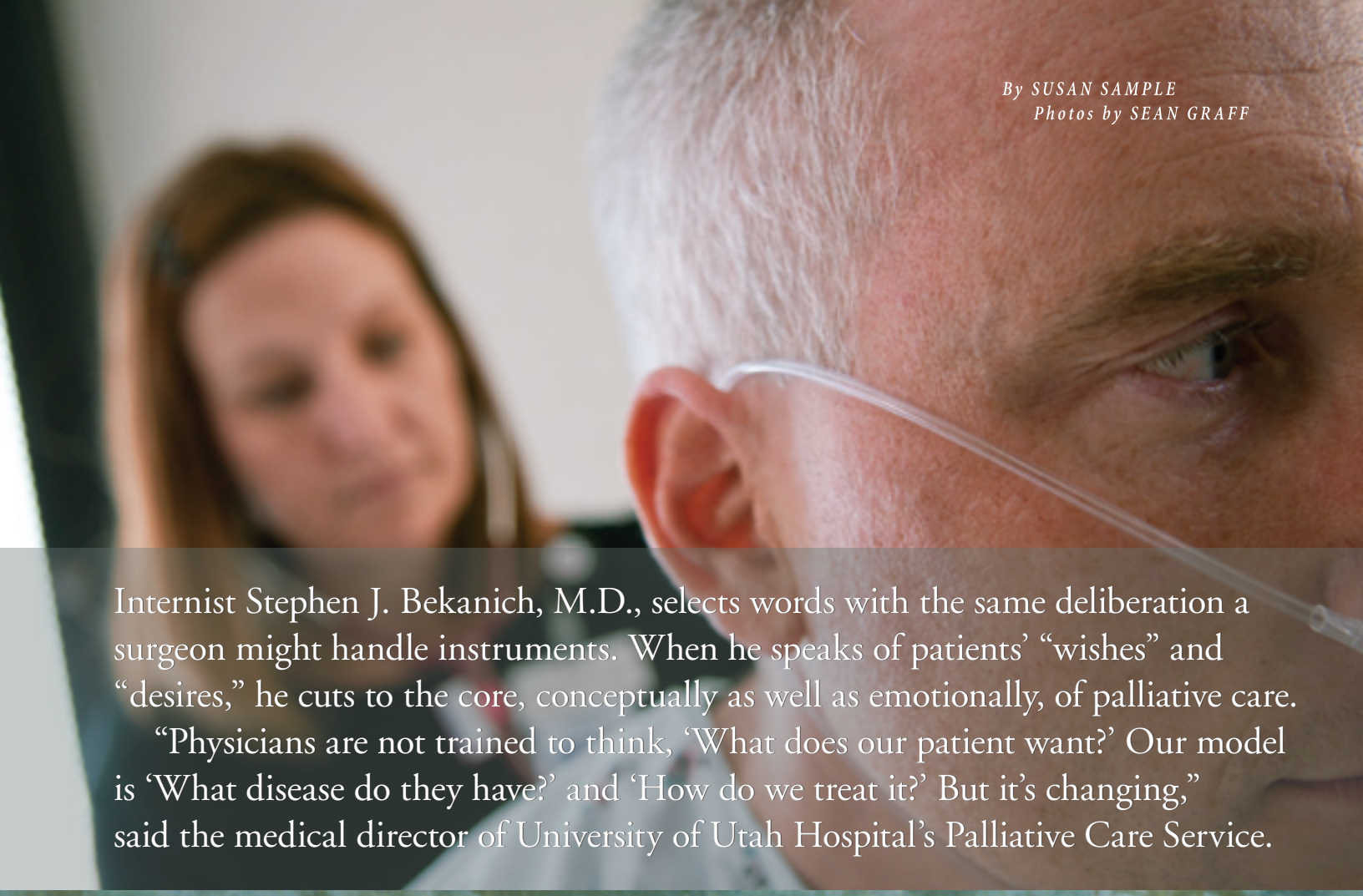


By SUSAN SAMPLE
Photos by SEAN GRAFF

Internist Stephen J. Bekanich, M.D., selects words with the same deliberation a surgeon might handle instruments. When he speaks of patients' "wishes" and "desires," he cuts to the core, conceptually as well as emotionally, of palliative care.

"Physicians are not trained to think, 'What does our patient want?' Our model is 'What disease do they have?' and 'How do we treat it?' But it's changing," said the medical director of University of Utah Hospital's Palliative Care Service.

Palliative Care

"There's so much more to helping patients than having a curative mind-set," said Holli Martinez, M.S.N., F.N.P.-B.C., clinical nursing instructor and member of the service. "We try to preserve our bodies at all costs. Death is either seen as not an option or as a medical failure. We value life—which is good. But patients have choices."

Palliative care is about options. Patients with serious chronic or life-threatening diseases don't have to choose between curative care—chemotherapy, radiation therapy, or other treatments that carry the hope of cure—and comfort care that promises the relief of suffering, but the relinquishing of life-prolonging medical care. They can opt for treatments that will help sustain the quality of life they want through a plan drawn up in consultation with the team of specially trained physicians, nurse practitioners, social worker, and chaplain.

"The global purpose of palliative care is to provide excellent care for progressive chronic disease, to relieve symptoms, and mitigate suffering," said Kathie Supiano, L.C.S.W., referring to the 1990 definition by the World Health Organization. She has been a member of the palliative care service at University Hospital since its inception in January 2006. "You don't see the word 'death' in there. You don't see the word 'dying' in there. You don't see the word 'prognosis' in there."

Those belong to the definition of hospice—the "H word" often confused with palliative care. British physician Dame Cicely Saunders introduced the concept of specialized care for dying patients and, in 1967, founded the first hospice in London, according to The National Hospice and Palliative Care Organization. Utah's late Sen. Frank E. Moss and the late Sen. Frank Church, D-Idaho, co-sponsored the nation's first legislation in 1974 to federally fund hospice programs. Twelve years later, Medicare extended permanent coverage. Terminally ill patients with a prognosis of six months or less who forego curative treatment can qualify for pharmaceuticals, medical equipment, and nursing care, in addition to psychosocial and spiritual help, offered to their families as well. Usually hospice is provided in the home.

"Hospice is always palliative, but palliative care is not always hospice," said Ginger Marshall, M.S.N., A.C.N.P.-B.C., A.C.H.P.N., a nurse practitioner on the service who is certified in acute care and

palliative care. First offered to hospitalized patients in the United States in the late 1980s, palliative care extends the concepts of hospice to patients who may benefit from them earlier in their illness. University Hospital provides palliative care to hospitalized patients on a consult basis: physicians, patients, or family members must request the service. It's provided in conjunction with—not in place of—active medical interventions.

Like hospice, palliative care focuses on the quality of a patient's life, whether measured in years or hours. "It's about how *you* want to live your life," said Marshall, a clinical instructor in the U College of Nursing.

To help patients arrive at their own definition, the team begins a "conversation." The word belies its significance. It is not a casual exchange, but a structured, often emotionally intense, meeting that can last up to two hours. "That's one of the gifts of palliative care: we give the time," noted Supiano. She arranges the meeting with the patient, family members or advocate, in a private space away from interruptions. A clinician typically leads off: "Tell me, what do you understand about your condition?"

"It's amazing to me how, when you ask patients who have chronic illness for maybe 15 years, they'll have maybe three things right," said Martinez, who joined the palliative care team last fall after completing a master's degree at the U College of Nursing. "The biggest part of our job is education. We're teaching about the disease process, about symptoms and stages, about what to expect. And we do a lot of listening to learn where they might need more knowledge."

Bekanich shares the service's 24-hour on-call beeper with the two nurse practitioners and physician Amanda Lund, D.O., assistant professor of geriatrics in the School of Medicine. After completing an internal medicine residency at the U in 1998, he became a hospitalist "unraveling mysteries—I like that." But he didn't like always being in "rapid-fire mode, going from problem to problem, room to room." Six years later, after his grandmother's unfavorable patient experiences in New York, where she died of metastatic breast cancer, Bekanich shifted gears.

Board-certified in hospice and palliative care medicine, the physician, who still spends about a quarter of his time as a hospitalist, finds his new work enormously gratifying. "It's not detective work. It's really being trusted by family members in a couple of hours.

"We're answering questions so the patient feels like the priority. We're helping families make well-supported decisions. We're allowing them to have as much voice and control over their care as they'd like to."

To which Marshall—who describes palliative care as her second calling; nursing, her first—adds the caveat, "as long as it's medically appropriate." Palliative care is evidence-based. If a patient with a large

Team members include: physician Stephen Bekanich and chaplain Susan Roberts; nurse practitioner Holli Martinez, far left; and below, left to right, nurse practitioner Ginger Marshall and social worker Kathie Supiano.

The Art of Providing Comfort, Compassion, Choices—and Cures

"The global purpose of palliative care is to provide excellent care for progressive chronic disease, to relieve symptoms, and mitigate suffering."

Kathie Supiano, L.C.S.W., referring to the 1990 definition by the World Health Organization

malignant mass wants to have surgery, but the medical literature indicates that it would not cure him, "I would be doing a disservice to encourage a goal he can't reach," she explained.

Once everyone in the family meeting understands the nature of the illness, patients are asked to define what makes their life worth living. Maybe, it's spending their final weeks at home with their children; maybe, it's being able to see their toes in the morning. The palliative care team helps them develop a plan, or "goals of care," after discussing the benefits and burdens of potential treatments. An obese woman suffering heart failure declined to wear a restrictive oxygen mask that might have prolonged her life when she realized it would prevent her from talking to friends. She also did not want to return to the hospital. So the team made sure her discharge plans to the nursing home specified hospice care, preventing future calls to 911.

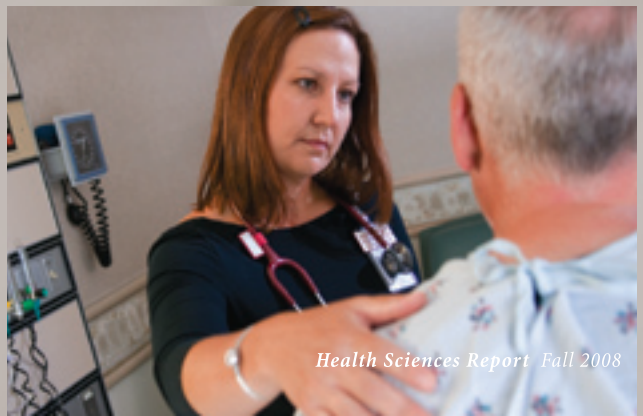
Goals of care are documented in patients' charts at University Hospital, which improves transitions in care, should a patient be moved from an ICU, for example, to a medical-surgical floor to rehabilitation. Wherever they go, however, the palliative care team follows. "We're with them the whole way," noted Supiano. "Continuity of care really matters."

Ideally, family meetings are scheduled soon after a patient's diagnosis, allowing time to draw up a plan of care. In reality, many occur in the final days. Then the focus shifts to goals for the end of life. Supiano, a licensed clinical social worker, draws upon her experience as director of Caring Connections: A Hope and Comfort in Grief Program at the College of Nursing. "A peaceful death," she said calmly, "takes planning."

"A lot of what we do is to protect the dying process. It's natural. It's sacred," said Martinez. She served six years as clinical director of a Salt Lake area hospice, where she still volunteers as an educator. "We encourage the family to talk about it, to review the patient's life, rather than focus on the intensity of their last breath.

"And when we open that door, everyone feels better." She paused. "You know patients think about it. They'll say, 'I see the terrified look on my wife's, or husband's, face. I can't put this terrible burden on her by talking about death.' But the second they meet us, you see the worry wearing off."

To alleviate existential or spiritual pain, Susan Roberts, University Health Care's interfaith chaplain and a member of the service, will meet with patients and their families at their request. "Inner wellness is



Playing her Native American flute, chaplain Susan Roberts can help relieve spiritual pain. Above, nurse practitioner Ginger Marshall teaches nursing staff about palliative care. Her colleague, Holli Martinez, reassures a patient at right. Physician Stephen J. Bekanich, far right, is medical director of the hospital's Palliative Care Service.

"Continuity of care really matters."

essential for living with a chronic illness and going through the journey of death," she said. "I want to support, to foster, to nurture the patient's inner voice." Through open-ended questions and close observation, she conducts spiritual assessments to determine which rituals, sacraments, or practices—perhaps playing her Native American flute—will help individual patients during their health crisis.

Physicians and nurses, too, find support in palliative care. The longer doctors knew their patients, according to one study, the longer the life expectancy they gave. "There are many physicians who have cared for patients for years and still want to be involved," said Supiano, adding emphatically, "and we want them to be, too."

For all that it offers to patients and providers alike, palliative care seems like it could benefit every hospitalized patient. Bekanich was thoughtful as he worded his response: "Not really. If we look at the history of hospitalized patients, they're staying much shorter times, and we're able to do much more for them at home or at extended care facilities.

"But some of the concepts of palliative care—empathy, compassion, listening, availability of doctors—yes, we want to be sure we always extend these to all patients." ◩

FOLLOWING

Patients

through treatments and transitions

Caring for individuals between hospitalizations enables the staff of the Pain Medicine and Palliative Care Program to develop "long therapeutic relationships" with patients at the University's Huntsman Cancer Hospital (HCH) and the George E. Wahlen Veterans Affairs (VA) Medical Center in Salt Lake City.

"Though we provide the full spectrum of care, the bulk of what we do is ambulatory care," said Sharon M. Weinstein, M.D., program director. "We maximize quality of life for patients and their families and, in so doing, improve patients' lives and their life spans. We also provide end-of-life care, but we're not about hastening death."

When Weinstein was recruited to the U School of Medicine 10 years ago to direct the program, "pain medicine" was named first, because "no one knew what palliative care was," she noted. The professor of anesthesiology—and adjunct associate professor of neurology and medicine (oncology)—is board-certified in both hospice/palliative medicine and pain management. The latter overlaps with one of the tenets of palliative care: management of pain and other symptoms, including nausea, fatigue, and shortness of breath. Other emphases are psychosocial and spiritual support of patients and their families, and advance care planning.

This fall, joining Weinstein and her team—an advanced practice nurse, registered nurse, social worker, chaplain, and research associate—is Paul Thielking, M.D. A former U of U psychiatry resident, Thielking received the first Albert A. Weinstein Memorial Award for Training in Palliative Medicine, established in memory of Weinstein's father who died suddenly last year of lung cancer. For 2009, she has applied to the American Council of Graduate Medical Education to establish a palliative medicine fellowship. The broad interdisciplinary training would extend to University of Utah Hospital and Primary Children's Medical Center, in addition to HCH and the VA.

The fellowship follows the news that, as of October 2008, palliative medicine is being recognized officially by the American Board of Medical Specialties as a new medical specialty, according to Weinstein. She already works with students from the School of Medicine and colleges of Nursing, Pharmacy, and Social Work who rotate through the program's hospitals and outpatient clinics.

"With life-limiting illness, if you start palliative care at the time of diagnosis, you'll follow patients through all of their treatment and transitions," said Weinstein. "Some patients might live decades."

—Susan Sample