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Palliative Care for "Margaret"

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A few years ago, when I was the medical director of our hospice program, I was asked whether we would be able to provide palliative care for "Margaret." More specifically, if palliative sedation were needed to provide relief of her symptoms, could we — would we — be willing to provide it? When Coleen Reid, MD, a palliative care physician at Hospice of North Shore, contacted me, we discussed her review of the patient's records, assessment of the patient, options for treatment, symptoms, consultations from the medical, psychiatric, and ethics services, and her meeting with Margaret's professional caregivers and children.

Dr. Reid sent me the medical, psychiatric, and ethics consult notes, Margaret's advance directive, and a letter from her children [which appears in this issue of *JCE,* "A Letter from the Children"]. I reviewed Dr. Reid's recommendations and notes on Margaret's initial response to treatment with narcotics. Based on that information, I agreed that we would care for Margaret at Tippett Home — a 10-bed former mansion with homey common rooms, private patients' rooms, and 24-hour nursing and assistant staff on-site, dedicated to providing care and support for patients and families, along with a team of other staff, to help when needed.

Palliative care refers to whole-person care for patients whose diseases are not responsive to curative treatments. It is provided by an interdisciplinary team (IDT), includes very aggressive measures to control pain and other distressing symptoms, and can be provided in combination with treatments to control the progression of the disease or to facilitate remission.

Hospice is a program that provides coordinated comprehensive palliative care to patients who are terminally ill — and to their families — through an IDT who address clinical symptoms and psychosocial and spiritual needs.[1] Typically, hospice provides comprehensive care to patients with terminal illnesses. In the United States, the criteria for hospice care that has been stipulated by Medicare (and in Massachusetts by Medicaid and most private insurers) include the following:

- Having a terminal diagnosis,
- Having a prognosis of six months or less if the illness takes its usual course, and
- Selection of hospice care by the patient or surrogate.

Palliative care and *hospice,* even though occasionally confused, are commonly used and are generally well understood.

Palliative sedation (PS), on the other hand, is not common and not well understood. PS involves treating the patient's distress by inducing as deep a level of sedation as necessary, with the sole intent of relieving refractory symptoms. It stands in contrast to the usual goals of palliative care, in which every effort is made

to preserve consciousness while controlling pain, anxiety, agitation, the experience of breathlessness, existential suffering, and the like. PS may be defined and clinically characterized as the primary intention of deliberately inducing a temporary or permanent light-to-deep sleep, but not deliberately causing death, in patients with terminal illness and specific refractory symptoms.[2] While PS still requires a consistent definition and well-designed research, and is not infrequently confused with assisted suicide or with euthanasia, experience is demonstrating that PS can offer an important option for a more comfortable and dignified death for some patients. Within hospice it is increasingly recognized as a valuable palliative intervention, although it is used rarely — and with great care.

Our hospice program, acknowledging the occasional need to offer the choice of decreased consciousness to relieve significant refractory symptoms, developed a policy and procedure for PS with help from the Ethics Committee, Professional Advisory Committee, Board of Directors, and an attorney. Education about PS was provided for IDT staff, hospice residence staff, and volunteers. Our policy and procedure provides definitions of PS and refractory symptoms and also defines the purpose and intent of PS. A decision to use PS requires the following:

1. Review by the hospice medical director and vice president for hospice.
2. A do-not-resuscitate order and designated healthcare agent.
3. An option for psychiatric consultation at the discretion of the attending physician.
4. A meeting of the patient and family with the hospice medical director, appropriate members of the IDT, and, if possible, the attending physician for full discussion and consent.
5. The agreement of the attending physician.

We have a protocol for administration of the sedating agent (usually not a narcotic) and references for the sedating agents that are most commonly used.

PS is rarely used in the hospice programs with which I am familiar. Within the past year I have met with six patients in family meetings to describe the option of PS (out of the approximately 1,300 patients who received care during this time in the two programs for which I am medical director). All were relieved to know that PS would be possible if needed. In only one case have we resorted to PS when symptoms became unbearable. We didn't know whether Margaret would need it.

First, we needed to consider whether Margaret's end-stage dementia was a terminal illness. According to U.S. statistics for the most recent years, more than 50 percent of patients who receive hospice care now have end-stage system diseases with non-cancer diagnoses. Patients with dementia are well represented in this group. As hospice experience has increased, the National Hospice and Palliative Care Organization has developed guidelines for determining prognoses for non-cancer diseases. Combined Medicare and Medicaid services have adapted these guidelines to provide similar guidelines for local coverage determinations.

The guidelines for dementia refer to *primary, chronic, and progressive* cognitive impairment. Patients with very advanced dementia may live for a long time — years — depending on whether they have comprehensive care and other minor medical problems). Indicators of six-month mortality for advanced dementia include:

1. Functional decline, indicated by an inability to be independent in activities of daily living such as ambulating, dressing, bathing, toileting, and an inability to speak or communicate meaningfully.
2. The presence of medical complications, such as aspiration pneumonia or other significant infections, difficulty swallowing, or refusing to eat resulting in insufficient intake to sustain life, with a patient's or a surrogate's decision not to have tube feedings or intravenous nutrition provided medically. An unintentional weight loss of more than 10 percent in six months is considered an indicator for the likelihood of death within six months.[3]

Margaret's dementia was somewhat atypical in its early onset, frontotemporal symptoms, and marked agitation. Nevertheless, it had progressed to a very advanced stage, despite extensive work-up and efforts to reverse and/or treat its manifestations. Margaret's nutritional status had declined, and she had lost about 65

pounds because of her agitation and difficulty eating, either by herself or when fed. She weighed 132 pounds when she came to hospice. Her written directives for care, and the representations of her children (including her designated healthcare agent) regarding their understanding of her wishes, were clear that Margaret did not want medical nutrition and hydration even though she had lost considerable weight because of her diminished oral intake. Inadequate oral intake is common in end-stage dementia, though patients who are calm and willing can often be fed fairly adequately for a long time if their caregivers are persistent and patient. With Margaret's aggressive agitation, I assume that it was difficult or impossible for staff to supplement what she was able to eat on her own. There is increasing clinical evidence that, for patients with severe dementia, the benefits of tube feeding do not outweigh the burdens.[4]

So Margaret clearly met the guidelines for hospice care. The primary goal in our plan of care for Margaret was relief of her distress, whatever the cause. After several unsuccessful trials of medications primarily intended to control her agitation, her physicians at the psychiatric facility determined that a trial of opioids should be attempted, supplemented by medications to further relieve restlessness and other symptoms. At this point it might be of academic interest, but not necessarily helpful, to make a distinction between pain due to *physical causes,* pain due to *existential suffering,* and distress due to *other causes.* In any event, if the opioids would provide relief, they were clearly indicated. If Margaret could be calmed enough to accept care, we could help her with personal hygiene and feeding. The risk of aspiration while eating and drinking and the possibility of falling would remain, although standard precautions could be taken to reduce them.

Another important goal was support for Margaret's children. These young adults had cared for their mother for several years at home and had remained very involved through Margaret's long hospitalization. For some time she had not known them. Margaret was divorced from their father, who was in a nursing home with a degenerative chronic illness. The children were already coping with significant losses. The involvement of members of our team might be helpful to them — a social worker, a pastoral care coordinator, a bereavement coordinator, and a volunteer coordinator. Since Margaret was no longer able to participate in decision making, although she had prepared directives three years prior when she must have experienced earlier stages of cognitive loss and perhaps anticipated to some extent her eventual impairment, the burden of making ethical choices for her would fall upon her children, especially her son, whom she had appointed as her healthcare agent. Fortunately, Margaret's written preference for non-aggressive treatment, no feeding tube, and care focused on comfort was clear.

So Margaret left the geri-psych ward and came to Tippett Home. According to her transfer and admission records, she was alert, disoriented, confused, and unable to communicate. She did not appear to be in pain, but was anxious and agitated. Occasionally she vocalized with loud screeching, and attempted to walk. Due to recent falls, she was bruised on both knees. She required total care and was incontinent. There was an order in her chart not to do cardiopulmonary resuscitation if her breathing or heart stopped. On the Karnofsky Performance Status Scale (a standard measure of function) she scored 30 percent (severely disabled although death not imminent). Described as having very poor po [oral] intake, she was able to drink some fluids and take a high-calorie dietary supplement. Her psychosocial and spiritual needs were assessed, and a priest, who was a friend of the family, visited Margaret and performed the Sacrament of the Sick.

Upon admission, Margaret's main medication was methadone 5 milligrams [mg] to be given by mouth at 9 a.m., 1 p.m., and 9 p.m. for agitation. She could also be given any of the following medications if she needed them: olanzapine (commercially named Zyprexa or Zydis), an orally disintegrating tablet, 5 mg every six hours as needed for agitation; lorazepam (Ativan), 1 mg by mouth under the tongue every six hours as needed for agitation; haloperidol (Haldol), 1 mg by mouth under the tongue every four to six hours as needed for agitation; acetaminophen (Tylenol), 650 mg by rectal suppository every four hours as needed for fever; hyoscyamine (Levsin), 0.125 mg by mouth under the tongue every four hours as needed for secretions and airway congestion; scopolamine (Transderm Scop), one to four transdermal patches every 72 hours as needed for airway congestion. In addition, she received laxatives because the medications to treat agitation tend to slow down bowel activity.

During most of her time at Tippett Home, Margaret was in bed and unresponsive, her condition very

poor. She was weak and had significant congestion, which was treated with hyoscyamine four times a day for the first three days — then none. Aside from occasional sips, she took very little orally. One or more of her children were with Margaret day and night, often with several other family members visiting. The hospice chaplain offered her supportive presence, encouragement, and a blessing for spiritual comfort. The social worker noted that the children seemed ready for their mother's death after her prolonged illness, and that she had been a strong model for them before her illness. Because of Margaret's young age, her children were young adults and would be at higher risk for severe bereavement, although this seemed to be offset by the close supportiveness of the children and family.

During the first three days, Margaret had recurring fevers (100.6° Fahrenheit). Her attending physician visited and thought the most likely cause was aspiration pneumonia. Margaret was given acetaminophen three times on the second and third day of her stay, with good effect. It was needed only once on days four and five. On the second day, Margaret had an episode of inconsolable screaming and occasionally had lesser degrees of agitated behavior. Lorazepam was given three times on days two and three, usually with apparent relief. Haloperidol was given once on days two and three only.

Margaret's nurse noted increasing restlessness at night, possibly secondary to pain. This was discussed with the attending physician who ordered an increase in the frequency of methadone to every six hours, and morphine (Roxanol), 5 mg to 10 mg under her tongue every three to four hours when she needed it for breakthrough pain. From this time on, Margaret was given olanzapine every six hours and lorazepam every four to six hours fairly regularly, which calmed her episodes of agitation.

On the third day, Margaret's care was discussed at the weekly meeting of our IDT. They noted Margaret's increased agitation that day, the changes in her medication orders, and the likelihood that she was developing aspiration pneumonia. Since diagnostic procedures would not provide more comfort or quality of life, palliative measures were continued to control the fever and to provide as much comfort as possible without a medical investigation into the cause of her fever.

I visited Margaret in the residence on day four. She appeared to be comfortable in bed, her eyes open but not seeming to connect with those in the room. One of her daughters sat beside her, gently patting or holding Margaret's hand, while enjoying conversation with a cousin, the cousin's young child, an aunt, and one or two other extended family members. They were very grateful for the homelike setting and greatly relieved that Margaret seemed to be peaceful most of the time. Their reminiscing was delightfully upbeat. While I was present, Margaret received some medications, coughing a bit and becoming agitated with unintelligible moaning for about five minutes until she again settled into what seemed a restful state. I had the impression that Margaret had some deep sense within her of the presence of those she knew — her family agreed. Although I knew that might be wishful thinking, it seemed a welcome comfort for her family members. They were aware that the end was near and did not want her to suffer any more.

From day four, Margaret declined more quickly, with increasing spells when she didn't breathe, choked when taking medications, and had congestion in her airway. Her final week was marked by periods of seeming to be comfortable, sometimes arousable, mostly unresponsive, interspersed with occasional episodes of agitation treated with lorazepam and olanzapine. Her condition precluded being able to take more than occasional fluids. Advanced dementia and minimal nutrition certainly contributed to her debilitated state. Medications that provided relief from episodes of agitation probably contributed to her decreasing ability to swallow and to handle secretions. It was not necessary to resort to PS to relieve Margaret's symptoms.

On the sixth day, one dose of Roxanol 5 mg was given. Later that day, Margaret died peacefully with her son, aunt, and uncle at her bedside. Her children expressed relief that their mother was comfortable in her last days. They continued to be included in bereavement support by hospice staff through the year following Margaret's death.

Margaret's young age and prolonged severe behavioral disturbance were unique features in an otherwise quite typical case of far-advanced dementia. The hospice team and staff were happy to provide comfort and support to her and her family during the final days of Margaret's untimely dying.

NOTES

1. P. Storey and C. Knight, *UNIPAC One: The Hospice/Palliative Medicine Approach to End-of-Life Care, Hospice/Palliative Care Training for Physicians,* 2nd ed. (American Academy of Hospice and Palliative Medicine, 2003), 17.

2. P. Rousseau, "Palliative Sedation in the Management of Refractory Symptoms," *Journal of Supportive Oncology* (March/April 2004): 181-6.

3. *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases,* 2nd ed. (Arlington, Va.: Medical Guidelines Task Force, Standards and Accreditation Committee, the National Hospice Organization, now the National Hospice and Palliative Care Organization, 1996), 12-3; C. Wolfson et al., "A reevaluation of the duration of survival after the onset of dementia," *New England Journal of Medicine* 344, no. 15 (2001): 1111-6.

4. M. Gillick, "Rethinking the role of tube feeding in patients with advanced dementia," *New England Journal of Medicine* 342, no. 3 (2000): 206-10; T. Finucane et al., "Tube feeding in patients with advanced dementia: A review of the evidence," *Journal of the American Medical Association* 282, no. 14 (1999): 1365-70; R. McCann, "Lack of evidence about tube feeding — food for thought," *Journal of the American Medical Association* 282, no. 14 (1999): 1380-1.

Note: Throughout this case, the names of the patient and her children have been changed. Quotation marks have been used around these changed names at their first appearance in an article. No other information has been masked or changed in this case. The information presented in this case is used with the permission of the patient's children and the other parties involved.