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Mapping Community Palliative Care

A SNAPSHOT

Mapping
COMMUNITY PALLIATIVE CARE

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About the Project

More than 87% of all hospitalized Americans are admitted to hospitals with palliative care teams.[1] More recently, health care organizations are providing palliative care in the community to meet the needs of patients with serious illness who are neither hospitalized nor ready or eligible for hospice. Community settings include office practices, medical clinics, long-term care facilities, and patients' homes. Several studies show that community palliative care reduces hospital and emergency department visits, lowers acute care costs, and improves care continuity, quality of life, and survival outcomes.[2–11]

Little information exists on the availability or characteristics of community palliative care. Whereas the American Hospital Association's annual survey tracks palliative care services in the inpatient setting, there is no similar survey for programs delivering services outside the hospital.[12]

In 2016, the Center to Advance Palliative Care (CAPC) began a three-year project to identify community palliative care programs nationwide. In this project, health care organizations providing community palliative care were invited to complete a short online survey. In order to participate, they were required to read the following and confirm that they fit this description of what palliative care is and what services a palliative care program provides:

> Palliative care is a team approach to improving quality of life for people living with serious illness. It focuses on providing relief from the pain, symptoms, and stress of a serious illness for both the patient and family. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment. At a minimum, a palliative care program should provide: expert pain and symptom management; effective communication with patients and families to support autonomous decision making for medical treatment and care priorities; and screening and support for the emotional, social, and spiritual needs of patients and their families.

To identify as many programs as possible, CAPC used a multipronged approach that included outreach to hospitals, hospices, home health agencies, long-term care facilities, physician groups, and other health care organizations through partnerships with national and specialty organizations, email marketing, direct mail campaigns, advertising, social media, blog posts, and faxes. Despite these extensive efforts to publicize the project and garner responses, it is likely that we were unable to identify all community programs. Thus, this report underrepresents the true number of palliative care programs present in the community and describes only the responding programs' self-reported availability and characteristics.

Key Findings: Responses from Community Palliative Care Program Survey Participants

Eight hundred ninety (n=890) community palliative care programs completed the survey. These programs serve 3,162 individual sites of care.

→ **Hospitals and hospices are equally likely to operate community palliative care programs, and taken together they operate two-thirds of all the identified community programs.** The remaining third are operated by home health agencies, long-term care facilities, and office practices or clinics.

FIGURE 1

Administering Organizations of Community Palliative Care Program Respondents

Two-thirds are operated by hospitals or hospices.

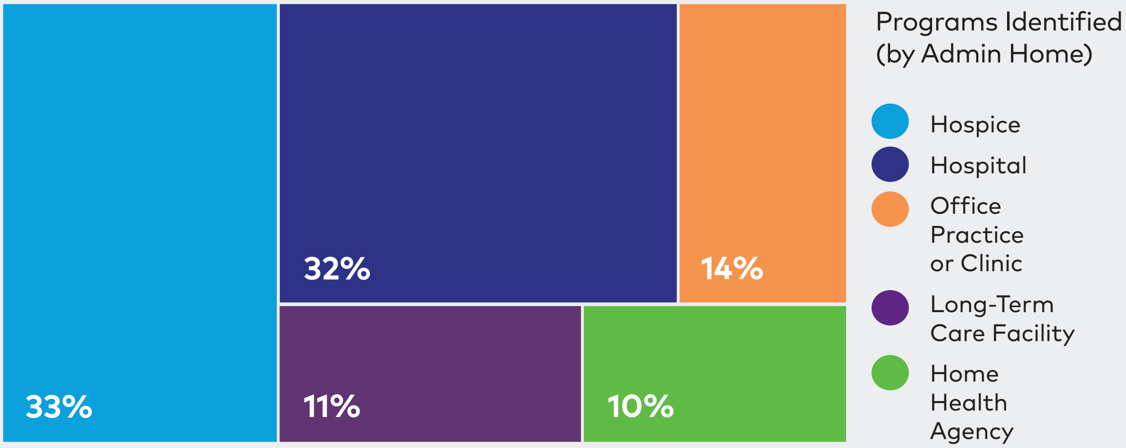


FIGURE 2

Care Settings Served by Community Palliative Care Program Respondents

More than half provide palliative care in patients' homes.

→ **Two-thirds of programs provide in-home palliative care.** Of those programs delivering care in the home, 49% are operated by hospices, with an additional 23% operated by hospitals, 15% operated by home health agencies, 12% operated by office practices or clinics, and fewer than 1% operated by long-term care facilities.

→ **Almost half of community programs (46%) provide palliative care services in an office practice or clinic setting.** Of these, 54% are operated by a hospital, 29% are operated by office practices or clinics, 15% are operated by hospices, 1% are operated by home health agencies, and fewer than 1% are operated by long-term care facilities.

→ **Almost one-third (28%) of respondents serve long-term care settings.** Of the programs delivering palliative care in long-term care settings, 38% are operated by long-term care facilities, 32% are operated by hospices, 21% are operated by hospitals, 5% are operated by office practices or clinics, and 4% are operated by home health agencies.

FIGURE 3

Care Settings of Community Palliative Care Program Respondents by Administering Organization Type

Nearly half of programs delivering in-home palliative care are administered by a hospice.

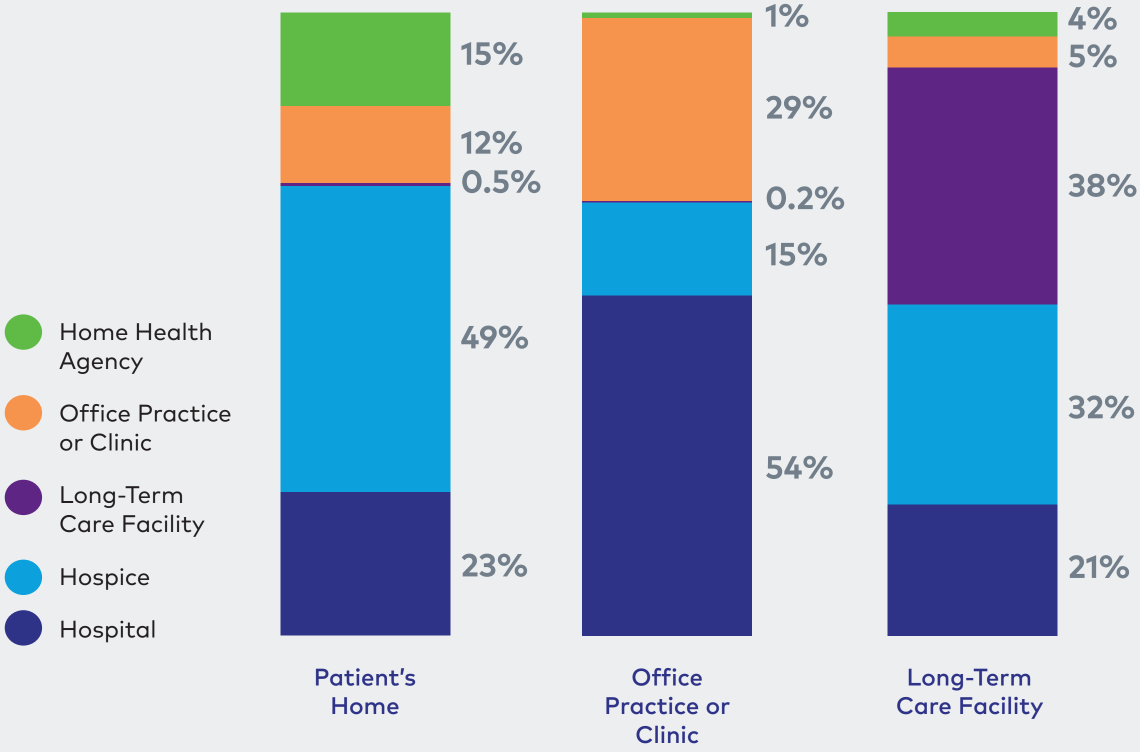
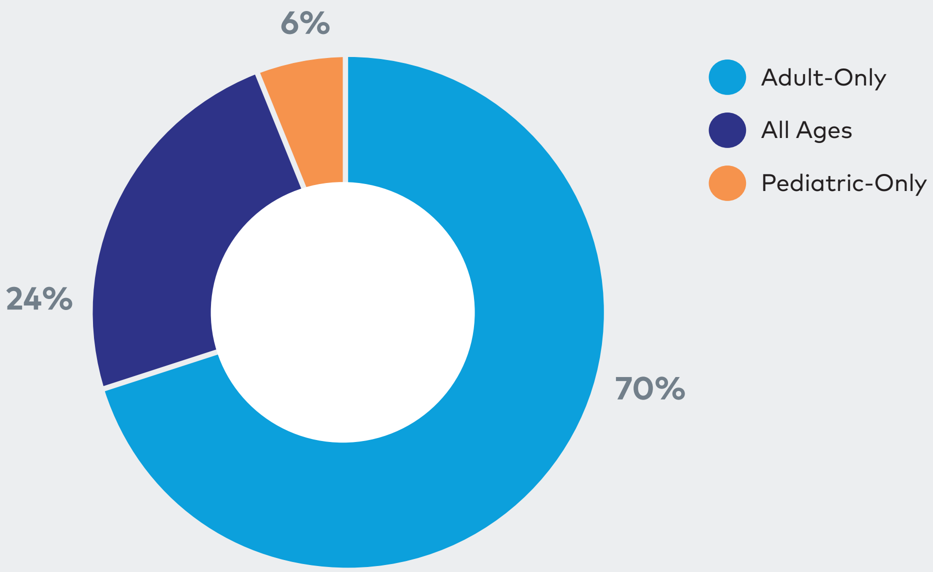


FIGURE 4

Patient Populations of Community Palliative Care Program Respondents

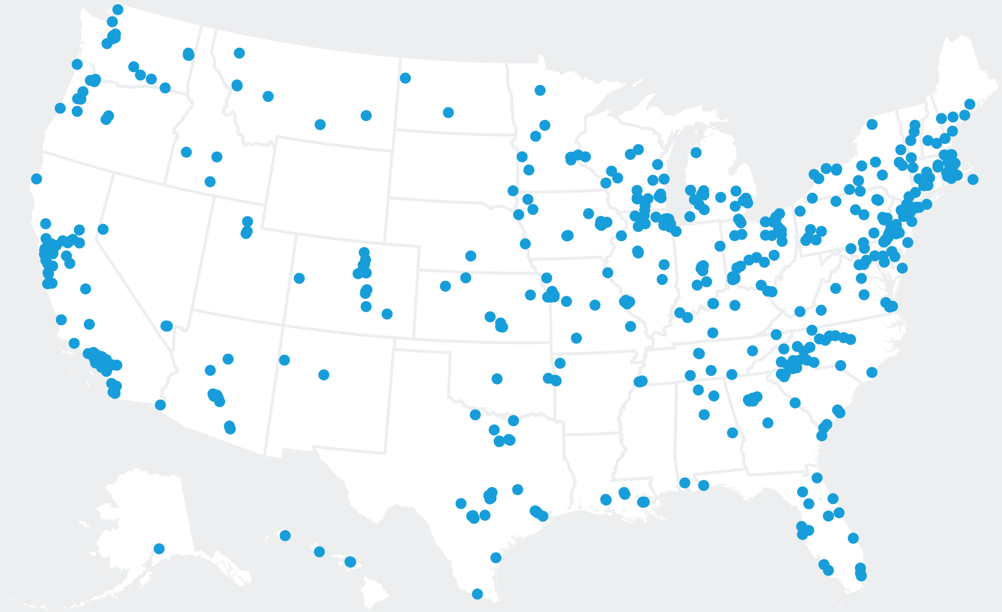
The majority of community programs treat adult patients only.



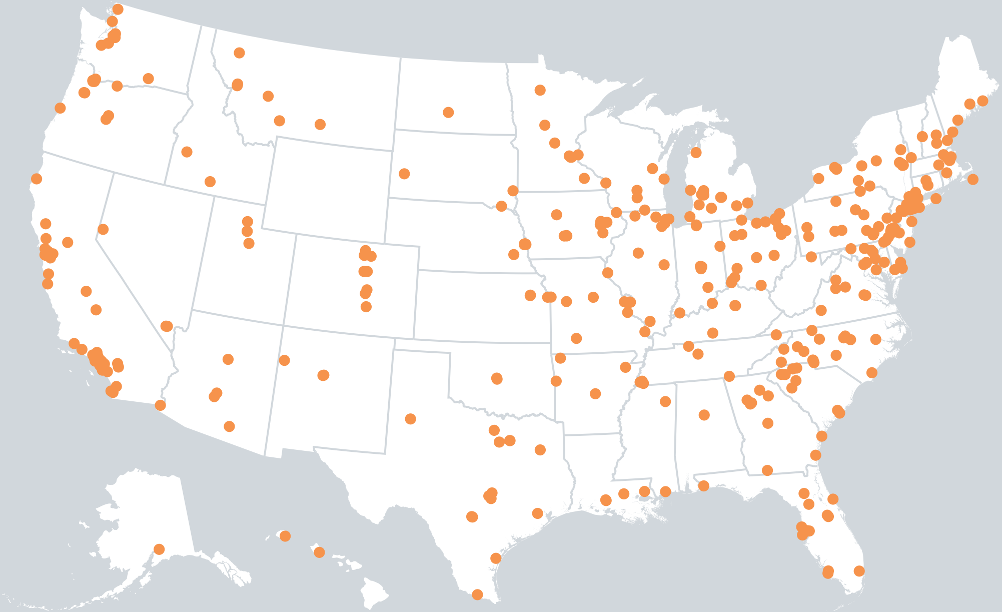
→ **Few community palliative care programs serve only children.** Six percent of programs identified (n=53) focus solely on pediatric patients, and 24% of identified programs noted they will treat children in addition to adults.

→ **Community and hospital palliative care programs are often interwoven.** Among community palliative care program respondents, 48% indicated that they provide both hospital and community services.

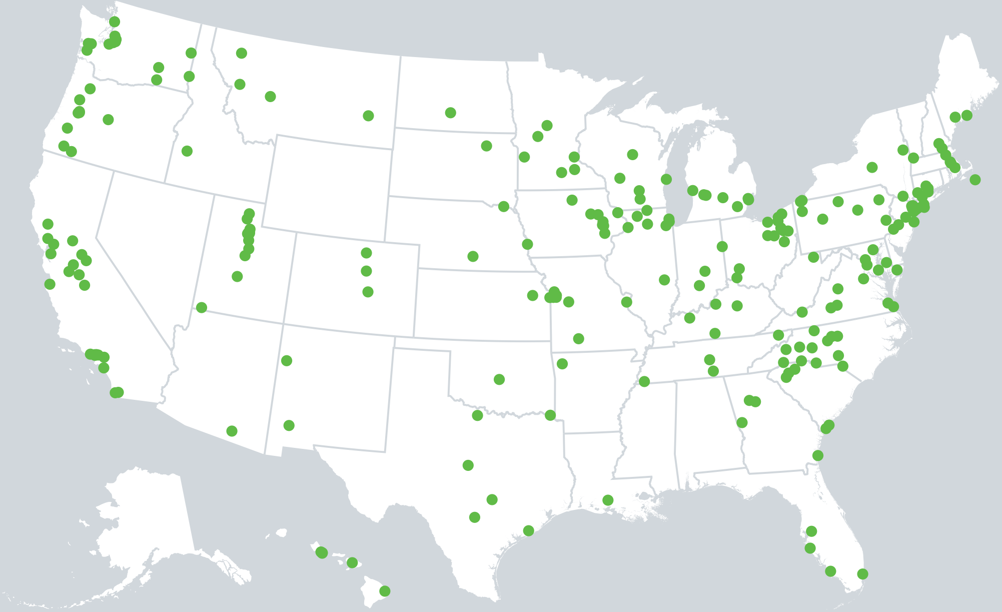
Respondents Who Provide Palliative Care in Patients' Homes



Respondents Who Provide Palliative Care in Office Practices or Clinics



Respondents Who Provide Palliative Care in Long-Term Care Facilities



Implications

This foundational report provides the first scan of community palliative care programs in the United States. Although likely an underrepresentation of the true number and not nationally representative, our data provide important insights as to what types of organizations are developing community palliative care capacity, what settings of care are being served, and the ages of patients being cared for.

Future work is needed to better identify community palliative care programs and to characterize care models, populations served, clinical capacity, and adherence to quality guidelines.[13]

Citations

1 Center to Advance Palliative Care and the National Palliative Care Research Center. *America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in our Nation's Hospitals*. New York, NY: Center to Advance Palliative Care; 2019.

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Acknowledgments

The publication of this report was made possible through the generous support of the Gordon and Betty Moore Foundation. We would also like to thank the National Coalition for Hospice and Palliative Care for its project endorsement and assistance in reaching potential partner organizations, and the following organizations for their assistance in conducting project outreach:

- → American Academy of Home Care Medicine
- → American Academy of Hospice and Palliative Medicine
- → American Geriatrics Society
- → American Health Care Association®
- → Association of Professional Chaplains®
- → Coalition for Compassionate Care of California
- → Commission on Cancer®
- → Community Oncology Alliance
- → HealthCare Chaplaincy Network™
- → Hospice and Palliative Nurses Association
- → National Coalition for Hospice and Palliative Care
- → National Hospice and Palliative Care Organization
- → National Palliative Care Research Center
- → LeadingAge®
- → Patient Quality of Life Coalition
- → Physician Assistants in Hospice and Palliative Medicine
- → Social Work Hospice and Palliative Care Network
- → The Society for Post-Acute and Long-Term Care Medicine™ (AMDA)
- → Society of Pain and Palliative Care Pharmacists
- → Supportive Care Coalition
- → Visiting Nurse Association of America

We gratefully acknowledge state hospice and palliative care organizations, as well as the numerous state palliative care advisory councils and pediatric palliative care coalitions, that helped to increase participation on a local level; and we thank Kayla Sheehan, MS for her help in compiling research for this project.

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Center to Advance Palliative Care
The Center to Advance Palliative Care (CAPC) is a national organization dedicated to increasing the availability of quality health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively meet this need. CAPC is funded through organizational membership and the generous support of foundations and private philanthropy. It is part of the Icahn School of Medicine at Mount Sinai, in New York City.

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