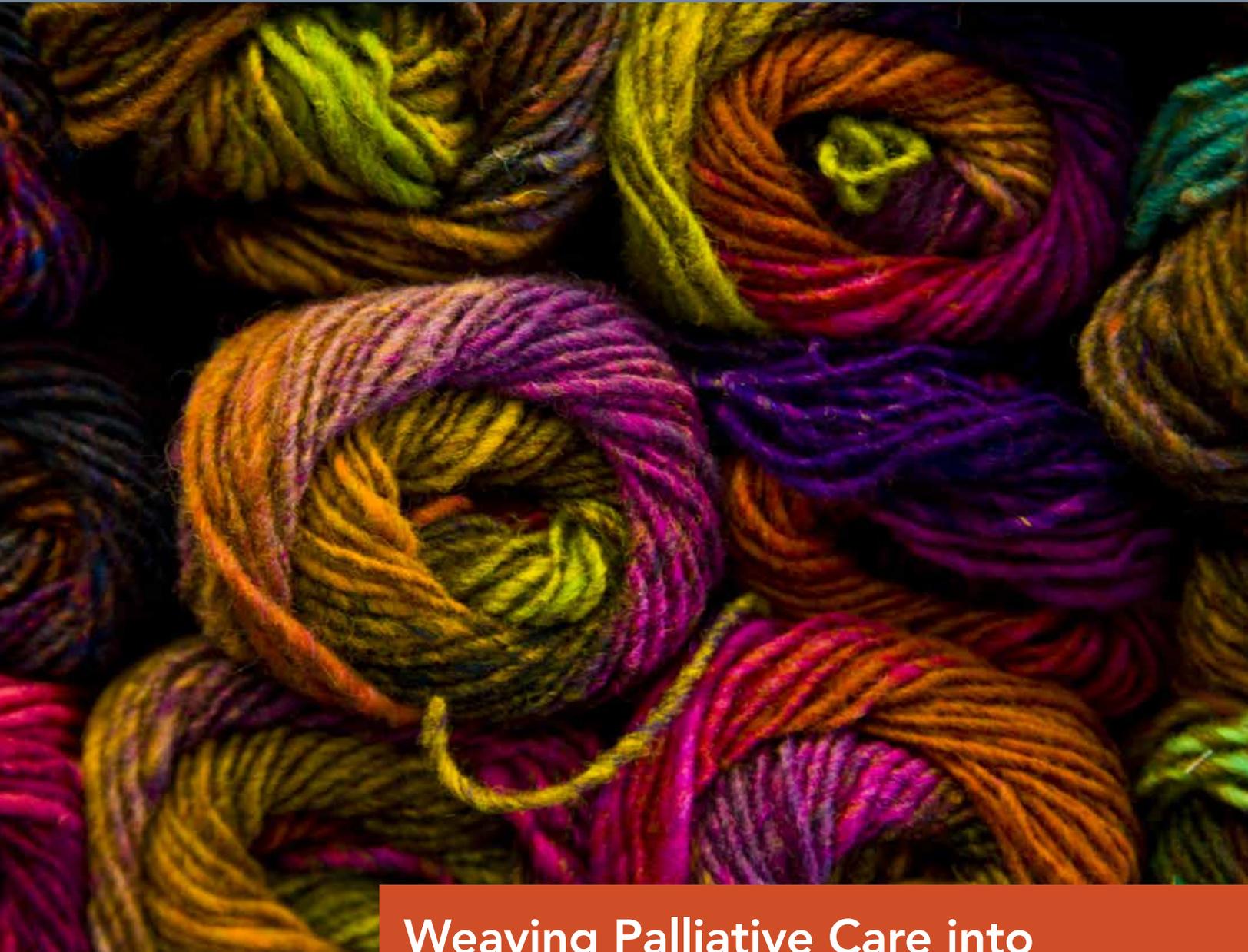




CALIFORNIA HEALTHCARE FOUNDATION



**Weaving Palliative Care into
Primary Care: A Guide for
Community Health Centers**

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Introduction

In the groundbreaking 2014 report *Dying in America*, the Institute of Medicine recommended that all people with advanced serious illness have access to palliative care specialists.¹ While the recommendation is important, the reality is that there are not enough of these highly trained providers to meet all of the current or future need in the US.² This gap is likely to grow as people live longer and the population ages.

There are, however, primary care providers (PCPs) offering some palliative care services to their seriously ill patients, and many more who want to do so. The purpose of this guide is to offer primary care providers — particularly those working in clinic settings — information and tools for integrating primary palliative care into their practices. Because populations served by community health centers (CHCs) tend to have relatively little access to palliative care, this guide is primarily focused on the needs of primary care providers working in CHCs.

Explicit integration of palliative care into primary care has been recommended by a number of health care experts as a means of fulfilling an unmet need while reserving scarce specialist palliative care for the most complex cases. The approach is similar to the role of primary care in providing the bulk of basic care for patients with cardiovascular disease, while cardiologists are consulted for the most complex patients.

Primary care supports many core principles promoted by palliative care. Both focus on and treat the whole person, not just the disease or health condition. Both recognize that physical, psychological, social, and spiritual issues and concerns, and primary relationships (family and community) impact health and well-being. And both educate, support, and advocate for patients, families, and caregivers across all health care settings.³

PCPs are optimally positioned to address the initial palliative care needs of many patients and families. Patients often first turn to their trusted PCP to discuss their new diagnosis or issues related to advanced care planning, anticipatory grief, and bereavement.³ PCPs have the opportunity to facilitate early palliative care interventions and consults and can also identify community resource referrals.

Common Abbreviations

ACP	Advance Care Planning
AHCD	Advance Health Care Directive
ADL	Activities of Daily Living
CHC	Community Health Center
DO	Doctor of Osteopathic Medicine
EHR	Electronic Health Record
IDT	Interdisciplinary Team
LVN	Licensed Vocational Nurse
MA	Medical Assistant
NCP	National Consensus Project
NQF	National Quality Forum
NP	Nurse Practitioner
PA	Physician Assistant
PC	Palliative Care
PCP	Primary Care Provider
POLST	Physician Orders for Life-Sustaining Treatment
SNF	Skilled Nursing Facility
SW	Social Worker

What Is Palliative Care?

Palliative care is a recognized medical specialty as well as a philosophy and an approach to care. Rooted in the interdisciplinary hospice model of care, palliative care offers relief from suffering for patients with serious and complex illness, and addresses and promotes patient and family quality of life.

Similar to hospice, interdisciplinary palliative care teams include doctors, nurses, social workers, and chaplains. However, the Medicare hospice benefit is limited to patients in the last six months of life who are no longer pursuing curative treatment. Unlike hospice, palliative care can be provided at any age and any stage of illness, even combined with curative treatment.⁴

Many benefits of palliative care have been documented. It improves patient symptoms, quality of life, and patient and family satisfaction.⁵⁻⁷ Outcomes also include greater clarity in goals of care, avoided health crises, increased

Palliative Care Treats the Whole Person

MJ is a Caucasian woman diagnosed with breast cancer 23 years ago at age 38. She has lived with Stage IV disease for the past 18 years.

“After my spinal cord compression, I had no energy. I was grieving the loss of my full capacity. And I was tired with so much death — of people I had come to know through my illness. People don’t often discuss the weariness of illness, but the level of weariness is extraordinary.

“What works best is my relationship with my palliative care doctor. He listens; he is very present. He understood my weariness. I wish my other doctors were fluent in palliative care and the range of alternative treatments that can aid in healing.

“My one recommendation is that listening should be both taught and held as an essential part of palliative care; actually, of all care.”

capacity to receive care safely in the home, and improved planning. In addition, patients reduce use of some health services (hospital admissions, intensive care unit stays, emergency department visits), and increase use of others (home-based health services and hospice care), resulting in lower overall health care costs.⁸⁻¹³

In their study of patients with metastatic non–small-cell lung cancer, Temel et al. found that patients assigned to early palliative care had significantly higher quality of life and mood scores than those assigned to standard care. In addition, median survival for this patient group was longer than for patients receiving standard care.¹⁰

Palliative care is provided in settings across the health care continuum. A growing number of hospitals have

palliative care programs, and much of the research on palliative care is based on the inpatient setting.

Outside of the hospital setting, palliative care is also provided almost anywhere that patients are: skilled nursing facilities (SNFs), assisted living locations, community centers/clinics, extended care facilities, private residences, and residential hospice facilities. Services can also be available through telephone and videoconferencing technology.

Such community and outpatient settings are often closely linked to primary care, which can facilitate access to palliative services earlier in the disease process. In fact, outpatient palliative care clinics have been shown to have a profound impact on patient satisfaction with care.¹⁴ In other research, outpatient palliative care patients consistently report feeling “cared for,” “valued,” “listened to,” and receiving “compassionate” treatment from the palliative care team.¹⁵ (See Appendix D for more about the benefits of clinic-based palliative care.)

Palliative Care in SNF

TMH, a refugee from Viet Nam, became a caregiver when her mother fell ill. When the mother’s care needs exceeded what TMH could manage while working, she placed her mother in an SNF where she received palliative care.

“For seven months I went to the nursing home to be with my mother during dinnertime. She liked me to feed her. After dinner she liked me to walk her to a small balcony so she could light a stick of incense. Every night she prayed to get well, so she could go home. Every night she would want me to clean her and put her to bed. The staff respected this ritual.

“Staff took care of me while I took care of my mom. They looked at me, and at my pain, and respected our culture and spiritual beliefs.”

Core Components of Primary Palliative Care

Providing primary palliative care in a CHC setting requires:

- ▶ Involvement of an interdisciplinary team of providers to meet patients' and families' needs
- ▶ Creating systems for routine, reliable assessments of symptoms and care needs
- ▶ Creating pathways for triaging patients who screen positive for symptoms/distress
- ▶ Committing to continuing education and skills training for staff

The following description of the scope of primary palliative care services that might be offered in CHCs is adapted from the McCormick, Chai, Meier article "Integrating Palliative Care Into Primary Care."³

Addressing Physical Needs

Pain and Other Physical Symptoms

Patient assessments are a central feature of palliative care and can be part of an initial palliative care screening process or a comprehensive evaluation. Protocols vary, however, in comprehensiveness and length, and in how they are administered (self-assessment or assessment by health care providers). CHCs are encouraged to formalize screening procedures with standardized tools and defined processes, and evaluate which assessments can be integrated into the electronic health record (EHR) and into clinic workflow.

Once symptoms are identified, CHCs can determine how to triage patients based on the competence of providers and staff to address them.

Clinics frequently have guidelines regarding the use of opioids in chronic pain. Typically these guidelines have exceptions for the management of patients at the end of life to accommodate the differences in goals of treatment. Providers and staff need to understand in which cases the monitoring policies will apply to palliative care patients, and when requirements (e.g., urine drug screens, or refill policies) will be waived.

Functional Status

Functional assessments describe how patients function in their everyday lives with respect to activities of daily living (e.g., eating, bathing, dressing, etc.). Patients' level of independence with these activities is a determinant of their caregiving needs and often impacts their goals of care.

Because patients frequently do not share their functional and performance difficulties with providers, unless asked, assessments can bring out needs that would not otherwise be identified during a routine visit.

Primary Palliative Care Can Meet Unmet Needs

MB is an African American nurse who works the evening shift and cares for her mother with Alzheimer's disease.

"When my father was diagnosed with terminal lung cancer, he had a great hospice team. They were there for him and we depended on them.

"My mother's care has been completely different. Every day is different. As her condition worsened, we had to increase her days in adult day health care from three to four, which is financially burdensome because we have to pay out of pocket.

"I don't feel supported by my mother's community medical providers. They don't seem to understand our financial struggles, what my mother's daily care needs are, or her or our values. We don't put family in nursing homes. When my mother dies, I want to be by her side."

Addressing Psychological/ Psychiatric Needs

Depression and Anxiety

Depression, anxiety, insomnia, and other symptoms are frequent complications of serious illness; however, providers may underappreciate their impact on patients' lives. Primary palliative care should include routine screening using validated tools and direct treatment for individuals whose symptoms can be managed in the primary care setting. Those with more serious psychiatric symptoms should be appropriately triaged to specialists. Clinics can choose from a variety of screening instruments to assess psychological and psychiatric symptoms, depending on patient population and clinic needs.

Clinics with on-site behavioral health services or psychiatry may choose more comprehensive screening instruments, while those without mental health services may perform a basic screening and refer patients to other community providers for comprehensive psychiatric assessment. Some CHCs already integrate depression and anxiety screening into primary care (e.g., PHQ-Patient Health Questionnaire – 2 or 9). These tools can be used in palliative care as well.

Grief/Bereavement

Primary palliative care includes screening for and addressing patients' and caregivers' grief and/or bereavement. Even before reaching the terminal phase, patients with serious illness may experience grief due to a new or changed diagnosis, loss of functionality, or changing social roles. Directly addressing patients' sense of loss allows providers to facilitate healthy grieving and detect signs of more complicated grief that could require additional help and support.^{16,17}

Assessing the state of bereavement — grief of loved ones following a death — is equally important. It gives providers an opportunity to support patients and families during an emotionally difficult time.

Once grief or bereavement has been identified, depending on clinic resources, symptoms can be managed internally or patients/caregivers can be referred to appropriate community resources.

Addressing Social Needs and Spiritual Needs

Primary palliative care includes routine assessment of the dimensions of patients' social lives — living situation, family and community networks, roles, responsibilities, personal history, and religious/spiritual affiliation. These assessments help providers understand, value, and respect the life patients lead outside of the health care system, which in turn enables them to better support patients' choices.

Assessments are done with standard screening tools (for a sample of these tools, see Appendix C). Patients' and caregivers' needs can be addressed internally or referred for assistance in the community.

People express their spiritual and existential concerns and needs uniquely. Some identify strongly with organized religion; others pursue meaning through art and nature, philosophy, or other avenues. Encouraging patients to share their spiritual or existential beliefs and values is essential to giving them the resources and supports they need to cope with a serious chronic or terminal illness.^{18,19}

Although having in-depth conversations with individuals about their spiritual or existential beliefs and needs may be difficult in a primary health setting, eliciting basic information and then directing patients to resources for more in-depth help can be very beneficial. CHCs can use validated screening assessment tools to assess needs and then develop referral processes.

Communicating with Patients and Families

Primary care clinics often serve as the most trusted providers for patients and families, having built rapport and relationships over time. They often inform patients of serious diagnoses and routinely discuss treatment options. Primary palliative care encourages important conversations with patients and families on crucial issues including prognosis; treatment options (including implications of treatment); goals of care; code status; and advance care planning. The following is information about the elements and purpose of these discussions.

Important Conversations

Prognosis, Treatment Options, and Implications of Treatment

In order for patients and caregivers to make informed choices about their health care, they need clear, timely information regarding their diagnosis, prognosis, and various treatment options. Primary palliative care programs support providers in facilitating these conversations by sharing useful communication techniques and tools for estimating prognosis, and, when necessary, changing clinic structures to provide the necessary time for providers. (See Appendix G for communication resources, including the ADAPT framework for discussing prognosis.²⁰)

Primary palliative care helps patients explore the various treatments available as their disease progresses. For example, providers could begin conversations with patients with chronic kidney disease regarding the natural history of this illness and future decisions regarding dialysis. These conversations regarding treatment options are often informed by discussions with specialty care providers.

Primary palliative care also includes discussions regarding emergency interventions in the event of cardiac or respiratory arrest. Code status conversations need to be anchored in the patient's goals of care, and informed by data regarding expected morbidity and mortality following resuscitation attempts.²¹ For patients who wish to forego advanced life-prolonging therapies, providers should encourage the completion of appropriate documentation to communicate these preferences (i.e., POLST or pre-hospital DNR forms).

Goals of Care and Facilitating Family Meetings

A member of the primary palliative care team can elicit patient goals of care (treatment and care choices) during the initial patient assessment process or follow-up visits. Goals-of-care discussions can occur at any point in a patient's care, but are most often triggered when a patient is diagnosed with a serious illness, when there is a change in status for patients, or when the value of current treatments needs to be re-evaluated.

Goals-of-care discussions initially focus on asking patients about their quality of life — what they value, their daily

activities and interests, what their personal aspirations and goals are, and how they imagine their future. Subsequently, patients are asked what they know about their condition and what is important to them in their treatment process. Integrating these conversations into the goals-of-care discussion offers the primary palliative care team an opportunity to better align patient needs, preferences, and goals with a defined care plan.^{22,23}

In order to include key stakeholders, goals-of-care discussions are often conducted in the context of a family meeting. Family meetings bring patients, family (includes family members, surrogates, and other members of a patient's community) together to discuss the patient's quality of life and treatment goals. CHCs should consider what structural or logistical preparation may be needed to accommodate family meetings, such as reserving two provider appointment slots or reserving a conference room for larger family groups.

In specialty palliative care, goals-of-care discussions are more complex. They are typically preceded by the palliative care team's review of the patient's medical history, current treatment, treatment options, prognosis with and without continued disease-directed treatments, and discussion with the patient's treating physician about the utility of the current treatments. During the goals-of-care conversations, the palliative care medical team lead goes into depth discussing which current and potential tests and treatments will improve, worsen, or have no impact on the patient's function, quality of life, and duration of life.^{24,25}

Advance Care Planning

Although providers often equate advance care planning with the completion of specific documents, advance care planning is a process of communication that often occurs over time. Conversations are typically between the patient, the family or health care proxy, and health care staff. The foci of these talks includes prospectively identifying a surrogate, clarifying treatment preferences and values, and developing individualized goals of care near the end of life.²⁶

In many cases, this process leads to the completion of specific forms, such as advance directives or POLST. In other cases, patients or caregivers may be reluctant to complete these legal documents. In primary palliative

care, providers offer education regarding the utility of these documents. They work with patients and families to complete these forms when appropriate — or refer to outside supportive resources — and help ensure that patients' care preferences are honored across all care settings.

Advance Health Care Directives

Advance health care directives (AHCD), also known as living wills, are legal documents in which individuals can specify what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity. They also allow patients to designate one or two individuals as their Durable Power of Attorney for Health Care (DPOA). A DPOA is

Primary Palliative Care Case Example

In their article, *Integrating Palliative Care Into Primary Care*, McCormick, Chai, and Meier present examples of patients who would benefit from primary palliative care.³ The following excerpt is an example of how a PCP might approach offering primary palliative care services.

Mrs. Williams is a 72-year-old female with diabetes, hypertension, and chronic kidney disease. At her follow-up appointment you ask her about the appointments she missed with the nephrologist. Mrs. Williams expresses concern about the possibility of needing dialysis in the future. She shares that her sister and mother both received dialysis at the end of their lives and that they spent much time in and out of the hospital. She was fearful that the kidney doctor would say she needed dialysis, and therefore did not go to her return appointment.

The care of patients with chronic kidney disease (CKD) requires special attention to advanced care planning. Primary care providers are able to initiate important conversations about advanced care planning early in the disease, before decisions are made regarding initiation of dialysis. As illustrated in this case, primary care providers have the opportunity to learn about patients' experience with their illness. Ongoing discussions about patients' goals and fears, as well as education about the progression of CKD, will help to prepare the patient and her family for future consultation with specialists.

Pre-dialysis education should include a discussion of treatment options, including initiating dialysis and the available dialysis modalities, not initiating dialysis and continuing conservative management, a time-limited trial of dialysis, or stopping dialysis with expectation of death. Primary care clinicians can also assist in educating patients about prognosis of disease, both with and

without dialysis, and the expected effects of the disease and treatment on function.

The relationship the primary care provider has with the patient's family can often facilitate the involvement of other family members in advanced care planning discussions. Inclusion of family members in these conversations is important. Patients with CKD often find it difficult to initiate conversations with loved ones about preferences. They may choose to extend dialysis due to family pressure or may be unable to make decisions later in the disease course due to cognitive impairment. Surrogates and proxies are then left with difficult decisions without the guidance of the patient's wishes.

The long-standing relationship primary care clinicians have with patients allows them to be present throughout the course of disease as goals and decisions evolve. Primary care clinicians can also consult palliative care specialists to assist with time-intensive complex decisionmaking regarding goals of care and treatment options, recommendations regarding pain and symptom management, and to help address complicated psychosocial, spiritual, and social issues.

Later in the course of this patient's illness, a consultation to a palliative care specialist team would be helpful if the patient's primary physician notes that the patient has had frequent visits to the emergency department, one or more hospital admissions in 30 days, prolonged hospitalization, a prolonged intensive care unit (ICU) stay, or an ICU stay with poor prognosis.

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empowered to make medical decisions if the patient is incapacitated and has not made specific choices in advance regarding particular treatments.

Advance health care directive forms are widely available to the public online for free, as are other resources dedicated to helping individuals and families have conversations about end-of-life wishes. (An example of a website to help people and families go through these decisions is [prepareforyourcare.org](https://www.prepareforyourcare.org)).

POLST

Physician Orders for Life-Sustaining Treatment (POLST) is a patient-driven document for patients of any age who are seriously ill or medically frail. POLST is a standardized, easy-to-access, readable, and portable physician order that transfers with the patient from one care setting to another. (See detailed information about advance health care directives and POLST in Appendix C.)

Building and Integrating a Primary Palliative Care Program

Many health insurers and primary care clinics are now focusing on care coordination, especially for patients with complex care management needs. Such attention to person-centered care opens the door for CHCs to consider providing primary palliative care services to a targeted group of patients.

CHCs can develop their own palliative care program through a series of strategic planning steps that allow for flexibility in designing the most appropriate initiative for the organization and its patients.

Gathering Information

Get the Conversation Started

Most staff and providers have had exposure to friends and family with advanced illness, and may have strong feelings about negative or positive experiences. To create momentum for the strategic planning process, a 60- to 90-minute all-staff basic training on palliative care and advance care planning (ACP), with the opportunity to break up into small groups and discuss personal experiences or painful cases, can reap profound benefits.

Additionally, the short training may help palliative care champions emerge and will increase staff understanding about the need for change. Most importantly, all staff will become alert for patients who can benefit from palliative care. Sometimes the clerk at the front desk knows the patient and family the best, and can be a great referral source.

Clarify Current Service Availability and Quality

The first step in strategic planning for a primary palliative care program involves assembling a group of interested CHC interdisciplinary team (IDT) members. Have a robust discussion with the group about the components of palliative care. Ask providers: “How are you providing palliative care now? What components do we already have in place? What do we need to learn?”

This process allows providers to assess current practices and helps identify gaps in knowledge about palliative care among staff and providers. (See page 15 as well as appendices for tools to assist CHCs with assessing current and potential primary palliative care interventions.)

After current primary palliative care services have been identified, an important follow-up question to ask is: “How do we know that the palliative care services we are providing are high quality?”

Measuring quality is an essential component of all palliative care programs, according to the National Consensus Project (NCP) Clinical Practice Guidelines for Palliative Care, the Joint Commission Advanced Certification Program for Palliative Care, and the Centers for Medicare & Medicaid Services (CMS). Palliative care quality measurements are continually being refined to advance the goal of improving quality of life for patients and families. (See Appendix B.)

Identify Your Palliative Care Champions

After assessing the presence and quality of current primary palliative care services in the CHC, the next step is to identify CHC providers who may be able to serve as palliative care champions. These providers may have attended continuing education or skills training conferences to supplement primary training in their specialty or discipline. Other providers may not have yet pursued additional training in palliative care, but have an interest in developing a more robust skill set in the practice.

Palliative care champions can be a resource for the CHC in a variety of ways:

- ▶ Serve as a local “expert” in addressing various palliative care needs because of their additional training or experience providing primary palliative care
- ▶ Spearhead staff education and training in palliative care
- ▶ Coordinate palliative care quality improvement activities
- ▶ Address CHC self-care and sustainability practices

Inventory Specialty Services Available to Patients

CHCs deciding to implement a primary palliative care program are encouraged to identify and refer patients with more complex palliative care needs to palliative care specialists.

If palliative care specialty services are either limited or unavailable, sites should consider establishing a connection with palliative care specialists operating in local hospitals, home health agencies, and hospices. This group may be able to provide support for CHCs expanding into primary palliative care through a variety of methods: email or e-consults, informal telephone advice, on-site lectures or training sessions, or technical assistance with programmatic questions. CHCs might also consider referring patients to other specialists (pain specialists, oncologists), and communicating their specialty palliative care needs.

The *Palliative Care Mapping Project*, a comprehensive mapping project of California’s current inpatient and community-based specialty palliative care capacity in California, identifies counties with these specialty palliative care services. Primary care sites developing their palliative care model can review the mapping website (www.chcf.org) to identify inpatient and community-based specialty palliative care programs in their area.

Sites may find it useful to develop a directory of local palliative and supportive care resources including hospitals, community-based providers, home-based providers, hospice, etc. The *San Francisco Palliative and Supportive Care Resource Directory* is an example: www.sfdph.org. It provides extensive information about resources that would be helpful to patients.

Conduct an Environmental Scan

To understand how a primary palliative care program might work, the IDT should have a general discussion about the environment, addressing the following questions:

- ▶ Which groups of patients would benefit most from primary palliative care services (e.g., congestive heart failure patients, cancer patients, etc.)?
- ▶ Which clinical staff, individually or together, could offer the services (e.g., one provider, one team, several teams)?
- ▶ What additional training would be needed for staff to provide services?
- ▶ When could services start?
- ▶ What resources are needed to launch the services? What would it cost in terms of staff time or lost productivity?
- ▶ What is the business case for administration? Is there a way to make the service cost-neutral or revenue generating?
- ▶ What administrative and leadership support is necessary to start new palliative care services?
- ▶ What barriers and challenges can be expected and how can they be mitigated?
- ▶ Why would integrating palliative care be beneficial (e.g., from quality, satisfaction, or cost perspective) to patients, providers, the clinic, and payers?
- ▶ What patient data analyses are necessary to identify target patients for the program?
- ▶ How would the patient referral process work?
- ▶ What infrastructure needs to be in place (workflows, documentation, billing, community resources, etc.)?
- ▶ Where will patients needing specialty palliative care be referred? If there are no local specialists, are there other options and resources (telehealth, email consults, etc.)?

Responses to these questions form the basis of an environmental scan — a summary of an organization’s internal and external strengths and weaknesses. Environmental scans provide valuable information for determining an organization’s readiness for change.

Identifying Patient Needs

Palliative Care Needs for the General Patient Population

Using data and informal case review, patients can be divided into three distinct groups based on data such as diagnosis, age, hospitalizations, and ER visits during the past 12 months. If the data are not available in the electronic health record (EHR), there may be an opportunity to partner with a managed care plan to get data for certain populations.

- ▶ **All patients** need education regarding the importance of advance care planning, and in identifying a surrogate decisionmaker.
- ▶ **At-risk patients** include those diagnosed with one or more serious illness, which may result in

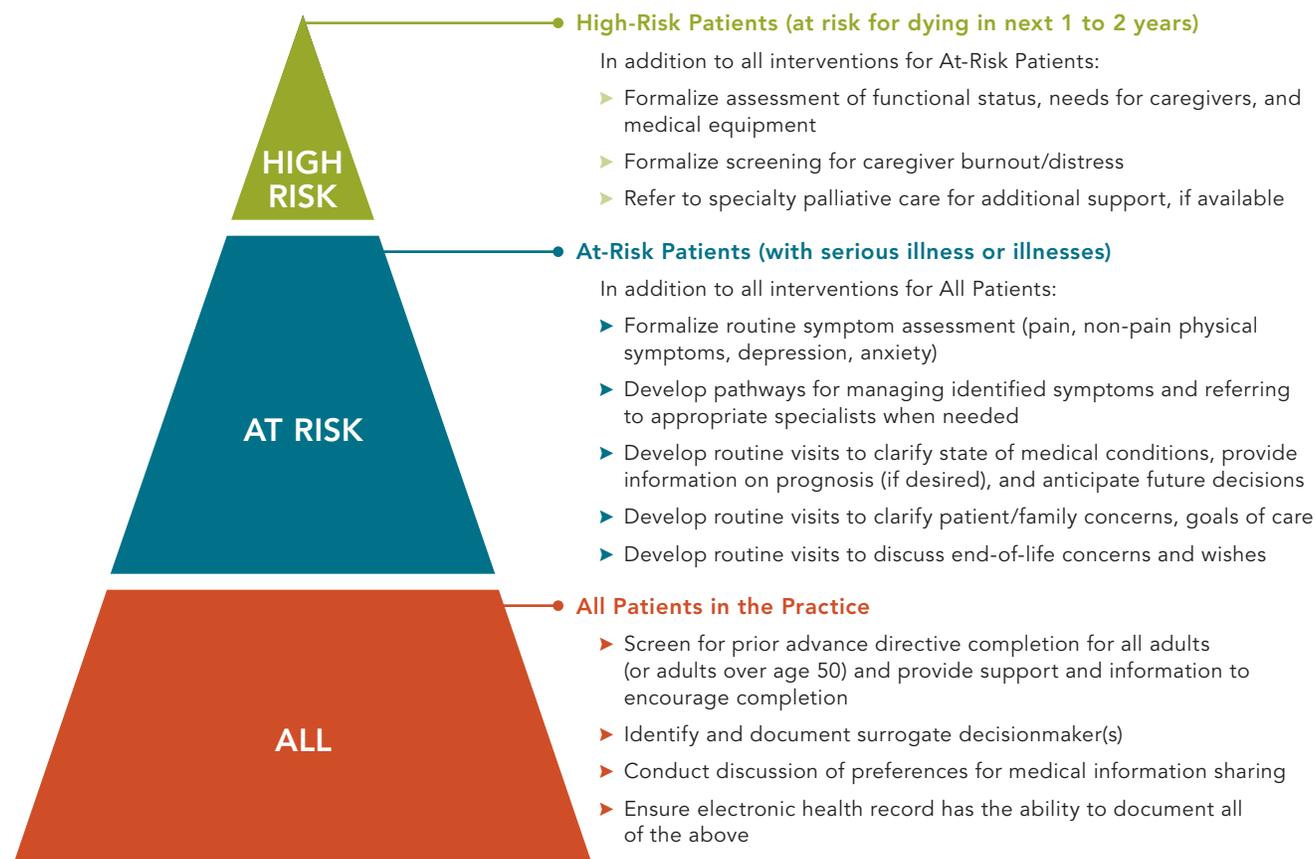
distressing symptoms, psychosocial or spiritual needs, or may progress to a terminal phase. These patients would benefit from routine screening and more specific advance care planning.

- ▶ **High-need patients** are those with shorter prognosis (<2 years), those with higher symptom burden or more significant psychosocial or spiritual needs.

Patients can have a wide variety of primary palliative care needs, and CHCs may be unable to address all of them; however, by performing an assessment of patients' needs, staff can identify the areas of greatest need and opportunity for providing primary palliative care.

Figure 1 breaks down the types of interventions that might be appropriate for each patient group.

Figure 1. Primary Palliative Care Need and Possible Interventions



Primary Palliative Care Needs that CHC Is Prepared to Address

After the range of potential patient needs has been assessed, CHCs should determine the size of the patient population in each group and the proportion that will need specialty care.

The following questions can help CHC providers and staff determine their level of readiness to organize primary palliative care services:

- ▶ Are there distressing physical (pain/other) symptoms that the CHC can address?
- ▶ Are providers prepared to routinely assess functional or performance status and address any functional or caregiving needs?
- ▶ Are there distressing psychological (depression/anxiety) symptoms that the CHC can address?
- ▶ Is CHC staff able to assess and/or address patients'/caregivers' grief or bereavement needs?
- ▶ Is CHC staff prepared to assess and/or address patients'/caregivers' social concerns affecting daily life?
- ▶ Is CHC staff prepared to assess and/or address patients' spiritual concerns affecting daily life?
- ▶ Are providers adequately equipped and willing to routinely assess patients'/families' understanding of the patient's current illnesses, likely trajectory, and treatment options?
- ▶ Are providers equipped and able to routinely assess patients' goals of care at key points in their clinical trajectory?
- ▶ Are providers equipped and able to assist patients or their surrogates to complete documentation of their treatment preferences?

As part of their planning, CHCs will need to consider whether to address a small subset of needs for a large group of patients (e.g., ACP interventions for all clinic patients) or a larger bundle of interventions for a small subset of patients (e.g., routine, comprehensive screening for palliative care needs among patients with end-stage liver disease).

Two frameworks that may be considered by CHCs are the Coordinated Palliative Care Model and the Integrated Palliative Care System Model.

The Coordinated Palliative Care Model divides areas of responsibility between primary palliative care and specialty palliative care, which is performed by trained specialists — many board-certified in palliative care. See Appendix E for a table comparing primary and specialist palliative care in this model.

The Integrated Palliative Care System Model includes three levels of palliative care, depending on patient need and provider training, and community education and engagement. In addition to palliative care generalists and specialists, this framework includes palliative care champions. These providers serve a greater proportion of patients with advanced illness or symptom burden (often oncologists or geriatricians). They also serve as local resources for palliative care generalists, and are able to facilitate education and quality improvement initiatives in palliative care.

Payment Considerations

Reimbursement for primary palliative care may depend on the payment system, e.g., capitated or bundled, through a health plan or fee-for-service structure. A reasonable business plan for primary palliative care will help identify the financial benefits of what is already being provided and how to support expanded services.

Information about how to bill for time during office visits is available from the American Academy of Hospice and Palliative Medicine (www.aahpm.org).

Even more important than fee-for-service billing in most instances will be shared savings/risk models for more global payment for improved health care value and population management. A model for demonstrating palliative care value in outpatient palliative care, *Community-Based Palliative Care Opportunity Analysis*, is available from the Coalition for Compassionate Care of California (CCCC) (www.coalitionccc.org).

For additional detailed information on community-based palliative care operations (billing, service structure, staffing, visits, etc.), see *Up Close: A Field Guide to Community-Based Palliative Care in California* (www.chcf.org).

Most federally qualified health centers, unless they have a close relationship with a primary care plan, will need to provide palliative care services within their current

financial model, relying on in-person visits to generate revenue. However, many primary care clinics have already invested in integrated behavioral health. Such clinics may be able to take advantage of the fact that medical providers, social workers, or therapists can all bill for palliative care services. Integrated behavioral health and other team models are excellent foundations for team-based palliative care services.

Some clinics use nurses, health coaches, navigators, or other “nonbillable” providers to help complex patients navigate the health care system. After a longer visit with the nurse, a medical provider greets the patient and performs a brief face-to-face encounter, enabling the service to be billed. Similar models can be used to support the costs of palliative care services provided by an interdisciplinary team.

Recognizing Challenges and Opportunities

A number of challenges come to the fore as clinics plan their primary palliative care program. However, important opportunities arise as well. The following challenges and opportunities were identified by a focus group of CHC providers.

Challenges to Overcome

- ▶ Not enough time to address palliative care communication elements such as goals of care and advance directives.
- ▶ Integrating palliative care in a busy practice may be more of an “add-on” responsibility and function.
- ▶ There is no viable payment mechanism in the current fee-for-service environment, and ACP takes time that would detract from the number of billable provider visits.
- ▶ Implementation varies by site, based on differing resources and needs. This may decrease standardization of primary palliative care delivery.
- ▶ Not all primary care providers understand palliative care or are comfortable with ACP or prognosis conversations.

Opportunities for Action

- ▶ Educate all providers and staff about palliative care.
- ▶ Clarify what primary palliative care within the CHC might look like based on interest, staffing, and capacity (model may include enhanced pain and symptom management support, or ACP with a social worker or psychiatrist).
- ▶ Develop a template in the electronic health record (EHR) to record palliative care patients and their surrogate decisionmakers, palliative care need levels, and services provided.
- ▶ Insert palliative care referral/service triggers in the EHR based on need. For example, ACP for all patients and functional assessment for high-risk patients.
- ▶ Clarify viable payment mechanisms including coverage under current billing codes and bundled payments through managed care. Consider scheduling more time such as double bookings to provide an initial consult or address ACP.

Defining the Program

The following process steps provide structure for developing and defining a primary palliative care approach that reflects the resources, interests, and culture of the CHC.

Select Components and Means of Quality Tracking

For each primary palliative care component that the CHC decides to offer, it will need to do the following:

- ▶ Choose a standardized tool for assessing the component (e.g., see Appendix C).
- ▶ Determine how and who will screen patients.
- ▶ Survey providers who will participate in providing/managing the component to identify relevant knowledge gaps.
- ▶ Identify appropriate continuing education and training programs to address providers’ knowledge gaps.
- ▶ Develop strategies to triage and manage identified patient needs related to the component in a timely manner.

The next step is deciding how the quality of the intervention will be assessed. For example, a clinic might choose to assess the functional status of all patients with moderate-severe congestive heart failure (CHF), using the Katz Index of Independence in Activities of Daily Living. Quality could be assessed through structure, process, or outcome metrics, e.g., 80% of patients with moderate-severe CHF have completed functional assessment in the last six months, or 90% of patients who screen positive for ADL dependence are referred for comprehensive needs assessment by the CHC social worker or nurse.

There should be a mechanism to demonstrate the impact of the intervention and to allow for feedback and iterative quality improvement. Several national entities such as CMS, NCP, and NQF have compiled quality indicators for palliative care. CHCs organizing a primary palliative care program can review these peer-reviewed metrics and select a measure that will be meaningful to CHC staff and patients/families. References for these quality guidelines can be found in Appendix A. For every quality measure selected, CHCs should consider how, when, and by whom the quality data will be collected, reported, and analyzed.

Clarify Roles and Identify Workflow Adjustments

Some adjustments to CHC staff workflow may be necessary to incorporate new or revised services and referrals. It is useful to involve multiple members of the IDT to help collaboratively address patient needs and limit the impact of additional responsibilities.

Following are some considerations for organizing the services and workflow:

- ▶ When would routine assessment with the selected tool take place? Which IDT members should perform the screening? How will they be prompted to perform the screening?
- ▶ What adjustments in other responsibilities or scheduling will be necessary to enable the IDT members to carry out the routine assessments?
- ▶ How will assessment results be interpreted, triaged, and/or managed?
- ▶ Where will the assessment be documented in the medical record for tracking, reporting, and quality improvement purposes?

- ▶ Are there structural changes needed in appointment scheduling to accommodate longer appointments, if necessary (particularly for important goals of care and ACP interventions)?
- ▶ How will the program quality measure(s) be tracked, reported, and analyzed?

Address Staff Education and Training Needs

Educating and training staff, by discipline, to expand their primary palliative care skills, is essential to preparing and implementing quality services.

There are many continuing education opportunities available in palliative care, in a wide variety of formats. Educational topics span the range from symptom management and communication to program development and enhancing self-care and resilience. Learners also have flexible options for how they want to receive the content, including online-only courses and on-site single- or multi-day conferences (see Appendix F).

Finalize Program Goals and Objectives with Timeline

The final phase of strategic planning is developing clear program goals, objectives, and a timeline for achieving each. Below are examples of primary palliative care program goals and related objectives.

Goal Example A. Provide basic pain and symptom management to pilot group of congestive heart failure patients. *Objectives:* 1) analyze patient data to identify congestive heart failure patients for pilot; 2) research and select assessment tool; 3) develop provider protocols and patient referral pathways.

Goal Example B. Offer ACP to all patients hospitalized with a diagnosis of chronic disease (e.g., heart failure, renal failure) in the last 12 months. *Objectives:* 1) analyze patient data to identify target group; 2) identify and train staff to provide ACP; 3) outline protocol and stages for facilitating ACP.

Reaching Out to the Community

Over the next decade, more and more Americans will be living with and managing serious health conditions. This trend coupled with significant health care delivery system changes has led to national, state, and local initiatives promoting patient empowerment, chronic disease self-management, and health literacy. Community-based

primary care clinics can contribute to these efforts by engaging in conversations about palliative and end-of-life care.

The Institute of Medicine highlighted in their recent report, *Dying in America*, the need for public education and engagement about end-of-life care planning at several levels:¹

- ▶ The societal level, to build support for public and institutional policies that ensure high-quality, sustainable care;
- ▶ The community and family levels, to raise awareness and elevate expectations about care options, the needs of caregivers, and the hallmarks of high-quality care; and
- ▶ The individual level, to motivate and facilitate advance care planning and meaningful conversations with family members and caregivers.

Clinics offering primary palliative care services can garner support for their program by engaging the surrounding community. Outreach objectives should include educating the community about palliative care, advance health care directives, and the specific primary palliative care services the clinic will provide.

To ensure a culturally competent and responsive community engagement approach, clinics should ask community stakeholders what additional information they want to know as well as what is important to them regarding these topics.

Below are strategies that clinics can pursue to engage communities in these issues:

- ▶ Organize information meetings at the clinic or health facility about the palliative care service for patients and family members.
- ▶ Hold classes for the community in advance care planning, with time at the end of the session to help people fill out forms.
- ▶ Host community meetings to introduce palliative care at faith-based, civic, and community organizations.
- ▶ Develop and disseminate service brochures/flyers.

Essential Tools for Planning Primary Palliative Care Programs

The following tools were designed to help CHCs in their strategic planning. More resources can be found in the appendices that follow and at: www.chcf.org.

Primary Palliative Care Planning Tool and Worksheets

The *Primary Palliative Care Planning Tool* has three worksheets to assist sites with summarizing the following: primary palliative care services currently provided, members of the interdisciplinary team able to take on aspects of primary palliative care, and the site's top priorities for primary palliative care. (See pages 16 to 18.)

Following the worksheets is a decision tree (Figure 2, page 19) that demonstrates how a CHC might approach decisions geared to its particular patient population and available services.

Worksheet 1. What primary palliative care services are already being provided, by whom?

	CLERICAL STAFF	LVN/ MA	RN	SW/ THERAPIST	NP/PA	MD/DO	OTHER STAFF/ SUPPORT (VOLUNTEER, PSYCHOLOGIST, CHAPLAIN)
Screening for pain							
Screening for non-pain physical symptoms							
Screening for depression							
Screening for anxiety							
Management of pain							
Management of non-pain physical symptoms							
Management of depression							
Management of anxiety							
Screening for psychosocial distress							
Screening for spiritual care needs, spiritual distress							
Functional assessment							
Screening for needs for medical equipment, assistance with ADLs							
Screening for caregiver burnout, needs							
Advance Care Planning (ACP)							
Screening for prior ACP							
Refer patients to health classes/staff for ACP education and support							
Assist/coach patients with completing ACP							
Assist patients with identifying surrogate decisionmaker							
Document patient surrogate and preferences regarding life-sustaining treatments (AHCD/POLST)							

Worksheet 2. In your practice setting, who has the capacity and competence to begin providing the following elements of primary palliative care?

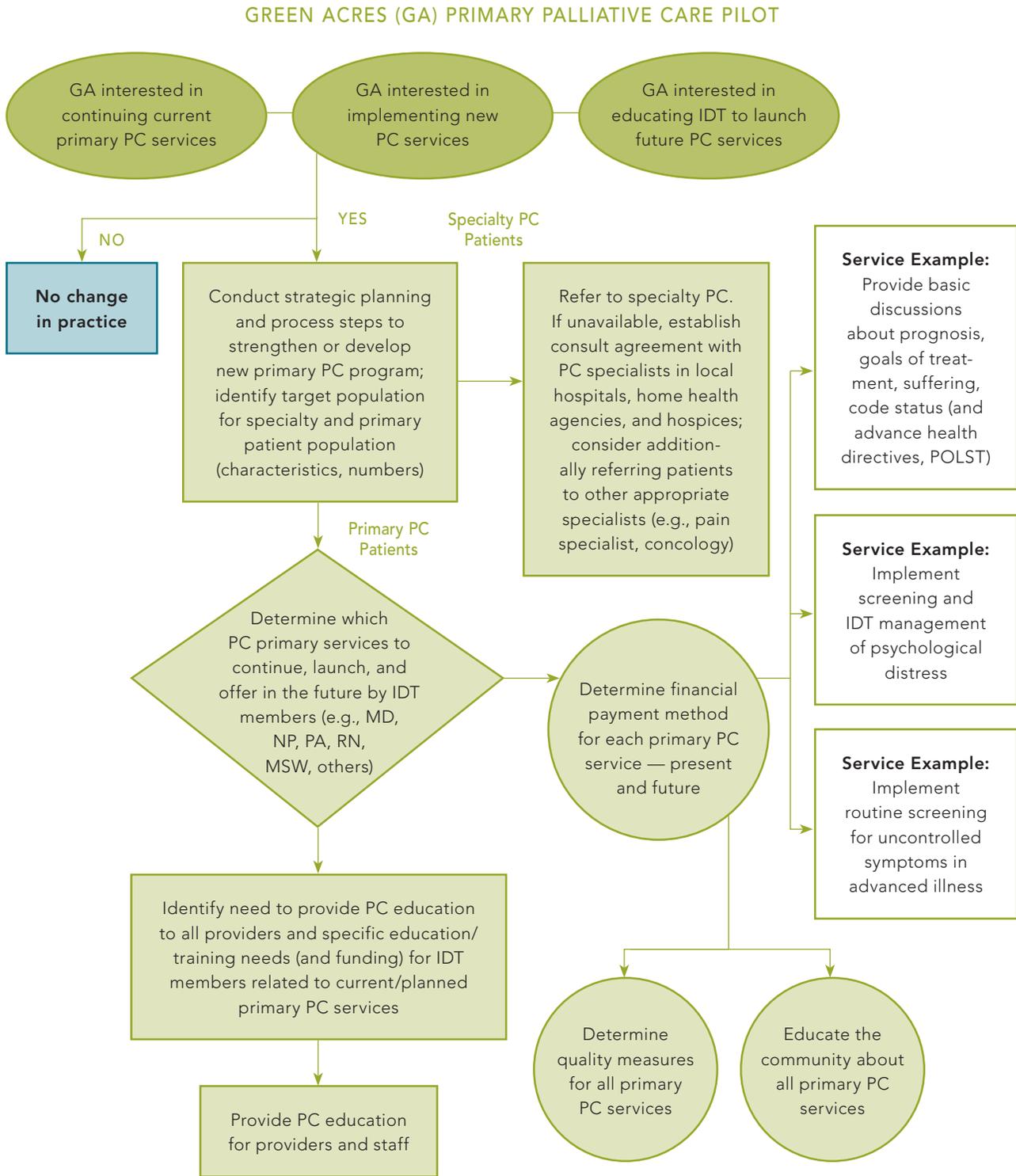
	CLERICAL STAFF	LVN/ MA	RN	SW/ THERAPIST	NP/PA	MD/DO	OTHER STAFF/ SUPPORT (VOLUNTEER, PSYCHOLOGIST, CHAPLAIN)
Screening for pain							
Screening for non-pain physical symptoms							
Screening for depression							
Screening for anxiety							
Management of pain							
Management of non-pain physical symptoms							
Management of depression							
Management of anxiety							
Screening for psychosocial distress							
Screening for spiritual care needs, spiritual distress							
Functional assessment							
Screening for needs for medical equipment, assistance with ADLs							
Screening for caregiver burnout, needs							
Advance Care Planning (ACP)							
Screening for prior ACP							
Refer patients to health classes/staff for ACP education and support							
Assist/coach patients with completing ACP							
Assist patients with identifying surrogate decisionmaker							
Document patient surrogate and preferences regarding life-sustaining treatments (AHCD/POLST)							

Worksheet 3. Based on your patient population and available staffing, what are your top priorities in providing primary palliative care?

	NOT A PRIORITY	LOW PRIORITY	MODERATE PRIORITY	HIGH PRIORITY	NECESSITY
Screening for pain					
Screening for non-pain physical symptoms					
Screening for depression					
Screening for anxiety					
Management of pain					
Management of non-pain physical symptoms					
Management of depression					
Management of anxiety					
Screening for psychosocial distress					
Screening for spiritual care needs, spiritual distress					
Functional assessment					
Screening for needs for medical equipment, assistance with ADLs					
Screening for caregiver burnout, needs					
Advance Care Planning (ACP)					
Screening for prior ACP					
Refer patients to health classes/staff for ACP education and support					
Assist/coach patients with completing ACP					
Assist patients with identifying surrogate decisionmaker					
Document patient surrogate and preferences regarding life-sustaining treatments (AHCD/POLST)					

Figure 2. Planning a CHC Primary Palliative Care Pilot

This decision tree shows the decision process of a fictitious CHC that primarily serves Medi-Cal beneficiaries with hypertension, diabetes, heart disease, asthma / chronic obstructive pulmonary disease (COPD), chronic depression and other mood disorders, and mental health issues / substance abuse.



Note: IDT = interdisciplinary team.

Appendix A. Description of Palliative Care Services and Key Resources

Physical Assessment

- ▶ **Pain and symptom management.** **FOCUS:** Assess and track the level of pain and other physical and mental/emotional symptoms of serious illness — fatigue, frustration, difficulty breathing, difficulty swallowing, lack of appetite, constipation, hope and hopelessness, confusion — in seriously ill patients.

Providers can address patient suffering by assessing the four components of total pain, beginning with the physical symptoms.^{27,28} Providers often address physical symptoms and distress first, and then focus on emotional, psychosocial, and existential/spiritual issues; however, since all may be expressed through physical complaints, it is often necessary to address multiple facets of pain simultaneously.

Four Components of Total Pain

P — Physical problems, often multiple, must be specifically diagnosed and treated.

A — Anxiety, anger, and depression are critical components of pain that must be addressed by the physician in cooperation with other health care professionals.

I — Interpersonal problems, including loneliness, financial stress, and family tensions, are often woven into the fabric of a patient's symptoms.

N — Not accepting approaching death, a sense of hopelessness, and a desperate search for meaning can cause suffering that is unrelieved by medications.

- ▶ **Functional or performance status.** **FOCUS:** Assess patient functional status, defined as an individual's ability to perform normal activities of daily living (ADLs), such as feeding, toileting, grooming, bathing, etc., required to meet basic needs, fulfill usual roles, and maintain health and well-being. Performance status can also be used to help assess prognosis and treatment eligibility in certain disease states, such as cancer. Decline in functional status is measured by an individual's loss of independence in ADLs over a period of time.
- ▶ **Performance status.** **FOCUS:** Measure performance status with validated tools (e.g., Karnofsky Performance Status, Palliative Performance Scale Version 2 [PPS v2]).

- ▶ **Caregiving needs.** **FOCUS:** Determine patients' caregiving needs based on functional status assessment.

Psychological/Psychiatric Assessment

- ▶ **Psychological/psychosocial.** **FOCUS:** Assess the psychological (depression, anxiety, coping) and psychosocial (emotional impact of illness on the patient, patient's environment, stressors, strengths) impact of serious or life-threatening illness on the patient and family.

Social Assessment

- ▶ **Patient roles/responsibilities.** **FOCUS:** Assess the roles, responsibilities, and expectations patients have for themselves, both connected to and separate from their illness, to promote patient self-advocacy (i.e., patients speaking and acting on their own behalf, articulating their values, preferences, and goals).
- ▶ **Referrals to community services.** **FOCUS:** Assess patients' needs for community services and supports and then make appropriate referrals, mindful of patients' cultures, psychosocial and economic needs, severity of illness, etc.

Spiritual Assessment

- ▶ **Spiritual and existential support.** **FOCUS:** Assess the religious, spiritual, and existential needs and concerns of palliative care patients struggling with a serious illness or who are at the end of life, and subsequently develop a plan based on identified needs and concerns, providing information about available spiritual support. (See Fast Facts and Concepts: Taking a Spiritual History.¹⁹)
- ▶ **Support network.** **FOCUS:** Assess the person's supportive community, i.e., family, friends, neighbors, community-based services; where needs exist connect patients with resources.

Other Core Components

- ▶ **Family meeting.** **FOCUS:** Create formal or informal venue for communicating with patients and families (note: families may include surrogate decisionmakers, caregivers, and other members of the patient's community), which has the potential to optimize interdisciplinary collaboration among health care providers, and can create a climate of inclusion and

empowerment for families to discuss and process prognosis and treatment options and express care preferences and decisions.²⁹ Family meetings may be one-time events but may also occur on multiple occasions.

- ▶ **Suffering/quality of life.** **FOCUS:** Assess and support, to the greatest degree possible, patients' and families' quality of life. This includes screening for different forms of suffering (physical, emotional, social, spiritual, religious, existential), and determining the values, aspirations, and activities, which contribute to patients' quality of life.
- ▶ **Goals of care.** **FOCUS:** Elicit patients' broad values and wishes, and assist them in translating them into concrete health care goals that are in keeping with their values and preferences and that are recognized by the patient, family — or substitute decisionmaker — and the health care team.
- ▶ **Disease/prognosis/treatment options/treatment implications.** **FOCUS:** Discuss patients' diagnosis, deliver appropriate prognostic information, and review treatment options. Review the implications of each treatment option, discussing likelihood of treatment success and failure, and the possible impact (medical, psychological, spiritual, financial, etc.) of each treatment.

Prognosis tools. A variety of disease-specific prognostic tools exist for many chronic, progressive illnesses (e.g., CHF, COPD, liver disease, cancer), as well as global prognostic tools and websites (e.g., ePrognosis). Use of the surprise question ("Would I be surprised if my patient died in the next year?") has also been used to help clinicians quickly identify patients who may be at high risk of morbidity or mortality.

- ▶ **Code status.** **FOCUS:** Guide patients through decisions regarding code status based on the patient's larger goals of care.²¹ It is helpful to start by assessing the patient's level of insight into his/her condition (e.g., "What do you understand about your current health situation?" and "What have the doctors told you about your condition?") These questions allow patients to discuss what they know while providing opportunities for the medical provider to address what they don't know, providing education regarding morbidity and mortality outcomes after codes. Following

discussion of patients' goals, understanding, and providing education, ask patients whether they would like a recommendation regarding whether various interventions (e.g., mechanical ventilation, CPR, defibrillation) would be beneficial. If the patient and doctor mutually recognize that death is approaching and the goals of care are comfort, CPR is not an appropriate medical intervention, and a recommendation against CPR should be made. Whenever patients express preferences to forego specific medical interventions such as CPR and mechanical ventilation, providers should help provide appropriate documentation for the patient (e.g., POLST or pre-hospital DNR forms) to help communicate these preferences across care settings.

- ▶ **Patient care plan.** **FOCUS:** Develop a care plan with articulated treatment preferences that address a patient's physical, cultural, spiritual, ethical, legal, and social needs and preferences, and reflect the goals set by the patient, family, or surrogate in collaboration with the interdisciplinary team.
- ▶ **Advance care planning.** **FOCUS:** Introduce and discuss advance health care directives (legal documents such as living wills in which individuals specify what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity); support patient completing the advance health care directive (identifying a surrogate decisionmaker if necessary). As appropriate — particularly if a patient prefers to withhold specific treatments or acute hospitalization — additionally introduce and discuss POLST form.

Additional Elements of Palliative Care

- ▶ **Collaboration with case managers.** **FOCUS:** Utilize nurse case managers to address the complex needs of seriously ill patients. Collaboration with case management facilitates doctor-patient continuity, improves patient/family/physician communication, provides patients with assistance in decisionmaking, ensures quality care in the patient's preferred setting, and promotes efficient use of health care resources.³⁰
- ▶ **Referral to hospice.** **FOCUS:** Refer patients to hospice when the following two general requirements are met: (1) the patient has a life-limiting condition or terminal illness with an expected prognosis of

six months or less and (2) the patient and/or family have elected treatment goals directed toward relief of symptoms, rather than cure of the underlying disease, and generally prefer to avoid hospitalization and use of emergency services.³¹

Key Palliative Care Resources

Appendix C: Palliative Care Measurement and Evaluation Tools

Center to Advance Palliative Care, *Fast Facts and Concepts* — concise, practical, evidence-based palliative care summaries
www.capc.org/fast-facts

Measuring What Matters — set of palliative care quality metrics endorsed by the American Academy of Hospice & Palliative Medicine and the Hospice & Palliative Nurses' Association (PDF)
www.aahpm.org

National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (PDF)
www.nationalconsensusproject.org

National Palliative Care Research Center, *Measurement and Evaluation Tools*
www.npcrc.org

National Quality Forum, *NQR Endorses Palliative and End-of-Life Measures*
www.qualityforum.org

Appendix B. Quality in Palliative Care

The National Consensus Project (NCP) Clinical Practice Guidelines for Palliative Care, the Joint Commission Advanced Certification Program for Palliative Care, and the Centers for Medicare & Medicaid Services (CMS) affirm that measuring quality should be an essential component of all palliative care programs.

To evaluate quality, many health care organizations and systems use the Donabedian framework, which identifies three primary categories for collecting information related to quality:

- ▶ **Structure.** The stable elements of the health care system in which care is delivered, such as buildings, staff, financing, and equipment
- ▶ **Process.** The health care services that are provided and the transactions between patients and providers throughout the delivery of care
- ▶ **Outcomes.** The end results or effects of health care — for the patient and family

To promote quality palliative care, foster consistent and high standards in palliative care, and encourage continuity of care across settings, NCP has identified the following set of palliative care core elements and domains, with clinical guidelines.^{4,32}

Palliative Care Elements

Patient population. Population served includes all patients of all ages experiencing a debilitating chronic or life-threatening illness, condition, or injury.

Patient-family centered care. The uniqueness of each patient and family is respected, and the patient and family (as defined by the patient) constitute the unit of care.

Timing of palliative care. Ideally, palliative care begins at the time of diagnosis with a life-threatening or debilitating condition and continues through cure or until death and into a family's bereavement period.

Comprehensive care. Palliative care uses a multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social, and spiritual distress. Palliative care requires the regular and formal clinical process of assessment, diagnosis, planning, intervention, monitoring, and follow-up.

Interdisciplinary team. Palliative care presupposes indications for, and provision of, interdisciplinary team evaluation and treatment in selected cases.

Attention to relief of suffering. The primary goal of palliative care is to prevent and relieve the burdens imposed by disease and its treatments and consequent suffering, including pain and other symptom distress.

Communication skills. Effective communication skills are a requisite in palliative care.

Skill in care of the dying and bereaved. Palliative care specialist teams must be knowledgeable about prognosis, signs and symptoms of imminent death, and the associated care and support needs of patients and their families before and after the death.

Continuity of care across settings. Palliative care is integral to all health care settings, and palliative care teams collaborate with professional and informal caregivers in each of these settings to ensure care coordination, communication, and continuity of palliative care across institutional and home-care settings.

Equitable access. Palliative care teams should strive to provide equitable access to palliative care for patients of all ages, diagnoses, and health care settings, regardless of race, ethnicity, sexual orientation, or ability to pay.

Quality assessment and performance improvement. Palliative care services should be committed to the pursuit of excellence and high-quality care, and palliative care teams should participate in regular and systematic evaluation of the processes of care and measurement of outcomes data using validated instruments.

Other Resources

For resources addressing palliative care quality measures, see the Key Palliative Care Resources section of Appendix A.

For information about the Joint Commission Advanced Certification Program for Palliative Care, see: www.jointcommission.org.

National Consensus Project Palliative Care Domains with Guidelines

GUIDELINES

Domain 1: Structure and Processes of Care	<ol style="list-style-type: none"> 1.1 A comprehensive and timely interdisciplinary assessment of the patient and family forms the basis of the plan of care. 1.2 The care plan is based on the identified and expressed preferences values, goals, and needs of the patient and family and is developed with professional guidance and support for patient and family decisionmaking. Family is defined by the patient. 1.3 An interdisciplinary team (IDT) provides services to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapy disciplines that provide palliative care services to patients and families may include: child-life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapists, massage, art, and music therapists, psychologists, and speech and language pathologists. 1.4 The palliative care program is encouraged to use appropriately trained and supervised volunteers to the extent feasible. 1.5 Support for education, training, and professional development is available to the interdisciplinary team. 1.6 In its commitment to quality assessment and performance improvement, the palliative care program develops, implements, and maintains an ongoing data-driven process that reflects the complexity of the organization and focuses on palliative care outcomes. 1.7 The palliative care program recognizes the emotional impact of the provision of palliative care on the team providing care to patients with serious or life-threatening illnesses and their families. 1.8 Community resources ensure continuity of the highest quality palliative care across the care continuum. 1.9 The physical environment in which care is provided meets the preferences, needs, and circumstances of the patient and family, to the extent possible.
Domain 2: Physical Aspects of Care	<ol style="list-style-type: none"> 2.1 The interdisciplinary team assesses and manages pain and/or other physical symptoms and their subsequent effects based upon the best available evidence. 2.2 The assessment and management of symptoms and side effects are contextualized to the disease status.
Domain 3: Psychological and Psychiatric Aspects	<ol style="list-style-type: none"> 3.1 The interdisciplinary team assesses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life. 3.2 A core component of the palliative care program is a grief and bereavement program available to patients and families, based on assessment of need.
Domain 4: Social Aspects of Care	<ol style="list-style-type: none"> 4.1 The interdisciplinary team assesses and addresses the social aspects of care to meet patient-family needs, promote patient-family goals, and maximize patient-family strengths and well-being. 4.2 A comprehensive, person-centered interdisciplinary assessment (as described in Domain 1, Guideline 1.1) identifies the social strengths, needs, and goals of each patient and family.
Domain 5: Spiritual, Religious, and Existential Aspects of Care	<ol style="list-style-type: none"> 5.1 The interdisciplinary team assesses the spiritual, religious, and existential dimensions of care. 5.2 A spiritual assessment process, including a spiritual screening, history questions, and a full spiritual assessment as indicated, is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family, as well as symptoms such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness. 5.3 The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.
Domain 6: Cultural Aspects of Care	<ol style="list-style-type: none"> 6.1 The palliative care program serves each patient, family, and community in a culturally and linguistically appropriate manner. 6.2 The palliative care program strives to enhance its cultural and linguistic competence.

GUIDELINES

Domain 7: Care of the Patient at the End of Life

- 7.1 The interdisciplinary team identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families
 - 7.2 The interdisciplinary team assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatment and procedures.
 - 7.3 Respectful post-death care is delivered in a respectful manner that honors the patient and family culture and religious practices.
 - 7.4 An immediate bereavement plan is activated post-death.
-

Domain 8: Ethical and Legal Aspects of Care

- 8.1 The patient or surrogate's goals, preferences, and choices are respected within the limits of applicable state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.
 - 8.2 The palliative care program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.
 - 8.3 The provision of palliative care occurs in accordance with professional, state, and federal laws, regulations, and current accepted standards of care.
-

Source: See the full NCP report, *Clinical Practice Guidelines for Quality Palliative Care*, Third Edition (2013) at: www.nationalconsensusproject.org.

Appendix C. Palliative Care Measurement, Evaluation, and Program Tools

This appendix includes palliative care assessment tool examples and accompanying online materials and related resources. Tools are from the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC). Advance care planning resources and information are from National Healthcare Decisions Day (NHDD), Coalition for Compassionate Care of California, and POLST California (CAPOLST).³³⁻³⁶

Screening Tool

- ▶ Palliative Performance Scale Version 2 (PPS v2)

Pain and Symptom Assessment

- ▶ Edmonton Symptom Assessment Form

Functional Assessment

- ▶ Katz Index of Independence in Activities of Daily Living

Spiritual Assessment

- ▶ Taking A Spiritual History

Caregiver and Family Assessment

- ▶ Caregiver Strain Index

Advance Care Planning

- ▶ List of Advance Care Directive Resources
- ▶ About POLST (Physician Orders for Life-Sustaining Treatment) and the POLST Form
- ▶ Advance Care Planning Models for Health Care Settings
 - ▶ Coalition for Compassionate Care of California Advance Care Planning
 - ▶ Respecting Choices Advance Care Planning

Palliative Performance Scale Version 2 (PPS v2)

%	AMBULATION	ACTIVITY AND EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUSNESS LEVEL
100	Full	Normal activity No evidence of disease	Full	Normal	Full
90	Full	Normal activity Some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort Some evidence of disease	Full	Normal or Reduced	Full
70	Reduced	Unable normal job or work Some evidence of disease	Full	Normal or Reduced	Full
60	Reduced	Unable hobby or house work Significant disease	Occasional assistance necessary	Normal or Reduced	Full or confusion
50	Mainly sit or lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or Reduced	Full or confusion
40	Mainly in bed	Unable to do any work Extensive disease	Mainly assistance	Normal or Reduced	Full or drowsy or confusion
30	Totally bed bound	Unable to do any work Extensive disease	Total care	Reduced	Full or drowsy or confusion
20	Totally bed bound	Unable to do any work Extensive disease	Total care	Minimal sips	Full or drowsy or confusion
10	Totally bed bound	Unable to do any work Extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	—	—	—

COMMENTS:

Note: This scale is a modification of the Karnofsky Performance Scale. It takes into account ambulation, activity, self-care, intake, and consciousness level.

Copyright © 2001 Victoria Hospice Society. Available at www.npcrc.org. It cannot be altered or used in any way other than as intended and described here. Programs may use PPSv2 with appropriate recognition. Available in electronic Word format by email request to judy.martell@caphealth.org. Correspondence should be sent to Medical Director, Victoria Hospice Society, 1900 Fort St, Victoria, BC, V8R 1J8, Canada.

Pain and Symptom Assessment: Edmonton Symptom Assessment Form

Source: NCPRC. Entire 6-page document available at: www.npcrc.org.



Edmonton Symptom Assessment System: Numerical Scale Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____

Date _____ Time _____

Complete by (*check one*)

- Patient
- Caregiver
- Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

Functional Assessment: Katz Index of Independence in Activities of Daily Living

Source: NCPRC. Available at: www.nprc.org.

Katz Index of Independence in Activities of Daily Living

Activities Points (1 or 0)	Independence (1 Point) NO supervision, direction or personal assistance	Dependence (0 Points) WITH supervision, direction, personal assistance or total care
BATHING Points: _____	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity	(0 POINTS) Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
DRESSING Points: _____	(1 POINT) Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING Points: _____	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING Points: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE Points: _____	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder
FEEDING Points: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.

Total Points: _____

Score of 6 = High, Patient is independent.

Score of 0 = Low, patient is very dependent.

**Slightly adapted. Katz S., Down, TD, Cash, HR, et al. (1970) progress in the development of the index of ADL. *Gerontologist* 10:20-30. Copyright The Gerontological Society of America. Reproduced by permission of the publisher.

Taking A Spiritual History, by Bruce Ambuel, PhD

Source: CAPC, Fast Fact #19 (accessed December 10, 2014), www.capc.org

Categories. Communication; Psychosocial and spiritual experience

Background. Illness raises fundamental questions – For what may I hope? Why do I suffer? Does my suffering have meaning? What happens after I die? When a physician stands with a patient as they face death, the physician inevitably plays a role in supporting the patient's inquiry into these spiritual questions. In addition some patients have specific preferences or needs regarding medical care, death, and dying that are based upon their religious beliefs. The physician often plays an important role in supporting a patient's exploration of these issues. Taking a spiritual history is one way to support the patient in this exploration. Maugans (1997) presents a framework for taking a spiritual history; the interview below comes primarily from Maugans' article with some modification based upon the other sources cited.

Taking a Spiritual History

S — Spiritual belief system

- ▶ Do you have a formal religious affiliation? Can you describe this?
- ▶ Do you have a spiritual life that is important to you?
- ▶ What is your clearest sense of the meaning of your life at this time?

P — Personal spirituality

- ▶ Describe the beliefs and practices of your religion that you personally accept.
- ▶ Describe those beliefs and practices that you do not accept or follow.
- ▶ In what ways is your spirituality/religion meaningful for you?
- ▶ How is your spirituality/religion important to you in daily life?

I — Integration with a spiritual community

- ▶ Do you belong to any religious or spiritual groups or communities?

- ▶ How do you participate in this group/community? What is your role?
- ▶ What importance does this group have for you?
- ▶ In what ways is this group a source of support for you?
- ▶ What types of support and help does or could this group provide for you in dealing with health issues?

R — Ritualized practices and restrictions

- ▶ What specific practices do you carry out as part of your religious and spiritual life (e.g., prayer, meditation, services, etc.)?
- ▶ What lifestyle activities or practices do your religion encourage, discourage, or forbid?
- ▶ What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

I — Implications for medical care

- ▶ Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?
- ▶ What aspects of your religion/spirituality would you like to keep in mind as I care for you?
- ▶ What knowledge or understanding would strengthen our relationship as physician and patient?
- ▶ Are there barriers to our relationship based upon religious or spiritual issues?
- ▶ Would you like to discuss religious or spiritual implications of health care?

T — Terminal events planning

- ▶ Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
- ▶ Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?

- ▶ Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
- ▶ From what sources do you draw strength in order to cope with this illness?
- ▶ For what in your life do you still feel gratitude even though ill?
- ▶ When you are afraid or in pain, how do you find comfort?
- ▶ As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?

References

Maugans TA. The SPIRITual History. *Arch Fam Med*. 1997; 5:11-16.

Ambuel B, Weissman DE. Discussing spiritual issues and maintaining hope. In: Weissman DE, Ambuel B, eds. *Improving End-of-Life Care: A Resource Guide for Physician Education*, 2nd Edition. Milwaukee, WI: Medical College of Wisconsin; 1999.

Griffith JL, Griffith ME. Hope in suffering/pain in health: Talking with patients about spiritual issues. Presented at The 18th Forum for the Behavioral Sciences in Family Medicine, Chicago, Illinois, October 1997.

Version history. This Fast Fact was originally edited by David E Weissman MD. 2nd Edition published August 2005. Current version re-copy-edited March 2009.

Caregiver and Family Assessment: Caregiver Strain Index

Source: NCPRC. Available at: www.npcrc.org.

Caregiver Strain Index (CSI)

I am going to read a list of things that other people have found to be difficult. **Would you tell me whether any of these apply to you?** (GIVE EXAMPLES)

	Yes = 1	No = 0
Sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)		
It is upsetting to find . . . has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about . . . ; concerns about how you will manage)		
Total Score (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

Robinson, B. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*. 38:344-348. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

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Advance Care Planning: Advance Directive Resources List

Source: NHDD.

All adults can benefit from thinking about what their health care choices would be if they were unable to speak for themselves. These decisions can be written down in an advance directive so that others know what they are. Advance directives come in two main forms:

- ▶ A “health care power of attorney” (or “proxy” or “agent” or “surrogate”) documents the person you select to be your voice for your health care decisions if you cannot speak for yourself.
- ▶ A “living will” documents what kinds of medical treatments you would or would not want at the end of life.

National Healthcare Decisions Day (NHDD) is dedicated to inspiring, education, and empowering the public and providers about the importance of advance care planning. NHDD lists a wide range of resources on its website that provide information about advance care planning and state-specific advance directives. Most are free although some require payment. Below is a partial list, for more resources see: www.nhdd.org.

- ▶ Aging With Dignity (Five Wishes)
www.agingwithdignity.org
- ▶ Coalition for Compassionate Care of California (PDF)
coalitionccc.org
- ▶ Compassion & Choices
www.compassionandchoices.org
- ▶ Empath Choices for Care
www.empathchoicesforcare.org
- ▶ Institute for Healthcare Advancement (PDF)
www.ih4health.org
- ▶ MedicAlert Foundation
www.medicalert.org
- ▶ MyDirectives (platform to complete free advance directives online)
- ▶ National Resource Center on Psychiatric Advance Directives
www.nrc-pad.org

Additional Resources include the following (for more see www.nhdd.org):

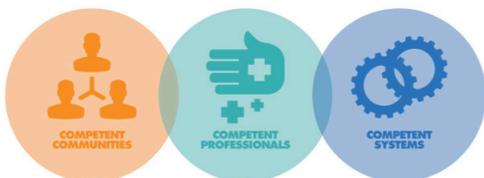
- ▶ **Conversation Project** is dedicated to helping people talk about their wishes for end-of-life care. They are focused on generating conversations about health care wishes with family members and ensuring individuals have thought through what they want at the end of life.
theconversationproject.org
- ▶ **DeathWise** is passionate about motivating people to talk about, make decisions, plan for the end of their lives and then documenting their wishes in an advance directive to ensure their preferences are communicated to their medical services providers, family, and friends.
www.deathwise.org
- ▶ **Prepare for Your Care** is an online program that guides individuals and families through the advance care planning process.
www.prepareforyourcare.org

Advance Care Planning Models for Health Care Settings

Many health care settings are choosing to adopt advance care planning models systemwide. The Coalition for Compassionate Care of California's Advance Care Planning System and Respecting Choices® are two examples of these models:

▶ **The Coalition for Compassionate Care of California's Advance Care Planning System** integrates patient-centered ACP into a health care organization's daily operations. Through education, training, evaluation, and assessment, the System focuses on creating competent communities, competent professionals, and competent systems.³⁶

Advance Care Planning System



Patient Experience



By training staff in how to address advance health care directives, POLST, and real-time medical decisions with patients and families, the System ensures that patient wishes are explored, expressed, and honored. For more information about the Advance Care Planning System, see coalitionccc.org.

- ▶ **Respecting Choices®** is an advance care planning approach integrated into the routine of patient-centered care and appropriately staged to the individual's state of health. Respecting Choices honors that the advance care planning process is complex and challenging, not necessarily a one-time event. The model identifies and embeds all stages of care planning into the routine of health care — making it a norm for the people in the community — through four essential elements:³⁷
 - ▶ Systems redesign
 - ▶ Competency training of health care professionals and others including the creation of the advance care planning (ACP) facilitator role
 - ▶ Patient and community engagement
 - ▶ Continuous quality improvement of the other three elements so they create an effective, organized approach that improves people and family-centered care.

For more information see www.gundersenhealth.org.

About POLST

Physician Orders for Life-Sustaining Treatment (POLST) is a patient-driven document for patients who are seriously ill or medically frail — at any age. POLST is a standardized, easy-to-access, readable, and portable — it transfers with the patient from one care setting to another — physician order.

POLST focuses on three areas: *cardio-pulmonary resuscitation, medical interventions, and artificially administered nutrition*. A fourth area is for patient and doctor signatures. The purpose of POLST is to give medically frail and seriously ill patients more control over their health care.³⁸

To complete the POLST form patients discuss their end-of-life preferences with their doctor and then choose treatments they want. Once signed by doctors and patients, or patient surrogate decisionmakers, the POLST form is recognized throughout the health care continuum. POLST is a complement to — and not a replacement for — the advance health care directive (AHCD).

The following questions can help providers determine the appropriateness of having conversations addressing code status, advance health care directives, and POLST.

- ▶ Has the patient participated in an advance care planning process?
- ▶ Has the patient completed an advance care planning document?
- ▶ Based on the patient's health condition and diagnosis, would a conversation about DNR or POLST be appropriate?
- ▶ Regarding transition of care post-discharge: What are the key considerations for a safe and sustainable transition from one setting to another?

POLST vs. Advance Healthcare Directive

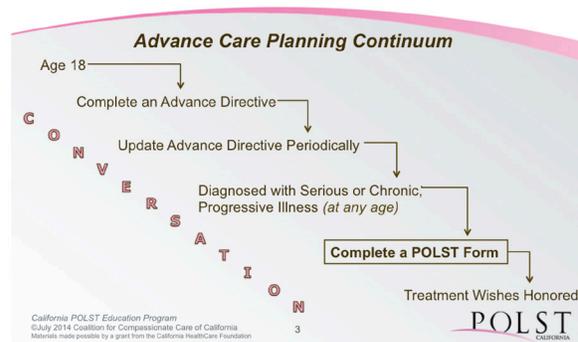
POLST	AHCD
<ul style="list-style-type: none"> • For seriously ill/frail, at any age • Physician orders for medical treatment 	<ul style="list-style-type: none"> • For anyone 18 and older • General instructions for treatment • Appoints decisionmaker

California POLST Education Program
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Materials made possible by a grant from the California HealthCare Foundation

POLST
CALIFORNIA

The figure above highlights differences between POLST and AHCD. The figure below shows where POLST fits into the Advance Care Planning Continuum.³⁶

Where Does POLST Fit In?



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROVIDERS AS NECESSARY		
Patient Information		
Name (last, first, middle):	Date of Birth:	Gender: M F
Healthcare Provider Assisting with Form Preparation <input type="checkbox"/> N/A if POLST is completed by signing physician		
Name:	Title:	Phone Number:
Additional Contact <input type="checkbox"/> None		
Name:	Relationship to Patient:	Phone Number:
Directions for Healthcare Provider		
Completing POLST		
<ul style="list-style-type: none"> • Completing a POLST form is voluntary. California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician who will issue appropriate orders that are consistent with the patient's preferences. • POLST does not replace the Advance Directive. When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts. • POLST must be completed by a healthcare provider based on patient preferences and medical indications. • A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient's physician believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known. • A legally recognized decisionmaker may execute the POLST form only if the patient lacks capacity or has designated that the decisionmaker's authority is effective immediately. • POLST must be signed by a physician and the patient or decisionmaker to be valid. Verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy. • If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form. • Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient's medical record, on Ultra Pink paper when possible. 		
Using POLST		
<ul style="list-style-type: none"> • Any incomplete section of POLST implies full treatment for that section. <p><i>Section A:</i></p> <ul style="list-style-type: none"> • If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a patient who has chosen "Do Not Attempt Resuscitation." <p><i>Section B:</i></p> <ul style="list-style-type: none"> • When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort-Focused Treatment," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture). • Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations. • IV antibiotics and hydration generally are not "Comfort-Focused Treatment." • Treatment of dehydration prolongs life. If a patient desires IV fluids, indicate "Selective Treatment" or "Full Treatment." • Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel. 		
Reviewing POLST		
It is recommended that POLST be reviewed periodically. Review is recommended when:		
<ul style="list-style-type: none"> • The patient is transferred from one care setting or care level to another, or • There is a substantial change in the patient's health status, or • The patient's treatment preferences change. 		
Modifying and Voiding POLST		
<ul style="list-style-type: none"> • A patient with capacity can, at any time, request alternative treatment or revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line. • A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician, based on the known desires of the patient or, if unknown, the patient's best interests. 		
<p>This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force. For more information or a copy of the form, visit www.caPOLST.org.</p>		
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED		

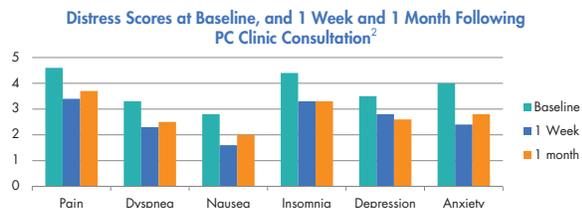
VALUE SNAPSHOT | Palliative Care Clinics



Clinic-based palliative care decreases symptoms and improves patient satisfaction

Palliative care (PC) clinics supply a critical, extra layer of support to patients with complex conditions or uncertain prognoses. By providing early access to expert assistance with symptom management and medical decision-making, and by attending to the social, emotional and spiritual issues that often arise in the setting of serious illness, PC clinics positively affect patient health, well-being and satisfaction. In a review of the literature addressing the impact of outpatient palliative care, including results from four controlled trials, Rabow and colleagues noted evidence of **improved symptoms, improved quality of life, and greater satisfaction** among patients who used such services.¹

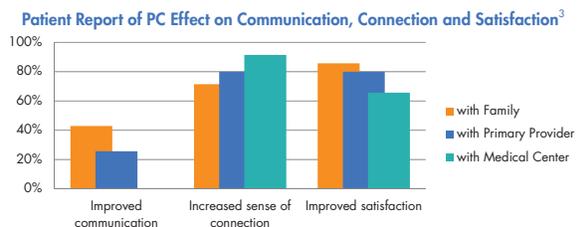
For example, in a prospective study of **patients with metastatic cancer cared for in an oncology PC clinic, Follwell et al. found statistically significant improvements for pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, dyspnea, insomnia, and constipation** at 1 week (all $p \leq 0.005$) and 1 month (all $p \leq 0.05$) following initial consultation.² The investigators also found **significant improvement in patient satisfaction with multiple aspects of care following initial PC consultation**. Areas that showed the greatest



1. Rabow M, et al. Moving upstream: a review of the evidence of the impact of outpatient palliative care. *J Palliat Med* 2013; 16(1):2.
 2. Follwell M, Burman D, Le L, et al. Phase II study of an outpatient palliative care intervention in patients with metastatic cancer. *J Clin Oncol* 2009; 27(2): 206-213.
 3. Rabow MW, et al. Patient perceptions of an outpatient palliative care intervention: "It had been on my mind before, but I did not know how to start talking about death." *J Pain Symptom Manage* 2003;26:1010-1015.

Kathleen Kerr, Kerr Healthcare Analytics
 Developed with support from the California HealthCare Foundation

improvement were "Information given about how to manage pain," "Doctor's attention to symptoms," "Pain relief," "How thoroughly the doctor assesses symptoms," and "Speed with which symptoms are treated" (all $p < 0.0001$).



In addition to improving physical and psychological symptoms, PC clinics can have a profound impact on patient satisfaction with care. In a controlled trial of interdisciplinary PC integrated in primary care practices conducted by Rabow et al., **participants reported that the PC intervention led to improved satisfaction with family caregivers (85.7%), primary care providers (80%), and the medical center (65.7%).³** All participants reported feeling "cared for," "valued," "listened to," or receiving "compassionate" treatment from the PC team.



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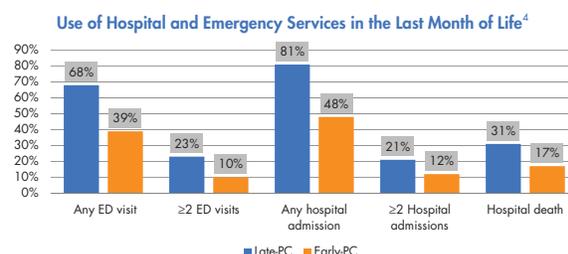
Early, clinic-based palliative care reduces aggressive end-of-life care

Clinic-based palliative care (PC) services can be expensive to operate. Personnel costs for a specially trained interdisciplinary team are significant, and the relatively long appointment times, which are needed to explore complex, sensitive issues such as goals of care and end-of-life planning, combine to create costs that are often double the revenues generated through billing.¹ However, by engaging with patients early in the disease course, clinic-based PC services are able to support patients, over time, in achieving maximum symptom control and in making informed choices about which health services they wish to utilize, in which settings. As a result, patients who receive early, clinic-based PC often consume fewer and more appropriate health care services, compared to patients who receive no palliative care, or late palliative care. This pattern has been validated in several well-designed studies.

In a landmark randomized trial, Temel and colleagues found that **patients with non-small cell lung cancer who received standard oncologic care plus concurrent (early) palliative care received less chemotherapy in the final two weeks of life and had fewer hospitalizations in the last month of life** ($p=0.05$), compared to patients who received standard oncologic care.² Further, compared to patients who received standard oncologic care, **patients who received early palliative care were less likely to receive chemotherapy within 60 days of death** (odds ratio, 0.47; 95% CI, 0.23 to 0.99; $p=0.05$), **had a longer interval between the last dose of**

chemotherapy and death (median, 64.00 days [range, 3 to 406 days] v 40.50 days [range, 6 to 287 days]; $p=0.02$), **and were more likely to be enrolled in hospice care for longer than 1 week** (60.0% v 33.3% $p=0.004$).³

Hui and colleagues found similar advantages when they examined how the timing of PC referral can affect end-of-life care.⁴ Among the 366 decedents studied, 120 (33%) had an early PC referral (>3 months before death), and 246 (67%) had late PC referral (≤ 3 months before death.) **Earlier PC referral was associated with fewer emergency room visits** (39% vs 68%; $p<0.001$), **fewer hospitalizations** (48% vs 81%; $p<0.003$), **and fewer hospital deaths** (17% vs 31%; $p<0.004$) **in the last 30 days of life.** In multivariate analysis, outpatient PC referral (odds ratio, 0.42; 95% confidence interval, 0.28-0.66; $p<0.001$) was independently associated with less aggressive end-of-life care.



*Early PC= initial referral >3 months before death;
Late PC= initial referral ≤ 3 months before death

1. Rabow MW, Smith AK, Braun JL, et al. Outpatient palliative care practices. *Arch Intern Med* 2010; 170(7): 654-655.
2. Temel J et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine*, 2010;363:733-42.
3. Greer JA, et al. Effect of early palliative care on chemotherapy use and end-of-life care in patients with metastatic non-small-cell lung cancer. *J Clin Oncol* 2012;30:394-400.
4. Hui D et al. Impact of Timing and Setting of Palliative Care Referral on Quality of End-of-Life Care in Cancer Patients. *Cancer*. 2014 Jun 1;120(11):1743-9.

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Appendix E. Comparison of Primary Versus Specialty Palliative Care Services and Supports

KEY PALLIATIVE CARE SERVICES/SUPPORTS	PRIMARY PALLIATIVE CARE	SPECIALTY PALLIATIVE CARE
Physical Assessment		
<ul style="list-style-type: none"> ▶ Pain and symptom management ▶ Functional (performance) status <ul style="list-style-type: none"> ▶ Assessment of unmet needs at home ▶ Assessment of caregiving needs 	<ul style="list-style-type: none"> ▶ Basic assessment and management of pain and other physical symptoms ▶ Basic assessment of functional status, unmet needs at home, and caregiving needs 	<ul style="list-style-type: none"> ▶ Management of complex pain and refractory symptoms ▶ Team approach to manage unmet functional needs and support families in obtaining supportive services
Psychological/Psychiatric Assessment		
<ul style="list-style-type: none"> ▶ Psychological/psychiatric <ul style="list-style-type: none"> ▶ Assessment of depression and anxiety ▶ Grief/bereavement assessment <ul style="list-style-type: none"> ▶ Assessment of fear, grief, and bereavement 	<ul style="list-style-type: none"> ▶ Basic assessment and management of psychological/psychosocial needs, e.g., depression and anxiety ▶ Basic assessment of and response to grief/bereavement 	<ul style="list-style-type: none"> ▶ Management of refractory psychiatric symptoms ▶ More in-depth assessment and discussion of psychological distress ▶ Team approach to assessing and addressing fear and grief, and providing support (uses social work and chaplain)
Social Assessment		
<ul style="list-style-type: none"> ▶ Assessment of patient's social role/responsibilities, support network, and need for community referrals 	<ul style="list-style-type: none"> ▶ Basic assessment of unmet social needs and referral to known community resources 	<ul style="list-style-type: none"> ▶ In-depth assessment; access to more comprehensive social and community resources and referral sources
Spiritual Assessment		
<ul style="list-style-type: none"> ▶ Assessment of patient spiritual/existential needs 	<ul style="list-style-type: none"> ▶ Discussing spiritual needs and encouraging patients to seek religious or spiritual support 	<ul style="list-style-type: none"> ▶ Team approach, including clergy, to support spiritual and existential concerns and identify resources
Communication		
<ul style="list-style-type: none"> ▶ Patient Consult/Family Meeting <ul style="list-style-type: none"> ▶ Assessing patient and family values and preferences ▶ Goals of care discussions ▶ Discussing prognosis and treatment options ▶ Discussing options regarding advanced medical therapies such as CPR, mechanical ventilation ▶ Translating values/goals into concrete care plans ▶ Advance care planning <ul style="list-style-type: none"> ▶ Developing patient-centered plans for emergency care and/or end-of-life care ▶ Introduction and completion of the advance health care directive 	<ul style="list-style-type: none"> ▶ Discussing values and goals of care with patients and families: <ul style="list-style-type: none"> ▶ Clarifying – what is most important? ▶ Helping patients understand choices and consequences ▶ Coaching patients on working with oncologists or other specialists with conflicting recommendations ▶ Developing a care plan ▶ Advance care planning <ul style="list-style-type: none"> ▶ Completing code status, POLST or other advance care planning forms ▶ Identifying proxy decisionmakers ▶ Referring to community resources for more information 	<ul style="list-style-type: none"> ▶ In-depth discussions: <ul style="list-style-type: none"> ▶ Assessing patient and family values and preferences ▶ Goals of care discussion: <ul style="list-style-type: none"> • Quality of Life / Suffering • Disease / Prognosis / Treatment Options / Implications of Treatment • Code status • Care Plan ▶ Assistance with conflict resolution regarding goals or methods of treatment: <ul style="list-style-type: none"> ▶ Within families ▶ Between staff and families ▶ Among treatment teams ▶ Assistance in addressing cases of near futility ▶ Completion of advance directive

Source: Parrish, Monique, Quill, TE, Abernathy, AP. "Generalist Plus Specialist Palliative Care — Creating a More Sustainable Model." *New England Journal of Medicine* 2013;368:1173-5.

Appendix F. Education and Training Resources

Educating and training staff, by discipline, to expand their primary palliative care skills is essential to preparing and implementing quality services. The following are selected education and training resources.

American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA) offers education at the Annual Assembly and summer courses; provides high-quality educational resources (self-study courses, primers) and specialty certification, etc. aahpm.org

Target Audience: MD, NP, PA, RN

Advanced Care Planning Decisions (ACP) offers video support tools for patients and providers. Video title examples for providers include: *Having the Conversation: Training Video*; *Communicating Code Status: Skilled Nursing Facilities*. Video title examples for patients include: *Palliative Care: An Introduction*; *Goals of Care: General Overview*; *Hospice: An Introduction*. www.acpdecisions.org

Target Audience: MD, NP, PA, RN, SW, patients, families, caregivers

California HealthCare Foundation's (CHCF) High-Value Care Program supports appropriate care toward the end of life, as well as the expansion of palliative care through various projects and initiatives. Provides numerous publications addressing palliative care in California, i.e., *Up Close: A Field Guide to Community-Based Palliative Care*; *Next Generation of Palliative Care: Community Models Offer Services Outside the Hospital*, etc. www.chcf.org

Target Audience: MD, NP, PA, RN, SW

California State University Institute for Palliative Care offers a broad range of online courses and certificate programs taught by national experts in palliative care for nurses, social workers, chaplains, caregivers, and others. A sampling of courses include: *The Business Case for Palliative Care*, *Palliative Care Certificate for Advanced Practice RNs*; *Fundamental Palliative Care Skills for Social Workers*; *Mental Health Fundamentals in Palliative Care for Spiritual Care Providers*; *Post-MSW Certificate in Palliative*; *Chaplaincy Specialty*

Certificate; *Culturally Competent Palliative Care of Latinos*; *Interprofessional Palliative Care Documentation*. The Institute website also offers *free* access to videos, articles, and other resources addressing palliative care. www.csupalliativecare.org

Target Audience: MD, NP, PA, RN, SW, chaplain, patients, families, caregivers

Center to Advance Palliative Care (CAPC) is the leading resource for palliative care program development and growth. As of January 2015, CAPC became a membership organization. CAPC offers members access to palliative care tools, education, resources, and online training (current courses cover *Hospital Cost Avoidance*, *Calculating Staffing Needs*, *Billing and Coding*, *Philanthropy*, *The Business Plan*, *Strategic Planning*, *Updating Your Business Plan*, *Consultation Etiquette*, *Education Techniques in Palliative Care*, *Marketing for Palliative Care Programs*, *Organizational Change*).

Although a membership organization as of January 1, 2015, CAPC offers *free* Fast Facts & Concepts — concise, practical, peer-reviewed, and evidence-based summaries on key topics important to providers and trainees caring for patients facing life-limiting illnesses. www.capc.org

Target Audience: MD, NP, PA, RN, SW

End-of-Life Nursing Education Consortium (ELNEC) is a national education initiative to improve palliative care. The project provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students and practicing nurses. www.aacn.nche.edu

Target Audience: NP, RN

EPEC – Education in Palliative and End of Life Care® curriculum teaches fundamental palliative care skills in communication, ethical decisionmaking, psychosocial considerations, and symptom management. The curriculum combines didactic sessions, video presentations, interactive discussions, and practice exercises. Modules include: *Legal Issues*; *Goals of Care*; *Whole Patient Assessment*; *Advance Care Planning*;

Pain Management-Analgesic/Opioid Dosing; Pain Management-Equianalgesic Dosing; Pain Management-Managing Specific Pains; Common Physical Symptoms; Communicating Bad News; Physician-Assisted Suicide; Depression, Anxiety, and Delirium; Sudden Illness; Medical Futility; Withholding/Withdrawing Treatment; Last Hours of Living; Gaps and Elements of Care.
www.epec.net

Target Audience: MD, NP, PA, RN, SW

Get Palliative Care provides clear, comprehensive palliative care information for people coping with serious, complex illness. The site includes a *Palliative Care Provider Directory of Hospitals*, a definition of palliative care, and detailed descriptions of what palliative care does and how to get it. The site is provided by CAPC.
getpalliativecare.org

Target Audience: patients, caregivers, families

Coalition for Compassionate Care of California (CCCC) is a statewide collaborative of organizations and individuals representing health care providers, assisted living facilities, nursing homes, hospices, consumers, state agencies, and others that promotes high-quality, compassionate care for all Californians who are seriously ill or approaching the end of life. CCCC provides expertise, training in Advance Care Planning and POLST, tools, and resources to families, patients, policy makers, and health care providers to help ensure that all Californians receive high-quality palliative and end-of-life care.
coalitionccc.org

Target Audience: MD, NP, PA, RN, SW, patients, caregivers, families

National Palliative Care Research Center (NPCRC) is committed to improving the care for patients with serious illness and the needs of their families by promoting palliative care research. NPCRC provides access to a range of palliative care measurement and evaluation tools.
www.npcrc.org

Target Audience: MDs, NPs, PAs, RNs, SWs

Stanford Palliative Care Training Portal's goal is to improve the quality of life for patients and families facing serious illnesses through education of multi-disciplinary doctors, nurses, psychologists, social workers, and other allied health personnel. Developed by Stanford eCampus, this *free* training portal features learning modules, resources, and training materials from leaders in the field of Hospice and Palliative Medicine.
palliative.stanford.edu

Target Audience: MDs, NPs, PAs, RNs, SWs

Vital Talk is a nonprofit with the mission of nurturing healthier connections between patients and providers. The organization specializes in developing and facilitating advanced communication skills courses, and faculty-training courses focused on balancing honesty with empathy, when discussing serious illness and end-of-life care. In addition to offering *free* one-page quick guides on a variety of conversation topics (such as Talking About Dying and Goals of Care), Vital Talk offers brief videos and other exercises to assist providers with interacting effectively with patients.
www.vitaltalk.org

Target Audience: MDs, NPs, PAs, RNs, SWs, chaplains

Appendix G. Strategies and Roadmaps for Difficult Conversations

Having conversations with patients and families about their goals of care and preferences, including discussions about a referral to hospice, requires patient-centered communication and patience. Because of the sensitivity and emotional content of these discussions, talking maps have been developed to help guide professionals.

This section presents the following conversation strategies which can help palliative care team members communicate effectively with patients and families during complex conversations.^{39,40} Also included in this section are roadmaps for challenging provider-patient conversations. The roadmaps, provided by VitalTalk (www.vitaltalk.org), a nonprofit that promotes healthier connections between patients and providers include: Goals of Care; Discussing Prognosis; Articulating Empathy.⁴¹

Strategies for Difficult Conversations

Ask-tell-ask. Alternate between asking and telling to discover what the patient knows and what information the patient may need.

Ask the patient/family to describe their current understanding of the issue.

- ▶ *What have other doctors told you about your prognosis?*

Ask permission prior to giving information to build a relationship.

- ▶ *Is this a good time to talk more about what you might expect with your diagnosis?*

Tell the patient/family the information they have given you permission to give, and then ask the patient/family if they understand what you just said.

- ▶ *We just discussed a few options for treating your diagnosis, and that was a lot of information. So I am sure I explained the options clearly, can you repeat them to me?*

Tell me more. When you are stuck, ask for more information — *Tell me more...*

- ▶ *What are your thoughts?*
- ▶ *How are you feeling?*

- ▶ *What does this information mean to you?*

Use reflection and paraphrasing. Reflective statements allow the family member to steer the conversation. Simple reflections paraphrase what the patient said.

- ▶ *What you are saying is that you are not ready to make a decision about hospice? Do I have that right?*
- ▶ *We have been talking for a while about how things are going for you. Let me see if I can summarize what you have said, then you can let me know if I'm on track...*

Complex reflections. Include providers' thoughts about the speaker's underlying emotions, values, and beliefs.

- ▶ *I can imagine this is a very difficult time right now and you may be feeling scared.*

Reflect thoughts, emotions, and behavior. Recognize and respond to emotion. Name the emotion and respond with empathy.

- ▶ *It seems like you are having a hard time deciding between ____ and ____...*
- ▶ *You have been feeling ____...*
- ▶ *I see that you are crying...*
- ▶ *You seem very...*

Address anger. It is essential to stay with the emotion expressed by the patient and family using empathy.

- ▶ *This is very hard to deal with and I can understand you may be feeling angry. Can you tell me what you are thinking and feeling right now?*
- ▶ *It sounds/appears that you are angry?*
- ▶ *You appear angry; can you tell me what is upsetting you?*
- ▶ *So, you are telling me that you are angry about ____, is that correct?*
- ▶ *I wish things were different. How can we move forward? How can I help?*

Assess decisionmaking and coping style. Using open-ended questions, assess patient decisional capacity and coping style.

- ▶ *Tell me what's most important to you.*
- ▶ *I'm wondering if you can tell me what I can do to help you feel more comfortable making some of these difficult decisions.*

Affirmation and respect. Use expressions that convey respect for patients.

- ▶ *Thank you for describing your feelings and thoughts.*
- ▶ *I can do a better job as your doctor when I know how you are feeling.*
- ▶ *Please tell me more about the sadness you are feeling.*

Use "I wish" statements. "I wish" statements enable the medical provider to align with the patient while acknowledging the reality of the situation.

- ▶ *I wish I could say that the chemo always works.*

Make a plan. Prior to leaving conversations with patients clarify "next steps."

- ▶ *How can I help? or, What, if anything, would make a difference for you?*
- ▶ *I would like to check in with you next week and see how things are going. In the meantime, please let me know if you need to talk before then.*

Addressing Goals of Care: “REMAP”

We designed this talking map to give you a just-in-time route through a complex conversation. Think of it as a series of signposts—you might find that not all apply to a particular patient.

Step	What you say or do
1. Reframe why the status quo isn't working.	You may need to discuss serious news (e.g., a scan result) first. “Given this news, it seems like a good time to talk about what to do now.” “We’re in a different place.”
2. Expect emotion & empathize.	“It’s hard to deal with all this.” “I can see you are really concerned about [x].” “Tell me more about that—what are you worried about?” “Is it ok for us to talk about what this means?”
3. Map the future.	“Given this situation, what’s most important for you?” “When you think about the future, are there things you want to do?” “As you think towards the future, what concerns you?”
4. Align with the patient’s values.	As I listen to you, it sounds like the most important things are [x,y,z].
5. Plan medical treatments that match patient values.	Here’s what I can do now that will help you do those important things. What do you think about it?
EXTRA: Expect questions about more anticancer treatment.	Here are the pros and cons of what you are asking about. Overall, my experience tells me that more chemo would do more harm than good at this point. It’s hard to say that though.
EXTRA: Talk about services that would help before introducing hospice	We’ve talked about wanting to conserve your energy for important things. One thing that can help us is having a nurse come to your house to help us adjust your medicines so you don’t have to come in to clinic so often. The best way I have to do that is to call hospice, because they can provide this service for us, and more.

Roadmap: Discussing Prognosis — Using Prognosis “ADAPT” Map

Source: VitalTalk. Available at: www.vitaltalk.org/quick-guides.

Discussing Prognosis “ADAPT”

We designed this talking map to give you a just-in-time route through a complex conversation. Think of it as a series of signposts—you might find that not all apply to a particular patient.

Step	What you say
1. Ask what the patient knows, what they want to know	What have other doctors told you about your prognosis, or the future? How much have you been thinking about the future?
2. Discover what info about the future would be useful for the pt	For some people prognosis is numbers or statistics about how long they will live. For other people, prognosis is about living to a particular date. What would be more helpful for you?
3. Anticipate ambivalence	Talking about the future can be a little scary. If you’re not sure, maybe you could tell me how you see the pros and cons of discussing this. If clinically deteriorating: From what I know of you, talking about this information might affect decisions you are thinking about.
4. Provide information in the form the patient wants	To provide using statistics: The worst case scenario is [25 th percentile], and the best case scenario is [75 th percentile]. If I had 100 people with a similar situation, by [median survival], 50 would have died of cancer and 50 would still be alive with cancer. To provide without statistics: From my knowledge of your situation and how your cancer has been changing/responding, I think there is a good/50-50/slim chance that you will be able to be around [on that date/for that event].
5. Track emotion	I can see this is not what you were hoping for. I wish I had better news. I can only imagine how this information feels to you. I appreciate that you want to know what to expect.



Roadmap: Responding to Emotion — Articulating Empathy

Source: VitalTalk. Available at: www.vitaltalk.org/quick-guides.

NURSE statements for articulating empathy

	Example	Notes
Naming	"It sounds like you are frustrated"	In general, turn down the intensity a notch when you name the emotion
Understanding	"This helps me understand what you are thinking"	Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don't)
Respecting	"I can see you have really been trying to follow our instructions"	Remember that praise also fits in here (e.g., "I think you have done a great job with this")
Supporting	"I will do my best to make sure you have what you need"	Making this kind of commitment is a powerful statement
Exploring	"Could you say more about what you mean when you say that..."	Asking a focused question prevents this from seeming too obvious

Three fundamental skills

	Example	Notes
Tell me more	"Tell me more about..."	Use when you are not sure what someone is talking about (rather than jump to an assumption).
Ask-tell-ask	"What do you think about..." "Here's what the tests show" "Does that make sense...?"	Related to Assess-Knowledge-Respond in SPIKES. Think of this as one unit of information transfer.
"I wish" statements	"I wish I could say that the chemo always works"	Enables you to align with the patient while acknowledging the reality of the situation.



Endnotes

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