![Coalition for Compassionate Care of California logo] COALITION FOR COMPASSIONATE CARE OF CALIFORNIA

SNAPSHOTS
of Palliative Care Practices

Insights from the
2015 Coalition for Compassionate Care of California Annual Summit

ABOUT THE AUTHORS

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ABOUT CCCC

The mission of the **Coalition for Compassionate Care of California** is to help people get the care they want in the face of serious illness.

With partners, CCCC is shaping the future of palliative care at the local, state and national level. As the voice of palliative care in California, CCCC incubates and disseminates models and ideas to improve access to quality care for all people.

CCCC is a collaboration of thought-leaders in healthcare systems, providers, government agencies and individuals. Through advocacy, education and resource development, CCCC is working to ensure that organizations and communities have the information, knowledge and tools to create the future of palliative care. For more information visit **CoalitionCCC.org**.

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INTRODUCTION

As practitioners in an emerging field, palliative care providers and leaders can benefit from learning about others' approaches to common clinical and operational issues, yet opportunities for such collaborative learning are limited.

The intention of *Snapshots of Palliative Care Practices* is to build off of the California HealthCare Foundation resource, "**Up Close: A Field Guide to Community-Based Palliative Care**." The Field Guide provides insights into the shared learning of a group of 21 palliative care provider organizations in California.

The Coalition for Compassionate Care of California (CCCC) Annual Summit in April 2015 brought together some 300 palliative care experts and providers from across the state, creating a unique opportunity to gather information on and share current practices. As part of a session on palliative care capacity, need, and resources, participants were asked to share examples of their approaches to working with patients, working with providers, and measuring the impact of their services. Participants were encouraged to share brief written descriptions of approaches that were working well and practices that had failed. These descriptions were collated and synthesized into this summary document.

The information provided by participants included both specific practices and general observations about variables that can facilitate or impede success. These practices and reflections span the continuum of palliative care settings, from inpatient to community-based to hospice services.
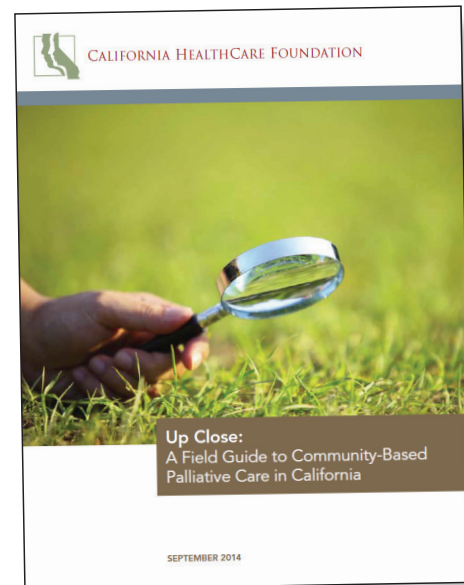
"Up Close: A Field Guide to Community-Based Palliative Care." *California HealthCare Foundation.* 2014. 25 April 2015 <http://www.chcf.org/publications/2014/09/up-close-field-guide-palliative>.

This summary is not intended to be a comprehensive description of palliative care practices – rather, it provides a snapshot of approaches shared by Summit participants, and is one example of how networks of people working on similar issues can learn from each other. Readers can use the information in this summary to identify practices that might be adopted or adapted for their own palliative care services, to consider how their services are similar to or different from those of their peers, and to inform strategies for sustaining, growing or strengthening their programs.

WORKING WITH PATIENTS

Summit participants were asked to share clinical and operational approaches to working with patients. For community-based services (palliative care clinics, home-based services, and telephonic services) respondents were invited to highlight practices that were used before the first visit (pre-visit), during the initial visit, and throughout the course of follow-up care. This could include practices related to:

- **Identifying patients:** Which patients the palliative care (PC) program aims to serve, and how they are identified and referred
- **Care processes:** Who does what, when, and where for the patient and family
- **Goals:** What the PC team aims to achieve during each stage of interaction
- **Managing expectations:** Helping patients understand the specific role of the PC service and supporting patients and families through transitions off of the service.

Sample Practices

Pre-Visit: Proactive outreach and setting the stage

- A PC team member calls the patient before the first visit to remind the patient of the appointment, describe the palliative care service and team, set appropriate expectations, clarify the purpose of the upcoming visit, and respond to any questions. This can help reduce no-shows to appointments, improve the patient's understanding of and comfort with palliative care, and improve the PC team's understanding of the patient's key issues.
- In the inpatient setting, teams hold an informal "pre-visit" with the patient and family as a prelude to a formal PC consult, to help establish trust and begin identifying friends and family members that may participate in decision-making. When a hos-

pitalization is planned, the PC team meets with the patient and family before the hospitalization to get a head start on identifying likely needs and addressing patient and family anxiety or other issues.
- In organizations with inpatient and outpatient services, the inpatient PC team can introduce patients to the outpatient PC team before hospital discharge.

The First Visit:
Learning about patient needs and building trust

- Some services deploy only part of the PC team for the initial patient visit; for example, a social worker may conduct an initial assessment to identify needs and determine which other team members are most needed in subsequent visits. Alternatively, a social worker and nurse may conduct the first visit together to assess a broad spectrum of physical, emotional, and spiritual needs.
- Teams allow time for extended conversations and comprehensive assessment during the first visit by scheduling 1–2 hours for these appointments. Teams can use this time to get to know the patient and family and understand their top concerns; if it is anticipated that follow-up visits will take place, teams may defer addressing issues such as code status.
- The first meeting between the patient and PC team opens with a period of silence/reflection or prayers, to help everyone focus on the moment

and connect each person with their own source of strength and hope.

- After the first visit, the interdisciplinary team meets to discuss all patient needs and craft a comprehensive care plan.

Ongoing Care: Staff roles and care processes

- PC programs often look to specific team members/disciplines to support patients in a variety of ways; for example:
  » A nurse serves as the liaison between the physician and the patient/family and provides the bulk of support around goals of care, documenting preferences, and referrals to other services.
  » A social worker is embedded in sub-specialty treatment centers (infusion, radiation, dialysis) to support patients and address concerns.
  » A nurse case manager meets with patients at home or in the hospital to assess their goals and address symptom issues.
  » A nurse practitioner rounds wherever her medical group's severely ill patients are and discusses POLST forms with them.
  » A social worker interviews patients to assess their understanding of their medical condition, their values and concerns regarding quality of life, and whether they want to involve others in their decision-making processes.
- Teams lacking particular disciplines try to access those skills by engaging volunteer professionals or students; for example, an inpatient PC team without a designated social worker has a social worker volunteer for the service for one to three hours per week; a hospice without a funding stream for palliative care has their volunteer coordinator (a social worker) assess needs of non-hospice patients and assigns a social work intern to conduct weekly visits and provide information back to the primary physician.

- Patients receive a "member card" that identifies them as a palliative care patient; the card includes a phone number that is accessible 24 hours a day, 7 days a week. Providers can use the number to access information about the patient's goals of care, care plan, medication list, and treating providers.
- Teams create disease-specific care pathways (e.g., CHF, COPD, dementia) to guide other care providers in how to address some of the primary palliative needs of patients with these diseases.
- In the inpatient setting, PC team members do daily pain rounds to identify patients with unresolved symptoms.
- Services use a variety of strategies to help patients and families feel comforted during the care process, from simple gestures such as offering coffee, tea, and crackers during a visit to arranging for alternative/complementary services such as massage or music therapy. Complementary services are often provided by volunteers.
- Teams make follow-up phone calls to patients shortly after their PC visit to answer questions or address concerns.
- Teams send personal letters of condolences and information on bereavement services to families of their patients who have died.

Coordination across settings

- Teams have created a variety of partnerships across care settings, such as a hospital partnering with a local skilled nursing facility (SNF) to improve care coordination of seriously ill patients through SNF visits by a hospital-supported PC nurse practitioner; an inpatient PC service creating an outpatient clinic that offers post-discharge follow-up for PC issues; an inpatient PC nurse practitioner continuing to follow patients once discharged to SNF; and a hospice nurse coming to a local hospital to talk to patients and families about hospice and community-based PC services.

- Teams also work to ensure smooth transitions for patients across care settings. Practices include calling patients/families a few days after the patient is transitioned to hospice to check in; or if the patient/family has been reluctant to transition to hospice care, a PC team member may do a few home visits after the patient begins receiving hospice care to help ensure a more comfortable transition.

Using technology to expand reach

Teams use technology such a phone calls or videoconferencing to connect patients and families with palliative care providers when in-person visits are not practical or feasible; for example, a nurse visits the patient in the home and, while there, sets up videoconferencing between the patient and palliative care physician; a physician/nurse practitioner team conduct "virtual consults" and follow-up visits by videoconference to reach patients who live in rural communities where travel would be a hardship.

Observations, Reflections, and Challenges

- Certain populations have unique needs that PC teams should consider and accommodate, such as people with limited English proficiency (ideally, a member of the PC team would speak the preferred language of the patient; alternatively high-quality interpretive services should be sought) and patients with cognitive impairment, who may need innovative approaches to connect and build trust with the team.
- Some teams that have tried to expand their PC services from inpatient to outpatient settings have been challenged to get their new services up and running, often due to lack of staff, scheduling challenges, patient cancellations/no-shows, and insufficient planning around expected volumes, required resources and methods for assessing impact.
- Teams are challenged by situations where the referring provider has not had a frank discussion with the patient about prognosis, and the patient is not aware they are facing a life-limiting illness when they are referred to the PC team.

WORKING WITH PROVIDERS

Summit participants were also asked to share clinical and operational approaches to working with providers. For community-based services (palliative care clinics, home-based services, and telephonic services) respondents were invited to highlight approaches to partnering with referring providers, supporting appropriate referrals, and addressing resistance. This could include practices related to:

- **Clarifying roles:** Differentiating the PC team from other providers
- **Building interest:** Strategies to build interest in PC services among potential referral sources
- **Leveraging knowledge:** Learning from the knowledge that primary providers have of their patients
- **Communication:** Collaborating and communicating to ensure patients' needs are met
- **Balancing growth and capacity:** Being responsive to referring providers' needs without overwhelming the PC service.

Sample Practices

Supporting appropriate referrals and clarifying goals for PC involvement

- Teams use a variety of approaches to identify patients who may be appropriate for palliative care and to facilitate referrals, such as:
  - » Implementing referral "triggers" in primary and specialty care clinics, emergency departments, and inpatient settings.
  - » Building electronic systems or processes that make referrals easy or allow anyone to make a referral.
  - » Requesting that referrals contain "critical components" to help the PC team understand the patient's needs: for example, history and physical, copy of POLST, patient goals, purpose of referral.
  - » Nurturing relationships with non-physician providers who may be more likely to refer (e.g., inpatient social workers).
  - » Using clinical or utilization criteria to create a list or registry of PC-appropriate patients and contacting their providers if they have not already been referred to PC.
- Teams ensure that their services meet the goals of referring providers by creating EHR workflows that require referring providers to list specific goals for the consult, and by talking directly with providers about their goals before the PC team sees their patients.
- Prior to engaging with patients, teams ask referring providers what has been discussed with the patient and family about disease progression, goals of care, palliative care, or hospice.

Building relationships and educating other providers

- Teams build the expertise of other providers by offering education about what palliative care is and how it benefits patients, families and providers. Some teams also offer instruction in basic palliative care skills. Examples of such practices include:
  - » An academic medical center family medicine program teaches residents about the changing nature of end-of-life care, advance care planning tools, and communication skills.
  - » Education about the unique needs of certain types of patients, such as approaches to assessing pain in individuals with developmental disabilities.

- » Offering educational sessions in skilled nursing facilities, assisted living facilities, and hospitals to describe palliative care, differentiate PC from hospice, and answer questions.
  - » Videoconference-based case reviews with the PC team.
  - » Educational sessions or roundtable dinners for local providers.
- Investing in relationship-building activities can go a long way towards cultivating existing or potential referral sources; examples of such practices include:
  - » Inpatient PC service makes a courtesy call to the patient's oncologist to inform them a PC consult was requested on their patient.
  - » PC team invites other specialties or departments to PC meetings to discuss specific cases.
  - » PC team members attend regular Oncology and tumor board meetings to discuss cases.
  - » Inpatient PC team member attends daily ICU rounds and family meetings to identify ways PC could support the patient, family, and involved providers.
  - » Cultivate PC champions among primary and specialty providers to help other providers within a group/department understand how PC can help their patients.
  - » Offer specific ways the PC team can support or save time for the referring providers, such as offering to conduct POLST/advance directive/ advance care planning conversations, or offer to work with patients with complex family dynamics or complicated pain syndromes.
  - » Follow up with the referring provider a couple weeks after a PC consult or after patient death to ask if the PC service met expectations and ways the service could be improved.

Collaboration and communication with other providers to improve patient care

- After the initial visit and throughout the course of care, the PC team informs the referring provider and other involved providers about what has been accomplished, remaining needs, specific recommendations, goals of care, and plan of care. This communication can take place through medical record notes, phone calls, or in-person conversations.
- The PC team and referring providers can improve care continuity and communication with the patient by offering joint visits, having a PC team member attend a patient's appointment with the primary provider, or by embedding the PC service within a specialty clinic (e.g., Oncology) to increase the likelihood of regular consultation between PC and other specialty providers.

Collaboration between PC providers in different settings

Inpatient and outpatient PC services can collaborate to streamline care for patients and families through practices such as:

- An outpatient PC liaison (a member of the inpatient PC team) meets with patients and families while in the hospital to facilitate the transition to the outpatient program.
- The inpatient PC team meets with home health PC nurses and social workers to review cases and care options; in turn, the home health PC team informs the inpatient PC coordinator when their patients go to the emergency department or hospital to allow for close follow-up and eventual discharge back to the home health PC program.
- The outpatient PC physician works one day a week with the inpatient PC team, doing inpatient consults and meeting with hospitalists. Many of the patients seen in the inpatient setting are later transitioned into her care in the outpatient PC service.

- In one community, physicians from different hospice organizations have convened for dinner meetings to network, share ideas, and participate in educational sessions.

Addressing providers' resistance to PC

When working with providers who are less inclined to refer to palliative care, PC team members emphasize education and relationship: they approach resistant providers in a spirit of collaboration; spend time with them to help them better understand palliative care; reassure the provider that the patient/family can decline the PC service even if they are referred; have the PC physician contact the referring provider before the PC consult to discuss goals and expectations for the consult; and provide care that the referring provider may feel less comfortable with (e.g., completing POLST forms).

Observations, Reflections, and Challenges

- Some providers advocate for care that the PC team sees as overly aggressive or futile, and some providers may state that they do not "believe in" palliative care or hospice. In these cases, it may be useful for PC physicians to focus on peer-to-peer education and communication, including case conferences to elicit information on the provider's goals and the patient's goals.
- Relying solely on provider judgment about which patients are appropriate to refer to PC can be problematic – for example, some refer patients very late in their disease course, patients who need intensive case management rather than palliative care. This underscores the need for clear referral criteria, clinical or utilization triggers, and feedback channels about referrals.
- Communication about patient care is a significant challenge for some. For example, some referring providers resist engaging in dialogue with PC teams before and after the PC consult to gather and convey information, instead limiting communication to faxed consults and written orders. Some PC teams have difficulty getting information about a patient as they move across care settings, such as from outpatient to inpatient to SNF. Some PC teams discharge a patient from their service with clear expectations and recommendations about what will happen in the next care setting, but those recommendations may not be followed reliably.

MEASURING IMPACT

Finally, Summit participants were invited to share their approaches to assessing the reach, quality, and impact of their PC services. Participants offered general and specific examples of their efforts related to measurement and metrics, including:

- Experiences with assessing patient and family satisfaction
- Metrics that describe how the service addresses specific domains of PC such as advance care planning (ACP) and spiritual aspects of care
- Efforts to document PC service impact on the use and cost of health care services.

Some participants offered descriptions of the combination of metrics that their services use; these "measure sets" highlight how teams are combining data to create a layered picture of service structures, processes, and outcomes. Many participants described frustrating or unsuccessful measurement efforts, highlighting how this topic presents ongoing challenges for the field.

Sample Practices

Patient and family experience of care

- **Strategy for collecting and interpreting data:** The inpatient PC program has responsibility for administering a patient/family satisfaction survey and tracks outcomes month to month; results are considered in relation to an agreed upon bench-mark/target score.
- **Types of questions:** Patients are asked, "Did you feel your decisions were supported by the team?" Families are asked if they received grief counseling, even if patient was not in hospice care.
- **Strategy for quantifying impact:** Historical comparison of family satisfaction with end-of-life care, contrasting assessments made before and after implementation of a palliative care service.

Process measures

- **Assessing volume and productivity:** Number of visits per provider per day; total visits (new and follow-up) per year; total number of new patients engaged by the PC service per year
- **Engagement with specific disciplines:** Proportion of PC patients receiving social work interventions and proportion receiving chaplain services
- **Referral practices:** Monthly tallies of number of referrals, number referred who declined services, number where the referral was not appropriate

Goals, preferences and concordance

- A hospital-based program assesses the percentage of patients who have a goals-of-care (GOC) note present in a dedicated GOC section of their electronic health record (EHR).
- A system with a formal Life Care Planning (LCP) program reviews charts of decedents who participated in a LCP conversation to determine how often documented wishes were followed.

Utilization outcomes

- Average hospital length of stay after the initial inpatient PC consult
- Number of hospital admissions and readmissions, emergency department (ED) visits, and the cost of care 12 months prior to and after engagement with the PC service
- Proportion of patients dying in the hospital
- Proportion of patients transitioning from PC to home health or hospice

Sample measure sets

- Number of contacts with specialist PC services across the continuum of care; patient and family satisfaction with pain management; cost in the last 6 months of life and the last 2 months of life; percentage of patients with a POLST form in medical record; percentage of patients with an advance directive (AD) in medical record; hours of operation; staffing model for inpatient and outpatient PC (FTE for social workers, physicians, nurses, etc.)
- Patient/family satisfaction after palliative visits; hospitalizations; ED visits; readmissions
- Provider and patient assessment of functional status; whether/when advance care plans are recorded in the EHR; proportion of cancer patients receiving chemotherapy in the last two weeks of life

- Demographics (age, gender, payer, etc.); diagnosis; reason for referral; length of time followed by PC service; reason for discharge from program (recovered, died, self-discharged)
- Readmissions when patient was discharged to SNF; presence of ACP/POLST in health record
- Family satisfaction with EOL care; cost savings for PC patients (comparing costs before and after PC consultation)
- Number of consults; care concordance with documented preferences; number POLST discussions; proportion of patients participating in ACP conversations
- **Metrics planned for PC integration into mental health:** Average life span; number of crisis episodes; number of ACP conversations documented in EHR; number of patients with ADs; number patients with POLST forms completed
- **Metrics planned for multi-state, multi-hospital system:** Whether a spiritual support visit occurred; documentation of code status; discussion of ACP noted in the health record

Observations, Reflections, and Challenges

Accessibility and quality of data

- We had hoped to measure the number of AD's and POLST forms completed by our patients, but these documents don't end up in our medical record so tracking was not feasible.
- Absence of reliable data identifying which health plan members had died and date of death hampered analysis of end-of-life utilization patterns.
- The absence of standardization in how diagnoses are entered into our EHR made it difficult to consider diagnosis when describing our patients, assessing which patients could have benefited from palliative care, or in designing referral triggers.

Survey challenges

- Our tools for measuring patient/family satisfaction do not have appropriate wording about effectiveness of and satisfaction with goals of care communications, nor do they allow respondents to comment on improvement opportunities.
- The questionnaires used for family satisfaction have poorly worded questions that are too long and use terms families don't understand. Our center has not used statistical analysis to determine if survey results are significant.
- Our SNF-based PC team found that mailing patient satisfaction/family satisfaction surveys post-discharge didn't work well; people didn't return the surveys even though many had verbalized their satisfaction with the service.
- We tried administering a survey with a web-based commercial survey tool, but found that many patients or family members didn't use computers. We tried asking the questions verbally and inputting the answers into the tool but that didn't work well, either.

Inadequate resources to gather or analyze data

- We are struggling with metrics—the only measure we can consistently get is number of consults.
- We are unable to take the time to even track data! We only measure the number of people who complete an AD, and the number of people referred to hospice (after PC consult).
- The person tasked with reporting data has no time to do it [properly]. They report the data anyway!
- We used to collect pain and symptom information but lost the manpower to do so—we plan to resume that practice this year.
- We were not tracking the number of consults done. We have started and are now reporting these numbers to leadership—they were unaware of team's work.