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Suffering in Advanced Dementia: Diagnostic and Treatment Challenges and Questions about Palliative Sedation

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"Margaret" appeared to be afflicted with Pick's disease, a form of dementia that is often associated with personality changes; the age of onset for Pick's is 10 years earlier than Alzheimer's dementia. Margaret's family had her admitted to a psychiatric facility for treatment of violent agitation. During this six-month stay, she was noted to have intermittent vaginal bleeding. Although the palliative care consultant was aware of the bleeding and wondered if Margaret had a gynecologic source of pain, her physicians did not pursue this possibility. They may not have fully recognized the potential relationship between bleeding, pain, and agitation. Pain is a well-recognized cause of agitation, combativeness, and increased vocalization in demented patients.[1]

Vaginal bleeding and pain syndromes may be caused by a number of conditions including endometrial cancer, cervical cancer, or even uterine fibroids. An ultrasound of the abdomen is a simple and non-invasive test that may have helped Margaret's physicians identify the cause of the bleeding, as well as the source of her pain. Information from an ultrasound may have assisted in the development of a more effective palliative treatment plan, improved cooperation from the nurses in providing narcotic medication, and may have helped the family in at least two other ways. First, assuming that the bleeding was from a uterine malignancy, Margaret's daughters would have found this information relevant to their own personal health. Second, it could have helped the family make better sense of her behavior.

Why did Margaret's physicians leave her vaginal bleeding unaddressed? We can only speculate. Medical decision making is highly complex, and it is well recognized to be compromised sometimes by one or more cognitive shortcuts. For example, the *availability heuristic* describes a tendency to limit decisions to choices that most readily come to mind, and the *anchoring heuristic* describes a tendency to limit decisions to initial or established impressions. Research on judgment and decision making identifies numerous other challenges in decision making, such as biased thinking and framing effects.[2] These obstacles in clinical decision making give rise to the admonition attending physicians direct towards medical students: "You can't make the diagnosis if it isn't in your differential."

Hypothetically, if Margaret's vaginal bleeding led to a provisional diagnosis of uterine cancer, the palliative care physician, in anticipating difficulties in controlling Margaret's pain, could begin to discuss pallia-

tive treatment options. When traditional use of systemic opioids fails to control pain or other symptoms, an accepted but still somewhat contentious option is terminal sedation (TS). TS would have likely caused her to die sooner, since it necessarily causes the cessation of all oral intake, and the dehydration that follows usually causes death within a few days. Obviously, TS palliates both physical and existential suffering.

While it would be imprudent to comment on this case specifically, an alternative palliative treatment option for some patients with severe visceral pelvic pain is a hypogastric nerve plexus block that can provide significant relief in 70 to 75 percent of patients and allows for a 50 percent reduction in the use of systemic opioids.[3] Although the procedure, which involves inserting a needle through the skin to reach the nerve plexus, carries with it some risks and the procedure itself may be uncomfortable, it is generally recognized as safe and tolerable. For demented and agitated patients, however, sedatives may need to be administered to safely complete the procedure.

Even though Margaret's clinical course did not require use of TS or invasive palliative procedures, a dilemma that clinicians, patients, and families could conceivably face is the choice between these two options: certain and complete symptom palliation at the cost of earlier death or less complete pain relief at the cost of an imperfect, invasive procedure. Professional guidelines typically require that physicians make exhaustive efforts to palliate symptoms without compromising consciousness before resorting to TS.[4] Yet a patient, relative, or even a physician might ask: Should TS always be an option of last resort? Consider a patient with widespread colon cancer suffering from refractory nausea, vomiting, and abdominal pain due to a related bowel obstruction. A diverting loop colostomy is a relatively straightforward and effective palliative surgical procedure. Should TS always be the last intervention, or should other considerations, such as the patient's expected survival, the burdens of the invasive treatment, and expected extent of palliation, existential suffering, and patient's preferences, permit TS to be chosen over a nonterminal intervention?

What are physicians' professional and ethical obligations when a nonterminal invasive palliative treatment will preserve a quality of life that is not valued by the patient? Although TS has substantial support in the treatment of physical suffering, whether TS is appropriate for existential suffering alone remains quite controversial, particularly because, in the minds of many, TS abuts the boundaries of active euthanasia.[5] Does choosing terminal sedation over nonterminal invasive palliative treatments also blur the boundary between treatment and active euthanasia?

The case of Margaret illustrates some of the challenges often present in geriatric medicine and dementia care, palliative medicine, and end-of-life care. One challenge is to diagnose and treat patients who often are limited in their ability to participate in their care. Another challenge is to resist making assumptions about patients' or families' goals of care, because, despite many shared features among these kinds of cases, each one is unique. Lastly, a great challenge is for health professionals to work with patients and families in developing a consensus around care goals and for these professionals to work with one another to implement plans of care that are often ethically charged.

NOTES

1. D.B. Reuben et al., *Geriatrics at Your Fingertips,* 7th ed. (New York: American Geriatrics Society, 2005); M.D. Buffum et al., "A pilot study of the relationship between discomfort and agitation in patients with dementia," *Geriatric Nursing* 22, no. 2 (2001): 80-5.

2. A.S. Elstein, "Heuristics and biases: Selected errors in clinical reasoning," *Academic Medicine* 74, no. 7 (1999): 791-4; N.V. Dawson, "Physician judgment in clinical settings: Methodological influences and cognitive performance," *Clinical Chemistry* 39, no. 7 (1993): 1468-78; F.M. Wolf, L.D. Gruppen, and J.E. Billi, "Differential diagnosis and the competing hypotheses heuristic: A practical approach to judgment under uncertainty and Bayesian probability," *Journal of the American Medical Association* 253, no. 19 (1985): 2858-62.

3. T. Kitoh et al., "Combined neurolytic block of celiac, inferior mesenteric, and superior hypogastric plexuses for incapacitating abdominal and/or pelvic cancer pain," *Journal of Anesthesia* 19, no. 4 (2005): 328-32; R. de Oliveira, M.P. dos Reis, and W.A. Prado, "The effects of early or late neurolytic sympathetic plexus block on the management of abdominal or pelvic cancer pain," *Pain* 110, no. 1 (2004): 400-8.

4. T.C. Braun, N.A. Hagen, and T. Clark, "Development of a Clinical Practice Guideline for Palliative Sedation," *Journal of Palliative Medicine* 6, no. 3 (2003): 345-51.

5. T.E. Quill and I.R. Byock, "Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids," *Annals of Internal Medicine* 132 (2000): 408-14; T. Morita et al., "Similarity and difference among standard medical care, palliative sedation therapy, and euthanasia: A multidimensional scaling analysis on physicians' and the general populations' opinions," *Journal of Pain and Symptom Management* 25, no. 4 (2003): 357-62; B. Lo and G. Rubenfeld, "Palliative Sedation in dying patients: We turn to it when everything else hasn't worked," *Journal of the American Medical Association* 294, no. 14 (2005): 1810-6.

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.