

Research Priorities in Geriatric Palliative Care: Policy Initiatives

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Abstract

Coordinated palliative care matched to patient needs improves quality of care for vulnerable patients with serious illness and reduces costly use of hospitals and emergency departments. Unfortunately, there is a disconnect in translating geriatric palliative care models and principles into policy and widespread practice. Gaps in policy-relevant research are addressed, including implementation strategies to scale up existing care models, the role of palliative care and geriatrics in health care payment reform efforts, development of quality measures for complex patients, strategies to address workforce shortages, and an approach to hospice reform.

"I told the doctor that I never wanted to go back to the hospital again. It's torture—you have no control and can't do anything for yourself. And you get weaker and sicker. Every time I'm in the hospital it feels like I'll never get out." This 88-year-old man with mild dementia presents to the emergency department for management of back pain due to spinal stenosis and arthritis. He had been admitted to the hospital four times in the past six months—twice for pain, once for weight loss and falls, and once for altered mental status due to constipation. His overwhelmed 83-year-old wife tells the emergency department physician, "He hates being in the hospital, but what could I do? The pain was terrible and I couldn't reach the doctor. I couldn't even move him myself, so I called the ambulance. It was the only thing I could do."

THE FIELDS OF PALLIATIVE CARE AND GERIATRICS have developed a growing body of evidence in support of customized care models aimed at meeting the needs of frail, vulnerable, and seriously ill patient populations. The problem is not that we don't know what to do—the problem is that we don't do what we know. The business of translating evidence into real-world practice for frail older adults is critically dependent on changes in public and payment policy. As in any aspect of health care, gaps do remain in our understanding of treatments and the optimal approach to delivering services to vulnerable populations. Allocation of research dollars to address these questions is an urgent public health priority. Health care spending in the United States not only fails to deliver quality but quite realistically poses the greatest threat to the American economy and way of life—the 18% of GDP in dollars spent on high cost, low value health care cannot be allocated to other crucial public needs: education, repair of roads and bridges, food and air quality and safety, and protection from

the consequences of rising income inequality and poverty. The good news here is that improving quality of care for high risk, vulnerable patients—so that the patient described above does not have to turn to the emergency department for every symptom crisis, but instead receives coordinated palliative care matched to his changing needs at home—leads to much lower need for spending in emergency departments and hospitals. It is critical that federal, state, and local regulatory and payment policies evolve to support the delivery of high quality palliative care to a growing elderly population who often live for many years with the burden of serious, chronic illnesses.

Outline of the Scope of the Problem

Health care costs are concentrated on the 5% to 10% of the population with serious illnesses.¹ People who have both multiple chronic medical conditions and functional impairments are particularly high cost to the health care system.² Multiple studies have also documented high costs near the end of life.^{3–5} Recent research found that half of older Americans visited the emergency department in the last month of life and 75% did so in their last six months of life.⁶ While a recent analysis of Medicare beneficiaries found that more people are dying at home with hospice services, hospice length of stay is short because of an increase in hospital and intensive care unit stays in the last month of life that occur before referral to hospice. Further, there has been an increase in the number of people who experience multiple transitions across health care settings near the end of life.⁷

Half of people over age 85 are afflicted by dementia. The Alzheimer's Association estimates the cost of caring for people with dementia at \$180 billion per year.⁸ Geriatric patients

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with dementia experience more hospital, skilled home health, and nursing home use than other older adults, which also translates into more transitions across settings of care.⁹ Continuing current health care utilization patterns, there will be a tenfold growth in dementia related hospitalizations between 2000 and 2050.¹⁰

In addition to utilizing the health care system, most geriatric patients with functional impairment need long-term care services and supports, which can be provided in a variety of settings ranging from nursing homes to the patient's home. Experts project a threefold increase in the need for formal long-term care between now and 2050, from 9 million to 27 million.¹¹ Access to home and community based long-term services and supports is associated with lower use of nursing homes and their associated costs to Medicare and Medicaid.

Despite the vast resources we are spending on geriatric patients with serious illnesses, we regularly fail to meet basic needs of this vulnerable population. Often, providers neglect to elicit patient and family goals and preferences for care and patients are shuttled through a health care system in a manner inconsistent with their values. Even when patient preferences are known, as in the case study in the beginning of this article, lack of home based services or other supports leave families and providers unable to honor patient wishes.

The concentration of risk and spending for older adults with both chronic disease and functional impairment presents a compelling case for the integration of principles of geriatrics and palliative care practice. Improving care quality and preventing predictable crises reduces use of costly emergency departments, hospitals, and nursing homes.

Summary of the Current Evidence

Models of care

Palliative and geriatric care models improve value by both increasing quality and decreasing costs. These care models, centered around matching care to patient-centered goals, have been found to improve symptom burden; quality and length of life; and patient, family, and provider satisfaction. Cost reductions have been found related to many outcomes important to policymakers, including decreased hospital costs; decreased hospitalization, emergency department, and intensive care unit rates; reduction in 30-day readmission rates; and decreased hospital mortality.¹²⁻²⁷

Most successful models involve some degree of care management. Some are focused on increasing safety and patient-centered care in the inpatient setting, such as Acute Care for the Elderly (ACE) units, the Hospital Elder Life Program (HELP), Nurses Improving Care to Health System Elders (NICHE), and palliative care consult services.¹²⁻²² Care transitions programs seek to reduce readmissions to the hospital.^{23,24} The Hospital at Home program allows some patients with acute illness to entirely avoid a hospitalization.²⁵

Coordination of care among multiple specialists and settings is a challenge for this patient population. Geriatric Resources for Assessment and Care of Elders (GRACE) and Guided Care are two examples of interdisciplinary programs that have established a track record for increasing coordination of care for older patients with multiple chronic conditions.^{26,27}

Much of the intent of these programs is to overcome both the balkanized health system—hospital, outpatient practice,

nursing home, assisted living, hospice—and the disconnect between medical disciplines—primary care providers, hospitalists, cardiologists, oncologists, surgeons, and other specialists—that can frustrate and confound patients. Because there is no payment mechanism to support them, the “best practices,” exemplified in these models and others, have been difficult to scale up and have not reached the large numbers of patients who could benefit from them.

Palliative care and hospice

Palliative care encompasses assessment and treatment of symptoms, matching patient goals to treatments, mobilization of community resources to support people in their homes, collaborative care across settings, and practical support for patients and caregivers. Palliative care can be provided within the context of hospice or outside of it. Hospice, defined by the Medicare benefit, is restricted to patients with a terminal illness with a prognosis of six months of less who agree to forego “curative” care.²⁸ Palliative care, in contrast, is appropriate from the point of diagnosis of a serious illness and is delivered concurrent with disease modifying and/or curative therapies.

Both palliative care and hospice programs improve physical and psychological symptoms experienced by patients; improve caregiver well-being; and increase patient, family, and physician satisfaction.^{22,29-39} Treatment of distressing symptoms by interdisciplinary palliative care and hospice teams translates to reduced medical complications and hospital utilization.^{12,13,40-42} In addition to symptom management, palliative care providers have expertise in the conduct of conversations with patients and families dedicated to assuring understanding of what to expect in the future, including prognosis and the resulting goals of care. Such family meeting and goals of care discussions have been shown to both improve family satisfaction and to reduce health care costs.^{43,44}

Outline of Knowledge Gaps

- *Strategies to scale up successful models:* Diffusion of innovation continues to be a challenge, even for proven models that deliver high-quality geriatric palliative care. Given the variety of models that exist, it can be difficult for a health system or provider to determine which will best meet the needs of the population they serve. Targeting the population most likely to benefit from a given intervention is a central challenge. In addition, retaining fidelity to a tested approach is key to replicate successes of research studies. Defining barriers to implementation, and then developing strategies to overcome them, is needed. Funders of both implementation science research and clinical demonstration projects aim to scale and standardize effective interventions to all who can benefit. This potential impact cannot be realized without a similar investment in efforts to disseminate technical assistance in support of successful execution and implementation in a broad range of communities and markets.
- *Leveraging current health care system reform:* Payors are seeking to achieve better value from providers through delivery and payment reform mechanisms, such as Accountable Care Organizations (ACOs). Increasing value

TABLE 1. RECOMMENDATIONS FOR RESEARCH PRIORITIES

<i>Research priority</i>	<i>Study objective</i>	<i>Study setting</i>	<i>Sample</i>	<i>Study design</i>
Implementation science for dissemination of successful models	To identify health system, institutional, and cultural factors that facilitate implementation of a given model To understand needs of providers for technical assistance for implementation and mechanisms to provide this support	Local health care delivery systems Health and long-term care institutions or agencies Care providers: doctors, nurses, aides	Large	Implementation science Mixed-method case studies of successful model implementation
Integration of proven models for providing geriatric palliative care into novel payment mechanisms, i.e., ACOs, bundled payment	To demonstrate impact of geriatric palliative care models on the overall cost and quality of care provided to a targeted population Analyze current palliative care payment policies to identify gaps in coverage or inconsistencies in Medicare, Medicaid, or private insurance payment systems	Health system level—hospitals, SNFs/nursing homes, home health providers	Medium	Implementation science Economic modeling Policy analysis
Development quality measures relevant to geriatric palliative care that are not restricted to setting of care or a specific condition	To determine appropriate quality metrics meaningful to patients, families, and providers that can be reliably collected To integrate geriatric palliative care quality measures into existing reporting structures	Patients and families Providers Federal and state policymakers	Small to large	Survey/interview of patients, families, and providers as to meaningful quality metrics Measurement instrument validation Development and testing of palliative care quality indicators from Medicare and nursing home Minimum Data Set (MDS)
Developing a strategy to meet the growing demands for workforce trained to care for geriatric patients with palliative care needs	To assess current geriatric palliative care workforce needs across multiple disciplines To delineate strategies to train generalists and specialists in geriatric palliative care principles	Health care workers	Small to large	National survey of health care providers Curriculum development and testing
Hospice reform	To identify the elements of this complex intervention that most benefit specific populations. To describe the impact on populations to changes in the current benefit	Current hospice eligible patients, including those with cancer and noncancer diagnoses and those who live in specific settings such as nursing homes	Medium	Secondary analysis of existing data including Medicare data and hospice data, including patient and family satisfaction surveys Policy analysis

is defined as improving quality and/or reducing costs; however, much of the focus of these models is on reduction in costs. Although frail multimorbidity geriatric patients are heavy users of the health care system, given the needs and complexity of these vulnerable patients, many of their expenses are appropriate. The role of geriatric palliative care models and principles in caring for these patients is important to ensure delivery of high-quality care and to protect against cost containment efforts that may harm patients, concordant with patient and family preferences and goals. An expanded evidence base is crucial to demonstrate the extent to which geriatric palliative care models can improve quality while either reducing or having a neutral effect on health care costs, within the context of current health care delivery reform.

- *Quality measures:* There are multiple gaps in quality measures for the care of geriatric palliative care patients. Many of these patients have multiple chronic conditions, functional impairments, and receive care across multiple settings. They do not fall easily into the categories—focused on a single disease or single setting—currently required by measurement-endorsing bodies such as the National Quality Forum.
- *Workforce needs:* There are clear workforce shortages of providers trained in caring for older patients with palliative care needs.^{45,46} Further understanding of these shortages, by discipline, setting, and geography, is needed. In addition to expanding the number of medical and nursing specialists in palliative care and geriatrics, strategies to best incorporate key geriatric and palliative care principles and practices into the training and competencies of all providers (primary care and specialists such as cardiologists, oncologists, nephrologists, and neurologists) who work with these patients is needed.⁴⁷
- *Future direction of hospice:* Hospice is a rich and complex intervention that has become an integral part of the care of terminally ill patients in the United States, allowing many patients to receive palliative care services in their homes. Over the past few decades, the numbers of patients who receive hospice services has dramatically increased and has improved quality of care delivered at the end of life. As increasing numbers of patients with noncancer diagnoses have accessed hospice, some limitations to the current structure have been noted. Timing of referral is difficult for patients with unclear prognoses. Although some patients, such as patients in nursing homes with advanced dementia, may have longer than anticipated hospice stays, much larger numbers of patients are referred to hospice too late to benefit from hospice care. In 2011, 11% of hospice beneficiaries survived more than six months after hospice referral but 37% had a hospice stay of one week or less.⁴⁸ Reform of the benefit, in terms of eligibility, financing, and structure, is currently being debated by policymakers.^{49–51} The impact of proposed reforms on access to hospice for vulnerable populations is not well described. Within the comprehensive multicomponent statutory benefit that is hospice care, further work needs to be done to identify which critical elements must be retained for effectiveness, and which are less important.

Summary of Research Priorities and Proposed Studies

Geriatric patients who have some combination of serious illnesses, functional limitations, frailty, and cognitive impairment represent a high cost, high need group who are not well served in the current health care system. Palliative care principles, including early advance care planning, communication about prognosis, expert symptom management, practical support for families, and presenting a variety of treatment options and their pros and cons, are intended to relieve distress and improve quality of life.⁵² Despite evidence of multiple approaches that do “work” for this population, there has been a failure to translate the successes of research and clinical demonstration projects into widespread practice. Given the imperative to improve value by improving quality while reducing costs, we present the following research priorities (see Table 1) aimed at supporting rational policy development that will address the needs of geriatric palliative care patients:

- *Studies that create a roadmap for scaling successful implementation and dissemination of proven models of care:* This should include both the identification of factors in a particular environment that create barriers or facilitate implementation, as well as provision of strategies for technical assistance to support implementation.
- *Novel financing models for health care delivery:* Research on the role of geriatric and palliative care models within these new payment mechanisms is needed to demonstrate their value and incorporate them into payment reform. Economic modeling and policy analysis are two methodological approaches that could be employed to explore these questions.
- *Quality of care metrics and integration into payment and accreditation/regulatory models:* Investigation is needed into appropriate measures of quality for patients with multiple conditions across settings of care. This will require a variety of approaches, including surveys or interviews, to determine highest-priority areas for measure development, as well as development and testing of new quality measures.
- *Workforce development in geriatrics and palliative care:* Surveying providers is one strategy to increase understanding of current gaps in the workforce and needed skills. In addition, study is needed of effective development and dissemination of curricula leading to measurable provider behavior change and improved care quality for both generalists and specialists.
- *Current and future hospice benefit structure and practice:* Understanding current practice and its variations by region, facility type, tax status, care setting, and patient population through secondary data analysis will inform policy options for reform or expansion of the program. Modeling impact of potential changes in eligibility, payment, and design of the hospice care model both through qualitative and quantitative methods is important to avoid disruptions in access and quality before fundamental changes in the benefit are imposed.

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