

wife. "He's calm, he's quiet."

Photographs

Care

Difficult Decisions on End-of-Life

"Obviously, he's much different than he was when he came in," Dr.

Edward Halbridge, the hospice medical director, told Mr. Oltzik's

Mr. Oltzik's life would end not with a bang, but with the drip, drip,

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Haloperidol	Anti-psychotic.
Ketamine	Anesthetic; reduces pain
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Drugs for Palliative Sedation

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Ozier Muhammad/The New York Times

Barbara Walsh, a nurse on the hospice unit at Franklin Hospital, and Dr. Edward Halbridge are part of a team that works with patients and their families to map out endof-life care. More Photos »

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Mr. Oltzik received what some doctors call palliative sedation and others less euphemistically call terminal sedation. While the national health coverage debate has been roiled by questions of whether the government should be paying for end-of-life counseling, physicians like Dr. Halbridge, in consultations with patients or their families, are routinely making tough decisions about the best way to die.

Among those choices is terminal sedation, a treatment that is already widely used, even as it vexes families and a profession whose paramount rule is to do no harm.

Doctors who perform it say it is based on carefully thought-out ethical principles in which the goal is never to end someone's life, but only to make the patient more comfortable.

But the possibility that the process might speed death has some experts contending that the practice is, in the words of one muchdebated paper, a form of "slow $\underline{\text{euthanasia}},$ " and that doctors who say otherwise are fooling themselves and their patients.

There is little information about how many patients are terminally sedated, and under what circumstances — estimates have ranged from 2 percent of terminal patients to more than 50 percent. (Doctors are often reluctant to discuss particular cases out of fear that their intentions will be misunderstood.)

While there are universally accepted protocols for treating conditions like flu and diabetes, this is not as true for the management of people's last weeks, days and hours. Indeed, a review of a decade of medical literature on terminal sedation and interviews with palliative care doctors suggest that there is less than unanimity on which drugs are appropriate to use or even on the precise definition of terminal sedation.

Discussions between doctors and dying patients' families can be spare, even cryptic. In half a dozen end-of-life consultations attended by a reporter over the last year, even the most forthright doctors and nurses did little more than hint at what the drugs could do. Afterward, some families said they were surprised their loved ones died so quickly, and wondered if the drugs had played a role.

Whether the patients would have lived a few days longer is one of the more prickly unknowns in palliative medicine. Still, most families felt they and the doctors had done the right thing.

Mr. Oltzik died after eight days at the hospice. Asked whether the sedation that rendered Mr. Oltzik unconscious could have accelerated his death, Dr. Halbridge said, "I don't know."

"He could have just been ready at that moment," he said.

With their families' permission, Dr. Halbridge agreed to talk about patients, including Mr. Oltzik and Frank Foster, a 60-year-old security guard dying of cancer. He said he had come to terms with the moral issues surrounding sedation.

"Do I consider myself a Dr. Death who is bumping people off on a regular basis?" he asked. "I don't think so. In my own head I've sort of come to the realization that these people deserve to pass comfortably."

An Uncomfortable Topic

For every one like Dr. Halbridge, there were other doctors who, when asked about their experiences, would speak only in abstract and general terms, as if giving a medical school lecture, and declined requests to arrange interviews with families who had been through the process. It is a difficult subject to discuss.

The medical profession still treats its role as an art as much as a science, relying on philosophical principles like the rule of double effect. Under this rule, attributed to the 13th century Roman Catholic philosopher Thomas Aquinas, even if there is a foreseeable bad outcome, like death, it is acceptable if it is unintended and outweighed by an intentional good outcome — the relief of unyielding suffering before death. The principle has been applied to ethical dilemmas in realms from medicine to war, and it

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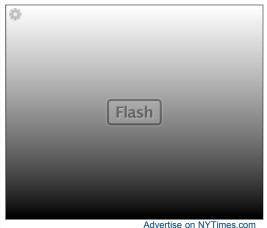


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Where the conversation begins.





is one of the few universal standards on how end-of-life sedation should be carried out.

At Metropolitan Hospital Center, a city-run hospital in East Harlem, Dr. Lauren Shaiova, the chief of pain medicine and palliative care, has issued 20 pages of guidelines for palliative sedation. The guidelines include definitions, criteria, what to discuss with family and hospital workers and a list of drugs to induce sleep, control <u>agitation</u> and relieve pain.

The checklist of topics to be discussed with the family includes whether to offer intravenous food and water. Another checklist anticipates that some hospital workers may be upset by the process, and recommends a discussion with questions like: "Were you comfortable with the sedation of this patient? If not, what were your concerns?"

But clarity, doctors say, is hardly the rule. In 2003, Dr. Paul Rousseau, then a Veterans Affairs geriatrician in Phoenix, wrote an editorial in the Journal of Palliative Medicine calling for more explicit guidelines and research. He noted that some researchers include intermittent deep sleep in the category of palliative sedation, while others limit it to continuous sedation, which he said might explain some of the variance in estimates of how often it occurs.

And he proposed more systematic research into the types of medications used, how long it takes for patients to die, and the feelings of family and medical staff.

Doctors at two prominent New York City <u>hospitals</u>, <u>Beth Israel Medical Center</u> and NewYork-Presbyterian Hospital, freely discussed their policies on terminal sedation, but were reluctant to allow a reporter to talk to patients or families. The policy adopted by Beth Israel's hospice endorses palliative sedation to "carefully selected patients" at the end of life. The three-page policy reviews legal, ethical and clinical considerations in broad strokes, but refrains from providing names of drugs and checklists.

Dr. Russell Portenoy, chairman of <u>pain medicine</u> and <u>palliative</u> care at <u>Beth Israel</u>, said the policy reflected the perceived perils of too much specificity. The hospice ethics committee decided that every patient was different, he said, and that "it was better to present a policy at this 10,000-foot level."

The Metropolitan guidelines authorize certain drugs to induce palliative sedation, or in conjunction with sedation for pain, <u>delirium</u> and agitation. The sedation drugs are lorazepam, midazolam, phenobarbital and, in the intensive care unit only, sodium thiopental.

For pain, the guidelines list opioid drugs, including morphine, methadone and fentanyl.

Doctors say that other drugs used for sedation are ketamine, an anesthetic and sedative popular at rave parties, and propofol, an anesthetic, which was ruled, with lorazepam, to have caused Michael Jackson's death. In very high doses, sodium thiopental is used as a sedative in the three-drug combination used for lethal injections.

There is one ethical guidepost for all the protocols: Terminal sedation should not become so routine that the end of life is scheduled like elective surgery, for the convenience of the doctor or the family, or because the patient's care is no longer economically viable.

Physicians occasionally feel pressure to turn up the medication, said Dr. Pauline Lesage, Beth Israel's hospice medical director. The pressure may come from weary relatives, who say, in effect, "Now it's enough; I just want him to disappear."

Sometimes the pressure is institutional. "You may be tempted to jump over because, oh well, 'I need the bed,' or 'That's enough, I don't see what we are doing here,' " she explained.

The doctors resist pressure to deliberately hasten death, she said. "Otherwise you see that you are jumping into a different field."

The Conversation

Leo Oltzik was a lanky man with a piercing gaze, a draftsman who, among many of his projects, worked on plans for the Second Avenue subway. In 57 years of marriage, he and his wife, Eleanor, had a son and a daughter and hardly ever argued.

They slept in the same bed, even after a railing had to be installed on one side to keep Mr. Oltzik from jumping out. But around Thanksgiving, Mr. Oltzik became too agitated for his wife and son to continue caring for him at home. "He was fighting death," Mrs. Oltzik said.

After three days of efforts to calm Mr. Oltzik in the hospice failed, Dr. Halbridge told the family that he was going to try an IV drip. Mr. Oltzik was connected to an intravenous bag of Ativan, a brand name of lorazepam, and he was given Roxanol, a liquid morphine, for pain and shortness of breath. He lay in a large room where the December sun washed over flowered curtain ruffs, plush carpeting and lavender chairs. He looked as if he was sleeping, except to his wife.

"That's not him," she said, pulling out a photograph from better times.

On the sixth day, the staff invited Mrs. Oltzik and their son into a cozy meeting room, equipped with an overstuffed couch and chairs. They were joined by Dr. Halbridge; Barbara Walsh, a nurse managing the hospice team; and Lynne Kiesel, a medical social worker, who called the Oltziks' daughter, Barbara Ladin, in Florida, and put her on a speakerphone.

"We have these meetings to talk about how you're doing, how he's doing, and to give you a chance to ask us questions," Ms. Walsh began, then turned to Dr. Halbridge, who signaled his profession with the stethoscope wrapped over his dark blazer like a shawl.

"Our biggest challenge was to try to get him not to be so agitated," Dr. Halbridge began.

The staff had tried to calm him with various medications by mouth, without success. "So we put him on an IV medication, which is dripping in at a continuous rate," he said.

The doctor pressed ahead, in a cheerful, upbeat voice, tinged with regret, saying that the staff had to decide what was better for Mr. Oltzik in the long run and wanted the family's opinion. His <u>blood pressure</u> was falling, "which implies that his body is slowing down, but he's comfortable, and that's what we're looking for," Dr. Halbridge continued. (Low blood pressure can be a side effect of Ativan and Roxanol, according to the drug manufacturers, as well as a consequence of the dying process.)

Ms. Walsh added consolingly, "He really looks like he's sleeping."

She said, apologetically, that the hospice had tried to find a balance between controlling Mr. Oltzik's agitation and making him too sleepy.

"We did go to this IV as kind of a last measure, because we know that people do get sleepy and may not be as responsive, and we know how hard that is for the family to see," she said.

Mr. Oltzik's daughter zeroed in on the question that had been hanging over the discussion: "This is the end?"

"Yes, pretty much," Dr. Halbridge said, "because what we're seeing is a man who had a rather significant blood pressure on admission, and over the past day now, and today again, his blood pressure is even lower. So we're talking about a poor prognosis and a shorter time."

Mr. Oltzik's son detected an almost imperceptible change in his mother. "Stay calm," he urged her.

Moments later, the social worker gently entered the discussion, saying, "You've given him excellent care at home."

"I worked very hard," Mrs. Oltzik said.

Although throughout the half-hour meeting the staff had never explicitly asked to continue sedating Mr. Oltzik, his daughter now gave them tacit permission: "We understand that the inevitable is here, but we wish him to go in peace and to find solace in that," Ms. Ladin said.

When the conference was over, Mrs. Oltzik still seemed to be ruminating. As many relatives do, she had hesitated over whether her husband should be given <u>nutrition</u> and water through tubes, now that he could not feed himself. The thought of someone dehydrating or starving is one of the most difficult emotional burdens for families, and was the crux of the famous fight over <u>Terri Schiavo</u>, a vegetative Florida woman whose husband wanted to let her die, but whose parents did not.

Palliative care doctors generally agree that sedated patients do not feel pain from <u>dehydration</u> or starvation, and that food and water may only prolong agony by feeding the fatal disease.

Mrs. Oltzik had done some research, and decided that nutrition and water would only burden her husband's system. "The idea is now not to make him work harder, but to be as peaceful and calm as he can," she said. "Common sense dictates that that would be the way to go."

Much of the conversation had proceeded not in black and white like a legal document, but in shades of gray. By the end, they all seemed to understand one another, though ultimately Mrs. Oltzik would express some sadness at being unable to interact with her husband.

The Family's Dilemma

From Karen Foster's perspective, watching her husband, Frank, die while sedated was the least in a series of cruel blows. Mr. Foster, who arrived at the Franklin hospice about the same time as Mr. Oltzik, had stoically hidden his <u>liver cancer</u> from his family for years. As recently as October, he was still driving, Mrs. Foster said; then he suddenly went downhill.

The night before Thanksgiving, her husband was acting bizarrely, and soon he was admitted to the

hospice, Mrs. Foster said. Dr. Halbridge put him on morphine for pain and Ativan to calm his shortness of breath and <u>anxiety</u>. It was terminal sedation, Dr. Halbridge said, but Mr. Foster's liver was failing so rapidly that no medication could have hastened his death.

Mrs. Foster sat stiffly at his bedside in a cloche hat and long coat, as if she expected him to go any second. She said she was relieved that her husband was no longer suffering. The sight of him sedated, his mouth open in a premonition of death that some doctors call "the O sign," was less shocking than the disease he kept secret, she said.

But families sometimes push back. Marguerite Calixte, a day care worker, asked Dr. Halbridge to wake her husband out of deep sedation — begun the day before because he had trouble breathing — so she could say goodbye.

Her husband, Alix, who was 53, had trained as a nurse and had told her that if he was going to die of his <u>colon cancer</u>, he wanted to die at home, with his wife and their two teenage children.

On a Thursday night, Dr. Halbridge began decreasing the morphine drip, and by the next morning, Mr. Calixte's eyes fluttered open. "I've been talking to him," his wife said on Saturday, in Haitian cadences. "I say, 'If you want to go home, squeeze my hand tight.' He keep doing it over and over."

Ms. Walsh, the team manager, patiently gave Mrs. Calixte a lesson in how to take care of her husband, but doubted that he would be able to go home on Monday, and she was right.

He died that Saturday night, when his wife went home to have dinner with their children.

Mrs. Calixte believed the morphine was to blame. "He died quicker," she said. "I don't know when it was going to be, but it wasn't going to be now. The thing is, he was going to suffer. I know that. But he wasn't going to die so quick."

Dr. Halbridge said there was "no way of knowing which would have taken him sooner," the medication or the disease. He said the conflict between his desire to make Mr. Calixte comfortable and Mrs. Calixte's wishes made the case "a tough one, I admit."

Teaching a Difficult Subject

The <u>American Academy of Hospice and Palliative Medicine</u> has endorsed "palliative sedation to <u>unconsciousness</u>" and in 2008, the <u>American Medical Association</u> issued a policy statement supporting palliative sedation, except when it is used primarily for emotional distress. Even the <u>United States Supreme Court</u>, while rejecting a constitutional right to physician-assisted <u>suicide</u>, has opened the door to palliative sedation.

There is general agreement that "a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death," Justice Sandra Day O'Connor wrote in a 1997 case, Washington v. Glucksberg.

One provision of the House health care bill, which passed in November, recognizes that palliative care may include treatment "furnished for the purpose of alleviating pain or discomfort, even if such use may increase the risk of death." The bill — but not the Senate version, passed on Thursday — also allows doctors to be reimbursed for discussions with patients about what treatments they would want or decline. This gave rise to charges by some Republicans that "death panels" would be convened to decide who deserves life-saving treatment.

Amid the furor, the bill was revised to make clear that patients would not be forced to forgo treatment.

Terminal sedation remains touchy enough that last month, Dr. Lyla Correoso, Bronx medical director of the Visiting Nurse Service of New York, and Dr. Shaiova spoke with doctors, nurses, administrators and social workers at Metropolitan Hospital about how to explain the process to families and colleagues, so no one would feel guilty or betrayed.

The title of the lecture, projected on a giant PowerPoint screen, conveyed the crux of the dilemma: "The Double Effect: Is it the Drug or the Disease?"

"Some people speculate that people are really covering up the fact that this is really perhaps a type of euthanasia or maybe something else that's really afoot," Dr. Correoso said. "You have to have good overall intent, and most physicians, that's what we're here for — we're here to do something good."

She advocated setting "goalposts" in advance, by asking patients to stipulate "the farthest line I'm not going to cross" — including sedation.

The most pointed questions came from a chaplain, Rabbi Isaac H. Mann. Was it possible, he asked, that a person under deep sedation could still be feeling pain, and how would the staff know?

"Yes," Dr. Shaiova replied. But they often expressed pain through agitation or grimacing, she said, adding, "Err on the side of treating them" with pain-controlling drugs.

The chaplain pressed for more clarity, even after the meeting had broken up. Was she trying to say, he asked Dr. Correoso, that if morphine killed a patient, "you wouldn't mind?"

"Then you've already broken the principle of double effect," Dr. Correoso replied.

"The doctor knows that this can kill the patient," Rabbi Mann insisted.

"The doctor doesn't know," Dr. Correoso said. Then she repeated a refrain often heard in the world of palliative medicine: "It's not easy to kill a patient. People think it's easy, but it's really not. That's why Dr. Kevorkian had to use all that" combination of drugs.

The Gray Zone

On the day Dr. Shaiova and Dr. Correoso lectured on terminal sedation, they were also consulting with a patient at Metropolitan Hospital who was dying of lung cancer. The patient, Gloria Scott, 50, had learned of her cancer in June.

End-of-life treatment often has a kind of studied ambiguity to it, and such was the case with Ms. Scott.

After she was moved to the hospice wing of <u>Margaret Tietz Nursing and Rehabilitation Center</u> in Jamaica, Queens, she received fentanyl, a synthetic opioid pain reliever, through an IV line that gave her the drug continuously, and allowed her or a nurse or doctor to push a pump for more when she had "breakthrough" pain. Under her right ear, she wore a scopolamine patch, used to reduce secretions. Scopolamine has sedative and mood-altering properties, and was once combined with morphine to induce "twilight sleep" for women giving birth. Ms. Scott also had standing orders for Ativan, the sedative, and Haldol, for delirium, two more drugs in the palliative sedation arsenal.

At first, though in pain, she was lively. She sat on the bed in the lotus position, which eased her pain, and in her Betty Boop voice, punctuated by an infectious giggle, she talked about her favorite Motown music and her plans to get a business degree.

She fiercely resisted signing a "<u>do not resuscitate</u>" order, although she would later change her mind. "I don't know when is my last day," she said. "I might outlive one of you all."

She asked her doctor at the hospice agency, Erik Carrasco, to keep the fentanyl, which she had begun taking at the hospital, turned down low. Otherwise, she said, "you sit here and you nod. I don't want to be like that."

Two weeks later, the change in Ms. Scott was marked. She was still alive but dessicated and barely responded to visitors. Her companion, Milton Cruz, was troubled by her "semi-dreamland" state, as he put it, but was shy about asking questions.

In her last days, she lost the desire to eat or drink, though nurses continued offering food and water, Dr. Carrasco said. The textbook survival time for patients who stop eating and drinking is two weeks, Dr. Carrasco said, but he said he had seen people last longer — elderly people who had survived the Holocaust and "people who are waiting for someone, like a son."

She died after 22 days. Dr. Shaiova said she did not consider Ms. Scott's sedation to be palliative or terminal sedation, because that was not her doctor's intention. Her body had sedated itself as a defense against the disease, Dr. Shaiova said, and she had been on fentanyl long enough to develop some tolerance, making it unlikely to have hastened her death.

"When you're sick, you're sick, and everything else is somewhere in the gray zone, and that's the problem," Dr. Shaiova said.

Dr. Carrasco said that while the medication might have contributed to her <u>drowsiness</u>, he believed she had died a natural death. "What I've been seeing sometimes is you release the pain," he said, "and even though you are using very small amounts of morphine or narcotic, they relax and pass away."

The Semantics

Even when everybody agrees that terminal sedation is a humane response to unyielding suffering, many doctors seem to feel a prick of conscience.

"There should be ambivalence," said Dr. Joseph J. Fins, chief of medical ethics at Weill Cornell Medical College. "If it became too easy and you weren't ambivalent, then I would really start worrying about it. But the fact that you're worrying about it doesn't mean you've done something wrong."

In a 1996 paper in the Journal of Palliative Care that is still debated within that community, Dr. J. Andrew Billings, a Harvard professor and palliative care doctor at <u>Massachusetts General Hospital</u>, and

Dr. Susan D. Block, a psychiatrist, took on the moral ambiguity surrounding terminal sedation. They argued that the main distinction between terminal sedation and euthanasia was time.

Terminal sedation would lead inexorably to death, but "not too quickly," they said. They derided the rule of double effect in this context as a rationalization, a subtle cover-up, of what they called "slow euthanasia."

Even a simple morphine drip, they said, could put patients into a stupor at the right dose or when combined with other drugs or when concentrated by the inefficiency of a damaged liver or kidneys.

"If the morphine drip becomes a code word for slow euthanasia," they wrote, "laypersons may be increasingly wary of the other uses of opioids."

Both Dr. Billings, who is still at Harvard, and Dr. Block declined requests to be interviewed.

The authors did not endorse euthanasia, but their arguments have been used by others looking to make the case for public acceptance of euthanasia, to the dismay of some doctors who defend terminal sedation

People who adopt this argument say, "We know what you're really doing, it's crypto-euthanasia," Dr. Fins said. "Polemics really have no place at the bedside."

Dr. Fins said he sometimes told families that terminal sedation was altruistic, because they might be giving up an extra day or two "of communication with the person you love in the service of that love."

As for the argument that double effect is overly scholarly, Dr. Fins said: "I can't imagine a world at the end of life without double effect. We'd be highly impoverished without it, and patients would suffer needlessly without it. We do need our philosophical contrivances in order to be pragmatic physicians and caregivers."

Ambivalent, Then Accepting

Mr. Oltzik died two days after the meeting between Dr. Halbridge and his family, and Dr. Halbridge was frank in describing his treatment.

Asked if he would call it palliative sedation, Dr. Halbridge said, "This would be called terminal sedation, almost." He said he hesitated only because the word "terminal" sounded negative and might make the family feel bad, when "it's really comfort care." The terms "palliative" and "terminal" were interchangeable, he said.

Speaking with considerable passion, he said he saw himself as the doctor who would not "forsake" patients by telling them he could do nothing for them. If there was no cure, he could at least offer comfort. "We are not gods who can cure everything, and I think at some point in time you have to accept that," he said, "and to me, it's the mark of an honest doctor who understands when that time has come."

The decision to administer terminal sedation was based on a review of the patient's history that convinced him that Mr. Oltzik was "terminally agitated," he said. "It means that he is entering the dying process and for whatever reason — whether it's physical, spiritual — something is interrupting the peaceful passing, and to me, because it's so uncomfortable for the family and for the patient, that's the time to medicate the patient and make them comfortable, because no matter what you do, he's not going to go back to the old Leo that he was."

He then told a self-deprecating joke about a doctor who gets to the gates of heaven and demands to jump to the head of the line, only to be turned back by St. Peter. But St. Peter opens the gates to someone else carrying a doctor's bag. "That's God," St. Peter explains. "He just thinks he's a doctor."

Young residents often challenge him, saying things like, "If I'm 105 years old, I want to be fed, no matter what," Dr. Halbridge said. His response is, "O.K., but did you ask your patient what he wants?"

Some patients are getting "multimillion-dollar workups" in the intensive care unit, he said, but make their wishes known by pulling out tubes. "I think a light bulb should go off in somebody's head after the third time he pulls it out. Am I going to change the outcome of this, and if I'm not, why am I doing it?"

At one point, however, Mrs. Oltzik changed her mind.

"She was having second thoughts on that, and then she was saying, 'I wonder if we should cut back on his medication,' " $\,$ Dr. Halbridge said.

She hoped for a last chance to communicate with her husband, but Dr. Halbridge said he warned her that Mr. Oltzik was more likely to wake up agitated and suffering. Dr. Halbridge did not want to feel like he was experimenting. "I have a little bit of a problem with using the patient as kind of a guinea pig and saying, 'Well, the medication worked nicely, now we'll take it away and see if they bounce back the

other way," he said.

Did he wake Mr. Oltzik? There was no need, Dr. Halbridge said: "He passed away within a couple of minutes."

A couple of weeks later, Mrs. Oltzik still felt a bit uneasy. "They had him so heavily sedated that he was in a stupor," she said. "I didn't say goodbye to him, which hurts me."

But she did not fault the hospice team's judgment. She could not think of any other way to handle her husband's agitation. As to whether his death had been speeded up, even a tiny bit, she said philosophically, "There was no way of knowing."

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