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Opinion paper

Scalable principles of community-based high-value care for seriously ill individuals: Diamonds in the rough



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ABSTRACT

Early, integrated palliative care has been shown to improve quality of life and reduce utilization in both inpatient and outpatient settings. As health systems shift to risk-based payment structures, palliative care will play an increasing role in improving value of care outside of the hospital. Based on successful models of community-based palliative care, we identify six principles – interdisciplinary team-based care; 24/7 access and responsiveness; concurrent palliative care with disease-directed treatment; targeting services to high-risk patients; integrated medical and social supports; and caregiver support – that are widely implemented because of their impact on improving value for seriously ill individuals.

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Starting in 2016, the Centers for Medicare and Medicaid Services (CMS) began reimbursing eligible providers for advance care planning discussions with patients. The decision comes at a time of wide recognition and implementation of palliative care service delivery in U.S. hospitals.¹ According to a field-tested definition developed by the Center to Advance Palliative Care and supported by national quality guidelines, “Palliative care is specialized medical care for people with serious illnesses...focused on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis.”^{2,3} As indicated, palliative care is not limited to care of the dying, though many current palliative care programs focus their efforts on end-of-life care. Palliative care teams have expertise in pain and symptom management; clarifying patient and family priorities and how best to achieve them; connecting patients with community resources; and care coordination across settings.

Palliative care has a disproportionately large role in improving value precisely because of its focus on seriously ill patients, logically the highest consumers of health care. A growing body of knowledge demonstrates that palliative care improves quality of life and quality of care and decreases unnecessary spending by averting preventable crises, thus reducing unnecessary and

inappropriate care. In recent years a diverse range of community-based palliative care (CBPC) delivery models – palliative care delivered outside of hospitals and the Medicare Hospice Benefit – have emerged to improve the value of care (defined as maximizing health outcomes at the lowest cost) for patients with serious illness. To support scaling and diffusing innovation for seriously ill individuals across all care settings, we identify six common principles of high-quality CBPC delivery models.

1. The need for value in care of the seriously ill

Patients with serious illnesses account for a significant proportion of health care outlays.^{4,5} Many assume that most of this spending occurs at the end of life. This is a misconception: a recent Institute of Medicine report entitled “Dying in America” found that only 11% of the costliest 5% of all patients are in their last 12 months of life (see Fig. 1).^{6,7} Roughly half of the costliest 5% have high spending attributable to a one-time process (such as a hip replacement or cardiac surgery) and then regress back to average spending levels in the subsequent year. The remaining 40% of the costliest 5% have continued high spending, year after year. Most of these individuals are older and have multiple co-morbidities, frailty, and functional or cognitive impairment, resulting in high long-term care and caregiver needs.⁸

Concurrently, health systems and providers bear increasing financial risk for seriously ill patients through readmission,

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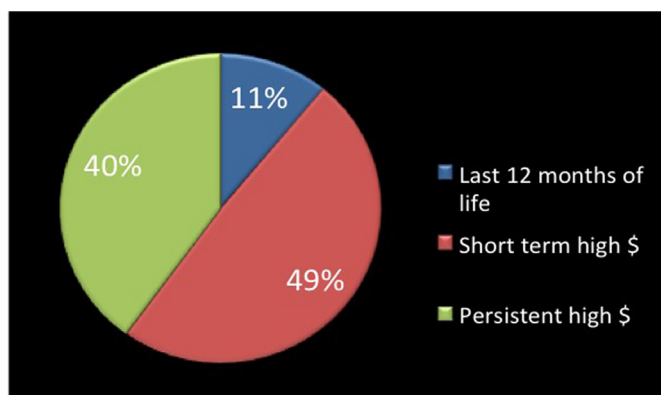


Fig. 1. Demographics among the costliest 5% of American patients, Source/Notes: SOURCE: Institute of Medicine. Dying in America: Improving quality and honoring individual preferences near the end of life; Appendix E [Internet]. Washington, DC: The National Academies Press; 2014. Available from: <http://www.nap.edu/read/18748/chapter/1>.

mortality, and patient-reported outcome penalties and value-based payments. Accountable care organizations (ACOs; 11% of all Medicare beneficiaries)⁹, Medicare Advantage plans (31% of all Medicare beneficiaries)¹⁰, and Medicaid managed care (now implemented by 47 of 50 states)¹¹ further drive delivery system efforts to lower costs while preserving or improving quality.

Palliative care improves value in these delivery models by improving quality to reduce reliance on unnecessary emergency and acute care services. Randomized trial data have shown that palliative care received early in the course of illness improves quality of life while reducing spending — and without decreasing survival.^{12,13} In the inpatient setting, patients receiving earlier palliative care consultation report higher satisfaction with care, fewer intensive care unit (ICU) admissions or deaths, and six-month net health cost savings of up to \$5000 per patient with no differences in survival compared to controls.^{14–16} Palliative care in the outpatient setting improves quality of life and mood while reducing inappropriate hospitalizations.^{17,18} Home-based palliative care reduces emergency and hospital admissions and increases the likelihood that patients remain at home.¹⁹

Despite evidence demonstrating its value in community settings,^{19,20} palliative care is predominantly available in hospitals and hospices.^{1,21} Waiting for palliative care to begin during hospitalization misses an opportunity for early integration of palliative care services and contributes to the high prevalence of late palliative care referrals seen in practice.²² Because the duration of any serious illness primarily occurs outside of hospitals and prior to hospice eligibility, better access to community-based palliative care earlier in the disease course is an untapped opportunity.

2. Models of value-driven care for the seriously ill

Some provider groups, health systems, hospices, and payers have responded to this gap by expanding the reach of palliative care services into home, clinic, and long-term care settings. Emerging models are sponsored by individual clinics, integrated health systems^{23–25}; hospice programs delivering non-hospice palliative care^{26,27}; and payers.²⁸ Many of these models (e.g. the University of California San Francisco [UCSF] Symptom Management Service, Sharp HospiceCare) are palliative care-specific in focus, whereas others (e.g. CareMore, Veterans' Affairs Home-Based Primary Care) are comprehensive models that incorporate palliative care. We highlight innovative delivery models, organized by the parent organization providing CBPC (see Table 1).

3. Scalable principles for CBPC

While not present across all models, six principles are present in many successful CBPC organizations that are linked to their impact on health outcomes or costs (see Table 1).

3.1. Interdisciplinary team training and structure

Given the complexity and needs of the high-risk patient population, quality palliative care is by nature and definition an interdisciplinary field. Team-based training and structure is a common theme among groups that have demonstrated value in CBPC delivery.

Team training and education in effective palliative care is essential for practitioners. Sutter Health's Advanced Illness Management (AIM) Program educates nurse case managers and other providers in disease processes, symptom management, and goal clarification. The Veterans Affairs (VA) Home Based Primary Care (HBPC) program emphasizes team communication training regarding what matters most to patients and families and how to translate these priorities into specific care plans. Other topics covered include the definition of palliative care, insurance and home care regulations, advance care planning, and managing the active dying phase.²⁹

Innovative team structures also characterize CBPC delivery models. The VA HBPC Program features one of the most robust interdisciplinary structures, consisting of Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs), physicians, physician assistants, social workers, dietitians, pharmacists, rehabilitation therapists, and psychologists, all of whom attend weekly meetings and sign a unified care plan to guide care of each patient. The entire team receives notification of hospital admissions and discharges. The interdisciplinary team enables responsiveness to a broad range of medical, psychological, spiritual, functional, and social problems that characterize the needs of seriously ill patients and their caregivers.

3.2. 24/7 clinical responsiveness and access across settings

Patients living with serious illness require access to responsive and knowledgeable clinicians whenever changes or concerns arise in the home or long-term care setting. Lack of reliable 24/7 access predictably leads to 911 calls, ED visits, and hospitalizations when family members feel uncertain in the face of acute situations such as worsening pain, dyspnea, or new functional decline.

Clinical accessibility can come in many forms. CBPC providers including the UCSF Symptom Management Service offer 24/7-telephone access to a call center staffed by physicians, APRNs, or RNs, who triage patient or family concerns. Some organizations offer extended clinic hours, targeted to patients who lack daytime transportation.

Others use telemedicine to reach patients beyond the clinic: CareMore and the VA HBPC utilize wireless devices, such as scales and blood pressure kits, to transmit real-time data to providers. For patients with heart failure, for example, such remote tools allow providers to respond to weight changes by remotely adjusting diuretic dosing before an acute exacerbation necessitates hospitalization. In CareMore's case, a two-pound weight gain triggers a phone call from the patient's assigned APRN who titrates medications according to protocol.²⁸ Randomized trials have shown that pre-emptive home-based management of heart failure using telemedicine tools avoids costly hospitalizations with no adverse impact on mortality.³⁰

CareMore's "extensivists" offer further clinical responsiveness by providing continuity of care both during and immediately after hospitalizations, performing fall and preoperative assessments, and rounding on patients in skilled nursing facilities.²⁸ CareMore APRNs make home visits to high-risk patients and provide home-based palliative care once patients transition home.

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