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Prescriptions for Excellence in HEALTH CARE

A COLLABORATION BETWEEN JEFFERSON SCHOOL OF POPULATION HEALTH AND LILLY USA, LLC

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Improving the Quality of Care at the End of Life

By JoAnne Reifsnyder, PhD, ACHPN

The National Priorities Partnership (NPP) has recognized that improving access to and the quality of palliative and end-of-life care is critically important.¹

Despite the growth of home-based hospice in the United States during the past 35 years, this interdisciplinary service aimed at supporting terminally ill patients and their families in the final months of life remains underutilized.

As a result, most patients who are approaching end of life and their families continue to struggle through the maze of acute illness-focused and poorly coordinated health care. Many are never referred to hospice; of those who are referred, 50% are referred in the final 3 weeks of life.²

NPP maintains that making palliative and end-of-life care a priority will reduce suffering, reduce disparities in access to and use of hospice services, reduce the burden of serious illness on family caregivers, and reduce expenditures for interventions that offer marginal benefit and/or are not consistent with the patient's goals for care at the end of life.¹ What changes must take place to assure that those who need palliative and end-of-life care receive these services? This article discusses 3 strategic areas to improve palliative and end-of-life care.

1. Building Consumer, Provider, and System Expectations

Hospice is a philosophy and business model that has achieved increasing

acceptance in the health care industry.

Hospice is a model for providing *palliative care* to patients who are approaching end of life. While hospice is often viewed as a parallel system to traditional care for serious illness, hospice providers have reached out to providers in other settings and created bridges to understanding and acceptance. The number of hospice programs has grown from a single program in 1974 to 4700 in 2007. Of the 2.4 million persons who died in 2007, nearly 40% died while enrolled in a hospice program.²

Despite the growing acceptance of hospice and positive evaluation by families who were supported by hospice teams, many barriers to access persist. Hospice referrals are frequently made very late in the illness trajectory (if at all), a time when physicians', nurses', and other health care providers' discomfort discussing end of life reflects a broader societal reluctance to view death as natural and inevitable.

Clinicians cannot change the fact that patients will die, but they can profoundly impact the way in which death is experienced by the patient and remembered by the surviving family members. Patients and their families want and need honest, supportive communication about their illness, treatment options, and

associated benefits and burdens.

At the same time, some patients may wish to avoid direct communication about prognosis, and may "collude" with their treating team to avoid frank discussions about life expectancy.

Because hospice benefits under Medicare, Medicaid, and most commercial plans require the physician to estimate life expectancy, the very real difficulties of prognostication can impede patient access to hospice care. To be eligible for hospice, a patient's goals for care must be palliative in nature – thus, hospice enrollment is often presented or perceived as a choice between "cure" and "care." Despite relentless education and outreach from hospice providers, delayed referral to hospice has persisted and is unlikely to change dramatically as long as consumers, providers, and systems see hospice care as second best to "mainstream" or traditional care.

Consumers must expect - even demand - attention to their pain and symptoms, support directed at their fears and suffering, and information that is understandable, culturally appropriate, and tailored to their needs. The onus is on providers and health care systems to develop appropriate communication skills and to use available resources, such as palliative care consultation teams in hospitals, to

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support difficult conversations and their emotional aftermath.

2. Seamless Care Coordination

Many experts and providers agree that providing high-quality *palliative* care to patients who need it, regardless of prognosis, is an important and necessary advancement in health care. Palliative care is focused on preventing and relieving symptoms associated with both illness and treatment and improving quality of life, regardless of disease stage or prognosis.³ Hospital-based palliative care has emerged as a trend in recent years, spearheaded by physicians who identified a need for better coordination of care, attention to symptoms, and advance care planning while patients with advanced illness are hospitalized.

While there are clinical guidelines for palliative care,³ “non-hospice” palliative care services delivered at home or in other residential settings are scarce, principally because there is no direct reimbursement. Many hospice experts believe that, as the “gold standard” for palliative care, hospices are the ideal provider base from which to expand palliative care services to the home. They argue that removing prognosis barriers (ie, eligibility when life expectancy is 6 months or less) would meet many more patients’ needs for palliative care and would create access to the providers best prepared to provide it – hospices.

Hospice is largely government funded through Medicare and state Medicaid programs. Although the hospice service bundle would greatly benefit patients with chronic illnesses, the cost is viewed by many policy analysts as unsupportable. Others argue that merely removing the prognosis requirement leaves hospices with public relations and social marketing challenges (eg, patients with heart failure who are uncomfortable receiving disease management and support services from an end-of-life care provider).

Patients with complex, chronic illnesses currently fend for themselves – receiving acute care when they

experience exacerbations, seeing multiple specialists, taking many medications, receiving some support and services in their communities (eg, transportation, meals, personal care), and frequently finding themselves incapable of independent living because of declining functional ability and inadequately *coordinated* resources to support them in the home environment.

These persons need palliative care – specifically, community-based services delivered by providers who guide and manage care over a period of time, anticipating and preventing health crises to the greatest possible extent, and permitting safe and effective care in the older adult’s own home. Emerging models will likely stress care management that addresses patient/family needs over many months or years, eases illness burden, facilitates care transitions, and allows seniors to age (and die) in place without an abrupt change in providers late in the illness.

Two such models are the Program of All-Inclusive Care for the Elderly (PACE), wherein hospice is a component of the *PACE service bundle*, and Continuing Care at Home (CCAH), which enables seniors to tap into a continuum of services beginning at a time when they are independent and continuing seamlessly throughout their lives. CCAH is neither licensed nor described as hospice, yet the services provided clearly meet the broadest definition of palliative care. Integration of palliative care and hospice into emerging models of chronic care management are likely to be more acceptable to consumers because they provide needed services without forcing a choice between disease-focused treatment and supportive care.

3. Measuring and Reporting Quality

Health care consumers and payers are demanding increased attention to quality and safety measurement, reporting, and transparency. The

Medicare Payment Advisory Commission (MedPAC) has called for more detailed data from Medicare-certified hospices to assess the relationship between patient characteristics and service provision, and to justify the rate of growth in Medicare spending for hospice care, which outpaces spending growth in other sectors.⁴ Under the revised Medicare Conditions of Participation for Hospice (2008), Medicare-certified programs must develop and implement quality assessment and performance improvement (QAPI) programs to measure and track indicators of quality across all functions and services, and determine strengths and areas for improvement.⁵ Hospices must use the findings to drive ongoing care improvement.

The new requirements did not include a specific set of indicators for hospices, but experts predict that a mandatory quality indicator set is on the horizon. A Centers for Medicare and Medicaid Services (CMS) study to develop measures for hospice and palliative care generated several products including assessment instrument sets, recommended quality measures and tools, and an organizational readiness screen to help hospice providers assess and improve their QAPI processes.⁶

Measuring quality with seriously ill patients in both hospice and palliative care programs is challenging. Hospice care is primarily provided at home, where clinicians are present only episodically to collect data. Collecting meaningful outcomes data requires that patients and family members participate, that the measures are valid and reliable indicators of quality, and that the data can be meaningfully aggregated to produce organization-level insights. A patient’s severity of illness often precludes self-reporting on important quality measures (eg, pain intensity).

Pain and other symptoms are subjective in nature and may fluctuate despite appropriate assessment and

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intervention. Timing of data collection on pain measures may influence findings at the patient level, and aggregated responses may be difficult to interpret at a quality level. For example:

- Is a hospice provider with an average pain score of “5” on a scale of 0-10 at 48 hours after admission delivering lower quality care than a hospice provider with an average pain score of “4”?
- How should hospices adjust for patients’ pain goals and their willingness to accept and continue treatment?

QAPI provided new impetus for hospice providers to apply and evaluate measures. These important insights will contribute to refinement

of existing conceptual models and guidelines for quality palliative and end-of-life care.

Conclusion

The NPP has established a national platform for “guaranteeing appropriate and compassionate care for patients with life-limiting illness.”¹ As the ideal is translated into expectations, new care models will emerge in which coordination of care across settings is emphasized and the goals of palliative care – comfort, support, and choice – are integrated.

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