



The Case

for Improving Communication and Symptom Management Skills

In the Care of Patients with Serious Illness

Center to
Advance
Palliative Care
capc

"We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being."

Atul Gawande

Being Mortal: Medicine and What Matters in the End

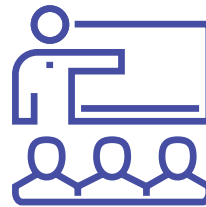
Thanks to modern medicine, more people are living longer with serious and complex illness—and their needs are growing exponentially.

But today's fragmented health care system makes it difficult to effectively treat the whole person behind the disease. That leads to unnecessary suffering, reduced quality of life, and higher costs.

Two things are critical to improving the current situation:



Initiating meaningful communication with patients about what matters most to them



Providing symptom relief, education, and other services to improve quality of life for people living with serious illness, and their families

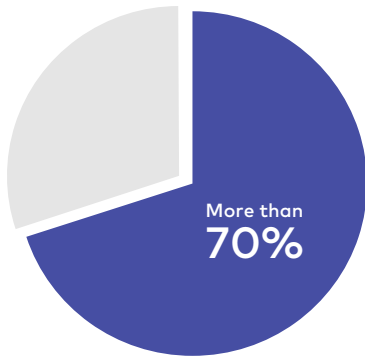
Health professionals cannot be expected to provide what they have never been trained to do. Our country is clearly in need of new and better training in communication and symptom management skills.

Despite the self-evident importance of strong communication skills in our nation's health care providers, the majority of physicians and nurses report being uncomfortable initiating difficult conversations about the future with their seriously ill patients. Moreover, clinicians admit to feeling hesitant about eliciting their patients' life priorities, and are uncertain about how to mobilize support for overburdened caregivers.

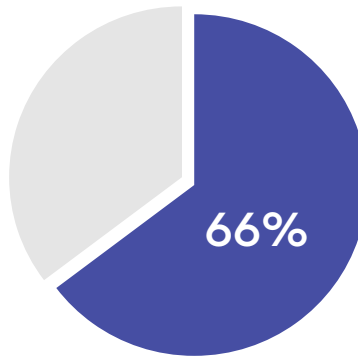
Clinician anxiety about these conversations is absolutely understandable. It is rooted in the near-total absence of communication skills training in our nation's medical schools, nursing schools, and graduate medical education programs.

In addition, most clinicians are not well trained in managing complex pain and other symptoms of patients living with a serious illness. And when treating patients whose needs are most complex, many clinicians are uncertain about when to request a palliative care consult — while others lack access to palliative care specialist teams.

- The majority of U.S. medical schools have no mandatory training focused on safe and effective pain management (a major contributor to the current opioid epidemic), and those that do teach pain management provide significantly fewer training hours than the standard in other countries.¹
- More than 70 percent of physicians report having had no formal training in how to have compassionate and effective advance care planning conversations — a deficit that is associated with physician stress and burnout.²
- Among ICU nurses, 66 percent report not having enough training to talk about prognosis, goals of care, or palliative care.³



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The evidence is clear:

These skills can be taught, and proper training results in measurably better quality of care, improved patient and family experience, and more time spent at home and out of hospitals.⁴

The bottom line:

When the clinical workforce develops the right skills to care for patients with serious illness — and when training focuses on communication and symptom management — organizations see a return on investment. Focusing on patients with serious illness saves institutional money and improves patients' quality of life.^{5,6}

Individuals living with a serious illness — such as cancer, COPD, heart disease, frailty, or dementia — face heightened risk of unnecessary suffering, crisis hospitalization, and preventable spending.

- More than half (51 percent) of Medicare beneficiaries visit the emergency department (ED) in the last month of life.⁷
- Recent analysis by Data Gen shows that people diagnosed with cancers of the brain, esophagus, liver, or lung have more than a one-in-three chance of at least one hospital admission every six months, and as much as a 40 percent chance of at least one ED visit in that same time period.⁸

The good news

Provider organizations are successfully improving both care quality and outcomes through clinician training. The benefits of training are huge. They include:

Improved patient experience

All Moffitt Cancer Center patients complete a symptom burden assessment in the waiting room, and then discuss the results with their oncologist, who has been trained in basic symptom management protocols. Moffitt oncologists are also trained in care pathways that include appropriate use of palliative care consultations. Both oncologists and patients report high satisfaction with this process.

Safer practices

In response to the opioid epidemic, clinicians working in both inpatient and outpatient care settings need training in safe opioid prescribing. This results in improved Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores and safer prescribing practices.

Reduced hospital days and patient spending due to advance care planning

The OSF HealthCare accountable care organization's communication skills training initiative resulted in an average reduction of nearly four inpatient days, without any adverse impact on readmissions or ED utilization. Cost of care decreased by \$9,500 for patients with advance directives resulting from conversations with trained clinicians.⁹

Less staff burnout

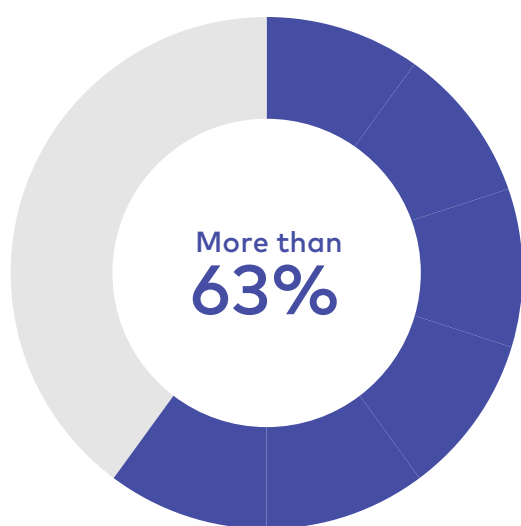
Communication skills training for physicians improves HCAHPS scores while improving physician empathy and reducing burnout.¹⁰

Reduced unnecessary hospital utilization

Well-controlled symptoms mean fewer ED visits and hospital admissions.

In a 2019 poll of health care executives and clinical leaders, more than 63 percent believed that their organizations should invest in the knowledge and skills needed to care for patients living with a serious illness — and that this training should be given to all clinicians who care for such patients.¹¹

While palliative care teams are expert at communicating with patients about their goals of care, and at managing pain and other symptoms, these specialists are most appropriate for the patients whose needs are most complex. We must ensure that all clinicians who treat seriously ill patients — including nonpalliative care specialists — have training in communication skills and pain and symptom management.



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A Case Example

Consider John

John is eighty-two years old. Diagnosed with esophageal cancer several months ago, he is undergoing second-line therapy. He now spends most of his time in bed.

The pain is "terrible," and in the middle of another sleepless night, his overwhelmed and exhausted daughter, Maria, with whom John lives, calls his doctor's office. She hears a recorded voice telling her to hang up and call 911 in an emergency. This results in their fourth trip to the ED in three months.

After his prior ED visit, John was admitted to the hospital for pain management.

- There he acquired a *C. diff* infection and required five days in the ICU, followed by twenty-one days of post-acute rehabilitation in a skilled nursing facility.
- He was discharged and returned home with a worsened level of function, confusion, and continued pain.
- Maria takes unpaid time off work to provide her father with twenty-four-hour care.

Two days after leaving the nursing home, John is back in the ED with severe pain.

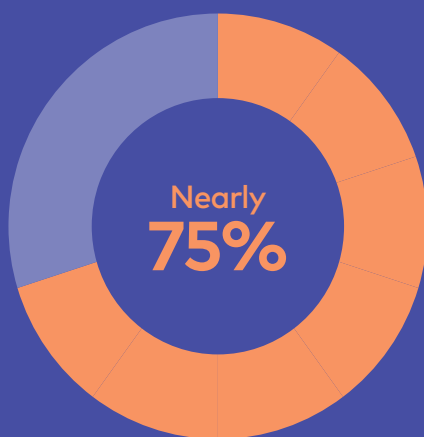
- He has been taking a dangerously high daily dose of 5,000 mg of acetaminophen, without relief.

At this point, John and Maria are labeled “frequent fliers” and considered to be “abusing” the ED, despite their appropriate use of the only solution available to them after 5:00 p.m. or on weekends.

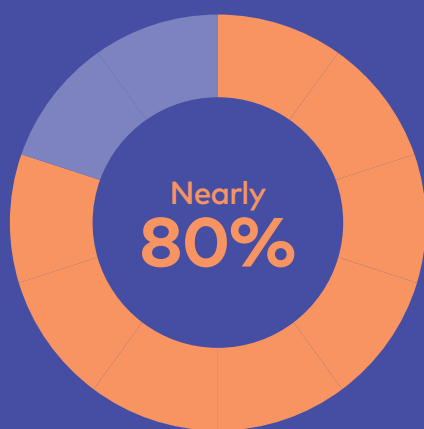
- John is readmitted for pain management.
- He is discharged to a nursing home for long-term care because his needs exceed his daughter’s physical and emotional reserves and financial capacity.
- Maria is distraught because she promised him she’d never send him to a nursing home.

Unfortunately, patients like John are not the exception. He is one of thirteen million people in the United States living with at least one serious illness—and the number of such patients will increase significantly over the next two decades.

While excellent disease management is a must in all situations, care for the sickest patients must also incorporate knowledge of patient priorities for function and quality of life, attention to physical and emotional distress, and support for the all-important family caregiver.



of hospital admissions are for patients with multiple chronic conditions.¹²



of crisis ED visits and hospitalizations (excluding those for pneumonia) are due to exacerbations of preexisting and chronic symptoms—such as shortness of breath in COPD, or chronic pain in cancer.¹³

- Caregiver distress, particularly severe fatigue, is independently and prospectively associated with higher care recipient Medicare expenditures and ED use, adding another \$2,000 in annual spending per beneficiary.¹⁴
- The quality of clinician communication is among the strongest independent predictors of readmission.¹⁵ Nearly half of all patients leaving the hospital acknowledge that they do not understand their care plan.
- Patients admitted with coexisting frailty, memory loss, or functional impairment are at very high risk for hospital complications, permanent functional and cognitive decline, and long-term nursing home placement—a result that the majority of patients consider a fate worse than death.¹⁶
- Most practicing clinicians have not had training in pain and symptom assessment, communication with patients and families about what matters most, or about the array of community- and faith-based resources that are available to support families like John and Maria. This lack of knowledge and skill can lead not only to preventable and severe pain and suffering, but also to bankruptcy for family caregivers and unwanted nursing home placement for people living with a serious illness.¹⁷

Through clinician training, it is entirely feasible for health care organizations to make necessary, sustainable changes. Only by addressing gaps in professional training can we improve outcomes and reduce spending.

There are many things John's care team could do better next time:

- Assess for, and safely manage, pain and other symptoms, making ED visits less likely.
- Schedule dedicated conversations to understand what matters most to John and his daughter as they grapple with his illness.
- Develop a care plan that reflects their family's preference for John to stay at home, if possible.
- Connect to community resources to help Maria cope with the challenges of caregiving.
- Administer low-dose morphine at home as needed for John's episodes of severe cancer pain.
- Help arrange care from a community-based home-visiting palliative care or hospice program.
- Connect the family to assistance in applying for Medicaid to support John's personal care needs so that Maria can get back to work to provide their only source of income.

Organizations that successfully address gaps in care for patients living with a serious illness use three proven strategies:

- **Train clinicians.** Midcareer training in pain and symptom management, communication skills, and caregiver support will equip your workforce to meet the unique needs of seriously ill patients. Learn more at capc.org/training.
- **Pay attention to workflow and infrastructure.** Can your electronic health record (EHR) accommodate advance directives or caregiver information? Are your teams held accountable for standard symptom and risk assessment for frailty, functional impairment, or memory loss? Do they know when to request help from a specialty palliative care consulting team?
- **Make culture change a priority—and really mean it.** Practice change starts at the top with a clear vision of better care, and a lucid assessment of what it will take to get there. It doesn't happen overnight. Whole-patient care for your sickest patients requires sustained commitment.

The Center to Advance Palliative Care

The **Center to Advance Palliative Care (CAPC)**, established in 1999, is a national organization dedicated to increasing the availability of quality health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively redesign care systems that meet this need. CAPC is funded through organizational membership and the generous support of foundations and private philanthropy. It is part of the Icahn School of Medicine at Mount Sinai, in New York City. Visit **capc.org**.

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55 West 125th Street

Suite 1302

New York, NY 10027

PHONE 212-201-2670

EMAIL capc@mssm.edu

WEB capc.org

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