Research Priorities in Subspecialty Palliative Care: Policy Initiatives

Lynn F. Reinke, PhD, ARNP^{1,2} and Diane E. Meier, MD³

Abstract

Palliative care demonstrably improves quality of life for the seriously ill in a manner that averts preventable health crises and their associated costs. Because of these outcomes, palliative care is now broadening its reach beyond hospitals, and hospice care for those near death, to patients and their families living in the community with chronic multimorbidities that have uncertain or long expected survival. In this article, we address research needed to enable policies supportive of palliative care access and quality, including changes in regulatory, accreditation, financing, and training approaches in the purview of policy makers. Mr. K. is an 86-year-old male with multimorbidities, including severe chronic obstructive pulmonary disease, congestive heart failure, peripheral vascular disease, and atrial fibrillation requiring anticoagulation therapy. He fell in his mobile home and was unable to reach the telephone to call for help. Six hours later, his neighbor found him lying on the bedroom floor in pain and confused, and called 911. On examination, he was found to have a cold blue foot complicated by a large hematoma. The vascular surgery service was consulted to evaluate Mr. K. for revascularization or amputation. Although Mr. K. had several risk factors complicating his candidacy for general anesthesia, the team thought the benefits of surgery would outweigh the risks. Mr. K's daughter agreed to surgery telling her father "the doctors know best." Mr. K. replied "I just want to be out of pain." Six months later, Mr. K. remains in a skilled nursing facility due to post-op complications, including pneumonia, worsened confusion, and the inability to recover to enough function to live safely at home. He now suffers from depression, cognitive deficits, and social isolation. His daughter has had to take on a second job because she is struggling to pay for his continued long-term care, which costs \$6000 per month. Money she had saved for her own retirement and her daughter's college tuition is already gone. In retrospect, she realizes the surgical team did not discuss the possibility of his survival with chronic debility and long-term functional dependency, nor the fact that Medicare would not pay for the care he now requires.

Keywords: chronic conditions; critical care; goals of care; palliative care research; subspecialty palliative care

Introduction

THERE IS A DRAMATIC INCREASE in the number of patients living with serious or complex medical illness defined as a condition that carries a high mortality risk, adversely impacts quality of life and function, and/or is burdensome in symptoms, treatments, or caregiver stress (e.g., dementia, frailty, chronic obstructive pulmonary disease [COPD], end-stage renal disease [ESRD], heart failure, and multimorbidity).¹ The Department of Health and Human Services (DHHS) reports that more than 25% of individuals in the United States have multiple chronic conditions, and the care of these individuals accounts for 66% of total healthcare

spending.² Patients with multiple chronic illnesses combined with functional impairments account for even higher costs to the healthcare system.³ Heart failure, for example, is a chronic, progressive illness marked by acute, potentially life-threatening deteriorations superimposed on gradual functional decline.⁴ These deteriorations increase the risk of hospital admission and intensive treatment.^{5–7} Nearly 80% of patients hospitalized with advanced heart failure are older than 65 years and Medicare costs exceed \$32 billion/year, more than any other diagnosis.⁸ Similarly, COPD is the third most prevalent disease in the United States, the leading cause of respiratory-related deaths, and the fourth leading cause of mortality globally.⁹

¹Department of Veterans Affairs, Puget Sound Health Care System, Health Services R&D, Seattle, Washington.

²Department of Biobehavioral Nursing and Health Informatics, School of Nursing, University of Washington, Seattle, Washington.

³Department of Geriatrics and Palliative Medicine, Center to Advance Palliative Care, Icahn School of Medicine at Mount Sinai, New York, New York.

Existing and Proposed Payment Models

Traditional fee for service (FFS) models base payments to hospitals and providers on high volume services delivered to patients, with no link to quality or efficiency. The time-intensive assessments, goals of care discussions, and care coordination required to deliver high-quality palliative care to patients with complex medical problems are not supportable under FFS. Risk-bearing entities, including not only health insurance plans but also Accountable Care Organizations (ACOs), health systems, hospitals, and providers, are demonstrating an increasing interest in improving access of palliative care, given its impact on both the numerator and the denominator of the value equation. The Medicare Access and CHIP Reauthorization Act (MACRA) is one example of value-based payment that provides an incentive for clinicians to match care provided to the actual needs of patients with serious illness.¹⁰ Table 1 provides examples of existing and proposed payment models relevant to palliative care.

While the field of palliative care continues to build an evidence base for improving quality of care and quality of life for patients with serious or complex medical illness and their families,¹¹ the majority of research has focused on testing interventions for patients with cancer and in limited settings (hospital, hospice, and oncology clinics). If the needs of a growing population of older adults with serious or complex medical illness and their families are to be addressed, research focusing on the development of new models of care delivery, appropriate interdisciplinary staffing for these models, and processes and outcomes for care delivery in these models needs to be undertaken. In prior articles in this series, we addressed the specific research priorities for individual diseases and conditions. In this article, we take a slightly broader view by examining what research is needed to build better models of care delivery for these conditions that align with new and proposed payment models. In each section, we outline the current state of the evidence, define research gaps, propose a needed research agenda, and describe how the proposed work aligns with existing payment systems and where it does not, suggest needed policy changes.

Summary of the Current Evidence, Research Gaps, and Recommendations for New Directions

Multiple professional societies endorse integrating palliative care into subspecialty services.^{7,10,12,13} The National Academy of Medicine affirms the need to improve the quality of care and honor preferences of individuals during serious illness.³ In 2014, The World Health Organization called for palliative care to be integrated into health services as an essential component of the care continuum.¹⁴ Despite these recommendations, at present, palliative care in the United States remains accessible mostly in hospitals or as hospice care for those who are dying. Access to palliative care for the much larger number of individuals with acute or chronic serious illnesses who are neither hospitalized nor dying is poor.

Critical illnesses

Research on palliative care interventions in the ICU has been a focus for well over a decade. Examples of targeted

interventions include testing triggered palliative care consults,¹⁵ using a brochure to educate and reduce symptoms of depression and Post Traumatic Stress Disorder (PTSD) for family members of critically ill patients,¹⁶ and educating ICU clinicians on how to conduct family conferences.¹⁷ Recent systematic and narrative reviews examining palliative care interventions in critical care settings conclude that the interventions reduce ICU length of stay and treatment intensity with mixed evidence on its effect on family emotional outcomes.^{18,19} However, the patient populations and interventions examined, as well as fidelity of implementation are highly heterogeneous, making broad effectiveness statements challenging. Research gaps include identifying which critically ill patients and families are most likely to benefit from proactive, ICU-based palliative care; which ICU-based palliative care models are most effective in what types of ICU structure or culture; how to identify high-risk patients and families of having unmet palliative care needs; what components of palliative care are most important for improving patient and family outcomes; and what outcomes are the most valid in determining effectiveness of ICU-based palliative care interventions. Testing palliative care interventions in ICUs that are sustainable, reproducible, and scalable is critical to demonstrate the value of palliative care. These research priorities align with current and proposed payment models, including MACRA, Care Coordination Fee, and Center for Medicare and Medicaid (CMS) Conditions of Participation. The Palliative Care and Hospice Education and Training Act (PCHETA) is proposed legislation that would provide funding for Graduate Medical and Nursing programs aimed to train healthcare professionals in palliative care. Given the interdisciplinary nature of ICU care delivery, PCHETA would facilitate accomplishment of the identified research priorities.

Pulmonary diseases

Few studies have specifically examined the benefits of palliative care for patients with COPD, although several studies include patients with multimorbidities, including COPD. Interventions vary from targeted symptom management,²⁰ home-based programs,²¹ improving clinicians' communication about goals of care and end of life care,²² and advance care planning.²³ Despite the heterogeneity of these interventions, findings support the integration of palliative and pulmonary care for patients and their caregivers for improving symptom burden and quality of life and reducing healthcare utilization.^{20,21,24,25} Models of care that hold hope for replication include an integrated respiratory care service for patients with advanced lung disease,²⁰ a home-based program targeted to improving patient and caregivers' confidence to manage symptoms, including dyspnea crises from COPD at home,^{21,26} and an advance care planning program to reduce unwanted intensive care and improve family satisfaction. These cited models of care are outside the United States, highlighting the differences among international palliative care strategies and payment systems. Research gaps for patients with pulmonary diseases include identifying the most effective and cost-effective pharmacological and non-pharmacological interventions to reduce symptoms, including dyspnea crisis, and improve quality of life; demonstrating the value and mechanism for early integration of palliative

TABLE 1. EXAMPLES OF EXISTING AND PROPOSED PAYMENT MODELS

<i>Existing payment models</i>	<i>Elements covered</i>	<i>How elements are/would be paid</i>	<i>Advantages/disadvantages for palliative care</i>
FFS	Payments based on volume, for example, procedures, hospitalization.	Based on current procedural terminology (CPT) or diagnosis-related group (DRG) codes, payment directly to hospital or provider	Disadvantage—no link to quality or value. Unbillable interdisciplinary team services
Medicare Access and CHIP Reauthorization Act (MACRA)	Payment based on value and provider incentive programs.	Reimburses Medicare B providers based on domains of quality, spending, performance improvement, and health IT.	Advantage—focuses on improving quality-of-care delivery and reducing costs (proven outcomes of palliative care.)
Medicare advantage plans	Part A and B + dental, hearing aid coverage, drugs discounts, care management programs.	Plans receive monthly payment from CMS, may incur loss if total cost exceeds the total premium.	Advantage—covers items and plans promoting health and wellness. Disadvantage—access to a narrower network of providers/hospitals in network. May exclude specific palliative care providers.
Care Coordination Fee	Activities supporting information sharing and patient decision making.	Practices/providers receive additional fixed fees to create and coordinate care plans.	Advantage—funds time for assessment and discussions with patients and family. Disadvantage—all nonbillable expenses may not be covered.
CMS Conditions of Participation	Specific conditions healthcare organizations must meet to receive reimbursement from CMS.	Facilities, for example, hospices, dialysis centers, nursing homes are reimbursed for care by CMS if standards of care are met.	Advantage—improves quality, protects health, and safety of patients. Potential for reproducible in-home palliative care programs or for specific serious illnesses, for example, advance care planning (ACP) before high-risk surgery for frail elderly patients
Proposed models CMMI—Oncology Care Model	Focuses on patient and family communication and outcomes.	In addition to usual services, practices receive a performance-based monthly enhanced fee for the duration of treatment.	Advantage—incentivizes partnership with palliative care. Processes may help avoid unnecessary emergency department (ED) visits and hospital admissions. Potential to be replicated in other subspecialties. For example, pulmonary clinics
Chronic Care Act 2017 Passed by Senate Finance Committee, May 2017.	Long-term supportive services and management of patients with 2≥ chronic care.	If passed CMS would devise incentives and standards for documenting treatment preferences and goals.	Advantage—aligns with palliative care domains.
Care Planning Act 2017	Promotes advanced illness planning and coordination.	If passed CMS would identify high-quality measures and revise requirements for advanced directives and portable treatment orders.	Advantage—tests innovative payment and service delivery models for the uptake of palliative care services.
PCHETA	Graduate Medical and Nursing education.	If passed provides grant funding for palliative care training programs for physicians, nurses and other professionals	Advantage—increases workforce and enables research agenda to be accomplished by training clinicians on palliative care topics.

CMMI, Center for Medicare and Medicaid Innovation; CMS, Center for Medicare and Medicaid; FFS, fee for service; MACRA, Medicare Access and CHIP Reauthorization Act; PCHETA, Palliative Care and Hospice Education and Training Act.

care; developing valid and responsive person-centered outcome measures; and effective implementation of advance care planning and goals of care discussions. These research priorities align with alternative payment models, including MACRA, Medicare Advantage Plans, Care Coordination Fee, and replication of Center for Medicare and Medicaid Innovations Oncology Care Model into pulmonary practices. Proposed legislation such as the Chronic Care Act of 2017 and the Care Planning Act will improve documentation of patients' treatment preferences and goals by incentivizing providers to engage in high-quality palliative care activities.

Heart failure

Clinical models integrating palliative and heart failure care exist in several hospital systems in the United States. Nurse-led heart failure programs are an example of a successful clinical model. The Nurse Practitioner bridges the gap between inpatient and outpatient services helping patients to avoid readmissions.^{27,28} Another clinical model is automatic palliative care consults for patients being evaluated for ventricular assistive devices.²⁹ Unfortunately, these clinical models have not been well tested and those that have demonstrated effectiveness and improvement in patient care have not been able to demonstrate exactly which elements of palliative care relate to better outcomes. A recent systematic review characterized interventions and effectiveness of palliative care for advanced heart failure patients.³⁰ Evidence suggests that home- and team-based palliative interventions improve patient-centered outcomes, documentation of preferences, and utilization, including emergency and urgent care visits, length of stay, and intensive care admissions. Research gaps for the heart failure population include the lack of data about symptoms and effective treatments; insufficient data about the needs of family caregivers and ways to support them; the effectiveness of shared decision making and methods to improve advance care planning; and identifying which models of palliative care delivery are the most efficacious and which elements can be exported. These research priorities align with several current and proposed alternative payment models, including MACRA, Medicare Advantage Plans, and the Care Coordination Fee Program. Proposed policy initiatives from the National Academy of Medicine calls for creating a multiagency research program to evaluate caregiver interventions in real-world healthcare and community settings across diverse outcomes.³¹

Chronic kidney disease

There are few studies of palliative care interventions in the chronic kidney disease chronic (CKD) population.^{32,33} These studies tested specific palliative care elements such as advance care planning or symptom management. Findings suggest that ACP and other supportive care can be delivered in the dialysis center setting by trained staff or peer mentors and improve a range of psychosocial outcomes for patients and their caregivers, including family bereavement outcomes. However, there are no reports of delivery of comprehensive, coordinated care services embedded into dialysis centers. Research gaps for older adults with CKD include identifying what matters most to patients and their caregivers at the end of life; determining how the nephrology commu-

nity best helps patients and their caregivers navigate complex treatment decisions throughout their illness trajectories; and testing methods of reconfiguring the healthcare system to promote patient- and family-centered care. These research priorities align with the several payment models such as CMS Conditions of Participation, which could require providers to conduct advanced care planning discussions before initiation of dialysis. One example of a current CMS payment and service delivery model is the Comprehensive ESRD Care (CEC) Model, intended to provide more patient-centered care³⁴ compared to the current model of prospective payment that bundles services such as laboratories, drugs, and equipment.³⁵ Person-centered quality measures aligning with palliative care domains in the CEC Model include quality of life, clinician communication and caring, and the provision of patient information. This model encourages dialysis centers and providers to work together in an ESRD Seamless Care Organization, to receive shared savings payments and accept shared risk for losses. Pilot data suggest that the rates of advance directive completion could be increased as part of the payment model, although the effect on care near the end of life is unknown.

Surgery

A systematic review of the literature from 1994 to 2014 revealed that only 25 studies focused on palliative care interventions for surgical patients.³⁶ These studies suggest that palliative care interventions may reduce healthcare utilization and improve advance care planning without increasing mortality for older patients undergoing elective surgery. Frailty screening is one example of an intervention that predicts post-op complications, length of stay, discharge to a skilled nursing facility, and mortality.^{37,38} Assessing frailty can help patients and clinicians make informed decisions, including not to perform surgery on high-risk elderly patients and ensuring pre- and post-op supportive care for those who do undergo surgery. Specific research gaps for elderly surgical patients include communication, such as preoperative advance care planning and postoperative decision making, to ensure treatments are aligned with patient-oriented outcomes; identifying patient-centered outcomes that are of value to patients; evaluating high-quality palliative care in surgery; and testing methods to integrate palliative care into a rescue-oriented surgical culture. These research priorities align with current and proposed payment models such as MACRA, CMS Conditions of Participation, and the Care Coordination Fee. Proposed legislation such as the Chronic Care Act of 2017 would provide additional long-term support services for this fragile patient population.

Table 2 presents research priorities aimed at supporting national policy initiatives that will address the unmet needs of patients with acute and chronic serious illnesses and their caregivers.

Settings

Hospital

Most hospitals with more than 50 beds have a palliative care program.³⁹⁻⁴¹ As of 2014, over 90% of the nation's largest hospitals, those accounting for over half of all admissions, have palliative care programs. Yet large variations

TABLE 2. RECOMMENDATIONS FOR RESEARCH PRIORITIES

<i>Research priority</i>	<i>Study objective</i>	<i>Range of settings</i>	<i>Sample</i>	<i>Study design</i>	<i>Policy initiatives</i>
• Development and evaluation of new palliative care delivery models for subspecialty services	<ul style="list-style-type: none"> • Integrate palliative care principles into subspecialty practices and cultures • Determine the best palliative care model fit for different subspecialties, for example, trigger consults, embedded, primary PC, nurse led • Determine the effectiveness of early versus late palliative care 	<ul style="list-style-type: none"> • Academic and community hospitals, outpatient clinics, home care programs, nursing homes, office practices 	<ul style="list-style-type: none"> • Large • Serious and critically ill patients and their family members. Diagnoses: COPD, HF, CKD, high-risk surgical patients, patients in ICU • Patients newly diagnosed with COPD, HF, CKD, or other serious chronic diseases 	<ul style="list-style-type: none"> • Randomized trials, quasi-experimental designs, Comparative Effectiveness Research, Implementation studies, policy analysis • Prospective and retrospective cohort studies, randomized trials, quasi-experimental studies 	Congress: Care Planning Act of 2017, GME reform, PCHETA Funders: PCORI, NIH, AHRQ, CMMI
• Determination of effective and cost-effective specific palliative care interventions	<ul style="list-style-type: none"> • Evaluate interventions to decrease symptom burden and improve quality of life • Identify the most effective components of multifaceted interventions • Improve communication and decision making among patients, families, and team members to reduce conflict and ensure goal concordant care. 	<ul style="list-style-type: none"> • Academic and community hospitals, outpatient clinics, home care programs, nursing homes, office practices 	<ul style="list-style-type: none"> • Large • Serious and critically ill patients, and their family caregivers. Diagnoses: COPD, HF, CKD, high-risk surgical patients, patients in ICU 	<ul style="list-style-type: none"> • Randomized trials, including patient and cluster randomization and cluster randomization; innovative experimental designs, economic modeling, policy analysis • Qualitative and mixed methods studies running parallel to intervention studies. Cohort studies • Comparative Effectiveness Research, randomized trials, cluster randomized trials, pragmatic trials 	Congress: Care Planning Act of 2017, The CHRONIC Care Act of 2017, GME reform, PCHETA Funders: PCORI, NIH, AHRQ, CMMI
• Development and validation of patient- and family-centered outcomes	<ul style="list-style-type: none"> • Validate palliative care outcomes that are of <i>value</i> and that <i>matter</i> to patients and families 	<ul style="list-style-type: none"> • Academic and community hospitals, outpatient clinics, home care programs, nursing homes, office practices 	<ul style="list-style-type: none"> • Large • Serious and critically ill patients and their family members. Diagnoses: COPD, HF, CKD, high-risk surgical patients, patients in ICU • Medium • Caregivers of patients with advanced chronic illnesses, for example, COPD, HF, CKD 	<ul style="list-style-type: none"> • Psychometric research, longitudinal descriptive studies, prospective and retrospective cohort studies, randomized trials, quasi-experimental studies 	Congress: CHRONIC Care Act of 2017 Funders: PCORI, NIH, AHRQ, CMMI
• Determination of Caregiver needs	<ul style="list-style-type: none"> • To create interventions to improve caregiver burden and distress 	<ul style="list-style-type: none"> • Inpatient and outpatient settings, home care programs 	<ul style="list-style-type: none"> • Medium • Caregivers of patients with advanced chronic illnesses, for example, COPD, HF, CKD 	<ul style="list-style-type: none"> • Cohort studies, qualitative and mixed methods studies 	Congress: CHRONIC Care Act of 2017 Funders: PCORI, NIH, AHRQ, CMMI

AHRQ, Agency for Healthcare Research and Quality; CKD, Chronic Kidney Disease; CMS, Center for Medicare Services; CMMI, Centers of Medicare and Medicaid Innovation; COPD, Chronic Obstructive Pulmonary Disease; GME, Graduate Medical Education; HF, Heart Failure; ICU, Intensive Care Unit; NIH, National Institutes of Health; PCHETA, Palliative Care and Hospice Education and Training Act; PCORI, Patient-Centered Outcomes Research Initiatives.

by state and hospital type remain. One-third of U.S. hospitals report no palliative care services. Even when palliative care programs are available in a hospital, it does not necessarily mean that seriously ill patients needing palliative care actually receive these services. As a result, most people with serious illness are unlikely to receive the care they need throughout their course of illness. Making palliative care available to the seriously ill is perhaps the single largest opportunity to improve value in the U.S. healthcare system.

Hospice

Among care settings, the best access to palliative care occurs in hospice. Access is high (46% of all decedents receive some hospice care), but the median length of stay (LOS) is only 17 days, and most hospice beneficiaries undergo extensive and repeated subspecialty and hospital care until very late in their disease course. In 2014, 36% of patients died or were discharged within 7 days of admission to hospice.⁴²

Home

In recent years, there has been a significant growth in the number of community-based palliative care programs due to evidence of programs improving patient satisfaction, improving symptom control and quality of life, and reducing healthcare utilization.⁴³ The growth of such programs continues to be driven, in part, by the healthcare needs of an aging population, the growing numbers of individuals with multiple complex chronic conditions or serious illness in need of comprehensive care in a cost-effective manner, and service gaps for those ineligible for hospice care or not in need of hospitalization.⁴⁴ A recent study examining the impact of a home-based palliative care program within an ACO was associated with significant reductions in total Medicare cost, fewer hospital admissions, and an increase in hospice utilization in the final months of life. This model is successful because of a unique opportunity within an ACO where high-value care, rather than care intensity, is financially rewarded.⁴⁵

Many organizations that have traditionally provided home health or hospice services are now developing comprehensive, community-based serious illness care programs, for example, Transitions Advanced Illness Management Program, Sharp Healthcare, San Diego, CA.⁴⁶ The program provides home care for patients with advanced chronic illnesses such as heart failure, COPD, neurological diseases, or a decline in functional or nutritional status due to illness. Transitions partnered with the County of San Diego, HHS Agency, Area Agency on Aging, and others receiving state and federal funding to implement a Care Transitions Intervention aimed to improve patients with chronic health conditions, to improve medication management, knowledge of “red flags,” and follow-up care with clinicians. The pilot program reduced readmission rates at 30, 60, and 90 days.⁴⁷ Collectively, evidence supports the ongoing expansion of innovative outpatient palliative care service models throughout the care continuum to all patients with serious illness.

Office practices

Palliative care providers are expanding their programs into outpatient or medical group clinics. Many of these programs are associated with medical oncology practices,^{48–50} for example, the Comprehensive Assessment with Rapid Evalua-

tion and Treatment (CARE Track) program in Virginia.⁵¹ Data on the prevalence of office practices integrating palliative care and the degree to which they are adherent to consensus guidelines for quality are needed.

Nursing homes

There is growing recognition of the value of palliative care on improving quality and reducing costs for complex patients with a range of diagnoses residing in nursing homes.⁵² Miller et al. found palliative care consultations, primarily delivered by nurse practitioners, improved end-of life nursing home care by reducing hospitalizations.⁵³ The National Consensus Project Guidelines for Quality Palliative Care⁵⁴ aim to promote consistent care and guide the development and structure of existing and new palliative care services in U.S. Nursing Homes. However, there is limited availability of palliative care programs in nursing homes and when they do exist, the services provision is variable.⁵⁵ One example of an innovative nursing home model funded by CMS is Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC).⁵⁶ This program aims to reduce avoidable hospitalizations of long-stay residents enrolled in nursing facilities in seven states using a registered nurse to implement an evidence-based quality improvement program with clinical support from nurse practitioners.⁵⁷ Early results based on the 2015 data indicate evidence of intervention effects on reducing hospitalizations, ED visits, and related Medicare expenditures in most of the seven Initiative states.⁵⁸ These findings support the benefits of palliative care and the need for expanding research into the nursing home setting.

Patients with acute and chronic serious illnesses represent a high-need, high-cost group with unmet palliative care needs. Palliative care principles such as symptom management, early and ongoing goals of care discussions, continuity and coordination of care, and support for family and caregivers are high-value components of care that improve quality of life. Investment in research beyond the 0.2% of the National Institute of Health budget that is currently being devoted to palliative care will be needed to accomplish the research priorities identified by the National Institute on Aging-National Palliative Care Research Center (NIA-NPCRC) working group. A new roadmap for research funding should be developed in concert with and guide a national strategy for palliative care. This strategic plan should be led by the government and supported by payers and regulators, and include defined structures and processes for palliative care programs, reimbursement schedules, quality and access standards, and healthcare education based upon a strong evidence base. Specifically, immediate and substantial investment in research are needed to guide the development of the new strategy, with interim results and outcomes continually guiding program development. A strategic plan will guide all aspects of palliative care resulting in concerted efforts to advance the field and help reconfigure the healthcare system based on high-value care delivery for the seriously ill with highest need and highest cost.

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Address correspondence to:
 Lynn F. Reinke, PhD, ARNP
 Investigator/Nurse Practitioner
 Health Services R&D
 VA Puget Sound Health Care System
 1660 S. Columbian Way
 Seattle, WA 98108
 E-mail: reinkl@uw.edu