Sedation for Intractable Symptoms in Palliative Patients: A tale of two patients

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Palliative sedation can be defined as the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness.[1] The reported worldwide incidence of intractable symptoms requiring sedation ranges from 7% to 52% with the most common indications for sedation being refractory delirium, dyspnea, pain, nausea, existential distress, catastrophic terminal events such as a massive hemorrhage or sudden asphyxia, and seizures[3]. Although a well-established therapeutic procedure in the palliative population, this option remains a controversial subject because of the ethical implications this decision holds for health professionals, patients and families. Often at issue is the differentiation between sedation for intractable symptoms and euthanasia. The key differentiation is in terms of intent. The intent of palliative sedation is the relief of intractable distress whereas the intent of euthanasia is to end life. Recent studies have indicated that the use of sedation does not hasten death in palliative care patients [2,4]. A systematic approach can help patients, family members, caregivers and health professionals determine whether sedation is an appropriate option.

The following two cases illustrate the value of such an approach when considering the use of sedation.

Case 1
A 60 year old man with a diagnosis of advanced ALS who was dependant on a ventilator wished to discontinue the use of the ventilator. He was assessed by a psychiatrist for the presence of depression and was found to be not depressed. In addition to support from family and friends, he was supported by members of the ALS society of Edmonton. An interdisciplinary meeting was held which included the patient, family members, the Palliative Home Care Nurse, his neurologist, an RN, a representative from Community Mental Health, the patient's clergyman, and his respiratory therapist. The decision was made to discontinue the respirator in two weeks time with ICU support available if necessary. His neurologist initiated the sedation with his Home Care Nurse and stayed during his few remaining hours.

Case 2 outlines a more complex situation in which patient autonomy, competence in decision-making, lack of multidisciplinary assessment and support, lack of family doctor support and family members' discomfort with the ethical issues surrounding the use of sedation were the prominent concerns.

Case 2
A 68 year old man with a diagnosis of non small cell lung carcinoma, Stage IIIB had received palliative radiotherapy but due to the advanced stage of his disease at the time of diagnosis, no further oncological options were available. This retired mechanic had a

substantial history of smoking and alcohol consumption as well as physical and verbal abuse towards family members. He shared a house with his wife and granddaughter.

Following his palliative radiotherapy, he functioned reasonably well for six months until he developed an irreversible agitated, paranoid delirium and was striking out at family members and health care professionals. He had consistently refused to consider the use of sedation or admission to acute care or to hospice up until this point and was now not competent to make decisions regarding health care options and was in danger of harming himself and others. The patient and the family doctor had declined a multidisciplinary assessment. A variety of sedative medications had been tried in order to relieve his agitation, but to no avail. His family wished to honour his desire to die at home without sedation, as they were concerned his life would be shortened by the use of sedative drugs. His family doctor was unable to make home visits and refused to provide prescriptions for medications at this time. After the involvement of two palliative care physicians, the family agreed to go ahead with sedation at home. The medications and equipment were ordered and delivered but due to the family's discomfort with the ethics of sedation, the patient's aggressive behaviour and the lack of support from the family doctor, the home care nurse felt she could not initiate sedation. Emotionally and physically exhausted, the family requested admission to the Tertiary Palliative Care Unit for palliative sedation. He was shortly thereafter admitted, sedation was initiated, and he died comfortably after a few hours, surrounded by family members who, after being supported by the staff on the unit were eventually content that they had made the right decision.

When should palliative sedation be considered?

- The patient has a terminal diagnosis and his or her prognosis is limited to hours to approximately one week
- A DNR order is in place
- The patient's symptoms have been determined to be refractory. A refractory symptom is one for which after repeated assessments, all reasonable therapeutic options have been exhausted and additional interventions have no realistic chance of providing relief to the patient or may cause significant or chronic discomfort.
- The patient or their proxy, family members and members of the multidisciplinary team have been involved in the decision regarding the goals of sedation. Preferably, this is accomplished when the patient is able to fully participate in the discussion. This provides an opportunity for airing of concerns regarding ethical implications as well as practical issues such as the timing of initiation.
- Palliative sedation for common intractable physical symptoms such as delirium, dyspnea, pain or nausea at the end of life is generally less controversial than for patients suffering irreversible existential distress, which has been defined as fear and suffering associated with the anticipated end of the human experience[3]. For the very few patients who are evaluated for sedation for existential distress, depression must be ruled out and psychological and spiritual assessments undertaken

What is required for sedation at home?

- Two full-time caregivers who are able to provide comprehensive and consistent care
- A committed family doctor who is able to make home visits
- Access to 24 hour palliative care nursing and physician consult services

In our program, palliative sedation is most often accomplished by the use of gradual titration of a constant subcutaneous infusion of midazolam. A copy of our clinical practice guidelines for this procedure can be requested by calling the Regional Palliative Care Program Office

References:

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