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ICU admissions twice as common in U.S.; fewer in-hospital deaths

Advance care planning, palliative care many have significant effect

Not surprisingly, intensive care unit (ICU) admissions were more than twice as common in the U.S. as in other countries, according to recent research comparing the site of death, healthcare utilization, and hospital expenditures for terminally ill cancer patients in seven developed countries.¹

On the other hand, the U.S. actually has the lowest proportion of deaths in the hospital — and patients spend the least number of days in the hospital in their last six months of life.

"It's surprising to us that the U.S.

was better on many measures of end-of-life care, and not worse on others," says lead author **Justin E. Bekelman**, MD, associate professor in the Departments of Radiation Oncology and Medical Ethics and Health Policy at University of Pennsylvania's Perelman School of Medicine in Philadelphia. Other key findings include the following:

- Only about one in five patients with cancer in the U.S. died in acute care hospitals, whereas, for example, in Belgium and Canada, one in two patients died in acute care hospitals.
- The U.S. did not spend the most

EXECUTIVE SUMMARY

ICU admissions are far more common in the United States than other countries, yet the U.S. has the lowest proportion of in-hospital deaths, according to a recent study. Key findings include the following:

- Only about one in five U.S. cancer patients died in acute care hospitals.
- U.S. patients spent the fewest days in the hospital in the last six months of life.
- Aggressive care was much more common in the U.S.

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EDITORIAL QUESTIONS
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per patient on care in the last six months of life. "Canada and Norway were just as expensive, if not more," says Bekelman.

The findings could be an indication that efforts to promote advance care planning, and palliative and hospice care, have had a significant effect on U.S. healthcare practices, says **Michael A. Rubin**, MD, MA, chair of the ethics committee at University of Texas Southwestern Medical Center in Dallas.

"In order for the U.S. to have a high ICU admission rate and low in-hospital death rate, we are likely recognizing when patients have reached end of life," says Rubin. "And we are establishing a plan of care to de-escalate interventions and provide adequate care at home."

Patient preferences

The overarching goal, says Rubin, is to optimize concordance between patient preference and the selection of a medically feasible care plan. "When we succeed at such, cost savings will follow, medical providers will endure less moral distress, and patients and surrogates will experience less suffering at end of life," says Rubin.

The researchers looked at not only where people with cancer die, but also how they spend their last six months — the last chapter of their lives. "What we found was that the last chapter is written very differently depending on country, and not necessarily in the ways we might have thought," says Bekelman.

The goal is to improve end-of-life care regardless of which country it occurs in. "Were the last chapter written by our patients, would it resemble the findings that we

report?" asks Bekelman. "The answer is no, and that's why we have more work to do."

The researchers advocate providing care that is more concordant with patients' wishes for fewer hospital stays and death at home. "The experience of the United States and the Netherlands suggest that end-of-life care can evolve to better reflect patient's preferences," says Bekelman. "But we have a ways to go."

Although the mix of services is different, dying with cancer involves a great deal of healthcare in all the countries studied, says **Julie Bynum**, MD, MPH, one of the study's authors. Bynum is associate professor at The Dartmouth Institute for Health Policy & Clinical Practice in Lebanon, NH.

"From my perspective as a health service researcher and geriatric medicine physician, the central ethical issue revolves around whether people have access to the type of care they prefer," says Bynum. A related ethical concern is whether their preferences are elicited and honored when they need those services.

In the U.S., hospital stays are shorter and fewer people die in the hospital. "This is related to the availability of other kinds of places to go — nursing homes or home with hospice support, for example," says Bynum. "In other countries, hospitals deliver palliative care."

Where the U.S. stood out as different from the other countries is the use of the ICU — a place where aggressive, life-supporting services are delivered. "The ethical question this raises is whether that type of service is being delivered based on a fully informed patient and family, who understand the prognosis and what those services can reasonably achieve," says Bynum.

Physicians need support

Wayne Shelton, PhD, professor in the Alden March Bioethics Institute at Albany (NY) Medical College, says, “In the U.S., there is a tendency to practice ‘rescue’ medicine, and to use the technology that we have available.”

In some cases, technology extends life in a meaningful way. “The problem is when you use it in situations where at best you are getting marginal benefits,” says Shelton. “In some cases, you are causing harm. This violates the ethical principle of nonmaleficence.”

Such scenarios stem from the expansive view of individual autonomy in the U.S. without consideration for the cost of care, says Shelton. “We tend to give people the right to have what they want at the end of life,” he adds.

This sometimes results in physicians providing care they believe is inappropriate. “As a physician, if you go outside the standard of care and do something inappropriate because of the fear you are going to upset someone, or fear you will be sued, that’s an ethical issue,” says Shelton.

Physicians are caught between pleasing patients and family and doing what is right medically and ethically. “Physicians should not be giving options to distressed families who are acting as surrogates of dying patients as though it were a Chinese food menu where everything is equally good and it’s just a matter of what they want,” Shelton says.

While clinical ethicists can provide support to physicians, institutional support is needed, he emphasizes. “One of the big drawbacks to end-of-life care is that there is no standardized approach to providing it,” says Shelton.

Policies and procedures can define the commitment to provide appropriate medical treatment and the limits of what options will be offered. “The leaders of institutions have to make that loud and clear, so physicians, when they do the right thing and refuse to practice outside the standard of care, aren’t left to hang out to dry as individuals,” says Shelton.

Appropriate end-of-life care and cost-effective care aren’t mutually exclusive. “This is an issue where cost and quality overlap,” Shelton says. “I’m not implying we should

right to have someone kept alive in a vegetative state for sometimes not only years, but decades.”

New generations of physicians with a different outlook and the determination to affect change are needed, says Shelton.

“It’s the medical culture in which new doctors train, and the clinical mentors from whom they pick up basic habits, that will have the biggest impact,” he says. “We have to be change agents, and it’s not easy.”

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deny appropriate care to anybody, I’m talking about treating patients appropriately.”

Cost of care is expected to be a driving force in changing the way end-of-life care is provided in the U.S. “Change will come, if for no other reason than we will go bankrupt if we don’t change,” says Shelton. “We are the most costly and least efficient system in the world. There is not even a close second.”

Part of the reason is that treatments are often utilized in the U.S. that don’t add to the quality of care. “There are some ethical issues that are uniquely American, that no other country would deal with,” says Shelton. “People are given the

Is family “waiting for a miracle,” yet aggressive care is inappropriate?

Chaplains play a critical role in resolution

Editor's note: This is the first in a two-part series on the role of chaplains in the hospital setting. In this story, we explore how chaplains can help to resolve conflicts over whether to withdraw life-sustaining interventions. Next month, we'll report on how chaplains and ethicists can work together to ensure ethical care.

We're waiting on a miracle." "We're not giving up on him." "If we pray hard enough, she will be healed."

When family members make these, or similar, statements, clinicians often find it difficult to respond. A chaplain can be of great help, says **F. Keith Stirewalt**, PA, MBA, MDiv, chaplain for clinical engagement at Wake Forest Baptist Medical Center in Winston-Salem, NC.

"While we might think that each of these arguments around arguably futile end-of-life treatments can be refuted with science, the faith components of these statements need to be addressed," says Stirewalt.

Stirewalt says the following are important considerations:

- **What does the patient/family mean by these phrases?**

- **How can theological hope be transitioned into end-of-life in a way that maintains meaning for the patient and his or her support system?**

- **What does a miracle look like?**

"I like to explain that dying while being surrounded by people you love and by people who love you is the greatest of gifts and miracles," says Stirewalt.

"Brainstorming" other miracles

When **Vance Goodman**, MDiv, a chaplain in the cardiac ICU at Children's Health in Dallas, encounters a patient or family who talks about "miracles," she asks how they'd define the term.

"Often, a miracle is defined as an event that is unexpected and inexplicable by natural laws or science," says Goodman. Many families talk about their faith and how their faith in God allows them to believe in miracles. "God will be the agent of healing," they may explain. "We are depending on God for a miracle."

Goodman then asks about the

exact miracle that the patient or family is expecting. "We brainstorm other miracles, still consistent with their beliefs, that may manifest during the course of treatment, that may not include full physical healing," she says. Emotional and spiritual healing is something that people hold onto even after the death of their loved one, for instance. "The small relational moments, hand holding, whispers and brief conversations are miracles that are granted to the patient, the family, and the staff observing the interactions," says Goodman.

If at the end of life, medical staff have no options to offer the family, and the family continues to insist that a miracle will happen, Goodman usually inquires about the machines, medicines, and decisions that may be getting in the way of a possible miracle.

"I attempt to do this gracefully, without judgment, so that the family might consider the miracle of death, freedom from suffering — the patient's and theirs — as a viable option," says Goodman.

Dying patients deserve the opportunity to explore theological meaning, says Stirewalt. "This exploration requires adequate time for a trusting relationship to develop, and for the patient and their support system to reconcile their life's meaning in the last days of earthly life," he says.

Direct challenges as to the existence of miracles can have the opposite of the desired effect, resulting in entrenchment and institutional distrust of the medical

EXECUTIVE SUMMARY

Chaplains can play an important role if family is requesting aggressive interventions and clinicians believe such care to be inappropriate. Chaplains can do the following:

- Explain that dying surrounded by loved ones is a blessing.
- Be realistic with the family during conversations and prayer.
- Make sure clinicians give the family the space and time they need.

team. "This is another opportunity for chaplain involvement," says Stirewalt. "In negative terms, the chaplain team should not be called upon to 'bust up' theology that the medical team feels is disserving."

While an attack on someone's faith is not appropriate, gentle probing is beneficial, says Stirewalt. "We seek to understand the grounding of stated faith. When appropriate, some risk can be taken," says Stirewalt.

In conversation with Christian families awaiting a miracle, Stirewalt has occasionally observed that none of the miracles of the Hebrew or New Testament scriptures mentions modern medical technology. "If miracles are caused by things unexplained in our realm of influence, does God need a ventilator to enact a miracle?" he asks.

Often, families are slower to understand what clinicians see as inevitable. "Guiding them through the process, we allow that understanding to influence a trajectory that families may have initially resisted," says Stirewalt.

Realistic and supportive

At Mercy Hospital Fort Smith (AR), chaplains recently played a key role in the care of an elderly gentleman who had been hospitalized for two months. "He had made it to inpatient rehab, but suffered a code blue early one morning," says Fr. **Paul Fetsko**, MDiv, BCC, director of ethics.

The patient was placed on a ventilator in ICU, but coded two more times. The patient's wife and daughter were present at the hospital, but the son, who was power of attorney, was not in the state.

Just a few days earlier, the patient

had executed a living will in which he stated he wanted "everything done" to save his life, unless he became permanently unconscious. The son communicated to Fetsko that it was important for him to honor his father's wishes as stated in the living will.

"After a few days, the son was able to arrive at the hospital and awaited further test results. He did consent to a DNR order," says Fetsko.

The medical team felt that continued support was futile, even though it could not be stated

"I LIKE TO EXPLAIN THAT DYING WHILE BEING SURROUNDED BY PEOPLE YOU LOVE AND BY PEOPLE WHO LOVE YOU IS THE GREATEST OF GIFTS AND MIRACLES."

with certainty the patient was permanently unconscious. "Visits by our hospice team did not change the son's mind," says Fetsko.

Several chaplains provided the family with daily support. "They described their role as a mediator between the care team and family, helping both to understand the perspective of the other," says Fetsko.

The chaplains were realistic with the family during conversations and prayer, but made sure clinicians gave the family the space and time they needed. "The chaplains did

a good job not taking hope away from the family, but also reminded them of the patient's Christian faith in eternity," says Fetsko.

After the neurologist had concluded the patient would not wake up, and the intensivist had done everything medically suitable, the son was satisfied that the wishes of his father had been met. The family arranged a time when they could all be present at bedside. The son agreed to remove life support, and the patient died peacefully in the hospice unit. "Our chaplains were critical in this case by providing continued and consistent care," says Fetsko. "Thankfully, their support to the family helped avoid a more protracted ethics consultation."

When a family has not come around to the recommendation of the medical team, Fetsko sometimes asks, "If God is calling the person home, why are we holding them down by the feet? The family needs assurance that they are not causing the person's death; rather, it is the underlying disease process," says Fetsko.

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New data on moral distress in the ED

Inadequate communication, lack of resources contribute

ED nurses participating in focus groups described a profound feeling of not being able to provide patient care as they wanted, a recent study reported.¹

"ED nurses' feelings of moral distress are the canary in the coal mine. They are a clear signal that there is something bad happening," says **Lisa Wolf**, PhD, RN, CEN, FAEN, the study's lead author. Wolf is director of the Institute for Emergency Nursing Research of the Des Plaines, IL-based Emergency Nurses Association.

Wolf and colleagues found that clinicians working in EDs experience moral distress as a result of threats to quality and safety of both patients and clinicians, inadequate or unsafe staffing, unnecessary pain and suffering, conflicting roles and expectations, triage and disposition of patients, and time pressures exacerbated by bureaucratic requirements that undermine nursing practice.

"Many of these issues reflect the burgeoning strain on the healthcare system to provide care to sicker, more complex patients without a sufficient infrastructure to do so in a safe, fair manner," says **Cynda Hylton**

Rushton, PhD, RN, FAAN, Anne and George L. Bunting Professor of Clinical Ethics at Johns Hopkins University's Berman Institute of Bioethics in Baltimore.

Rushton says external factors are undermining the integrity of ED clinicians to uphold their ethical obligations to provide safe, respectful, and equitable care to those in need of healthcare. "Organizations and external regulatory agencies must begin to take seriously the unintended consequences of policy decisions that are undermining ethical practice," she urges.

ED nurse practitioners experience moral distress due to inadequate staff communication and working with colleagues lacking the competence level needed for patient acuity, according to another study which suggested that moral distress influences ED nurse practitioners' intent to leave their position.²

"Improving interprofessional communication, developing competencies of all medical staff members, and maintaining sufficient staffing are a few of the important aspects of ensuring moral distress does not reach levels that have personnel consider leaving their

current position or their profession," says **Jennifer Trautmann**, PhD, RN, FNP-BC, the study's lead author. Trautmann is the Morton K. and Jane Blaustein Post-doctoral Fellow in Mental Health and Psychiatric Nursing at Johns Hopkins University School of Nursing in Baltimore.

The following are some underlying causes of moral distress in the ED setting:

- **There is a lack of resources for behavioral health patients.**

"There is a feeling like, 'I should be able to help these people, but I can't because their problems are so much bigger than I can address in the two hours that they are here,'" says Wolf.

Behavioral health patients are often boarded in EDs for days and weeks. "Nurses feel we are not doing anything for this person," she says. There is a larger issue at play, says Wolf: that society doesn't allocate resources for individuals who are homeless, addicted or mentally ill, and ED nurses feel unable to meet their needs.

"There is a pervasive sense, legislatively and socially, that some people deserve to be cared for and other people don't," says Wolf. "If we had an understanding that there is a social floor through which no one should fall, there would be more of a collective will to address this on a much larger scale."

- **When dying patients are brought to the ED, aggressive care is utilized when it may not be appropriate.**

"The ED is just a bad time to have advance care planning discussions," says **Mark McClelland**, DNP, RN,

EXECUTIVE SUMMARY

Moral distress reported by ED nurses stems from the inability to provide good care to complex patients because of insufficient resources, according to a recent study. Bioethicists can do the following:

- Make ED nurses aware that it's not a personal failure, but rather a systemic issue in need of fixing.
- Create mechanisms for ED clinicians to communicate their concerns to colleagues and leaders.
- Hold discussions of ethically challenging ED cases.

CPHQ, a nurse scientist in the Office of Research and Innovation at Cleveland Clinic's Nursing Institute.

If nurses experience moral distress in this scenario, he says, "You need to support the nursing staff throughout, and after the fact."

Bioethicists can help to identify possible solutions. "We are always going to have patients who probably shouldn't be coded, who come in and are coded," says McClelland. If the family wants aggressive care, says McClelland, "that's the route we are going to go, generally," he says. "We are not going to get away from that in the near future. But how we handle it overall could go a long way to decreasing moral distress."

One goal is to make community caregivers aware of how they can avoid sending dying patients to the ED. "We can say, 'Here's how you can keep them from coming to the ED. Let's talk about ways we can coordinate care,'" says Wolf.

• Admitted patients are held for hours or days waiting for an inpatient bed to become available.

Presumably, nurses chose the ED because it is a setting more conducive to their practice style. "ED nurses are forced to provide a level of care which is basically inpatient care, or sometimes ICU-level care, for which they are not accustomed or necessarily trained," says McClelland.

Some hospitals have made changes to ensure ED patients are admitted expeditiously. "That removes a major source of moral distress. Boarding is just flat-out preventable," says McClelland.

ED nurses need to see that unit leaders are responsive to their concerns. "It's one thing to say, 'Tell us your concerns,' and then the nurse not see anything grow from that, versus seeing a very

proactive approach," McClelland says. "I guarantee if there's one nurse experiencing moral distress, there's many."

EDs are viewed as unpredictable and chaotic. "We are coming to believe that's not true. The ED is really quite predictable," says McClelland. If an ED admits between 10 and 12 patients on the day shift every Monday, for instance, EDs should staff accordingly, and bed control should have 10 beds lined up

A formal ethics consult often isn't feasible to address an individual patient's needs in the ED setting. "An ethics consult takes at least a couple hours to get rolling, and sometimes a day," says McClelland. "That doesn't really help that patient and that family at that moment."

However, McClelland says, "an ethics consult could be called — not for an individual ED patient, but for the ED itself."

Wolf suggests ethicists can assist by making ED nurses aware that it's not a personal failure, but rather a systemic issue in need of fixing. "It's not that you are a terrible nurse. It's that you are unable to do what you are supposed to do," she says.

Rushton says bioethicists can help in the following ways:

- creating mechanisms for ED clinicians to communicate their concerns to colleagues and leaders,
- championing efforts for systemwide attention to the root causes of their distress,
- holding regular forums for discussion of challenging cases,
- engage organizational leaders in taking seriously the concerns of ED clinicians, and developing support systems to avoid burnout and moral distress,
- leading efforts that engage the broader community in devising

solutions aimed at redressing the root causes of their moral distress, and

- leveraging provisions of the American Nurses Association's Code of Ethics to support their concerns.

"Bioethicists can intentionally reach out to ED clinicians to explore their needs and to devise effective strategies to support their integrity," says Rushton.

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Do substance abusers have capacity to consent to participate in research?

Misconceptions about capacity are commonplace

When researchers assessed the capacity of addicted individuals to provide consent to research, they found that about two-thirds of participants had decisional capacity.¹

"There is a big misconception that substance abusers are not able to make rational decisions, and therefore do not have the capacity to consent," says **William W. Stoops**, PhD, associate professor at the University of Kentucky's College of Medicine in Lexington.

Many treatment providers avoid obtaining meaningful consent from substance users, however. "The thinking is that their 'disease' makes consent impossible. There is no scientific evidence to support this idea," says **Robert Walker**, MSW, LCSW, assistant professor of behavioral science at University of Kentucky Center on Drug and Alcohol Research.

Misconceptions about substance users' capacity to give consent are commonplace among treatment providers, elected officials, and the general public, notes Walker. "However, among those who either do research or who are more experienced with these

disorders, there is recognition that substance users can give consent both to treatment and to research," he says.

There are ethical concerns involving enrolling any individual without decisional capacity in a research study regardless of whether they have a substance use disorder, says **Barbara S. McCrady**, PhD, director of the University of New Mexico's Center on Alcoholism, Substance Abuse, and Addictions in Albuquerque.

"The one area of unique concern would revolve around an individual's ability to understand research requirements related to substance use, need for ongoing care within a study, and understanding the limits of an experimental treatment," says McCrady.

She gives the example of a long-acting form of naltrexone, an opiate antagonist administered as a monthly injection. When the medication is active, the risk of an opiate overdose is mitigated, but that effect lasts only about a month. "If a participant in a study of this medication does not understand that the injection is effective only for a month, he or she could be

at risk for an opiate overdose without realizing it," says McCrady.

Potential participants who present for a study intoxicated or in acute withdrawal cannot provide informed consent, notes McCrady. The long-term effects, particularly of alcohol, on comprehension and memory can also make it difficult to provide informed consent. "If a research protocol requires that participants abstain from the use of alcohol or other drugs, concerns about ability to sustain abstinence also have some merit," says McCrady.

Counterbalancing these concerns, however, is the importance of developing and testing appropriate treatments for the wide range of disorders that affect persons with substance use disorders as well as the general population, says McCrady.

"To test treatments only on a non-affected population raises the specter of not knowing the potential risks and benefits of a treatment with a substance use disorder-affected population," she says.

There are multiple important reasons to include persons with substance use disorders in scientific research, says McCrady. These include the following:

- to better understand the etiology, course, and resolution of these problems;
- to test potential prevention and intervention strategies;
- to understand the epidemiology of substance use disorders.

"Persons with substance abuse disorders often are excluded from biomedical research studies that are focused on physical and psychiatric illnesses other than substance use

EXECUTIVE SUMMARY

About two-thirds of addicted individuals had decisional capacity to provide consent to participation in research, a recent study found. Ethical considerations for this population include the following:

- Some treatment providers wrongly assume substance abusers are unable to give consent.
- Potential participants who present for a study while intoxicated or in acute withdrawal cannot provide informed consent.
- Researchers need to test appropriate treatments for the wide range of disorders that affect persons with substance use disorders as well as the general population.

disorders,” says McCrady. Some reasons for this include the following:

- the possibility of alcohol or drug use complicating response to treatments being tested,
- concerns about the number of co-occurring physical and psychological problems these individuals might have, and
- concerns about the likelihood of the individual complying with experimental treatment regimes.

“Given the high mortality and morbidity rates among persons with substance use disorders, as well as the economic and social costs of substance use disorders, to exclude them from research would violate, at a minimum, the principle of justice,” says McCrady.

It is vital that researchers remain actively concerned with their research subjects and revisit informed consent with them throughout the research process, advises Stoops. This makes it possible to detect if an enrolled subject lacks capacity to consent.

“This shouldn’t be a standard just for research with substance abusers, though,” says Stoops. “It should be a standard for all research subjects.”

The University of Kentucky’s institutional review board’s procedure states that where subject capacity is impaired, a legally authorized

representative must give consent to research either “in the person’s best interest” or as a “substituted judgment” about the procedure. “In the latter case, the legally authorized representative makes a decision as he or she thinks the person would have done, had he or she had decisional capacity,” says Walker.

Stoops says that excluding substance abusers from research, unless they would be harmed from participation, can violate the ethical principle of justice. This is especially true if substance abusers can benefit from the overall research findings.

“Of course, researchers need to ensure that substance users are able to provide consent to participate, and are not unduly influenced or coerced to participate,” says Stoops. Stoops uses the criteria of understanding, appreciation, reasoning, and expression of a choice when obtaining consent from the substance abusers he enrolls in research studies.

“Researchers enrolling substance abusers need to do their best to ensure participants have the capacity to provide consent, just as they would for ‘normal’ volunteers,” he says.

This could involve sobriety testing and an active discussion with subjects to assess their ability to meet criteria

of understanding, appreciation, reasoning, and expression of a choice. “I could imagine a scenario where someone who lacks capacity to consent could slip through,” says Stoops. “But I would encourage investigators to put adequate safeguards in place to minimize this possibility.”

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Cost-saving effect of palliative care larger for patients with comorbidities

May also shorten hospital lengths of stay

Cost savings linked to palliative care consultations were greater for adults with advanced cancer with higher numbers of comorbidities, according to a recent study.¹

Researchers compared a treatment group of advanced cancer patients

with numerous serious health conditions from six hospitals who were seen by a palliative care team with a separate group who received usual care. Key findings include the following:

- Patients from the treatment

group had a 22% reduction in costs compared to the group that did not receive palliative consultation.

- Patients with the highest number of comorbidities had up to a 32% reduction in costs.

“We found that those patients

with the greatest number of conditions who received a palliative care consult early in their hospital stay had lower costs,” says **Amy S. Kelley**, MD, MSHS, one of the study’s authors. Kelley is associate professor at Icahn School of Medicine at Mount Sinai’s Brookdale Department of Geriatrics and Palliative Medicine in New York City.

The study’s findings suggest that early palliative consultations with the sickest patients may decrease unwanted aggressive end-of-life care as well as shorten length of stays in hospital, according to the researchers.

Growing numbers of older adults in the U.S. are living with multiple chronic conditions. “This burden of illness adds complexity to treatment decisions, and may negatively impact symptoms and quality of life, particularly in the setting of a serious illness such as cancer,” says Kelley.

Palliative care has been shown to improve many outcomes for cancer patients — mood, pain, quality of life, and length of life — and that these improved clinical outcomes are usually accompanied by lower costs.^{2,3} “Yet we didn’t know what influence having multiple chronic conditions may have on [clinical outcomes], or on the costs of care,” says Kelley.

A very high proportion of

healthcare resources are spent on patients living and dying with serious chronic illness. Yet these patients typically receive fragmented and poor quality care, says **Peter May**, PhD, the study’s lead author. May is a research fellow at Trinity College Dublin’s Centre for Health Policy & Management in Ireland.

“The principle finding of this paper — that palliative care is more cost-effective for more complex patients — is entirely new, and was not hypothesised at the start of the study,” says May.

There are currently not enough specialist palliative care providers for all seriously ill patients. “So it is unclear where to focus that limited resource,” says Kelley.

The study helps demonstrate that the most complex patients with multiple conditions are most likely to benefit from this additional support, and that hospital systems can provide this service to their patients while minimizing costs, says Kelley.

The findings suggest that palliative care is a complex intervention that is not equally effective for all patients but, rather, is most effective for the most complex cases, says May. “It is important to be careful in drawing conclusions from a cost analysis without further verifying the impact on patient quality of life and

satisfaction,” he cautions. “This work is ongoing.”

However, on the evidence-based assumption that patient outcomes are at least as good for palliative care patients as those who receive usual care only, the results imply that a higher number of patients with advanced cancer and additional serious illnesses should be referred promptly to palliative care.

“Such referral could improve patient pain, mood, and distress, address patient goals of care and discharge preferences, and prevent the futile use of scarce resources,” says May.

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- Peter May, PhD, Centre for Health Policy & Management, Trinity College Dublin, Ireland. Email: mayp2@tcd.ie. ■

EXECUTIVE SUMMARY

Palliative care consultations resulted in greater cost savings for adults with advanced cancer who had higher numbers of comorbidities, according to a recent study. Other key findings include the following:

- There are currently not enough specialist palliative care providers for all seriously ill patients.
- Providing early specialist palliative care to complex patients with multiple conditions could improve care while saving costs.
- Targeted palliative care referrals could prevent the futile use of scarce resources.

Program offers tools, training for more ethical end-of-life care

Aims to ensure care consistent with patient preferences

Patients whose clinicians were trained in the use of a Serious Illness Conversation Guide were much more likely to have more comprehensive documentation in the electronic medical record (EMR) of their goals, values and priorities.¹ This is an early finding of a four-year randomized controlled trial that is currently being conducted at Dana-Farber Cancer Institute in Boston to evaluate the Serious Illness Care Program's effectiveness.

"Patients also reported meaningful positive changes in their well-being through improved peace of mind, decreased anxiety or depression, realistic planning for the future, and improved relationships with their doctors," reports **Justin Sanders, MD, MSc**, assistant director of innovation for the Serious Illness Care Program at Boston-based Ariadne Labs.

The Serious Illness Care Program is a multi-component intervention that aims to support clinicians in generating a personalized serious illness care plan for patients in the last year of life. Over 500 clinicians have been trained to date, and it is currently being piloted at multiple institutions.

"The Serious Illness Care Program aims to ensure care consistent with patients' preferences by implementing systems changes that support clinicians to effectively learn about and act upon their patients' values, goals, and priorities, as elicited through meaningful conversations in the right place at the right time," says Sanders. The system changes involve

the following steps:

- **Identification of patients who have a high risk of death or disability due to their illness.**

"In our trial with cancer patients, we have identified patients using the 'surprise' question," Sanders says. Clinicians answered the question, "Would you be surprised if this patient died in the next year?"

If the clinician answered "no," then the patient was eligible for enrollment in the trial. "This question has been shown to be predictive of one-year mortality in cancer patients and those with end-stage kidney disease," Sanders says.

- **Training clinicians to use evidence-based communication tools to improve the quality of their conversations.**

One of these tools is the Serious Illness Conversation Guide. Clinicians use this guide to elicit illness understanding and information preferences, share a clear, direct prognosis according to those information preferences, to elicit hopes, fears, strengths, and priorities for their healthcare, and to learn about the kinds of communication patients are — or are not — having with their families and loved ones.

Clinicians are trained using a 2.5-

hour session that involves reflection upon their current practice, skills training, and role-play. "This training has proven to be both feasible and highly acceptable to clinicians," says Sanders.

- **Documenting the conversations in ways that are accessible at multiple points of care.**

Outcomes for the conversations are documented in a standardized location in the EMR. "Different healthcare systems, with different EMRs, are taking on the challenge of creating templates in their EMRs to record the kind of information that these conversations elicit," says Sanders.

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SOURCE

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- Ethical responses if patients refuse to be discharged

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CME/CE QUESTIONS

1. Which is true regarding end-of-life care in the U.S. compared to other nations, according to a recent study?

- A. ICU admissions are far more common in the U.S.
- B. The U.S. has the highest proportion of in-hospital deaths.
- C. The U.S. spends the most per patient on care in the last six months of life.
- D. U.S. patients had the most days in the hospital in the last six months of life.

2. Which is recommended to address moral distress experienced by ED nurses, according to Cynda Hylton Rushton, PhD, RN, FAAN?

- A. Training nurses to provide ICU level care for boarded patients.
- B. Creating mechanisms for ED clinicians to communicate their concerns to colleagues and leaders.
- C. Encouraging community caregivers to send terminally ill patients to the ED for advance care planning.
- D. Routinely denying families' requests for aggressive care for dying patients unless there is clear evidence that the patient requested such care.

3. Which is true regarding substance abusers and decision-making capacity, according to

Barbara S. McCrady, PhD?

- A. Addicted individuals lack decisional capacity to provide consent to participation in research studies.
- B. It is unethical for researchers to enroll substance abusers in research studies that aren't looking specifically at substance abuse.
- C. Even potential participants who present for a study intoxicated or in acute withdrawal can provide informed consent in some cases.
- D. It is important to develop and test appropriate treatments for the wide range of disorders that affect persons with substance use disorders as well as the general population.

4. Which is true regarding palliative care, length of stay, and cost savings, according to a recent study?

- A. There was no evidence that palliative care consultations resulted in reduced length of stay in hospital.
- B. Palliative care consultations resulted in greater cost savings for adults with advanced cancer who had higher numbers of comorbidities.
- C. The fewer comorbidities a patient had, the greater the cost savings.
- D. Early palliative care consultations should be targeted toward patients except those with additional serious illnesses.