of this study is to explore nurses views in what factors play a role in determining sedation depth and the monitoring thereof during the course of palliative sedation. Within this context we aim to answer what views nurses have on the goal of palliative sedation and we will explore the role they assign themselves with respect to monitoring of the sedation. Furthermore, we will explore the circumstances (such as the presence of a physician, medication policy and communication between caretakers) under which palliative sedation is performed that may pose a restraint on the manner in which required sedation depth is achieved.

5.2 Methods
5.2.1 Participants
This study is part of a larger project aimed at studying the practice of palliative sedation in the Netherlands after the introduction of a national guideline on palliative sedation. In 2008 a questionnaire about palliative sedation was completed by 606 physicians and 278 nurses, employed in a range of academic and non-academic hospitals, home-care, hospices, or nursing homes in the region of Amsterdam and Rotterdam. In the questionnaire it was asked whether the respondent would be willing to participate in an in-depth interview. Nurses responding positive on this request, were contacted and 35 of them (13 hospital nurses, 12 home-care nurses and 10 hospice/nursing home nurses, table 1) were interviewed.
Table 1. Characteristics of interviewed nurses

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<th>Home</th>
<th>Hospice</th>
<th>Hospital</th>
<th>Total</th>
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<tr>
<td>Age (years) *</td>
<td>45.5</td>
<td>45</td>
<td>40</td>
<td>45</td>
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<tr>
<td>Female gender, No. (%)</td>
<td>10 (83)</td>
<td>10 (100)</td>
<td>13 (100)</td>
<td>33 (94)</td>
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<tr>
<td>Working experience (years)*</td>
<td>19 (8.5-25)</td>
<td>22.5 (13.5-29)</td>
<td>17 (5-28)</td>
<td>18 (9-27)</td>
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* median (IQR)

5.2.2 Interview construction

A semi-structured interview was developed where questions were formulated based on themes explored in the questionnaire. The interview was divided into several themes (box 1) containing case-specific and general questions. There were several open-ended questions for each theme with probes that could help the interviewer formulate further questions on the topic, hereby exploration of these themes was obtained.

The major focus of the interview concerned the case which they had already described in the questionnaire. If they could not properly remember this case at the time of interviewing, the interview was about the last case in which they were involved in which palliative sedation was performed, or they answered the questions in general.

<table>
<thead>
<tr>
<th>Box 1. Themes explored in the interview.</th>
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<tr>
<td>Refractory symptom</td>
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<td>Decision-making</td>
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<td>Sedation depth</td>
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<td>RDMA guideline palliative sedation</td>
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5.2.3 Data collection

Data for this study was collected in a 7 month period (October 2008-April 2009) through face-to-face interviews that generally lasted 45 minutes. Six researchers/research assistants conducted the interviews after participating in a one-day interview training by an experienced professional interviewer. Nurses who had stated willingness to participate in an interview in the questionnaire were approached via telephone and the study aims and methods were explained to them. An interview was arranged and they were interviewed in a location of their choosing.

Due to the semi-structured nature of the interviews, all general topics were discussed but the depth of the exploration varied between interviews. Participants gave consent for audio-taping of their interview. The recordings were transcribed verbatim by a professional agency and anonymized by one of the researchers.
5.2.4 Analysis
After reading 5 interviews two general topics that seemed to produce sufficient data and related best to the research questions were identified and coding trees were made by the author and reviewed by the research team. The interviews were coded with the support of QRS NVivo software for qualitative analyses (version 8)\(^{11}\) and analyzed using the constant comparative method.

Phase 1: After coding 3 interviews separately by two researchers the coding trees where expanded and revised to better identify and categorise the views of the nurses.

Phase 2: Consensus was reached on the revisions and another 6 interviews were coded after which the interviews and coding were discussed by the research team to ensure no relevant data was lost during coding and that no ambiguity existed in the coding trees. The remaining 26 interviews were then coded. Every coded text fragment was summarised by SvZ to increase clarity of the data and provide a more compact overview of different opinions on the subjects analysed.

Phase 3: Results were discussed in the research team and consensus was reached with regards to interpretation of the analysed data. Quotes to illustrate the arguments of the nurses were selected and translated by a researcher and reviewed by the research team.

5.3 Results
5.3.1 Goal of continuous sedation until death
The goal of sedation is an important factor in monitoring during palliative sedation because it determines the desired result and influences the decision-making with regards to the need for adjustment of medication. During the interviews three distinct goals were mentioned by the nurses: deep sedation, superficial sedation and symptom control.

The majority of nurses in the home care and hospital settings reported to aim at achieve deep sedation. In general, nurses had a clear idea of what they believe should be the goal of deep sedation. Most nurses reported that a relaxed sleep-like state should be achieved for deep sedated patients. However, opinions with regard to the patients’ response to stimuli differed. In about half the cases nurses reported that some reaction was still acceptable as long as the patient did not display signs of real distress, as illustrated by the following quote:

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R706 (home setting) “In my opinion deep sedation is that people are calm,…do not move arms or legs but just lie calmly. It is acceptable if they give a sign…if you touch them or speak to them that they still react to that, but I just think physically calm…during caring, if you turn someone, that they still…react...that is to be expected with deep sedation.”
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The other half of the interviewed nurses were of the opinion that the sedation should be deep enough to prevent any reaction to stimuli. One nurse when asked what she perceived as deep sedation stated this as follows:
R869 (nursing home setting) “That someone cannot be awoken and does not respond to stimuli (…) Stimuli you administer during care giving so to speak, so the turning, the touching of someone, the talking, the buzzing in the room, dealings with the patient, that he does not respond to that.”

None of the nurses found it acceptable if a patient would awaken during deep sedation, but some mentioned that this could not always be prevented. Other nurses had a more negative inclination towards this event, thereby arguing that awakening during deep sedation should be considered as a shortcoming in patient care. In addition, these nurses reported to struggle with the distress this could cause for patients and relatives as the following quote exemplifies.

A857 (hospital setting) “Once you make the choice for palliative sedation, I think you should see to it that people do not wake up anymore. Waking up is horrible, firstly for the one who is heading to another place, if you come back to earth…and everybody is sitting around your bed wondering what on earths name we are doing, so waking up is absolutely…If I notice that they start to wake up I immediately call a doctor and tell him I think they are waking up, surely this cannot be the aim. So in that case the pumps will go up considerably.”

Aiming for a superficial sedation was mentioned only by a few respondents. A possible explanation for this was characterized by one nurse in home care, whereby she stated that the use of superficial sedation was not common practice in her area. In this case the patient received more sedation at night than during the day but communication with the patient always remained possible to some degree.

R745 (home setting) “That is…during the day it was more superficial than at night. This was the first time people chose between different depths of sleep. Yes, that was the first time. So that was unusual.”

Symptom relief as the primary goal of sedation was only mentioned in the hospice and hospital setting. For nurses working in a hospice this amounted to about half of the cases, for hospital nurses this was the primary goal in 15% of cases. According to some of these nurses, only superficial sedation was deemed necessary to counter refractory symptoms, but even in cases where deep sedation was considered the only solution, the sedation was regarded as a means to achieve this end as stated below.

A783 (hospital setting) “Well, I don’t know if the goal was to sedate him…well the goal was to get him pain-free and comfortable. And if that led to him being not communicative anymore was more a consequence than a goal.”
5.3.2 Maintaining consciousness

In all settings the largest group of nurses felt that the importance of communication during sedation was dependent on patients’ wishes. Most nurses did state that it is not always possible to combine adequate symptom relief with maintaining consciousness. In these cases nurses generally choose symptom control over the wish to maintain consciousness as the aim of sedation:

R838 (nursing home setting) “I think it is dependent on the situation of the patient. If it means that he is still conscious, but also conscious of the pain or shortness of breath or whatever there was, well, naturally that should not be. Then they obviously should be kept in a deeper state. But if you achieve to sedate in such a way that they are still able to communicate, or sustain contact with relatives in some way, and it does not further burden that resident, then of course that is really good as well.”

A third of the nurses stated that maintaining consciousness does not play a role in the choice of sedation depth. The majority of these nurses only regard deep sedation as palliative sedation. In addition, some believe that adequate symptom relief can never be reached if the patient remains conscious, as the nurse states below.

A783 (hospital setting)

R: Well, if you really want to use palliative sedation, so keeping someone asleep until death, you do this for different reasons, because you want to get someone pain-free or itch-free or free of breathlessness, or free of something… and it is a fact that these people have those complaints when they are conscious. Otherwise I think it is more a case of pain relief than palliative sedation.

I: Yes, so it is not so much that they do not want the consciousness, but it is more the case that if they are conscious that they suffer from their complaints.

R: Yes, otherwise I would not call it palliative sedation I think. Then, in my eyes, it is more a case of pain relief.

Least common was the view that maintaining consciousness should always play a major role in choice for sedation depth. These nurses did also mention that the refractory symptoms should be controlled but they were more convinced that adequate symptom relief can be reached with preservation of consciousness. Or as a nurse explained why she felt that it was important to preserve the consciousness of the patient as long as possible in palliative sedation:

A766 (hospital setting) “Well, because sedation in my personal opinion is to take away the symptoms and not to take away consciousness of the patient. And there can be sedation while still being approachable of course.”
5.3.3 Monitoring depth of sedation during the beginning stage of sedation

In the RDMA guideline it is mentioned that as a rule the physician should be present at the start of continuous sedation because it is regarded as a medical act with substantial consequence as consciousness of the patient is lowered.2

In the interviews nurses were asked if they thought a physician should be present until the intended sedation-depth was reached. In the home setting the majority of nurses found that a doctor should remain present until the intended sedation depth was reached. The reasons mentioned were that individual patients react differently to the medication given, that the doctor is medically responsible, and that it is required by the guideline. However, only one nurse mentioned that the physician stayed present until the patient was sufficiently sedated in the case discussed. This nurse also felt that the physician should stay present until the intended sedation depth is reached or as she explained:

R708 (home setting) “Well, because it differs so much…not considering what causes it to differ so much, but that it differs a lot how people react. Then I think to myself, the doctor thinks ‘I will leave now and it is ok’, but then sometimes it is not ok.”

The nurses that did not find it necessary for the physician to stay present did feel that the physician must leave good instructions and must be available by telephone.

R706 (home setting) “Uhm...no, I don’t think he should stay present because naturally it can take quite a long time and I don’t think it is realistic that a physician sits with a patient for two hours. I can imagine that that is not feasible. But I do find it desirable if a physician than says you can call me at this or that time, because these people often receive care three times a day, you can call me, or if there is no change at 8.00 PM you can do this or that, that there is a clear agreement, or that at least you can get in contact with him.”

None of the hospice nurses believes it is necessary for the physician to stay present providing that the physician can easily be reached and left adequate instructions on medication and monitoring for the nurses. A minority of hospital nurses does feel that the physician should stay present at the start of the sedation. In general both hospice and hospital nurses felt they have a nursing team that is experienced enough to manage the situation, therefore they felt that the physical presence of a physician is not necessary. In all the interviews where the question was discussed the physician did not stay present until the intended sedation was reached but there was always a physician on call.

In the hospital setting some of the nurses mentioned that they themselves are responsible for the practical execution of the sedation and monitoring of the patient as illustrated below;

A773 (hospital setting) “The physician just gives an assignment and we execute that assignment and then it is up to us to objectify or monitor how it goes beyond that, and yes than we will keep the physician updated. And sooner or later the physician will drop in again (...) The physician definitely reachable, day and night, for sure.
In all settings some nurses mentioned they started the sedation, after instruction from the physician, but without the physician being present. To further investigate the responsibility nurses feel for monitoring during this stage nurses were also asked if a nurse should stay present until the intended sedation is reached. On this topic the majority of nurses in the home setting said a nurse should stay present, in the other settings this opinion was shared by a minority of nurses. In all three settings the reason mentioned most often was that the nurse should stay to support the family of the patient. Other reasons where that the process should be closely monitored and that it is part of your professional conduct to stay present. Nurses did mention that even though they would prefer to stay present this is not always possible in the reality of the workplace, mainly because they have other patients under their care. The nurses that did not find it necessary to stay present, did find it important to check the patients’ status on a regular basis by going into the room and talking to family.

5.3.4 Monitoring depth of sedation at the further course of sedation

During the course of sedation the patient is usually visited by family, nurses, physicians and other healthcare professionals. What role execution and amount of monitoring plays in sedation depth and adjustment of medication during this period was explored. In the home setting most nurses said they and family members shared the monitoring task. This differs from the opinion in the other settings where nurses mostly felt monitoring as the responsibility of the nurses or nurses and physicians. In the home setting it was often mentioned that instructions were given to family members on who to contact if problems arose.

R712 (home setting) “They always get the phone numbers of the acute service of the homecare that is available 24 hours a day (...) The district nurse usually are mobilised several times a day during that dying phase. So usually at least three times a day (...) and we usually have a night nurse who can support family members during the night if something occurs. And in the meantime if something happens they can always call the emergency service.”

As stated in the quote above, in the home setting nurses are not present 24 hours a day. Usually they visit the patient 3 to 4 times a day, hence they need to depend on family members of the patient to do a large part of the monitoring. In the hospital and hospice nurses usually do not have fixed monitoring moments, most nurses try to go to the patient every 10 to 15 minutes for a short check up and monitoring while giving the patient daily care. The nurses reported they can monitor the patient in several ways. In all settings observation was mentioned as the primary tool to monitor a sedated patients’ comfort and symptom relief. Looking at facial expression and breathing were mentioned most, other observation points were muscle tension, groaning and skin colour.
Another important monitoring tool mentioned in the quote above is reaction to handling of the patient during daily care. Administering a pain stimulus is an unpopular technique, of the nurses that mentioned this most said they did not use pain stimulus. One nurse mentioned that the necessary handling of the patient could be viewed as a pain stimulus. More popular stimuli were verbal, stroking eyelashes and non-painful touch.

A few nurses mentioned a specific protocol used for monitoring of patients in palliative sedation. One hospital nurse and five hospice nurses said they used a protocol, whereas none of the home-care nurses reported to have used a protocol. The hospital nurse used a list composed for research purpose. The hospice nurses that used a protocol all worked in the same hospice, where they used a care pathway palliative sedation, as mentioned with following quote.

Transfer of patient information from shift to shift between nurses is done face-to-face and by writing a report. The nurses in every setting are satisfied that continuity of patient care was never compromised by this transfer method. In a great majority of cases the nurses found the communication with the physician regarding sedation depth was good, most felt their observations of the patient were taken seriously and their opinion was respected.

R838 (nursing home setting) “It is mostly by what you see, what you observe, what you observe during physical care, but also just by entering the room regularly, do you see the tranquillity there should be? Or do you see a certain agitation developing during physical care? Well, those are things you can inspect. Or you might take a hand or arm and will notice a grimace of pain on the face. Well, than those are signs that indicate, well that is still not what we had expected.”

R878 (nursing home setting)
I: Well, are there specific observations here, or a fixed procedure?
R: Yes, when we perform deep sedation we start the care pathway palliative sedation. (...) That means that you have several benchmarks that you must check every six hours, of which you must write down the result as well, and if you don’t reach that result you must take action and that must be reported.

R838 (nursing home setting) “I personally think our nursing home physician, at least that is my impression, handles it very well. And evaluates it every time and gives us feedback, like “do you see that there is still a reaction? “ or “do you see this or that?” Also from our side if we see things we give feedback to the physician. Really any time and several times a day or it is evaluated whether it was actually done in the right manner.”
A recurring topic was the possibility to contact the own physician of the patient if problems occurred, this availability was mentioned most often with regards to the reason nurses were satisfied or dissatisfied with the communication with physicians. A satisfied nurse describes this as:

R990 (hospital setting) “And what is always very pleasant here, is that the pulmonologist who has arranged it was also available in the... I think that this took place during the weekend, it was started on Friday evening, or Friday afternoon, and that pulmonologist was not on duty but we could call him if something was wrong, so that was very pleasant indeed, yes.”

Another nurses gave an example of a bottleneck in the communication with the physician:

R878 (nursing home setting) “Well, unreachability. When it becomes difficult they are busy with a consult and at the moment you ask, when you need to start, if they could attend, than they have already spent too much time at it. And, well, I consider that a bottleneck.”

Problems in transfer of information were mainly mentioned when physicians did not know the patient involved. This was most apparent in the home setting, some nurses found the transfer of information by general practitioners insufficient which sometimes led to confusion on administration of medication and uncertainty on how to handle problems.

5.3.5 Reaching the goal of sedation
Problems in reaching the goal of sedation were mentioned by home-care nurses in a substantial portion of cases (n=5). Most frequently, the reported problems were the long duration to achieve the intended level of sedation, or that the required level of sedation was not reached at all. The reasons, in the opinion of the nurses, were differences in patient characteristics and inadequate use of medication by the physician. One nurses describes this bottleneck with medication as following:

R 708 (home setting) “I personally think that is where the big differences are, because why does one person keep waking up or is still in pain and still responsive... than you are not sedating, than you are trying something else or you stayed too low. Or that you have to increase the administration speed three times, while the doctor is gone for a long time, it took us three days before that lady was really sedated. While it was applied as sedation, not as a pain pump.”

If problems occurred, a common theme was that the physician did not give adequate written instructions to nurses or weekend physicians causing confusion and unnecessary delays in adjustment of medication. One nurses told about an experience from an earlier case where this occurred:
Some respondents indicated that problems can occur when guidelines are not followed,

R 706 (home setting) “…It is started (sedation), but what is that based on? You start with a certain dose and if that doesn’t work you change to that dose, but sometimes I have the feeling they just start at random and if it doesn’t work than we add a bit of this, and a bit of that (…) But it isn’t really, well there are good guidelines on how to build up medication but that is not often used. Not in that situation.”

while others mentioned problems due to rigid adherence to the guideline.

R878 (hospice setting) “ Well sometimes there is a long struggle with Midazolam before in a manner of speaking you go to the next step. And that next step is indeed very rigorous if you take that according to the guideline, because sometimes combining one with the other is more effective.”

In all cases in hospice and hospital the aim of sedation was reached. These nurses did mention that in some cases it took longer than they would wish to reach the goal of sedation but they all accepted this as a consequence of difference in reaction to medication by individual patients.

5.4 Discussion

This qualitative study shows that nurses have mixed opinions on what the goal of palliative sedation should be. Even though most nurses claim deep sedation is usually the most important goal, several nurses mention symptom relief as the most important goal when considering the value of maintaining consciousness for a patient. A possible reason for this ambiguity could be that in most cases, the physician made the decision on the depth of sedation, while the nurses feel responsible for the comfort of the patient during the sedation process.

Another important finding is that a substantial group of nurses consider deep sedation as the only true form of palliative sedation. The nurses that do consider superficial sedation as a form of palliative sedation often mentioned that few patients prefer this type of sedation. These ideas could influence the content of information given to patients or family when discussing options for relief. This is important considering the fact that earlier studies showed that the wish for palliative sedation is often mentioned first to nurses by patients or relatives.9,12
Nurses differ in their ideas on the required depth of sedation that is sufficient to reach deep sedation. This lack in uniformity could lead to different amounts of sedation given to patients. Many nurses find it unacceptable for a patient to respond to stimuli, or wake up during palliative sedation. This feeling can influence the depth of sedation because these nurses could be more inclined to propose extra sedation to prevent these events from occurring.

Problems with reaching the intended depth of sedation were mentioned most by nurses in the home setting. Where nurses in the other settings mostly mentioned patient characteristics as the reason, many home care nurses felt problems in communication and availability of physicians played a role when the intended depth of sedation was not reached. This is in line with a previous Dutch study that pointed out shortcomings in communication based on experiences from nurses providing medical technical care.

Another issue some nurses mentioned is reluctance by some physicians to use stronger medications deemed necessary by the nurse. The difference in perceived problems between the settings can, in part, be explained by differences in availability of information. In hospital and hospice settings patient information is kept in a file accessible at the site by every physician responsible for patient care at any time. In the home setting however, problems during the out-of-hours period can occur when the GP does not transfer information on patients receiving palliative care to the GP co-operative. In a recent study, for only a minority of patients receiving palliative care at home, a transfer of information including an anticipating management plan was present. This could also play a role in the different opinions between the settings regarding presence of a physician until intended sedation depth is reached at the start of palliative sedation. When a nurse does not feel confident that he or she can consult with a GP who knows the management plan for that patient at any time, which was mentioned as a problem in another study, it seems more likely that he or she ideally wants the physician to stay present until the intended sedation depth is reached. Another difference between the settings is that in home care the nurse usually works alone, if problems occur this nurse does not have the possibility to quickly ask another nurse for help. In the hospital and hospice settings, nurses overall felt confident in the strength of the nursing team to deal with problems occurring during palliative sedation, which can in part explain why they in general do not feel it is necessary for a physician to be present at the start of sedation. If the physician is not present and there is no adequate medication plan for nurses to follow, this can be a cause of problems with inadequate sedation depth and can cause delays in necessary adjustment of medication for a patient.

During the course of palliative sedation monitoring of sedation depth in the home setting by a professional occurred markedly less frequent than in the other settings. It does not become clear in this study, whether or not this lower frequency in monitoring will result in more problems concerning accidental awakening of the patient. It is also conceivable that patients in home care are sedated more deeply than in the other settings because during large parts of the day there is no professional present to make quick adjustments in sedation medication if the patient regains consciousness, this has not been studied in detail however.
Only a minority of nurses in this study used a protocol for sedation monitoring and methods used to monitor sedation depth varied considerably between nurses. These two factors can result in both under- and over sedation of patients. Researchers from a recent systematic literature review\(^6\) advised to start measurements of symptoms prior to the start of sedation and at regular intervals during the administration of sedation in order to evaluate change in symptom burden and monitor whether symptom control remains adequate. Unfortunately, no concrete recommendations were made concerning content or frequency of monitoring.

Our results seem to support this systematic approach to monitoring during sedation as it would be welcome to ensure monitoring at regular intervals and in a more unified way. This could also give nurses a tool to use that relies less on intuition and experience and more on specific tests a nurse can apply to monitor sedation depth.

This qualitative study finds its strength in the possibility for more in depth consideration of arguments regarding the factors that play a role in sedation depth during palliative sedation. Inclusion of a sufficient amount of respondents from all three settings in which palliative sedation is performed contributes to a reliable practice based description of nurses views on this topic. Instead of restricting ourselves to the most performed continues deep sedation we studied all forms of continues sedation until death to ensure a broad perspective on the subject. Moreover, discussing a concrete case as well as general opinion facilitates both actual practices and more general reflections. However, some limitations with regard to these results should be taken into account. Firstly, for the interview nurses selected themselves which could imply a selection bias towards nurses with strong feelings about palliative sedation or a greater than average interest in the subject. Secondly, cases completed in the questionnaire took place long ago, sometimes too long ago to remember properly, making the interview concerning a more recent case, or the questions were answered in general. Therefore, a recall bias may have occurred. Finally, conclusions of this study relate to the nurses vision about the subjects. As this was the aim of the study, only interviews with nurses were used, and not interviews with physicians, patients or relatives. Therefore some limitations with interpreting these results should be taken into account.

In conclusion this study showed that nurses consider a deeper form of sedation as the only true form of palliative sedation. However they seem to differ in their opinions concerning the required depth of sedation that is sufficient to reach deep sedation, making it warranted for future research to focus on creating uniform nurses guidelines to tackle this problem. Furthermore nurses most likely are the first caretakers to notice any changes in refractory symptoms and needs of the patients. Therefore it would be interesting to have more data on cases described by the nurses in order to compare doses of medication given to patients in the different settings and timing of adjustments of medication and to get a more complete picture of the differences between the settings. Another suggestion for further study would be to compare views of nurses and physicians concerning the depth of sedation in relation with the need for adjustment of medication.
References


