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Improving Care of People with Serious Medical Illness: An Economic Research Agenda for Palliative Care

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Too often, people facing serious illnesses do not get the care and support they—and their families and caregivers—need and want. Palliative care, an approach designed to improve the quality of life of patients with serious illness and their families, can help close the gap between the care people want and the care they actually receive. Palliative care “attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness.”^[1] As such, palliative care centers on pain and other symptom management, care coordination and planning, and assessment and support of caregiver needs.^{[2][3]}

The need to strengthen palliative care in the United States has never been greater considering the aging of the Baby Boom generation as well as changes over time in life expectancy and the very nature of disease and causes of death. Over the last century,

average U.S. life expectancy has increased from about 45 years to nearly 80. By 2034, for the first time, the United States will have more people aged 65 and older than those under age 18. With the exception of COVID-19, all leading causes of death today are related to chronic conditions, resulting in many people living with high-burden symptoms and needing help with daily living for many years.^[4] The COVID-19 pandemic has further highlighted the importance of palliative care, particularly in the early days of the pandemic, when hospitals faced overwhelming numbers of patients suffering from breathlessness and air hunger, delirium, anxiety, and isolation. Moreover, the pandemic has underscored the significant inequities facing members of racial and ethnic minority groups in the United States, both generally and specifically within health care.

At the same time, the United States spends nearly \$4.2 trillion annually on health care—much more per capita than any other industrialized nation—but ranks poorly on most health outcomes and patient experiences of care as compared to other high-income countries. In recent years, consensus has grown about the need to increase the value of U.S. health care by improving quality, increasing efficiency, and improving patient experience. Although much attention has focused on spending on patients in the last year of life, 40 percent of patients have high costs over time because of high disease burden from multiple chronic conditions causing functional impairment.^{[5][6][7]} To increase the value of U.S. health care spending, policymakers, payers, clinicians, and other stakeholders should consider thinking less about care at the end of life, which recent work shows is quite difficult to predict,^[8] and more about helping frail people with multiple chronic conditions live better. Advancing palliative care as the standard of care for Americans facing serious illnesses is one possible path to improving value.

Building an Economic Research Agenda to Overcome Barriers to Palliative Care

While early assessments show the potential of palliative care to improve quality and increase the value of health care spending, high-quality economic research is needed to

better identify effective components of palliative care and how to efficiently provide these services to those most likely to benefit. The USC Schaeffer Center convened a palliative care advisory panel in 2020 of clinicians and economists, along with select participants from the health system, payer, academic, and policy spheres, to develop a prioritized research agenda to advance the economics of palliative care ([background document](#)).^[9]

As well as identifying priorities specific to the economics of care for serious medical illness, the panel identified key contextual challenges in research on this population, including information gaps among stakeholders and difficulty in defining palliative care interventions.

Information Gaps Influence Treatment Choices in Advanced Medical Illness.

Policymakers, patients and families, clinicians, and payers lack a common understanding of palliative care and often [conflate palliative care with hospice](#).^[10] Palliative care is appropriate at any stage in a serious illness and can be provided along with curative, or disease-modifying, treatment, in contrast to hospice care, which focuses on comfort care near the end of life. Physicians often are not well-informed about palliative care and lack skills to seek or recognize patient preferences. Similarly, patients and their families often do not know much about palliative care and may be unaware of how palliative care vs. other care will influence outcomes, such as survival or quality of life.

Palliative Care Timing, Composition, and Intensity. Wide variation exists across palliative care delivery models, and the lack of standardization makes it difficult for patients and clinicians to understand what's being offered or to calibrate expectations. There also likely is a gap between what palliative care services are available and what patients want. Many patients receive hospital-based or clinic-based palliative care but may prefer home-based care, which is not widely available. Moreover, identifying when patients would benefit from specific palliative care interventions, and how that benefit varies over time, has not been well studied. There is a need to better understand how to appropriately define the treatment group/exposure variable in evaluations of palliative

care, as well as to consider applying the concept of dose response.

Priority Research Topics for Economics of Palliative Care

Charged with identifying where the field of economics can contribute to better understanding of palliative care outcomes, advisory panel members identified a combination of supply-side, demand-side, and methodological research topics and questions. The panel's hope is that a consensus-driven research agenda can guide potential funders and researchers in building the economic evidence base needed by public and private payers to improve care and experiences across settings and populations. To that end, the panel developed the following priority research topics:

- **Research Topic 1: Supply-Side Factors—Implications of Provider Payment Policy for Access to Palliative Care**
- **Research Topic 2: Demand-Side Factors—Preferences, Insurance Benefits, and Future Palliative Care Needs**
- **Research Topic 3: Developing Methods and Data to Evaluate Palliative Care Quality, Cost, and Patient/Family Experience Outcomes**

Research Topic 1: Supply-Side Factors—Implications of Provider Payment Policy for Access to Palliative Care

In U.S. health care, provider payment policy plays a large role in both care delivery and patient treatment choices. Having a better understanding of current payment practices related to palliative care could help identify barriers to adoption. Because most serious illness occurs in older adults, Medicare is the major U.S. payer of palliative care services. In fee-for-service (FFS) Medicare, which covers almost 3 in 5 beneficiaries, payment policies support palliative care in inpatient settings but not in ambulatory settings. Under Medicare's fixed diagnosis-related group, or DRG, payments, if palliative care reduces hospital costs and improves patient experience, palliative care creates value for both hospitals and patients. Conversely, in the outpatient setting, where most physician

payment remains FFS, palliative care programs receive minimal support for their non-physician team members and potentially reduce demand for other more lucrative tests, procedures, and treatments. Although less is known about commercial insurance coverage for palliative care programs and services, [private health plans often track Medicare coverage requirements](#).^[11]

The increasing prevalence of alternative payment approaches, such as accountable care organizations, Medicare Advantage plans, and bundled payments, may better align incentives with palliative care services. To advance understanding of supply-side factors influencing palliative care use, the advisory panel identified the following priority research questions:

1. How is palliative care paid for across different settings—inpatient, outpatient, and home-based care—and payers, including Medicare, Medicare Advantage, Medicaid, Medicaid managed care, commercial insurance, and Veterans Health Administration?
2. What are the effects of different payment approaches on utilization, spending, and quality of care for individuals with serious illness?
3. As payment shifts from FFS to capitated, or risk-based, payments, are incentives emerging for providers to recommend palliative care?
4. What actions are needed to ensure that providers understand what palliative care is and is not, e.g., how it differs from hospice?
5. Will new scalable palliative care service delivery models (e.g., telehealth systems set up by some large health systems during COVID) be adopted more broadly?
6. How can provider-focused incentives be incorporated to encourage adoption and use of promising palliative care models, and what research designs can be used to track individual and system outcomes?
7. To what extent are high costs for serious illness and at the end of life driven by supplier-induced demand, e.g., tests or interventions offering little value to patients that are provided due to perverse payment incentives? To what extent does palliative care ameliorate use of low-value care?

Research Topic 2: Demand-Side Factors—Preferences, Insurance Benefits, and Future Palliative Care Needs

The large role that insurance coverage plays in access to palliative care, information gaps among patients and clinicians about the very nature of palliative care, and wide variation in palliative care delivery models all combine to make estimating demand for palliative care extremely complex. At its heart, palliative care is patient-centered care that recognizes and incorporates individual patient and family/surrogate values, preferences, and needs—both clinical and nonclinical. Moreover, patient and family awareness of and attitudes toward hospice/palliative care, patient financial incentives and out-of-pocket costs, and ensuring equity in palliative care access and outcomes all affect demand for palliative care. For FFS Medicare beneficiaries, little coverage is available for ambulatory palliative care outside of the hospice benefit, and Medicare hospice eligibility is restricted based on disease prognosis and willingness to forgo curative therapies. Several pilots, including the Medicare Care Choices Model, are examining the impact of allowing beneficiaries to simultaneously receive hospice services and curative care. To advance understanding of demand-side factors influencing palliative care use, the advisory panel identified the following priority research questions:

1. What do people experiencing serious illness value, especially if they are nearing the end of life? How can patients and families best make treatment decisions that are in keeping with these values and goals? What new measures and methods are required to capture these preferences and priorities? [What can be done to improve serious illness conversations?](#)^[12]
2. How does insurance benefit design—especially patient cost sharing—affect the decision to use palliative care and the services it provides? How do current patterns of insurance coverage and use facilitate or inhibit access to palliative care?
3. To what extent do different patterns of end-of-life health care use among different groups, including racial and ethnic groups, reflect patient preferences and to what extent do they reflect inequities? What actions are needed to achieve equitable access

- to care consistent with preferences across different groups?
4. To what extent do patients and families understand their own financial liabilities for out-of-pocket costs when facing a serious illness? How does improved understanding of insurance coverage and risk of catastrophic household spending change treatment choices?
 5. What is the potential demand for palliative care services in the United States under different eligibility criteria? For example, what would demand be if we followed the guidelines for those with cancer, expanded to serious illness with functional and/or cognitive limitation challenges, or those with any serious illness? For example, the [American Society of Clinical Oncologists](#) now recommends concurrent palliative care within 8 weeks of diagnosis for all advanced cancer patients.^[13]
 6. As populations age and care for multimorbid persons becomes more complex, how should we define palliative care “need” in the population? Based on these definitions, how many people will need palliative care in the United States in the coming decades?
 7. What is the skill mix and workforce capacity required to meet future palliative care need?

Research Topic 3: Developing Methods and Data to Evaluate Palliative Care Quality, Cost, and Patient/Family Experience Outcomes

Randomized controlled trials have mostly found that palliative care interventions improve quality of life but generally have found no effect on costs in either direction. However, such trials are rarely sized to assess effects on costs. Moreover, like any randomized trial, they may not offer insights that are broadly generalizable. Observational studies often show large cost-saving estimates but can suffer from selection bias.

Econometrics may be able to supplement trials and noncausal cohort studies by applying causal analysis to observational data. In the short run, it may be possible to strengthen substantially the evidence base by applying econometric approaches to routinely collected data. In the longer run, researchers need a strategic plan designed to bridge

data gaps (such as outcomes, preferences, out-of-pocket costs, and unpaid care) through improved linkage of existing data, as well as collection of new data with good generalizability for inclusion in modeling evaluations. There is also a need to facilitate data linkage and pursue greater efficiencies in data linkage and sharing to avoid duplication of effort, which is a declared focus of the National Institute on Aging. To develop methods and data to evaluate palliative care quality, cost, and patient/family experience outcomes, the panel identified the following priority research questions:

1. What data exist to define relevant populations; identify receipt of relevant interventions; estimate costs to payers, families and patients; and measure outcomes and experiences of families and patients? What are the barriers to accessing and linking these data in government, private sector, etc.?
2. What are the opportunities to evaluate palliative care programs using current econometric methods? The significant expansion of palliative care programs over the last 20 years may provide natural experiments to measure effects on costs from different perspectives, conduct cost-effectiveness analyses, and examine cost-shifting between payers and households.
3. What are the needs and potential for new econometric methods to evaluate programs? The complexity of palliative care patients and interventions, and the piecemeal development of programs over time, mean that different populations have received different exposures at different points in times. [Recent innovations](#) equip researchers to model different doses and program roll-outs,^[14] and extensions of these approaches may improve our capacity to isolate the effect of service and policy changes.
4. How can new research address the lack of economic evaluation in palliative care? What new outcome measures need to be developed? What are the barriers to decision analysis modelling?

Conclusion

Improving care for people with serious medical illness and their families is a widely recognized priority. Economic evidence to inform improvement efforts is lacking. In 2020, the USC Schaeffer Center convened an expert advisory panel to develop a prioritized research agenda to advance the economic evidence base on palliative care. We aimed to develop a consensus-driven research agenda to guide potential funders and researchers in building the evidence base for palliative care and improving care and experiences for seriously ill people.

The panel identified key deficits on the supply side, on the demand side and in methodological approaches, as well as acknowledging significant generic challenges in research on this population. Notably, the many knowledge gaps and policy issues are interrelated. For example, closing the palliative care knowledge gap among physicians is a necessary first step but may be stymied by wide variation in insurance coverage, payment, and models of palliative care across payers.

Nonetheless, we must start somewhere or accept the status quo that too many patients facing serious illness will not get the care and support they, their families, and caregivers need and want. This research agenda provides a framework to guide more and better research on the economics of palliative care. While it is clear that there is no single starting point to address these problems, the corollary is that different researchers can address different questions and collectively these efforts can advance understanding on this essential but under-examined topic.

In 2020, the USC Schaeffer Center established an advisory panel to identify and consider how to address the gaps in research at the interface of economics and palliative care. The panel includes clinicians, economists and select participants from health system, payer and policy domains. The panel's hope is that this consensus-based palliative care research agenda can lay the foundation for building a strong evidence base to guide public and private policies meant to advance affordable, equitable, high-quality, patient-centered care.

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A viewpoint on this research agenda can be found JAMA Health Forum

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