Misunderstood specialty

Many physicians still don’t understand how palliative care works and how it differs from hospice.

BY HOWARD BELL
Cory Ingram’s palliative care moment came in 2008 when a co-worker with stage 4 ovarian cancer asked him to take care of her and her family for the rest of her life. “I did my best,” says Ingram, who was a Mayo Clinic geriatrician at the time. “But I felt my best wasn’t good enough.” He saw how the treatments were taking a toll on his patient and that she wanted her discomfort to end. In addition, he realized that the system was set up to try to cure the incurable, regardless of the patient’s desires. “Her relentless bowel obstructions, nausea and seizures were being treated in a reactive crisis-management way,” Ingram recalls.

The patient also wanted answers to questions that went beyond medicine: How would she manage her condition at home? Who will help her husband cope with all of this? Who will take care of her mom? “Altogether, this complex of physical and nonphysical needs near the end of life was hard stuff to manage,” Ingram says. “I had neither the training nor the time to deal with it properly.”

The experience inspired Ingram to learn how to better care for patients in this situation. Two years later, he completed a one-year hospice and palliative care fellowship at Dartmouth-Hitchcock Medical Center in New Hampshire, then returned to Mayo where he now does inpatient palliative care consults at Methodist and St. Marys hospitals. He also teaches physicians and residents about palliative care locally, nationally and internationally.

One important message he imparts is that palliative care is not the same as hospice. Hospice is a type of palliative care that focuses on comfort, not cure, during the last six months of life. Palliative care alleviates pain and suffering for all seriously ill patients, including those who aren’t near death and who are receiving other life-prolonging, curative treatments. “Palliative care is about helping seriously ill people live well,” Ingram says. “You might ask, Doesn’t the health care system do this? No, not well.”

Problems with caring for the seriously ill are well-documented. The 1994 Open Society Institute Project on Death in America called for new ways to provide care that prevent poorly managed inpatient deaths as well as conflicts between caregivers and families that often lead to painful, unhelpful treatments. A 1995 ar-
ticle published in JAMA urged that all doctors be trained in end-of-life care, its bleak conclusion stating, “most Americans die in hospitals often alone and in pain after days or weeks of futile treatment, with little advanced planning and at a high cost.” In its 2014 report, “Dying in America,” the Institute of Medicine noted that seriously ill people often don’t get the care they want, but often get care they don’t want, and recommended that all doctors and nurses receive palliative care training.

Growing numbers, increasing need

The concept of palliative medicine emerged at a few teaching hospitals a couple of decades ago. Since then, inpatient palliative medicine programs have been established at all Minnesota hospitals with more than 300 beds and 45 percent of those with fewer than 50 beds. Since 2008, the number of board-certified hospice and palliative medicine physicians in the state has grown from 25 to 156.

The demand for the services offered by these programs has grown as well—and will continue to do so. One reason: an increasing number of patients are living for years after being diagnosed with an incurable disease. Those patients are specifying what treatments they want, for how long and under what circumstances. In addition, the science behind palliative medicine is advancing, and specialists now can help with pain management and end-of-life symptoms such as shortness of breath, nausea and opioid-induced constipation in ways they couldn’t before.

Such care is paying off. A growing number of studies show that many patients receiving palliative care can better cope with their symptoms and treatments, are more satisfied with their care and report a higher quality of life. Because they are less likely to require emergency room visits and hospitalizations or undergo treatments that are ineffective or unwanted, palliative care can lower costs.

What palliative specialists do

Palliative specialists take care of patients with conditions such as incurable cancer, advanced progressive lung diseases, ALS, AIDS, degenerative brain disorders, and kidney, liver or heart failure. They help manage patients’ symptoms, have conversations with them and their families about their wishes and concerns, and serve as a bridge between the patient, family and the attending physicians.

“Most doctors aren’t adequately taught this set of skills in medical school or residency, nor are they given the time [to do this work],” Ingram says.

Typically, palliative care physicians work as part of a team that includes nurses, social workers and chaplains. In fact, palliative medicine is considered by some to be the ultimate team specialty. “That’s one of the things I like most about it,” says Carol Grabowski, MD, who was a full-time radiation oncologist until three years ago when she became board-certified in palliative medicine and started splitting her time between the two specialties.

Like most palliative medicine physicians, Grabowski begins her day at North Memorial Medical Center in Robbinsdale by meeting with the rest of the palliative care team. Together, they review patient needs, discuss successes and disappointments, and sometimes take a moment to remember patients who’ve died. Two years
ago, Grabowski’s team saw 12 to 16 patients per day. Now they see 30.

This collaborative approach to patient care is the secret ingredient to palliative medicine’s success, according to Ingram, who refers to his morning team meetings as “the kitchen table talk.” “These talks take time, but are well worth it to patients and families, and to the system, which is then better able to care for the patient more efficiently because we invested time on the front end,” he says.

Much of what palliative medicine physicians do the rest of the time is manage symptoms, such as delirium, hiccups, constipation, itching, nausea, anxiety and shortness of breath, many of which are side effects of treatment. “Shortness of breath can be more distressing than pain,” says Jeffrey Rubins, MD, director of the palliative medicine program at Hennepin County Medical Center. “Attending physicians are taught to ask about these symptoms, but don’t always know how to make them go away.” Rubins was a pulmonary/critical care physician at the Minneapolis VA for 21 years, where he helped create the inpatient palliative care unit in 2009. That unit became a model for other inpatient programs in the state and within the VA system. He’s been at Hennepin since 2011 and has seen the program grow from 150 consults per year to 800.

Grabowski says changing medication regimens is a big part of what she does for her palliative care patients. “A patient might be on a narcotic that’s the wrong dose or type,” she says. “We put some patients on methadone, which can be really helpful, but few physicians outside our team would consider it.”

She adds that her palliative care training has made her a better radiation oncologist. “I was always diligent about managing side effects of treatment, but now I have so many more options for treating the side effects of pain, diarrhea, nausea and depression.” Some are quite simple. For example, radiation causes pain in the mouth, throat and esophagus. “By simply giving the patient IV fluids and medications in the infusion room, I keep them comfort-
able and out of the hospital. Avoiding hospitalization is huge, and it’s such an easy intervention,” she says.

Grabowski says her palliative medicine training also has made her more comfortable with what is often one of the most difficult and necessary parts of an oncologist’s job—having end-of-life conversations with patients and families.

“Instead of giving them everything on the buffet, this can help prevent family discord, indecision and unwanted treatments later on. Such conversations can take an hour or more and must be documented in the medical record. “Hospitalists and other doctors don’t have time for this,” Grabowski says. “They’re rightfully focused on the patient’s immediate medical concerns.” That’s why attending physicians should request a family meeting with palliative care even if a patient is pursuing curative treatment.

Those conversations accomplish two important things. First, they inform physicians what the patient and family want. “The system moves seriously ill patients on a conveyor past a buffet of interventions,” Ingram says. “Instead of giving them everything on the buffet, conversations take an hour or more and must be documented in the medical record. “In palliative care our procedure is the family meeting,” says Kirstin LeSage, MD, a palliative medicine physician with Essentia Health in Duluth who also teaches palliative care to family medicine residents and medical students.

“We’ve been taught specific ways to do this that really help families feel supported,” she says. Although they can be emotional, those meetings help patients and their families understand their situation, what can be done for them and the likely outcome of treatment. They also allow patients to discuss how they want to live and their priorities regarding treatment. Patients also are encouraged to complete an advance care planning document after they leave the hospital, if they haven’t already done so. This can help prevent family discord, indecision and unwanted treatments later on.

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Where palliative medicine physicians work

Until recently, the only way to practice palliative medicine was to work in a hospice program. That’s still a common setting, but many palliative medicine specialists now do inpatient hospital consults for non-hospice patients, an area that is growing exponentially, according to Jeffrey Rubins, MD, medical director of the palliative medicine program at Hennepin County Medical Center.

Some split their time between palliative care consults and another specialty. Carol Grabowski, MD, for example, divides her time between inpatient palliative care consults at North Memorial Medical Center and radiation oncology procedures as a locum tenens physician in Willmar and other smaller Minnesota towns. Some internists trained in palliative care see general internal medicine patients in their clinic, then do palliative care consults in a hospital or nursing home.

In years to come, more outpatient palliative care clinics are expected to open, and palliative medicine is expected to find a place in nursing homes, home health services, and in oncology, urology and cardiology clinics. —H.B.
They’ll be better reimbursed for the lengthy conversations many of them are already having," she says. Some physicians have been slow to embrace palliative medicine because they don’t understand what these specialists do or when to involve them. LeSage says this is partly because of the way physicians are trained. “Doctors don’t like to ask for help,” she says. “We’re not trained to be collaborative and work in teams. I’ve had physicians tell me ‘I think I need help, but I’m not sure what help I need.’”

Confusion about what palliative care doctors do is understandable, LeSage says. “When a patient has a GI bleed, we know to call a gastroenterologist. But our skills don’t fit into one silo, so they’re sometimes harder to define and harder for others to understand.”

Rubins says even physicians confuse palliative care with hospice and that he says Jim Risser, MD, medical director for HealthPartners hospice and palliative care program and for the palliative care program at Regions Hospital in St. Paul. Time spent on such things as family meetings often goes unreimbursed.

That, however, is starting to change. On January 1, the Centers for Medicare and Medicaid Services began using two new diagnostic codes to reimburse up to one hour of advance care planning discussions between patients and licensed providers. “We’re happy to see it as a profession,” says LeSage, who adds that primary care and outpatient palliative care providers will benefit most from the change.

Money and misconceptions

Ingram says palliative care is not yet as much a part of medicine as it should be. One reason is the lack of reimbursement for such services. “The current reimbursement system is procedure-based and rewards rapid hospital turnover and late enrollment in palliative care,” says Jim Risser, MD, medical director for HealthPartners hospice and palliative care program and for the palliative care program at Regions Hospital in St. Paul.

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“I like helping patients and families better understand their medical problems and treatment options to ensure that their wishes are followed, and to help them at a very intimate and unique moment in their life’s journey.”

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REGIONS HOSPITAL, ST. PAUL

Palliative care resources

The American Academy of Hospice and Palliative Medicine offers webinars, self-study primers and other training (www.aahpm.org).

The Center to Advance Palliative Care offers online courses, webinars and a “Fast Facts” section on its website that addresses such topics as opioid-induced constipation, ALS, drug-induced acute urinary retention, palliative care consults in the emergency department, and how to deliver bad news (www.CAPC.org/fast-facts).

Vitaltalk.org offers short videos on how to establish rapport with patients and families, break bad news and conduct a family conference (www.vitaltalk.org).
often hears: “My patient isn’t ready for palliative care.” A big part of Rubins’ job is explaining palliative care’s value to established physicians, which he says has been an uphill struggle. “I explain that it’s not the same as hospice,” he says. “It’s not just about the last six months. We aren’t stopping curative or restorative treatments. Studies show palliative care actually helps patients get through treatments better. Some chemo and COPD patients survive longer.”

Physicians also mistakenly fear that palliative care specialists will take control of their patient. LeSage says they actually provide an extra layer of support for both the physician and the patient. “We can have the conversations, resolve family disagreements and help families reach consensus on difficult decisions about medical issues and treatments—the things a lot of doctors don’t have time for or don’t feel comfortable doing.” She adds that once physicians see the value of palliative care they start asking for it earlier in a patient’s illness. This allows the palliative care team to build a relationship with the patient and family.

**System changes are coming**
The first two decades of palliative medicine demonstrated that it improves the quality of care and patient satisfaction while lowering costs. The next decade will see health systems formalizing protocols, measuring outcomes, teaching basic palliative care skills to non-palliative care physicians, and making it easier for seriously ill patients to get palliative care earlier in their illness, and not just in the hospital. “Everybody knows end-of-life care needs to change,” Risser says. “That change is easier when the system supports it.”

“Triggers” are one way health systems are taking the onus off physicians regarding when to call for a palliative care consult. At Regions Hospital, for example, consults are triggered for patients admitted with chronic heart failure or advanced COPD. At North Memorial, palliative care consults are triggered for any patient with a stage 4 cancer admitted to the ICU, any nursing home resident admitted to the ICU, and all patients with chronic heart failure admitted to any unit. Grabowski tries to talk with the attending and make sure he or she approves the consultation. “A direct doctor-to-doctor talk with the attending is essential, rather than just relying on communication through the EMR,” she says.

Eventually, health systems will have better electronic medical record documentation of patient preferences and will give feedback to physicians about whether they followed best practices for having goals-of-care conversations with seriously ill patients and their families, as they currently do for management of diabetes and hypertension.

In addition, health systems are opening outpatient palliative care clinics. Hennepin County Medical Center has one for ALS patients. The University of Minnesota has four outpatient clinics at its cancer centers in the Twin Cities and a general palliative care clinic for other patients with serious illnesses. In the next few years, some oncology, urology and cardiology clinics in Minnesota are expected to offer palliative care to better serve patients with life-limiting illnesses who are still receiving treatment and are not enrolled in hospice.

Driven in part by the desire to keep patients at home when it’s safe to do so, health systems are experimenting with home-based palliative care. For three years, Mayo Clinic has offered home-based services for non-hospice patients in Eau Claire, Wisconsin, and Rochester. “It’s been very successful,” says Keith Mansel, MD, a Mayo palliative medicine specialist. “Quality of life improves, patients and families are more satisfied, and hospitalizations decrease.” Mansel, who initially practiced pulmonary critical care, made a career change after spinal stenosis made it difficult for him to stand for long periods. “Being on the other side of patient care was an eye-opener for me and one reason I went into palliative medicine.”

Mansel believes home-based palliative care is the future. Indeed, many experts believe that making palliative care available to the seriously ill at home or in community settings such as nursing homes may be the single largest opportunity to improve value in the U.S. health care system.

**Making all doctors palliative medicine doctors**
Another way palliative care’s reach is expanding is by training all physicians in it, which some feel is the best way to create widespread, sustained improvements in end-of-life care. North Memorial is teaching all of its physicians how to have ad-
“It can be emotionally challenging to be surrounded by patients you care about who are dying, and to see their loved ones grieve and deal with the stress of watching a loved one die. But it’s part of our training to know how to live with that, to remain professionally engaged with our patients, to stay focused, relieve suffering, and have careful, empathetic conversations to help them understand what’s going on. Most physicians spend some time talking to seriously ill patients about choices and desires. I get to do it all the time.”

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Advance care planning conversations. HealthPartners is starting to teach its primary care physicians a basic set of palliative care skills and is developing a mentorship program to reach more of its physicians. Mayo Clinic has taught some of its primary care physicians palliative care principles, and by spring, Fairview/University Hospitals hope to be teaching palliative care skills to all of its physicians. Meanwhile, Risser says, residents and medical students are getting far more palliative care training than they used to.

“All specialties can provide palliative care,” Ingram says, “because all physicians desire to treat the patient, alleviate suffering and adhere to the patient’s desires for care.”

Drew Rosielle, MD, director of the University of Minnesota’s hospice and palliative care fellowship program, believes that once more physicians are trained in palliative medicine the question will change from, “When should a patient see a palliative medicine specialist?” to “When can a patient’s palliative care needs be met by a primary physician who’s been trained in basic palliative care?” “We don’t have the answer yet,” he says. “But what’s certain is that with all the benefits it offers, the specialty of palliative medicine will keep growing.”

Howard Bell is a medical writer and frequent contributor to Minnesota Medicine.