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Caregiver's Perception of Palliative Sedation: A French Opinion and Survey

Serresse L*, Perigault F, Chenivesse C, Crozier S, Salachas and Varin FD

Department of Palliative Care, Hospital: Universitary hospital Pitié-Salpetrière, UMASP, Paris, France

***Corresponding author:** Laure Serresse, MD, Department of Palliative Care, Hospital: Universitary hospital Pitié-Salpetrière, UMASP, 47-83 Boulevard de l'Hôpital, 75013, Paris, France, Tel: +33619258838; E-mail: laure.serresse@psl.aphp.fr

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Abstract

Background: In end-of-life palliative care, appropriate medications may be ineffective in relieving symptoms. When this condition leads to intolerable suffering, palliative sedation (PS) must be considered. Although guidelines have been developed in France, ethical controversies and inappropriate requests appear to exist in clinical practice. We hypothesize that this situation is due to caregivers' inadequate knowledge.

Objective: We aimed at investigated caregivers' knowledge, experience and feelings related to PS.

Methods: We conducted a survey in a French University hospital. Caregivers from departments including dedicated palliative-care beds were asked to fill in a questionnaire composed of 6 items concerning PS definition, experience and emotional impact.

Results: 160 questionnaires were completed by nurses (39%), physicians (37%) and nursing assistants (18%). Of them, 38% had been involved more than ten times in PS. 23% knew the consensual definition of PS and 50% made a clear difference between PS and euthanasia. 24% of caregivers felt unsettled by PS practice. Crossing data showed that less caregivers were destabilized when they made a clear difference between PS and euthanasia than when they did not (18% vs. 36%, $p<0.025$). There was no statistical relationship between the experience in practice of PS and its emotional impact. Thinking that "the goal of PS is patient's relief" rather than "a decrease in consciousness" was associated with a better distinction between PS and euthanasia (73% vs. 55%, $p<0.05$).

Discussion: The present study showed that PS definition, indication and purpose were unclear in a raised awareness population. These results support the idea that PS remains a complex concept. This may lead to heterogeneous practices of PS and ambiguous perception of PS ethics including a deleterious confusion with euthanasia.

Keywords: Palliative care; Sedation; Euthanasia; Definition; Ethics

Introduction

Palliative medicine aims to relieve pain and other distress terminally-ill patients may be suffering, to improve their end-of-life quality, which is why an assessment and the management of patients' physical, psychological, social or spiritual needs and wishes are required [1,2].

Symptoms such as pain, dyspnoea, nausea, or psychological and existential suffering sometimes cannot be relieved without compromising a patient's consciousness, despite the use of appropriate medication.

These symptoms are known as refractory symptoms [3].

When refractory symptoms lead to a patient experiencing intolerable suffering, palliative sedation may be considered as a last resort to relieve it [4].

Despite its many years of existence, palliative sedation remains a source of confusion and controversy, not only in its definition but also in its indications, its terms of use and its ethical implications [5,6].

National and international guidelines have been published to highlight the debate and standardize practices [7-9].

We aimed at investigating health care professionals' knowledge, experience and feelings in relation to palliative sedation for terminally-ill patients.

Method

We conducted a survey from May to June 2014 in a French University Hospital. Health care professionals from ten units with dedicated palliative care beds were asked to fill in a questionnaire with six sections concerning the definition of palliative sedation, personal experience and emotional impact. This questionnaire was developed by the Palliative Care Committee of the Pitié Salpêtrière Hospital and was sent to palliative care referees in ten units, who were in charge of making sure it was filled in by the health care professionals. A statistical analysis was performed using a chi-square test. The approval of the Ethics Committee was not required, in accordance with national recommendations for medical research.

Results

160 questionnaires were filled in by nurses (39%), doctors (38%) and nursing assistants (18%). The other 5% of respondents were medical or nursing students. The average age of respondents was 38. The response rate was 53% which reflects the investment of the palliative care referee who distributed the survey. Almost half the questionnaires were completed by the medical units where the referee had been involved in the writing of the questionnaire (pneumology: 32%, cerebrovascular emergencies: 15%) (Table 1).

Medical Units	Dedicated Palliative Care Beds	Response
Pneumology	2	51
Cerebrovasc Emerg	1	24
Radiotherapy	4	19
Geriatry	2	19
Internal Medicine	2	15
Oncology	6	14
Gastroenterology	3	11
Neuro Oncology	5	3
Neurology	1	3
Hematology	1	1

Table 1: Responses.

Analysis of the responses shows that 38% of health care professionals know the definition of "terminal phase of illness" (doctors: 38%, nurses: 29%, nursing assistants: 44%) and 23% of them that of "palliative sedation" (doctors: 18%, nurses: 38%, nursing assistants: 24%).

Half the respondents perceive a difference between palliative sedation and euthanasia (doctors: 85%, nurses: 62%, nursing assistants: 50%).

38% of health care professionals declare having been involved more than ten times in the decision and/or implementation of palliative sedation. 24% of health care professionals feel disturbed by palliative sedation practice (doctors: 26%, nurses: 29%, nursing assistants: 33%).

Crossing data shows that health care professionals are significantly less disturbed when they make a clear difference between palliative sedation and euthanasia (18% vs. 36%, $p<0.025$).

5% of the health care professionals who know the definition of palliative sedation make a clear difference between palliative sedation and euthanasia whereas 74% of those who don't know the definition do make a clear difference between palliative sedation and euthanasia.

Emotional stress was not found to decrease significantly when the respondents knew the definition of palliative sedation.

Furthermore, the extent of their experience in making the decision and/or in implementing palliative sedation had no incidence on their emotional stress.

Believing that the objective of palliative sedation is to relieve the patient's suffering rather than lower his/her consciousness level was significant in the health carer's perception of the difference between palliative sedation and euthanasia (73% vs. 55%, $p<0.05$).

Discussion

Our hypothesis was that the definition of palliative sedation for terminally-ill patients remains controversial due to a lack of knowledge of its indications and purpose (symptom relief and not the hastening of death). This explains the confusion between palliative sedation and euthanasia and as a result the emotional stress related to palliative sedation.

As expected, the definitions of terminal illness and palliative sedation are not sufficiently clear for many health care professionals. However, knowing the definitions of terminal illness and palliative sedation does not mean they can make a difference between palliative sedation and euthanasia.

In our study, 24% of the health care professionals experienced moral or psychological stress when they performed palliative sedation. In Morita's study, 12% of the nurses stated that being involved in palliative sedation caused them emotional stress, 12% that they felt helpless faced with patients having palliative sedation, 11% that they would avoid a situation in which they had to perform palliative sedation [10].

Although recent guidelines outline the differences between palliative sedation and euthanasia, only half of the respondents perceived them. As evidenced by Ten Have's article, the ethical controversies remain [11]. In France, end-of-life care is influenced by the palliative care and hospice movement from the United Kingdom. The ethical and moral tensions brought to light in our study are consistent with the results in Seale's conclusion, that medical practices are influenced by local culture and legal context [12].

Anquinet's study focuses on physicians' experiences regarding the use of palliative sedation in the context of psychological distress. The use of palliative sedation in the context of physical refractory symptoms seems to cause less emotional stress for the health carer

than its use in the context of psychological and existential suffering [13].

In our study, we do not know if the moral or psychological burden differs according to whether palliative sedation is performed for physical or psychological suffering.

Due to the ignorance of palliative sedation definition but also in its indications, objectives and terms of use, the difference perceived by health care professionals between palliative sedation and euthanasia is only slight.

The results of this study show how palliative sedation remains complex due to the confusion, in its exact purpose, in the specific context of the terminally-ill: is it a way to relieve patients' distress or is it veiled euthanasia?

This preliminary study leads us to believe that further information on palliative care is needed; however this may not be sufficient as simply knowing the definition of palliative sedation does not mean a health care professional can perceive the difference between palliative sedation and euthanasia, nor does it mean less emotional stress is involved. A special focus on health care professionals' perception of palliative sedation for terminally-ill patients is also needed, to help them differentiate between palliative sedation and euthanasia.

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