Palliative sedation and moral distress: A qualitative study of nurses

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ABSTRACT

Background. Clinical nursing practice may involve moral distress, which has been reported to occur frequently when nurses care for dying patients. Palliative sedation is a practice that is used to alleviate unbearable and refractory suffering in the last phase of life and has been linked to distress in nurses.

Aim. The aim of this study was to explore nurses' reports on the practice of palliative sedation focusing on their experiences with pressure, dilemmas and morally distressing situations.

Methods. In-depth interviews with 36 nurses working in hospital, nursing home or primary care.

Results. Several nurses described situations in which they felt that administration of palliative sedation was in the patient's best interest, but where they were constrained from taking action. Nurses also reported on situations where they experienced pressure to be actively involved in the provision of palliative sedation, while they felt this was not in the patient's best interest. The latter situation related to (1) starting palliative sedation when the nurse felt not all options to relieve suffering had been explored yet; (2) family requesting an increase of the sedation level where the nurse felt that this may involve unjustified hastening of death; (3) a decision by the physician to start palliative sedation where the patient had previously expressed an explicit wish for euthanasia.

Conclusions. Nurses experienced moral distress in situations where they were not able to act in what they believed is the patient's best interest. Situations involving moral distress require nurses to be well informed and able to adequately communicate with suffering patients, distressed family and physicians.

INTRODUCTION

When being confronted with challenges in clinical practice, nurses and other healthcare professionals can experience moral distress[1]. Moral distress is defined as "the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action; yet, as a result of real or perceived constraints, participates, either by act or omission, in a manner he or she perceives to be morally wrong"[2 3]. Morally distressed nurses experience burnout and have a high tendency to leaving the profession[3-6]. A growing number of studies have reported on moral distress among nurses, but until now these are mainly restricted to intensive and acute care[7-9].

Moral distress has been reported to occur frequently when nurses care for dying patients. In a survey study of 47 critical care nurses, 79% reported that they had experienced moral distress[1]. Nurses play an important role in care at the end of life, as they are often the frontline caregivers for patients nearing the end of life[10]. Care at the end of life is often complex, nurses working in this field have to deal on a daily basis with difficult symptoms of terminal illnesses, distressed patients and families, suffering and death[11]. Moral distress among nurses working in end-of-life care seems to be inextricably bonded to the distress that is experienced by patients[1 12 13]. A study focusing on end-of-life care among 222 geriatric nurses showed that 8% of the nurses actually left their job and 12% considered quitting their job because of discomfort with the way patient care was handled[14].

A common practice at the end of life, which has been described as something nurses struggle with, is palliative sedation[15]. Patients who are nearing death sometimes experience symptoms that cannot be relieved with conventional therapeutic interventions, such as intractable pain, dyspnoea, and delirium[16 17]. Palliative sedation is a medical intervention used to alleviate unbearable and refractory suffering in the last phase of life by the deliberate lowering of a patient's level of consciousness to induce decreased awareness of symptoms[18-20]. Palliative sedation includes several subtypes: intermittent and continuous sedation, as well as deep and superficial sedation. Continuous deep sedation until death is the most far-reaching subtype[20]. In the Netherlands, the Royal Dutch Medical Association has issued a guideline on palliative sedation that states that continuous deep sedation until death can only be considered for patients who have a life expectancy of one to two weeks at most[20]. Palliative sedation is frequently used in end-of-life care, most often in hospitals and for patients with cancer[21-23]. Studies have indicated that palliative sedation was used in 12%-18% of dying patients in the UK, Belgium (Flanders), and the Netherlands[24-26].

Palliative sedation is a practice of last resort and is therefore often used in complicated cases, under stressful conditions and with time constraints[19 27 28 29]. In addition, a number of studies reported on experiences of physicians with pressure related to palliative sedation. Blanker performed a study among general practitioners (GP's) and found that one in six GPs had experienced pressure during a decision making process on the use of palliative sedation, from patients, relatives or other persons[30]. Also, pressure to increase the level of sedation as a means to hasten death has been described in other studies focusing on physicians[31]. Palliative sedation has been linked to (emotional) burden for nurses[5 32]. A study among 2607 nurses in Japan showed that 12% of nurses experienced emotional burden related to palliative sedation[5]. A qualitative study among 26 home care nurses and 25 (GPs) focusing on their collaboration, roles, and responsibilities during the process of palliative sedation showed that some nurses found performing sedation "burdensome"[32].

The aim of this study was to explore nurses' reports on the practice of palliative sedation focusing on their experiences of pressure, dilemmas and morally distressing situations by performing a secondary data analysis of an interview study among nurses.

METHOD

Participants

In this study we analysed data from qualitative interviews with nurses that were collected as part of a larger project about the practice of palliative sedation in the Netherlands after the introduction of a national guideline on palliative sedation[33]. The project focused on physicians' and nurses' experiences with continuous palliative sedation. The first part of the project was a questionnaire study; 185 nurses working in general practice, nursing homes, hospices and hospitals completed a questionnaire about their most recent case of continuous palliative sedation. Details of the study have been described elsewhere[33-35]. In the questionnaire, respondents were asked if they were willing to participate in an additional qualitative interview. In total, 36 nurses indicated willingness and were subsequently interviewed.

Procedures

A semi structured interview scheme was developed with open-ended questions that were based on themes from the questionnaire: refractory symptoms, decision-making and communication, the practice of palliative sedation, and experiences with the palliative sedation guideline from the Royal Dutch Medical Association[20]. Questions partly pertained to the case that respondents had described in the questionnaire, but also concerned other experiences with the practice of palliative sedation. Nurses who had stated willingness to participate in an interview were approached via telephone and the study aims and methods were explained to them. An interview was arranged and they were interviewed at a location of their choice. Participants consented to the audiotaping of their interview. The interviews were conducted during a 7-month period (October 2008 - April 2009) by four interviewers with a medical or health science background. Consistency among interviewers was ensured through the use of the interview scheme, a one-day training, and monthly meetings to discuss findings and interim analyses. The interviews lasted between 30 and 65 minutes. Information about the nurses' age, gender and work setting was obtained from the questionnaire. This study was exempt from review by a research ethics committee under Dutch law.

Analysis

The recordings were transcribed verbatim by a professional agency and anonymized. Analyses were performed with the constant comparative method[36]. Themes and subthemes were independently derived from a subset of five interviews by MEL and SJS. These (sub)themes were compared and organized in an initial coding tree which was discussed in depth by MEL, SJS and AvdH on several occasions after which the coding tree was adjusted. The final version was used for coding all interviews. Another five interviews were coded by MEL and SJS independently and differences in coding were discussed until consensus was reached. The final version was used for coding all interviews. The remaining interviews were coded by MEL, interview fragments that raised questions while coding were discussed in depth between MEL and SJS. The codes used in the interviews were connected to the main theme ´pressure´, with several subthemes. The coded fragments were discussed in depth by MEL, SJS and AvdH. Quotes were selected by MEL and AvdH to illustrate the arguments.

RESULTS

Table 1 shows the characteristics of the 36 interviewed nurses.

In the interviews, several nurses described that interacting with physicians and family members is an important part of their work in palliative care. Whether or not a patient is experiencing unbearable suffering can be judged differently by the family, the physician or the nurse. Nurses described situations in which they felt that providing palliative sedation was in the patient's best interest, but experienced (real or perceived) constraints that prevented them from taking action. They also described situations in which they experienced pressure to be involved in the administration of palliative sedation, but felt that their action was not in the patient's best interest.

Table 1 Nurses' characteristics (n=36)

Age	
< 40 yrs	14
40-49 yrs	13
50-59 yrs	9
>60 yrs	0
Gender	
Female	34
Male	2
Worksetting	
General practice/ home care	11
Nursing home/ Hospice	10
Hospital	15

Experiencing constraints preventing action.

Several nurses described situations in which they felt that starting palliative sedation was necessary to alleviate the patient's suffering, whereas the physician thought that it was too early to start. These situations related to differences in the assessment of the patient's situation leading to a discrepancy in opinion about the severity of the patient's suffering. The hierarchical difference between physicians and nurses in situations where such disagreement is present was also mentioned as distressing.

> *"A young person still, and it was clear that he couldn't go on like that any longer. It had already been discussed that when the situation would become unbearable sedation could be started. And the physician just refused. He thought it was not yet necessary... Clearly a case of "you're just a nurse, I'm the physician and I decide what 's going to happen". Not listening to your observations and your experience. Well that's it, you have to accept that. And that's really awful." R931 hospital*

Nurses are often the caregivers that spend the most time with the patient and his family, usually more than physicians. Explaining or justifying on behalf of the physician to the patient why it was not yet time to start palliative sedation when nurses themselves thought it was, was experienced as very troublesome.

> *"Talking, talking, talking, and of course you try to explain [to the patient and his relatives] why the physician isn't willing to start [the sedation]. Of course the need should be there, but I had the feeling that the physician's reluctance was not right; that it was perfectly okay to start with [the sedation]." R822 nursing home*

Differences in opinions between nurses and physicians seemed to occur relatively often during out of office hours or in the absence of a pro-active care plan.

> *"It happened during the night shift (....) it was obvious that the situation couldn't go on like that, and it had been agreed upon already that when the situation would not be under control anymore that sedation could be initiated. And the physician just refused. He did not find it necessary." R931 hospital*

Experiencing pressure to act

Feeling pressured to act but not being convinced that this act is in the best interest of the patient was a frequently reported theme in the interviews. Feeling pressure to act was described as occurring at two points in time, i.e. before the start of sedation and during the sedation process, and coming from different sources, i.e. the physician and the family.

Pressure before the start of palliative sedation

Several nurses reported on situations where they felt that the family was requesting action, i.e. the initiation of palliative sedation, but where the nurse did not feel that it was indicated or appropriate yet. Watching a close relative nearing the end of life can be a heavy burden for family members, sometimes an even greater burden than it seems to be for the patient himself.

> *“Sometimes the relatives say: “we can’t bear the sight [of our suffering relative] anymore” or “when will it end?” While you don’t observe this feeling in the patient. Sometimes you do, but not always. Sometimes I get the feeling that the relatives suffer most, more than the patient.” R869 nursing home*

Nurses indicated that intensive and careful communication with the family is needed to explain why their request may come too early. The Dutch guideline states that a life expectancy of one to two weeks at most is a necessary condition for starting palliative sedation. Nurses however seem to have a narrower view: they seem to consider the start of the dying phase, that is the moment at which it is recognized that the patient will very likely die within hours or days, as the only appropriate moment to start palliative sedation.

> *“(...) What we always try to do, if possible, together with the GP is to keep the situation as stable as possible until we can establish someone has entered the dying phase. (...) I have rarely seen... I can’t remember I’ve ever seen that a GP failed to resist the pressure [of family to start sedation]. But still a lot of communication with the relatives is needed. “R712 home care*

A decision by the physician to start palliative sedation can also be experienced by nurses as coming too early. Sometimes nurses felt that not all options to relieve the patient’s suffering had been discussed or explored yet and that therefore not all requirements to start palliative sedation had been met.

> *“Sometimes you doubt if the physician has done enough to address the symptoms. And if he has adequately judged whether or not the patient is in the dying phase” A863 home care*

Dealing with this situation required a lot of deliberation and the nurse sometimes felt a need to provide the physician with alternative options to relieve the patient’s symptoms. To be able to engage fully in these discussions, nurses require adequate knowledge about clinical and ethical aspects of palliative sedation. When the physician was receptive to the arguments of the nurse the decision to start palliative sedation was sometimes postponed, but this was not always the case.

> *“When he [the physician] wants to start continuous sedation, while you yourself aren’t convinced yet that that is necessary or useful at that moment, this sometimes led to the whole thing not taking place. (.....) [If you want to have an impact as a nurse,] you have to have alternatives available. When I don’t have an alternative, I can’t start the conversation.” R878 nursing home*

Several nurses stressed the difference between palliative sedation and euthanasia. Some of them described a situation in which a patient had expressed an explicit wish for euthanasia (i.e. active ending of life, a legal practice in the Netherlands as long as it is performed by a physician who acts in accordance with the legal criteria of due care), but where the physician decided to provide palliative sedation, either because the euthanasia procedure was judged as too time consuming or because of a conscientious objection of the physician to perform euthanasia. Nurses indicated that they felt distressed by the disregard of the patient's wish in such a situation.

> *"We've had a case of a man who had been ill for a long time, he had expressed a clear wish for euthanasia but his GP didn't want to cooperate. In the end these people were somewhat pressured into the direction of palliative sedation. Eventually he was sedated, but it took several days, and he even regained consciousness and was distressed. Afterwards, when I went there for a house call, his wife told me "this wasn't how he had wanted it". I feel bad about that." R706 home care*

Pressure during the sedation process

Nurses described experiencing distress when family members, after the goodbyes had been said and palliative sedation had been started, explicit or implicitly requested for expediting the patient's dying trajectory because it was taking longer than they had expected.

> *"Well sometimes the relatives are tired of waiting and they think: how long will this go on? Do we really have to sit here for another three days? We don't want that. That's when you sometimes feel pressured." A773 hospital*
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> *About continuous sedation, I think about the phase when a patient is sedated and relatives fairly soon start to ask if the pump can be turned up some more, they've had enough of it, they're all there now, so they think if the pump is turned up, their relative will die sooner, and that would suit them." A863 home care*

Nurses and family members may disagree upon whether a patient is comfortable while being sedated. Family members were reported to sometimes having a preference for a deep level of sedation and requesting an increase of the sedative drug dosage to suppress moves or noises from the patient, such as death rattle, while nurses indicated that these phenomena are part of the normal dying process.

> *"With every little movement or sound a patient makes, they want the pump to be turned up. And just after it has been turned up a little, they want it to be turned up some more. You can try to explain that the effect should be awaited, but then they may manage to pressure you in a way that makes you feel very ill at ease in the end. That's when you think, "I'm now doing something I don't feel comfortable with" R990 hospital*

DISCUSSION

Nurses described two distinct situations involving distress while working together with physicians in caring for patients in the last phase of life for whom palliative sedation is considered: (1) the nurse felt that palliative sedation was needed to alleviate the suffering of a patient, whereas the physician thought that it was not (yet) indicated; 2) the physician decided to start palliative sedation whereas the nurse viewed this as not indicated because not all requirements to start palliative sedation had been met (yet). Nurses' feelings of distress in both these situations can be characterized as feelings of powerlessness. The feeling of powerlessness as a cause of moral distress was also identified by Oberle et al[13] who studied acute care nurses' and doctors' perceptions of ethical dilemmas in end of life care decisions. In that study, moral distress as experienced by nurses was related to their 'lower' hierarchical position: not being listened to by doctors; being expected to remain silent even when witnessing choices they consider wrong; being unable to have an impact on decisions despite their professional assessment and detailed understanding of the patient's condition. In our interviews nurses described difficult situations when having to deal with physicians who are on duty and do not know the patient, physicians who are inexperienced in end-of-life care or in providing palliative sedation and situations in which a pro-active care plan was absent. Preferably the decision to start palliative sedation does not come as a 'surprise' to the involved healthcare professionals; instead, it should be the anticipated potential outcome of a process of efforts to control symptoms near the end of life.

It is obvious that nurses and physicians can have different interpretations of what the appropriate indication and time to start palliative sedation are. Nurses experienced their inability to alleviate the patient's suffering in situations where the physician disagrees with providing palliative sedation as evoking stress. Such stress can in turn result in suffering for themselves[13]. On the other hand, nurses judged recognition that the dying phase has started as an important prerequisite to start palliative sedation. Recognizing the start of the dying phase most often occurs hours or days before death. The Dutch guideline on palliative sedation states that continuous sedation can only be administered when a patient's 'life expectancy is less than one to two weeks[20]. This prerequisite is included to make clear that continuous sedation can only be used when there is no or a very limited possibility that it hastens death. There seems to be a discrepancy between the criterion on life expectancy in the guideline and nurses' views, where nurses appear to prefer a more limited life expectancy than the guideline. This may be related to nurses' concerns that sedation might hasten death, a concern previous reported by Anquinet et al. in a qualitative study of home care nurses and their experiences with palliative sedation[32]. In addition, adequately predicting patients' remaining life expectancy remains difficult, although such predictions have been shown to become more accurate when patients are closer to death[37-39].

Nurses may also feel uncomfortable when the course of sedation is not in line with expectations or preferences of patients. Especially waking up during continuous sedation can cause distress[40]. A protracted and seemingly disquiet dying process can also be very burdening for family. This may lead to implicit or explicit requests to increase the level of the sedation, either or not with the purpose of hastening the patient's death. A decision of the physician to grant such requests may evoke the feeling that the patient receives unnecessary or arguable treatment. Providing medical treatment and care that is perceived as not serving the patient's best interest has been described before as evoking moral distress[41-44].

Feelings of powerlessness and the experience of patients receiving unnecessary treatment have also been described as causes of moral distress by Hamric et al[42]. They distinguished different root causes of moral distress, including internal worker factors, such as perceived powerlessness, and factors related to the immediate clinical situation, such as the experience of patients receiving unnecessary treatment. Nurses seem to feel that they are very capable of estimating dying patients' needs, because of their experience and nearness to the patient, without having the authority to make decisions on care and treatment. In our study, we did not find other causes of moral distress as suggested by Hamric et al., such as lacking situational knowledge (an internal worker factor); a lack of truth-telling; a lack of patient consent to be treated (factors related to the immediate clinical situation); or external factors, such as inadequate staffing and lack of administrative support.

According to Epstein and Hamric[45] addressing moral distress is not a matter of analysing single cases. Instead, multidisciplinary interventions aimed at the organization of care are needed. Based on our interviews we feel that several actions may be needed to support nurses in dealing with stressful situations that may result from the use of palliative sedation. These actions may be focused on nurses as individuals or on a group-level. The first action would be education about the guideline and decision making process that precedes palliative sedation. When nurses are well educated they will better understand the procedure and considerations of the physician and more adequately discuss their concerns or feelings with physicians. A second action would be to focus on the communication between nurses and physicians. Epstein suggests to design and use forums for interdisciplinary problem solving such as interdisciplinary rounds[45]. When both physicians and nurses are included in discussions about the use of palliative sedation this could lead to a better understanding of each other's roles, thoughts and reasoning. A third action is related to the content of the Dutch guideline for palliative sedation. This guideline[20] describes the different steps in the decision making process and acknowledges dilemma's that can arise when palliative sedation is prescribed. However the guideline is not very specific about the roles and tasks of the physician and the nurse and could benefit from more explicit guidance in that area. A fourth action would be to investigate to what extent physicians experience moral distress related to the provision of palliative sedation. Insights from physicians could further substantiate strategies to support nurses in dealing with stressful situations related to palliative sedation.

Using interviews from a rather large group of nurses increased the validity of this qualitative interview study. However, our study also has some limitations. Due to the fact that the original data collection was not aimed at achieving saturation of information on the topics studied here, we cannot be sure that we have not missed any relevant information. Further, due to the retrospective design of the study we cannot preclude recall bias, which was however limited by asking about specific and recent cases.

To conclude, the nurses in this study described various situations in which they experienced moral distress when being involved in the practice of palliative sedation. Their main concern was that they felt that they were not able to act in the patient's best interest. To deal with these situations, nurses need to be able to adequately communicate with suffering patients, distressed family members and physicians and to have adequate knowledge about clinical and ethical aspects of palliative sedation. Empowering nurses in up taking their professional role seems to serve the best interest of both patients and nurses themselves.

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