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## Palliative Care Linked to Significant Reduction in Suicide Risk Among Veterans with Advanced Lung Cancer

Amid growing concern about the high rate of suicide among the nation’s veterans, researchers have found that Veterans Affairs (VA) health system patients with advanced lung cancer who had at least one palliative care visit were 81% less likely to die by suicide, according to a report published in the *Annals of the American Thoracic Society*.

However, while the rate of suicide among lung cancer patients in the study was 5.8 times greater than that of all age- and gender-matched VA patients who

died from other causes, the percentage of lung cancer patients receiving palliative care was just one-third of that received by patients with other causes of death.

“This is the first study to report suicide rates among patients with lung cancer in the VA,” write the authors. “Our study identifies an important subgroup of patients at considerable risk of suicide in need of enhanced detection, focused prevention, and close follow-up, particularly around the time of cancer diagnosis.”

In a large-scale patient population study, investigators analyzed merged cause-of-death and suicide data from U.S. federal departments on 20,900 patients diagnosed from 2007 to 2013 with advanced lung cancer (stage IIIB or IV) enrolled in the VA Central Cancer Registry. Rates of suicide in the VA general population were compared with rates in the lung cancer cohort.

### OVERALL

- 88% (n = 18,412) of patients had lung cancer as cause of death; other causes included infection/hematologic malignancy (5%) and non-lung solid tumor (4%).
- 0.14% (n = 30) of deaths were attributed to suicide; of these, 93% resulted from firearms.
- Mean age was 67 years (± 8.6) for patients who died by suicide and 68 years (± 9.6) for all others.
- Median time from cancer diagnosis

*“Although long-term survival among patients with lung cancer is low, suicide is a potentially preventable cause of death.”*

— Sullivan et al,  
Annals of the American Thoracic Society

to suicide was 91 days (interquartile range, 53 to 166 days).

### KEY FINDINGS

- Receipt of palliative care was associated with an 81% lower risk of suicide (odds ratio [OR], 0.19; 95% confidence interval [CI], 0.08 to 0.47; *P* < 0.001) among patients with advanced lung cancer.
- Only 20% of patients with suicide as cause of death received palliative care compared with 57% of those with a different cause of death.
- The suicide rate among advanced lung cancer patients was 5.8 times higher than among all veterans of a similar age and gender using VA healthcare services (210.2 per 100,000 person-years vs 36.3 per 100,000 person-years).
- Those who died by suicide were more than six times more likely to be non-

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# NEWSLINE

## Effective Patient-Driven Advance Care Planning Tool Now Available in Both English and Spanish

An easy-to-read advance directive (AD) coupled with a patient-directed, interactive, online advance care planning (ACP) program called PREPARE For Your Care substantially increased ACP documentation and patient engagement, without the need for additional clinician-level or system-level interventions, according to a report published in *JAMA Internal Medicine*.

Tested previously among patients in a VA medical center, the interactive tool had been found to be effective and was deemed comfortable to use and helpful by the patients. In this larger study, conducted in a general population of English and Spanish speakers in a community outpatient setting, the PREPARE program improved both documentation of patients' medical preferences and patients' engagement in the process.

"To our knowledge, this is the largest, most culturally diverse trial of patient-facing advance care planning interventions," says lead author Rebecca Sudore, MD, professor of medicine at the University of California, San Francisco Division of Geriatrics.

"This is important because historically, advance care planning rates have been very low among Spanish-speaking and diverse populations. These results suggest we can empower patients to plan for their future medical care in very scalable ways."

Investigators analyzed results of a randomized clinical trial conducted from 2014 to 2017 among 986 patients aged 55 years or older with two or more chronic or serious illnesses who were receiving care at one of four safety net, primary care clinics in San Francisco. Participants were randomized to either the AD-only arm or the AD plus PREPARE arm. Because of the benefits of ACP, all participants in both study arms received ACP materials.

### OVERALL

- Mean age of participants was 63.3 years; nearly one-third were women.
- 45.1% were Spanish speakers.
- More than one-half (51.3%) of participants reported their health as fair to poor.
- 39.7% had limited health literacy.
- Only 10% had documentation of ACP in their health records in the prior 12 months.

Using lay language in video stories and workbook-formatted questions, the interactive PREPARE program guides users

through five planning steps for medical decision making, helping them to explore their wishes and learn how to discuss their preferences with loved ones and clinicians.

The values and wishes questions, when answered, generate an action plan unique to the user. The action plan includes a printable "Summary of Wishes" to keep and/or share, as well as links to PDF copies of legally binding ADs for nearly all states and the District of Columbia, all in both English and Spanish.

"Advance care planning is all about empowering patients to have a voice in their healthcare, to feel empowered to speak up about who they are as a person and what is most important in their life," says Sudore.

### KEY FINDINGS

- Participants in the PREPARE arm had a higher rate of ACP documentation at 15 months, either through legal forms or discussions documented in the medical record, compared with the AD-only arm (43.0% vs 32.0%;  $P < 0.001$ ).
- PREPARE participants also showed a greater increase over time in self-reported engagement in the ACP process than AD-only participants (98.1% vs 89.5%;  $P < 0.001$ ).
- Ratings for ease of use and satisfaction were similarly high in both arms, although PREPARE was reported as significantly more helpful than the AD alone.
- There were no reported adverse events or changes in anxiety or depression scores in either arm.

### COMMON BARRIERS TO ACP

Clinician and health system barriers to engagement in ACP include time constraints and lack of resources, note the authors. Patient barriers can include limited health literacy and limited proficiency in English, especially when legalese is used in ADs. Among minorities, ACP can be complicated by lack of trust caused by a perception of bigotry and differing cultural views on decision making and patient autonomy.

"What most excites us about this study is that we were able to break down barriers to advance care planning by providing easy-to-use resources that English- and Spanish-speaking older adults can use on their own," says Sudore, who is also a staff physician at the San Francisco Veterans Affairs Health Care System.

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# NEWSLINE

## Palliative Care Linked to Significant Reduction in Suicide Risk Among Veterans with Advanced Lung Cancer (from Page 1)

Hispanic white race than those who died of other causes (OR, 6.4; 95% CI, 1.53 to 26.9;  $P = 0.01$ ).

“Patients with lung cancer, particularly advanced stage, suffer from significant physical and psychological symptom burden attributable to their disease,” write the authors. “Palliative care offers an approach focused on reducing symptom burden and improving quality of life, which may influence suicide risk.”

### **RISK FACTORS FOR SUICIDE AMONG LUNG CANCER PATIENTS INCLUDE:**

- High symptom burden
- Low physical functioning
- Lack of social support
- Depression, which can sometimes be linked to suicidal ideation

“Suicide is a significant national public health problem, especially among lung cancer patients and among veterans,” says lead author Donald Sullivan, MD, assistant professor of medicine, Oregon Health and Science University, Portland.

The psychological impact of a cancer diagnosis, especially

a diagnosis of lung cancer, which can cause patients to feel stigmatized by having an illness often considered self-inflicted, can sometimes be overlooked, notes Sullivan. “As a result, manifestations of this impact — like social isolation, depression, and anxiety — can go undiagnosed and untreated.”

The current study was an exploratory analysis, Sullivan notes, but further research in the form of a randomized trial would require an extremely large population, due to the incidence of suicide, and would likely take years to complete.

“We really can’t afford to wait for more data,” Sullivan says. “I would like to see more efforts to screen and treat comorbid psychological illness among patients with lung cancer for which there is good evidence. I also believe more efforts are needed to integrate palliative care earlier in the lung cancer treatment paradigm.”

*Source: “Incidence of Suicide and Association with Palliative Care among Patients with Advanced Lung Cancer,” Annals of the American Thoracic Society; November 2018; 15(11):1357–1359. Sullivan DR, Forsberg CW, Golden SE, Ganzini L, Dobscha SK, Slatore CG; Oregon Health and Science University and Veterans Affairs Portland Health Care Systems, both in Portland, Oregon.*

## Advance Care Planning Tool (from Page 2)

“We were able to do this by co-creating materials with and for diverse patients and without the need for additional clinical or healthcare system input.”

The gains in ACP documentation observed in both this trial and the earlier one “are likely the result of a combination of novel health communication components of the patient-directed, interactive, online PREPARE program” with its theory-based content designed to enhance self-efficacy and readiness, notes Sudore.

### **THE PREPARE STEPS INCLUDE:**

- Choose a Medical Decision Maker
- Decide What Matters Most in Life
- Choose Flexibility for Your Decision Maker
- Tell Others about Your Wishes
- Ask Doctors the Right Questions

Each step includes succinct explanations for the reason this

step is important and suggestions for what the user should do and how to do it, including brief questions to elicit the user’s values or preferences, followed by tips on what needs to be said, to whom, and how to say it. For instance, in the section covering how to talk to one’s physician, patients are encouraged to ask about treatment risks, benefits, and alternative options, as well as “what your life will be like after starting treatment.”

The PREPARE tool can be accessed free of charge at: <https://prepareforyourcare.org>.

*Source: “Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial,” JAMA Internal Medicine; Epub ahead of print, October 29, 2018; DOI: 10.1001/jamainternmed.2018.4657. Sudore RL et al; Divisions of Geriatrics and General Internal Medicine, Department of Medicine; Departments of Epidemiology & Biostatistics and Psychiatry, University of California, San Francisco; Geriatrics, Palliative, and Extended Care, San Francisco Veterans Affairs Health Care System; Northern California Institute for Research and Education; Center for Vulnerable Populations, Zuckerberg San Francisco General Hospital, all in San Francisco.*

# RESEARCH MONITOR

## Seriously Ill Patients Receive Community-Based Palliative Care from Hospice Agencies Nationwide

Most hospice member organizations responding to a recent survey reported they are involved in either providing (53%) or preparing to provide (35%) palliative care for seriously ill patients in the community setting — as a service separate and distinct from their hospice line of service, according to a report from the National Hospice and Palliative Care Organization (NHPCO).

“As the seriously ill population grows exponentially, so does the need for community-based palliative care, and we know that our members are offering these needed services throughout the country,” says NHPCO president and CEO Edo Banach, JD.

To determine how the national organization might best support its members in developing, sustaining, and expanding their formalized palliative care programs, the NHPCO conducted its Palliative Care Needs Survey from June to July 2018, releasing the results in November. Responses concerning palliative care services were received from 347 members across 48 states.

### OVERALL

- 88% of respondents indicated involvement in community-based palliative care.
- More than one-half (53%) of facilities reported they currently provide palliative care, while 35% are in the process of developing a formal program.
- More than 70% of these palliative care programs have been in effect for three or more years.
- 63% of programs served 101 or more palliative care patients in 2017; 29% served 501 to 5,000 patients.
- The number of palliative care patients served by a single facility during 2017 ranged from a low of two to a high of 5,000. The mean number of palliative care patients served by a facility was 635.
- More than 85,153 seriously ill patients were served in 2017 by one of the NHPCO-member palliative care programs.

The model of palliative care delivered by their members' programs closely mirrors that of hospice, notes the report, although the focus is different, because patients can receive palliative care concurrently with curative care, for any length of time, and at any point in their illness trajectory.

Nevertheless, both models of care provide “holistic care provided to the patient and family by an interdisciplinary team supporting symptom and medication management, goals of care discussions, advance care planning, and care coordination.”

Most member programs providing palliative care reported their core team consisted of, at a minimum, a physician, nurse practitioner, and social worker. Teams often also included a chaplain and registered nurse. The majority of physicians (67%) were certified in palliative care, with 38.3% of nurse practitioners and 37.6% of registered nurses also having such certification.

### SERVICES PROVIDED BY CURRENT HOSPICE PROGRAMS INCLUDE:

- Goals of care discussions (86.3%)
- Symptom management (85.8%)
- Patient/family education (85.8%)
- Comprehensive assessment (81.4%)
- Advance care planning (83.1%)
- Care coordination and transition management (77.6%)
- Medication management (75.9%)

The primary locations for palliative care services provided by NHPCO members in 2017 were community-based, delivered in the patient's home, an assisted care facility, or long-term care facility. Other care settings included hospitals, clinics, and state-run veterans' homes.

The most frequently cited barrier by survey participants was lack of accurate understanding of palliative care, not only among patients and their families, but also among referring providers.

### TOOLS AND RESOURCES

The NHPCO is currently developing tools and resources to support its members' programs and to help them address challenges, with the goal of expanding access to community-based palliative care services nationally for seriously ill patients and their families.

The organization also strongly urges its members to familiarize themselves with the most recent edition of the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care. [See page 5.]

The NCP Guidelines are used by accrediting organizations, notes the NHPCO report, and provide structure to agencies delivering palliative care. However, more education on the importance and value of these guidelines may be needed, as the survey found that while most palliative care providers use the guidelines, 32% are uncertain about or unfamiliar with them.

The survey report is available at [www.nhpc.org](http://www.nhpc.org).

# RESEARCH MONITOR

## Updated National Clinical Guidelines Urge Palliative Care Delivery to All Seriously Ill Patients Across All Settings

Newly updated clinical guidelines for quality palliative care call for “a seismic shift in the delivery of this specialized care” by urging all healthcare professionals and organizations to integrate palliative care into the services they provide for all patients with serious illness, regardless of age, diagnosis, prognosis, or care setting.

“Patients of all ages, living in all areas of the country, have unmet care needs that cause a burden on families and the U.S. healthcare system,” states the document, released in October 2018 by the National Coalition for Hospice and Palliative Care (NCHPC). “Individuals who are seriously ill need care that is seamless across settings, can rapidly respond to needs and changes in health status, and is aligned with patient-family preferences and goals.”

Entitled “National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, 4th Edition” (NCP Guidelines), the guidelines were first published in 2004, with periodic updates as palliative care continued to grow and evolve. The latest edition has been endorsed by more than 80 major professional and health advocacy organizations.

The guidelines aim to promote greater access to high-quality palliative care by encouraging and guiding healthcare organizations and clinicians (including non-palliative care specialists) to integrate palliative care principles and best practices — based on evidence-based processes and consensus recommendations — into their routine assessment and care of their seriously ill patients.

“We realize it may be overwhelming for providers to offer palliative care if they haven’t previously,” says NCP steering committee co-chair Betty Ferrell, PhD, MA. “That’s why the guidelines provide extensive real-world practice examples to illustrate what quality palliative care can

and should look like in the community.”

### KEY FEATURES OF PALLIATIVE CARE

- Appropriate at any stage of serious illness, to be provided concurrently with curative/life-prolonging treatments
- Provided based on need, not prognosis
- Offered in all care settings
- Focused on what the patient and family/caregiver deem most important and on providing relief from the symptoms and stress of serious illness
- Holistic in nature, delivered by a multidisciplinary team at the specialist level

The guidelines are presented in an arrangement of eight domains. How best to apply these guidelines is open to healthcare organizations and practices to decide, based on their patient populations and care settings. Palliative care is “not setting-specific;” it is available “across and between care settings,” notes NCP.

### EIGHT KEY DOMAINS OF PALLIATIVE CARE

- Structure and processes of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care
- Spiritual, religious, and existential aspects of care
- Cultural aspects of care
- Care of patients nearing the end of life
- Ethical and legal aspects of care

Each domain is organized into guideline criteria for each of the many outlined elements, plus sections describing clinical implications and necessary skills, as well as several practice examples of how palliative care programs were developed and/or integrated into settings such as a home-based primary care practice, a small

rural hospital, or a community hospice. An appendix offers a list of tools and resources for each palliative care domain.

### DOMAIN SECTIONS INCLUDE:

- Guideline Criteria
- Clinical and Operational Implications
- Essential Palliative Care Skills Needed by All Clinicians
- Key Research Evidence
- Practice Examples

The 4th edition has been expanded to include five new themes that have been added, according to their relevance, to the eight key domains.

### THESE NEW THEMES INCLUDE:

- **Comprehensive assessment:** Descriptions of the elements of a comprehensive assessment to determine needs and priority goals
- **Family needs:** Discussion of assessment of support and education needs of families and caregivers
- **Coordination:** Emphasis on the essential role of care coordination, especially during care transitions
- **Cultural awareness:** Expansion of culturally inclusive care as part of each domain
- **Communication:** Emphasis on communication — both within the care team and family unit as well as with other clinicians and providers of community resources — as a prerequisite of quality care

Other changes from previous editions include an emphasis on community-based resources and providers, greater attention to anticipatory as well as post-death grief, and greater emphasis on continuity of palliative care during ongoing care,

*Continued on Page 6*

# RESEARCH MONITOR

## Younger Thoracic Oncologists Refer Patients to Outpatient Palliative Care More Often and Earlier

Approximately one-quarter of patients with advanced thoracic cancer received outpatient referrals to palliative care at a large cancer center, with wide, oncologist-level variation in the pattern of referral. Those oncologists with a higher proportion of referrals were more likely to be younger than their peers and to refer patients earlier in the disease course, according to a report published in *The Oncologist*.

“[O]ncologist age was independently associated with higher rates of outpatient palliative care referral after adjusting for established patient-related variables,” write the authors. “Our preliminary findings highlight the role that oncologists have in facilitating timely palliative care access and potential strategies to improve referral through clinician education and standardized care pathways.”

Investigators analyzed data on 1,642 consecutive adult patients (median age, 65 years) with advanced thoracic malignancies (defined as advanced, metastatic, or recurrent lung cancer or mesothelioma) cared for at the University of Texas MD Anderson Cancer Center in Houston from 2007 to 2012. Patients were followed by the institution throughout the entire dis-

ease trajectory until their deaths.

Thoracic medical oncologists in the study (n = 26) were classified into two groups, using median frequency of referral as a cutoff: high-referring oncologists (median proportion of referral, 37%) and low-referring oncologists (median proportion of referral, 24%). Outpatient rather than inpatient palliative care referral was studied “because this is the only setting to facilitate timely referral,” note the authors.

“Among the different branches of palliative care services, outpatient clinics are essential to facilitate timely access and are associated with better outcomes than inpatient palliative care,” the authors report, referencing findings from their previous research.

### OVERALL

- 27% of decedents had an outpatient palliative care referral; 29% had an inpatient referral; and 44% had no referral before death.
- 85% of patients were diagnosed with non-small cell lung cancer.
- 46% were female.
- 70% were of non-Hispanic white race; 17% were black.

- Median time from initial oncology consult to death was 318 days.

### KEY FINDINGS

- The proportion of patients referred per oncologist varied widely, ranging from 9% to 45%; median referral rate was 30%.
- High-referring oncologists were significantly younger than low-referring oncologists (aged 45 years vs 56 years).
- High referrers were also significantly more likely to refer patients earlier (median interval from oncology consult to palliative care consult, 90 days vs 170 days), and to refer those patients without metastatic disease (7% vs 2%).

“The findings highlight the role of education to standardize palliative care access and imply that outpatient palliative care referral is likely to continue to increase with a shifting oncology workforce,” the authors conclude.

Source: “Pattern and Predictors of Outpatient Palliative Care Referral Among Thoracic Medical Oncologists,” *The Oncologist*; October 2018; 23(10):1230–1235. Hui D, Bruera E, et al; Department of Palliative Care, Rehabilitation and Integrative Medicine, University of Texas MD Anderson Cancer Center, Houston.

## Updated National Clinical Guidelines (from Page 5)

whether or not the patient is followed by a specialist-level care team.

While palliative care has been traditionally provided by specially trained interdisciplinary teams, patient access to such specialized care is not always available. Thus, “reliable access to palliative care in community-based settings is essential,” state the guidelines. The NCP encourages all healthcare professionals caring for patients with serious illness to incorporate

these palliative care principles and best practices into their routine care provision.

Therefore, the guidelines are intended to assist not only specialty palliative care and hospice practitioners and teams, but much more broadly, primary care and specialist physician practices, health systems, cancer centers, dialysis units, long-term care and assisted living facilities, Veterans Health Administration providers, home health and hospice agencies, prisons, and other

care providers.

Members of the NCHPC include the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, and the National Hospice and Palliative Care Organization.

A copy of the NCP Guidelines is available at <http://www.nationalcoalitionhpc.org/ncp>.

# CLINICIAN RESOURCES

## New Tool Helps Lawyers, Physicians Align Advance Directives with Patients' Clinical and Family Realities

A free online tool released by the American Bar Association (ABA) is designed to help lawyers, physicians, and other healthcare professionals understand and effectively communicate the medical care preferences of their clients/patients with serious illness as they navigate the advance care planning (ACP) process.

The 11-page guide, entitled "Advance Directives: Counseling Guide for Lawyers," urges greater coordination of ACP efforts between lawyers and medical providers, and is the collaborative work of a multidisciplinary group of experts from the ABA Commission on Law and Aging, the American Academy of Hospice and Palliative Medicine, and others.

Studies have shown that people discuss creating advance directives (ADs) with both their physicians and their lawyers, notes the ABA. "However, the two professions see the planning through a different lens. The guide provides guidance that allows lawyers to craft advance care directives that align with the clinical realities of family situations that clients may face."

### INCLUDED IN THE GUIDE

- **Description of eight principles of ACP:** Two principles covered are the importance of approaching ACP as an ongoing process that occurs over time through all stages of health and illness, as well as the importance of seeking to identify a person's values and wishes through "reflection, discussion, and communication." When a patient has a serious illness, the guide recommends, "For advanced illness, medical providers should consider introducing palliative care options, and the option of providing medical orders such as Physician's Orders for Life Sustaining Treatment (POLST) to ensure the individual's wishes are translated by medical professionals into actionable medical orders."
- **Step-wise checklist for lawyers:** The checklist prepares lawyers for the first meeting and the discussion on how to choose a proxy. It also helps lawyers talk with their clients about why ACP is important; encourage individuals with serious, progressive illness to discuss medical orders with their physicians; and advise their clients what to do after the AD is signed.
- **Sample cover letter:** The cover letter will accompany the completed AD when it is forwarded to the patient's primary care and other key physicians, who are encouraged to review the AD with the patient, address any unclear or unresolved medical options, and enter the directive into the medical record.
- **ACP resource list:** Resources include website links to free planning tools and palliative care information for patients, their families, and proxies, as well as guides to holding ACP discussions for law and healthcare professionals.
- **Sidebar tips:** Tips provide further insights, such as the AD "is only as strong as the thought and discussion it is based on," and caution against generating an overly long AD, because "clinical experience suggests that the longer it is, the less likely it will be consulted."

A PDF of the guide is available free of charge at [www.americanbar.org/content/dam/aba/administrative/law\\_aging/lawyers-ad-counseling-guide.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/lawyers-ad-counseling-guide.pdf).

## End-of-Life Care Websites

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

American Hospice Foundation  
[www.americanhospice.org](http://www.americanhospice.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.epec.net](http://www.epec.net)

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.nhpc.org](http://www.nhpc.org)

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

Promoting Excellence in End-of-Life Care  
[www.promotingexcellence.org](http://www.promotingexcellence.org)

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