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Sedation in palliative care – a critical analysis of 7 years experience

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Abstract

Background: The administration of sedatives in terminally ill patients becomes an increasingly feasible medical option in end-of-life care. However, sedation for intractable distress has raised considerable medical and ethical concerns. In our study we provide a critical analysis of seven years experience with the application of sedation in the final phase of life in our palliative care unit.

Methods: Medical records of 548 patients, who died in the Palliative Care Unit of GK Havelhoehe between 1995–2002, were retrospectively analysed with regard to sedation in the last 48 hrs of life. The parameters of investigation included indication, choice and kind of sedation, prevalence of intolerable symptoms, patients' requests for sedation, state of consciousness and communication abilities during sedation. Critical evaluation included a comparison of the period between 1995–1999 and 2000–2002.

Results: 14.6% (n = 80) of the patients in palliative care had sedation given by the intravenous route in the last 48 hrs of their life according to internal guidelines. The annual frequency to apply sedation increased continuously from 7% in 1995 to 19% in 2002. Main indications shifted from refractory control of physical symptoms (dyspnoea, gastrointestinal, pain, bleeding and agitated delirium) to more psychological distress (panic-stricken fear, severe depression, refractory insomnia and other forms of affective decompensation). Patients' and relatives' requests for sedation in the final phase were significantly more frequent during the period 2000–2002.

Conclusion: Sedation in the terminal or final phase of life plays an increasing role in the management of intractable physical and psychological distress. Ethical concerns are raised by patients' requests and needs on the one hand, and the physicians' self-understanding on the other hand. Hence, ethically acceptable criteria and guidelines for the decision making are needed with special regard to the nature of refractory and intolerable symptoms, patients' informed consent and personal needs, the goals and aims of medical sedation in end-of-life care.

Background

Sedation in the final stage of life is a controversial issue in palliative care with regard to medical and non-medical

indications, decision-making and ethical implications. It is widely agreed, even though this is controversial too, that in patients with advanced cancer and other terminal

diseases the provision of sedation leading to unconsciousness sometimes can be a necessary therapeutic procedure of last resort for symptom relief [1]. In the final stages of life, symptoms may remain refractory. However, there is much debate about where to draw the borderline between sedation for refractory symptoms that are of a mainly physical/somatic nature and for those psychological symptoms that are mainly due to existential suffering. Also, some think that sedation leading to unconsciousness should be an option, or an alternative, for terminally ill patients with intolerable suffering if they request euthanasia or physician assisted suicide [2–4] or for those who just want "to die in sleep".

The problems associated with sedation in end-of-life care and the different attitudes among clinicians and palliative care experts are reflected in inconsistent terminology [5], variation in techniques used to induce, maintain and monitor sedation [6], duration of and frequency of application, different concepts on the time of administering sedation and on intentions [7]. While the ambiguous term "terminal sedation (TS)" [8,9] is used most often, other terms more clearly reflect the different viewpoints: "sedation for intractable distress in the imminently dying [10,11];", end-of-life sedation [12] "slow-euthanasia" [13], "palliative sedation" [14], "total sedation" [15], "sedation in the final phase", "palliative sedation therapy" [16].

Sedation in the terminal or final stages of life can be defined as the use of sedative drugs (usually benzodiazepines with or without complementary opioids given by the intravenous or by the subcutaneous route) to reduce the level of consciousness sufficiently deep to provide comfort for the patient until death occurs. According to the EAPC Ethics Task Force "terminal' or 'palliative' sedation in those imminently dying must be distinguished from euthanasia. In terminal sedation the *intention* is to relieve intolerable suffering, the *procedure* is to use a sedating drug for symptom control, and the successful *outcome* is the alleviation of distress. In euthanasia the *intention* is to kill the patient, the *procedure* is to administer a lethal drug and the successful *outcome* is immediate death. In palliative care mild sedation may be used therapeutically but in this situation it does not adversely affect the patient's conscious level or ability to communicate [17]. The use of heavy sedation (which leads to unconsciousness) may sometimes be necessary to achieve identified therapeutic goals. The intention is the relief of otherwise intractable and refractory distress [18]. Target symptoms include persisting pain, delirium, dyspnoea, nausea and vomiting, massive haemorrhage, agitated anxiety and other forms of psychological distress. Sedation can be classified into mild to deep, intermittent to continuous, primary to secondary, sudden to slow [19]. Contro-

versies exist about the time limit and proximity to death [20], the clinical implications (e.g. the withdrawal of nutrition and hydration [21,22]), patient monitoring, the stage and circumstances of the illness in which sedation can be offered or employed, and the informed consent process with patients and surrogates [23]. Requests for sedation seem to become of increasing relevance in advance directives, but the ethical implications may rise to conflicts between patients' wishes to hasten death and physicians' intentions to provide the best care and not to shorten life.

In particular, there is controversy on the issues of dehydration in sedation for existential suffering [24]. The increasing acceptance and use of "terminal sedation" [25] in end-of-life care makes it necessary to scrutinize guidelines, which may help to continuously consider and reconsider the needs and wishes of patients and surrogates, as well as intentions and concerns of caregivers.

The use of sedation in terminally ill patients has been investigated by a number of studies in recent years. The wide variations in frequency to choose sedation as an procedure in end-of-life care across different centres suggest different attitudes of doctors and policies of institutions rather than the patients' preferences or needs [26]. The purpose of this retrospective study was to investigate reasons for the request and the application of sedation in terminal situations in our palliative care unit in the years 1995–2002, and the relevance of guidelines.

Methods

We performed a systematic retrospective analysis of the charts of all patients who received continuous or intermittent sedation by the administration of benzodiazepines intravenously within the last 48 hrs before death in the Palliative Care Unit (PCU) of GK Havelhöhe between 1995 and 2002. During this period there was no change in the medical staff of the unit. Indications, decision-making and techniques were regulated according to internal guidelines, which were introduced after discussion with the medical and nursing staff at the beginning of the observation period (Table 1). Indication and beginning of sedation was documented in the medical records.

The medical charts of all patients (n= 548), who died during the observation period where investigated in order to find out those, who had sedation in the final stage of their life. A ranking of symptoms on admission, during treatment and in the last 48 hrs was made according to our symptom assessment scale with the items: pain, gastrointestinal (nausea/emesis/intestinal obstruction), dyspnoea, anxiety/depression, fatigue/cachexia, cognitive disorder/delirium (drowsiness/agitation), bleeding, skin problems (ulcerations, oedema), neurological and others.

Table 1: Guidelines for the use of sedation in patients near death in PCU Havelhoehe

Indication:
Otherwise refractory and burdensome symptoms in terminal or final stages of the life of patients with incurable disease – If death can be expected within the next 48 hrs
Decision-making:
Informed consent of patient, surrogates and palliative care team
Technique:
Continuous or Intermittent infusion of sedatives (iv or sc e.g. midazolam 0,5 -mg/h +/- analgesics + co-medication). Lowest possible, adequate dosage to control symptoms under permanent observation and careful monitoring. Reduction of dosage in agony. Maintenance of all necessary medical and nursing support. Documentation.
Intention and ethics:
Reduction of distress, good sleep at night, adequate communication at daytime. Comfort and tolerance in the final phase – not to hasten death.

Data collection, rating and analysis was made by a single member of the medical staff. Reduction of rating and ranking errors in doubtful cases was achieved by complementary interviews with those involved more personally in the medical care of the patients. In this study the single rater method (by the clinically most experienced physician) was preferred to reduce disagreement on symptom definitions in trust on the experience and accuracy of an individual point of view though recollection of data sometimes was difficult to obtain. Charts of patients with sedation were reviewed and evaluated systematically and discussed with those involved in the decision-making on sedation in the terminal or final phase. A ranking was made to identify a single predominant symptom, which mainly lead to sedation and concomitant others. 6 predominant symptoms for sedation were differentiated: dyspnoea, pain, delirium/agitation, gastrointestinal, bleeding, anxiety/psychological distress. The recorded indications for sedation were classified into "mainly physical" when refractory physical symptoms predominated and "mainly psychological", when intolerable suffering by panic anxiety, refractory insomnia or affective decompensation persisted. Agitated delirium was separated due to the diagnostic uncertainty to relate this symptom to a more physical or more psychological origin retrospectively. Attention was given to the stage of disease at the time of admission, prevalence of symptoms on admission and in the final phase, changes of symptoms during treatment, type and duration of sedation until death, survival time after administration of the sedatives, provision of concomitant therapy, nutrition supply and fluids, state of consciousness and communication skills. Special interest was given to patients' attitudes and frequency of request for sedation in the final phase as documented in the medical records or in advance directives. Patients' characteristics were related to all patients admitted.

The data were analysed using SPSS Version 11. Chi-squared tests were used to examine associations between categorical data. Metric data (age, duration of stay, duration of sedation) were compared using Student's t-test for independent groups. Comparisons between groups for predominant symptoms were made using the Mann-Whitney U-test and Wilcoxon rank-sum test for paired comparison within patients' groups. $P < .05$ was considered statistically significant. On the base of these data a critical evaluation for the decisions on sedation was made comparing the periods between 1995–1999 and 2000–2002.

Results

- Patients' characteristics showed no significant difference in the stage of disease on admission (Table 2). But patients who finally received sedation were more likely to have experienced pain, dyspnoea and anxiety as the predominant symptom on admission than those who did not undergo sedation (Table 4).

- Sedation in the last 48 hrs was performed in 14,6 % (n = 80) of all patients who died in the PCU of GK Havelhoehe (n = 548) with significantly increasing frequency in the years 2000–2002 ($\chi^2 = 8.57$; $p = 0.003$) (Figure 1).

- No difference was found in the duration of stay in our unit until death between those patients who died with, and those who died without sedation. Mean age of patients, who finally had sedation was less with 54 years vs. 64 years in those without sedation ($p = 0.001$, Student's t-test).

- All patients had effective and sufficient pain control, but in those patients who were sedated in the last 48 hrs of life, burdensome dyspnoea, panic-stricken anxiety and agitated delirium had increased during the stay (Figure 2).

- The indications for performing sedation due to predominant psychological distress (anxiety, refractory insomnia, decompensation) and due to refractory symptoms (dyspnoea, gastrointestinal, pain) did not differ significantly during the two observational periods. Interestingly, there was a tendency that the main indications for sedation during the last three years shifted more and more to psychological distress.

- Mean survival time after administration of sedation was 63 ± 58 hrs during the whole observation period. In the years 2000–2002 patients with more psychological distress had a longer survival time than those with otherwise resistant control of more physical symptoms (Table 3).

- In the years 2000–2002 we noticed an increase in the request for sedation in the final days of life from 19% to

Table 2: Patients characteristics on admission – demographic and clinical data of all patients in comparison to those who died in PCU Havelhoehe 1995–2002. Significant differences were found between groups on age and stages on admission except preterminal stage.

	All admissions (A)	Subgroup (B)	Subgroup (C)	Significance p-values
	All patients (n = 1467)	† without sed. (n = 468)	† with sed. (n = 80)	
Gender (%)				
female	55.8	57.1	61.2	n.s.
Age (years)				
Mean (SD)	60,8 (17.8)	63.6 (13.3)*	54.3 (14.4)**	*p = 0.026
Range	(19.7–97.7)	(24.6–97.7)	(19.7–81.1)	**P < 0.001.
Stage on admission (%)				
Rehabilitative	33.3	15.1**	13.8**	**P < 0.001
Preterminal	44.3	42.2	43.8	P = 0.445
Terminal	19.6	36.6**	38.7**	**P < 0.001
Final	2.8	6.2*	3.8*	*P = 0.002
Duration of stay (days)				
Mean (SD)	21.0 (21.5)	21.1 (23.6)	21.5 (20.3)	n.s.
Median	16	14.0	15.5	
Range	(0 – 233)	(0 – 199)	(1 – 109)	
Primary cancer site (%)				
Gastrointestinal	21.6	24.4	27.2	n.s.
Breast	15.4	15.6	6.2	P = 0.06 n.s.
Lung, bronchus & trachea	12.8	14.9	16.0	n.s.
Prostate	8.8	5.2	3.7	n.s.
Female genital	8.6	9.7	14.8	n.s.
Bones, skin & soft tissue	6.3	6.7	7.4	n.s.
Nervous system	3.8	3.7	1.2	n.s.
Urinary system	3.8	3.7	7.4	P = 0.085 n.s.
Oropharynx & hypopharynx	3.7	4.1	7.4	P = 0.085 n.s.
Lymphoma	3.5	4.3	3.7	n.s.
Others	1.2	2.1	4.9	n.s.
Non-cancer diagnosis	10.5	5.6**	0.0	P = 0.001

34% by the patients themselves, documented in personal statements or advance directives. In those patients in which sedation was given also "on request", the mean survival time was found to be slightly shorter (52 ± 42 hrs) in the years 2000–2002, but not in the years before (Table 3).

- In most cases, sedation was performed with slowly increasing doses of midazolam 0,5 mg – 8 mg/h iv, aimed at achieving effective symptom control. When this was obtained, doses were reduced and sedation was continued intermittently with the documentation of the level of consciousness, comfort, eating, drinking and communication skills. 48 patients had continuous sedation (mean duration 53 hrs), 32 intermittent (mean duration 77 hrs). In 53 patients (66%) oral supply of fluids and in 10 patients also oral nutrition intake during sedation was reported in the records. 27 patients (33.8%), had no oral fluid or nutrition supply after sedation was introduced either because of the deepness of the sedation or because of refusal of oral fluid and nutrition intake. Infusion of fluids was continued in all patients with regard on comfort according to clinical signs of thirst with restriction of vol-

umes in cases of oedema, ascites and pulmonary congestion. Special attention was given to establish a good sleeping period at night and a more patient controlled sedative state with communicative skills and reports of comfort during the day.

- Abilities to communicate like asking for help or answering questions on pain, comfort, thirst etc. and preserved forms of cooperation under sedation were reported in 40 cases (50%).

- The following case of a 40 yrs old hospice worker, in whom oropharyngeal cancer was diagnosed during pregnancy, may illustrate the procedure of sedation in our PCU but also the difficulties associated with drawing the line in consideration of patients needs, personal intentions and adequacy of sedative procedures for refractory symptom control:

For several weeks she was treated for panic attacks, dyspnoea and dysphagia but relief of symptoms only lasted a few days. Her weakness increased rapidly. In her advance directives she had disclaimed tracheotomy and antibiotics but pleaded for

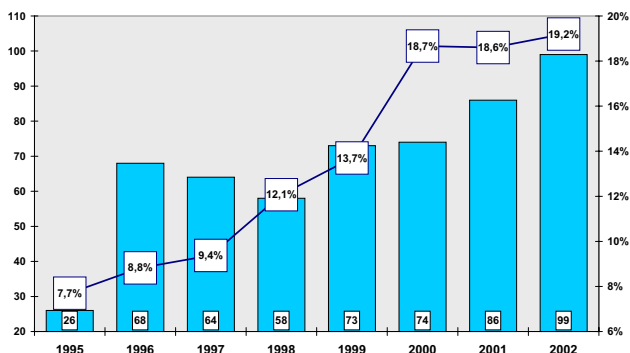


Figure 1
Percentage of patients with sedation in the last 48 hrs in relation to the number of annual deaths (bars) in care of PCU Havelhoehe between 1995 and 2002. Significant increase of incidence for sedation in the period 2000–2002 ($p = 0.015$ in paired t-test)

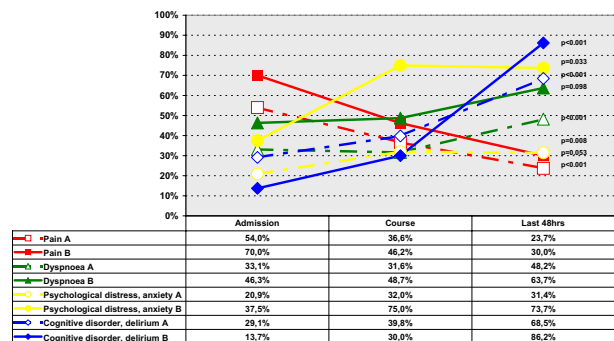


Figure 2
Course of pain, dyspnoea, cognitive disorder (delirium) and psychological distress (anxiety) in patients with regard to application of sedation in the final phase (A= Subgroup without sedation, B= Subgroup with sedation). Significance level $p < 0.05$ in Wilcoxon rank sum test.

good pain therapy and sedation "to die in sleep". In the final phase she suffered from extensive mucositis, exhausting breathlessness and agitated anxiety by upper airway obstruction due to local tumour progression, pulmonary and hepatic metastases and acute pneumonia. She said: "I think – now the time has come" and requested for sedation during the last hours of her life. The clinical situation was discussed with the nursing team according to our internal guidelines. Informed consent in presence of her husband was obtained before 5 mg iv midazolam were administered with good symptom relief. Sedation was continued with a dosage of 1–2 mg/h on which the patient insisted

on comfort by the sedation and fear of recurring distress. Survival time was 16 hrs in a peaceful, quiet atmosphere without distress, a light sedative state with diminished communication skills, oral fluid intake and support by the presence of her husband.

Discussion

To balance between therapeutic sedation to reduce burdensome distress in the terminal and dying phase and sedation in patients who voluntary request sedation "to die in sleep" is a difficult challenge. This is particularly important when anxiety, physical distress and anxiety with existential suffering appear together in the dying person like in the illustrated case.

The intention of this survey is to contribute to the international discussion on sedation in end-of-life situations. The analysis was primarily done to reconsider our internal guidelines by reflecting our clinical practice. Certainly a survey like this suffers from the drawbacks of a retrospective study. Nevertheless our results can be understood as a contribution to more transparency in this difficult issue. The increasing incidence and also the finding that sedation was more often used in situations with psychological distress and also requested by the patients themselves may indicate an increasing awareness and respect for the needs of the patients. It also seems to signify that in the care of patients with physical symptoms and psychological distress in situations near death needs and deficits exist, for which sensitive medical strategies must be combined and integrated with personal support, commitment and understanding. In our guidelines we tried to relate the possible benefits of sedation to the basic concerns of palliative care by using it as a reversible therapeutic procedure. Concentrating on communicated comfort as the main indicator for the value of this option means also, that in the care of the sedated patients personal support played an important role.

Our decisions for the administration of sedation were restricted to terminal and final situations when the course of the disease had so progressed that death due to the underlying disease could be expected within the next 48 hrs with or without this procedure. Nevertheless mean survival time after administration of sedation was 63 hrs. It is, in general, difficult to predict death in a particular patient because of individual variations and since "we do not know the exact borderline between life and death" [27]. To a certain extent the point in time to accept dying – at least in medical institutions – depends on empirically based decisions to abstain from potentially life-sustaining interventions e.g. pharmacological, technical or other artificial support of organ function "to prevent death" at least for limited moments of time [28,29]. In our internal guidelines we grouped patients according to the staging

Table 3: Indication for sedation, patients' request and observational reports on communication and oral fluid/nutrition intake comparing the periods 1995–1999 and 2000–2002 (*p < 0.05).

	Whole Period 1995 – 2002	Period 1995–1999	Period 2000 – 2002	Significance p-values
Patients with sedation in the last 48 hrs				
<i>n</i> (% of all deaths)	80 (14.6)	31 (10.6)	49 (18.9)*	**P = 0.007
Main indication for sedation, <i>n</i> (%)				
Dyspnoea	28 (35.0)	11 (35.5)	17 (34.7)	n.s.
Gastrointestinal	6 (7.5)	3 (9.7)	3 (6.1)	n.s.
Bleeding	1 (1.3)	1 (3.2)	0 (0.0)	n.s.
Pain	2 (2.5)	1 (3.2)	1 (2.0)	n.s.
Delirium, agitation	11 (13.8)	6 (19.4)	5 (10.2)	n.s.
Anxiety, psychological distress	32 (40.0)	9 (29.0)	23 (46.9)	P = 0.111
Requests for sedation, <i>n</i> (%)	23 (28.8)	6 (19.4)	17 (34.4)	P = 0.141
Duration of sedation (hrs)				
Mean (SD)	62.8 (58.0)	69.0 (57.5)	58.9 (58.7)	P = 0.445
Range	2–264	15 – 240	2 – 264	
Mainly somatic indication	63.3 (56.3)	84.7 (64.0)	47.3 (45.1)	P = 0.117
Mainly psychological indication	62.6 (60.3)	52.2 (46.0)	68.3 (67.1)	P = 0.145
Patients with request for sedation	57.3 (47.3)	73.0 (53.0)	51.8 (45.2)	P = 0.198
Type of sedation and clinical state:				
Continuous, <i>n</i> (%)	48 (60.0)	15 (48.4)	33 (67.3)	P = 0.092
Intermittent, <i>n</i> (%)	32 (40.0)	16 (51.6)	16 (32.7)	P = 0.092
With communication, <i>n</i> (%)	42 (51.3)	16 (51.5)	26 (53.1)	n.s.
With oral fluid intake, <i>n</i> (%)	53 (66.3)	15 (48.4)	38 (77.6)*	P = 0.007
With oral nutrition, <i>n</i> (%)	10 (12.5)	5 (16.1)	5 (10.2)	n.s.

system of Jonen-Thielemann into rehabilitative, preterminal, terminal and final phases [30]. With relation to intentions of care, life expectancy according to the progress of disease and empirical statistics, consideration on perhaps burdensome diagnostic and therapeutic procedures and communication strategies with patients and proxies a systematic staging of patients in palliative care on expected outcome seems to be useful. The predominant classification into the preterminal stage of most of our patients on admission signifies also the diagnostic uncertainty and difficulty with such a staging system with relationship to responsible decision-making and consequences of care.

We considered sedation as a palliative therapeutic option of last resort in the last stages of life. Many experts prefer the term "palliative sedation" instead of "terminal sedation". Though the term "palliative sedation" seems to be more appropriate, it must be distinguished from those situations in other phases of palliative care, when palliative sedation is used for burdensome diagnostic or painful therapeutic procedures (e.g. wound debridement and dressing of exulcerating tumours, insertion of catheters) and usually does not exceed the time in which the procedure is undertaken. Among the most controversial discussed issues of "terminal sedation" are the questions of when and for which forms of intractable suffering sedation may be indicated. Another central point refers to the

question of how to distinguish clearly the crucial intention of relief providing sedation from (slow) euthanasia by the application of lethal doses of sedatives [31].

In our study we found that dyspnoea, delirium and anxiety increased during the treatment period in those patients who finally had sedation while pain was significantly reduced by adequate treatment during the progressing course of the disease (Figure 2). This finding is in confirmation with other studies, in which besides acute bleeding and gastrointestinal symptoms, distressing dyspnoea, delirium and agitated anxiety also were found to be the main reasons for sedation in end-of-life care [32]. The adequate treatment and care of patients of patients with otherwise refractory symptoms certainly is a great challenge in palliative care and improvement in this field is needed urgently. Our target in sedation is calming and comfort without lowering the level of consciousness deep enough to lose communication. This also means, that sedation cannot compensate personal palliative support and care – it must be combined. Our study indicates also, that psychosocial distress contributed to the decision making, especially when patients had made an advance directive with requests for sedation in the last phase of life. In our study the shorter survival time after administration of sedation in patients who had made an request

Table 4: Predominant and concomitant symptoms on admission to PCU Havelhoehe.

Symptom	All admissions (A)		Subgroup (B)		Subgroup (C)		Significance p-Values
	All (n = 1467)		† without sed. (n = 468)		† with sed. (n = 80)		
	Predominant	Concomitant	Predominant	Concomitant	Predominant	Concomitant	
Pain	29,1%	56,3%	27,1%	54,0%	37,5%	70,0%	n.s.
Gastrointestinal (nausea, vomiting, constipation & bowel obstruction)	17,4%	71,3%	11,7%*	55,9%	8,8%*	67,5%	*p = 0.014
Dyspnoea	14,6%	31,2%	15,5%	33,1%	22,5%	46,3%	n.s.
Psychological distress (anxiety/depression)	2,4%	34,0%	1,7%	20,9%	5,0%	37,5%	n.s.
Cachexia/fatigue	9,3%	56,3%	17,4%**	65,9%	12,5%	66,3%	**p < 0.001
Cognitive disorder/ delirium (drowsiness/ agitation)	8,5%	29,1%	11,2%	29,1%	3,8%	13,7%	n.s.
Bleeding	2,4%	3,2%	1,3%	3,8%	0,0%	1,3%	n.s.
Skin (ulceration, oedema)	5,3%	42,5%	3,2%	31,4%	2,5%	35,0%	n.s.
Neurological	8,9%	33,6%	8,7%	27,1%	6,3%	26,3%	n.s.
Others	2,1%	34,2%	2,2%	22,0%	1,1%	14,5%	n.s.

for sedation might be due to the fact that in those patients the medical indications and preconditions were considered more intensively while the underlying disease progressed.

The ethical dilemmas and the possibilities to abuse sedation by turning it in a form of medicalised killing [33,34] are important aspects that seem to restrict the administration of sedatives in terminally ill patients. In studies on survival time of patients with and without sedation no significant differences were found. [35–37]. Certainly also the cultural background determines attitudes and view points to the goals of care and in which situations of "intolerable suffering" sedation is ethically acceptable [38]. In several retrospective and prospective surveys the reported frequency of sedation due to intractable symptoms in different palliative care settings ranged from 7–52% with increasing incidence especially for "existential suffering" [39–41]. Diagnostic criteria and clinical preconditions for the consideration of sedation in patients with far advanced disease have been described by several authors [42–44], but aims, targets, types of sedation and decision making remain conflicting issues.

In modern Western culture, the elements of a "good death" include, besides freedom of pain, death at home with the family members being around, amongst others also the element of "awareness". However, the technical possibilities of palliative care with concentration on quality of life also brought about a "diminished emphasis on

the good death" [45]. Consequently, the increasing requests of patients "to die in sleep" by terminal sedation could be an comprehensible alternative to euthanasia or physician-assisted suicide and must be reflected in the discussion on the value of sedation in end-of-life care. Though we could not make a clear differentiation between primary (when patients want to be sedated approaching the moment of death) and secondary sedation (when sedation results as a "side-effect" in otherwise refractory symptom control [46], it must be clear to all, that the intention of sedation in the terminal and final phase is not a concealed form of euthanasia [47]. Under ethical aspects the requests for sedation to reduce consciousness to a state of unawareness need an individual and balanced approach, especially when the wish for sedation is not connected with the intolerability of physical or psychological distress This makes it necessary to discuss the problem of "terminal sedation" like other forms of therapeutic and existential support with patients and family members at an early stage in palliative care. Sedation should be restricted as a reversible therapeutic option to otherwise refractory suffering by burdensome symptoms in the terminal and final phase, which may, but should not intentionally, hasten death. With regard to symptom relief the level of sedation must not necessarily need "deep sleep" or bring about unconsciousness. The recent consensus guidelines for dying intensive care patients released in Canada provide a clear, but certainly also problematic, definition of terminal sedation which distinguishes between "real" terminal sedation for therapeutic

intentions and terminal sedation as a possible form of euthanasia by lethal doses of sedatives. The Canadian guidelines define "Terminal Sedation" as "sedation with continuous IV narcotics and/or sedatives until the patient becomes unconscious and death ensues from the underlying illness". Emphasis is added that the balance between possible euthanasia and inadequate palliative care is achieved by titrating the dosage of sedatives so that one avoids over- or under medication to allow death to result from the underlying disease in a state of continuing unconsciousness [48].

According to our guidelines after the intended provision of relief and symptom alleviation initially our approach in most cases was to reach a state of "conscious sedation" by reducing the dosages of sedatives to a level of communication that revalidation of the clinical situation could be achieved. This form of a patient controlled sedative state was explained to the patients and family members before induction of sedation – especially to those who had a request for sedation in their advance directives. No objection to this procedure was mentioned except in one case, where a female patient requested for sedation after an emergency operation for intestinal obstruction in case that it would not bring the expected result. The intention on comfort in the terminal and final phase should be the main concern in finding ethically acceptable criteria for the use of sedation in end-of-life care and to avoid misuse of terminal sedation.

Conclusions

The results of our study indicate that sedation in end-of-life care seems to become an increasing ethical problem with attention to patients' wishes and needs and physicians' integrity. This is not only a problem for those involved in palliative and hospice care. "Since terminal sedation may arguably make the detection of euthanasia/assisted suicide more difficult... the intent of the physician is the most crucial distinction" [45]. But beside intention, the adequacy of what is done must also be taken into account. The concentration on comfort and symptom alleviation by titrating the sedative medication to a level that allows assessment and communication are important aspects which should be considered in the ongoing discussion on sedation in the last stages of life. Ethically acceptable criteria and guidelines for decision making with regard to the nature of refractory and intolerable symptoms, patients' needs, aims of sedation and informed consent are needed [49]. Based on these, prospective clinical studies with systematic documentation of cases, transparency and critical communication with regard to indications, intentions, procedures, alternatives, results and adverse effects would help to locate the appropriate place of sedation in end-of-life care and diminish misuse or moral prejudices.

Competing interests

None declared.

Authors' contributions

HCMB participated in the design, data collection, analysis, and drafting of the manuscript.

IA participated in the design and manuscript editing

TJ participated in the design and manuscript editing.

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