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Next Generation of Palliative Care: Community Models Offer Services Outside the Hospital

November 2012

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Prepared for

CALIFORNIA HEALTHCARE FOUNDATION

by

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Acknowledgments

The Coalition for Compassionate Care of California provided project management for development of this report. The Coalition is a statewide collaborative of health care providers, consumers, and regulatory agencies dedicated to the advancement of palliative medicine and end-of-life care in California.

About the Foundation

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Contents

2	Introduction	
2	Why Community-Based?	
3	Barriers and Challenges	
4	Opportunities and Leverage Points	
5	Emerging Models	
9	Developments that Would Promote CBPC	
10	Ten Steps Toward Specificity	
12	Endnotes	

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Introduction

Palliative care has emerged in the past decade as an important tool for improving quality and reducing costs of care for patients with serious illness. It is specialized, team-based care that focuses on the relief of symptoms and to improve quality of life for both the patient and family. Unlike hospice, a form of palliative care for patients who have a prognosis of six months or less to live, palliative care is appropriate at any stage in a serious illness, and can be provided together with curative treatment.¹ By empowering patients to make care choices that are consistent with their values, palliative programs usually result in less aggressive and less costly care.²

Acute care hospitals have been establishing palliative programs at a rapid pace; there are now more than 1,600.³ This growth has been fueled by an expanding body of research documenting a range of positive outcomes from palliative care, mostly focused on care provided inside the hospital.⁴

But the literature also indicates that many patients miss out on the benefits of palliative care because it is not available to them when and where they need it. In order to explore ways to help fill this gap for patients, this report looks at the opportunities and challenges of community-based palliative care — services provided outside of the acute hospital and outside of the regulatory and reimbursement structures of hospice care under Medicare.

Why Community-Based?

Most palliative care programs are hospital-based, but many patients with serious medical conditions traverse care settings. Once they leave the hospital setting, the lack of recognized program models becomes a problem. Funding sources are less certain, and service portals and

processes are not well defined. Many of these patients do not fit into the narrow definition for hospice care eligibility.

Such patients may well benefit from palliative care, research has found. A landmark study conducted at Massachusetts General Hospital found that providing simultaneous standard cancer care with office-based palliative care improved quality of life, reduced major depression, lowered the cost of care, and improved survival for patients with lung cancer.⁵ Similarly, a randomized trial of home palliative care for patients with chronic conditions demonstrated both improved satisfaction and reduced costs.⁶

Even patients who do receive palliative care may not have access to it soon enough. The National Hospice and Palliative Care Organization reported that more than 35% of patients referred to hospice had a length of service of less than seven days – meaning that for more than one-third of patients, hospice referrals are occurring so late in the course of illness that patients and families have relatively little time to benefit from the available supports.⁷

Unfortunately, most communities in California do not yet have non-hospice palliative care services outside of the acute care hospital. A survey conducted in 2011 found that while the majority (53%) of California's acute care hospitals now offer inpatient palliative care services, only about 18% offer outpatient palliative care.⁸

The aim of CBPC is to serve patients during the portion of the care continuum that lies prior to, after, or between the acute-care setting and hospice, the two relatively well-established venues for palliative care. These “between” realms of care are not well-defined, regulated, or reimbursed.

How would this need ideally be met? A group of clinical and administrative leaders from a variety of California care delivery organizations offered

the following elements of an ideal environment for palliative care:

- Patients with serious illness would have access to palliative services in all settings.
- Palliative services would address advance care planning, care coordination, pain and symptom management, and patient- and family-centered communication.
- Palliative services would be aligned with patient and family preferences and needs, and would be adjusted as needs change.
- Palliative services would be provided by trained, interdisciplinary teams.
- Physicians and other providers throughout the health care system would understand what palliative care is and which of their patients would benefit from it.
- Patients and families would understand what palliative care is. Palliative services would be integrated into the larger care delivery systems and paid for as part of standard care.

Barriers and Challenges

The biggest challenge to providing CBPC is financial. It is time-consuming to help patients talk through their values and priorities and to address the host of physical, psycho-social, and spiritual issues that can accompany serious illness. Even established primary care practices struggle to make ends meet, so a palliative care medical practice, with greater time demands, will be hard-pressed to cover its costs by billing. In fact, there are few models or examples of how a palliative care service can break even in a fee-for-service billing context, regardless of setting.

Palliative care stakeholders such as hospitals or health plans thus require persuasive arguments for

why they might choose to subsidize it. Providers under capitation or bundled payment might have a different experience, and it is predicted that health care increasingly will move toward these types of financial arrangements, where the potential efficiencies generated by palliative care would more obviously justify its support from the organization.

There are a number of other challenges to palliative care, including the following:

- The evidence base demonstrating positive outcomes of CBPC, including cost avoidance, is still under-developed. The lack of standardized methods for documenting the impact of CBPC hampers the development of normative data for staffing, outcomes, benchmarks, and best practices.
- Partnerships that would align the fiscal burdens and incentives for CBPC are difficult to forge because of the data access, administrative skills, and time required for such undertakings. Such partnerships ensure that the entity that benefits from reduced utilization (i.e., health plan, integrated system, public health department) needs to be engaged to pay for the CBPC services.
- Lack of qualified and credentialed professional personnel in palliative care. In particular, physicians who are board-certified in hospice and palliative medicine are far fewer than available positions. Shortages have also been reported for palliative care-credentialed nurses and social workers, while gearing up to provide palliative care in community settings on a widespread basis will only exacerbate these shortages.
- Clarifying the relationship between primary and specialist-level palliative care. Primary care providers could be trained to offer the basics of

pain and symptom management and goals of care clarification in the context of routine patient encounters, while referring the more complex cases to the specialist palliative care team. But these processes have not been worked out on a wide scale.

- Increasing consumer understanding of palliative care, its benefits, its value when provided prior to the end of life, and the relationship between palliative care and the patient's primary physician require considerable outreach, such as through social marketing campaigns.

Opportunities and Leverage Points

In spite of the challenges, many organizations have developed a variety of CBPC services. These efforts reflect the growing interest in palliative care at the health system level, within the context of the national attention to care management, disease management, transition management, and integration of care across health systems, payers, and patient populations. Emerging efforts to strengthen medical homes and create accountable care organizations are the leading edge of a larger trend toward improving coordination of care across the board. In an environment like California, with extensive managed care penetration, there are plentiful opportunities to leverage emerging payment mechanisms to promote CPBC.

Similarly, large private insurers like Aetna, United HealthCare, HealthNet, and a number of Blue Cross/Blue Shield plans have experimented with models of care that resemble many aspects of palliative care, as well as offering hospice benefits earlier in the disease process, and including treatments that might be considered “curative” under the current Medicare rules.

Federal attention to reducing preventable hospital readmissions naturally overlaps with the interest in CBPC. Other federal activities include:

- Hospice concurrent care pilots, authorized by Congress but with funding not yet appropriated;
- Medicare Independence at Home demonstration projects;
- Bundled payment pilots under Medicare set to begin in 2013;
- The recent release of guidelines to shape the development of accountable care organizations; and
- Other initiatives in the context of Medicare's new Center for Innovations and its \$1 billion Partnership for Patients.

Across all of these activities is recognition of the importance of better integration of services across settings to make sure they get the right care in the right place at the right time.

Emerging Models

In California, there is high recognition of the need for palliative care in community settings. There are a number of pilot projects to provide forms of palliative care in clinic settings, private homes, long-term care facilities, and other places where patients could benefit from palliative care. At this time many of these efforts are experiments, pilot projects, individual and/or volunteer efforts, teams of one, and other approaches not yet amenable to dissemination or replication.

Despite the many challenges, multiple entities have developed mechanisms for providing CBPC. Their efforts to leverage opportunities in the current environment — briefly described below — will inform the next generation of CBPC in the state.

Hospice-based CBPC

Hospice care under Medicare has significant eligibility barriers for patients who could benefit from CBPC, yet hospice programs may be the best repositories of the knowledge, skills, and professional resources to provide it if the regulatory barriers could be overcome. One approach for spreading CBPC would be for hospice programs to mobilize their clinical teams to provide a community-based service that might be called non-hospice palliative care. In such a model, palliative care services affiliated with the hospice would be available to provide home-based palliative care and consultations for patients in extended living facilities. Hospices might partner with primary care providers to offer co-management services for patients with complex, serious illnesses.

Although some hospice leaders believe that California's hospices could provide this service right now, the lack of clear reimbursement models and funding streams is a potential barrier.

Some of the best models of hospices providing extensive non-hospice palliative care can be found in other states, including Hospice of the Bluegrass in Lexington, Kentucky; Capital Caring in Falls Church, Virginia; and Four Seasons in Flat Rock, North Carolina. All three have significant palliative care initiatives spearheaded by physician leaders — and all have drawn clear distinctions between what they offer as hospice care and what they offer as palliative care. None have shown an ability to break even on professional services billing for palliative care; however, in many cases these services lead to more and earlier referrals and enrollment in hospice care, as well as opportunities to better serve their patients and families. In some cases, the financial benefits of more and earlier hospice referrals (and resulting economies of scale) may justify subsidizing palliative care, although a number of factors,

CASE EXAMPLE

A Hospice Opens a Palliative Care Clinic

Hospice of the Valley in San Jose has long recognized the unmet needs of patients who don't fit neatly into the regulatory box of hospice care, yet who have many of the same complications and supportive care needs. A nonprofit, community-based hospice, HOV operates in the shadows of large medical centers and health plans. In attempting to provide palliative as well as hospice services, the organization ran into a host of barriers, including:

- California's prohibition against the corporate practice of medicine, which prevents using salaried physicians to provide billable clinical services — which is sometimes more cost-effective than contracting with an incorporated physician or group for these services.
- Medicare rules say hospices should be primarily engaged in the provision of hospice care, which can necessitate corporate reorganization in order to offer palliative care.
- When a Medicare agency provides a valued service such as palliative care that if free might be construed as an inducement to refer for other, Medicare-covered services, it needs to be priced and charged at fair market value.
- Although synergies might be achieved from simultaneous inpatient and outpatient palliative care, HOV has found it hard to make inroads into local hospitals to provide palliative care consultations.
- Providing symptom management and support for patients with advanced illnesses in the home can be very time consuming, and launching an outpatient clinic raises new challenges in the realms of real estate, leases, staffing, and logistics.
- Further, Medicare has been exposing hospices to increased regulatory scrutiny of their core business, with claims reviews, rate cuts, and resulting belt-tightening.

In short, said Medical Director Neal Slatkin, MD, palliative care is a huge gamble for any hospice. Nevertheless, HOV is now proceeding with plans for an outpatient palliative care clinic. "It's the right thing to do for our community," explained CEO Sally Adelus. "It's congruent with our mission, and it's in the best interests of our patients, even if not economically viable and requiring philanthropic support. We're going to get it done."

including regulatory compliance, must be part of the calculation.

Outpatient Clinics

Though relatively rare compared to inpatient services, outpatient clinic-based palliative care services are an emerging trend in California.⁹ A recent national survey reported that such practices generally are small in size, serving approximately 500 patients per year, and are most often affiliated

with an oncology medical practice.¹⁰ Palliative care clinics offer assistance with pain and symptom management, understanding prognosis, advance care planning, and medication management.

These clinics typically have been championed by inpatient palliative care providers, who are keenly aware of the drop-off in supports and services available once patients leave the hospital. Clinic-based services are typically subsidized by a hospital or health system, often with an expectation that

the service will reduce non-beneficial utilization of acute care or emergency services, while increasing the quality and consistency of care.

Key operational considerations for clinic-based palliative care include:

- Site of care — a standalone palliative care clinic versus integration of staff into an existing primary care or oncology practice;
- Deciding whether to assume primary responsibility for a patient's care versus using a co-management or a purely consultative model;
- Referral processes and triggers;

CASE EXAMPLE

Outpatient Services at UCSF

More than a decade ago, UCSF Medical Center started a pioneering palliative care clinic called the Symptom Management Service, offering consultations and co-management services in its comprehensive cancer center's outpatient clinic. The clinic is staffed by a physician and a nurse, and is now being extended to transplant and congestive heart failure clinics on the main UCSF campus.

"UCSF subsidizes what we do, pretty close to the national average of half of our costs," said Medical Director Michael Rabow, MD. Though philanthropy and research bring additional revenue streams, the bottom line is that the UCSF program, like other outpatient palliative care practices, is unable to exist on billing alone. Rabow believes that the field is at least two years away from clarity on best practices. "We know palliative care offers good continuity — so it's good for us and good for the patients we see in the hospital. We also know earlier involvement in the lives of patients with advanced illness improves outcomes," Rabow said.

- Protocols for charting and communicating findings to referring physicians;
- Quality and performance metrics;
- Payment authorization; and
- Staffing, scheduling, and facility logistics.

Though challenges abound, many hospital-based palliative care professionals argue that the outpatient clinic is the logical next step for the field. In November 2012, the Center to Advance Palliative Care launched a set of tools, models, and resources to help advance practice in this realm.¹¹

Medical Groups

Medical groups, especially in environments where managed care is strong, such as urban and suburban California, can also be an important focal point for organizing CBPC. In Southern California, several large medical groups are already under significant capitated or risk-based relationships with health plans for defined patient populations — or else run their own health plans. Some of these groups have leveraged expertise gained by hospital-based palliative care and applied those skills to other settings such as primary care practices. This is where many patients access medical care currently, making it a logical setting for introducing CBPC.

Risk-bearing medical groups such as CareMore and HealthCare Partners have found ways to address hospital readmission concerns through cross-setting teams, short-term post-discharge clinics, and the use of "extensivists." These are hospitalists who extend their services beyond the hospital's walls to better manage patients with complex medical needs that are beyond the scope of their primary care physician.

Integrated Delivery Systems

Many experts believe that the most promising avenue for CBPC lies with the forward-looking, successful integrated delivery system that operates, at least in part, under capitated or risk-bearing managed care payment. Jeffrey Hay, MD, care continuum vice president for Sharp HealthCare, said there are 30 to 50 such integrated health systems nationwide that could quickly roll out CBPC when reimbursement and regulatory incentives become aligned — and are poised to do just that. Kaiser Permanente and the VA health system are examples of large, integrated systems that have devoted considerable attention to experimenting with models of palliative care in and out of the hospital. Examples from other states include Partners medical group in Boston, the University of Pittsburgh, and the Long Island-Jewish hospital system in New York State.

A key advantage of the integrated delivery system in the coordination of palliative care across settings is its ready access to all three necessary supports — information, communication, and financing.

Other Models and Settings

Other potential settings for CBPC include home health agencies, long-term care facilities, and independent community clinics, although these may be constrained by regulatory demands and because financial incentives give these entities less leeway to experiment or invest in “loss leader” palliative care programs. However, they will be important to community palliative care, as either innovators or collaborating partners, and they need to be drawn into the conversation about CPBC.

The Sutter Health System’s AIM (Advanced Illness Management) initiative is a distinct model for providing coordination outside of a hospice benefit context, receiving national attention for these efforts. AIM started 11 years ago based within a

CASE EXAMPLE

An IPA Demonstration Project

Irvine-based Monarch HealthCare is a large medical group IPA that is exploring options for developing CBPC. Monarch was already participating in an accountable care organization demonstration project of the Brookings Institution and Dartmouth College.

Opportunities for palliative care depend in part on whether the group is partially or fully capitated and at risk for hospital costs, explained Dr. Vincent D. Nguyen, Monarch’s medical director of geriatrics and palliative care services. A group of hospitalists employed by Monarch has been receiving supplemental training in palliative medicine at UC-Irvine, with the goal of eventually staffing a palliative care practice.

Nguyen has spearheaded a demonstration project to provide home visits to palliative care patients. He follows the framework established by the National Consensus Project for Quality Palliative Care, using a team composed of a physician and nurse practitioner.* Finding qualified staff has been a challenge, said Nguyen, who has been making the initial home visits himself under the pilot project. He is testing the program’s return on investment for the group from indirect cost savings under capitation and the prevention of rehospitalizations. Nguyen believes that palliative care is the next logical extension in care coordination for patients with complex needs, and that it should be offered from the point of diagnosis of a serious illness.

*National Consensus Project for Quality Palliative Care, www.nationalconsensusproject.org.

home health care model, linking this benefit to the hospice team in order to capture patients upstream from hospice eligibility. But now it is evolving into a more clinically integrated model that is being piloted in two regions of the 24-hospital Northern California health system, reported Brad Stuart, MD, senior medical director of Sutter VNA and Hospice. Patients are identified while they are in the hospital. A telephonic call center coordinates care planning with medical office-based care managers, inpatient palliative care services, hospitalists, and emergency

CASE EXAMPLE

Complex Palliative Services at Sharp

Sharp HealthCare in San Diego offers palliative and end-of-life care, as well as advance care planning support services, through its hospice and advanced illness management programs. Hospice director Suzi Johnson said Sharp has tried to approach palliative and end-of-life care in formalized and systematic ways, identifying this care as one of five major priorities for senior administrators.

Sharp started out providing CBPC for heart failure patients in their homes, working with its two internal medical groups, through its Transitions Program. The aim is to break down cultural barriers regarding how heart failure patients should be cared for and to provide state-of-the-art care outside of the hospital. It subsequently added COPD and dementia and, in 2010, advance care planning professional consultation visits.

Measurable outcomes include reductions in emergency room visits and hospitalizations, enhanced caregiver support, higher rates of executing advance directives, and earlier referrals to hospice. The ultimate goal, Johnson said, is to truly offer enhanced end-of-life care systemwide.

departments, while home visits are provided to extend the package of clinical care coordination.

Developments that Would Promote CBPC

A number of policy shifts could encourage spread of CBPC. The clearest need is to adjust reimbursement mechanisms, specifically development of financial incentives to support care coordination and palliative care — whether part of larger changes (e.g., bundled payment) or under a benefit specifically designed for palliative care, either in or outside of the hospital, or both. One approach could be a benefit similar to the Medicare hospice benefit for a coordinated package of services provided in the home or community; it might be paid on a per-diem or per-episode basis, although with a different rate structure than the current hospice benefit. However, any new health entitlements are problematic in the current legislative climate.

Further, investments need to be made to develop evidence that will give payers and providers more confidence in the fiscal, operational, and quality benefits of CBPC. Much of the evidence needed to support widespread adoption of CBPC services could be generated by funding pilot projects of community-based palliative care. Some possibilities:

- A home care-based palliative care benefit for a limited, late-stage patient population could be structured under the home health agency model, but with different eligibility criteria and care goals not based on rehabilitation.
- A specific benefit could provide palliative care consultations in the nursing home, or at least place a palliative care nurse practitioner in every nursing home.
- The current hospice benefit might need changing, not just to allow concurrent care, as proposed for

demonstration projects passed by Congress in 2010, but to better match payment with patient need and the cost of meeting it.

- Support could be provided for advances in quality measurement, monitoring, and improvement.

Ten Steps Toward Specificity

Organizations and providers interested in creating or enhancing CBPC programs will need to develop local information about needs and goals for their program, what it will do, who it will serve, how it will function, and how it will be financed. While the specifics of each model will vary, the issues that need to be considered will likely be similar across settings. They can be summarized as follows:

1. **Clarification of goals.** Which patients would benefit from CBPC? What supports or services are not being provided? Which services are in place, and how can duplication of effort be avoided? Answering these questions will require development teams to conduct needs assessments and gap analyses, and to consider issues of mission alignment when envisioning new programs.
2. **Operating model.** What is the operating model that would best respond to the information gathered from the needs assessment and gap analysis?
3. **Business model.** What is the return on investment? If subsidy is required, how much, who would provide it, what is their motivation? What is the long-term strategy for sustaining the program?
4. **Interdisciplinary team.** National standards dictate that palliative care is best undertaken by an interdisciplinary team, as each professional

brings essential perspectives to the work. Still, development teams need to consider staffing ideals in the setting of available resources, and some may need to accumulate a full complement of clinical team members over time. Aside from funding limitations, many development teams will need a strategy for overcoming professional staff shortages, for example opting to train existing staff rather than recruiting fully trained individuals.

5. **Palliative care expertise.** Hospice and hospital-based palliative care services already understand the palliative care needs of seriously ill patients, so the challenge is to determine how to extract and use that expertise. Teams will need to understand the role of primary care practitioners in providing primary palliative care in conjunction with the specialist team.
6. **Access to patients.** Where do palliative care needs get identified? What is the conduit for referral? Is there a triggering mechanism, algorithm, or referral criteria? What is the marketing strategy to reach primary providers or others who are well-positioned to first recognize palliative care needs?
7. **Organizational culture.** Are stakeholders committed to the imperative of implementing patient-centered palliative care? If not, what kind of outreach or education is needed to gain their support?
8. **Alignment with health care reform.** Is there a strategic vision to align with new funding models and trends toward ACOs, bundled payment, medical homes, or other configurations that are transforming the larger health care system?

9. **Standard of practice.** How will outcomes — financial, operational, quality — be measured, benchmarked, and continually improved?
10. **Clear message.** Palliative care is not well understood by various audiences and constituencies. What is the audience-friendly message, and how will it be communicated?

Endnotes

1. There are more than 5,000 hospice programs in the US, enrolling 1.6 million people annually. National Hospice and Palliative Care Organization, “NHPCO Facts and Figures: Hospice Care in America, 2010 Edition” www.nhpco.org.
2. Morrison, R.S., J.D. Penrod, J.B. Cassel, M. Caust-Ellenbogen, A. Litke, L. Spragens, D.E. Meier. “Cost Savings Associated With US Hospital Palliative Care Consultation Programs.” *Arch Intern Med* September 8, 2008; 168:1,783.
3. The Center to Advance Palliative Care, “Growth of Palliative Care in US Hospitals 2011 Snapshot,” www.capc.org.
4. Smith and Cassel. “Cost and Non-clinical Outcomes of Palliative Care.” *JPSM* 2009, 38(1):32–44.
5. Temel et al. “Early Palliative Care for Patients with Non-small-cell Lung Cancer.” *NEJM* 2010;363: 733–42.
6. Brumley, R.D. et al. “Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care.” *JAGS* 2007 55:993–1000.
7. National Hospice and Palliative Care Organization, “NHPCO Facts and Figures: Hospice Care in America, 2011 Edition” www.nhpco.org.
8. “When Compassion Is the Cure: Progress and Promise in Hospital-Based Palliative Care,” California HealthCare Foundation, www.chcf.org.
9. Berger, G.N., D.L. O’Riordan, K. Kerr, S.Z. Pantilat. “Prevalence and Characteristics of Outpatient Palliative Care Services in California.” *Arch Intern Med*, published online October 10, 2011.
10. Rabow, M.W., A.K. Smith, J.L. Braun, D.E. Weissman. “Outpatient Palliative Care Practices.” *Arch Intern Med* April 12, 2010; 170:654–655.
11. The Center to Advance Palliative Care, IPAL-OP, www.capc.org.



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