Ethics Rounds
Edited by Joseph J. Fins, MD

To Sedate or
Not to Sedate?
Sophie Pautex, MD,
and Gilbert B. Zulian, MD

Case Presentation

Mrs. D., an 84-year-old woman, was well until October 2004, when she was admitted for asthenia and dysesthesia of the right hemibody. Magnetic resonance imaging of the brain revealed a large tumor mass infiltrating the left parietal cortex. Radiologic enhancement after gadolinium administration suggested the diagnosis of aggressive glioblastoma. She refused diagnostic craniotomy, surgery, radiation therapy, and chemotherapy. She thus received symptomatic treatment with corticosteroids and returned home. Two months later, she was admitted to the Geriatric Hospital with marked asthenia, anorexia, anxiety, and right-side weakness.

The patient lived alone at home since her husband died five years earlier. She had no children. Her social network was small, but she had two friends. Past medical history was notable for hypertension and chronic back pain. Mild depression that followed the death of her husband required an antidepressant drug during a few months.

Mrs. D. was willing to make her own decisions about end-of-life care and asked to write advance directives according to a specific legislation. She wrote down her advance directives with the help of specialized health professionals. Her concerns about physical symptoms such as pain and dyspnea were discussed in detail, but psychosocial problems such as loss of self-esteem, loss of intellectual and social functions, anxiety and agitation were apparently left aside. An advanced treatment plan about sedation, partial or complete, transient or terminal, reversible or irreversible, was not discussed, and neither hydration nor nutrition was mentioned during the interviews. No surrogates were identified.

Mrs. D. finally wrote down:
- I refuse admission to the ICU.
- I refuse attempts to be resuscitated.
- I want symptoms to be alleviated even if I would lose consciousness.
- I want to be sedated in case of intractable symptoms.

One month later, during the same hospitalization, Mrs. D.’s cognitive functions progressively deteriorated, and she became increasingly anxious and agitated. She was dysphasic, and existential distress related to communication impairment was prominent. Modifications of her body image and general functioning, together with increased dependency, added to her distress. Finally, hopelessness and the perceived meaninglessness of her present condition were increasing her concerns about death. Somatic causes or chemical reasons for delirium were not found.

Corticosteroids were first increased to control the possibility of raised intracranial pressure, but without any apparent effect. Psychiatric opinion was obtained and various drugs, such as oxazepam, alprazolam, quetiapine, amisulpridum,
and citalopram, were administered, with few results. Mrs. D. remained anxious and agitated; physical symptoms were well controlled.

According to her advance directives, the introduction of palliative sedation was then discussed by the multidisciplinary team. Mrs. D.’s quality of life was clearly undermined because of anxiety, agitation, irritability, and loss of intellectual and social functions. Several nurses, the junior and the senior residents, and the consultant psychiatrist attended the meeting. The nurses emphasized her existential suffering and the need to relieve her symptoms. The physicians focused on the objective to find the right pharmacological treatment for her anxiety and agitation. Despite this apparent disagreement, a multiprofessional consensus was eventually reached. It was decided not to introduce palliative sedation, although distress was recognized, because Mrs. D.’s condition was assessed as too good. Thus, the existential distress was not considered as a refractory symptom. Temporary sedation for a few hours—during the day or at night—or a mild conscious sedation was considered as a therapeutic option by the team during their meeting. However, the risk that Mrs. D. would develop delirium with further agitation because of the combined factors of age, advanced central nervous system (CNS) disease, and hospitalization was estimated high enough to prohibit safe implementation of the procedure. The clinical situation was, therefore, not modified, and no improvements were seen over the few next days. One week later, Mrs. D. developed chest symptoms as the result of probable pneumonia. Antipyretic drugs were prescribed, and she died three days later.

**Commentary**

Today, physical symptoms such as pain, dyspnea, or nausea are considered valid indications for sedation, but this has not always been the case. In recent history, before strong opioids were made widely available, many would have accepted pain as an inevitable companion of the last portion of life. With the advent of palliative care and the perceived right to pain relief, physicians are now faced with the obligation to do something effective in the presence of refractory pain that is not responding to the best analgesic treatment. Sedation has become the appropriate medical answer. Not so long ago, severely dyspneic patients in palliative care would have been left with some oxygen, bronchodilators, diuretics, anxiolytic drugs, and reassurance until their last breath. Sedation was not considered as an alternative medical treatment for their suffering. However, the analogy with the supposed suffering of drowning and suffocation has now made severe dyspnea an almost standard indication for sedation. The same applies to intractable nausea and vomiting resulting from intestinal obstruction, which in the past was routinely offered a nasogastric tube and continuous aspiration until the end of life. Sedation here also eventually became a valid alternative.

In contrast, sedation is rarely administered in the case of refractory psychological symptoms and existential suffering. Cassel defines suffering as a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. Physicians are primarily trained to find out what is wrong with the body in terms of disease or pathophysiology. Medical decision making thus follows different lines in the presence or in the absence of identifiable causes of symptoms.

Since Jean-Paul Sartre, a French novelist and philosopher who developed “existential philosophy,” focused on the human experience of “being,” the notion has been advanced that humans should be able to create for themselves a meaning or purpose, to find a sense in life, a symptom or maybe in existential suffering. In the case of communication incapacity and cognitive impairment, this attempt is much more difficult. Furthermore, suffering is a subjective phenomenon, and only patients can determine the level of tolerability. In the case of communication difficulties and in the absence of proxies who could estimate the degree of discomfort, it is left to the care team to assess the level of tolerable suffering. Advance directives are important in helping clinicians decide on the best of care according to patients’ wishes. Although personal thoughts of health professionals have to be taken into account during the care process, assumptions and preconceived ideas should be left aside if the objective is to fully respect patients’ autonomy.

Mrs. D. had many reasons to suffer from existential distress. She complained of dysphasia, alterations of her body image, and a decline in general functioning, together with increased
dependency. A sense of hopelessness or meaninglessness in her present condition was most probably increasing her own concerns about death. But sedation was not provided to Mrs. D. Moreover, temporary sedation to evaluate whether better symptom control was achievable was considered inappropriate in this case.

In an effort to do no harm, the health professionals were more concerned about the hypothetical side effects of sedation rather than the expected symptomatic relief of suffering. This may indicate a paradoxical excess of beneficience—a troubling attitude.

The lack of well-established therapeutic strategies for existential suffering made it difficult to conclude that the symptom was refractory, and this was a barrier to the introduction of palliative sedation by the team. Another important point was the prognostic uncertainty of her condition. Despite such a high level of suffering, Mrs. D. could walk and take small amounts of food and fluid. This may well have been misinterpreted as a reassurance of her state of health.

"Quand l’apéritif va, tout va," i.e., literally "When appetite is OK, everything is OK," is a popular French proverb. This may have added to the false appraisal of her general condition. At the time, nobody was prepared to accept that Mrs. D. was in her last days of life. The usual criterion of apparent imminence of death was not present, although the median survival of patients with Mrs. D.’s kind of tumor is six months.7–9 The absence of pathological diagnosis also may have added to the uncertainty about the imminence of death.

Although whole patient care and the recognition of the impact of psychosocial suffering on quality of life are championed by health professionals involved in palliative care, there is a tendency to remain silent on how to manage troublesome situations when all best efforts otherwise have failed. Cultural differences, religious beliefs, and social environment are sometimes advocated to explain that the best of care is not provided to the patient in need. This should not be accepted in palliative medicine, specifically in the presence of established and recognized advance directives.

The appropriateness of terminal sedation in the presence of nonphysical symptoms remains controversial, and further research is needed to establish standard therapy for existential distress of terminally ill patients, in particular when patients cannot communicate. Palliative care specialists are among the few clinicians capable of establishing existential suffering at the same level as physical suffering. When a patient with advanced disease decides to complete advance directives, information and education about palliative sedation are crucial. A clear goal must be established with the patient, the surrogate, and the caregivers. The difference between intractable physical and nonphysical symptoms should be openly discussed, and a detailed treatment plan should be developed to include hydration and nutrition, and the depth and duration of sedation.

References