

Nurses' Attitudes and Experiences Surrounding Palliative Sedation: Components for Developing Policy for Nursing Professionals

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Abstract

Background: Nurses play an integral role in providing care for patients with end of life (EOL) symptoms refractory to conventional treatments and that may necessitate palliative sedation (PS). A paucity of research on nurses' attitudes, knowledge, and experience with PS exists, despite nurses being instrumental in evaluating its appropriateness and carrying out the care plan.

Objective: The objective of the study was to elicit nurses' perspectives and conceptualizations of knowledge and skills needed to administer PS in order to inform development of a hospital policy that addresses identified concerns.

Methods: Four focus groups were conducted with nurses likely to have had exposure to PS (oncology, intensive care, and hospice) at an academic medical center. Focus groups were audiotaped, transcribed verbatim, and coded for salient themes. Grounded theory principles were used for the analysis.

Results: Among the four focus groups ($n=31$), 87% were female, 58% between the ages of 36 and 55, and more than 40% reported 10-plus years of providing patient care. Five domains emerged as important in developing a PS policy: 1) ability to define PS; 2) criterion for using PS; 3) skill set for administering PS; 4) policy and procedural guidelines; and 5) education on PS and EOL care.

Conclusions: Nurses identified knowledge, skills, and guidelines as key considerations for implementing PS. Comprehensive policies along with adequate training are needed to expand the availability of PS in acute care hospitals and hospice programs.

Introduction

THE MAJORITY OF PHYSICAL SYMPTOMS reported in advanced illness, for example, pain and shortness of breath, can be adequately managed with traditional therapies such as opioids.^{1,2} Control of physical symptoms is an important goal of health care providers because patients report this as one of the most important aspects of care at the end of life (EOL).^{1,2} However, despite receiving state-of-the-art symptom management, a portion of terminally ill patients continue to experience burdensome symptoms.³⁻⁷ In such cases, palliative sedation (PS)—the use of sedatives to induce unconsciousness at the EOL—has been introduced as a medical therapy to achieve better symptom control and relieve suffering.⁵

Even though PS is considered an acceptable and effective treatment for dying patients with refractory symptoms, it is not universally available where most patients in the United

States die, that is, hospitals.⁷⁻⁹ One recognized barrier to the use of PS is a lack of a standard policy that can be adopted across care settings and that incorporates a standardized approach to ensure appropriate use and optimal patient care and safety. At the same time, a lack of consensus on terminology of various aspects exists.^{5,6} For example, what symptoms are indicative for using PS? What determines whether or not a symptom is refractory to traditional therapies? When are we providing aggressive symptom control versus instituting PS? Another concern is that PS leads to a "slippery slope" wherein sedation could be used in cases where not indicated, thus becoming more consistent with euthanasia.^{4,8-12}

While the current process of PS among U.S. hospitals remains uncertain, one key component to establishing acceptance and availability of PS is to understand the opinions of health care providers who care for patients and families at EOL.^{13,14} Nurses serve as key stakeholders in the

decision-making process including clarifying the indication for PS, helping in estimating patient prognosis, quantifying patient and family distress, selecting pharmacologic therapies and route of administration, and assessing response to the treatment plans.¹⁵ These contributions are warranted as nurses are responsible for executing and monitoring the plan of care, interacting and communicating with patients and families, and maintaining a trusting relationship between the patient and health care team.

It is critical to better understand nurses' perspectives because they often report feelings of distress and/or emotional, spiritual, and ethical burdens when using PS.¹⁴⁻²⁰ Also, despite the growth of literature surrounding EOL care, a paucity of research on nurses' attitudes toward PS exists.^{10,11,14-20} In fact, we could only identify seven publications that addressed this question—two from North America, one from Japan, and four from Europe. The purpose of the current study was to elicit nurses' perspectives and conceptualizations of knowledge and skills needed to administer PS in order to inform developing a hospital policy that addresses identified concerns.

Methods

Study overview

To elicit nurses' perspectives on PS, we conducted four focus groups (8 to 10 participants per group) with nurses from acute care (medical and surgical intensive care units [ICUs] and oncology) and home hospice settings. We used a purposeful sample to allow for valuable feedback from nurses who were more likely to have exposure to, and/or experience with, PS.

The University of Chicago Institutional Review Board approved the study. Focus groups were conducted between August and October 2008. A focus group guide was developed to include questions on what constitutes PS, identifying patients who meet criteria for administering PS, recent experiences with PS, ethical concerns about implementing PS, and suggestions for improving care while using PS. The guide was created based on a literature review and expert opinions from the palliative care team including physicians and nurses. It was pilot tested and modified based on feedback from two nurses with experience with PS; these nurses were not included in our data analysis. We started the focus group discussions by asking nurses to define PS in their own words, and subsequently provided definitions instituted by the Hospice and Palliative Care Nurses Association (HPNA) and a local hospital that has an existing PS policy.

Recruitment

Nursing directors from each location provided written consent allowing recruitment of nurses for an hour-long focus group. Recruitment flyers were posted in all ICU and oncology nurse conference rooms. Hospice nurses were recruited from a local not-for-profit community hospice. The breakdown of nurse participants include: nine oncology (93 eligible), 10 ICU (213 eligible), and 12 hospice (13 eligible). To participate, nurses needed to be fluent in English and have at least 6 months experience caring for patients with life-limiting illnesses. We did not specifically require nurses to have experience with PS given the range of differences in opinion on

what constitutes PS and to ensure the elicitation of a broad range of attitudes and experiences.

Focus groups

All participants gave written informed consent and completed a brief demographic survey before the start of the discussion. Four focus groups (range: 45 to 60 minutes) were moderated by an expert in qualitative research (RGB) with another team member (BP) present to observe/take notes. The focus group guide served as a framework for the discussion. The moderator made a concerted effort to avoid transferring her own assumptions about any of the topics to participants in the session. The audiotaped focus groups were transcribed verbatim and checked for accuracy by comparing segments of written text with corresponding audio-recordings.

Data analysis

Data were analyzed using grounded theory principles.²¹ The initial phase involved two investigators (RGB and BP) independently reviewing two focus group transcripts and identifying provisional themes that surfaced. Next, they jointly discussed these themes, and came to a consensus on provisional themes of salience to nurses, which were used to review and code the remaining two transcripts. When the team felt they had reached theme saturation (no new themes emerged), emergent provisional themes along with accompanying quotes were noted. In the second phase, the two other team investigators (JS and SL) joined the discussion meetings with the major goal of identifying recurring themes, and to discuss competing explanations for the findings, and to reduce redundant themes through the process of selection, ordering, and clustering. All four investigators independently and then jointly (in group discussion meetings) clustered similar themes, enabling early provisional themes to be superseded by more definitive final themes.

Results

Nurses' demographics are summarized in Table 1. The majority of nurses (87%, 27/31) were female, between the ages of 36 and 55 years (58%; 18/31), and Caucasian (81%, 25/31). Most nurses (55%, 17/31) held bachelor's degrees in nursing and had more than 10 years of nursing experience (80%, 24/31). A little over half of the nurses (52%, 16/31) reported being Catholic with most of these (94%, 15/16) indicating that their religious beliefs were important or very important to them in their work.

Nurses perceived five key concepts necessary for consideration and implementation of PS:

1. Ability to define palliative sedation

Nurses stated that an operational definition of PS should include language that addressed: goals of care for comfort, factors for patient eligibility, risks and ethical concerns, and how PS differs from procedural sedation. Table 2 displays quotes that highlight these themes.

2. Factors that determine eligibility for PS

Nurses suggested triggers for decision making on use of PS to include: a) intractable physical symptoms, b) severe non-physical symptoms, c) patients' wishes, and d) families' distress over patient's suffering.

TABLE 1. PARTICIPANT DEMOGRAPHICS, N=31

	Total	%	Hospice	Intensive care unit	Oncology
	N=31		12	10	9
Age					
<26	3	9.68%	1		2
26-35	4	12.90%		3	1
36-45	8	25.81%	4	2	2
46-55	10	32.26%	3	5	2
56-65	6	19.35%	4		2
Gender					
Female	27	87.10%	10	8	9
Male	4	12.90%	2	2	
Ethnicity					
White	25	80.65%	11	7	7
African American	1	3.23%			1
Hispanic	1	3.23%	1		
Asian	4	12.90%		3	1
Education					
LPN	1	3.23%	1		
AD-N	5	16.13%	5		
BSN	17	54.84%	5	6	6
APN	8	25.81%	1	4	3
Experience					
<5 years	5	16.13%	2		3
5-10 years	2	6.45%		2	
11-20 years	13	41.94%	6	4	3
>20 years	11	35.48%	4	4	3
Religious Beliefs					
Important	23	74.19%	5	10	8
Less important	8	25.81%	7		1

AD-N, Associate Degree in Nursing; APN, Advanced Practice Nurse/Masters Prepared; BSN, Bachelor of Science in Nursing; LPN, Licensed Practical Nurse.

a) Intractable physical symptoms

Frequently experienced physical symptoms, accompanied by substantial suffering and distress at EOL (nausea, vomiting, pain, shortness of breath, and terminal restlessness) were identified as appropriate for using PS:

"...Respiratory distress. You know, like end of life. Not the normal amount that can be managed by Roxanol, but, you know, sometimes somebody has to come off the ventilator, and you know, just to struggle, coming off the ventilator, and know

that by taking them off the ventilator they are going to die, but you want to keep them sedated so they are comfortable, and they are not struggling for air, or struggling to breathe. Because, I think that is very disconcerting for the family to witness that."

b) Severe nonphysical symptoms

Many nurses observed that in addition to physical symptoms, many patients at EOL experienced substantial psychosocial and existential distress that contributes to additional physical symptoms. And, even though nonphysical and

TABLE 2. NURSES' PERCEPTIONS OF KEY VARIABLES IN DEFINING PALLIATIVE SEDATION (PS)

<i>Goals of palliative sedation</i>	"The goal is to get the patient some pain relief...A level of medication to make the patient comfortable with regard to their level of consciousness." "Palliative sedation is for the terminal patient, to control symptoms, and to manage the pain, because the patient is never going to get better. Some think it's used only as an end-of-life measure, and others believe it is used during certain periods to aid in controlling pain."
<i>Patient eligibility/symptoms</i>	"People who are really, truly at the end, you know, they only have a couple days left and are really in a lot of pain and suffering." "... Palliative sedation is...when a patient is at a place that nearly is unmanageable, [in] intractable pain, where the family and the patient decide that bringing the patient to a level of, um, sedation would be the best thing to do, given the current situation...and that level of sedation would be more of a semiconscious place."
<i>Risks and concerns</i>	"There is a fine line in comfort care; we are trying to keep the respiratory rate to certain levels as much for the family as for the patient. We want the quality of the patient's life to be assisted as well as interaction with family to continue for as long as possible."
<i>Difference from procedural sedation practices</i>	"You're going to sedate the patient to a point where they are just out of pain." "With PS you wake people up once in awhile, you give them a choice. Wake them up and say "how are you feeling now?" "Do you still want to continue with this?"

physical symptoms led to suffering through different mechanisms, each required the same degree of skilled management and treatment. For example,

“Suffering is suffering, regardless. I mean, you can’t make a decision about my suffering, my level of suffering. Whether it’s psychological, or physical, or whatever. My suffering is my suffering and it’s your job to relieve it. So you can’t make a judgment like that.”

In contrast, other nurses felt that while unrelieved physical suffering could lead to psychosocial suffering, it would be ethically questionable to treat only psychosocial suffering with PS.

“I think when people are in pain; this stuff becomes more than physical. It becomes emotional, existential...But, I couldn’t see putting somebody into palliative sedation, just because they were depressed.”

c) Patients’ wishes

Nurses felt it important to consider patients’ wishes when deciding to use PS. As one nurse confided:

“To me, it kind of depends on the wishes of the patient. You know, I would be comfortable with it, as long as it was the wishes of the patient, and not somebody inflicting their wishes onto the patient. If the patient was able to speak for themselves, or had decided on a surrogate decision maker, I would be comfortable with that, but if there was somebody from the outside stepping in and saying, let’s sedate for that reason, I would probably feel a little more uncomfortable with it.”

d) Family’s distress around intractable suffering

Whereas nurses’ goals involved relieving the patient’s suffering, often the family’s distress, including fears about the patient’s suffering, were compelling reasons to consider using PS. For instance:

“A woman was very tearful watching her husband die, and wanted something done for him, so the nurse called the doctor who said there is nothing we can do. The intern had no

knowledge of how to make the patient comfortable...The family cannot stand watching them suffer.”

3. Skills needed for administering palliative sedation

According to nurses, administration of PS requires unique skills, including the ability to work within a team; communicate with other care providers, patients, and families; complete an accurate bedside symptom assessment; utilize technical skills; and to be culturally competent. The following quotes illustrate these findings:

“I would say it’s the assessment skills, it’s heightened. I think it takes more intense assessment and monitoring.”

“Another important skill you need is to realize what information the family might need in order for them to feel more comfortable with what you’re doing. As they go through this process they require a lot of reassurance so we have to be able to certainly assess what their informational needs are as well as emotional support.”

4. Policy and procedural guidelines

Nurses felt that policy should delineate criteria for receiving PS and also incorporate titration parameters for sedation. Such a stance would assure clinical competence, enable providers to achieve consensus on the care plan, and minimize institutional system-related issues. This latter point speaks to policies that vary between institutions; for example, at our institution nurses cited a concern about being competent in procedural-related sedation versus sedation for symptom management at EOL. Further guidelines would help to define terminology ensuring consistency in use and interpretation of language surrounding PS. A policy with guidelines for PS would serve as an invaluable resource of health care team members. One nurse captured it succinctly:

“Yes, I really believe that with a policy in place and with education, the floor nurses will feel comfortable also. Their main complaint is that with no policy in place they don’t feel comfortable titrating on how high to go and they are afraid.”

TABLE 3. NURSES’ PERCEPTIONS OF NEED FOR EDUCATING PATIENTS, FAMILIES, NURSES, AND PHYSICIANS ON PALLIATIVE SEDATION

<i>Patient</i>	“Doctors, social workers, family members as well as the patients all need to be made knowledgeable and that this is truly last resort.”
<i>Family</i>	“Before you start palliative sedation you first must inform the family of all the levels. There needs to be education in order to see a true change in understanding.” “Family members, you often find, need a lot of information about what they might expect to occur with the patient. As they go [through] this process, which is normal, they require a lot of reassurance so we have to be able to certainly address what their informational needs are as well as [provide] emotional support” “I think we need to educate the families, because someone might hear palliative sedation and it just sounds awful to them or it might draw up flags for them.”
<i>Nurse</i>	“In our nurse residency program, we issued a class on death and dying, where we talk about end-of-life care and sedation. That’s all that has really been covered. There are eight hours of end-of-life education.” “I don’t think there has been any formal education as to what palliative sedation is, you kind of go along being a nurse for 10-20 years and have been exposed to situations such as this, but if you have only been a nurse for a couple of years it is hard.” “If the nurses don’t understand it, how can we explain it to our patients?”
<i>Physician</i>	“There has to be education for the physicians, a formal education for everyone who goes to medical school to give them an understanding.” “I think the entire team should be educated on it, and be able to discuss it, talk about it, and discuss whether this would be beneficial or not to the patient.” “One patient was uncomfortable, thrashing around in bed and I called the doctor and said, ‘This isn’t cutting it; I’ve medicated her every 2 hours for the past 12 hours and she’s uncomfortable.’ The doctor said, ‘Well she doesn’t talk and I don’t know if she’s in pain or not.’ The doctor would not change it. She was definitely uncomfortable, but because she wouldn’t talk, he wouldn’t do anything about it.”

5. Education on palliative sedation and end-of-life care

The need for education on pain and symptom management for both nurses and physicians (medical students, residents, and attending physicians) was a universal theme that emerged across all topics in each focus group. Table 3 displays quotes indicating the need for patient, family, nurse, and physician education.

Discussion

Nurses play an invaluable role in the care of dying patients, for whom PS represents an important tool to improve the management of refractory symptoms. Nurses in our study supported and advocated for the development of comprehensive policies related to PS. They mentioned that key domains to incorporate as part of a policy should include a well-developed definition of PS, criteria for PS, plans for implementation, training to ensure competence in PS, and guidelines for administration and monitoring. Additionally, education in PS and EOL care was a predominant theme that emerged across topics, disciplines, and level of training.

Research on nurses' perspectives and attitudes regarding PS remains limited even though nurses play a key role in caring for patients and families with distressing symptoms at EOL.^{11,15-17,22,23} Similar to other studies, nurses reported PS as an important therapy to improve the care of dying patients with refractory symptoms. Nurses overwhelmingly agreed PS was salient for the management of refractory physical symptoms; however, differences in opinions emerged on whether PS was appropriate for nonphysical symptoms such as depression and existential suffering. Concern over the appropriateness of PS for nonphysical symptoms has previously been reported among nurses in North America.^{16,22} However, we were not able to identify similar concerns in published European studies. In fact, a survey of physicians and nurses in the Netherlands found PS was frequently employed for nonphysical symptoms, which may reflect a difference in the culture surrounding PS given the availability, acceptance, and the practice of euthanasia.²³ Consensus on the use of PS for nonphysical symptoms is paramount as unresolved psychological, social, and spiritual issues could exacerbate physical symptoms, which was noted by several nurses in our study and has been well-described in the literature.²⁴ Research also suggests that other interdisciplinary team members, such as psychologists, social workers, and chaplains, are underutilized in this situation and that including them may alleviate the need for PS.^{25,26}

The importance of clarifying terminology surrounding PS has surfaced in earlier studies. A Canadian study of palliative care unit nurses reported confusion on how to define PS including concerns over blurring of the use of medications for symptoms versus for PS.¹⁶ Another U.S. study found nurses would benefit from a better understanding of terminology as several cited concerns that PS was in fact physician-assisted suicide or euthanasia, and nurses reported being uncomfortable and struggling when these lines were not clear.²² In a nationwide study of Japanese nurses, the lack of understanding surrounding sedation was one of the most frequently cited reasons for emotional burden by nurses.¹⁷ These findings were echoed in our study as nurses cited the importance of clarifying patient eligibility and how PS differed from other treatments.

The benefit of an interdisciplinary team was another emergent theme in our study that corroborated earlier studies.^{11,17} Nurses reported working within a team as a key skill and process for decisions surrounding PS. This includes a nurse-physician relationship that fosters "collaborative decision making."¹⁶ The health of the team was underscored by one study that found nurse-perceived burden increased in PS-related decisions when misunderstandings between physicians and nurses arose, a team conference was unavailable, and supportive colleagues were unavailable.¹⁷ These findings reinforce the fact that a hospital policy on PS must incorporate an interdisciplinary team including nurses, physicians, social workers, and chaplains. Palliative care often serves as the role model for the interdisciplinary team as hospital-based care is traditionally multidisciplinary.

An important contribution of our study was the appreciation by nurses for the increased need for EOL education in general and surrounding PS in particular, and including hospice nurses. Previously published studies on nurses' views surrounding PS have not reported this as an emergent theme.^{15-17,22,23} Nurses were cognizant that despite caring for many dying patients, limited formal education on EOL care existed and was necessary for a policy on PS to move forward. EOL care nursing education continues to surface in the literature as an important need.¹⁸⁻²⁰

Strengths of our study include a purposeful sample of nursing professional ranging in educational background, and caring for patients with refractory symptoms at the EOL in three distinct practice settings. Thus, our findings benefit from the breadth of nursing professionals practicing in a range of relevant settings. This study has some limitations. Nurses volunteered to participate, so they were self-selected into the study. One would anticipate that a selection bias might favor nurses who had an interest in or pre-knowledge of EOL care and PS. Second, participants in the focus groups may have influenced each other's responses, which is an inherent characteristic of this methodology. Third, one of the investigators (BP), present as an observer in the focus groups, was part of the hospital's inpatient palliative medicine service, which may have influenced nurses' responses, in that their responses may have been constructed to be socially desirable. Fourth, focus groups included only nurses working on the day shift; night shift workers could have different responses. Lastly, nurses were recruited from one health system with a relatively homogenous ethnicity, thus our findings may not be generalizable to other settings or cultural groups.

PS has been regarded as a viable and at times indispensable treatment option for alleviating a dying patient's refractory symptoms. This type of palliative intervention benefits from the strengths inherent in an interdisciplinary approach to care; nurses represent a key member of this team. They tend to have more frequent contact with patients and their families, and may be more likely to notice changes in symptoms and patient needs. Therefore, it becomes imperative to explore nursing perspectives on the use of PS, acceptable reasons for administration, and key factors that need to be considered to safely practice PS. By better understanding these variables, PS policies can be developed including all relevant stakeholders of the interdisciplinary team to ensure that acute care hospitals and hospices meet the needs of health care providers, patients, and families.

Acknowledgments

This paper was presented at the fifteenth annual AAHPM/HPNA (2010) national conferences.

Author Disclaimer Statement

No competing financial interests exist. All the data reported here were gathered and analyzed using funding from the Hartford Center of Excellence Pilot Research Grant. Funding for these analyses came from a career development award (JWS) from the National Palliative Care Research Center and the National Institute on Aging (K23AG029815).

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