California
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In It Together:
How Palliative Care Spread to All of California's Public Hospitals

March 2013

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Prepared for
California HealthCare Foundation

by
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About the Author

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About the Foundation

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I. Background

With a mission to serve the poor, underserved, uninsured, and vulnerable, public hospitals are the first medical provider many adults ever have. They are also sometimes the last.

Public hospitals in California serve 2.5 million people each year.[1] Because many public hospital patients do not have the resources for preventive care or care at the early stages of illness, many present for treatment when their illness has progressed to a late stage.[2] For these patients, palliative care, with its specialized focus on relief from the pain, symptoms, and stress of serious illness and with the goal of improving quality of life, is often the most appropriate care.

In 2008, a California HealthCare Foundation (CHCF) report on California hospital-based palliative care programs found that although 43% of all hospitals in the state had palliative care programs, only 22% of public hospitals (four of 17) had palliative care programs.[3] Due to the state's fiscal crisis, many public hospitals lacked the funds to establish or expand palliative care services.

Recognizing that a lack of palliative care services in public hospitals was a barrier to providing appropriate care for their underserved populations, in 2008 CHCF launched a partnership with the California Safety Net Institute (SNI) and the University of California, San Francisco, Palliative Care Leadership Center (PCLC). The goal of this five-year initiative, Spreading Palliative Care in Public Hospitals (SPCPH), was to develop new, sustainable in-patient palliative care programs in California's public hospital system and to support expansion and enhancement of existing public hospital palliative care programs, with an emphasis on reaching diverse communities. (See Table 1.)

This report chronicles the work of the SPCPH initiative, including three projects that were created along the way to respond to challenging situations faced by participating palliative care teams. The report highlights the initiative's successes and challenges and describes the elements that paved the way for the establishment of sustainable palliative care programs in all of California's public hospitals. (See Figure 1 on page 4.)

Palliative Care Defined

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing relief from the symptoms, pain, and stress of a serious illness — no matter the diagnosis. The goal of palliative care is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, social workers, chaplains, and other specialists who work with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.[4]

Table 1: Spreading Palliative Care in Public Hospitals Phase I and II Grant Awards

	PHASE I			PHASE II
PUBLIC HOSPITAL	PLANNING 2009 (6 months)	EXPANSION 2009–2012 (6–12 months)	IMPLEMENTATION 2008–2012 (24 months)	IMPLEMENTATION 2011–2014 (24 months)
Alameda County Medical Center		●		
Santa Clara Valley Medical Center		●		
LAC+USC Medical Center		●		
UC Irvine Medical Center		●		
UC San Diego Medical Center	●		●	
San Francisco General Hospital			●	
Contra Costa Regional Medical Center			●	
Riverside County Regional Medical Center	●		●	
San Mateo Medical Center	●		●	
Kern Medical Center	●			●
Harbor-UCLA Medical Center	●			●
Olive View-UCLA Medical Center	●		●	
UC Davis Medical Center	●		●	
Arrowhead Regional Medical Center	●		●	
Natividad Medical Center				●
San Joaquin General Hospital				●
Ventura County Medical Center				●

PURPOSE OF EACH GRANT PHASE:

Planning grants supported grantees in the development of a vision for a hospital-based palliative care service and prepared them to submit an implementation grant proposal.

Expansion grants allowed existing public hospital palliative care programs to expand their services. For example, one hospital received a grant to hire a bilingual social worker to increase the program's ability to serve Spanish-speaking patients in the evenings and on weekends.

Implementation grants were awarded to hospitals with well-designed plans to implement viable palliative care programs with clear leadership, administrative support, clinical protocols, and strategies for targeting underserved and ethnically diverse patients.

Source: LifeCourse Strategies.

Figure 1. Spreading Palliative Care in Public Hospitals (SPCPH) Initiative Grantee Sites

Source: LifeCourse Strategies.

II. Helping Hospitals Establish and Expand Palliative Care

The SPCPH initiative gave California's public hospitals critically needed funding for palliative care, support that was fortuitously timed given the national recession and the state's budget crisis. The funding also helped raise the profile of palliative care as a viable and essential specialized medical service, giving it the gravitas necessary to garner support from hospital administrators.

The initiative received guidance from a strategic advisory committee (SAC), an executive committee, and expert consultants — palliative care physician leaders from three of the state's public hospitals. The SAC, composed of palliative care experts, health system representatives, and experts in cultural competence, guided initial development and expansion of the initiative. (See Appendix A for a list of SAC members.)

Members of the California Safety Net Institute (SNI) board of directors, which includes California public hospital system leaders, served as the initiative's executive committee and monitored the initiative's progress and outcomes. In addition, three physician leaders of established public hospital palliative care programs were engaged as consultants to advise the project team, serve as PCLC faculty, and support the implementation grantees.

Support from the Project Team

The project team that shaped and managed the initiative included representatives from CHCF; the SNI, a nonprofit quality-improvement affiliate of the California Association of Public Hospitals and Health Systems and a critical liaison to the state's public hospitals; and the University of California, San Francisco (UCSF), Palliative Care Leadership Center (PCLC), well-recognized for its technical expertise in palliative care. LifeCourse Strategies was brought onto the project team as the project manager, and Learning Partnerships was hired as the initiative's evaluator. The End-of-Life Nursing Education Consortium (ELNEC) became a member of the project team in 2010.

Throughout the initiative, the project team met regularly to review grant applications, make funding recommendations, plan activities such as grantee site visits and the annual grantee meeting, coordinate presentations and papers for professional conferences, provide guidance on special projects, and track the progress of the initiative overall.

From 2008 through 2013, project team members conducted 38 hospital site visits to provide in-person support to hospital teams. Each implementation and expansion grantee received a site visit prior to the project's start and again mid-project. Those hospitals experiencing difficulties were visited more frequently. Project team members helped hospitals solve challenges and identify ways to promote project sustainability.

The project team provided continuous support during a complex undertaking and helped ensure that the knowledge gained through working with the hospital teams was shared and integrated into the work of all the teams.

Natalie Moy, LCSW, director of patient care management at Riverside County Regional Medical Center, talked about how the project team helped her center's palliative care program: "We appreciated being able to meet with project team members to review clinical and financial data to help prove our

program's financial viability to the hospital during difficult budget times."

PCLC Technical Training and Assistance

Since many hospital leaders were not familiar with how to establish or run a comprehensive palliative care program, technical training and ongoing assistance gave initiative participants a solid foundation on which they could build or expand their programs.

UCSF provided all 17 public hospitals with comprehensive PCLC training in the operational, clinical, and financial requirements for creating and sustaining successful palliative care programs.

PCLC's expert faculty provided hospitals with ongoing mentoring and support throughout the project.

To help implementation grantees prepare a business case — a grant requirement — UCSF developed a public hospital-specific business-case summary, *The Business Case for Palliative Care Consultation Services in California's Public Hospitals.*[5] The summary presents five different financial analyses that capture reduced or avoided costs resulting from palliative care service activities.

Sheira Freedman, MD, hospice and palliative care specialist at the Alameda County Medical Center, shared how the project team and PCLC training helped her program secure the support of hospital executives: "Daily, I think about how important it was to have the project team support us in developing a strong business case. It was like getting a set of great instructions for new furniture — we had all the pieces already, and all we had to do was assemble it at home. Honestly, I had never gone to our hospital executives before to ask for support for our program, I was too busy with daily service. But the project team gave us the necessary tools and push to do it."

PCLC Training Agenda

Module 1: Systems Assessment & Mission Alignment

Module 2: Clinical Models & Staffing

Module 3: Financial Case & Sustainability

Module 4: Measurement

Module 5: Internal Marketing

Module 6: Community Partnerships

Module 7: Palliative Care Education

Module 8: Program Implementation

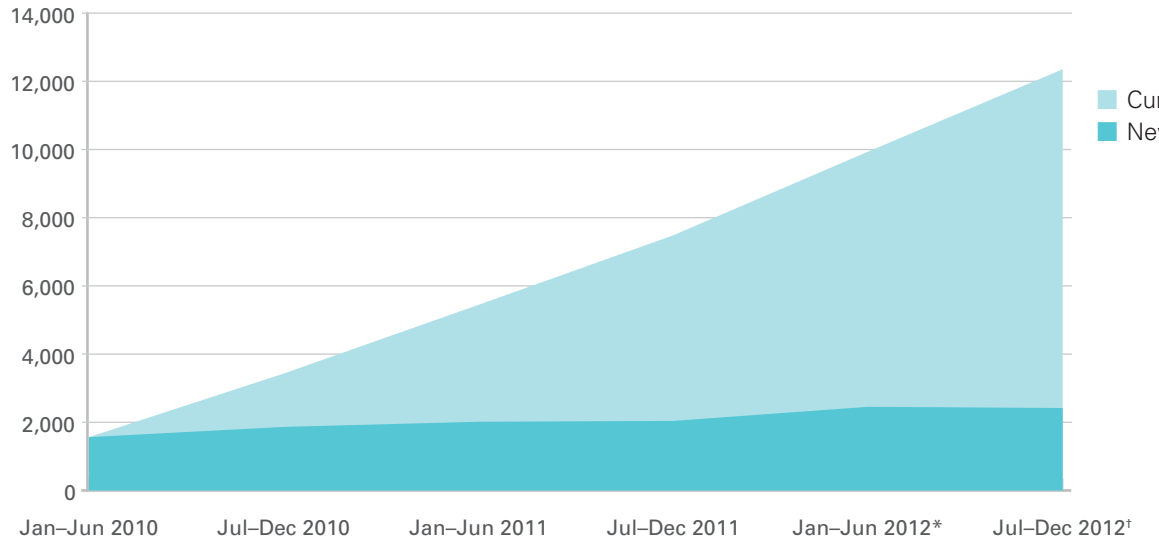
III. Positive Results

THE INITIATIVE ACHIEVED ITS MISSION: to establish palliative care programs in 100% of California's public hospitals. The first state in the country to accomplish this feat, California now serves as a model for other states.

A primary goal of the SPCPH initiative was to increase the provision of palliative care to diverse and underserved patient communities in California. The first step for each public hospital was to hire clinical staff — a physician, nurse, social worker, and/or chaplain — to serve on the palliative care team. Teams then participated in the Palliative Care Leadership Program at UCSF and learned from experts how to establish and grow a service. Specific strategies varied somewhat based on the needs of each hospital's program. For example, at UC Irvine Medical Center, a bilingual social worker was hired to meet with families and offer palliative care service work on evenings and weekends. Teams developed referral strategies (for example, materials in languages other than English) and provided educational programs for hospital physicians through grand rounds and for nurses thorough the End-of-Life Nursing Education Curriculum (ELNEC).

In the first two years of the initiative, the number of palliative care patients grew steadily at most sites. By December 2012, more than 12,000 palliative care patients had been served by initiative hospitals.

Figure 2. Number of SPCPH Patients, New and Cumulative, All Sites, 2010 to 2012



Note: 2010 and 2011 data includes 12 implementation and expansion sites.
*Data includes 15 sites (3 new: San Joaquin, Natividad, and Ventura).
†Data includes 16 sites (2 new: Harbor-UCLA and Kern). Does not include data from Contra Costa, which was experiencing EHR challenges at the time of data collection.
Source: Learning Partnerships evaluation data taken from reports submitted by SPCPH initiative participants.

(See Figure 2.) The number of new and cumulative palliative care consults for the same reporting period also climbed incrementally.[6] (See Figure 3.)

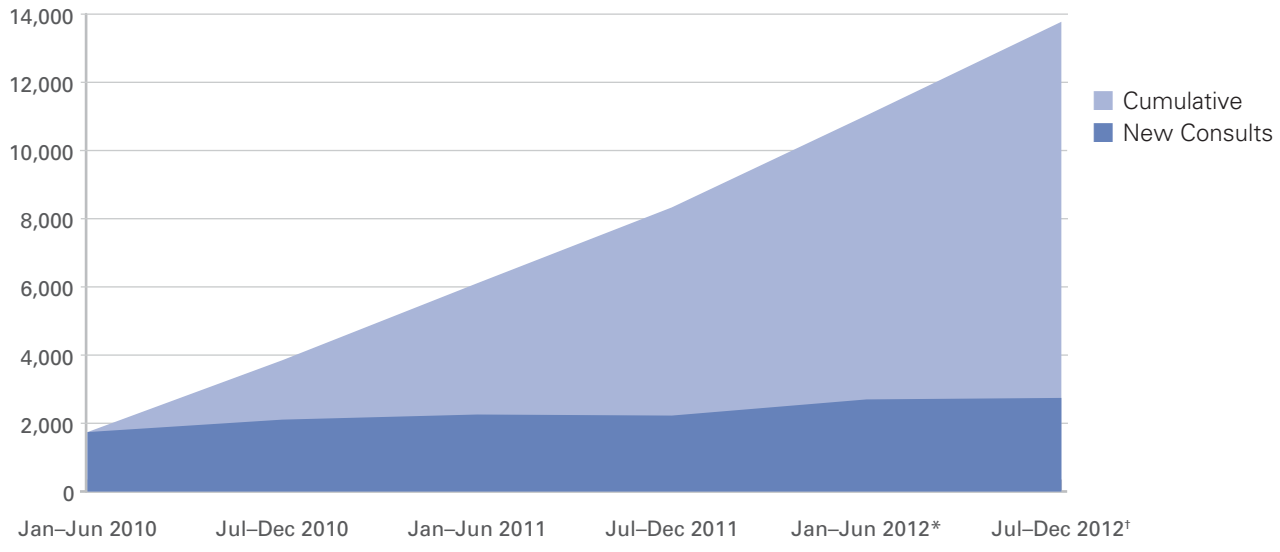
Throughout the program period, the average age of public hospital palliative care patients — between 59 and 62 years — remained significantly lower than the state's average age of death, which is 80 years. (See Figure 4.) That patients who die in a public hospital die as much as 20 years earlier than Californians overall reflects the reality that, compared to the general population, public hospital patients are poorer, sicker, more likely not to have health insurance, and less likely to receive preventive care. Consequently, by the time their symptoms cannot be ignored and they come to a public hospital seeking care, they are more likely to be in a terminal phase of illness — at a much younger age than if they had had appropriate care at an earlier stage.

The data also reflect the tremendous diversity of public hospital patients. Across sites, one-third of public hospital palliative care patients had limited English proficiency (LEP) — they spoke a primary language other than English. In all of the public hospitals, palliative care patients were racially and ethnically diverse; as of June 2012, of all the palliative care patients served since the start of the program period, more than 65% were non-White. (See Figure 5.)

Consultation Defined

To be considered a consultation, a member(s) of the palliative care consultation service must have completed an evaluation and communicated the findings/recommendations to the primary physician/medical team.

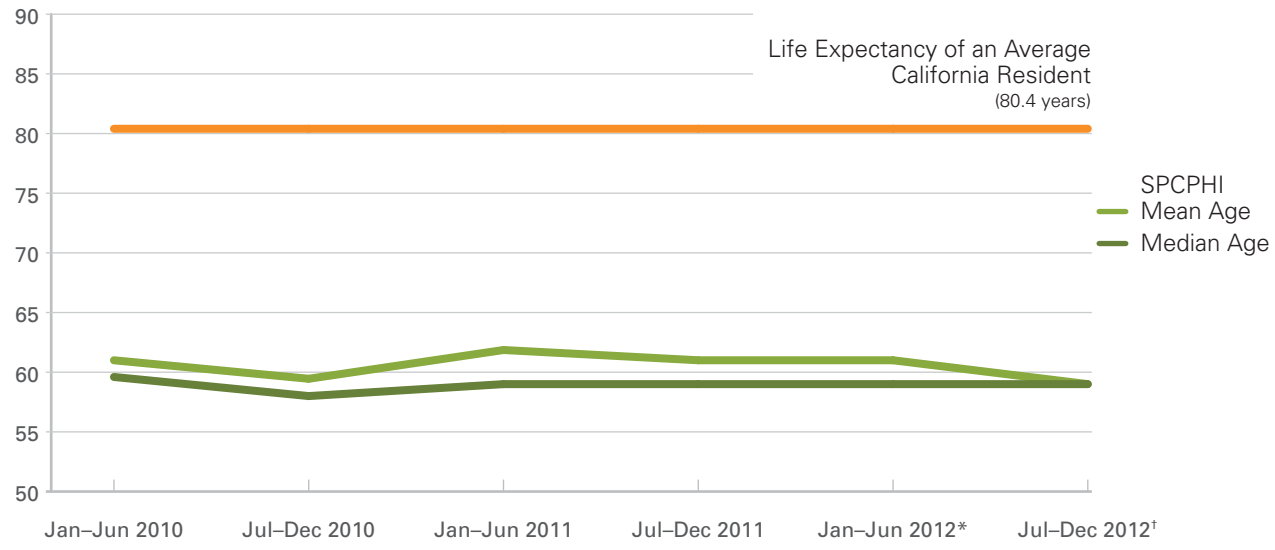
Figure 3. Number of SPCPH Consults, New and Cumulative, All Sites, 2010 to 2012



Note: 2010 and 2011 data includes 12 implementation and expansion sites.
*Data includes 15 sites (3 new: San Joaquin, Natividad, and Ventura).
†Data includes 16 sites (2 new: Harbor-UCLA and Kern). Does not include data from Contra Costa, which was experiencing EHR challenges at the time of data collection.

Source: Learning Partnerships evaluation data taken from reports submitted by SPCPH initiative participants.

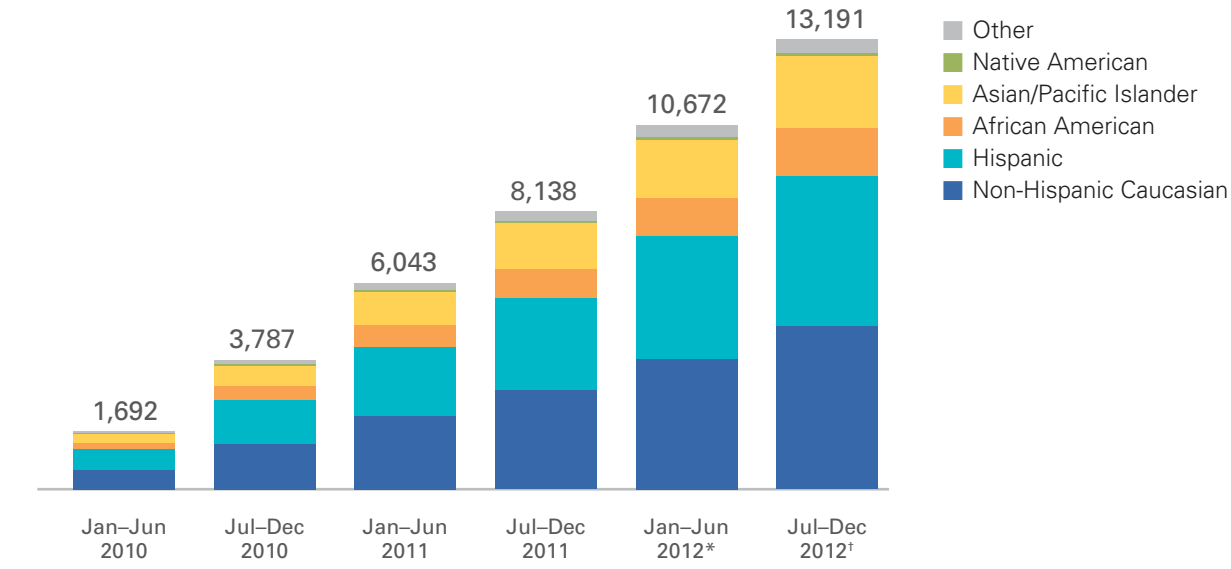
Figure 4. SPCPH Initiative Patient Average Age, Compared to California Life Expectancy, 2010 to 2012



Note: 2010 and 2011 data includes 12 implementation and expansion sites.
*Data includes 15 sites (3 new: San Joaquin, Natividad, and Ventura).
†Data includes 16 sites (2 new: Harbor-UCLA and Kern). Does not include data from Contra Costa, which was experiencing EHR challenges at the time of data collection.

Sources: Learning Partnerships evaluation data taken from reports submitted by SPCPH initiative participants. 2007 California average life expectancy from birth data are from the Kaiser State Health Facts, www.statehealthfacts.org.

Figure 5. SPCPH Patient Ethnicity, Cumulative, All Sites, 2010 to 2012



Note: 2010 and 2011 data includes 12 implementation and expansion sites.
*Data includes 15 sites (3 new: San Joaquin, Natividad, and Ventura).
†Data includes 16 sites (2 new: Harbor-UCLA and Kern). Does not include data from Contra Costa, which was experiencing EHR challenges at the time of data collection.

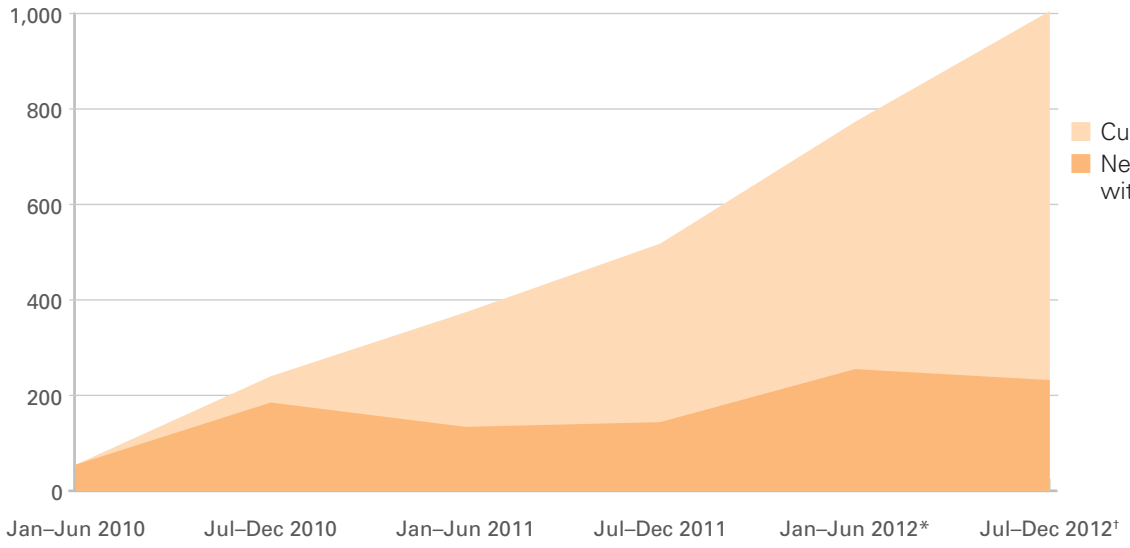
Source: Learning Partnerships evaluation data taken from reports submitted by SPCPH initiative participants.

The January-June 2012 data report showed that more than 50% of palliative care patients at the two Los Angeles public hospitals (Olive View and LAC+USC) were Hispanic. During this same time period, nearly 50% of the palliative care patients at Alameda County Medical Center were African American, and Asian/Pacific Islanders made up the largest ethnic group at San Francisco General Hospital. During this period, at all sites, Hispanics were the most commonly represented ethnic group (34%), followed by Whites (32%).[7]

Another outcome of the initiative was the introduction of Physician Orders for Life-Sustaining Treatment (POLST) forms to public hospitals. In a POLST form, patients have a concise document that details their medical treatment preferences which is then signed by the patient and physician and intended to be honored in all care settings. These forms were introduced by initiative teams to patients and their family members during family meetings.

Most initiative sites had difficulty facilitating widespread adoption of POLST forms. Some palliative care team members were confused about the form and its role in relation to an advance directive (living will), and some teams were not clear about which team members were responsible for coordinating the POLST discussion between the patient and the physician. POLST form completion was often seen as a post-discharge responsibility. Teams also reported feeling too rushed in their work, with little time to address the POLST form. Only half of the hospitals have a formal POLST policy in place. Despite the low numbers of patients with signed POLST forms, most palliative care teams strongly endorsed POLST. (See Figure 6.)

Figure 6. Number of SPCPH Patients with POLST, New and Cumulative, 2010 to 2012



Note: 2010 and 2011 data includes 12 implementation and expansion sites.
*Data includes 15 sites (3 new: San Joaquin, Natividad, and Ventura).
†Data includes 16 sites (2 new: Harbor-UCLA and Kern). Does not include data from Contra Costa, which was experiencing EHR challenges at the time of data collection.
Source: Learning Partnerships evaluation data taken from reports submitted by SPCPH initiative participants.

IV. Meeting Public Hospital Needs: Special Projects

"I really enjoyed the open discussion on cultural concerns that both interpreters and patients face when it comes to palliative care. Also, to hear the different ways that other interpreters handled certain situations was beneficial. The exercises were really helpful."

— INTERPRETING IN PALLIATIVE CARE COURSE PARTICIPANT

DURING THE COURSE OF THE INITIATIVE, TEAMS identified specific training needs: palliative care training for health care interpreters; palliative care training for staff nurses, who play a formative role in palliative care referrals, especially in busy teaching hospitals, with their constant rotation of interns and residents; and training in how to provide culturally responsive palliative care. To address these needs, three special projects were developed and funded: *Interpreting in Palliative Care Project, ELNEC Public Hospital Nursing Project,* and *Culturally Responsive Palliative Care Workshops.*

Interpreting in Palliative Care

With as many as 35% of public hospital palliative care patients having limited English proficiency (LEP), the need for trained interpreters became apparent early on in the initiative.[8]

As part of the initiative, UCSF completed a national study and found that the majority of health care interpreters surveyed feel that palliative care encounters are stressful and that interpreters want more support from providers in these sessions.[9,10] A national search for palliative care training for interpreters found only a handful of workshops and local programs throughout the country.

To address these concerns, a curriculum — Interpreting in Palliative Care — was developed that includes: an overview of palliative care, three videos of interpreter-mediated encounters modeling best practices in palliative care interpreting, an introduction to palliative care terms and exercises to practice interpreting from English to seven other languages, and exercises for managing the emotional impact of interpreting end-of-life conversations.[11]

A group of 14 experienced interpreter trainers representing six regions of California were trained to teach the curriculum. Each participating trainer committed to teaching the course at least once over the following year. Overall, trainers and participants gave the training format and curriculum content high scores. Participants reported a significant increase in their level of comfort interpreting palliative care discussions.[12] The curriculum is available for free on the Health Care Interpreter Network (HCIN) website: www.hcin.org.

To make the course directly available to health care interpreters, the in-person curriculum for trainers was adapted to an online version for health care interpreters. This curriculum for interpreters is available on the HCIN website for a modest fee: learn.hcin.org. Participants who pass the final test receive a certificate of completion and seven hours of continuing-education unit credit from the International Medical Interpreters Association.

An issue brief, *Language Lessons: Palliative Care Training for Interpreters,* documents the interpreter survey findings and curriculum-development process and is available at www.chcf.org.[13]

A Spanish-speaking on-site interpreter shared her enthusiasm for the course: "I've interpreted before for the hospice nurse and for doctors offering hospice care or palliative care. Also for family meetings. And it's hard — there are lots of family disagreements, and it gets highly emotional. Also, there are a lot of cultural and religious nuances that are hard to capture. I never had any training specific to this type of encounter."

To build on the success of the Interpreting in Palliative Care course, as part of SPCPH initiative activities in 2013, SNI will facilitate a nine-month-long community of practice (CoP) for health care interpreters. Interpreters from California public hospitals who have completed the Interpreting in Palliative Care course will be invited to participate in regular web meetings and conference calls to build a CoP dedicated to reducing professional isolation, discussing common challenges, and exchanging best-practices strategies, information, and resources.

ELNEC Public Hospital Nursing Project

Because staff nurses play a key role in palliative care referrals in busy teaching hospitals, where there is constant rotation of interns and residents, they were identified by initiative participants as important recipients of palliative care training. The multi-year ELNEC Public Hospital Nursing Project was designed to provide ELNEC training and mentoring to public hospital nurses, and to promote enhanced connections between trained nurses and their respective hospital palliative care programs.

Nurses from 16 public hospitals participated in the following activities:

ELNEC training. Three nurse champions from each hospital participated in a two-and-a-half-day train-the-trainer course that included sessions on pain and symptom management, communication, culture, ethics, loss grief and bereavement, care in the final hours of life, leadership, integration of best evidence into policy and practice, and models of excellence.

Mentoring. One member of the ELNEC project team visited each participating hospital to help identify viable solutions to the challenges of training nursing peers in palliative care. The ELNEC project team called each public hospital monthly and organized networking and educational opportunities. Participating nurses were encouraged to schedule meetings with the hospital palliative care team to discuss communication and palliative care referrals.

Online palliative care education. Through a grant from the Archstone Foundation, beginning in 2012, project hospitals were given a two-year subscription to the Hospice Education Network (HEN), an online education provider. Eight ELNEC public hospital modules were made available to nurses affiliated with project hospitals to share with other nurses in their respective hospitals. In the first

nine months of 2012, the modules were viewed more than 2,000 times.

Since the start of the ELNEC Public Hospital Nursing Project, nurse champions have successfully promoted palliative care education for staff nurses, other medical providers, and hospital administrators. Some examples include:

- At Harbor-UCLA, the palliative care team nurse practitioner, an ELNEC champion, facilitates monthly calls with the hospital nurses who attended the November 2011 ELNEC training. The Harbor-UCLA team's goal is to educate nurses throughout the hospital about palliative care, aiming to train one nurse champion on every hospital unit.
- Riverside County Regional Medical Center's ELNEC champion has organized ELNEC trainings for ED nurses, respiratory therapists, and nurses in the hospital's nurse residency program.
- At UC San Diego, the six ELNEC trained nurses have offered six multidisciplinary palliative care classes since 2011, reaching over 300 staff members. They have conducted two studies that have been approved by their Institutional Review Board: "Intensive Care Nursing Triggers for Initiation of a Palliative Care Consult" and "The Effects of Palliative Care Consults and Education on ICU Nurses' Moral Distress and Compassion Fatigue."

Culturally Responsive Palliative Care Workshops

Recognizing the diversity of the population served by public hospitals, initiative participants saw the importance of responding to these patients' palliative care needs in a culturally responsive manner.

Palliative care teams in the initiative reported feeling satisfied with their overall efforts to meet the needs of culturally diverse patients, but they also identified several areas in which they felt they could use more training.[14]

Cultural Competence Defined

Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations.[15]

In 2012, SNI organized a Culturally Responsive Palliative Care Workshop, which was offered in both Northern California and Southern California. The workshop used interactive exercises, video presentations, and group discussions to help participants reflect on the personal and cultural challenges of providing end-of-life care; enhance their understanding of health care disparities in end-of-life care; enrich their set of tools and strategies for effective, culturally responsive interventions; and help participants develop strategies to take care of themselves in this emotionally difficult line of work.

During one workshop, participants heard from Rosemary, a young Chinese American woman whose family fled to the US from Vietnam in 1982 after the Vietnam War. She shared the story of her father's death in a California hospital and her family's experience with care that was not culturally responsive.

"Learning Rosemary's story was amazing — especially as a nurse who also had a negative experience with the care my own father received at the time of his death. Her story enabled us to look hard at ourselves to find where we can improve and hopefully truly show caring and compassion and empathy, not just technical care."

— WORKSHOP PARTICIPANT

"The hospital staff used medical terms that they didn't explain and expected us to understand," Rosemary said. "Because the staff did not communicate well or express empathy, my family felt they were not providing good care and were instead waiting for our father to die. We were desperate to understand and resorted to searching the internet to look up medical terms and facts, which should have been information we received from the staff. The experience left a lasting impression and was worse for my mother, who had never had any prior contact with a hospital in America. To this day, she still feels a sense of distrust and believes that part of the reason her husband died is because our family is poor and not White."

Rosemary's powerful testimonial confirmed the need for health care providers to be aware of how they interact with patients who face multiple struggles: severe poverty; limited English proficiency; little or no access to health care; limited support systems; racial, ethnic, and cultural discrimination; and life-limiting conditions and terminal diagnoses.[16]

The workshops were attended by 78 individuals from public hospital palliative care teams throughout California. On a scale of 1 (poor) to 7 (excellent), participant ratings averaged 6.53. A clinical nurse specialist from San Joaquin General Hospital wrote on her evaluation form, "I thought last week's workshop was one of the best I have ever attended, particularly regarding culturally based care. And I heard the same thing from several other attendees. … We're looking forward to using [these tools] to facilitate some discussions."

Communication: Inside and Out

Communication — among initiative partners to sustain momentum and share ideas, and with the greater community to encourage the spread of lessons learned — was prioritized throughout the initiative.

Learning Community

A learning community was created to promote the teaching and sharing of best practices and program innovations, and to provide a group forum for critical problem solving. The community convenes through monthly calls, the annual grantee meeting, and web-based communication tools.

On each monthly call, an expert in the field was invited to address a specific aspect of palliative care, such as diversity issues or strategies for working with referring clinicians. (See Appendix B for a list of guest experts and call topics.)

The case presentations by initiative members during the calls inspired discussion, and sometimes debate, about the most effective clinical, psychosocial, and spiritual practices in palliative care. The regularity of the calls and the interaction among initiative members helped build a sense of community among participants.

Participation on the calls was difficult for a number of hospital team leaders, however, due to their clinical schedules; several also said that not all the topics were relevant to their practice. On balance, the learning community calls received high marks. Many teams asked that the calls continue on a less frequent basis after the conclusion of the initiative "to keep the initiative together."

A uniformly appreciated component of the learning community was the annual grantee meeting, which was attended by at least three members from every participating public hospital team. The meeting format varied but always included hands-on workshops, data updates, plenary sessions, a keynote address, and time to socialize informally. (See Appendix C for a list of keynote speakers.) On every evaluation form, attendees reported feeling renewed and inspired by the meeting and time spent with colleagues.

A less successful component of the learning community was its web-based communication efforts: a web portal, private Facebook group, and Google group. Initiative members reported several reasons for their lack of participation with these tools: busy work schedules, hospital firewalls and a ban on use of social media sites, and concerns about mixing professional and personal information through social media. In the end, email proved the most effective means of communication.

Telling the Initiative Story

Individual hospitals shared their achievements through a host of diverse communication vehicles: hospital newsletters and grand rounds, community newspapers, blogs and websites, peer-reviewed journal articles, and presentations at national conferences. (See Appendix D for a full list of media coverage.)

Along the way, the work of one initiative member from San Francisco General Hospital was recognized with high honors: She received the 2011 American Academy of Hospice and Palliative Medicine Young Investigator Award, and her application to develop a special-interest group for public hospitals through the AAHPM was approved. Now, public hospitals around the US have their interests represented in a large, nationally known membership organization with a sole focus on palliative care.

V. Evaluation

The evaluation program measured the success of the initiative in two ways: by counting the number of patients served over time and by describing the growth and development of the teams, their challenges, and success.

Data from each hospital were reported quarterly:

- Service use – number of palliative care consults and unique patients served
- Number of patients with family meetings
- Number of patients with POLST — a form that allows individuals to state what kind of medical treatment they want toward the end of their lives
- Number of palliative care patients who died in the hospital
- Patient demographic data such as age, gender, ethnicity, languages spoken, and interpretation services received
- Primary patient diagnosis and discharge information
- Palliative care education provided to hospital physicians, nurses, and other staff
- Composition of palliative care teams

Expansion and implementation grantees submitted demographic, use, and hospital discharge data semiannually. Following each data submission period, the evaluator prepared summary reports about sites' progress in building their service capacity and characteristics of the populations that were served. Through this process, palliative care teams gained hands-on experience with using data to monitor and improve services and to build a business case for service sustainability.

Late and incomplete data proved a challenge in the evaluation process. A handful of sites submitted data weeks or months after the due date because they were short-staffed or needed extra time to manually enter the data into the reporting system. Other sites submitted incomplete data. Despite these difficulties, every hospital team affirmed that data collection and reporting was key in helping them compare their program to other California public hospitals, assess their progress to goals they had set for program growth, and provide information for the business case.

Hospital team leaders were also surveyed about the structures and processes of their palliative care service, barriers to and promoters of service development, their perceptions of the sustainability of the program in the post-grant period, and the usefulness of the various supportive and educational activities that were offered in the initiative. Annual grantee meeting participants were also surveyed. Findings from these surveys were used by the project team to improve initiative activities, including the annual meeting. For example, participants indicated on their surveys that they wanted more unstructured time to network with others, so this time was worked into the schedule of future annual meetings. The surveys also indicated that self-care was a topic of interest, so segments on self-care were incorporated into future meetings.

VI. Conclusion: The Journey Continues

THE SPCPH INITIATIVE DEMONSTRATED that system change is possible, but only with the efforts of many team players. In California, change involved members of all 17 public hospital palliative care teams, hospital administrators, project team members, patients, and their family members. Each element of the initiative contributed to its success: data collection and analysis, business case development, staff training in palliative care, integration of palliative care for nurses at the bedside, and establishment of a learning community. The result — many more public hospital patients and families in California today receive culturally responsive palliative care committed to preserving patient dignity and quality of life than before the initiative began.

The percentage of hospitals in California with palliative care programs increased from 43% in 2007 to 53% in 2011. During the same period, the percentage of public hospitals with such programs jumped from 22% to 71%.[17] In 2012, 100% of California's 17 public hospitals had palliative care programs in place.[18]

Today, California's safety-net system is a national leader in the availability and sustainability of palliative care services. The success of the SPCPH initiative has also highlighted opportunities to spread palliative care to other care settings. As the nation's health care system undergoes its most significant transformation yet, under health reform, palliative care, which has proven to positively improve the quality of a patient's life and reduce health care costs at the same time, should continue to flourish.[19,20]

Appendix A: Project Leadership, 2008–2013

PROJECT TEAM

Erin Bowman
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California Health Care Safety Net Institute

Ruth Brousseau, PhD
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Learning Partnerships

Betty Ferrell, RN, PhD
Professor and Research Scientist
Nursing Research and Education, City of Hope

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Susan Stone, MD
Lead Physician, Palliative Care
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Virginia Commonwealth University

Judy Citko, JD
Executive Director
California Coalition for Compassionate Care

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Chaplain
Alta Bates Medical Center
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Pete Delgado, MS
CEO
LAC+USC Medical Center

Richard Della Penna, MD
Medical Director, Kaiser Permanente Aging Network
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Santa Clara Valley Medical Center

Elyse Salend, MSW
Program Officer
Archstone Foundation

Margaret Szczepaniak, MA
Associate Director
San Joaquin County Health Services Agency

Charles von Gunten, MD, PhD
Provost and Vice President, Center for Palliative Studies
San Diego Hospice & Palliative Care
Editor in Chief, *Journal of Palliative Medicine*

Ellen Wu, MPH
Executive Director
California Pan-Ethnic Health Network

Appendix B: Sample of Learning Community Calls

ART AND CULTURE OF PALLIATIVE CARE

Caring for Dying: The Art of Being Present, a film by Michelle Peticolas, PhD

Creating a Culture for Palliative Care to Flourish, Fred Meyers, MD, Executive Associate Dean, UC Davis School of Medicine

Improving Spiritual Care as a Domain of Palliative Care, Christina Puchalski, MD, George Washington Institute for Spirituality and Health

CARE TEAM

The Role of Nurses in Palliative Care, Betty Ferrell, RN, PhD, Professor, Nursing Research and Education, City of Hope

Promoting Palliative Care in Public Hospitals: Opportunities for Palliative Social Work, Shirley Otis-Green, MSW, LCSW, Department of Population Sciences, City of Hope National Medical Center

Working with Referring Clinicians, Charles von Gunten, MD, PhD, Provost and Vice President, Center for Palliative Studies, San Diego Hospice & Palliative Care

Model for Running a Palliative Care Interdisciplinary Team Case Conference, Rabbi Edith M. Meyerson, BCC, Palliative Care Chaplain, Lilian and Benjamin Hertzberg Palliative Care Institute, Mount Sinai School of Medicine

DECISIONMAKING AND ETHICAL ISSUES

Assessing Capacity to Make Decisions About Clinical Care, and Managing Palliative Care Patients with Psychiatric Conditions, Scott Irwin, MD, PhD, Director, Psychiatry Programs, Institute for Palliative Medicine at San Diego Hospice

Where's the POLST? POLST Paradigm: Respecting the Wishes of Patients and Families, Steve Lai, MD, Geriatrician and Palliative Medicine Physician, Palo Alto Medical Foundation, and Shoshana Helman, MD, Medical Director, Palliative Care, Santa Clara Valley Medical Center (now with Kaiser Permanente Redwood City)

Understanding Conservatorship and Other Ethical Challenges, Doris Hawks, JD, Adjunct Professor of Elder Law at Santa Clara University School of Law

DIVERSE PATIENT POPULATIONS

Interpretation and Palliative Care, Sally McFalone, Public Health Program Specialist and Director of the Linguistic Access Unit, Contra Costa Health Services

International Experiences in Palliative Care and Primary Medicine, Pamelyn Close, MD, MPH, Director, Adult and Pediatric Palliative Care, LAC+USC Medical Center, and Shannon Moore, MD, MPH, Assistant Director, International Programs, Institute for Palliative Medicine at San Diego Hospice

Dancing with Broken Bones (a presentation addressing how class and race intersect with the experience of dying in the inner city), David Wendell Moller, PhD, Chair, Department of Bioethics at Kansas City University of Medicine and Biosciences

When a Parent Dies: Responding to Bereaved Children/Teens, Claire Towle, LCSW, Associate Director, Bereavement Services, Providence TrinityCare Hospice

PROGRAM ADMINISTRATION

Data and Evaluation, Ruth Brousseau, PhD, Learning Partnerships (Initiative Evaluator)

Development of the Business Case, Kathleen Kerr, PCLC Faculty

Health Care Reform and Palliative Care, Howard Tuch, MD, MS, American Academy of Hospice and Palliative Medicine, and Judi Buckalew, MPH, RN, American Academy of Hospice and Palliative Medicine

Appendix C: Annual Meeting Keynote Speakers

2010 Annual Meeting
Melanie Tervalon, MD, MPH
Associate Director
PolicyLink
Self-reflection and working with diverse and underserved communities

2011 Annual Meeting
Meg Campbell, PhD, RN
Nursing Director
Detroit Receiving Hospital
The art of sustaining public hospital palliative care services

2012 Annual Meeting
Diane Meier, MD
Director, Center to Advance Palliative Care
Hertzberg Palliative Care Institute, Mount Sinai School of Medicine
The future of palliative care

2013 Annual Meeting
Anthony Back, MD
Professor, Department of Medicine, Division of Oncology
University of Washington
Opportunities to continue the work as leaders in the palliative care field

Appendix D: Media Coverage

BLOGS

Health Affairs GrantWatch Blog (March 2011) featured the California HealthCare Foundation's effort to spread palliative care in California public hospitals.

One Foundation's Path to Expanding Palliative Care in California's Public Hospitals
www.healthaffairs.org/blog

AUTHORS: Kate O'Malley, RN, MS, California HealthCare Foundation; Ruth Brousseau, PhD, Learning Partnerships

National Association of Public Hospitals and Health Systems Safety Net Matters (March 2012) addressed the Spreading Palliative Care in Public Hospitals initiative to establish palliative care in all 17 public hospitals in California.

Palliative Care in California Public Hospitals: Getting to 100%
www.naph.org

AUTHOR: Kate O'Malley, RN, MS, California HealthCare Foundation

CONFERENCE POSTER SESSION

Center to Advance Palliative Care (CAPC) Poster Session – 2011 National Seminar
Members of the initiative and project team presented two posters at the Center to Advance Palliative Care National Seminar in November 2011. The first profiles the SPCPH initiative and the statewide system change it inspired, spreading palliative care in 96% of California public hospitals, and the second details the Interpreting in Palliative Care Project, showcasing core elements of the curriculum.

CONFERENCE PRESENTATIONS AND AWARDS

American Academy of Hospice and Palliative Medicine (AAHPM)/Hospice and Palliative Nurses Association (HPNA) 2012 National Annual Assembly, Denver
The paper session *Promoting Development of Hospital Palliative Care Services: Finding Common Ground* discussed the features and impact of a cohort-based palliative care service development initiative, Spreading Palliative Care Services in Public Hospitals, which supported the creation, expansion, and sustainability of palliative care programs in California safety-net hospitals.

PRESENTER: Steven Z. Pantilat, MD, UCSF Palliative Care Leadership Center

The paper session *Preventing the Lost-in-Translation Phenomenon: Piloting a Curriculum for Health Care Interpreters in End-of-Life Conversations* profiled the innovative SPCPH training program, *Interpreting in Palliative Care,* which prepares health care interpreters for the linguistic, cultural, and personal challenges of interpreting for palliative and end-of-life discussions.

PRESENTER: Anne Kinderman, MD, San Francisco General Hospital

AAHPM Special Interest Group Status
Through the coordinating efforts of initiative member Anne Kinderman, MD, director of palliative care at San Francisco General Hospital, and public hospital palliative care leaders in other states, AAHPM granted public hospitals the status of Special Interest Group (SIG) in 2011. AAHPM SIGs provide a forum for interested members in a particular topic area to meet and discuss matters of common interest. AAHPM SIGs are multidisciplinary, and each meets at the AAHPM/HPNA Annual Assembly.

AAHPM Young Investigator Award in the Junior Faculty Category
Anne Kinderman, MD, director of palliative care at San Francisco General Hospital, was the recipient of the 2011 AAHPM Young Investigator Award in the Junior Faculty Category for her research and work on the *Interpreting in Palliative Care* project and 2012 AAHPM/HPNA Annual Assembly Paper Session, *Preventing the Lost-in-Translation Phenomenon: Piloting a Curriculum for Health Care Interpreters in End-of-Life Conversations.*

AAHPM/HPNA 2013 National Assembly, New Orleans
The Special Interest Group Symposium *Cultivating Grass Roots in Drought Condition: Enhancing Palliative Care in Safety Net Hospitals Through a Statewide Initiative* includes a presentation addressing the SPCPH initiative and the process and unique challenges of providing and expanding palliative care programs in public hospitals.

PRESENTERS: Anne Kinderman, MD, San Francisco General Hospital; Betty Ferrell, RN, PhD, City of Hope

California Hospice and Palliative Care Association 2010 Conference, Las Vegas
The workshop *Interpretation and Palliative Care in the Public Hospital Setting* addressed the challenges of providing culturally competent palliative care interpreting in public hospitals and practical solutions.

PRESENTERS: Anne Kinderman, MD, San Francisco General Hospital; Heather Harris, MD, San Francisco General Hospital; Nora Gonzalez, LCSW, Riverside County Regional Medical Center

HOSPITAL NEWSLETTERS/PUBLICATIONS AND COMMUNITY NEWSPAPERS/INTERVIEWS

Alameda County Medical Center ACMC Intranet
Palliative Care Consult Service Comforts Patients, Families
November 2012

Arrowhead Regional Medical Center
San Bernardino Sun, July 8, 2009
Arrowhead Regional starts new patient care program

Inland Empire Community Newspapers, July 9, 2009
New hospital program promotes quality, not quantity, of life

Harbor-UCLA Medical Center
Los Angeles Biomedical Research Institute
Considerations on the Aeromedical Transfer of Terminal and Palliative Care Patients

AUTHORS: Janice Suh, MD; Maria Sun, MD; and Bahman Chavoshan, MD, MAvMe (submitted to the *Journal of Palliative Care*)

Natividad Medical Foundation
Palliative Care Program
www.natividadfoundation.org

Olive View-UCLA Medical Center
Fast Facts from Dr. Katz
Social Workers Help Navigate End of Life
October 2012

LA Now, LA County Channel
Television interview with the Olive View-UCLA Medical Center Palliative Care Service team
December 2012
www.lacountychannel.com

San Francisco General Hospital Foundation
Palliative Care Service: Providing Quality of Life in the Face of Illness, Winter 2010

"A Hospital Wedding Ceremony." Learning to Let Go: Saying Goodbye Peacefully. Chinese American Coalition for Compassionate Care. H.A. Harris, R. Epperhart, A. Kinderman. In press.

Santa Clara Valley Health & Hospital System
Our Stories: The Palliative Care Team Makes Wishes Come True

Valley Medical Center Foundation:
Finally, proof that palliative care works…
www.vmcfoundation.org

Amazing device improves patient/doctor communication!
www.vmcfoundation.org

JOURNAL ARTICLES

Journal for Healthcare Quality, March/April 2012
A Multifaceted Approach to Spreading Palliative Care Consultation Services in California Public Hospital Systems describes the SPCPH initiative's distinctive design, features of the public hospital palliative care services, patient and team characteristics, palliative care service provider perceptions of environmental factors, and SPCPH features that promoted or impeded their success, as well as lessons learned.[21]

AUTHORS: Ruth Brousseau, PhD, Learning Partnerships; Wendy Jameson, MPH, MPP, California Health Care Safety Net Institute; Boris Kalanj, MSW, LISW, California Health Care Safety Net Institute; Kathleen Kerr, UCSF Palliative Care Leadership Center; Kate O'Malley, RN, MS, California HealthCare Foundation; Steven Z. Pantilat, MD, UCSF Palliative Care Leadership Center

Journal of Palliative Medicine, July 2012

Interpretation for Discussions about End-of-Life Issues: Results from a National Survey of Health Care Interpreters presents findings from a national survey that assessed the experiences of health care interpreters when interpreting discussions about end-of-life issues; interpreter characteristics and experiences that may be associated with improved satisfaction and comfort with interpreting these discussions; and interpreter training needs.[23]

AUTHORS: Yael Schenker, MD, Assistant Professor, University of Pittsburgh; Alicia Fernandez, MD, Professor of Clinical Medicine, UCSF; Kathleen Kerr, UCSF Palliative Care Leadership Center; David O'Riordan, PhD, Senior Research Specialist, UCSF; Steven Z. Pantilat, MD, UCSF Palliative Care Leadership Center

Journal of Social Work in End-Of-Life & Palliative Care, September 2012

Public Hospital Palliative Social Work: Addressing Patient Cultural Diversity and Psychosocial Needs describes palliative social workers from six public hospitals who participated in the initiative forming a group to discuss palliative social work in the public hospital setting; the article highlights the group's insights and experiences as they address the significant cultural diversity and psychosocial needs of public hospital patients receiving palliative care.[22]

AUTHORS: Monique Parrish, DrPH, MPH, LCSW, LifeCourse Strategies; Yvette Cárdenas, MSW, Olive View-UCLA Medical Center; Regina Epperhart, MSW, San Francisco General Hospital; Jose Hernandez, MSW, Olive View-UCLA Medical Center; Susana Ruiz, LCSW, Arrowhead Regional Medical Center; Linda Russell, MFT, Contra Costa Regional Medical Center; Karolina Soriano, MSW, UC Irvine Medical Center; Kathryn Thornberry, LCSW, UC San Diego Moores Cancer Center

WEBSITE PROFILES

National Association of Public Hospitals and Health Systems (May 2010) profiled three initiative palliative care programs.

- San Francisco General Hospital
- Olive View-UCLA Medical Center
- UC San Diego Health System

www.naph.org

System Change:

Spreading Palliative Care in Public Hospitals in California

Monique Parrish, DrPH, MPH, MSSW, California HealthCare Foundation, Oakland CA

Anne Kinderman, MD, University of California San Francisco Department of Medicine at San Francisco General Hospital

California HealthCare Foundation

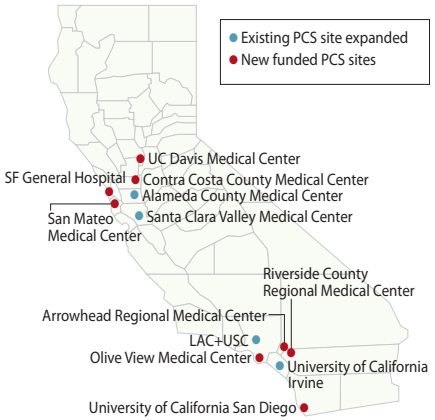
UCSF University of California San Francisco

California Health Care Safety Net Institute

Background

- Over 8.2 million Californians (nearly 1 in 4) are uninsured. Safety-net hospitals provide care for nearly half of uninsured Californians, and 30% of Californians with Medicaid.
- In 2007, only 4 of California's 17 safety-net hospitals offered palliative care services (PCS), leaving many millions of Californians without access to PCS.
- We hypothesized that a cohort-based approach could significantly expand PCS in California safety-net hospitals.

Public Hospitals Participating in Spreading Palliative Care Initiative



Project Description

Partners: CHCF; University of California San Francisco, Palliative Care Leadership Center (PCLC); and Safety Net Institute

Grant Awards

Twelve grants awarded: eight to develop new PCS where none existed, four to expand existing PCS

Support provided to grantee sites:

- Technical Assistance: PCLC staff provided guidance for data collection, financial impact analyses, and best practices
- Networking Opportunities/Project Management Support: Annual conferences, monthly conference calls, shared web portal
- Sustainability Coaching: On-site visits with the project leadership team and each hospital's PCS team and hospital administrators to determine barriers to sustainability and growth of PCS

Outcomes

- By 2010, **all 12 sites had active PCS** in place, resulting in:
  - More than 6,000 consults
  - 374 POLST forms completed
  - 385 education/training sessions for hospital staff across the state
- All 12 sites have tracked and reported on key operational and outcome measures for their PCS. 9 sites (75%) have evaluated financial outcomes and submitted these reports to hospital administrators.
- **All 12 sites have funding or commitments to sustain their services** in the post-grant period

Summary

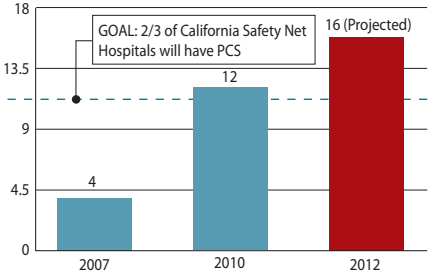
A comprehensive implementation program led to the massive expansion and growth of palliative care services in 12 safety net hospitals in California. 96% of California safety net hospitals are expected to have PCS by 2012.

Future Directions

Findings from the initiative have prompted the following additional efforts to improve care in safety net settings:

- Development of a palliative-care specific curriculum for professional healthcare interpreters
- Development of an ELNEC program specific to palliative care in public hospitals
- Continuation of learning community conferences through 2013 to promote long-term sustainability
- Expanded initiative funding to develop PCS in 4 new sites in California. 94% (16/17) of California's safety net hospitals now have or will have by 2012 active PCS (up from 24% in 2007).

Number of California Safety Net Hospitals with PCS



Education Initiative:
Improving Interpreting in Palliative Care

Anne Kinderman, MD, University of California San Francisco Department of Medicine at San Francisco General Hospital
Cynthia Roat, MPH, National Consulting on Language Access in Health Care, Shoreline WA
Monique Parrish, DrPH, MPH, MSSW, California HealthCare Foundation, Oakland CA

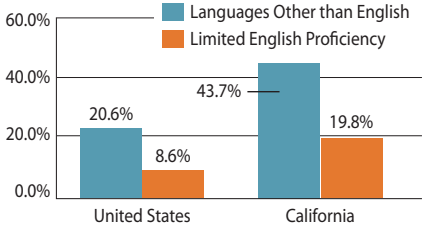
California HealthCare Foundation

UCSF University of California San Francisco

Background

- Professional healthcare interpreters can help minimize communication errors between language-discordant patients and providers.
- However, even when professional interpreters are utilized, there can still be significant communication errors during critical conversations, such as family meetings in the Intensive Care Unit.
- A nationwide search for training programs for palliative care interpreting revealed no existing curricula in this field.
- The California HealthCare Foundation funded the development of a novel curriculum to address this problem: *Interpreting in Palliative Care*.

2010 US Census Data



1 in 5 Californians Reports Limited English Proficiency

Curriculum Content

Lesson 1: Introduction to Palliative Care

Lesson 2: The Vocabulary of Palliative Care

Lesson 3: Interpreting Skills Applied to Palliative Care

Lesson 4: Sight Translation in Palliative Care

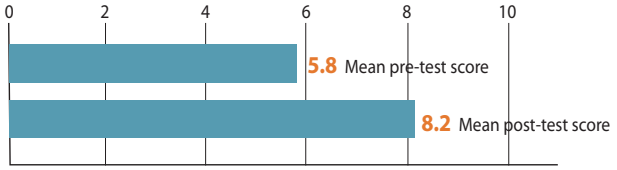
Lesson 5: Impact of Belief and Emotion on Interpreting

Curriculum's Unique Features

- Allows participants to **practice key interpreting skills**:
  - ▶ Using palliative care vocabulary terms
  - ▶ Recognizing when flow of session should be interrupted if miscommunication or misunderstanding occurs
  - ▶ Interpreting a family meeting and goals of care discussion
- Models best practices in palliative care interpreting through **3 videos of end-of-life encounters** between providers and a Spanish-speaking patient and family:
  - (a) Doctor relaying bad news and discussing goals of care with the patient
  - (b) Doctor facilitating a family meeting
  - (c) Chaplain visiting and praying with the patient
- Interpreters can receive **certificates and continuing education credits** following course completion

Curriculum Evaluation

- We pilot-tested the curriculum with a group of 16 professional healthcare interpreters.
- **81% of participants showed improvement** in knowledge and understanding of palliative care from pre- to post-testing.



Dissemination Plan

- We plan to make the curriculum available through 14 on-site trainings in California in 2011-12.
- The curriculum will be posted online (www.chcf.org)
  - ▶ Interpreter trainers will have open access to training materials, so that they can facilitate additional on-site trainings at their own institutions or agencies, nationwide.
  - ▶ For a nominal fee, individual interpreters will be able to complete an online-only version of the curriculum.

Summary

A novel curriculum, *Interpreting in Palliative Care*, may improve professional healthcare interpreters' knowledge and understanding of palliative care.

Endnotes

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2. Grudzen, C.R., et al., "I want to be taking my own last breath. Patients' reflections on illness when presenting to the emergency department at the end of life," *Journal of Palliative Medicine,* 2011. 14(3): p. 293–296.
3. "When Compassion Is the Cure: The Case for Hospital-Based Palliative Care," 2008, California HealthCare Foundation: Oakland, CA, www.chcf.org.
4. Center to Advance Palliative Care. *Get Palliative Care* 2012 [cited December 1, 2012]; available from: www.getpalliativecare.org.
5. Kerr, K., et al., "The Business Case for Palliative Care Consultation Services in California's Public Hospitals," 2011, University of California, San Francisco, CA.
6. Weissman, D., D. Meier, and L. Spragens, "Center to Advance Palliative Care Palliative Care Consultation Service Metrics: Consensus Recommendations," *Journal of Palliative Medicine,* 2008. 11(10): p. 1294–1298.
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8. Brousseau, R. and M. Ramos, "Primary Language Other Than English," Progress tracking, Editor 2012, Learning Partnerships: Oakland, CA.
9. Roat, C.E., "Language Lessons: Palliative Care Training for Interpreters," 2012, California HealthCare Foundation: Oakland, CA, www.chcf.org.
10. Schenker, Y., et al., "Interpretation for discussions about end-of-life issues: results from a National Survey of Health Care Interpreters," *Journal of Palliative Medicine,* 2012. 15(9): p. 1019–1026.
11. Kinderman, A.L., C.E. Roat, and M. Parrish, "Preventing the Lost in Translation Phenomenon: Piloting a Curriculum for Health Care Interpreters in End-of-Life Conversations," in *Annual Assembly of the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association,* 2012: Denver, CO.
12. Brousseau, R., "Palliative Care Interpreter Training Interviews and Surveys," 2012, Learning Partnerships: Oakland, CA.
13. See note 9.
14. Brousseau, R., B. Kalanj, and M. Parrish, "Cultural Bridging: Summary of Interviews Regarding Cultural Competence," 2012, Learning Partnerships: Oakland, CA.
15. Cross, T., et al., *Towards a culturally competent system of care, volume I.,* G.U.C.D. Center, Editor 1989, CASSP Technical Assistance Center: Washington, D.C.
16. Parrish M., et al., "Public hospital palliative social work: addressing patient cultural diversity and psychosocial needs," *Journal of Social Work in End-of-Life & Palliative Care,* 2012. 8(3): p. 214–228.
17. "When Compassion Is the Cure: Progress and Promise in Hospital-Based Palliative Care," 2012, California HealthCare Foundation: Oakland, CA, www.chcf.org.
18. Ibid.
19. Morrison, R., et al., "Cost savings associated with US hospital palliative care consultation programs," *Archives of Internal Medicine,* 2008. 168(16): p. 1783–1790.
20. Temel, J., et al., "Early palliative care for patients with metastatic non-small- cell lung cancer." *New England Journal of Medicine,* 2010. 368(3): p. 733–742.
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22. See note 16.
23. See note 10.

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