



## Walking the line. Palliative sedation for existential distress: still a controversial issue?

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**Abstract** Adequate symptom relief is a central aspect of medical care of all patients especially in those with an incurable disease. However, as an illness progresses and the end of life approaches, physical or psychoexistential symptoms may remain uncontrollable requiring palliative sedation. Although palliative sedation has become an increasingly implemented practice in the care of terminally ill patients, sedation in the management of refractory psychological symptoms and existential distress is still a controversial issue and much debated. This case report presents a patient who received palliative sedation for the treatment of existential distress and discusses considerations that may arise from such a therapeutic approach.

**Keywords** Palliative sedation · Existential distress · Medical oncology

### Palliative Sedierung in der Behandlung von existenziellem Leid – noch immer eine kontroverse Angelegenheit?

**Zusammenfassung** Adäquate Symptomkontrolle ist ein zentraler Aspekt in der medizinischen Behandlung von

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Patienten, insbesondere jener mit einer unheilbaren Erkrankung. Gerade am Lebensende kann es zu therapierefraktären physischen, psychischen und psychoexistenziellen Symptomen kommen, welche in weiterer Folge einer palliativen Sedierung bedürfen. Obwohl die Palliative Sedierung in den letzten Jahren eine zunehmend eingesetzte Therapiemethode für unheilbar kranke Patienten darstellt, ist sie in der Behandlung von therapierefraktären, psychologischen Symptomen und existenziellem Leid weiterhin eine kontrovers diskutierte Angelegenheit. Der nachfolgende Fall schildert die Geschichte eines Patienten welcher eine palliative Sedierung auf Grund von ausgeprägtem existenziellen Leid erhielt und beschreibt die Gesichtspunkte welche bei diesem therapeutischen Vorgehen in Betracht gezogen werden müssen.

**Schlüsselwörter** Palliative Sedierung · Existenzielles Leid · Onkologie

### Introduction

Adequate symptom relief is a central aspect of medical care of all patients especially in those with an incurable disease [1]. However, as an illness progresses and the end of life approaches, satisfactory symptom control sometimes becomes difficult [1–3]. In situations when physical or psychoexistential symptoms remain uncontrollable, palliative sedation (PS) [2–5] is a valid therapeutic intervention to relieve the patient from the burden of otherwise intractable suffering [1, 4–6]. Importantly, the intent of PS is to minimize symptom burden in a manner that is ethically acceptable to the patient, caregivers and all health-care providers involved in the sedation process [1, 4, 6]. Although PS has become an increasingly implemented practice in the care of terminally ill patients, sedation in the management of refractory psychologi-

cal symptoms and existential distress is still a subject of ongoing debate [4, 7–9]. In the following we report on a patient who received PS for the treatment of existential distress and discuss considerations that may arise from such a therapeutic approach.

### Case Report

Mr. D., a 74-year-old man was admitted to the palliative care unit for the management of recurrent episodes of asphyxia in October 2014. He had been diagnosed with squamous cell carcinoma of the oral cavity (bottom of the mouth) in November 2013. At the timepoint of diagnosis the tumor had already metastasized to the locoregional lymph nodes as well as the second and third thoracic vertebral body. The patient subsequently received debulking surgery, radiation therapy, and three cycles of combined antibody-chemotherapy with cetuximab, docetaxel, and cisplatin. A positron emission tomography scan in August 2014 showed stable disease and antibody monotherapy was continued for another two cycles.

On the day after admission the patient suffered an exacerbation of asphyxia and a lifesaving tracheotomy had to be performed. Airway obstruction had been caused by local tumor progression and was further resolved with tracheostomy. After one night at the intensive care unit, the patient was retransferred to the palliative care department in a stable and oligosymptomatic condition. Furthermore, despite the serious situation he had acutely been through his mood was positive. He communicated via written messages and his biggest wish was to regain speech with the tracheostomy and to be discharged home. Mr. D. had always been a socially active and self-determined person and seemed to cope with the new circumstances. Psychological and spiritual support was offered to the patient and his wife who was emotionally heavily burdened and was further on regularly utilized by both of them.

On day two after tracheostomy an examination revealed constant pulmonary aspiration and pneumonia and the patient was put on oral abstinence and intravenous antibiotics. A percutaneous endoscopic gastrostomy was not performed because of elevated C-reactive protein levels. Instead the patient received a peripherally inserted central catheter and artificial nutrition and hydration was begun.

Mr. D. received speech and physiotherapy therapy every day. He was still motivated to regain speech and was mobile without need for assistance. However, he then began to get weaker and his mood was worsening. In the second week after tracheostomy the patient was told that a regain of speech would be impossible because of damages of the vocal cords caused by radiation therapy and local inflammation. Furthermore Mr. D's oncologist and otolaryngologists involved were unable to provide further meaningful therapy to prevent tumor growth. Mr. D. reacted with desperation and during the nighttime subsequently experienced recurrent episodes of anxi-

ety and panic which were accompanied by suffocation attacks. During daytime Mr. D. did not leave his room, refused physiotherapy and visitors with the exception of his wife and daughter. A consulted psychiatrist recommended the use of intravenous antidepressants and sleeping medication.

In a family conference with the patient, his wife and daughter, Mr. D. clearly stated that he wanted to die. Specifically, he requested physician-assisted suicide and therefore got informed that this practice was illegal in Austria and thus not an option. At the core of Mr. D's distress was the inability to bear the burden he felt that he was imposing on his family, as they were forced to watch him die slowly. He agonized about the prospects of being unable to speak and eat and not being able to continue the life he was leading before. He clearly refused life-prolonging medications such as artificial nutrition and antibiotics.

In order to relief the patient's existential distress, intermittent sedation overnight with continuous low-dose midazolam (0.2 mg/h) was begun. With this treatment Mr. D. had calm and restorative night rests. Despite exhaustive attempts from the multiprofessional team, Mr. D's psychological and existential distress did not alleviate. Physical weakness began to get worse. A few days later Mr. D. again experienced great despair and anxiety and requested sedation throughout the day. Midazolam was now continuously infused with a dose of 0.5 mg/h and Mr. D. was calmly dozing but easily woke up when someone approached and spoke to him. On the basis of this decision a discussion in the palliative care team arose if continuous PS in this situation was appropriate and sedation rate was reduced again. A few hours later Mr. D. got agitated and anxious and PS was increased back to 0.5 mg/h. For the next 2 days sedation rate was kept the same and Mr. D. seemed calm, relaxed, and interaction with his family was still possible. His physical condition worsened, he got fever and urinary infection was suspected. Mr. D. again clearly refused antibiotic treatment and died 3 days later in the presence of his wife.

### Discussion

PS is an increasingly used therapeutic approach in the treatment of terminally ill patients who suffer from severe and refractory symptoms [1–5, 7, 9–11]. In its clinical practice however, health-care professionals are still facing numerous clinical and ethical challenges and literature indicates a considerable heterogeneity concerning frequency as well as indications [1, 4, 9]. In the last years international medical associations [4, 12], national bodies [13–15] as well as local institutions [16, 17] have tried to develop guidelines and policies with the aim of defining PS but to date there are no randomized studies addressing this intervention and assertions are based on expert opinions and case control series [7, 18].

Refractory delirium and dyspnea are among the most common symptoms requiring sedation at the end of

life [11, 19]. Older studies show an overall prevalence of refractory symptoms requiring sedation ranging from 10 to 50 % with a median estimate of 20–30 % which is confirmed by newer data [10, 11, 20–24]. However, sedation may not only be considered for physical symptoms but also for nonphysical suffering such as refractory depression, anxiety, demoralization, and existential distress [1, 4, 8]. Although sedation for existential stress has been actively discussed in palliative care literature [1, 4, 8, 21, 25, 26], empirical reports about its practice are still limited.

The EAPC framework for the use of PS demands at least four special considerations to be taken into account for the treatment of refractory existential or psychological distress [4].

- Due to the nature of psychological symptoms it is much more difficult to establish that they are truly refractory.
- The severity of distress of these symptoms in the course of a disease may be dynamic and idiosyncratic and psychological adaptation or coping in the course of the disease are common.
- The presence of psychological symptoms does not necessarily indicate a far advanced state of psychological deterioration.
- The standards of treatment approaches have low intrinsic morbidity such as the use of psychotherapy and spiritual support or religious counseling.

But how to translate those considerations into clinical practice [27, 28]? Importantly, sedation especially for psychological symptoms should be reserved for patients in advanced stages of a terminal illness [4]. Furthermore the designation of refractoriness should only be made following a period of repeated assessment by clinicians who are also skilled in psychological care. Because of the complexity that may arise of such situations, evaluation should only be made in the context of a multiprofessional team involving representatives from psychiatry, psychology, ethics as well as chaplaincy [1, 4].

If sedation as therapeutic approach seems appropriate and proportionate to the clinical situation it should always been done on a respite basis [1, 4]. Respite sedation is defined as sedation for a predetermined amount of time (usually 6–24 h) with a planned downward titration of the sedating medication after a pre-agreed interval. After reawakening of the patient, reassessment of the extent of symptom relief and the further need of sedation is possible. Continuous sedation should only be favored if repeated trials of respite sedation have failed to achieve sufficient symptom control [4]. As many terminally ill patients are confronted with an overwhelming vicious circle of symptoms of fear, fatigue, anxiety, and insomnia, respite sedation may break a cycle of sleep deprivation and existential distress and allow the individual to regain psychological strength [26, 27].

As described in our case report, special attention has to be paid to psychological care for patients with head

and neck cancers. Particularly facial disfigurement which may arise from tumor destruction may result in changes in appearance and difficulties with communication and eating [29]. This further may have tremendous social consequences and leads to increasing anxiety, depression, and social isolation for the individual and his caregivers [29, 30]. Importantly, situations in which a patient requires sedation for existential distress can often be profoundly distressing for the patient's family as well as the team. Through multidisciplinary assessment, stress for health-care professionals involved in the caring situation can be reduced. Furthermore, feelings of finality and guilt which may arise in caregivers may be alleviated through such an approach [1, 26].

In conclusion this case report shows the complexity of the management of refractory psychological symptoms and existential distress. Given that existential suffering can be just as consequential and debilitating as physical suffering, PS is a critically important therapeutic tool of last resort in the management of terminally ill patients to provide relief from intolerable distress. However, especially in the management of refractory existential distress special caution and multiprofessional effort should be undertaken to ensure that all required preconditions for palliative sedation have been met. As with many other questions in medicine, the controversy that still surrounds PS and especially sedation for the management of psychological distress is probably not a question of "for or against?" but "when and how?."

#### Conflict of interest

Schur S, Radbruch L, Masel EK, Weixler D, and Watzke HH declare no conflict of interest.

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