

Ensuring High-Value Care for People with Serious Illness

Millions of Americans Living with Serious Illness Have Unmet Needs

At least 12 million adults in the United States are living with serious illness,ⁱ and this number is expected to increase significantly over the next two decades.ⁱⁱ These individuals, along with upwards of 400,000 children living with serious illness,ⁱⁱⁱ heavily utilize healthcare and spend a significant amount of money on such care. Unfortunately, this population receives poor care from our current health care system. Their symptoms are often inadequately treated, they experience poor communication with healthcare providers, and their family members or other caregivers face enormous strain^{iv,v}

Serious illness is a health condition that carries a high risk of mortality AND either negatively affects a person's daily functioning or quality of life, or excessively strains caregivers. Examples of serious illnesses include metastatic cancer, advanced dementia, and frailty.

Improving care for the seriously ill and their families requires a health system that routinely elicits their values and goals, aligns treatment decisions with those goals, assesses and addresses symptom burden, and – in the most complex cases – facilitates access to consultation from board-certified palliative care specialists.

Current Gaps in U.S. Health Care

The U.S. health care system, built on treating acute illness and injuries, has significant gaps in caring for patients with serious illness and their families. These include:

- Insufficient knowledge and skill among treating clinicians for safe and effective pain and symptom management, and for the communication skills necessary to hold difficult conversations with patients and families about their priorities for care
- Clinician inability to consider quality of life when offering treatment recommendations
- Inconsistent access to certified palliative care specialists and programs that adhere to national quality guidelines,^{vi} due to workforce, payment, and regulatory barriers
- Insufficient data and systems to proactively identify the seriously ill, largely due to the lack of functional and cognitive status data collection across care settings
- Insufficient access to meaningful and timely response to crises on a 24/7 basis

These gaps often result in avoidable spending as people seek emergency care for preventable problems or undergo unnecessary procedures that they may not have chosen if they had had a full understanding of the benefits and risks. Only 5 percent of the US population – many of whom have long term and serious illness – drive over 50 percent of total health care expenditures,^{vii} and yet much of this spending is both unnecessary and preventable.

Driving Towards Standardized High Value Care for Seriously Ill Patients

Numerous studies show that palliative care^{viii} significantly improves patient and family caregiver quality of life and lowers symptom burden.^{ix,x} This results in fewer symptom crises, 911 calls, emergency department visits, and hospitalizations.^{xi,xii,xiii} This is a triple win – better outcomes for

patients and their families, clinicians, and payers of health care. Yet, reliable access to clinicians who can deliver quality palliative care is highly variable. To improve system-wide care for this population, policymakers must modify existing requirements and/or incentive systems to adhere to national palliative care guidelines.^{xiv} For example:

- In 2014, California passed a law that required the state’s Department of Health Care Services to establish benefit standards for access to palliative care services for all patients served by Medicaid managed care plans.
- In 2014, Wells Fargo required its health insurance plan to develop benefits and services for seriously ill participants, in accordance with the National Consensus Project (NCP) Clinical Guidelines for Quality Palliative Care^{xv} for comprehensive palliative care.
- In 2017, Anthem’s health plan bonus incentives for network hospitals included access to quality hospital-based palliative care, along with training and commitment of resources as a criterion for contract payment increases. To earn credit for this measure, network hospitals can either achieve Advanced Certification for Palliative Care from The Joint Commission or demonstrate similar policies and capabilities.
- In 2017, California passed a law allowing licensed hospices to provide palliative care services concurrently with curative treatment to a person who does not have a terminal prognosis or who has not elected to receive hospice services.

Recommendations for State Policymakers

States leaders can play an important role in improving care for people with serious illness through legislation and/or regulation in the domains of specialty workforce, payment, quality and standards, research, clinical skill building, and public awareness. Activities might include:^{xvi}

Domain	Recommendation
Specialty Workforce	<ul style="list-style-type: none"> • Establishing or expanding loan forgiveness programs for certified clinicians who work as palliative care specialists
Payment	<ul style="list-style-type: none"> • Enabling Medicaid to pay for high-value services beneficial to those with a serious illness by using existing codes, particularly advance care planning • Adding palliative care coverage requirements in all settings to Medicaid managed care organization contracts,^{xvii} including special considerations for pediatrics, adolescent and young adult, and perinatal • Enhancing Dual Special Needs Plan and Managed Long-Term Services and Supports contracts to incorporate advance care planning and symptom assessment into care manager responsibilities • Incorporating serious illness quality measurement reporting requirements and/or incentive programs into provider and managed care organization contracts^{xviii}
Quality and Standards	<ul style="list-style-type: none"> • Using state policies and regulations to define palliative care services and standards^{xix} • Expanding or establishing new licensure to allow for the provision of home-based palliative care

Domain	Recommendation
Clinical Skill Building	<ul style="list-style-type: none"> Revising state health professional licensure and continuing education requirements to include a minimum number of hours of instruction in both communication skills and symptom management Investing in targeted professional education opportunities in both communication skills and symptom management through grantmaking or other programs
Public Awareness	<ul style="list-style-type: none"> Increasing the role of state public health agencies in promoting palliative care by creating a public awareness campaign
Research	<ul style="list-style-type: none"> Conducting a state palliative care needs and capacity assessment (foundational to state work)

Additional recommendations can be found in the 2019 State-by-State Palliative Care Report Card and individual State Reports.^{xx} The Center to Advance Palliative Care (CAPC) has information and resources to help promote high quality palliative care. For more information, please contact PaymentandPolicy@capc.org.

ⁱ The Commonwealth Fund “High-Need, High-Cost Patients: Who Are They and How Do They Use Health Care?” August 2016

ⁱⁱ U.S. Department of Health and Human Services, Administration for Community Living (September 2014). “Administration on Aging (AoA) Projected Future Growth of Older Population.” Administration on Aging, Administration for Community Living, <https://www.acl.gov/aging-and-disability-in-america/data-and-research/projected-future-growth-older-population>

ⁱⁱⁱ Field JF, Behrman RE. When children die: Improving palliative and end-of-life care for children and their families. Washington, DC: National Academies Press; 2003.

^{iv} Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association* 7 January 2004; 291(1):88-93.

^v Meier DE. Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care. *The Milbank Quarterly* September 2011; 89(3):343-380.

^{vi} National Consensus Project. *Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition*. (2013). <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013/>

^{vii} Mitchell EM, Machlin SR. Concentration of Health Expenditures and Selected Characteristics of High Spenders, U.S. Civilian Noninstitutionalized Population, 2015. (December 2017) Statistical Brief #506. Agency for Healthcare Research and Quality, Rockville, MD.

https://meps.ahrq.gov/data_files/publications/st506/stat506.pdf

^{viii} Palliative care is defined as specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

^{ix} Kavalieratos D, Corbelli J, Zhang D, et al. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. *JAMA*. 2016;316(20):2104-2114. doi:10.1001/jama.2016.16840.

^x Lustbader D, Mudra M, Romano C, Lukoski E, Chang A, Mittelberger J, Scherr T, Cooper D. The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization. *J Palliat Med*. 2016 Aug 30

^{xi} Nipp RD, El-Jawahri A, Moran SM, et al. The relationship between physical and psychological symptoms and health care utilization in hospitalized patients with advanced cancer. *Cancer*. 2017 Dec 1; 23(23):4720-4727. doi: 10.1002/cncr.30912

^{xii} Morrison RS, Dietrich J, Ladwig S, et al. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff*. 2011;30(3):454-463.

^{xiii} May P, Normand C, Cassel JB, et al. Economics of palliative care for hospitalized adults with serious illness: A meta-analysis. *JAMA Intern Med*. Published online April 30, 2018. doi: 10.1001/jamainternmed.2018.0750

^{xiv} National Consensus Project. *Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition*. (2013). <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013/>

^{xv} National Consensus Project. *Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition*. (2013). <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013/>

^{xvi} It is up to states to review and implement these recommendations based on feasibility within their local environment.

^{xvii} These requirements can be modeled after recent guidance from the Centers for Medicare and Medicaid Services (CMS) which: 1) allows Medicare Advantage (MA) plans to cover supplemental benefits and cites home-based palliative care as an allowable benefit; and 2) provides new flexibility for plans to vary benefits for subsets of enrollees based upon their disease state or health status, as long as these variations are available to all similarly-situated enrollees. Guidance retrieved from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/HPMS/HPMS-Memos-Archive-Weekly-Items/SysHPMS-Memo-2018-Week4-Apr-23-27.html>

^{xviii} Measures could include: number of days at home in the last 90 days of life; proportion of patients who died from cancer receiving chemotherapy in the last 14 days of life (NQF #0210); proportion with more than one hospitalization in the last 30 days of life (NQF #0212); number of burdensome transitions in last week of life; hospice utilization (as a percentage); and hospice length of stay (in days).

^{xix} Example definitions from Colorado

(<http://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-1%20Chap%2002>) and Maryland

(https://health.maryland.gov/ohcq/Documents/Palliative%20Care_10.07.01.31_5_18_2016.pdf) can provide a helpful starting point.

^{xx} Center to Advance Palliative Care and the National Palliative Care Research Center. *America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals* (2019). <https://reportcard.capc.org/>