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BY CAROLYN SHAPIRO

DECISION TIME

EXPANDING PALLIATIVE CARE TRAINING AND PRACTICE AT UVM

BOB GRAMLING, M.D., D.Sc., entered an intensive care room at The University of Vermont Medical Center and approached a patient sitting upright in the hospital bed. The patient's eyes were closed and a thick bandage covered his chest. A nearby machine hissed loudly, delivering a high flow of oxygen through a tube into the patient's nostrils.

The man had suffered trauma to his chest and underwent a subsequent surgery. Doctors couldn't figure out why his lungs still weren't functioning and feared he might not recover. On an early summer morning, they summoned the palliative care team.

Bob Gramling, M.D., D.Sc., (at left) the Holly and Bob Miller Chair in Palliative Medicine, came to UVM in 2016 to expand palliative care training at the Larner College of Medicine and the UVM Medical Center's offerings in palliative medicine.

Gramling, chief of palliative medicine at the UVM Larner College of Medicine and UVM Medical Center, pulled a chair very close to the bed and introduced himself to the patient. He explained that he was there to address anything causing the man pain or discomfort.

"My job is to see if I can make it better and move mountains to do so," Gramling said. He asked the patient about his concerns.

"I think I'm dying," the patient said quietly, without opening his eyes."Is that scary to you?" Gramling asked, his voice calm and soothing. When the man said it wasn't, Gramling prompted: "What worries you most about dying?"

Did the patient think that he'd be in pain? Gramling wondered. Yes, the man replied.

"No matter what comes, we'll work to make sure we take care of the pain," Gramling assured him.

Conversations like this are becoming a more essential and more appreciated part of medical care for people with serious illnesses. With the Baby Boomer generation now beginning to pass age 70, increased attention on palliative medicine accompanies a national movement to confront the challenges of aging. At the same time, the push for overall healthcare reform has nudged changes in payment and infrastructure to encourage better outcomes and patient wellbeing, rather than the number of services, visits or treatments.

Recognizing this, UVM embarked on an expansion of the medical school's training and the medical center's offerings in palliative care in 2016. It began with a $3 million endowment from Burlington residents Holly and Bob Miller, who have long had an interest in and supported end-of-life assistance in Vermont, to create the first Chair in Palliative Medicine at UVM. In June 2016, Gramling assumed that title and leadership of the newly formed Division of Palliative Medicine within the Department of Family Medicine at UVM.

Palliative care seeks to relieve a patient's suffering, whether physical or emotional, from a serious illness and improve quality of life for the patient and family members. Working with patients presumed to have a high likelihood of dying within a year, a palliative specialist supports people as they consider their final goals.

"The benefits of what we do are particularly relevant to that time of life when dying is possible or at least something that might influence our decision-making," Gramling says. "We might make different decisions about the types of treatments we wish or where we wish to spend our time, who we wish to spend our time with and how, if our time were limited."

Palliative medicine addresses these questions at any point in a patient's serious illness. Hospice, which is one mode of palliative care and dates to the 1960s, is covered by Medicare specifically for people who have six months or less to live and decide to forgo further treatment efforts.

Gramling and his colleagues often consult with patients, both in and outside of the hospital, as they continue therapy. This is expanding the reach of palliative medicine to more people and "responding to the fact that a lot of people wouldn't seek this help until they're days to weeks from dying," he says.

"You still may have a year or more to live," Gramling explains. "But you're sick and there's a lot going on, and the treatments you're facing might have trade-offs for you."

Embracing the chance to broaden such care to more patients, UVM's palliative specialist team is growing. It currently includes two registered nurses, four nurse practitioners, four physicians and a social worker, plus several chaplains working outside but collaborating with the division. Another nurse and physician are scheduled to join them soon, and Gramling plans to hire a sixth doctor.

"I can't overstate the importance of understanding and trying to eliminate suffering," says **Thomas Peterson, M.D.,** professor and chair of family medicine at Larner. "And at some point, that's going to be most important to each and every one of us."

In the next five years, the portion of Vermonters over age 65 will grow by 15 percent, Peterson says. Nationally, the youngest Baby Boomers will reach age 65 by 2029, when they and older individuals will represent more than 20 percent of the total U.S. population, according to the U.S. Census Bureau, which also estimates the number of Americans who are at least age 65 will nearly double between 2016 and 2050.

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Holly Miller says her gift to UVM highlights the crucial role of palliative medicine at the onset of a serious illness. After watching both of her parents die at home — with little oversight from professionals — Miller grew convinced that people must have the chance to choose the kind of death they want and the care that makes them as comfortable as possible.

"We can't always be cured, but we can be healed," she says. "We want to cure everyone, but we can't. We need to give them some time to find some meaningful days before they die."

With advances in medicine and technology, Americans are living longer with illness, even serious illness — requiring ongoing or repeated periods of palliative care. Meanwhile, the number of specialists in palliative medicine — those who have completed fellowships and dedicated training — isn't expanding fast enough to keep up with demand. Each year, fewer than 300 fellowship slots are available to medical school graduates who want to focus on palliative medicine, Gramling says.

A 2010 study funded by the American Academy of Hospice and Palliative Medicine cited an "acute shortage" of specialists and estimated the gap between expected need and available supply at 6,000 to 18,000 physicians, depending on how much time each devotes to palliative practice. The World Health Organization projected in 2015 that 40 million people worldwide need palliative care each year, but only 14 percent of those in need receive such treatment.

To offset the shortage, UVM now is working to spread conversational proficiency to more clinicians. Using tools developed by VitalTalk, a nonprofit training organization, 30 palliative care experts at UVM have started courses to learn how to convey their knowledge to others.

"We're creating our own army of communication coaches," Gramling says.

Those coaches will receive certification to teach "Mastering Tough Conversations," a one-day VitalTalk workshop, every month or so for the next three years, starting this fall, for UVM physicians and others who want to hone their dexterity at dialogue.

Medical schools emphasize good patient-doctor relations, but in practice, that can fade into the background as advances in therapeutics push to the forefront, Gramling says. "In the modern era of medicine we've gotten good at diagnosing and curing disease," he says. "And because of that, we've spent more of our efforts towards those ends — which are important — and less on communication about what to expect and prognosis in case we can't cure those things."

These are difficult discussions involving fear, emotional distress and often family conflict. The ability to broach these subjects and get to the crux of a patient's concerns requires a delicate touch. It's more than a good bedside manner or inclination to chat.

"There's skill to this," Peterson says. "And those skills are developed. They're not innate."

VitalTalk brings in "scaffolding" to develop these skills, says **Stephen Berns, M.D.,** a VitalTalk instructor and education director of palliative care at Mount Sinai Beth Israel Health System in New York City. The course covers a "talking map" of steps and goals, guidance on word choice and question patterns, and ways to verbally and nonverbally show empathy. If a patient is overwhelmed, and the doctor begins talking about treatment options, the patient likely will miss that part of the conversation, Berns says.

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"As clinicians, we have things to share, and then the patient has things to share, but we need to create space for each other," says Berns, who joined the UVM Division of Palliative Medicine and Larner College faculty the summer of 2017.

Care providers who do this well can make a significant difference for patients. Research indicates that palliative medicine can reduce anxiety and pain, relieve symptoms and improve quality of life and mood. A 2010 study of patients with advanced lung cancer found that those who received early palliative care had less aggressive treatment at the end of their lives but survived longer than those who underwent standard care. Researchers also have quantified a cost benefit to palliative medicine, because it decreases the use of invasive measures that tend to add little benefit and cause discomfort and that patients often choose to decline in their remaining time.

For palliative care specialists, the ability to uplift patients balances the intensity of immersing themselves in someone's grave and vulnerable experience.

"These things are happening to people even if we're not involved," says **Lindsay Gagnon,** a nurse practitioner in the UVM palliative care division. And once the efficacy of drugs and other therapy wanes, "there's always more that we can do to provide care and relieve suffering."

Holly Miller speaking at the 2016 investiture of Bob Gramling, M.D., D.Sc., as the inaugural Miller Chair in Palliative Medicine.

Andy Duback, David Seaver

Stephen Berns, M.D., leads a discussion with palliative care team members on clinical communication.

VITAL SIGNS

How do you gauge the quality of a conversation? Even a chat between two friends could be considered constructive by one but difficult for the other. A good talk is subjective.

Bob Gramling, M.D., D.Sc., wants to pinpoint the attributes of an effective conversation, specifically one between a palliative medicine specialist and a patient with a serious illness. That way, the healthcare system could measure the value of serious illness conversations for patient care — the same way it would a drug treatment or procedure, says Gramling, chief of palliative medicine at the UVM Medical Center and the Holly and Bob Miller Chair of Palliative Medicine in the Robert Larner, M.D. College of Medicine.

To assess something as complex and dynamic as a conversation, Gramling solicited the help of **Maggie Eppstein, Ph.D.,** chair of the UVM Department of Computer Science and a founder of the University's Complex Systems Center, which applies high-level mathematical modeling techniques to real-world challenges, and **Donna Rizzo, Ph.D.,** UVM professor of engineering and computer science, who specializes in machine-learning tools for complex environments.

Together with national scholars from linguistics, communication science, anthropology, nursing, health services research, psychology and epidemiology, they comprise the new Vermont Conversation Lab at the Larner College of Medicine. The mission of the VCL is "to understand and promote high-quality communication in serious illness," Gramling says.

They are using audio recordings of almost 400 palliative care consultations collected from around the country, funded by the American Cancer Society, for which Gramling is the principal investigator.

Currently, the team isn't focusing on the actual words in the conversation but, rather, the times when the speaking stops. Some types of silence indicate "moments of connection" in a conversation, Gramling explains.

Usually, discussions between doctors and patients are rushed, he says. "Oftentimes there isn't space for people's voices to be heard. So what silence can offer is a recognition that what you've just told me is important, and if you want to tell me more, I'm going to give you space to tell me."

With discussions of illness and death, a palliative specialist might just sit for a moment when a patient expresses fear or sadness, he says. "The pause and that space provides a potential moment of connection. And it's not just in palliative care. It's in any conversation."

Capturing silence amid the constant din of a hospital setting poses a challenge. Machines beep. Nurses talk in the hallway. TVs blare. The computer must learn to focus only on the conversation and the moments that conversation stops. It also must discern the difference between "distracted" silence, perhaps when a physician pauses to take notes, and purposeful or "contemplative" silence.

Eppstein, Rizzo and Viktoria Manukyan, a Complex Systems graduate student doing her thesis on computer analysis of silence, are using different techniques of machine learning — including decision trees and artificial neural networks — to pinpoint the characteristics of the silence they seek. From there, they'll develop an algorithm for computers to identify that silence with high accuracy.

"The point of it is being able to create a tool that would aid in potentially training or assessment of quality of conversations in a variety of applications," even beyond the medical setting, Eppstein says. "To date, there is no way of assessing the quality of conversations in medicine, even though it's critical to good care, especially to palliative medicine."

Without methods to seamlessly and meaningfully measure actual conversation quality, researchers and health policy makers generally have relied on patient feedback to evaluate a conversation. These questionnaires can be quite valuable as important outcomes of communication (eg. "How much do you feel heard and understood by the doctors, nurses and hospital staff caring for you?") but tend not to accurately reflect the content or process of the actual conversation.

The Vermont Conversation Lab aims to create an objective, automated measure that could be used routinely in natural healthcare settings. Voice-recognition and machine-learning technology can pick up clues in real time without recording the conversation or collecting identifying information in order to maintain confidentiality.

The technology would allow collection of data for research on conversations and assist with palliative care training, so students can learn techniques and receive immediate feedback.

Perhaps most important, it would give hospitals and other medical practices a means to evaluate conversational quality and to support — with financial incentives and other means — those systems that do it best.

At UVM, the new Division of Palliative Medicine grew from the longtime efforts of a small and successive group that championed this work. **Zail Berry, M.D.,** an internist with expertise in geriatrics and hospice care, came to UVM in 1996 and teamed up with Barbara Segal, a clinical nurse specialist, to provide palliative services in the hospital.

Back then, seriously ill patients ended up on a "conveyor belt" moving from one treatment to the next without providers stopping to find out what they wanted, says Berry, UVM associate professor of medicine and associate medical director for the Visiting Nurse Association, which oversees hospice services in Chittenden and Grand Isle counties.

Berry's push to expand the palliative program met with some resistance, she recalls. But the culture of medicine has since shifted, she says, from a focus on keeping patients alive to a recognition that their hopes and personal wellbeing matters as much. UVM medical leadership now stands firmly behind the enhancement of palliative care, Berry adds.

Palliative care at UVM remained a hospital-based program until the creation of the Division of Palliative Medicine in the Larner College of Medicine. This move allows greater opportunities for scholarship, research, educational advancement and interaction with the community, Gramling says.

This past year, the College launched a week-long "bridge" course devoted to palliative medicine for all third-year students. They work with standardized patients enacting palliative scenarios in the medical school's simulation lab. Students also have more frequent and routine interactions with the palliative team during their rotations in family and internal medicine.

Traditionally, patients had to be admitted to the hospital to get palliative care, though individual clinicians such as Berry have seen patients in their homes for years. Now, UVM is restructuring its palliative team to do outpatient work, including in primary care offices or via video technology for a "teleconsult."

Last fall, Gramling began an effort with Milton Family Practice to take referrals from primary doctors or cardiologists there. Palliative specialists can meet face-to-face with patients or coach clinicians who seek feedback on complex cases.

The UVM Health Network also has stretched palliative care across its medical centers and other clinical settings in Vermont and northern New York. One of the palliative team's longtime specialists and prior program leader, **Diana Barnard, M.D.,** now practices at Porter Medical Center, part of the UVM network, in Middlebury, Vt.

All these initiatives target a rural population that might prefer to stay close to home for care. "Even if it wasn't only a geographic barrier, there are other potential benefits of being able to get people in the same room, including relatives from California or Nebraska or Arkansas or wherever," Gramling says of the teleconsult option.

In many ways, Vermont is leading national trends in palliative care, says Susan Block, M.D. director of the Serious Illness Care program for Ariadne Labs, founded by renowned physician and writer Atul Gawande and operated jointly by Brigham and Women's Hospital in Boston and the Harvard T.H. Chan School of Public Health.

Ariadne is developing ways to redesign healthcare at its most critical junctures in people's lives. UVM plans to further collaborate with Ariadne to identify clinical practices that could revamp their systems to better target patients most in need of serious-illness conversations. The new operation would indicate ideal times to schedule those talks, methods to document them and follow-ups tied to patients' goals.

With the commitment of both state and medical center leadership, Vermont has an opportunity to cast a wide influence in this area across its population, Block says. UVM continues to work with state policy makers to encourage payment for communication as a treatment tool that's as effective as any drug or device.

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"I think we're ahead of the curve here both because our health financing models are moving to being able to value an incentivized system, and our leaders here at UVM are very attentive to caring well for people in our population," Gramling says. "We're thinking innovatively about what that looks like."

Gramling came to UVM from the University of Rochester in New York, where he oversaw extensive research in palliative care. He received his medical degree from Dartmouth Medical School, and his doctorate of science from Boston University School of Public Health. Two years ago, he took a six-month sabbatical to learn more about computational linguistics (including natural language processing and artificial intelligence) at the University of Cambridge in England, and during that time, received a Fulbright scholarship to join a palliative care team in Kyoto, Japan, for six weeks.

No palliative care specialty existed in medical training until 2008. When Gramling graduated from medical school, following in the footsteps of his physician father, he envisioned himself as the old-fashioned, small-town family doctor who saw his patients in their homes as often as in his office, with a simple goal to make them feel better.

"As a physician, I love being able to focus on a concept of relieving suffering," he says. "And to have a meaningful experience with other human beings, that buoys me more than drains me."

On that early summer morning, Gramling's visit with the ICU patient kicked off a typically busy day for the UVM palliative team. It started with the morning "huddle," when team members share notes and insights on patients. By 2 p.m., the team had ten consultations stacked up.

Just before seeing the first patient, he got a page about another. In the hospital's neurosurgical ICU, he picked up the phone and asked that second patient's doctor a series of questions:

"Has she signed a healthcare proxy?"

"Was this from a fall or is this spontaneous?"

"From what you can see, do you think the plegia would resolve, or is that an unknown?"

Palliative specialists make sure they understand the full scope of a patient's status. It's their job to clear up any confusion and explain — as gently as possible — what the patient can expect. They work in tandem with the patient's other caregivers.

"Sometimes, it's really important for the patient or the family or the provider to hear the perspective of the palliative specialist," Peterson says, particularly when other clinicians are focused on action and treatment. "We lose the bigger picture here."

Earlier this year, when Kate Laud's mother was diagnosed with liver cancer and told she had just weeks to live, they were in shock, Laud says. Gramling, along with the oncologist and internist, offered a level of solace she never expected and somehow ensured "that my mom could be very comfortable and also lucid," she recalls.

"For my mom, it really was a spiritual aid," she says. "It really did help her emotionally understand, to be that much less afraid of death, because you're not going to be in pain."

And the value to her family was immeasurable, she adds. "That was the touch we needed. It humanized the process, and it gave us a great sense of relief." VM

Bob Gramling, M.D., D.Sc., meets with colleagues during a Monday morning "huddle" of the UVM palliative care team.

David Seaver, Andy Duback