

SAN FRANCISCO PALLIATIVE CARE TASK FORCE

ISSUE BRIEF #1

PALLIATIVE CARE OVERVIEW

In her presentation “What is Palliative Care?” Redwing Keyssar, Director of the Palliative Care Program at Jewish Family & Children Services, San Francisco, summarizes the essence of palliative care:

The great 13th Century poet Rumi tells us, sometimes a door opens and a human being becomes a way for grace to come through. I like to think palliative care is a new door opening in the world of modern medicine, allowing health care professionals to be a way for grace and compassion, as well as knowledge, to come through. Palliative care is about relieving suffering. It is about relieving suffering, not only physical suffering, but emotional, psychological, and spiritual suffering as well. It is a holistic approach to caring for a person at any stage of an acute or chronic illness, from day of diagnosis through the end of life.[2]

Palliative care is a dynamic person-and family-centered practice of care that focuses on improving quality of life during serious or life-threatening illness. Rooted in the interdisciplinary hospice model of care, palliative care addresses the relief of pain and other symptoms. Like hospice, the delivery of palliative care is based on patient needs, preferences, and goals of care; but unlike hospice, palliative care can be provided at any age and any stage of an illness, even alongside curative treatment. Palliative care is primarily provided by interdisciplinary teams—doctors, nurses, social workers, and chaplains—and can be delivered in multiple settings: from acute care hospitals and skilled nursing facilities, to outpatient settings and long-term care facilities, to community programs within home health and hospice, to hospices.[3]

Broadly, palliative care has the potential to benefit many patients, often beginning at the moment of diagnosis of a serious illness or condition. To aid the San Francisco Palliative Care Task Force in its work of assessing current San Francisco palliative care resources and anticipating future needs however, the primary palliative care patient population for consideration will be patients with serious life threatening illnesses or conditions in their last year or two of life. This group of patients is frequently identified through the use of the “surprise question.” The surprise question asks providers, *Is the patient’s diagnosis serious enough that you would not express surprise if the person died in the next year or so?*[4] The question has proven helpful in identifying patients with chronic conditions in need of palliative care earlier in their disease process.

PALLIATIVE CARE ELEMENTS

Palliative Care Elements[1]

- Relieves symptoms, pain, and stress of a serious illness—whatever the diagnosis.
- Facilitates communication with patients about patient care goals and provides support for complex medical decision-making.
- Improves quality of life for both the patient and the family.
- Is provided by a team of doctors, nurses, social workers, chaplains, and other specialists (e.g., Psychologists, Pharmacists, etc.) —who provide an extra layer of support— in conjunction with all other appropriate medical treatments, including curative and life-prolonging therapies.
- Is appropriate at any age and at any stage in a serious illness.

SETTINGS OF PALLIATIVE CARE

Palliative care is currently provided in hospital-based, outpatient/community-based, and hospice-based settings, demonstrating the flexibility and responsiveness of this field of care.

Hospital-Based Palliative Care

The most well established palliative care program is the Hospital-Based Palliative Care Program. In 2011, the prevalence of palliative care in large hospitals—300 or more beds—was 85 percent, and that percentage is expected to increase dramatically over the next decade. [5]. A palliative care consultation team generally provides hospital-based palliative care. The team often includes a Board certified palliative care physician or nurse specialist, nurse, social worker, and chaplain. Referrals for hospital palliative care consultation are typically initiated at the request of the treating physician. Once received, the team meets with patients, and their families, usually in a series of consultations, to conduct a comprehensive, formal assessment of the patient and family. The assessment clarifies the reasons for the patient admission, as well as problems and symptoms the patient is experiencing. Throughout the assessment, the patient’s physical, psychosocial, social, cultural and spiritual needs are also assessed.

Working closely with patients’ treating physicians, the team helps patients select treatments and discharge options that meet their goals and preferences. Once the assessment is completed, a patient-centered care plan is developed that covers a range of issues, from symptom and side effect management, to preferred religious/cultural practices and rituals, to goals for medical care. Family meetings are customarily held with the patient, family, and members of the consultation team. Meetings focus on reviewing and discussing patient goals of care, prognosis, treatment options, and, as appropriate, plans for post-discharge care.[6, 7]

Outpatient/Community-Based Palliative Care Services

The success of hospital-based palliative care has inspired a growing interest among health care organizations, policy makers, and funders throughout the country to finance, operationalize, and deliver community-based palliative care—non-hospice palliative care services outside of the acute care hospital. Outpatient and community-based palliative care can be found in hospital outpatient and community clinics, office-based care, home-health services, long-term care facilities, and increasingly in managed care and integrated care delivery systems.

Because people live in the community and experience health encounters across settings, the need for palliative care after or between hospital stays and hospice is becoming more acute. But the availability of palliative care outside the acute care setting remains limited.[8] The chief barrier to providing palliative care in community settings is financial. With its emphasis on understanding, discussing, and honoring patient preferences and goals of care, the time required to provide this care is not sufficiently reimbursed under the current fee-for-service billing structure.

In the near future, financing for palliative care across the continuum of care is expected to undergo significant change. Dedicated national, state, and local efforts to integrate community-based palliative care into accountable care organizations, patient-centered medical homes, and within payer coverage benefits and population health management initiatives, indicate that payment structures are aligning to support palliative care beyond the hospital setting.[9]

Hospice-Based Palliative Care

Although palliative care is not the same as end-of-life care, palliative care encompasses the hospice model of care, which provides care to terminally ill patients who have six months or less to live, and are no longer receiving curative treatment for their underlying disease. As with palliative care provided outside of the hospice setting, the hospice model is an interdisciplinary team approach to providing medical care, pain management, and emotional and spiritual support according to the patient's needs and wishes. Hospice care provides access to compassionate care 24/7—in the patient's home, or in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities, offers respite services to caregivers and extends bereavement support to families after their loved one's death.

Hospice care in the United State is a capitated form of care with restricted eligibility criteria that is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.[10] For Medicare certified hospices, because the capitation rate does not account for expensive treatments, many patients are unable to receive certain costly curative or palliative care therapies under the hospice benefit.

Similar to palliative care provided in hospitals, the hospice team works with the patient and family to develop a care plan that meets the patient's needs. In addition to pain management and symptom control, the hospice benefit includes:

- Assistance with the emotional and psychosocial and spiritual aspects of dying;
- Provision of needed drugs, medical supplies, and equipment;
- Guidance to the family on how to care for the patient;
- Delivery of special services like speech and physical therapy when needed;
- Short-term inpatient care for when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time; and
- Bereavement care and counseling to surviving family and friends.

THE IMPACT OF PALLIATIVE CARE ON TREATMENT, PATIENT QUALITY OF LIFE/CHOICE, AND COSTS

Advances in disease prevention, disease-modifying therapies, medical technology, and the aging of the population have resulted in a dramatic growth in the number of adults living with serious illness. The impact of these developments has also resulted in costly treatments that often are not in alignment with patient treatment preferences, goals in care, and quality of life. Palliative care has proven effective in addressing each of these issues, as well as the costs of care.

Treatment Preferences

A survey of Californians sponsored by the California HealthCare Foundation, found a majority of respondents were interested in speaking with their doctor about palliative and hospice care, but few had. In addition, most respondents said they would prefer to die at home; however in 2009, more deaths occurred in the hospital than at home. And hospitals are where variation in clinical care—including the potential for patients at the end-of-life to receive costly treatments they do not want—occurs most.[11, 12]

What patients want at the end of life and the care they receive has long been recognized as a serious gap in health care.

Source: Brownlee, S., Measuring Up? End-of-Life Cancer Care in California.

In the Dartmouth Atlas 2013 report, *Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life*, two significant findings emerged.

First, care for chronically ill patients near the end of life varies significantly across regions and hospitals; and second, despite rapid improvement in the care provided for this population of patients, patients in some hospitals continue to receive more aggressive and less palliative care than others.[12] In research on Californians with poor-prognosis cancer, Brownlee writes that “regions and hospitals where cancer patients are hospitalized more often in the last month of life, receive more-aggressive treatment in their last month, and spend relatively few days in hospice,” may suggest that patients are receiving treatment that they do not want.[13]

Quality of Life

Palliative care has consistently demonstrated improved quality of life and mood for patients managing end-stage and serious chronic illness. Results of a randomized, controlled trial of

early palliative care in addition to standard oncologic care for patients with newly diagnosed metastatic non–small-cell lung cancer, affirmed that palliative care initiated early, at the time of diagnosis of a serious or life-limiting illness, and simultaneous with other appropriate treatments and therapies, improved quality of life for patient participants. [14] Study participants receiving early palliative care actually experienced increased survival (by approximately two months), and clinically meaningful improvements in quality of life and mood compared to those assigned to usual care. Numerous studies have found similar associations between palliative care and quality of life. [15, 16] Central to these outcomes is the opportunity for palliative care patients to express their treatment preferences, life choices and values, as they relate to the course of their illness and goals of care.

Patient Choice

Once informed, consumers want to be able to have access to palliative care if they need it.

Despite the benefits of palliative care, most consumers do not know what it is, how it differs from hospice care, and how they might benefit from it. A Center to Advance Palliative Care 2011 national survey found that once consumers understand what palliative care is, they have an extremely positive feeling about it.[17] The survey presented two additionally compelling findings: *Once informed, consumers want to be able to have access to palliative care if they need it*, and, *Once informed, consumers say they would be very likely to consider using palliative care if they or a loved one had a serious illness*.

In the report, *Measuring Up? End-of-Life Cancer Care in California*, Brownlee concludes that well-informed patients have strong opinions about the care that they want and don't want. She further notes that it is the responsibility of clinicians and health care systems to help patients understand their options and to articulate their goals.

Costs

Palliative care not only increases patients' goal alignment and informed choice, with respect to their care; it is bending the cost curve. In addition to longstanding research findings that support the cost effectiveness of palliative care, a recent comprehensive literature review of studies assessing the costs and cost-effectiveness of palliative care interventions in any setting from 2002–2011, reported, "palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant." [18-21]

PALLIATIVE CARE IN CALIFORNIA

Palliative care is increasingly recognized as a valued health care service that would benefit Medicare and Medicaid beneficiaries. The Centers for Medicare & Medicaid (CMS) recently announced a new demonstration project (Medicare Care Choices Model) that will provide an option for Medicare beneficiaries to receive palliative care services from certain hospice

providers while concurrently receiving services provided by their curative care providers. CMS's Center for Medicare and Medicaid Innovation (CMMI) has also funded a number of projects that feature palliative care as a critical component of health care transformation, consistent with delivering better health, improving care and lowering costs—CMS's Triple Aim.

In April 2013, California was one of 16 states awarded a CMMI State Innovation Model Design Grant, to develop a State Health Care Innovation Plan (SHCIP) to support multi-payer payment and health care delivery system transformation in the state. Building on California's *Let's Get Healthy California* (LGHC) Task Force Framework, California identified palliative care, a key LGHC indicator, as one of four initiatives in the SHCIP (under review by CMMI for a State Innovation Model Testing grant). Palliative care was selected because it was identified as a fundamental element of health system and payment reform with its focus on care coordination, team-based care, and link with community-based organizations. The plan includes the following key objectives to support and improve the provision of palliative care:

- Incorporate palliative care capacity within Health Homes for Complex Patients.
- Identify and adopt new benefit and payment approaches to better meet patient preferences for palliative and hospice care.

In addition to the SHCIP focus on palliative care, the California Senate Committee on Health recently approved a measure to expand a children's palliative care pilot program to the adult population of California, anticipating the benefit for California's aging population. The bill would direct the Department of Health Care Services to seek a waiver to evaluate a palliative care benefit in the Medi-Cal program. Behind the proposed legislation is evidence that the palliative care benefit for children has increased quality of life and lowered health care costs.[22]

Before the state's recent focus on palliative care as a critical element of health system and payment reform, California demonstrated steady gains in the provision of hospital-based palliative care. In 2011, the National Health Foundation and the University of California, San Francisco, Palliative Care Team, conducted a follow-up survey of California hospital-based palliative care programs, originally reviewed in 2007. In the survey's report, *When Compassion is the Cure: Progress and Promise in Hospital-Based Palliative Care*, several key findings showcase the significant growth in hospital-based palliative care programs in California.[23]

- Of the 361 responding hospitals [to the 2011 California Hospital-Based Palliative Care Survey], 53% have a palliative care program, up from 43% in 2007.
- Palliative care consultation services have experienced dramatic growth in recent years: Between 2007 and 2011, pediatric services increased by 128%, while adult services increased by 24%.

California's public hospital safety-net system is a national leader in the availability and sustainability of palliative care services.

Source: In it Together, How Palliative Care Spread to All of California's Public Hospitals, The California HealthCare Foundation

- In 2007, only 4% of hospitals without palliative care programs had plans to start one; in contrast, in 2011, of the 169 California hospitals without a palliative care program, 43 (25%) have an effort underway to begin one.

The substantial growth in California hospital-based palliative care in recent years has not however, been matched by similar growth in community-based palliative care around the state. California hosts a number of palliative care pilot projects in clinic settings, private homes, and long-term care facilities, beyond the small percentage of outpatient palliative care programs offered by acute care hospitals around the state. But many of these efforts are still in the experimental phase, not yet amenable to dissemination and replication.[8] Likewise, reimbursement for these services is not yet aligned to provide them in a sustainable way.

Because community-based palliative care is dramatically underdeveloped and underutilized in California—in a 2013 report the Berkeley Forum found only 20 percent of potentially appropriate patients in the state have access to community-based palliative care services—the state emphasized in the recent SHCIP plan that the incongruence between patient preferences and care delivery results in health care costs toward the end of life that are significantly higher than they need to be.[24, 25] To reduce these healthcare expenditures and increase quality of life for patients with serious illness in the last year of life, the Berkeley Forum proposes a model of concurrent curative and outpatient, community-based palliative care.

THE NEED FOR PALLIATIVE CARE IN SAN FRANCISCO

With increased national and state attention on quality, cost-effective palliative care across the continuum of health care, identifying a plan for making this service available to more San Francisco residents is essential. At this time however, there is no summary description of the different forms of palliative care presently offered across the city's rich array of health care institutions and providers, and community-based health and social service organizations. Similarly, San Francisco has no blueprint for addressing its future palliative care needs, in spite of a growing older adult population.

Prior to developing a viable plan to meet current and future palliative care needs for San Francisco, several population characteristics merit thoughtful consideration. These include the aging population; residents living with dementia/Alzheimer's disease and chronic conditions, including serious disability; and, San Francisco's cultural and socioeconomic diversity.

San Francisco's Senior Population is Growing

In the 2012 report, *Community Health Status Assessment: City and County of San Francisco*, prepared for the San Francisco Department of Public Health, it was estimated that 55 percent of San Franciscans will be over the age of 45, and the population over age 75 will increase from seven percent to 11 percent by 2030.[26] The report's population projections by age also

estimate that seniors age 65 and older are expected to compose approximately 21 percent of San Francisco’s population by 2030 (Exhibit 1). The report further underscored that this anticipated demographic change would take place in a culturally diverse city, actively committed to eliminating health care disparities and inequities. As such, a key finding for the report is the need for more long-term care options that are culturally responsive and accessible.

Exhibit 1: San Francisco 2020 and 2030 Population Projections by Age

Age Group	Percent of Total San Francisco Population			
	Current	2020 Estimate	2030 Estimate	Trend
Young children (0-5)	5	5	5	
Children (6-14)	6	8	6	
Teens and Youth (Age 15-24)	12	7	8	
Adults (Ages 25 to 44)	37	30	26	
Adults (Ages 45 to 64)	26	33	34	
Seniors (Ages 65 to 74)	7	10	10	
Seniors (Ages 75+)	7	8	11	
Total Population	805,235	844,466	854,675	

Source: California State Department of Finance

Advanced Dementia/Alzheimer’s Disease, Chronic Conditions, and Disability

Quality of life is often impacted for individuals with advanced dementia/Alzheimer’s disease, as well as for those living with chronic conditions, including serious disability. Only in recent years has more attention been given to extending palliative care services to these individuals. This change is critical. Between 2010 and 2030, there will be a 49 percent increase in the number of San Francisco residents with Alzheimer’s related dementias (from 23,445 to 34,837).[27] Given the city’s aging population, the number of people living with heart disease, diabetes, and multiple chronic conditions is also expected to rise. And, the number of city residents with serious disability currently estimated at 10.4 percent is also likely to increase over the next several decades. Acknowledging the needs of residents managing serious diagnoses, conditions, and disability in the development of strategic recommendations to meet San Francisco’s palliative care needs is imperative.[28]

Financially Accessible Palliative Care Services

San Francisco has a high rate of income disparity with significant implications for low-income seniors and persons with disabilities. [29] Given the likelihood that many individuals from both communities will need future palliative care services over the next few decades, ensuring their accessibility to the broad range of future palliative care services in diverse settings will be central to developing a comprehensive and inclusive palliative care plan for San Francisco.

13.6 Percent

Percentage of San Franciscans age 65 years and older living below the federal poverty level.

Source: U.S. Census Bureau, 2008-2012 American Community Survey 5-Year Estimates

SAN FRANCISCO PALLIATIVE CARE TASK FORCE: NEXT STEPS

The goal of the San Francisco Palliative Care Task Force is to examine the likely demand for palliative services, along with currently available San Francisco palliative care resources, and make recommendations for future needs, responsive to the city's projected demographic changes and socioeconomic and cultural diversity. In the process, the Task Force has the opportunity to become a national example of cross-collaboration in providing culturally responsive, high-quality, cost effective palliative care.

The following draft principles and questions are presented to aid San Francisco Palliative Care Task Force members in their discussion of the Task Force goal and work process.

Draft Principles

Five key draft principles were identified to guide the San Francisco Palliative Care Task Force in its work:

- **Least Restrictive Setting:** Support palliative care in the least restrictive setting according to an individual's needs and preferences.
- **Cultural Competence and Cultural Responsiveness:** Support palliative care that is inclusive of and responsive to cultural and population diversity, including consideration of race, ethnicity, class, age, gender, sexual orientation, disability, language, religion and other indices of difference.
- **Equity:** Support palliative care that does not vary in quality because of characteristics such as gender, race, ethnicity, geographic location, and socioeconomic status, so health disparities are reduced.
- **Accessibility:** Support palliative care that ensures that all individuals and families have equal access to palliative care services.

- **Dignity:** Support the dignity of palliative care patients and families—their choices, wishes, and desire to live and die free of pain.

Guiding Questions

The following questions are presented as a framework for members' discussion of the strategic focus for the Task Force:

- What should palliative care look like in San Francisco? How can the Task Force help the city to move forward with developing a vision for palliative care?
- How might an informed public and healthcare community change perceptions and the use of palliative care? Should the task force focus on a particular aspect of palliative care (such as promoting discussions about communicating treatment preferences) as a means of educating the public about palliative care and end-of-life choices?

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