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Medicating "Margaret"

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Nothing was going to be typical about this consult. I have seen only a few patients on in-patient psychiatric wards for palliative consultation. None of them were easy. So much of what I do is dependent on heart-to-heart conversations about what really matters most to people. When a person's faculties and judgment are impaired, the most powerful tools in my toolbox have been taken away. I also knew from my telephone conversation with the physician requesting this consult that it was out of the enormous distress of all concerned that I was being called in to help out in this very difficult situation.

It was a beautiful autumn evening, a Friday, in fact. I drove to the psychiatric hospital on my way home. I should have been forewarned when, misstepping off of the curb, I fell and twisted my ankle on the way into the hospital. Nevertheless, the pain I felt truly paled in comparison to the distress I was just about to witness.

Although I was a complete stranger to the staff, the nurses were very kind to me. They quickly found cold packs and a roll of gauze to tie around my swelling ankle. They also shared with me a packet of notes that the referring physician had left for me. It included the admission history and physical, consult notes from several esteemed psychiatrists, an ethics consult note, a living will, and most profoundly, a passionate and stirring letter by this patient's three children. Several of the night shift nurses were most helpful in sharing with me the extreme distress and conflict that had exploded amongst the staff regarding "Margaret's" care. Her continuous screaming had given way to outbursts of aggressive behavior, hitting, and biting. This had recently become less of a problem as she became increasingly less stable on her feet with frequent falls. She was also developing some periodic difficulty with swallowing. More of a problem were her frequent attempts to spit out oral medications the staff gave her. Although the patient's suffering was very serious, clearly she was not the only one suffering in this extreme and sad situation.

In a letter, Margaret's three children implored in unison that their compassionate mother be allowed comfort, peace, and dignity. They asked that she receive whatever medications would be necessary to keep her comfortable and sedated so that her remaining days of life might be quiet, without pain and suffering, and dignified.

It doesn't get much clearer than that; and yet, I read on. To ease my distress about not having access to the patient's own thoughts, feelings, and goals, Margaret had even written a living will:

To my Health Care Agent, my family, my physicians, my attorney, and to any medical facility in whose care I may be . . . I, [M.S.], hereby make the following declaration of my carefully deliberated wishes and intentions. . . . In the event that it has been reasonably determined that, on account of mental or physical illness or disability, I am no longer able to make cognitive decisions concerning myself, and if it is further determined, as described below, that there is no reasonable expectation of my recovery from such . . . disability, to the extent that artificial and so-called heroic measures are required

to keep me alive, I request that I be allowed to die a dignified death, that I not be kept alive by such measures, that medication be liberally and mercifully administered to me to alleviate suffering even though this may hasten the moment of death, and that any action may be taken or withheld, as the case may be, so as not to unreasonably prolong my death or destroy the dignity of my life.

This witnessed declaration was authored exactly three years and three days before I met Margaret.

What still stands out these many months later was how inconsequential the pain in my ankle felt when I turned down the hall towards Margaret's room. A sitter occupied an old school chair in the middle of the hall outside her room. There Margaret was, lying flat on her back on a mat on the floor, eyes closed, moaning and groaning, bouncing her feet, crossed at the ankles, up and down on the floor. She had elbow pads because of contusions on both elbows, as well as a bruise on her forehead. Her room was otherwise stark and empty. Reluctant to scare her (or more honestly, reluctant to get bitten or hit), I just sat on the floor near her. I spoke softly. I slid a little closer. I reached over and touched her leg. She maintained a constant moan, and rhythmic bouncing of her outstretched legs, one foot on top of the other. Tears welled up as I leaned over to auscultate her chest and abdomen.

Reading through the notes and talking with the evening nurses, I learned that Margaret had lived this way for more than four months. Indeed, her current appearance sounded woefully improved from the constant screaming of the preceding months. Now, she was mostly moaning or pacing, repeatedly falling to the ground or bumping into walls. I heard the pain the nurses were also experiencing as they witnessed this profound and prolonged suffering, this loss of self, and the suffering of her three devoted adult children. Because of advanced dementia, Margaret had come to the in-patient psychiatric unit aphasic. They only knew Margaret through the constant presence, love, devotion, and stories of her three children. The nurses also told me of some recent vaginal bleeding Margaret had, explaining the diaper she wore. She'd also had several episodes of coughing and choking with meals and, less often, with meds.

Margaret had a most remarkable history. She had been diagnosed with dementia at the age of 46. She was now only 54. More recently, both her family and neurologists thought she might have Pick's disease. Her children had cared for her at home with 24-hour supervision for at least three years before this admission. Because of gradually worsening outbursts of uncontrollable screaming and crying, they brought her to an emergency room. A thorough radiologic, infectious, toxicological, metabolic, heavy-metal work-up unveiled no reversible cause for her worsening behaviors. She was transferred to this in-patient psychiatric hospital for help controlling her behavior. The children felt enormously guilty and remorseful that they were no longer able to manage their mother's care at their family home.

A methodical trial of the following therapies had failed to control Margaret's outbursts: olanzapine, perphenazine, clonazepine, quetiapine, haloperidol, chlorpromazine, fluphenazine, valproic acid, lithium carbonate, gabapentin, clonazepam, alprazolam, escitalopram, and mirtazepine. Lorazepam caused disinhibition and escalation of behavioral problems. Desperate to help, her physicians had tried several electroconvulsive therapy treatments with no improvement. A one-week trial of a 25 mcg [microgram] fentanyl patch also had no effect.

Given her diagnosis of a progressive, life-limiting illness, Margaret's clearly expressed wishes written in advance, and the severity of her suffering, Margaret could very persuasively be considered a candidate for palliative sedation (sometimes referred to in the past as "terminal sedation"). However, it still was not clear to me that Margaret had received an adequate trial of pain medication to treat an underlying source of somatic pain that she was unable to tell us about. Why was she having irregular vaginal bleeding? Could she have an undiagnosed endometrial cancer? Cramping? She clearly would not tolerate a work-up, ultrasound, or exam. And even if something bad was found, what would we do differently? According to her own advance directive, she would not want treatment that would prolong her in this state, unless it was entirely pain relieving. There were several reasons that methadone was a very attractive choice: Margaret's nurses were reluctant to give her opioids and other as-needed pain medication, Margaret would spit out oral medi-

cation, and Margaret occasionally had trouble swallowing. Not only is it the least-expensive long-acting pain medication, it can be absorbed under the tongue, and comes in a concentrated liquid suspension. The analgesic effect lasts an average of 10 hours, and it can be given two to three times a day for around-the-clock analgesic coverage.

I paged the covering physician for confirmation that all possible reversible causes of delirium had been ruled out, and commented on the medical literature showing the benefit of pain management regimens for demented elders with behavioral issues who are simply unable to give a history of their experience of pain. I explained my reasoning for wanting to start Margaret on methadone 5 mg [milligrams] by mouth every eight hours. The physician at the other end of the phone took a deep breath, paused, and said he wasn't comfortable with this and that it could wait until Monday. In fact, to order any opioids, I had to get the covering house officer to come over to actually write the order. After calling the pharmacist to discuss what options he had on formulary, we had to settle on oxycodone 5 mg tablets every four hours scheduled and an additional 5 to 10 mg every four hours, as needed, for grimacing or increased screaming. I knew I couldn't rely on an as-needed order, as the nursing staff had clued me in that a number of the nurses would not use an opioid medication to treat Margaret's pain. Apparently, they felt (incorrectly, I might add) that this was tantamount to euthanizing her. We already knew that Margaret had tolerated a 25 mcg fentanyl patch, which is equivalent to somewhere between 50 and 90 mg of oral morphine. Nevertheless, perception is everything. Margaret did get a few doses of oxycodone, which has a duration of effect of about three to four hours. However, she ended up getting it irregularly. By the end of the following week, methadone was started, 5 mg every eight hours. She did not receive more than a couple extra doses for breakthrough pain. Though she did not show overwhelming changes the first week, Margaret seemed less agitated and slept more of the time. She was still awaking, attempting to ambulate, crying out occasionally, and taking in some, though less, oral intake.

At least 10 days later, I met with the children, the committed physician, the social worker, and the risk manager to assess the effect of the medication and to discuss the next options. I found Margaret still lying on the mat on the floor of her room, although she did appear slightly more peaceful. I met all three of her children, who joined in a wonderfully devoted and meaningful life review. They were able to express how this illness had impacted their own lives. They very lovingly supported one another in expressing their wish for her — that she be allowed a compassionate escape from agitation and suffering, and that a peaceful death free her from her current entrapment. They knew, as evidenced by many stories, that she would not choose to be sustained in her current state. We spoke about whether an underlying problem might be causing this behavior. We talked about the principle of double-effect. They understood that euthanasia was not a legal option, but that carefully titrating medications to treat presumed pain was ethically appropriate, even if the medication brought sedation, potential aspiration, and even if it meant an increased risk of hastening death. We also discussed whether, once their mother's pain and behavioral outbursts were under control, they would want to take her home to care for her there with the support of a hospice team. Through abundant tears, they all admitted that they just did not have it in them to take on her care again. So we discussed the possibility of an in-patient or residential hospice, which would allow them to be with her as her family rather than as her constant caregivers. They were comforted by this idea.

I had already spoken with Rosemary Ryan, MD, the medical director of the nearest hospice, prior to the family and team meeting. I wanted to be sure that the hospice would take Margaret on before offering it as an option. I called the hospice from our meeting room, and it was determined that transfer to the residential hospice, Tippett Home, could happen the next day. Margaret's methadone was increased to 7.5 mg every eight hours, and she remained on that dose until her death. The family recalls that she walked into the hospice facility under her own steam, still moaning and crying at times. While at Tippett Home, Margaret received morphine when she needed it for breakthrough agitation or pain, along with lorazepam as needed. In speaking with Dr. Ryan and the children, I learned that Margaret's last days were peaceful. She died on the same regimen with her family at her side. They were grateful that hospice and medications were available for Margaret.

It is true that opioids can sedate, as do benzodiazepines. However, titration of pain medications or anxiolytics to effect pain relief, without rendering someone unconscious, does not constitute palliative sedation. Palliative sedation is the aggressive use of medications (typically intravenous lorazepam, midazolam, phenobarbital, propofol, haloperidol) to achieve a comatose state in a patient with a terminal illness whose suffering cannot be ameliorated any other way. To do my work, I need to know I have a back-up plan when pain management efforts don't work. I want my patients to know that they won't be abandoned, that their symptoms can and will be addressed, and that, although we can't always control their illness, we can control their pain. When they are able, I want my patients to be able to choose. I don't usually start off talking about sedation as an option; it is a last resort in my repertoire. I need to try all the other ways I have to manage pain or other symptoms, allowing patients to remain involved and open to the miracles that may happen along the way. I have definitely seen many miracles in the course of my work, even though they do not necessarily have to do with cure.

For me to get up in the morning to meet the challenges of the day as a palliative care physician, and to go to bed at night without gnashing my teeth, I need to know that I can bring comfort to those who request comfort above all else. Margaret's regimen was used to achieve comfort *first*. The intent was to relieve her suffering. Her medications were titrated to that effect. This is not euthanasia, an action intentionally taken to cause death. Although I am still uncertain about many things in Margaret's case — Did Margaret have somatic or psychic pain? How much was she suffering? How can we best support caregivers in these most stressful of circumstances? How could we have pre-empted this terrible scenario from unfolding the way it did? — I am certain that, in the end, Margaret and her family received the best possible, life-affirming care that medicine has to offer.

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.