Statement on Principles Guiding Care at the End of Life

The following "Principles Guiding Care at the End of Life" were developed by the American College of Surgeons Committee on Ethics and were approved by the Board of Regents at its February 1998 meeting.

- Respect the dignity of both patient and caregivers.
- Be sensitive to and respectful of the patient's and family's wishes.
- Use the most appropriate measures that are consistent with the choices of the patient or the patient's legal surrogate.
- Ensure alleviation of pain and management of other physical symptoms.
- Recognize, assess, and address psychological, social, and spiritual problems.
- Ensure appropriate continuity of care by the patient's primary and/or specialist physician.
- Provide access to therapies that may realistically be expected to improve the patient's quality of life.
- Provide access to appropriate palliative care and hospice care.
- Respect the patient's right to refuse treatment.
- Recognize the physician's responsibility to forego treatments that are futile.

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Communication: Part of the Surgical Armamentarium

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This is the second in a planned monthly series addressing end-of-life issues written for and by surgeons.

What the Doctor Said

He said it doesn't look good
he said it looks bad in fact real bad
he said I counted thirty-two of them in one lung before
I quit counting them
I said I'm glad I wouldn't want to know
about any more being there than that
he said are you a religious man do you kneel down
in forest groves and let yourself ask for help
when you come to a waterfall
mist blowing against your face and arms
do you stop and ask for understanding at those moments
I said not yet but I intend to start today
he said I'm really sorry he said
I wish I had some other kind of news to give you
I said Amen and he said something else
I didn't catch and not knowing what else to do
and not wanting him to have to repeat it
and me to have to fully digest it
I just looked at him
for a minute and he looked back it was then
I jumped up and shook hands with this man who'd
just given me
something no one else had ever given me
I may have even thanked him habit being so strong

—Raymond Carver, *A New Path to the Waterfall*

There was a time when the analytic and technical skills of the surgeon were sufficient to carry the day of the doctor-patient relationship, when the ability to diagnose and neatly cut and sew alone sufficed to meet the norms and expectations of the surgical encounter. The ability to share information sensitively and thoroughly and to plan for care, perhaps called "bedside manner," was often regarded as an optional attribute or one not congruent with the "heroic" stance of the surgeon. This is no longer the case.

Buoyed by the ascendancy of the bioethical principle of patient autonomy, reinforced by case law and litigation, competency in communication skills is now a professional and public expectation. Done well, it is also a source of considerable satisfaction, both to surgeon and patient. This is true not only in such formulaic application as obtaining informed consent (disclosure by the physician, understanding and free choice by the patient), but particularly when confronting the more challenging issues and changing goals of care involved in chronic, progressive, or fatal illnesses.

Although barriers to such conversations may involve the patient and family, or even the health system itself, the physician bears the major responsibility for conducting them well. Regrettably, insufficient emphasis has been placed on the broader subject in medical school education or postgraduate training. Few schools have coordinated curricula for teaching effective communication, and standard texts in surgery contain little substantive information.[1] If fortunate, the student or houseofficer will encounter a role model who does it well and has the time and opportunity to mentor, but all too often the learning curve follows the course of "see one, do one, teach one." Subsequently, as with any technique inadequately taught, the surgeon tends to avoid using it, delegating its performance to others, or doing it poorly.

This is especially so because these are often uncomfortable conversations. Many physicians feel they lack the interpersonal skills to deal with the strong emotions (theirs and the patient's) that may be evoked, or fear causing pain by giving bad news. Some view disease as an implacable enemy, progressive disability, or death as equivalent to defeat. Others may anticipate disagreements with the patient or family, or envision medical-legal issues.

Fortunately, the knowledge, skills, and attitudes desirable for effective communication can be learned, much as is any operation, by familiarity with a few tech-

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niques applied in logical sequence. These constitute the "atlas" of steps with which the nuances of different clinical situations can be dealt, a framework that can be personalized and embellished to address the circumstances. Then, as with any operation, practiced over time they can be improved and performed with increasing facility and comfort.

One of the most popular is the CLASS protocol of Robert Buckman,[2] which applies to all clinician-patient interviews. The mnemonic stands for physical Context, Listening skills, Acknowledgment and exploration of emotions, Strategy of management, and Summary closure. In its explication, it contains clinical pearls to facilitate communication: ensure privacy; sit down; eyes on same level as patient; look unhurried; ask open questions ("Tell me what you know about . . . ," "What are your fears?"); facilitate patient responses by pausing and tolerating short silences, using repetition of the patient's words to clarify and assure understanding; developing an empathic response, which is the capacity to identify a patient's emotion and its origins, and to respond to the patient that you have made those connections; proposing a management plan the patient understands and which is in line with his expectations and goals; summarizing the discussion; inquiring about uncovered issues or topics; and making a contract for the next contact.

Perhaps most frightening to the surgeon is the centrality of the empathic response to the ultimate success of the encounter. Empathic capacity may have been undervalued recently because of the increasing value we have collectively placed on reasoning capacity in medical care. But identifying and acknowledging a patient's emotion (empathy) does not require the surgeon to experience the emotion personally (sympathy). "Consolation not explanation" is an admonition often heard in palliative care that summarizes the fundamental differences between responding with one part of our brain versus another. Buckman warns that failure to acknowledge strong emotions in a medical interview dooms further communication. A final significant point in the communication of major medical news is the recognition of varying cultural patterns concerning decorum, disclosure, information sharing, and timing. Conferring with fellow healthcare workers familiar with a specific culture or asking the patient or patient's family directly about their cultural norms can prevent profound embarrassment to everyone involved.

Buckman has also developed a SPIKES protocol, adapting many of the above steps for situations of giving important medical information or "bad news." This acronym pertains to the Setting and listening skills, eliciting the patient's Perception of his condition and its seriousness, the Invitation from the patient to share information, Knowledge giving, Exploration of the patient's reactions and emotions, and finally Summary and strategy. As with the CLASS protocol, these are fleshed out with insights and suggestions designed not only to provide a road map for these discussions, but also to lessen the awkwardness and performance anxiety of making a mistake or by virtue of not having a "gold standard" by which to measure performance.[3]

More expansively, the American Medical Association and Robert Wood Johnson Foundation have developed a training program titled Education for Physicians on End-of-life Care (EPEC).[4] Its curriculum teaches not only basic communication skills, but also a full spectrum of tools for dealing with such issues as pain and symptom management, bioethical dilemmas, and advance directives. Based on a "train the trainer" model, the entire 12-module course is presented at various sites throughout the year, while the modular nature of its content lends itself to more focused, topic-specific presentations in venues such as grand rounds and teaching conferences.

Other teaching models in communication skills have also been developed and validated. However awkwardly titled, works such as "A Physician's Guide to Talking about End-of-Life Care"[5] and *Advanced Illness Coordinated Care Communication Training Manual*[6] provide not only the framework for structuring these conversations, but also the scripting that facilitates them.[7] In addition, other guides point out that there are a number of common pitfalls that can be avoided in these discussions. These include: giving premature reassurances ("You're going to be all right," or "We got it all"); normalizing feelings and failing to react to strong emotions; selective responses (eg, responding to physical rather than emotional concerns); arguing with denial; failing to assess changes in attitudes or desires over time; and assuming, rather than eliciting or confirming, the effects on the patient of bad news, good news, or no news. And the statement "There's nothing more we can do" not only threatens the patient with implied abandonment, but also ignores the contributions palliative care can make to patient well-being at any point in the disease trajectory.

This is all particularly helpful to surgeons, who are used to working to an idealized standard in the controlled environment of the operating room, whom performance anxiety may leave essentially stage-struck. Coupled with an attitude perceived to be caring, "It may not be what you tell, but how you tell it that is important."[8]

Finally, the clinician can obtain assistance from a number of different services likely to feature practitioners skilled in communication, especially regarding end-of-life issues. These may include palliative care consultation services, hospice consultation teams, advance directives initiatives, and advanced illness coordinated care programs.[9]

This article began with a free verse that speaks to the patient's perceptions of a dialogue with his physician. Poetry is not a frequent finding in surgical writings, and so it might be more comfortable to close with a form familiar to surgeons, to make the point that communication skills can be acquired and practiced with the same dexterity and finesse as any well-done operation.

Preoperative diagnosis:	Progressive disease
Postoperative diagnosis:	Same
Procedure:	Discussion of disease prognosis
Anesthesia:	Coffee stand-by
Indications:	42-year-old woman with refractory stage III ovarian carcinoma presents with increasing signs of distress related to her illness and concerns about her family.

After identification of the patient and obtaining informed consent concerning the purpose of the discussion, the patient was offered 250 mL of fresh coffee and seated in a comfortable chair at eye level with the surgeon, with no physical barriers between patient and surgeon.

After adequate exposure, gentle exploration of the current state of the patient's understanding was carried out. This was found to be minimal, and after confirming the patient's preparedness to proceed, the patient gave a narrative account of her illness as she understood it. When the patient indicated the extent of new information she was prepared for, her course was reviewed and her prognosis was discussed in terms of adjectives, not numbers. Her emotional responses were promptly identified, after which there was brief period of tearing that subsided with gentle sponging. With adequate "emo" stasis, initial discussion concerning the goals of care and life reconstruction was then carried out. The procedure concluded with satisfactory closure and the patient was transferred to the recovery room in stable condition.

Drains:	none
Estimated blood loss:	negligible

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Appendix

Surgeons Palliative Care Workgroup