

Mapping Palliative Care Need and Supply in California: Methodology

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Palliative care is specialized medical care that provides patients with relief from the symptoms, pain, and stress that often occur with serious illness. Palliative care (PC) is appropriate at any age and at any stage of a serious illness, and can be provided alongside curative treatment. In recent years the availability of specialty palliative care programs has increased dramatically, as payers, providers, and consumers have come to appreciate its benefits. The California HealthCare Foundation sought to understand the supply of specialty palliative care in the state relative to the estimated need for such services.

Types of Specialty Palliative Care

For this research two types of specialty palliative care services were inventoried: *inpatient services* and *community-based services*.

Inpatient palliative care (IPPC) is delivered to hospitalized patients, usually by an interdisciplinary team that provides consultation to other hospital staff. IPPC services are usually sponsored by and affiliated with the hospitals and health systems in which they operate.

Community-based palliative care (CBPC) – defined as non-hospice palliative care delivered outside of the hospital setting – is delivered in clinics, patient homes, and over the phone. CBPC services are sponsored by and affiliated with many types of organizations, including health systems, hospices and home health agencies, medical groups, and social service organizations.

Hospice is a specific type of PC reserved for patients with terminal illness. In the United States, hospice is a formal benefit available through government and commercial payers and commonly includes as conditions of eligibility forgoing further curative treatments and a prognosis of six months or less. According to data compiled by the California Hospice and Palliative Care Organization, in 2013 only 42% of terminally ill patients with Medicare fee-for-service insurance elected to use hospice. Further, the National Hospice and Palliative Care Organization reports that in 2013, among individuals who used hospice, 61.5% did so for fewer than 30 days, including 34.5% who were enrolled for a week or less.¹ Because many individuals do not elect to use hospice, or do so very late in the disease course, optimal end-of-life care requires availability of both palliative care *and* hospice services – the availability of

¹ NHPCO's Facts and Figures Hospice Care in America 2014 Edition at <http://www.nhpco.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care>.

hospice does not eliminate the need for palliative care. Therefore our prevalence and capacity figures exclude hospice services, but do include CBPC services that are sponsored by hospices.

Estimating IPPC Supply and Capacity

To determine the supply of IPPC, we turned to the California Office of Statewide Health Planning and Development (OSHPD) Utilization Report of Hospitals (URH), a survey that is completed annually by all non-federal licensed hospitals in California and includes questions about IPPC programs and staffing.² We limited our assessment to non-specialty, short-stay, acute-care hospitals, as these facilities are the most likely to offer IPPC. We validated responses to the palliative care questions in the 2013 URH, which documented services available in calendar year 2013. The validation strategy included direct outreach to system or PC program leaders, or, if that was not possible, verification of concordance among 2013 URH responses, 2012 URH responses, and responses to the American Hospital Association (AHA) survey, which also asks about the presence of IPPC programs. If OSHPD/AHA data did not agree and no hospital or PC program leader contact was made, we then reviewed hospital and health system websites and other public sources for evidence of IPPC.

IPPC service volumes were obtained from many system and PC program leaders. When actual volume data were not available, we developed an estimate of volume based on the median service volume for hospitals with similar numbers of general acute-care beds.

For this research, *IPPC capacity* was defined as the number of admissions that the PC team sees annually. We assumed that most IPPC programs are seeing as many patients as possible given staffing levels.

Capacity for hospital-based programs was attributed to the county in which the hospital is located.

Estimating CBPC Supply and Capacity

Because CBPC services are sponsored by many types of provider organizations, we used a layered approach to identify programs, including:

- Review of data submitted to OSHPD by hospitals and hospices/home health agencies³
- An online survey distributed through the Coalition for Compassionate Care of California and the California Hospice and Palliative Care Association
- Direct email or phone outreach to the leadership of systems with established CBPC programs
- Direct email or phone outreach to programs accredited by the Commission on Cancer

² See http://www.oshpd.ca.gov/hid/Products/Hospitals/Utilization/Hospital_Utilization.html

³ For data reported to OSHPD by hospices and home health agencies, see http://www.oshpd.ca.gov/HID/Products/Hospitals/Utilization/HHA_Utilization.html

- Review of information from various CHCF projects and other public data

CBPC service volumes were obtained from many system and PC program leaders. When actual volume data were not available, we developed an estimate of volume based on the median service volume for similar types of programs (clinic-based, home-based, and cross-setting).

For this research, *CBPC capacity* was defined as the number of individuals that the service sees annually. We assumed that most CBPC services are seeing as many patients as possible given staffing levels.

Capacity for clinic-based PC services was attributed to the county in which the clinic is located. Home-based and cross-setting PC services often care for patients in multiple counties. If a service leader indicated that a program serves multiple counties, then program volume was apportioned to each county based on population. For example, PC program XYZ sees 100 patients per year and serves County A, with a population of 50,000, and County B, with a population of 100,000. Here, 33% of PC program XYZ's volume would be attributed to County A and 67% of the volume would be attributed to County B.

Definitions of Palliative Care

Because information about the presence of PC programs came from various sources, several definitions of PC were in play.

1. OSHPD Utilization Report of Hospitals

OSHPD's URH survey includes questions about the presence of inpatient palliative care programs, the number of nurses, physicians, social workers, and chaplains staffing the programs, and the number of PC staff with specialty certification/training. The URH survey defines a palliative care program as:

An interdisciplinary team that sees patients, identifies needs, makes treatment recommendations, facilitates patient and/or family decision-making, and/or directly provides palliative care for patients with serious illness or their families.

Separately, the URH asks about the presence of "outpatient palliative care services," which are not further defined.

2. OSHPD Utilization Report of Home Health Agencies/Hospices

In the OSHPD Annual Utilization Report of Home Health Agencies/Hospices, hospices and home health agencies that provide hospice services are asked if they provide "non-hospice palliative care," which is defined as:

Non-hospice palliative care: *These are visits made to patients who have NOT elected hospice care but are receiving visits for purposes of palliation. They do NOT include hospice physician consultation visits. These are provided as part of a palliative care service and could be visits from any discipline.*

3. Online Survey and Phone Outreach

An online survey was used to identify CBPC programs, and included the below definition of PC:

For the purpose of this survey, a palliative care service is defined as: An organized service that sees patients, identifies needs, makes treatment recommendations, facilitates patient and/or family decision making, and/or directly provides palliative care to patients with serious illness and/or their families. Most palliative care is provided by interdisciplinary teams of specially trained health care professionals, who work together to address patients' physical, emotional, social, and spiritual needs.

For this survey we are seeking information about only:

- *Clinic-based palliative care*
- *Home-based palliative care, provided in private residences, assisted living facilities, nursing homes – wherever patients reside*
- *Cross-setting (mobile) palliative care programs, where palliative care teams follow patients across outpatient settings*

This survey is not intended to track availability of hospice services, inpatient palliative care, or telephonic case management/care coordination programs.

The above definition was conveyed verbally when program or system leaders were contacted by the project team.

Estimating Need and Sufficiency

It is useful to conceive of palliative care as being delivered in three types of situations: over the duration of a chronic progressive illness, during an acute health crisis that eventually resolves, and in the last year of life. While individuals in all three groups may need palliative care, *this research estimates the need for PC only among individuals in the last year of life.*

Our estimate of individuals who are in the last year of life was based on the 2014 County Health Status Profiles, which includes data describing annual deaths in each California county.⁴

Several studies estimating population-based need for PC have been done in Europe and Australia. To determine the proportion of individuals in the last year of life that might need PC, we used an approach similar to that endorsed by Murtagh⁵ et al., which defines PC need as a range. Our “low estimate of need” is the number of individuals dying of seven conditions specified in the County Health Status Profiles that commonly need PC:

⁴ County Health Status Profiles are at <http://www.cdph.ca.gov/programs/ohir/Pages/CHSP.aspx>.

⁵ Murtagh FEM et al., *How many people need palliative care? A study developing and comparing methods for population-based estimates.* Palliat Med. 2014 Jan;28(1):49-58.

- Cancer (all types)
- Diabetes
- Alzheimer’s disease
- Coronary heart disease
- Cerebrovascular diseases (stroke)
- Chronic lower respiratory diseases
- Chronic liver disease and cirrhosis

In 2014, these seven conditions accounted for **61% of deaths** statewide.

Our “high estimate of need” is the number of all deaths excluding those caused by accidents, homicides, or suicides. In 2014, this corresponded to **93% of deaths** statewide.

In presenting results on the maps, we report *estimated need* as the average of the low and high need estimates for each county.

Sufficiency is presented as PC service capacity divided by the estimated need.

Example: County C has 100 deaths each year. The data from the County Health Status Profiles indicates that 61 of those deaths were from the identified seven conditions (low estimate of need) and 39 of those deaths were from natural causes (high estimate of need). Here, we would report estimated need as the average of the low and high estimates, or 77. County C has two CBPC programs that together serve 50 patients a year (capacity). We would therefore report sufficiency of CBPC services as 50 divided by 77, or 65%.