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# Quality of Life Matters®

News & clinical findings about serious illness

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## Patients Less Likely to Receive Palliative Care at Minority-Serving Hospitals, Regardless of Race/Ethnicity

Site of care, not race or ethnicity, may be a key determinant of whether or not seriously ill patients receive palliative care, a new study has found. Advanced cancer patients treated at hospitals that primarily serve minorities were 33% less likely than those at other facilities to be provided any palliative care, regardless of their race, ethnicity, or insurance carrier.

“We found that treatment at minority-serving hospitals was associated with significantly lower odds of receiving palliative care, but black and Hispanic race/ethnicity was not,” write the authors of a report published in *JAMA Network Open*.

“The policy implications of this finding are significant,” the authors point out. “Given that care for minority patients is concentrated at a comparatively small number of hospitals in the U.S., it is likely that one important strategy to address racial/ethnic disparities in palliative care is to focus on improving access to palliative care at the small number of hospitals that care for most minority patients.”

Investigators analyzed data maintained by a hospital-based cancer registry (the National Cancer Database) on 601,680 patients aged > 40 years (mean age, 67.4 years) diagnosed from 2004 to 2015 with metastatic lung, breast, prostate, or colon cancer who were cared for at one of 1500 U.S. hospitals.

The hospitals were ranked by the proportion of minority patients (black or Hispanic) treated at each. Those serving the largest percentage of minorities (the top decile) were designated “minority-serving hospitals” (MSHs). The other 90% were considered to be “non-minority-serving hospitals” (non-MSHs).

black patients, and 15.9% of those who were Hispanic ( $P < 0.001$ ).

### KEY FINDINGS

- In adjusted analysis, treatment at an MSH had a statistically significant association with lower odds of receiving palliative care (odds ratio [OR], 0.67; 95 % confidence interval [CI], 0.53 to 0.84).
- Compared to patients with private insurance, those with Medicaid or who were uninsured were more likely to receive palliative care (OR, 1.16; 95% CI, 1.13 to 1.19 and OR, 1.17; 95% CI, 1.13 to 1.21, respectively)

“The finding that palliative care is more common in Medicaid patients and uninsured patients was...surprising, given that these patients seem to receive worse care, based on many other health metrics,” the authors note. They suggest that these patients may be presenting when their disease is more advanced, or that the absence of a strong fee-for-service reimbursement incentive may ease the way to providing comfort care only.

### OVERALL

- 21.7% of patients in the full study cohort received palliative care services for their advanced cancer.
- Palliative care was received by 18% of those treated at MSHs vs 22.3% of those at non-MSHs, regardless of race/ethnicity ( $P = 0.002$ ).
- Palliative care services were provided for 22.5% of white patients, 20.0% of

### PALLIATIVE CARE BY CANCER TYPE, MSH VS NON-MSH

- Non-small cell lung cancer, 21.5% MSH vs 25.8% non-MSH
- Breast cancer, 15.0% vs 19.0%
- Prostate cancer, 11.7% vs 16.0%
- Colon cancer, 9.8% vs 11.3%

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# NEWSLINE

## 'Neuropalliative Care:' Neurologists Offered Practical Tips for Provision of Primary Palliative Care

Patients with serious neurologic illness can benefit from palliative care throughout the disease trajectory, yet neurologists may lack the training or confidence needed to incorporate primary palliative care principles into their routine practice. In a review article published in *Seminars in Neurology*, experts outline skills crucial to delivering "neuropalliative care," which includes conducting goals-of-care discussions and managing burdensome symptoms.

"Neuropalliative care is a new and growing field," write the authors. "Many neurologic diseases have no cure, and lead to significant disability, emotional distress, and chronic, debilitating symptoms."

While some neurologic patients will benefit from specialty palliative care when appropriate, all patients can benefit from primary palliative care, which focuses on improving quality of life for neurology patients and their caregivers. Because "[p]atients with many neurologic diseases view their neurologist as a primary care provider," the authors urge neurologists to adopt essential palliative care skills.

### CHALLENGES OF NEUROPALLIATIVE CARE

Several aspects of neuropalliative care make it different from — and more challenging than — palliative care for non-neurologic patients, point out the authors, because the needs of neurologic patients are so often unique to their specific disease. Challenges include:

- Prognostication with a high degree of uncertainty and variability
- A need for surrogate decision makers earlier in the disease course than with other illnesses, as patients become unable to communicate their wishes
- Behavioral changes accompanying certain neurologic diseases

- The psychological distress associated with neurology patients' changing sense of self

Despite the widely understood importance of neuropalliative care, "significant gaps" exist in its delivery, due in large part to lack of training, note the authors. "All neurologists need to master the core competencies required for effective symptom management, communication, and advance care planning," they write. Their article outlines a number of crucial neuropalliative care skills, drawn from relevant research in the field.

### RECOGNIZING TRIGGERS FOR SERIOUS ILLNESS CONVERSATION

A key step in palliative care is the timely identification of patients who would benefit from a serious illness conversation. The authors point out that while the "surprise question" model ("Would you be surprised if this patient died within the next year?") works well for many patient populations, it may be less applicable to neurology, due to the often unpredictable trajectory of neurologic illnesses.

Instead, the authors suggest certain triggers as indicators that a serious illness conversation may be needed. While they note there is no current consensus as to the best triggers for use in neuropalliative care, they highlight several event-based triggers suggested by experts, including:

- Hospitalization (especially if frequent)
- Development of a serious comorbidity
- Change in functional status (including cognitive changes or frequent falls)
- Unintentional weight loss

### KEY ELEMENTS OF SERIOUS ILLNESS CONVERSATIONS

"Serious illness conversations may take place over multiple visits and can be initi-

ated by the patient or clinician," write the authors. These discussions should cover the patient's understanding of the prognosis as well as goals and values to be taken into account when choosing future care. Research has shown that discussion of care preferences is associated with "better quality of life, less aggressive medical care near death, goal-concordant care, and better bereavement for families," they note. Neurologists can:

- **Assess the patient's understanding of the illness.** Beginning with a question, such as, "*What have you heard about your illness?*" or "*What is your sense of what is happening?*" can open the conversation and provide a framework for ongoing discussion.
- **Elicit patient goals and values.** Asking about and understanding the patient's hopes, concerns, and wishes is important for determining future care. ("*As you think about the future, what things are you hopeful for?*" and "*What are your biggest worries about the future?*") It is also important to acknowledge the need for hope. "Hope is an important coping mechanism, and often is not a reflection of denial," write the authors.
- **Determine the patient's preferences for information sharing.** Not all patients want to know prognostic information, and those who do may have preferences about the type and scope of the information. ("*Would it be okay if I tell you about the prognosis for this condition?*" or "*What information would be helpful to you?*") Some patients wish to know "how well" rather than "how long" they might live, and some will prefer to have a caregiver present. Clinicians can use the "Ask, Tell, Ask" method: **Ask** for permission to discuss

*Continued on Page 3*

# NEWSLINE

## Patients Less Likely to Receive Palliative Care (from Page 1)

### ADJUSTED ODDS OF MSH BY CANCER TYPE

- Lung cancer: AOR, 0.73; 95% CI, 0.57 to 0.93
- Breast cancer : AOR, 0.73; 95% CI, 0.59 to 0.89
- Prostate cancer: AOR, 0.67; 95% CI, 0.55 to 0.82
- Colon cancer: AOR, 0.86; 95% CI, 0.67 to 1.09

Previous studies have found systemic differences between MSHs and non-MSHs, with MSHs often showing higher readmission rates, poorer clinical performance, and less expertise or interest in quality-of-care issues by the leadership. The authors

recommend finding strategies to improve palliative care use in MSHs as a way to address palliative care needs that are likely unmet among minorities.

*Source: "Association of Care at Minority-Serving vs Non-Minority-Serving Hospitals with Use of Palliative Care among Racial/Ethnic Minorities with Metastatic Cancer in the United States," JAMA Network Open; February 1, 2019; 2(2):e187633.DOI: 10.1001/jamanetworkopen.2018.7633. Cole AP, Nguyen DD, Meirkhanov A, Golshan M, Trinh QD, et al; Center for Surgery and Public Health; and Division of Urological Surgery, Brigham and Women's Hospital, Harvard Medical School, Boston; and Faculty of Medicine, McGill University, Montreal, Quebec, Canada.*

## 'Neuropalliative Care:' Neurologists Offered Practical Tips (from Page 2)

prognosis, **Tell** the information in the way the patient prefers, then **Ask** how well the explanation was understood.

- **Prepare to share prognostic information.** The following model can be used to formulate a prediction prior to sharing it with the patient: 1) anticipate types of prognostic information needed in the encounter; 2) anchor to available data by considering the overall illness trajectory; 3) tailor the best evidence available to patient-specific factors; and 4) de-bias one's own understanding of the patient's disease to avoid overly optimistic or pessimistic predictions.
- **Share prognostic information.** When delivering bad news, the "SPIKES" protocol can be used (Set up the interview, assess the patient's **P**erception, obtain the patient's **I**nvitation, give **K**nowledge and information, address the patient's **E**motions with empathy, formulate a **S**trategy and **S**ummarize). Also, make an effort to align with the patient by using "I wish" statements when delivering bad news, rather than "I'm sorry" statements.
- **Use strategies to build trust.** Cultivate rapport and build trust through expressions of empathy. When responding to emotion, the "NURSES" mnemonic can be helpful (Name the emotion,

check to make sure one **U**nderstands correctly what the patient is communicating, demonstrate verbal and nonverbal **R**espect, provide expression of **S**upport, and **E**xplore the patient's emotions). In addition, expressing longitudinal support for the patient can help ease feelings of abandonment.

### OTHER COMPONENTS OF NEUROPALLIATIVE CARE

In addition to core communication skills, "knowledge of fundamental non-neurologic symptom management is a key component of neuropalliative care," write the authors. This includes both neurologic and non-neurologic physical symptoms, as well as emotional and spiritual symptoms. Non-neurologic symptoms comprising an important part of palliative care assessment include pain, dry mouth/increased saliva, constipation, loss of appetite, fatigue, and insomnia. Common psychosocial symptoms include grief, depression, anxiety, spiritual suffering, loss of dignity, and depersonalization.

"Palliative care emphasizes treatment of not only the patient, but also the family and caregivers," the authors state. Because "caregiver stress is high in neurologic disease," caregiver assessment is especially important in neuropalliative care.

Caregivers of neurologic patients face a high risk of depression and overall poor health, note the authors. Helping caregivers to feel appreciated and avoid burnout can improve the quality of life for both caregivers and patients.

As a patient approaches the end of life, conversations with the patient and family should revisit patient preferences regarding comfort-only care, and hospice care can be recommended. This will ensure the patient and family feel supported in valuing the patient's wishes and avoiding potentially harmful and unwanted aggressive treatment near the end of life.

Training in palliative care is needed for neurologists, the authors declare. "Given the vast number of patients with neurologic conditions requiring palliative care interventions, neurologists are tasked with providing primary palliative care," they write. Moving forward, standardization of training, along with research to define the scope of the palliative care needs of this population are needed, the authors conclude.

*Source: "Neuropalliative Care: A Practical Guide for the Neurologist," Seminars in Neurology; October 2018; 28(5):569-575. Brizzi K and Creutzfeldt CJ; Department of Neurology and Division of Palliative Care, Department of Medicine, Wang Ambulatory Care Center, Boston; and Department of Neurology, Harborview Medical Center, Harborview Medical Center, Seattle.*

# RESEARCH MONITOR

## Unmet Needs, Opportunities to Introduce Palliative Care Identified for ESRD Amputees

Medicare patients with end-stage renal disease (ESRD) are nearly 10 times as likely as non-ESRD patients to undergo lower extremity (toe, foot, or leg) amputation in the last year of life, as well as more likely to spend prolonged time in acute care and to die in the hospital. Yet these patients receive palliative care from hospice services for fewer days than even other ESRD patients do, according to a report published in the *Journal of the American Society of Nephrology*.

“This study suggests that end-of-life care for these patients may not align with the kind of care that many seriously ill patients say they prefer — that is, to die at home and focus on comfort rather than prolonging life,” says lead author Catherine R. Butler, MD.

“More work is needed to learn about the experiences of these seriously ill patients with ESRD who undergo amputation, and to identify opportunities to improve their care.” Butler is a practicing nephrologist affiliated with the University of Washington in Seattle.

Compared with other patient groups with critical limb ischemia, ESRD patients with lower extremity peripheral vascular disorder often receive surgical intervention when the condition is more advanced, putting them at higher risk for rehospitalization, re-amputation, and mortality, note the authors.

Because of the likely poor prognosis, the Renal Physicians’ Association recommends that lower extremity amputation should trigger “discussions about end-of-life care and the benefits and burdens of ongoing dialysis,” write the authors. They note, however, that few studies have described the type of care these patients receive.

Investigators analyzed data from a

national ESRD registry on Medicare beneficiaries who died between 2002 and 2014. ESRD patients who did (n = 62,075) and did not (n = 692,702) undergo one or more lower extremity amputations in the last year of life were compared with a parallel cohort of beneficiaries without ESRD who did (n = 8,937) and did not (n = 949,475) undergo similar amputations during the same time periods.

### OVERALL

- All ESRD patients, both those with and without amputation(s), were more likely than non-ESRD patients to be younger, male, and black, with a higher prevalence of most comorbid conditions and a higher overall comorbidity burden.
- 8% of ESRD patients underwent amputation of at least one lower extremity in the last year of life vs 1% of non-ESRD beneficiaries.

### ASSOCIATION OF ESRD WITH AMPUTATION:

- After multivariate adjustment, patients with ESRD were more than twice as likely as non-ESRD patients to have at least one lower extremity amputation in the last year of life (adjusted odds ratio [AOR], 2.37; 95% confidence interval [CI], 2.31 to 2.43).
- ESRD was more strongly associated with multiple amputations in the last year of life (AOR, 3.56; 95% CI, 3.28 to 3.86) than with a single amputation (AOR, 2.25; 95% CI, 2.20 to 2.32).
- The most likely level of ESRD amputation was below the knee (AOR, 2.97, 95% CI, 2.83 to 3.11).

### ESRD HEALTHCARE USE, AMPUTATION VS NO AMPUTATION

In the last year of life, ESRD patients

who underwent amputation were more likely than other ESRD patients to:

- Be admitted to a skilled nursing facility (AOR, 2.34; 95% CI, 2.29 to 2.38)
- Discontinue dialysis before death (AOR, 1.16; 95% CI, 1.14 to 1.18)
- Be admitted to an ICU (1.41; 95% CI, 1.38 to 1.45)
- Die in the hospital (AOR, 1.18; 95% CI, 1.15 to 1.20)

In addition to having more intensive patterns of healthcare in the last year of life, ESRD patients with amputations entered hospice closer to death than did those with no amputation; amputees spent less time in hospice (AOR, 0.77; 95% CI, 0.74 to 0.80), despite having about the same likelihood of being enrolled at the time of death (AOR, 1.02; 95% CI, 1.00 to 1.04).

“It is striking that despite widespread recognition that the presence of peripheral arterial disease and receipt of lower extremity amputation portend an exceedingly poor prognosis in this population, [these Medicare patients] receive more — not less — intensive patterns of care than other patients with ESRD,” comment the authors.

### THE ‘BIG PICTURE’ NEEDED FOR TIMELY HOSPICE REFERRAL

Possible reasons for brief enrollments in hospice among ESRD patients with amputations may include:

- Viewing lower extremity wounds and ischemia as isolated, “fixable” problems while overlooking the broader, prognostic significance.
- Focusing on recovery after amputation rather than, again, on the bigger picture of prognosis indicated by the need for amputation.
- Possible lack of palliative care services in the subacute facilities where a large

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# RESEARCH MONITOR

## Polypharmacy Linked to Significant Decrease in Quality of Life for Patients with Life-Limiting Illness

For adult patients with advanced illness, the use of an excessive number of medications — or polypharmacy — is associated with both higher symptom burden and worse total quality of life, according to a report presented as the first analysis of these associations published in the *Journal of General Internal Medicine*.

“We were not completely surprised by the results,” says lead author Yael Schenker, MD, MAS, of the University of Pittsburgh School of Medicine. “We’ve known for a while that polypharmacy is a burden for patients near the end of life, and the study confirms the importance of addressing appropriate medication use and developing systematic approaches to deprescribing.”

Although it is an increasingly common health problem, “there is no uniformly accepted definition of the number of medications that constitutes polypharmacy,” note the authors. For the purposes of this investigation, polypharmacy groups were defined as “low” (0-8 medications), “medium” (9-13 medications), and “high” ( $\geq 14$  medications), based on the number of non-statin medications used by participants in the week previous to baseline.

The investigators conducted a secondary analysis of data on adult patients ( $n = 372$ ) with advanced, life-limiting illness enrolled in a large, 15-center clinical trial to evaluate the effects of statin discontinuation. Eligible patients were those who had recently experienced deterioration in functional status, and were assessed by their physicians as having a life expectancy of more than one month but less than one year.

### OVERALL

- The mean symptom-burden score was 27.0 (standard deviation [SD], 16.1) on a patient-rated scale of 0 to 90 (as a total of scores for nine common symptoms, each rated from 0 to 10), with higher scores indicating greater symptom burden.

- The mean QOL score was 6.97 (SD, 1.32) on a patient-rated scale of 0 to 10, with higher scores denoting better QOL.
- The average number of non-statin medications was 11.6 (SD, 5.0).
- One-third of participants took  $\geq 14$  medications.
- 47% of participants were aged  $\geq 75$  years; cancer was the primary diagnosis for 52% of participants (the most common non-cancer diagnoses included COPD, CHF, and dementia); and 35% were enrolled in hospice at baseline.

In fully adjusted models, “higher performance status and being enrolled in hospice were associated with higher quality of life,” write the authors.

### HIGHER POLYPHARMACY WAS ASSOCIATED WITH:

- Greater symptom burden (adjusted beta, 0.81;  $P < 0.001$ ). “This implies that each additional medication was associated with a higher symptom burden of 0.81 points,” explain the authors.
- Lower QOL (adjusted beta, - 0.06;  $P = 0.001$ ). “This implies that every additional medication was associated with lower quality of life by 0.06 points.”

Source: “Associations Between Polypharmacy, Symptom Burden, and Quality of Life in Patients with Advanced, Life-Limiting Illness,” *Journal of General Internal Medicine*; Epub ahead of print, February 4, 2019; DOI: 10.1007/s11606-019-04837-7. Schenker Y, Park SY, Jeong K, Pruskowski J, Kavalieratos D, Resick J, Abernethy A, Kutner JS; Section of Palliative Care and Medical Ethics, Division of General Internal Medicine; Center for Research on Healthcare Data, Division of General Internal Medicine; and Department of Pharmacy and Therapeutics, UPMC Palliative and Supportive Institute, School of Pharmacy, all University of Pittsburgh, Pittsburgh; Flatiron Health, New York City; and Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora.

## Palliative Care for ESRD Amputees (from Page 2)

percentage of ESRD patients spend a substantial portion of their time post-amputation.

“Similar to other populations, most patients with advanced kidney disease would prefer to die at home, and would value relief of suffering over life prolongation if they were to become seriously ill,” write the authors.

“These findings suggest that there may be substantial unmet palliative care needs among seriously ill patients with ESRD who undergo lower extremity amputation, as well as opportunities to improve their care.”

Source: “Lower Extremity Amputation and Health Care Utilization in the Last Year of Life among Medicare Beneficiaries with ESRD,”

*Journal of the American Society of Nephrology*; Epub ahead of print, February 19, 2019; DOI: 10.1681/ASN.2018101002. Butler CR, Schwartz ML, Katz R, et al; Department of Medicine and the Kidney Research Institute, University of Washington, Seattle; Department of Surgery, Medical College of Wisconsin, Madison; Division of Nephrology, Department of Medicine, Stanford University School of Medicine, Palo Alto, California; and Division of Nephrology, Department of Medicine, Veterans Affairs Puget Sound Healthcare System, Seattle.

# RESEARCH MONITOR

## Patients' Top Hope for Advanced Cancer Treatment: Quality of Life

The most frequently expressed hope of adult patients receiving treatment for advanced cancer is for maintaining or improving their quality of life, followed by the hope of living longer. However, younger patients and those who do not discuss their hopes with their primary care physicians are more likely than others to hope for a complete cure, according to a report published in the *Journal of Pain and Symptom Management*.

"It is important for physicians to understand their patients' hopes for treatment to facilitate informed patient-centered decision making," write the authors. "By asking about hopes for treatment, physicians and other care team members can provide empathetic education and guidance to help patients establish realistic goals for treatment."

Investigators analyzed survey data collected as part of the Values and Options in Cancer Care (VOICE) trial, a randomized clinical trial measuring the effect of clinician training and patient coaching on oncologist-patient communication among community-dwelling patients with advanced, non-hematologic cancer enrolled from 2012 to 2014 and their area medical oncologists.

For the current study, researchers reviewed responses of adult patients with advanced cancer in surveys — conducted either in person or by telephone — which posed the open-ended question, "What are you hoping for from your cancer treatment?" both at baseline (n = 265) and at three-month follow-up (n = 216). Eight categories of participants' expressed hopes were identified.

### OVERALL

- Mean age of participants was 64.3 years.
- Median survival was 16 months.
- Half (50%) were diagnosed with "ag-

gressive" cancers, including lung, gastrointestinal (except colon), and genitourinary (except prostate) cancers.

### PATIENTS' HOPES FOR TREATMENT, RANKED BY PREVALENCE

1. Quality of life (42% at baseline; 36% at three-month follow-up)
2. Life extension (32% and 26%)
3. Tumor stabilization (26% and 31%)
4. Remission (20% and 16%)
5. Reaching/achieving a milestone (14% and 4%)
6. Cure, unqualified (12% and 8%)
7. Control, unspecified (9% and 12%)
8. Cure tempered by realism; i.e., the patient hopes for a cure while acknowledging that this is unrealistic (5% and 1%)

Some participants expressed more than one hope. The average number of hopes at baseline was 1.6 (standard deviation [SD], 0.77), but had slightly diminished to 1.3 (SD, 0.66) at three months. "At both time points, the most frequently expressed hope was for improved or maintained quality of life, while patients infrequently expressed unqualified hopes for cure and cure tempered by realism," write the authors.

### DISCUSSIONS OF HOPE

- Most patients reported having discussed their hopes "somewhat," "quite a bit," or "very much" with their spouse/partner (86%), other family members or friends (77%), or their oncologist (65%).
- Only about one-third said they had discussed their hopes with their primary care physician (36%) or a nurse/nurse practitioner (37%).
- Even fewer had discussed their hopes with a clergy member (21%) or with

members of a support group or online community (11%).

Hoping for an unqualified cure was more likely among patients aged < 57 years (adjusted odds ratio [AOR], 3.92; 95% confidence interval [CI], 1.63 to 9.40;  $P = 0.002$ ) and those who had not discussed their hopes with their primary care physician (AOR, 3.21; 95% CI, 1.13 to 9.14;  $P = 0.029$ ).

Although they were a minority, patients who had discussed their hopes with their primary care physicians were much less likely to harbor unrealistic hope for cure than were those who had discussed their hopes with their oncologists.

"While we cannot assume causation from these associations, primary care physicians may play a role in helping patients reframe what is important and realistic," due to a longstanding, trusted relationship with the patient, the authors suggest. "Alternatively, patients with more unrealistic expectations may be less likely to seek, remember, or seriously consider counsel from a primary care physician," they add.

Both in the current study as well as in a previous literature review, the two most common patient hopes for treatment were for good quality of life and life extension, note the authors. "These two treatment goals are consistent with the aims of both palliative cancer-directed therapy and of palliative care more generally — and therefore could be construed as realistic in this setting of advanced cancer."

Source: "Patients' Hopes for Advanced Cancer Treatment," *Journal of Pain and Symptom Management*; January 2019; 57(1):57–63. DeMartini J et al; Department of Psychiatry; Department of Family and Community Medicine, University of California, Davis; Department of Family Medicine; and Department of Psychiatry, University of Rochester, Rochester, New York; Department of Pediatrics; Division of Hematology and Oncology; and Division of General Medicine, University of California, Davis, Sacramento.

# CLINICIAN RESOURCES

## Experts Recommend a ‘Softened Approach’ to Discussing Prognosis

To ease the difficulty of prognostic discussions, physicians are encouraged to soften their approach and align themselves with patients against the disease, by using “I” statements to share their hopes and worries, rather than attempting to declare objective, time-based predictions when the exact trajectory of a serious illness is uncertain, according to an article published in *JAMA Internal Medicine*.

“We propose that to succeed in prognostic communication, what clinicians most need is not precision about the time ahead or the fortitude to discuss it, but rather a softened approach,” write the authors, two palliative care specialists. “We have found this approach to be popular with colleagues — they like it and incorporate it into practice quickly.”

### CHALLENGES IN PROGNOSTIC DISCUSSIONS

- Prognostic uncertainty
- Fear of upsetting the patient
- Concern that the patient lacks needed information, however imprecise
- Worry that patients will think their physician can’t handle tough but needed discussions

“Uncertain about the information and not wanting to cause emotional harm, we hesitate to talk with patients about their futures,” write the authors. “Clinicians don’t need to ‘know’ the prognosis, they just need to have an opinion.”

### ADVANTAGES OF THE SOFTENED APPROACH

- Using “I” statements can make it easier and more comfortable for clinicians to discuss a prognosis, through sharing a personal viewpoint on life expectancy, rather than stating an objective prediction. (“*From what I can see, I am worried...*”)
- Pairing hope with worry allows clinicians to feel more comfortable about delivering a prognostic estimate while expressing its uncertainty. Patients and families can receive important information in a way that is less emotionally overwhelming and leaves space for hope. (“*I am hoping that you have a long time to live with your heart disease, and I am also worried that the time may be short, as short as a few years.*”)
- Expressing both hope and worry in “I” statements promotes connection with the patient and family, indicating that the clinician is on their side in facing the problem — the uncertain future of the patient’s illness — together.

Source: *Softening Our Approach to Discussing Prognosis*, JAMA Internal Medicine; January 1, 2019; 179(1):5–6. Lakin JR, Jacobsen J; Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Ariadne Labs; Brigham and Women’s Hospital; Harvard School of Public Health; Division of Palliative Care and Geriatrics, Massachusetts General Hospital; and Harvard Medical School, all in Boston.

## End-of-Life Care Websites

American Academy of Hospice  
and Palliative Medicine  
[www.aahpm.org](http://www.aahpm.org)

Information and Support for End-of-Life  
Care from the National Hospice and  
Palliative Care Organization  
[www.caringinfo.org](http://www.caringinfo.org)

Center to Advance Palliative Care  
[www.capc.org](http://www.capc.org)

The EPEC Project (Education in Palliative  
and End-of-Life Care)  
[www.bioethics.northwestern.edu/  
programs/epec/about/](http://www.bioethics.northwestern.edu/programs/epec/about/)

Palliative Care Fast Facts and Concepts,  
a clinician resource from the Palliative  
Care Network of Wisconsin  
[www.mypcnow.org/fast-facts](http://www.mypcnow.org/fast-facts)

Hospice and Palliative Nurses Association  
[www.hpna.org](http://www.hpna.org)

Hospice Foundation of America  
[www.hospicefoundation.org](http://www.hospicefoundation.org)

Medical College of Wisconsin  
Palliative Care Program  
[www.mcw.edu/departments/palliative-  
care-program](http://www.mcw.edu/departments/palliative-care-program)

National Hospice & Palliative  
Care Organization  
[www.nhpco.org](http://www.nhpco.org)

Division of Palliative Care  
Mount Sinai Health System  
[www.stoppain.org](http://www.stoppain.org)

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## End-of-Life Care Meetings for Clinicians

**Topics in Family Medicine, Palliative Care, and Pain Management.** August 6–16, 2019, 10-night Blue Danube River cruise conference from Vienna, Austria, to Bucharest, Romania. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: [www.continuingeducation.net](http://www.continuingeducation.net)

**Supportive Care in Oncology Symposium: Advancing Palliative Research Across the Care Continuum.** October 25–26, 2019, San Francisco, CA. Sponsor: American Society of Clinical Oncology. Website: [www.asco.org](http://www.asco.org)

**National Hospice and Palliative Care Organization Interdisciplinary Conference 2019.** November 4–6, 2019, Gaylord Palms Resort and Convention Center, Orlando, FL. Website: [www.nhpco.org/education/nhpco-conferences](http://www.nhpco.org/education/nhpco-conferences)

**Center to Advance Palliative Care National Seminar 2019.** November 14–16, 2019, Atlanta Marriott Marquis, Atlanta, GA. Areas of focus include: Palliative Care and the Opioid Crisis, Quality with Efficiency, and Telehealth. Website: [www.capc.org/seminar](http://www.capc.org/seminar)

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