

Palliative Care by the Surgeon: How to Do It

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Presenters: Robert A Milch, MD, FACS, Anne C Mosenthal, MD, FACS, K Francis Lee, MD, FACS

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Chronic Pain Management and Neuropathic Pain

Malignant Bowel Obstruction

Dyspnea and Withdrawal of Ventilatory Support

Asthenia and Cancer Cachexia

Lingering in the Intensive Care Unit

Geoffrey P Dunn, MD, FACS: This is a symposium, Palliative Care by the Surgeon: How To Do It. This symposium is actually the continuation of an idea that has been evolving in the course of several consecutive symposia held by the American College of Surgeons. The shot across the bow for this ongoing discussion and for this symposium came back in 1997 when the College held a general symposium on the subject of physician-assisted suicide. Many of us took this as a huge red flag or a sign of great distress that surgeons were wrestling with this question. There was controversy within the surgical community with people taking positions pro and con.

One thing that was agreed on by everybody at that symposium was the utility, the lasting value, and the moral imperative of good palliative care. Everybody also agreed that in many ways, although we may be temperamentally very committed to the idea, and might have had personal experiences in our practices and also in our families that drove home the point of the value of good compassionate care for people with advanced illness,

many of us felt very unprepared to do the basic work, the day-to-day activity at the bedside, to know which kinds of medication to order or how to engage in difficult discussion. That led to a series of initiatives with ongoing and increasing cooperation, interest, and support by the American College of Surgeons.

Last year we had a symposium on the subject where we got more at the level of the surgeon identifying and finding a place in palliative care. At the very heart of that discussion was this almost palpable struggle: Is a surgeon really temperamentally suited to do this kind of thing or would it be best left to be done by others? At that point we believed that was a choice that every surgeon would make personally.

What we can do is offer the tools, the nuts and bolts, and from that point carry forward; that is the purpose of the symposium today: to provide some basic practical concepts that would be helpful at the bedside. The panelists are members of a newly formed Workgroup for Surgical Palliative Care. This is a Robert Wood Johnson-funded initiative. The group members were selected because of their demonstrated and proactive interest in these areas. The Workgroup recognizes that many important areas of surgery are not yet represented in this work.

The purpose of the Workgroup is to facilitate introduction of the precepts and techniques of palliative care to surgical practice and education in the United States and Canada. The Workgroup will do this by bringing together surgeons with demonstrated interest in palliative care to share resources, strategies, and expertise, and in so doing act as a catalyst for a change. There are a number of definitions of palliative care and that term will be used frequently. This is the very orthodox teaching in any current textbook or article about palliative care. You will see that the World Health Organization definition goes back to 1990 (Table 1). This was specifically applied to oncology but was rapidly accepted as applicable to all areas of palliative care. I find it a very cumbersome and dry definition, and when people ask

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Table 1. World Health Organization Definition of Palliative Care, 1990

“The active and total care of patients whose disease is not responsive to curative treatment. Control of pain and other distressing symptoms, and of psychological, social, and spiritual problems, is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with [anti-cancer] treatment.”

WHO: Cancer pain relief and palliative care. Technical Report Series 804. Geneva: 1990.

me what palliative care is, even after all the times I have seen the definition, I wouldn't be able to repeat this. What may be more to the point and a more operational definition is that palliative care strives to maintain or restore the integrity of a person and their family as they define it through the course of incurable illness. And I use *integrity* in the sense of *integer*, the sense of wholeness. The American College of Surgeons has found its own understanding of what palliative care is. Its “Statement on Principles Guiding Care at the End of Life,” approved by the Board of Regents in 1998, serves as sort of a moral compass for the conduct of care not only at end of life but in all patient encounters (see first page of this article). The spirit of what we are talking about as palliative care is easily discernible within this document.

Among the principles we need to review, one is bullet number four in the “Statement on Principles Guiding Care at the End of Life,” the alleviation of pain and management of other physical symptoms. We will focus most on that, although not losing track of bullet number five, the ability at least to recognize and assess the associated psychological, social, and spiritual dimensions of the problems that we encounter at the bedside. Management and successful alleviation of physical distress is the very pediment on which all other undertakings for the purpose of palliative care rest. For those of us uncertain about our abilities to do this for ourselves, we are reminded of the fact that the principles also encourage us and instruct us to access individuals who do have that sort of expertise.

The January 2001 edition of *Surgical Oncology Clinics of North America* is a reference you should be aware of. Although this was for surgical oncology clinics, all chapters were written with the intention of being applied to the entire field of surgery, not just oncologic surgery. Starting in September 2001, *The Journal of the American College of Surgeons* initiated a series on palliative care for

the surgeon, by the surgeon. This is an ongoing series and can be seen as a companion piece for some of the things you will be hearing about this morning.

Our first speaker is Dr Robert Milch, Associate Professor of Surgery at the State University of New York in Buffalo. He has been the medical director of the Center for Hospice and Palliative Care in Buffalo and was one of the founders of one of the very first hospice programs in the United States. If I ever had to have someone at my bedside in my darkest hour, he is the kind of person I would want to have there.

Chronic Pain Management and Neuropathic Pain

Robert A Milch, MD, FACS

Thank you very much, Geoff, for those kind words. It's good to have an opportunity to speak about a subject central not only, of course, to palliative care but also to the management of all patients. At the risk of giving too encyclopedic a presentation, trying to cover in 40 minutes what tomes have been written about, I think it's important that we reflect that there's an element of knowledge, skills, and attitudes or behaviors that can reasonably be expected of all surgeons, an area of expertise, a level of comfort in practice that all patients and their colleagues can reasonably expect.

A little bit of a didactic first. Nociceptive pain is divided into two types. The one with which we're most familiar, of course, is somatic, characterized as dull, sharp, or aching, throbbing, gnawing. These are the different descriptors patients use in telling us about pain. Typically it's well localized and it's seen most frequently with trauma, for example, or injury to bone or myofascial, musculoskeletal structures. Incisional pain is typically somatic, and the important thing is that somatic nociceptive pain responds well to opioids and to nonsteroidal medication.

The other type of nociceptive pain we encounter frequently is called visceral and that comes from nociceptive impulses generated in sympathetically innervated organs, whether the disease mechanism or the traumatic mechanism comes from infiltration or compression. Just stretching or the distension of viscera—typically this is less well localized—and patients will tell us that it's a deep or dragging sensation or they may describe it as squeezing or pressure. If it happens to be a hollow viscus

that is affected such as a gallbladder, ureter, or bowel, for example, there may well be colicky pain described with autonomic symptoms: diaphoresis, tachycardia, nausea, and so on. It's often referred to remote sites.

We are all familiar, for example, with hepatic capsular distension being referred to the subscapular area or the shoulder. And this pain, too, responds well to opioids and nonsteroidals. Neuropathic pain, on the other hand, engendered by injury to the peripheral or central nervous system, and compression or infiltration damage, and any one of a number of sources, typically is described differently as burning, lancinating, stinging. This is seen with plexopathies, with postherpetic neuralgia, after certain types of chemotherapies, and in certain postsurgical conditions. Typically neuropathic pain responds less well to opioids and used to be called opioid-resistant pain or morphine-resistant pain, but these are misnomers.

In any pain therapy regimen it is critical that adequate assessment be carried out. This is an adaptation of an acronym, PQRSTU, used by Dr Twycross and Dr Jim Ray. These are the elements in a review of systems or a history that are imperative that we elicit so we can understand what the patient is experiencing. PQRSTU stands for: Precipitating or palliating features, what brings it on, what makes it better, what makes it worse, what is the Quality looking at those descriptors we just spoke about; where is it, is it Referred; what is its Severity, Temporal relationships, day, night, activity; and what medications have been Used in the past and with what effect or lack of effect.

In terms of severity, using a verbal analogue scale, I think, is something we are all familiar with now. The Joint Commission on Accreditation of Healthcare Organizations has mandated that pain be evaluated in acute care settings as the "fifth vital sign," and this is the 1 to 10 scale. As physicians, we communicate by numbers. I know that I can anticipate a certain response from my colleagues and from staff if I tell them that a potassium test is 7.6, that a calcium level is 14.2, that blood urea nitrogen is 120, and so on. The point of the verbal analogue scale is to give the patient a language with which to communicate so that we can train ourselves to respond appropriately according to the severity of what the patient is telling us.

Here is a little exercise we use in talking with house officers and students to postoperative patients, one of whom is 24 hours postoperation, going to be assessed for

pain. The patient is laughing and joking, has a couple of visitors. You ask about his pain, and he rates it as an 8 out of 10, and then you are asked how you rate his pain and what you do about his order for postoperative analgesia.

The second patient has had the same operation, vital signs are stable, but when you go in to see this patient he is curled in a ball, lying on his side. We have all seen this patient, most likely behind a drawn curtain, behind a closed door, with fewer staff contact hours because we are frustrated that he is not feeling well. He rates his pain as 8 out of 10 and the question is how do you rate his pain, what do you do about his order?

Many will look at the first patient and will either not rate his pain as 8 out of 10, rate it as a 6 or a 4, and either continue with his current pain medication or even decrease the dose. In the second patient almost everyone says the pain is believable and is an 8 out of 10, and they will either continue the same medication or they will increase the dose. The point is that there is no difference between these two patients. They are the same patient. The experience of pain is so uniquely individualized that there is no single test that we can use except to train ourselves to believe the patient. It is the experience that is individualized and is constant for that patient. Ideally we would all respond by at least rating the patient's pain where the patient says it is and increasing his pain medication.

What if I told you the first patient's two visitors were his wife and mother and he didn't want to convey to them, for example, how much distress he was in. Maybe he comes from a culture that values stoicism. Think in terms of any stereotype you like, that he is Sicilian, that he is from Latin America with the sense of machismo, that he is from a Muslim culture, and so on. Again, there's no snapshot we can take that confirms or refutes how much pain someone else is in. The challenge is for us to change our prescription patterns and behaviors so that we believe the patient and respond appropriately.

Drugs useful in the management of pain include the nonopioids such as acetaminophen and the nonsteroidals. All these drugs have a ceiling effect, but they have an opioid-sparing effect as well. That is why, for example, acetaminophen is so often combined with low-dose opioids to improve its analgesic efficacy. We don't know exactly how acetaminophen works; it has no antiinflammatory activity, but its contribution to pain management is not inconsequential. At doses of more than four

grams a day—a point we will continue to emphasize—it can be hepatotoxic.

Nonsteroidals act at the site of tissue injury and they block prostaglandin synthesis, usually by interruption of the cyclooxygenase pathways. We have all become familiar now with the Cox 1 and Cox 2 nonsteroidals and the different mechanisms by which they exert their effect. Side effects for some include thrombasthenia. Gastrointestinal irritation is not uncommon. They all decrease renal blood flow, so must be used with caution on patients with known renal insufficiency and particularly in the elderly, and they all, to some extent, increase sodium and fluid retention.

Opioids include all drugs that have morphine-like action, and classically they have been categorized two ways. One is looking at the so-called weak opioids, which would include codeine or propoxyphene, and then the so-called strong opioids, morphine, oxycodone, methadone, hydromorphone, and fentanyl.

It would probably be better to characterize opioids as useful for mild pain or moderately severe pain rather than as weak or strong because in equianalgesic doses all opioids are relatively effective to one degree or another. They all mediate their action through central opioid receptors, the most potent of which is the mu receptor, so-called because that is the site where morphine exerts its activity. The strong opioids have no ceiling effect. There is no upper limit of drugs that can be used in this category. The more drug you use the more analgesia you can expect, and the only limiting factor is the presence of side effects.

So, then, how would we start to incorporate some of this information into our prescription practices? Certainly through your patient in pain, the character and intensity of pain needs to be documented. Ideally what we are looking for is the least obtrusive route by which to give analgesic. This is usually oral. It can also be buccal or sublingual. Medication, particularly liquid medication, but also a number of formulations of immediate-release opioids, are absorbed by placing them in the buccal recess, in the sublingual position so that even patients who are having dysphagia, even patients who are comatose because of the extraordinarily rich blood supply of the oral pharynx, can absorb these medications.

The transdermal route is very unobtrusive and the fentanyl patch can be used. Rectal absorption is feasible for most of these medications once one gets beyond the social and cultural objections. The subcutaneous or in-

travenous route should be used for patients who need opioid analgesics parenterally. Avoid the intramuscular route. These drugs are absorbed every bit as well, if not more reliably, from a subcutaneous site as from an intramuscular site. Think about intramusculars. Very often in this patient population they are given to patients with shrinking muscle mass. They hurt. They are labor intensive. They can cause infection and bleeding. And can you think of anything sillier than saying to a patient, “I am going to have to hurt you six times a day to give you pain relief?”

In addition, subcutaneous route of administration is available with indwelling ports: a 27-gauge needle and a pack of sticky disks with a little injection port that can be placed and left in place for 7 to 10 days for repetitive injection. You don't even have to inject the patient repeatedly to give the drug subcutaneously.

Patients with intermittent pain receive immediate-release medications on an as-needed or PRN basis. This is what we are most used to working with. Immediate-release medication would be defined as one that peaks at 90 to 120 minutes and is gone in 4 hours. Patients with constant moderate to severe pain either get around-the-clock medication, in other words, something every 4 hours or sustained-release medication.

Sustained-release medications are those with a serum peak between 4 and 8 hours and then disappear, usually within 12 hours. If patients are on sustained-release preparations, they have immediate-release medication ordered for breakthrough pain on an as-needed basis. Only one combination analgesic or pure opioid is ordered for PRN—and there should be an “or” inserted there—for PRN or breakthrough pain. What we want to do is simplify our analgesic order writing. It's not Darvocet one or two every 4 to 6 hours for mild pain and Lortab one or two every 4 to 6 hours as needed for moderate pain. All we do is increase the risk of drug interactions, and we usually wind up with a far less effective pain management regimen. So we want to keep it simple and we want to keep it down to one immediate-release drug.

Only one opioid is ordered for moderate or severe pain: MSContin, Oramorph, two preparations of sustained-release morphine, Oxycontin, Duragesic, for example. And short-acting opioids are ordered at intervals no longer than 4 hours around the clock or every 2 hours as needed. Again, remember, with the immediate-release drugs the peak is at 2 hours. If it isn't working at

Table 2. Equianalgesic Dosing

Drug	Oral	IV/Subcutaneous
Morphine	30 mg	10 mg
Dilaudid	7.5 mg	1.5 mg
Oxycodone	20–30 mg	NA

Duragesic 25 μ g is equianalgesic to 60 to 90 mg oral morphine/24 hours or 20 to 30 mg IV/subcutaneous morphine/24 hours.

2 hours, it won't be working at 3 hours, it won't be working at 4 hours, and it most certainly won't be working at 6 hours, which is all too often when we see drugs such as, for example, Lortab or Tylenol and codeine ordered. If we are using it for breakthrough pain we need to know that it is going to be effective at 2 hours.

If doses need to be escalated, they can be escalated reasonably according to the patient's report of pain. For pain rated at a 3 to 6 out of 10, increase by 25% to 50% of the current dose, at 7 to 10 out of 10 at 50% to 100%.

Our expectation programmatically is that pain reported as 3 to 6 out of 10 will have the pain regimen changed for that patient within 4 hours. Our expectation programmatically is that pain rated at 7 or more is regarded as a pain emergency and that regimen for that patient will be changed within the hour. In addition, how much do we escalate the frequency? Every 1 to 2 hours for short-acting products, every 24 hours for sustained release. Again, you can proceed right along the path of increasing every 1 to 2 hours with immediate-release drugs for patients whose pain is poorly controlled.

One point is that there is a relationship between different forms of the same drug, relationship potency (Table 2). I can expect to get the same amount of pain relief from 30 mg of morphine given by mouth as I get from 10 mg given intravenously or subcutaneously or even, God forbid, intramuscularly. I can expect to get the same amount of analgesic from 7.5 mg of Dilaudid orally as I get from 1.5 mg given parenterally. I can expect to get the same amount of pain relief from 30 mg of morphine as I get from 7.5 mg of Dilaudid given by mouth. Oxycodone, you see the relationship there, and the relationship with Duragesic as well.

Morphine is the drug of choice. It's the reference point for all other opioids we use. Dilaudid is an excellent drug. It is equipotent with morphine but it is not as pharmaceutically versatile. It does not in come in as many forms. Oxycodone is not available in this country parenterally. It is now, of course, available in a sustained-release form as Oxycontin, which you've heard about.

Duragesic is an excellent drug delivery system. It's a little bit more difficult to use in many ways than the other drugs because it has a dose peak at 12 to 15 hours. There are other elements in the kinetics that are important to remember from the time it is applied. It diffuses across the skin into the subcutaneous tissue, where it establishes a reservoir and the capillary blood flow passes and the reservoir is where it is picked up.

So if it's applied in a patient who has lost a great deal of body mass, does not have much subcutaneous tissue, for example, and it is put on over a bony thorax distribution, it may not be effective. If it's given to a febrile patient, who has increased blood flow through the subcutaneous tissue, the reservoir may be dissipated more quickly. If it is given to a patient who is diaphoretic, the patch may get displaced because the patient sweats underneath it, so there can be some problems. But for patients who are cognitively impaired or who have unreliable care-giving systems it's an excellent drug delivery system.

Methadone is a drug that is seeing a resurrection in popularity and used particularly for patients with neuropathic pain. Propoxyphene is equianalgesic to one commercial or over-the-counter Motrin tablet. It has a toxic metabolite, and it comes with 650 mg of acetaminophen. Innumerable studies show that Darvocet is no more effective than Tylenol alone, so chronic use is not recommended. Codeine is effective for mild to moderate pain, but once you get above the dosing ratio of 1.5 mg per kg per dose you get more side effects and not as much analgesic. That would be, for most people, one Tylenol and codeine #4. In addition, I am sure we have all seen patients who tell us that Tylenol with codeine just doesn't work for them. One reason it may not work is that about 10% of the population lacks the cytochrome enzyme needed to convert a portion of the codeine to morphine, and that is why it is much less effective for these patients and in patients on certain other drugs that can impact this system.

Drugs that should be avoided, especially for chronic use, include Demerol at the top of the list, a short-acting drug. The half-life of Demerol is 2.5 to 3 hours. It is ineffective by mouth. One tablet of 50 mg Demerol is roughly equianalgesic to two Tylenol tablets. That's why it's always given by injection. It has a toxic metabolite that is neuroexcitatory and it lowers the threshold of seizures, increases the incidence of myoclonus, and for

all these reasons Demerol should not be used for more than 48 hours, if ever.

Talwin, Nubain, and Stadol are mixed agonist-antagonists, and they have disadvantages of having a therapeutic ceiling. They have a very high incidence of psychotomimetic side effects. The only thing they have to recommend their use, in most places, is that they don't require a triplicate prescription and that would account for some of their use. Phenergan and Vistaril, we were all taught, of course, potentiate the action of opioids and, in particular, Demerol doesn't. What they do is increase sedation, but we are looking for patients who are not sedated but who are active and able to participate in activities of everyday care.

Beware of medications that increase sedation and do not improve analgesia. What do we know about the sedated patient? He or she complains less of pain. That was the take-away from the original bad studies done in the 1950s that led us to think that perhaps Demerol could be potentiated by these other drugs. Use adjuvants for bone pain. An adjuvant is a drug that improves the quality of analgesia from an opioid. It is useful for bone pain especially because there are two components to bone pain. One is centrally mediated and is well dealt with by the opioids. The other prostaglandin-mediated nonsteroidals or steroids themselves have a role for use in these situations. Use adjuvants for neuropathic pain.

He who orders the opioid orders the laxative. The most common side effect of opioids is constipation, and it occurs in essentially 100% of patients; and because the opioids slow down peristalsis and increase absorption from gut content, you need both a stool softener and a stimulant. You would use Peri-Colace instead of Colace. You would use Doxidan instead of Surfak and so on. Intervention should be made known before activities are carried out that are known or anticipated to increase pain, for example, before hands-on wound care. Before patients with painful bony metastases take road trips for CAT scans, for bone scans, and other interventions, anticipate that they are going to need some increase in immediate-release analgesic and treat them for that. Watch out for acetaminophen accumulation of more than 4 g a day.

For patients who are poorly controlled, get control with immediate-release forms. Do not start by slapping on 50 μ g of Duragesic, because it will take 12 to 15 hours before you know where you stand, and you don't know if you're overdosing or underdosing. Understand

how much opioid a patient needs to be comfortable through the course of the day using immediate-release forms and then convert to sustained-release forms. So, if your patient was comfortable, for example, taking 30 mg of immediate-release morphine every 4 hours and was stable with this for a day or two, then total daily dose would be 180 mg. The patient would be well served, for example, by putting him or her on 90 mg MSContin twice a day, and you would accomplish the same thing in a much more convenient dosing regimen. Breakthrough dosing, as-needed dosing, is calculated as 20% to 25% of the total daily dose given every 2 hours. So for your patient on 180 mg total daily dose of morphine, for example, a very reasonable breakthrough dose would be 40 mg of immediate-release morphine, again, every 2 hours as needed. Not every 4 hours, and certainly not every 6 hours. If you are using more than three breakthrough doses a day, calculate the total daily dose of opioid consumed, convert that to sustained release, and then recalculate what you're using for breakthrough pain.

We will take a quick look at a case study of a patient with metastatic cancer to the bone with pain in the hip, now taking 12 Percocet tablets a day. Increasing pain is most likely from worsening metastatic cancer. The definition of addiction, of course, is preoccupation, a psychological phenomenon typified by preoccupation with obtaining a drug despite known harm for reasons other than pain control. This certainly does not meet the definition of addiction.

We develop opioid tolerance, particularly to the side effects of opioids, but also, uncommonly, to the analgesic effect. It is very uncommon, particularly for patients with malignant disease, to develop clinically significant opioid tolerance. The most appropriate next step would probably be getting an equianalgesic dosing of hydromorphone. We know if the patient is taking 12 tablets of Percocet a day, that's 5 mg of oxycodone in each tablet, and 60 mg of oxycodone would give you "X" amount of equianalgesic dosing with Dilaudid. You probably wouldn't want to use a sustained-release form again because the pain is not well controlled. We certainly wouldn't want to use oral Demerol because it is ineffective, or oral hydrocodone because switching to a different combination drug with acetaminophen will not give any added benefit.

Of all the laxative choices, lactulose would probably be the most appropriate for this patient. It's both a stool

softener and an evacuant. The most appropriate adjuvant drug, those nonsteroidals, would be any one of those because they all have a benefit to them. Some are Cox 1 active, some are Cox 2. Prednisone, of course, can be used as an adjuvant. They all have benefit.

The patient with a carcinomic breast, with known metastasis to liver or lung, is getting into trouble with increasing pain, using Lortab, two every four hours as needed. The pain is worsened by deep breathing and there is postprandial emesis without nausea. The most likely explanation would be rapid expansion of hepatic metastasis. This is not an uncommon syndrome that we see, which is really a compressive gastropathy.

Remember, this patient was taking MSContin, 120 mg morphine a day, plus Lortab, so her total opioid dose and morphine equivalent is probably up around 180 mg. And so looking at morphine, 30 mg (this is on the low side) would be appropriate for her morphine breakthrough dose prescribed every 2 hours, not every 4 and certainly not a sustained-release preparation prescribed every 6 hours. She should be on parenteral morphine by patient-controlled analgesia to get this pain under control, and an appropriate dose would be close to 3 mg an hour. And we want to dose it as a continuous infusion instead of just in the patient-controlled analgesia mode that gives you this picket fence type of pain management to give her the effect of long-acting, continuous opioid serum levels and a breakthrough dosing mechanism.

The chance of her developing respiratory depression is an overwhelming concern. The patient at risk for respiratory depression is the patient who has not been on opioids for 24 to 36 hours, the patient who has not had chronic repetitive dosing. Tolerance to the respiratory depressant effect of opioids develops within 36 hours of repetitive dosing. That's why we can have patients on such large doses of morphine, 180 mg a day, who are obviously breathing, because they have developed tolerance to it. The opioid-naïve individual is the one who is at greatest risk and even then dosing can be done very safely. Her chances of developing respiratory depression are less than 1 in 1,000. Her chance of becoming addicted is less than 1 in 10,000; there are innumerable studies that confirm this. Some of the elements of neuropathic pain, as we pointed out before, differ in several ways from somatic or visceral pain, as does its management. That's why its identification is important.

A typical case study is a 51-year-old woman with post-mastectomy syndrome. She had axillary positive nodes,

worsening pain in the axilla, hot flashes, numbness, the typical distribution, trouble sleeping, and no relief from Darvocet or Lortab. Rating the pain as fluctuating between 3 and 7 out of 10, she can no longer work as a data entry technician. She presents with the three features common to the cardinal clinical features of neuropathic pain. Dysesthesia, the burning usually recorded as near constant, and the very uncomfortable sensation of pressure. The paroxysmal component is the lancinating type of pain typical of so-called "wind-up" neuropathic pain and is indicative of changes in the dorsal root ganglia; the spinal cord is evoked just by little movement or by tactile stimulation. This is an exaggerated response even to modest stimulation that can be evoked by either a single stimulus or by repeated stimuli that then produce this crescendo type of pain.

If there is tissue injury associated, it can evolve to the syndromes we are all familiar with of causalgia or reflex sympathetic dystrophy with the typical vasomotor and sweating abnormalities, the trophic changes and edema, which can be very difficult to differentiate, particularly if one is dealing with recurrent disease, nodal obstruction, or venous obstruction.

Generators can be peripheral, central, from distortion or compression producing nerve sheath pain by disturbing the nerve. This can result in axonal injury itself, which generates nerve sprouts, and then if these nerve sprouts are trapped in scar tissue we have typical painful neuromas. The important thing is that there can be several different causes to the generation of neuropathic pain, and that is why we almost always need coanalgesics in addition to opioids to deal with it.

You are all familiar with the different types of syndromes that are produced by direct tumor involvement, in particular, the brachial plexopathies seen with different types of lung tumors or metastatic breast or ovarian tumors. For example, the polyneuropathies in which the onset of neurologic symptoms can antedate the discovery of the tumor by months and, of course, which is not dependent on the course of the tumor.

A number of syndromes typical for postsurgical patients, like postmastectomy syndrome such as our patient had, is seen in 5% to 10% of patients. Post-thoracotomy, where we are trying to figure out if we have recurrent tumor or just a neuroma, and postradical neck, phantom limb, or stump pain are examples. Patients who typically develop phantom limb syndrome, who have had significant pain for a period of time before the

surgical intervention, are much more likely to develop this postoperatively.

For patients who have had amputations for tumor, reappearance of phantom limb pain may argue for recurrence of tumor, while a patient with stump pain more than likely has a neuroma. Other therapy-associated syndromes are postradiation, where the syndrome can develop anywhere from 4 months to 20 years after completion and postchemotherapy. Typically, after chemotherapy-induced neuropathy, the neuropathy is described as glove-like or stocking-like. Again, opioids are the mainstay of therapy, even for neuropathic pain.

Methadone has a unique role to play. Antidepressants are very helpful, particularly the tricyclics. They are not being used for their antidepressant effect but because of their effect on neurotransmitters in the central nervous system. We most frequently use Elavil (amitriptyline). We will start dosing 25 mg at night, to take advantage of some of its sedating properties to assure a good night's rest, watching for the anticholinergic side effects of dry mouth and urinary retention, but because it inhibits serotonin and norepinephrine reuptake, it's probably the first line of coanalgesic therapy. Paroxetine or Paxil, Venlafaxine or Effexor, again, which affect neurotransmitter reuptake, are effective in some syndromes. Anticonvulsants would be the next line of therapy. Gabapentin or Neurontin, carbamazepine or Tegretol have a role to play. Neurontin (gabapentin) is found very effective, especially pushed to very high doses.

Muscle relaxants have a role in certain situations, as do topical creams such as capsaicin, which depletes the neurotransmitter's substance P. In nerve endings it can be very helpful in situations where you are dealing with a painful neuroma or a stump syndrome or in postherpetic neuralgia, for example. It is important to recognize that our anesthesia colleagues may well have something to offer the patient in chronic pain, and we should recognize the opportunity to refer the patient to them.

So what would we do for this patient whose case we started with? Increase the potency of the opioid, escalate the dose to the point where disturbing side effects may or may not occur. Also, consider rotating to methadone again because it's an NMDA inhibitor and it works at the level of the dorsal horn and also affects neurotransmission and blocks reuptake of a number of important neurotransmitters, so it has a unique role to play in situations such as this.

We should certainly begin Elavil 25 mg at night with

the caveats that we discussed, and begin Neurontin 100 mg every 8 hours, slowly increasing it as tolerated. Because the persistence of chronic pain spills over from the truly physical into the psychosocial and spiritual realms, consider the patient's needs for support in these areas.

Dr Dunn: Our next panelist this morning is Dr Anne Mosenthal. She is Assistant Professor of Surgery at New Jersey Medical School, and she is a Faculty Scholar for the Project on Death in America, which is a Soros Foundation initiative. She will be speaking this morning about malignant bowel obstruction.

Malignant Bowel Obstruction

Anne C Mosenthal, MD, FACS

I am going to begin with a brief case presentation of a 67-year-old man 9 months posttotal gastrectomy for gastric carcinoma. At the time of operation he was found to have nine positive nodes. He had done fairly well in the last 8 months or so but over the last month had worsening of abdominal pain, cramping, and weight loss, and now presented to the emergency room with nausea, vomiting, abdominal cramping, and had passed no flatus for 3 days. He had a CAT scan that demonstrated multiple loops of dilated small bowel, diffuse carcinomatosis with multiple implants. There was no specific transition point on the CAT scan. Strangely enough his liver was not positive for metastasis.

So the patient was admitted and started on IV fluids, a nasogastric tube was placed, and it was clear that this man was not going to be cured of his disease and needed palliative care. The palliative care management options for this patient and others like him are essentially three- or fourfold. There are surgical options with which you are all familiar: bypass resection, a decompressive ostomy, or a gastrotomy. An exploration is an option for this patient for palliation. There are other options such as endoscopic placement of stents, which is not really an option for this patient. This would be more useful in a patient with a sigmoid obstruction or gastric outlet obstruction.

Conservative therapy, as we call it, which is a nasogastric tube and hydration, is an option although not a great one. And then there's medical palliation, which is really the focus of this talk, using somatostatin analogues, antiemetics, and antispasmodics.

The goal of palliative therapy is really to address the

Table 3. Outcomes of Surgical Palliation from Malignant Bowel Obstruction

First author	Year	n	Morbidity (%)	Mortality (%)	Palliation (%)
Blair ¹	2001	63	44	21	45
Sadeghi ²	2000	370	37	21	NA
Wolfson ³	1997	32	NA	22	53
Turnbull ⁴	1989	89	44	13	74

Modified from: Blair SL, Chu DZ, Schwarz RE. Outcome of palliative operations for malignant bowel obstruction in patients with peritoneal carcinomatosis from nongynecological cancer. *Ann Surg Oncol* 2001;8:632–637, with permission.

symptoms that the patient has. In this case the most common symptoms from malignant bowel obstruction are somatic pain and cramping pain, nausea, and vomiting. About 80% to 90% of patients with malignant bowel obstruction will have all of the symptoms.

You really want to eliminate the need for a nasogastric tube. They are very uncomfortable and very unpleasant. Try to manage without IV hydration so the patient can go home or go to hospice. The important goal of palliative therapy is to weigh the benefits and the burdens of each therapy that is considered.

What are the benefits and burdens involved in surgical options? The benefits of surgical laparotomy for possible alleviation of obstruction are that there is a fairly high rate of successful palliation depending on which studies one looks at. About 40% to 70% of patients will have relief of the obstruction and improvement of their symptoms after surgery. Indeed, some will have a known cause of their obstruction, mostly from adhesions. This is more likely in patients who have had a long interval from initial diagnosis to presentation of their obstruction.

But the burdens of surgical decompression are considerable. Perioperative mortality in most studies on this type of patient is probably 12% to 20%. And morbidity is considerable, with wound infection and fistula fairly significant. In addition, there's a fairly large group of patients who, despite the best intentions at laparotomy, will not be able to have successful palliation of their symptoms.

What are the outcomes of surgical palliation for malignant bowel obstruction? This is really not clear. There are very, very few studies on operation versus no operation for these patients. Table 3 is taken from an article by Blair and others¹ in the *Annals of Surgical Oncology*. I just listed a sampling of four articles. Note the first one, and you can see the morbidity is fairly high for all of these series, as is the mortality. Palliation that was successful is highly variable; it is as high as 74% in the last article and as low as 45% in Blair's article. Part of the difficulty is

that the way we define palliation in these series is highly variable. Dr Blair defined it as the ability to tolerate solid food, and only 45% of the patients who had surgery were able to tolerate solid food. Dr Sadeghi had the largest series of patients with nongynecologic carcinomatosis, but they did not look specifically at palliation. They looked at the outcomes and morbidity and mortality from surgery.

So how to select patients who might benefit from surgery? The patients who are less likely to benefit from surgery are those with ascites or those who have multisite obstructions, such as our patient, those who are nutritionally deprived, or have an albumin of less than 3 g/dL; in general, those patients who have a poor performance status. Those more likely to benefit are those with a better nutritional status and those with a long interval from their first operation and diagnosis of cancer.

To get back to our case report. This man had a nasogastric tube, he was begun on IV hydration, and he improved somewhat over the course of 3 days. His nasogastric tube output decreased, and on the third day he passed flatus and the tube was removed. But within 24 hours he vomited again and the nasogastric tube was reinserted.

Nasogastric tube decompression is clearly part of the initial management, but as definitive therapy it's really very unsuccessful. Only 14% to 15% of patients will respond in the longterm to this therapy and it's clearly very uncomfortable; for dying patients it is not a good option.

One possibility is to place a venting gastrostomy so the patient can actually have the stomach decompressed without the discomfort of a nasogastric tube. Clearly, in our patient this was not an option because he'd had a total gastrectomy. The patient was then started on somatostatin analogue to decrease his gastrointestinal output and morphine was added for pain. His nasogastric output decreased over the course of several days to less than 400 mL a day and was able to be removed. He was able to tolerate small amounts of liquids with intermittent

vomiting, and he went to hospice and died there without a nasogastric tube, having probably one to two episodes of vomiting every several days.

The goals of medical palliation are really to treat the vomiting and nausea, which are the main symptoms, as well as intestinal colic and continuous abdominal pain. The mainstays of this therapy are somatostatin analogues or octreotide, the antiemetics such as haloperidol, scopolamine to decrease the spasmodic pain, and, obviously, use of analgesics.

Octreotide successfully controls vomiting by decreasing the volume of gastric and gastrointestinal secretions. There's about a 70% response rate in patients with bowel obstruction. It may also decrease some of the colic and nausea as well. It works by inhibiting most of the gastrointestinal hormones and growth hormone, and decreases the volume of secretions in the bowel. It also inhibits peristalsis and decreases blood flow, probably decreasing some of the colic pain by this mechanism.

The starting dose is 50 to 100 μg every 8 hours. This can be given subcutaneously or IV at a continuous infusion of 10 to 20 μg per hour. The patient should be reassessed every 24 hours for vomiting, volume of gastrointestinal losses, and other symptoms and can be titrated up to a maximum of 600 μg per day.

For the symptoms of nausea, haloperidol is very effective in small doses. It also decreases the spasmodic pain. Five to 50 mg per day can be used in either IV or subcutaneous infusion. It can also be given orally if the patient is able to tolerate it. It does have some side effects, but these are fairly rare in an IV dose.

Many of these patients have severe abdominal colic and spasmodic pain, and the best option for this is the use of scopolamine in the form of a patch. Again, we are trying to avoid intramuscular or oral doses for these patients. This can be used in 10 μg per hour. It does have a lot of central nervous system side effects; these patients can become very delirious. Glycopyrrolate is the second option, and it does not have those side effects. In addition, there should be analgesics prescribed for the somatic pain.

There are adjuncts that may be helpful. Corticosteroids are recommended by some, usually in a dose of 8 mg dexamethasone per day. It's unclear how this works or why it works. In some patients it's very effective, possibly by decreasing edema. Sometimes laxatives may be helpful in a venting gastrostomy. Some recommend using

metoclopramide HCl, which may or may not be helpful. In some cases this may exacerbate spasmodic cramping.

In summary, the goal of palliative care for these patients is relief of symptoms, primarily nausea, vomiting, and abdominal pain. A selective palliative operation is clearly the first option considered. These patients should be selected carefully because the outcomes are not clear.

Medical therapy, the mainstay is really octreotide, the antispasmodics, and antiemetics. About 70% to 90% of these patients will have good symptomatic relief without surgery and without a nasogastric tube.

Dr Dunn: The content of this morning's discussion will be published in the *Journal of the American College of Surgeons* as part of its series begun in September 2001, "The Surgeon in Palliative Care: Palliative Care for Surgeons and by Surgeons."

The next speaker this morning will address dyspnea, which, for many people, is the most terrifying of symptoms facing patients with life-limiting types of illnesses. Closely associated with this, of course, is the whole issue of withdrawal of ventilatory support where there's anticipation or dread of dyspnea being its consequence.

Our next presenter is Dr K Francis Lee. He is Assistant Professor of Surgery at Tufts University. He is the medical director of Bay State Surgical Associates in Springfield, MA. He has a background in cardiovascular and trauma surgery.

Dyspnea and Withdrawal of Ventilatory Support

K Francis Lee, MD, FACS

I was given the topic of dyspnea and withdrawal of life support. It's a very broad topic. Dyspnea in palliative care can involve patients in end-stage pulmonary disease, congestive heart failure, and patients with pleural effusion from malignant disease. I am going to focus on dyspnea and symptoms and signs of distress during withdrawal of life support.

Life support can mean many different things. It can mean life support in the form of hydration, in the form of tube feeding. Our topic is ventilatory support withdrawal. We will talk briefly about the prevalence and elements involved in the decision-making process and then focus on the practical steps, one of the most important parts of which is how to prevent dyspnea and symptoms of distress during withdrawal of life support.

Is death by withdrawal of life support a standard practice today? In a study by Prendergast et al, from UCSF in 1998, it was discovered that death after a full CPR occurred in 26% of the patients. Twenty-four percent of the deaths occurred after DNR or placement of the DNR order. In 14% of the patients, death occurred after withholding life support, and 36% occurred after withdrawal of life support.

If one combines the three groups as representing limitation of maximal possible intervention in the ICU, nearly three-quarters of patient deaths occurred after some limitation of life support in the ICU, and only about one-quarter of the patients went through “full court press,” as we refer to it. This demonstrates that withdrawal of life support, at least in 130 ICUs throughout the country representing roughly 6,000 deaths, is indeed a very common practice today. But one must not be complacent because, in fact, a lot of these deaths probably occurred with withdrawal of support being instituted just shortly, just imminently before death, as we know from the SUPPORT studies. Also among these ICUs there is a great deal of variation. For instance, the mean of 36% was a mean of a range of 0% to about 80%.

Let's review some of the issues to consider when going through the decision-making process to suggest withdrawal of life support. First, the surgeon ought to know the following ethical and legal principles that guide us in the 21st century.

- (1) The principle of patient autonomy. Patient autonomy takes precedent over the medical professional's preference of what is best for the patient. The patient's right to die or right to refuse treatment is a valid legal principle and the state's interest, such that if the patient has a right to refuse treatment, that preference should be well documented and clearly indicated. Surrogate decision making is another very important principle. The next of kin or proxy has the substitute of judgment that is legally protected in most cases.
- (2) Truth telling is a very important concept that surgeons must adhere to. Honest prognostication is an expected right of the patient from the surgeon. Previous practices, such as putting purple dots in medical records, as in the case in a New York hospital, to indicate which patients should undergo sham codes because they didn't have DNR orders, or any such practices are inappropriate and not standard practice today.
- (3) There is a clear difference between withdrawal of life sup-

port and euthanasia, and I think this is a very important issue, addressed later.

- (4) Last, palliation that results in hastened death is legally protected or is legally defensible by the philosophical principle of double effect. But these are the principles that one ought to know well when approaching the issue of withdrawal of life support.

In addition to knowing the principles of ethics and legal ramifications, one must always apply outcomes data and discuss patient preferences. When approaching outcomes data one must always remember that there's no absolutely perfect prediction model. Neither MPM or APACHE, nor any other models, accurately predict mortality for individual patients. And at some point qualitative, clinical, and surgical judgment must come into the picture. Obviously a surgeon must withhold personal values and biases until knowing the patient's preferences, and consensus must be sought among the patient care team, among the nurses and physicians of different specialties.

When discussing these options with the family it's important to allay their fears of legal liability for the person who is making the decision. And even when the decision for withdrawal of support is made, continuity of care should be provided for optimal palliation of suffering because families usually have fear of abandonment. It's important to educate families so that the surrogates can start to articulate their personal goals of care for their loved one, and it's important to understand some cultural biases toward end-of-life care decisions. For example, in some minority populations withdrawal of life support can imply another form of discrimination that they have experienced in their own population.

If there are complex issues that arise, consider getting a consultation from a third, disinterested party such as an ethics committee, if available. Withdrawal of life support is a sort of a special procedure and there should be ample documentation. It is not necessary to obtain a formal informed consent, although many people suggest that this is a good idea. But I believe that the possible benefits and risks of those issues ought to be clearly documented in the chart.

The practical steps involved in withdrawal of life support are as follows. One must create the appropriate environment. A lot of this is fairly intuitive and doesn't need elaboration. It's important to separate the patient from the ICU environment as much as possible. Some hospitals have a special unit where these patients can be

Table 4. Cardinal Physical Symptoms During Withdrawal of Life Support

Pain
Dyspnea
Excessive secretions

taken with a ventilator so they are not disturbed by the hustle and bustle of the ICU activities. As much as possible the monitors and instrumentation ought to be discontinued because they can distract from the process of the final passage, and laboratory tests should be discontinued because they are no longer of any use. Visitation access must be increased so that every member of the family and all friends can have a chance for resolution and visit.

The important issue is how do we treat the physical signs of discomfort during the withdrawal process. There are three major discomforts the patient might exhibit (Table 4). Excessive secretion is something very disturbing to onlookers, and that can be easily managed by suctioning and by anticholinergics and other pharmacologic interventions.

But dyspnea is something we really need to address in order to make sure the patient does not show signs of breathlessness during withdrawal of life support or withdrawal of ventilatory support. By definition, dyspnea is a subjective sensation of an objective abnormality. It is an uncomfortable awareness of breathing, of breathlessness. There are chemoreceptors of oxygen and carbon dioxide, and there are mechanical receptors from the lungs, irritants, and stretch receptors, which all contribute to both the medulla and the cerebral cortex to produce the sensation of dyspnea, associated with a great deal of psychologic and emotional experience.

There are many causes of dyspnea (Table 5). In patients in the ICU undergoing final or "terminal" wean, however, we need to make sure that the very process of

Table 5. Causes of Dyspnea at End of Life

Anemia
Chronic obstructive pulmonary disease
Congestive heart failure
Muscle weakness
Pleural effusion
Pneumonia
Psychological or spiritual distress
Pulmonary embolism
Withdrawal of life support

Table 6. Randomized Clinical Trials of Opioids for Dyspnea*

First author	Year	Duration (wk)	Increased exercise tolerance	Decreased breathlessness
Woodcock	1981	Single dose	Yes	Yes
Bar-Or	1982	2 weeks	Yes	Yes
Johnson	1983	1 week	Yes	Yes
Light	1989	Single dose	Yes	Yes
Rice	1987	4 weeks	No	No
Eiser	1991	2 weeks	No	No
Poole	1998	6 weeks	No	No

*Modified from Manning HL. Controlled trials of opiates in COPD. Dyspnea treatment. *Respiratory Care* 2000;45:1344, with permission.

withdrawal of ventilatory support does not in and of itself cause dyspnea for the patient.

A lot of these data (Table 6) that I am presenting come from chronic dyspnea management rather than from acute ventilatory withdrawal. The principles may be similar. As Dr Milch previously explained, opioids work on mu receptors as well as kappa and delta receptors. Opioids have been shown to be the best drugs and the standard therapy for treatment of dyspnea in this kind of setting because their mechanisms are varied. Not only do they provide analgesia, but they provide euphoria and venous capacitance to increase in the abdomen and lower extremities, at least in the studies that have addressed this. So, they decrease venous return and cardiac congestion, cause pulmonary vasodilation, and reduce pulmonary hypertension. By the effect of reducing metabolism opioids also decrease oxygen consumption. Last, they block cough reflex within the central nervous system. Table 6 shows a series of clinical trials studying the effects of opioids on patients with chronic dyspnea symptoms. In four studies when given as single dose or repeated doses over 1 to 2 weeks, opioids have been shown to increase exercise tolerance and decrease the sensation of breathlessness. But it is interesting that the longer that they are given in these clinical trials the effects seem to be not as clear. But certainly for the discussion of acute withdrawal of ventilatory support, giving opioids would be perfectly reasonable and would be the first line of treatment.

Here are some principles of dose titration for opioids in end-of-life care. Granted, I think these are more relevant to chronic dyspnea management but they apply to the acute withdrawal of ventilatory support. First, the dose of opioids must be titrated to the patient's symptoms. In patients who are undergoing withdrawal of

Table 7. Dose Titration of Opioids in End-of-Life Care

Respiratory depression is not common when dosage is titrated to patient symptoms.
15 patients with advanced cancer and severe pain
Morphine every 10 minutes until symptom relief as "bolus"
Maintenance based on initial "bolus" dose/hour
No respiratory demise with average maintenance dose of morphine 20 mg/h up to 360 mg/h
One patient developed bradypnea and somnolence

Summary of findings from Citron M, Johnston-Early A, et al. Safety and efficacy of continuous intravenous morphine for severe cancer pain. *Am J Med* 1984;77:199-204.

ventilatory support the symptoms include tachycardia, actual physical movement, and agonal breathing.

I think dose titration is important because one must consider the development of tolerance, as Dr Milch briefly discussed. When we increase opioids it is important that we increase them by sufficient increments. Often we see, in the ICU during withdrawal process, that the morphine is increased from 2 mg an hour to 4 to 6 to 8 and then 10 and 12. If you look at certain other drugs we commonly use such as furosemide, when we give furosemide and don't get the response we want, we increase from 10 mg IV, to 20, and then to 40, and then to 80. We give oxycodone HCl; acetaminophen as one tablet per 3 or 4 hours, but sometimes need to increase it to two tablets. Oxycodone HCl SR doses are given as 10 BID, then increased to 20 BID, and then to 30 BID.

When there's dyspnea exhibited during withdrawal of life support, morphine should be given in increments that are significant, such as 2 mg to 4 mg to 8 mg to 16 mg and so on, as Dr Milch described for pain. These are from the data from chronic pain management, but it's equally appropriate for the discussion of dyspnea. For patients with mild to moderate signs of dyspnea, doses of morphine should be increased by 25% to 50%, and for those with moderate and severe pain, the dose should be increased by 50% to nearly double every time you increment them.

Last, the half-life of the drug should determine the frequency of the escalation. In a study of 15 patients (Table 7) with advanced cancer and severe pain, morphine was given every 10 minutes until symptom relief was achieved and was given as bolus. Maintenance of those was based on the initial bolus dose per hour. They discovered that there was no respiratory demise with an average maintenance dose of 20 mg up to 360 mg per hour, which is a whopping amount of morphine. But in

these patients there's only one episode where the patient developed bradypnea and somnolence, which was easily treated by just reducing the dose.

Basically, this study and other studies like this support the thesis from Dr Milch that respiratory depression in chronic opioid treatment is probably an overheightened concern and not necessarily supported by literature data. Of course, once in a while we do have patients who die immediately after a morphine dose and one is always concerned about that fact. Did I kill the patient or what else happened? The spectre of euthanasia is a big barrier to adequate treatment of dyspnea and pain in patients undergoing withdrawal of life support.

It is important to distinguish euthanasia from palliation because of the different legal ramifications of each. The definition from Merriam Webster's dictionary says that euthanasia is "the act or practice of killing or permitting the death of hopelessly sick or injured individuals in a relatively painless way for reasons of mercy." If I just replace some of these words I can arrive at a definition of palliation: "the act or practice of alleviating the suffering of hopelessly ill or injured individuals with or without double effect for reasons of mercy."

And I put this "with or without double effect for reasons of mercy" to discuss the legal and ethical ramifications. "Double effect" is a philosophical and ethical concept. And there are many definitions for that, but I am going to borrow one from the *Stanford Encyclopedia of Philosophy*. "Double effect is an act with primary intention of doing good, producing a secondary effect that is harmful." If we replace a few words with what we are talking about now, palliation, we can come up with a definition of double effect appropriate for our setting: "withdrawal of ventilatory support with high-dose opioids (which is the act) with the primary intention of doing good, in other words, palliation, produces a secondary effect, death, that may be considered harmful." Now, that's the situation of double effect.

But for this to be fully operative, four criteria need to be met. One, that death occurs as a side effect to the achievement of the good, which is palliation, that is directly aimed or intended by the high-dose opioids. Two, that palliation by high-dose opioids is directly aimed at is itself morally good or at least morally neutral. Three, and this is the controversial part, the good effect of palliation is not achieved by way of the bad, the death, that is, the death is not the means to the effect of palliation. This distinguishes palliation from euthanasia.

Table 8. Ordering and Administration of Sedatives and Analgesics During Withholding and Withdrawal of Ventilatory Support from Critically Ill Patients

Two University of California, San Francisco, medical-surgical ICUs, 1988–1989
Prospective case series of withhold or withdrawal: n = 44 patients
Medical (39%) and surgical (61%) patients
33 patients (75%): Diazepam 9.8 mg/h, morphine 11.2 mg/h, Mean time to death: 3.5 h
11 patients (25%): No sedatives or analgesics. Mean time to death: 1.3 h (p = not significant)

Summary of highlights from Wilson W, Smedira N, Fiak C, et al. Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *JAMA* 1992;267:949–953.

And last, the bad consequence, which is death, must not be so serious as to outweigh the good effect, which is palliation.

This is a judgment call. Who is to decide that death in these patients is more serious than the good effect of palliation through high-dose morphine? In 1997 the Supreme Court gave a considerable legal defense to those surgeons who might use high-dose opioids for treatment of dyspnea and pain in their patients undergoing withdrawal of life support. The chief justices' majority opinion states that "just as a state may prohibit assisting suicide while permitting patients to refuse unwanted life-saving treatment, it may permit palliative care related to that refusal, which may have the foreseen but unintended double effect of hastening the patient's death." Justice O'Connor also wrote 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 practitioners to alleviate that suffering, even to the point of causing unconsciousness and hastening death.

I believe that surgeons, in general, ought to feel protected using high-dose opioids as necessary to relieve dyspnea and pain in these patients undergoing withdrawal of life support.

In this study, outlined in Table 8, the concept of double effect may be a moot point for most practices. In this small study of about 44 patients, they discovered that the patients who actually received high doses of sedatives and morphine had longer times to death after withdrawal of ventilatory support than the patients who did not receive sedatives and analgesic, when the mean time to death was only 1.3 hours. There were a lot of prob-

lems with the study, which was not a randomized clinical trial, but at least it raised the possibility that, again, high-dose opioids do not necessarily mean hastening death.

Extubation follows a couple of different methods. Some just take the tube out. Others leave the endotracheal tube in with a T-piece. I don't think there's really that much difference. In fact, I think removing the tube directly is more straightforward and does not involve many other complexities in the final minutes. Document very clearly the events that take place. Pharmacologic paralysis—what do you do about that? What happens when you have a patient who survives after you withdraw ventilatory support? A lot of factors are involved in dealing with those situations. And, finally, bereavement counseling is something that we surgeons don't feel comfortable as experts at, but we should provide resources the patients' families.

Dr Dunn: Dr Alexandra Easson is a surgical oncologist on the faculty of the University of Toronto. She works at University Health Network in Toronto. She will give a presentation on cachexia.

Asthenia and Cancer Cachexia

Alexandra M Easson, MD

I will discuss the approach to asthenia and cancer cachexia, beginning by presenting a patient. Mr X is a 57-year-old man who, over the past months, has been progressively refusing to leave bed, to eat, to speak to his family, or to seek medical care. Finally, in desperation, his wife obtained a court order to bring her husband to the emergency department for medical assessment. His past medical history is quite significant, because two years ago he had a total laryngectomy for cancer of the larynx, but there is absolutely no evidence that he had any recurrence from the larynx cancer. On clinical examination he was noted to be malnourished, profoundly anemic, with an extremely flat affect. Further physical examination revealed a bleeding metastatic rectal cancer with metastasis to lung and liver. On questioning he complained of no pain, had no signs and symptoms of gastrointestinal obstruction, and his only explanation for his behavior was that, "I am too tired."

The assessment of patients with advanced cancer can be complex, because they can present with multiple symptoms. Managing these symptoms may be difficult, because as you manage one symptom you may develop

Table 9. Frequency of Symptoms in Palliative Cancer Patients

Symptom	Frequency (%)
Asthenia	90
Chronic nausea	90
Anorexia	85
Delirium	85
Pain	80
Constipation	65
Depression-anxiety	25

Bruera E, Bealtie-Palmer LN. Surgical Oncology Clinics of North America. Jan. 2001, with permission.

problems with another one. Let's start with some definitions. Asthenia comes from the Greek word *asthenos*, which means generalized weakness. It primarily comes with three components. First is profound fatigue after even beginning minimal amounts of exertion. Second, patients develop generalized weakness that makes any activity difficult to initiate or to maintain. The third part of this is mental fatigue, which makes mental concentration difficult with or without cognitive impairment, emotional lability, or difficulty in concentration.

Anorexia, as you all know, is a reduced desire to eat, and both of these are prominent symptoms in the syndrome of cancer cachexia, again from the Greek words *cacos* and *hexis*, meaning poor condition, and this refers to the progressive wasting and weight loss seen in patients with advanced illness not limited certainly in advanced cancer but not limited to advanced cancer, and this is a catabolic metabolic change.

So when you are considering bedridden patients with weight loss, you have to think of these three factors together. They may not be able to eat, or may just not have an appetite. They find themselves more and more tired, and these two symptoms may be manifestations of the cancer cachexia. When you are considering treating these patients, you must think of all these three things together.

Table 9 shows frequency of symptoms in palliative care patients. These are in advanced cancer patients who were admitted to a palliative care unit. Note that asthenia and chronic nausea were the most frequent symptoms in 90% of all patients. Anorexia and delirium were present in 85%; these symptoms were present in more patients than was pain.

Asthenia in and of itself is a very poorly studied symptom and has a variable onset. It may precede the diagnosis. Remember, it's a feeling of fatigue and may present

throughout the illness and it may be made worse particularly by treatments such as anticancer treatments, chemotherapy, radiation, and surgery. It is rarely assessed and treated.

In the context of advanced cancer patients there is a manifestation of cancer cachexia, but it's also a very interesting symptom because it is seen in chronic illness and infections and it is also seen in cancers where cachexia is rare, such as breast and hematologic malignancies. The cause is poorly understood; there have been implications that some of the cytokines like interleukin 6, tumor necrosis factor alpha, and interferon have been implicated, as have the elevated acute-phase proteins. These are very similar metabolic changes that you can see in cancer cachexia.

So how to access this? Well, there are some symptom scales that have been developed. There are unidimensional and multidimensional scales. The Roden fatigue scale is one performance status. These are validated scales, as is the Edmonton Functional Assessment Tool. These scales must be simple but in practice they are not really used outside palliative care trials.

To ask the question, "How tired are you?" will often provide a very clear answer because patients are usually not ashamed to discuss this. An acknowledgment and explanation that this is a normal part of the advanced illness can do a lot to alleviate the distress seen in both patients and family members.

Management is multifactorial. Patients may have metabolic abnormalities or dehydration. Untreated symptoms, especially untreated pain, may be a contributing factor, as may anemia, sleep problems, psychologic problems such as depression and anxiety, prolonged immobility from being in bed, and presence of organ failure.

What is cachexia? Cachexia is common in advanced illness. It is seen in malignancies, primarily lung and upper gastrointestinal tract. It is also seen in organ failure (cardiac, lung, renal, and liver), and in chronic infections such as AIDS. Its manifestations are quite patient dependent. It is remarkable that even in patients with the same tumor burden and the same tumor type, there are differences that manifest the syndrome. It may be potentially reversible with successful disease treatment. It is a profoundly different metabolic response than starvation. Although anorexia or not being able to eat or not wanting to eat is a part of cancer cachexia, the metabolic response is quite different. In simple starva-

tion, within a few days fatty acid oxidation elevates ketone levels and this signals the rest of the body to shut down on glucose production and shut down on protein breakdown.

This does not happen in cachexia. As a matter of fact there's an increasing catabolic rate that goes on. Especially initially, the metabolic rate may, in fact, increase, and glucose consumption increases. There's an increasing signal for protein breakdown, especially muscle, made worse by decrease in protein and fat synthesis. Once again, you can see an elevation in the acute-phase protein response.

The cause is unclear. A number of animal and clinical studies have suggested a number of different abnormalities. Again, the same cytokines that we saw before have been implicated. There are tumor- and disease-mediated products described. Glucagon and cortisol abnormalities are seen, as are some of the neurotransmitters, particularly serotonin, which may cause weight loss.

What is clear is that this is a chronic change and it is from malnutrition, so it is difficult and impossible to correct with shortterm artificial nutritional supplementation with total parenteral nutrition and enteral feeding. The diagnosis is made by history and clinical examination. Patients have weight loss, anorexia, and asthenia. As the condition progresses they show muscle wasting, loss of body fat, and dependent edema; they exhibit poor wound healing; and they have pressure sores.

When you look at their biochemical profile they may be anemic, they may have a low albumin, although this is also seen in malnutrition, and an elevated C reactive protein. And there's been a new protein identified called proteolysis-inducing factor identified in the urine of patients who are cachexic and absent in those who are not, which can produce cachexia in mice, showing promises of a diagnostic tool.

It may not be clear at first that a patient is cachexic, but with progression of disease this diagnosis will become clear, as in a patient with AIDS who's got marked muscle wasting with cachexia. Of course, here the diagnosis is easy.

Basically, with cancer first you have to clarify the treatment options. Assess the patient for asthenia and anorexia using a combination of physical examination and history. Try to determine whether or not cachexia is present. Are there any good anticancer treatments that the patient is a candidate for? The cachexic patient may

not be a candidate for aggressive therapy such as surgery or chemotherapy. This option should be explored with the patients and the families and clearly dismissed if this is not to the satisfaction of everybody so that realistic care levels can be set.

Identify and treat reversible causes of anorexia and asthenia. These include metabolic abnormalities as mentioned previously. Untreated symptoms such as pain, constipation, and nausea are very common reasons for anorexia and asthenia and they include medication side effects, treatment effects, or just effects of disease progression.

Rule out mechanical obstruction. Patients with upper gastrointestinal or particularly head and neck cancers may not in fact be cachexic. They may simply be malnourished. Patients with small bowel obstruction from diffuse intraabdominal disease should be distinguished from patients with bowel obstruction from one simple source, which can then be dealt with.

Malabsorption is very common in patients with pancreatic cancer, with a history of radiation to the abdomen; pancreatic enzyme supplementation can be useful. And psychologic factors such as depression and anxiety are both very important causes of anorexia and asthenia. There have been a number of pharmacologic approaches tried; most common is use of corticosteroids. Dexamethasone and prednisone have been shown to increase appetites in patients with advanced cancer but have not showed any effect on weight loss. In one trial methylprednisolone has been shown to improve quality of life.

The effect of these agents is quite rapid. The problem is that the effect doesn't last very long, so it is usually best reserved for preterminal stages of life later in the course of the disease. Progestational agents have also been studied in randomized trials and this actually is shown to produce weight gain, but the problem is that this weight gain is really fat and water and this drug is also associated with a number of side effects including venous thrombosis; its real role in this treatment isn't very clear.

Nonsteroidal antiinflammatory drugs offer promise; ibuprofen and indomethacin have been shown to decrease resting energy levels and interleukin 6 levels. Unfortunately there haven't been any prospective trials in patients. Fish oil supplements may be effective as there is now animal and early clinical evidence that taking fish oil supplements may, in fact, maintain weight gain in patients with advanced cancer, and this is a subject of several ongoing randomized trials.

Eating is a very important social interaction, and Dr Mosenthal has discussed the pharmacologic management of bowel obstruction. It is very important that even in those patients, by eliminating diet restrictions, with small appetizing meals, you can create some kind of environment where the patient is able to tolerate small amounts of oral intake.

The other important issue is to encourage the family to explore other forms of social interactions outside of eating so they can maintain a relationship with the patient who is dying.

Because the goal of therapy in palliative care is the relief of symptoms, and these phenomena are really inevitable and can be seen throughout the course of disease, there is some controversy within the palliative care community of how aggressively to treat this. You have to go back to what the goals of care are. Is this something that is causing a distress and is a problem for the patient?

Presentation or appearance of these symptoms does offer an opportunity to educate and support patients and families about the progression of illness. Recognizing what is normal can do a lot to alleviate distress. Explore sources of distress with the patient and the family; this can allow directed advanced planning around the terminal phase of the illness.

Our patient, Mr X, I presented because he was one of the most profoundly asthenic people I've ever met. There were a number of reasons for his asthenia. He had electrolyte abnormalities because he wasn't drinking. He was profoundly anemic. He had a laryngectomy and had stopped taking his thyroid medication and so he was hypothyroid. He was very depressed, and had been probably since the loss of his larynx. The cancer cachexia did not help, considering he had an advanced rectal cancer and he was profoundly malnourished. Other causes that you couldn't see in him but you must consider are drugs that he may be taking, effects of anticancer therapy, and the presence or absence of concurrent infection.

What ended up happening to Mr X is that we corrected a lot of these abnormalities. He was not a candidate for chemotherapy but did receive radiation to control the bleeding. He started to communicate with his family a little bit better and was discharged home with home palliative care.

Dr Dunn: Our final panelist is Dr Joan Huffman. She is acting director of trauma and surgical critical care at Crozer-Chester Medical Center in suburban Philadelphia.

Lingering in the Intensive Care Unit

Joan L Huffman, MD, FACS

I would like to recognize the Robert Wood Johnson Foundation for giving us a grant for our surgeons' palliative care group. As noted, I am the acting director of the trauma program and surgical critical care. I am also a cochair of our hospital task force on end-of-life care and our group is called the Peaceful Journey Partnership.

When we think about end of life, one of the things we see many times is that our patients linger in the ICU. Seventy-year-old Mary had a known thoracoabdominal aneurysm and renal artery stenosis. She had been offered operative intervention but initially had refused. She did agree to undergo serial evaluation surveillance. She then began to develop abdominal pain and symptoms, and on evaluation was found to have a marked increase in aortic diameter. She was afraid to live with this time bomb, but she was also afraid of the surgical intervention. She underwent consultation with the surgeon and her family when she learned the potential risks, the risk of a paralysis, the risk of renal failure, paralysis, or even death. Because of fear of the absolute rupture, she did agree to undergo an operation, but she told her family and the doctor that if the worst happened she didn't want to be kept alive by machines.

She subsequently underwent the operation. Postoperatively it was clear that she was now paraplegic. She was in acute renal failure and she was unresponsive. But is this the worst that she had expected? A family meeting was again called. It was clear she was not going to recover from the paralysis but the surgeon believed that if she underwent some time-limited hemodialysis she might recover from the renal failure. She was unresponsive and couldn't concur with this decision. But the family agreed to a shortterm period of hemodialysis as long as she was kept comfortable and she was placed on continuous morphine drip.

In about 2 weeks her renal failure resolved. Hemodialysis was discontinued, and she was now awake and alert. She remained ventilator-dependent, but she was interacting with her family and seemed to be happy with the interactions that she was having with them. Now, however, she developed ongoing diarrhea, incontinence, and developed a sacral pressure wound. There was another family meeting about what her ongoing care was going to be, and at this point it was decided with her also

in concert that she would undergo another procedure for her palliation because clearly she wasn't going to recover from the paralysis, but perhaps some additional procedures might make her care more comfortable.

So she underwent a tracheostomy, a gastrostomy tube for feeding, and a diverting colostomy for her wound care. She began to rally and she was almost ready to be released from the intensive care unit and think about home care settings when she unfortunately developed a suture line breakdown from one of her enteric procedures and became septic. She was now delirious. She went into septic shock. Pressers were initiated.

At this point another meeting was called, and they declined surgery. They did agree she could have CT-guided drainage and IV antibiotics. At this point they said, "You know, she is elderly, and if anything else occurs we don't want CPR. We don't want any cardiac events corrected."

This period of care went on for another few days. She began to have a lot more respiratory symptoms; she was obviously very uncomfortable and an additional family meeting was called. At this point the decision was made to withdraw care. So after 6 weeks in the intensive care unit, care was withdrawn with the patient on morphine and sedatives and her family at the bedside.

This is what we see many times in the ICU. How do we look at this in the face of palliative care in the ICU? The ICU is a place of high technology, invasive procedures, advanced life support. And our priorities are to cure illness and prolong life, and we do this many times, regardless of resource use or suffering of the patient.

This is in contradistinction to what the World Health Organization's definition of palliative care is, and that is active total care of the patients when disease is not curable. There the priorities are control of pain and symptoms, and looking once again at when we looked at the statement on end-of-life care to aid with social, psychological, and spiritual symptoms. One thing that we have to understand is that in the ICU, despite all our aggressive treatment, in reality 10% to 20% of patients die. And even if they don't die in the ICU the 6-month mortality is really increased in elderly patients in the unit.

Unfortunately, too many times the pain and suffering that these patients undergo while we are doing the aggressive procedures is unnecessary pain. It may be unrecognized by us or go untreated. It's also, as Dr Lee showed us, why support is often withdrawn in the majority of ICU patients.

Regarding the statements on principles of guiding care (see first page of this article), the first two are respect for dignity of patient and caregivers and sensitivity and respect for the patient's and family's wishes. There is also the patient's right to refuse treatment.

Our other body of medicine, the Society of Critical Care Medicine, also recognizes that palliative care is an important issue. The whole topic during 2001 was blending science and compassion. In fact, there were sessions throughout the whole conference on palliative care and there was a poster submission.

For us, as surgeons, this can be a big cultural shift, a fundamental shift. We are used to being very aggressive in our curative intent rather than looking at the quality of life or perhaps even the management of death. Also our goals of care may need to change. As surgeons we are very procedure-oriented and we may need to look sometimes at being more patient-oriented. We are also very oriented to morbidity and mortality with our weekly M & M conferences; perhaps our goals and orientation need to change more to pain and symptom control.

Some of the issues that we deal with in this area are unanticipated illness, for example, traumatic injury. Perhaps it's a 20-year-old patient who has been in a severe motor vehicle collision and now is in a vegetative state. Perhaps it's a complication of an operation like the one I just discussed. One procedure led to one issue, to another problem, to another problem. Maybe it's an acute progression of a chronic disease. Perhaps it's a patient who has what would seem to be an uncomplicated procedure, something as simple as a colon resection for a noncancer issue, and then suddenly has an acute MI or CVA or an exacerbation of COPD and becomes ventilator dependent. So these may be unanticipated issues.

This can be exacerbated by the fact that the patient's wishes may be unknown and they may not have ever discussed them with the family. They may not have an advance directive, or they may not have delegated a durable power of attorney. And so the family may not really know what the patient wants. Also the family may never have met the physician before so the family doesn't have a relationship to build on.

Another issue we may see is an unclear prognosis. Many times it's not certain what is going to happen, and in the case of Mary, what started as a serious procedure with potential complications went on and on and on and on, and this ended up to be a 6-week picture in someone who eventually died.

So a patient may have multiorgan failure and linger in the ICU. And then we have to think about where we are going with aggressive therapy and at what point it becomes futile care. As Dr Lee also mentioned, we have a lot of scoring systems that can give us an idea of prognosis in patients with similar diagnoses, but they don't tell us for sure what is happening in the individual patient.

One thing we need to look at is timing and end-of-life orders. When looking at some of the papers, DNR orders many times are initiated only 1 to 2 days before the patient's actual death, or patients may even have the decision for support to be withdrawn anywhere from 5 to 10 days after an ICU admission. In Mary's case it was actually 6 weeks. In various articles, whether this is a medical practice or a surgical practice may vary by institution and institutional culture. Even in the SUPPORT study that looked at end-of-life decisions, sometimes even communication didn't produce a change. We all have to remember that death is, if not a certain, at least a possible outcome in the ICU. In fact, it's a certain outcome for all of us.

So we need to look at this in terms of end-of-life goals of care. We should be looking at comfort, relief of symptoms. We should be thinking about whether we should avoid and not even start a therapy, or should we stop ongoing therapy. We need to make sure family visits are available, and then think of spiritual closure both for the patient and the family. This may differ per individual. A lot of it depends on what the patient's situation is. If you have a patient in a vegetative state, the patient may not be able to participate in the decisions, and a lot of it may depend on previous communications with the family.

It should be our goal to promote relief of symptoms and not to prolong the dying process, and at this point we really need to be supporting the family. The other side of the coin is that you may have a patient who is awake and alert but has impending death. Once again, our first goal should be to minimize pain and suffering, but to make sure the family is available to interact with the patient and look at spiritual closure for both of them, and if it's the patient's and family's goal, to see what we can do to enable discharge to hospice.

It's important to realize that our goals are dynamic, that they have to change as the patient's condition changes. In Mary there were five different family meetings every time there was a change in her condition. So communication has to be ongoing. We have to discuss

the potential outcomes. What are the benefits, what are the risks of each decision-making process? When we make treatment decisions we have to think whether these are shortterm. For example, the dialysis was considered to be a shortterm decision for her, but it was decided right from the beginning this was not going to be an ongoing process.

What are burdens and risks, and what is palliating versus extending? With the second decision-making process in Mary's case, it was that she was now awake and alert and she was enjoying visits from the family, she was seeing pictures of her grandson's communion, and she was happy to interact at that stage. So, for her at that point, it was important to continue on and she was involved in that decision-making point, so additional procedures to make her more comfortable were appropriate.

It's important to realize that this is a continuum of care, that palliative care doesn't start at the end of life. It should start at the beginning of therapy. Because we can do less and less of our aggressive procedures we should do more and more of our palliative ones. But palliative care needs to begin right at the very beginning.

We've talked a lot about pain and symptom management. Communication is the key. We should have a goal to communicate and if the patient is awake, also family and patient meetings as soon as possible after admission to the ICU so that we can communicate our thoughts about the patient's disease, potential prognosis, and potential treatment. And then we need to have ongoing communications at regular intervals whenever there's a significant change in patient care, or at least on a weekly basis if this is an ongoing therapy.

We talked some about ethics and legal situations. It's important to remember it's the patient, not physician preference that has to guide therapy and that patient autonomy is important. In 1990 the US Supreme Court said every individual has the constitutional right to control his or her own treatment. Also, in the case of Cruzan, if there's clear convincing evidence, a person's wishes must be followed by medical personnel even if those wishes are directly opposed by the patient's family. So the patient, patient, patient.

There are times when the patient has not told us and the patient cannot communicate to us because of current state, and that's when we look to healthcare surrogates. If the patient has designated a surrogate, that makes it easy for us but we have to realize the surrogate may be some-

body that we may not expect. It may be a spouse. It may be a sibling. It may be a partner or a friend. So we can't just assume who the surrogate is if the patient has legally designated some other individual. Sometimes we may want to limit our use of technologies and therapies.

I want to talk briefly about levels of care. This is the way we do it in our hospital. We actually have a form we use as a discussion tool with families. Then we even sometimes give it to them to look over and then come back and meet again. We actually have four levels of care that we look at. Level one is full therapeutic effort. Everybody that comes into our hospital is considered to be at this level unless designated otherwise. This is where we do everything technologically and physically possible.

Level two would be selective therapeutic effort; whether or not the patient would want to have CPR. We are going to continue with all the other therapies but perhaps the patient does not want CPR or perhaps does not want defibrillation or perhaps does not want to be put on a ventilator.

Other things we may also think about is whether or not the patient wants blood transfusions, feedings, additional operations, dialysis. So all these things can be considered selectively and individually as the patient desires, and it may not make sense to us what the patient's choices are, but he or she may have specific reasons why those areas were chosen.

Level three would be a maintenance therapeutic effort, where the patient and family decide they don't want any additional new therapies added. They don't want CPR. They want to be kept comfortable and not suffer. So if they get a new pneumonia, new therapies are not initiated.

We also state that just because we have gone up to a level three doesn't mean we can't go back to a level one if the patient improves or the patient or family changes. So it's not written in stone.

What is key in pain and symptom management? This may be certainly the pharmacologic measures that we talked about, but also involve good mouth care, good skin care, turning the patient, having the patient's family available.

Level four would be withdrawing life support. This would be stopping the respirator, stopping pressers, stopping all therapy. But remembering even from the very beginning that we are continuing comfort measures. Everybody gets comfort measures from level one,

level two, level three, level four, and the patient needs to be reassured that he or she will not be abandoned. At some point we all die, and our goals should be to help this with minimal emotional and spiritual suffering, that we can achieve as peaceful a death as possible, that we achieve closure.

One thing that is important is the legacy that we leave to the people behind and how we die is a very important legacy. For those left behind we have to remember that they are a very important part of the picture, too. We, as doctors, are not expected to be priests and not expected to be social workers. We can certainly comfort the families, but we also need to be aware of what team members are available. At our hospital when we meet with the patients and the families all along, every family meeting in the ICU has the physician, sometimes a team of physicians if there are more than one involved, the bedside nurse, and a social worker. In your facility that might be a priest or other clergy person. Our goal in all of this should be that the patient can have a good death and the family doesn't suffer additionally at the patient's death.

Thank you.

Dr Dunn: Now we begin the audience Question & Answer Session.

Questions and Answers

Audience Member: The last case presentation raises questions I struggled with. An elderly patient comes to you for a major operation. My last one was a lung lobectomy for a cancer. She knew she was high risk. I told her so and actually gave her every opportunity to refuse the operation. She called back to say she wanted to go ahead because she was afraid of dying of lung cancer. I operated on her, and she did fine for a few days and then deteriorated, and then at that point said that she did not want anything else done. Your hands are tied, and even though it may just be a short-term complication and you could address it and treat it, here you are with someone who has tied your hands and now you think that you never should have operated on her in the first place because if I had known this was going to happen, I wouldn't have offered the operation.

Dr Dunn: Basically, the scenario that was presented was one in which an elective major case was done. Initially a good outcome, then a setback, and then a request from the patient about not doing anything further, causing certainly a sense of regret or, I guess you could fairly say, some degree of inner conflict on the part of the

surgeon: "Am I comfortable now with doing what looks like a total switch in priority?"

Dr Easson: I will answer that because I had a somewhat similar situation. It was again a malignant metastatic lung cancer but she had a bleed from a bad metastasis to her abdomen. I guess the important thing about that particular case was that we discussed all the potentially bad outcomes beforehand, and she went to the ICU and again initially did well and was able to be extubated. After 4 or 5 days she began to deteriorate, and that potential had been discussed with the family and with the patient. I have to say that the ICU staff was quite surprised that this had happened, and they anticipated the whole question about withdrawal of care but it never really arose because it had been anticipated. As a matter of fact it was decided not to reintubate her and in her case she did fine and ended up not requiring intubation. The way to deal with that is to try to anticipate all those issues before you go ahead.

Audience Member: I did do that. Again, the question is what do we do when the patient has reversed tack in the immediate postoperative period?

Dr Milch: Why do you think she changed her mind?

Audience Member: In retrospect, in this patient's case, her husband had died of lung cancer and she had this terrible fear of dying the way he did. She told them this later, not me. She would rather have died in the operating room or in the ICU postoperatively than to die a progressive death of lung cancer.

Dr Milch: Was there the opportunity to pursue this with her? Once a patient's fears are identified it seems much easier to meet his or her needs. I am not sure that we can ever go through the smorgasbord of every possible complication. That seems to me to be very thin soup of informed consent. But if we can understand what the patient's goals, fears, and values are and put these things in that context, we stand a much better chance of identifying and meeting the needs. This is not to say that you came up short in any way, because it's very disappointing and very frustrating. I think the approach is better served by trying to understand what is behind the process and sometimes that doesn't come from the patient. Sometimes it comes from the family.

Dr Dunn: The bravest surgeon is the one who asks why is this bothering me, not just, what is changing in the patient. The flip side of what is changing in the patient is, how is this affecting me, what are my reservations and what are my fears about the future? I think this

is when our colleagues and our collegiality are so important. The most soothing thing that can happen to me as a surgeon when I have some horrible setback or screw-up is to hear that somebody else had one in surgery. Because that becomes the opportunity to share all that that means, what our fears are, whether they are litigation, loss of referrals, or whatever. Somehow, sharing of that kind of misery does something to mediate it, make it seem a little more tolerable, which is what we trying to do for the patients in the same situation.

Dr Huffman: Just a quick comment, too. We all talked about bereavement support for the family and for the patient. I think we have to remember that many times we need to give bereavement support to each other. Perhaps a patient has been in the ICU for a long time. The nurses may have been taking care of the patient for 6 weeks. You may have had a longstanding relationship with this patient, maybe even following him or her for 10 years for multiple issues. So I think we have to support our colleagues in bereavement, too, and remember that we are human beings and we have feelings associated with death and dying, too.

Dr Dunn: And we all know just how well a morbidity and mortality (M & M) conference addresses those needs. Next question?

Audience Member: I wonder if any of the panelists have run into a situation like I have that was along similar lines. Postoperatively, a patient was not doing very well in the shortterm, and was not conscious, so could not participate in any of the decisions. The family was more aggressive about trying to withdraw support than I felt comfortable with, and I felt conflicted about becoming the person to prolong this family member's or the relative's suffering. On the other hand I felt that maybe they were being a little bit too quick or maybe I was being too slow. It's hard to judge. My judgment was that they weren't giving the patient an adequate chance to at least try some shortterm measures.

Dr Mosenthal: I think that's a very common scenario at least in my practice in trauma and critical care. One of the helpful things that I found in dealing with this is that the family doesn't usually understand what all the possible outcomes of the therapy are going to be. They may see things as meaning that the patient would die tomorrow and that may not be so. To communicate the potentially different outcomes and uncertainty is very helpful. With that, if you can communicate to the family that based on what you see today, you know, if we try venti-

lation support for the next 3 days there may be improvement. If there's not, we then can change the goals and our paths. They are often reassured by the fact that you're flexible, and that you have the best interest of the patient in mind.

Dr Dunn: One of the most helpful concepts in breaking this kind of a stalemate is that of the time trial where we negotiate: "We have a potential course of action that could result in this. Could we agree that we will follow this course of action as long as there's reason to think it's working?" They need to be informed about the pros and cons, and to give it that trial for 24, 48 hours, whatever. Very often that will help guide you because then you get what you need, which is at least some chance to test your own hypothesis. But it also gives them more time to prepare and to begin the shift and make the necessary accommodations to change their expectations. That maneuver of the time trial is, I think, one of the most useful things you can try in these situations in critical care. Next question?

Audience Member: When you have a patient you should expect a good outcome on and you have a complication and perhaps it is your mistake, you should stand up and take your beating as we all have done. I think it's wrong, though, that we continue to keep that mentality for these patients who are dying of cancer, and when we have to stand up at an M & M to present a patient who's dying from carcinomatosis of the abdomen, the residents are handed their heads about this death. That is something that attendings have to run interference for. It continues to propagate this attitude that no one can die when a surgeon is taking care of him or her. It's that kind of attitude that leads us to patients dying with unnecessary pain, unnecessary procedures, and our unwillingness to listen to them. Has anyone on this panel done anything to try to stop that?

Dr Dunn: That's exactly what the panel and the whole Workgroup is trying to do. We are talking about nothing less than changing not only the techniques and practice of surgery, but also doing something to change its perspective so that this kind of thing does not happen. I am a lover of the M & M conferences that helped shape my soul as a surgeon. I was proud of those beatings and they were entertaining sessions. I look back fondly on them. I think one thing we can do rather than ditching M & Ms is to say, "Well, why don't we assess the efficacy of our palliation in an M & M conference?" Because when I think about most of the last 50 patients I have

seen for palliative care who had surgical treatment for their problems, and I assess the success of their palliation, those are cases I would have torn apart in M & M. Maybe we ought to use this old cultural ceremony that we have developed and are all very much a part of, but add to it by including questions about whether we are meeting the mark in measuring up to our ability to relieve distress. Anyone intelligent in M & M is going to know that somebody with carcinomatosis probably isn't going to expect to survive even a haircut, let alone a laparotomy!

Audience Member: I agree with you, but yet that's not what is happening out there.

Dr Dunn: It won't happen right away. We didn't get to that position overnight. I think this is really something that is going to take time and it's going to take hundreds of educational meetings like this, instilling the values or the concepts or the perspective in medical students, surgery students, and residents. This is really nothing less than a multipronged effort necessary to address the very issue that you put your finger on.

Dr Milch: If I had to capsule your questions and the frustration I hear in your voice and some of the comments Geoff has made, I think one of the secrets of palliative care is redefining a good outcome. And in that context, the M & M conference has a great deal to offer. Given the circumstances, what are our goals of care, and how effective were we in achieving them, recognizing that the avoidance of death or the staving off of death is not the only bona fide outcome to which we subscribe.

Dr Huffman: We are working with these symposia and we are working with the Surgical Palliative Care Group, and medicine has already begun to educate residents. David Weisman began a program with the medical residents, and part of our Workgroup's training will start with a pilot group to begin to train surgical residents and it will be through the surgery department. It's the beginning of changing a culture. Obviously if we train the residents, but as attendings we don't serve as good role models, it's not going to be effective. Another thing we are working on and we want to develop is a general-interest group of other people of the same mind, and, Geoff, you may want to say something more about that.

Dr Dunn: We are very interested in any surgeon interested in this type of problem. We already have about 25 people in the Workgroup, representing a number of disciplines in surgery, but we anticipate the formation of

a much larger group of people who we can see as a sort of list serve to pass along information we have, requests for information we have, people who may have research agendas or interests and want to run it by other people who have had a lot of comfort and familiarity with these things. So we would invite you to pass that along. Everybody is welcome at the table. There's certainly plenty to do.

Audience Member: During the last presentation when Dr Easson was discussing the case of Mary, she said Mary had thoracoabdominal aneurysm and she elected not to have surgery but she did agree to undergo screening. So many times when our patients decide on a course of treatment that we don't agree with we begrudgingly say, okay, but we try to browbeat them into doing something. Personally I think if the patient said she wouldn't want an operation, you shouldn't have been doing the ultrasounds to find that the thing was growing. Part of palliation is that we have to go along when a patient in a clear mind says he or she wants to do this or doesn't want to do that, that we don't browbeat him or her to come back to what we want eventually by saying, "Well, we will repeat your CT scan in six months." If that's what the patient wants, then that's what the patient wants. We have to learn sometimes to say okay. I think that's the whole goal of what we need to get into, and that's probably the hardest thing I ever learned to go along with.

Dr Dunn: It's often been said that the mark of the best, most mature surgeon is knowing when not to operate.

Audience Member: How do you deal with the problem of families who want to withhold information about patients who certainly have advanced disease? I have a patient in the hospital right now, and Dr Easson and I work in Toronto, Ontario, and there are a lot of cultural factors, a lot of Mediterranean families, who, if you even mention the word *cancer*, say mama or papa is just going to die from that.

Dr Lee: When the family has that kind of approach, and usually it's from the cultural background, I think there has to be a long process of negotiation. We surgeons are so used to getting quick results from our intervention, and when we walk into the family conference we want everything tied up in that meeting. My experience with some of those families is that it takes several meetings and in those several meetings we have to figure out why they want not to tell the patient. What do they hope to achieve by not telling the patient? Usually dur-

ing two to three to four meetings, by exploring the reasons for their approach, we come to an agreement that what they are really concerned about is how the patient responds to his or her own death and everything else that goes with it. I assure them we will address all of those by other means, whether it's counseling or whether it's giving antidepressant medication. Just the fact that we are very attuned to those needs and that we will take care of the needs usually helps the family come around to agree that it's better to tell the patient at some point. I have not in my personal experience had a case where we ended up not telling the patient.

Audience Member: I just wanted to add this particular family also requested an oncology consult at the same time. And I said, well, that's kind of a contradiction. If you don't want to tell your mother or father what his or her underlying disease is and the oncologist walks into the room—this is the kind of situation we face.

Dr Mosenthal: One trick I learned from our bereavement nurse practitioner is that if that comes up I believe our obligation is to the patient. So I ask patients, "What do you want to know about your diagnosis?" If they say they want to know, I tell them. If they say they don't want to know, I let it go and it usually comes up over time that they do want to know. I try to tell the family that I have an obligation to inform patients if they want to know.

Dr Easson: I have some sympathy for this doctor because I know these patients' families won't let you near the bedside to talk to the patient alone because they are so afraid. But usually through a process of negotiation, as Dr Lee said, you can get some formal communication going. It takes a long time.

Audience Member: I refer to an article written in *JAMA* around March 2001, about an 83-year-old internist in Chicago, and he answered a lot of questions. He was having insight into his own situation at 83, and he had practiced many years and he simply said that doctors have a moral, ethical, legal responsibility to reduce pain and suffering but no moral, legal, or ethical obligation to interfere with the dying process.

Dr Huffman: That's a very good point. I think we all have to think of this in terms of not just what the patient wants and the family wants but what our family members would want and what we would want if it came to our own death.

Dr Dunn: One problem is the actual inability of many clinicians to recognize that dying, in fact, is occur-

ring. I am amazed at how often dying or active dying is not in the differential diagnosis of situations we see. So how can we figure out whether we are guiding a natural process or interfering with it when we can't even recognize the process itself? One of the articles in *JACS* will discuss the signs of imminent demise. Some of them are familiar to all of us, but some of them are a little more subtle. I would be willing to bet probably about 50% of physicians don't know that dysphagia not related to any kind of neuropathy or mechanical obstruction is one of the normal signs of approaching demise. Increased awareness and education of the actual natural process of dying would help us. We have grown up in a time where it's been virtually impossible to witness natural death unless someone was actually in a hospice type of situation.

Dr Lee: The crux of the matter for a lot of these issues is that as surgeons we are so used to one type of outcomes measure, which is mortality and survival outcome. And even these days, when we have quality of life as the emerging model of outcome, it still has not sunk in. In fact, it's a very uncomfortable topic, and it's really like the soft side of Sears. This is a the soft side of surgical care, which is very difficult to quantify. If this is going to evolve as a discipline within surgery, I believe that it behooves us to discipline ourselves to establish outcomes that are not based on a lot of the live or die issues, not even quality of life, but based on the meaning of life for these patients at the end of life and how, as surgeons, we help them achieve their goals at the end of life. Those are just very difficult outcomes to even verbalize, let alone stratify and develop into models and perform clinical studies to substantiate what we intuitively feel is the correct thing to do.

Audience Member: First I would like to congratulate the panel on an outstanding presentation. When we have this discussion with colleagues, we sometimes talk about the fact that we have to remember that we were physicians first and then we became surgeons. That's probably what is happening in this whole arena, that we forgot what the physician is supposed to do. We became surgeons going for the end point.

One of the things that I did not hear but I think was implicit is that we are not getting the buy-in of the patient as we encounter the patient the first time about what the patient wants us to do. Because sometimes you will see the Marys, and we all have had those patients where 10, 12 days after the fact we are all scrambling to

figure out what the directives are. There may not have been advance directives. We have problems identifying who the surrogate decision maker is. There's been this particular individual who's been signing all the consents up to that point, and the long-lost cousin came from California and said, "Where there's a will there's usually a large family." We don't know who is making decisions. In that context what do you do? What we do when we don't know the individual well enough—and we checked it with our in-house legal office—we have added an at-the-station statement to the consent that says, "To the best of my knowledge I am the legal surrogate;" where there's no document, there's no power of attorney. We don't have any relationship of knowledge, and we just are leery that someone totally unknown to us to is making these very critical decisions in the case of the patient who cannot make decisions. If patients are able to make decisions for themselves, I think we ought to differentiate competency, which is a legal term, from capability. We have a lot of patients who may be very rational, but because of medication at the moment we talk to them, are not capable. I try to have a witness there if at all possible, a family member, and I congratulate you on having family conferences. Also try to include family that is not there by conference speaker phone, and document that in the record. But I would want to hear about the business of the unknown surrogate decision maker and how comfortable you feel that the individual is the legal person.

Dr Milch: It's a difficult problem. I think what your institution has done is codified a good-faith effort made, which is somewhat protective in perplexing cases. I would take this to the institutional ethics committee and ask for assistance and guidance, if not adjudication. I have a question for the panel and for the audience. At the risk of just word-smithing presentations, comments from the audience have reflected a phrase "withdrawal of life support," which I have difficulty with for a couple of reasons. One, I think anytime you mention withdrawal to patients and families you connote abandonment, which is one of the great fears that patients and families have. The other is the concept of our intervention as life support rather than function support, because I think that is inherently what a ventilator does. It supports a function that is no longer optimally, and perhaps barely suboptimally, working. Is there another phrase we might use or consider that more accurately depicts what is going on and what the patients' and families' needs are at

that moment other than the fearsome “withdrawal of life support?”

Audience Member: How about comfort care?

Dr Dunn: I think the more we ask this kind of question the more we realize the whole lexicon of surgical care is a deck stacked against us when we are trying to address the problem of meaning rather than just the problem of survival, not necessarily the same thing.

Audience Member: The reality is that the better term is that we will no longer continue to prolong this patient’s dying.

Dr Dunn: Well, that’s one thing. I think you fall into some of the maybe adverse associations that were talked about. The question relates to how to deal with nonsurgical colleagues creating expectations that are unrealistic. I think the first step is to get rid of unrealistic expectations that we have, because I have seen surgeons recommend things that have had no demonstrated utility for prolongation of life or palliation. Once we are clear on that as a surgical community, it is going to be much easier to draw the line with medical people and tell them to stick to running the emergency room or radiation therapy and leave the surgical opinions to us. We are in that dilemma all the time anyway. I don’t think end-of-life care is going to be any exception to that.

Audience Member: We have been communicating about death, bad news. Most of the discussion has been dominated by the western notion of autonomy, and the right of each person to know everything. One of the things we are going to need to deal with if we are going to educate healthcare practitioners, and specifically surgeons, about communicating, is that we really do live in a pluralistic society and many of the cultures in this country do not think this way.

In palliative care, one of the cornerstone principles is that the family is the unit of care and in other cultures, for example, in Spain, communication occurs through the family. Often patients are not told directly about their prognoses, but they figure them out. It’s sort of a secondhand kind of body language and other kinds of communication that we are less familiar with in northern European mindsets.

Dr Dunn: It’s very identifiable in their spiritual understanding of that time of life.

Audience Member: It’s also true in some of the Asian cultures. Japan has been noted for not communicating about fatal prognoses. This is something we are going to have to work on, because patients should be told what

they want to know. That was certainly brought out in the discussion. But we shouldn’t be forcing information on them that may add to their suffering.

Dr Dunn: I think the pendulum has swung, even in our own culture, which tends to be more deterministic, where the first thing the medical house officers are saying before they introduce themselves is, “Do you have a DNR order?” You know, it’s almost enforced advocacy, which is not advocacy.

Dr Huffman: I do want to echo again that we are very ethnocentric as Americans, but many Native American cultures will not even discuss advanced directives, because if you speak it, it is so. Even to discuss the advanced directive has to be done in the third person. So we have to be very careful not to put our values into other people’s values and goals.

Dr Lee: Sorry to go back to a question here. But I’d like to respond to your question about how to protect ourselves in those two types of situations. There are two levels that I am seeing where you need to protect yourself. One is the local level, where you do not want to get pegged as a surgeon who won’t operate and therefore lose future referrals. I think that’s an issue that takes many different forms. The other is a legal level, where patients and families have an expectation and you believe that you are put into a corner and if you don’t provide the expected surgical intervention you are somehow going to be liable legally. The principle of palliation has been deeply established at this point as a primary goal of treatment for physicians, and as long as you document that your intent for treating or not treating—operating or not operating—is for palliation and then document this in detail, you will be fully protected. In fact, I just reviewed a chapter written by a legal associate who went as far as to say that in the last 20 years no one has been sued or has been found liable for his or her treatment choice when the primary intent was palliation and it was fully documented.

Appendix

Surgical Palliative Care Workgroup

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BOOKS

Doyle D, Hanks G, MacDonald N. *The Oxford textbook of palliative medicine*. 2nd ed. Oxford: Oxford University Press; 1998. This textbook is to palliative medicine what Schwartz's *Principles of Surgery* is to surgery. It contains contributions from recognized leaders in the field from a worldwide distribution. A must for anyone with serious interest in palliative care.

MacDonald N, ed. *Palliative medicine: A case based manual*. Oxford: Oxford University Press; 1998. A selection of clinical cases based on clinical problems commonly encountered in end-of-life care, edited by Neil MacDonald, Professor of Oncology at McGill University, who has encouraged surgeons in the US and Canada to develop the concept of palliative care in surgical practice and research. Most chapters address specific physical symptoms and syndromes, though some address issues such as communication, social impact of illness, and bereavement.

Dunn G, ed. *The surgeon and palliative care*. *The Surgical Oncology Clinics of North America*. Philadelphia: WB Saunders; 2001. This volume was written to bring the worlds of surgery and palliative medicine closer together. It was also intended to provide surgeons an

opportunity to find their own voice in palliative care recognizing that consensus will be a matter of ongoing effort. The volume contains chapters written by several current and former ACS Symposia panelists and commentators. Consider it as both a reference book and a reference point for the philosophy and history standing behind today's symposium.

Chronic illness, rehabilitation and terminal care. In: Kirk, Mansfield AO, eds. *Clinical surgery in general*. RCS course manual, 3rd ed. Edinburgh: Churchill-Livingstone; 1999. A concise synopsis of end-of-life care, its principles, and techniques written by two consultants in palliative medicine for the Royal College of Surgeons training manual. This chapter would make an excellent model for the minimum standard of instruction on this topic during surgical training in the US.

Management of cancer pain. Clinical Practice Guideline No. 9, Agency for Health Care Policy and Research. US Department of Health Clinical Practice Guidelines for management of cancer pain. Useful tables and extensive list of references.

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Schonwetter RS, ed. *Hospice and palliative medicine*. Core curriculum and review syllabus. AAHPM. Dubuque, IA: Kendall-Hunt Publishing Co; 1998. This is curriculum and syllabus for end-of-life care published by the American Academy of Hospice and Palliative Medicine with interesting introductory historical information about the development of hospice philosophy and subsequently palliative care.

UNIPAC Series. The American Academy of Hospice and Palliative Medicine's self study training program. Six booklets. Order information via the Web: aahpm@aahpm.org/unipac's.htm. These are very user-friendly self-education manuals with handy, detachable charts. The topics covered include: (1) Hospice/palliative medicine approach to end-of-life care, (2) Alleviating psychological and spiritual pain in the terminally ill, (3) Assessment and treatment of pain in the terminally ill, (4) Management of selected non-pain symptoms in the terminally ill, (5) and (6) Ethical and legal decision making when caring for the terminally ill. Each UNIPAC is designated for 3 credit hours in Category 1 of the Physician's Recognition Award of the AMA.

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panelists, about ethical questions relating to surgical care in patients with terminal illness.

Simpson KH, Budd K, eds. *Cancer pain management*. Oxford: Oxford University Press; 2000. This book presents a comprehensive approach to cancer pain management using nonpharmacological approaches including a chapter on selected surgical approaches by Dr Geoffrey Dunn, a member of the Surgeons Palliative Care Workgroup. Wrede-Solomon L. *Symptom management algorithms. A handbook for palliative care*. 2nd ed. Yakima, WA: Intellicard; 1999. Orders: www.intelli-card.com. This is as handy as the *Washington Manual* is for internal medicine during daily palliative medicine practice. It was written by a physician working in a region known for its sophistication in hospice care. All nurses in my program receive a copy when they join us.

Joishy S, ed. *Palliative care secrets*. Philadelphia: Hanley and Belfus, Inc; 1999. This book, from the "Secrets" series, is a handy reference paperback for day-to-day problems of palliative care, written in a question and answer format. The editor, a medical oncologist, has had extensive palliative care experience in England and the Cleveland Clinic. Excellent chapters by many of the supportive disciplines and services such as pharmacy and spiritual care.

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PROGRAMS

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WEBSITES

These addresses come from a Web site directory compiled by the AMA’s Education of Physicians on End-of-Life Care program: **American Academy of Hospice and Palliative Medicine:** <http://www.aahpm.org>. AAHPM is an organization for physicians who are

committed to furthering and fostering the practice of hospice/palliative care for the terminally ill and their families.

American Academy of Pain Management: <http://www.aapainmanage.org>. This resource provides the names of credentialed pain practitioners and pain management programs by zip code; offers direct access to the National Pain Data Bank for outcomes measurement; provides links to other pain-related sites; has information about the agenda for the annual clinical conference in September of each year.

ABCD-Americans for Better Care of the Dying: <http://www.abcd-caring.com>. ABCD is a nonprofit coalition of citizens and professionals united to ensure that public policy addresses the needs of individuals and families coping with a fatal illness.

Cancer Net: <http://cancernet.nci.nih.gov/>. Cancer Net is a wide range of accurate, credible cancer information from the National Cancer Institute. The comprehensive cancer database includes summaries on cancer treatment, screening, prevention, and supportive care as well as information on ongoing clinical trials.

Caregiver Survival Network: <http://www.caregiver911.com/>. Caregiving is becoming a significant issue for many people. This resource provides help to others to cope with the demands of caregiving.

Dying Well: <http://www.dyingwell.com/>. Defining wellness through the “end of life.” Resources for patients and families facing life-limiting illness.

Elizabeth Kubler-Ross, MD, “On Death and Dying”: <http://doubleclickd.com/kubler.html>. Elizabeth Kubler-Ross, MD, is widely recognized as one of the foremost authorities in the field of death and dying. “On Death and Dying,” is required reading in most major medical and nursing schools and graduate schools of psychology and theology.

International Association of the Study of Pain: <http://www.psigroup.com/dg/1ff02.html>. IASP is open to scientists, physicians, dentists, psychologists, nurses, physical therapists, and other health professionals actively engaged in pain research and to those who have an interest in the treatment of pain.

Last Acts: <http://www.lastacts.org>. Last Acts is a call-to-action campaign dedicated to improving end-of-life care through the sharing of ideas and solutions by professional care givers, institutions, and individuals.

Medical College of Wisconsin Palliative Care Program: <http://www.mcw.edu/pallmed/>. This program is committed to improving care for the dying in America through the development, implementation, and dissemination of innovative education and clinical care programs.

National Hospice Organization: <http://www.nho.org/>. Founded in 1978, the National Hospice Organization is the oldest and largest nonprofit public benefit organization devoted exclusively to hospice care. NHO is dedicated to promoting and maintaining quality care for terminally ill persons and their families, and to making hospice an integral part of the US healthcare system.

Oregon Health Sciences University Center for Ethics in Health Care: <http://www.ohsu.edu/ethics/>. The Center for Ethics combines the perspectives of health professionals, patients, and families to improve teaching, research, and clinical consultation about ethical issues in patient care and health policy.

The Center for Clinical Ethics and Humanities in Health Care is an interdisciplinary academic center, which draws upon a wide range of individuals from the School of Medicine and Biomedical Sciences as well as various healthcare and academic institutions.

US Palliative Medicine Fellowship Programs www.capcmssm.org/fellowship.html. Existing and planned, as of August 2000, listed in chronological order, this fellowship directory will also be posted to and updated on the EPERC Web site.

UW Pain and Policy Studies Group: <http://www.medsch.wise.edu/painpolicy>. The UW Pain and Policy Studies Group is the study of public policy in relation to pain management, identifying and addressing the barriers to medical use of opioid analgesics.

The following addresses come from a directory compiled by J Andrew Billings, MD, Massachusetts General Hospital Palliative Care Service, August 2000.

The author invites any additions or changes to the directory, as well as comments. Please forward to: dweissmn@hemonc.mcw.edu.

American Hospital Association Circle of Life Award: www.aha.org/circleoflife. Presented annually to recognize outstanding initiatives to improve end-of-life care.

Community-State Partnerships to Improve End-of-Life Care Midwest Bioethics Center: www.midbio.org. Provides grants to support statewide coalitions composed of citizens, healthcare professionals, educators, and policymakers that identify problems, make recommendations, and build public support for practical policies, regulations, and guidelines to improve care of the dying. Publishes State Initiatives in End-of-Life Care.

Education for Physicians on End-of-Life Care (EPEC): www.epec.net. Educates physicians, through its core curriculum, on essential clinical competencies required to provide quality end-of-life care.

End-of-Life Nursing Education Consortium (ELNEC): www.aacn.nche.edu/el nec. A comprehensive national education program to develop a core of expert nursing educators and to coordinate national nursing efforts in end-of-life care.

End-of-Life Physician Education Resource Center (EPERC): www.eperc.mcw.edu. Assists physician educators and others in locating high-quality, peer-reviewed training materials. Visitors to the site can search for educational materials indexed by end-of-life care topic areas and educational formats.

Growth House: Guide to Death, Dying, Grief, Bereavement, and End-of-Life Resources: www.growthhouse.org. Search engine offers

access to the Internet's most comprehensive collection of reviewed resources for end-of-life care.

Innovations in End-of-Life Care: www.edc.org/lastacts. On-line journal features peer-reviewed examples of promising practices in end-of-life care. Each bimonthly issue focuses on a different theme.

On Our Own Terms: Moyers on Dying: www.thirteen.org/onourown/terms. Supports the On Our Own Terms outreach campaign with various tools, articles, personal stories, audio and video clips, and interactive opportunities.

Partnership for Caring: America's Voices for the Dying www.partnershipforcaring.org. National non-profit organization devoted to raising consumer expectations and demand for excellent end-of-life care. Offers resources for talking about end-of-life choices, the process of healthcare agency and state-specific advance directives.

Project on Death in America: www.soros.org/death. Dedicated to understanding and transforming the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts, and to foster innovations in the provision of care, public education, professional education, and public policy.

Promoting Excellence in End-of-Life Care: www.promotingexcellence.org. Manages 22 grant-funded projects designed to demonstrate excellence in end-of-life care in diverse institutional settings. The project is a National Program Office of The Robert Wood Johnson Foundation, headquartered in Missoula, MT.

The RAND Center to Improve Care of the Dying: www.rand.org/organization/health/dying.html. Conducts research designed to improve a system of care in which persons with serious and eventually fatal chronic illness can live comfortably and meaningfully until death.

Supportive Care of the Dying: www.careofdying.org. Develops and tests innovative projects with individuals and organizations working to improve delivery of care to those facing the end of life. Videos and facilitator guides are available to help improve physician communication with patients and families.

Toolkit of Instruments to Measure Care at the End of Life: www.chcr.brown.edu/pcoc/toolkit.htm. An authoritative bibliography of instruments to measure the quality of care and quality of life for dying patients and their families.