

## How Much Do Americans Know about Palliative Care?

Palliative care refers to a constellation of services provided to individuals with serious illnesses in order to prevent or treat, as early as possible, the symptoms of the disease, side effects caused by treatment of the disease, and any psychological, social, and spiritual problems related to the disease or its treatment. Palliative care has been shown to alleviate symptom burden, reduce psychosocial distress, and improve quality of life among patients with serious illnesses, and some studies suggest that palliative care (when used alongside treatment) can improve survival. Research also suggests that palliative care can reduce hospitalizations, decrease health care costs, and improve caregiver bereavement outcomes.

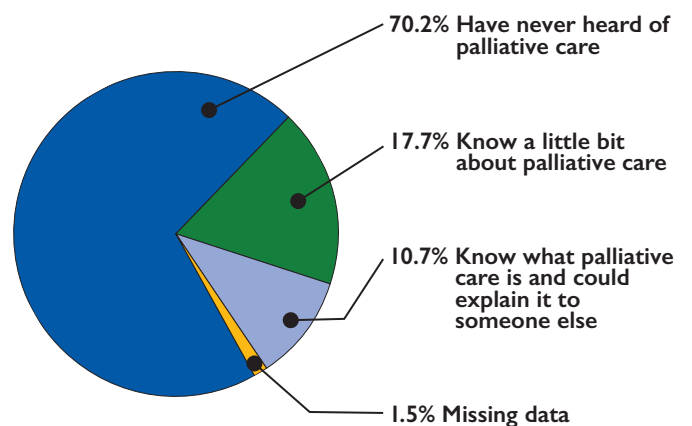
Despite the demonstrated benefits of palliative care and the growth of palliative care programs over the past two decades, uptake of palliative care has remained relatively low, especially among racial/ethnic and sexual/gender minorities, individuals of low socioeconomic status, and those residing in rural areas. Some research has suggested that lack of awareness regarding palliative care; inaccurate understanding of palliative care among patients, caregivers, and providers; and limited patient-provider communication about palliative care contribute to low utilization of these services. Research has also demonstrated that many people, including patients and caregivers, have never heard of palliative care, and those who are familiar with the term frequently conflate it with hospice or end-of-life care. This may prevent patients and their caregivers from requesting palliative care services or accepting palliative care when offered. In order to better understand barriers to the optimal utilization of palliative care services, it is necessary to assess what people (especially patients and caregivers) know about palliative care, and to identify specific subgroups that could benefit from targeted interventions to increase awareness of these beneficial services.

This HINTS *Brief* looks at palliative care awareness and knowledge among Americans in general, and caregivers in particular.

## Quick Facts

- The goal of palliative care is to relieve suffering and improve quality of life for patients who have a serious or life-threatening disease.
- Palliative care services include pain control/symptom management, spiritual counseling, psychosocial support, and help with medical decision-making.
- Palliative care can alleviate symptom burden, reduce psychosocial distress, improve quality of life, reduce hospitalizations, decrease health care costs, and potentially increase survival among patients with serious illnesses.
- Palliative care is currently underutilized, especially among certain sociodemographic groups.
- Many people are either unaware of palliative care or wrongly equate it with hospice/end-of-life care.

## Awareness of Palliative Care among U.S. Adults



Source: HINTS 5 Cycle 2, 2018

## Current Prevalence and Sociodemographic Predictors of Palliative Care Awareness among Adults and Caregivers

Several recently published studies used HINTS 5 Cycle 2 (2018) data to assess current levels of palliative care awareness and identify potential knowledge gaps in the general population and among caregivers specifically.

**Awareness.** In 2018, among the general U.S. population, 7 in 10 adults had never heard of palliative care, 18% knew “a little about it,” and 11% felt they would be able to explain what palliative care is to someone else. Palliative care awareness was found to be patterned by sociodemographic characteristics, with older individuals (compared to those aged 18–34), those with higher educational attainment (compared to individuals with a high school education or less), women (compared to men), and white individuals (compared to non-white individuals) being more likely to report knowing at least a little bit about palliative care. Among caregivers, palliative care awareness was higher than in the general public, but still relatively low at 55%.

**Knowledge.** Among those in the general population who reported having at least “a little” knowledge about palliative care, many endorsed three common misconceptions about the topic: “accepting palliative care means giving up” (20%), “if you accept palliative care you must stop other treatments” (30%), and “palliative care is the same as hospice care” (49%). Endorsement of these misconceptions was less common among caregivers. Although 40% of caregivers incorrectly believed that “palliative care is the same as hospice care,” only 13% believed that “accepting palliative care means giving up” and 12% believed that accepting palliative care means “you must stop other treatments.”

### How Can This Inform Your Work?

HINTS data suggest that awareness and knowledge of palliative care are lacking, especially among racial/ethnic minorities, younger individuals, men, and those without a college degree. Educational initiatives (in both clinical and community settings) can increase the use of palliative care among patients, as research indicates that when individuals are informed about palliative care, they largely choose to receive it. In addition to outlining the benefits of palliative care, interventions should strive to reduce the stigma and fear associated with the term. To that end, providers should discuss palliative care with patients and their caregivers early in the disease trajectory, taking care to dispel common misperceptions and to draw a clear distinction between palliative care and hospice. Decision aids, information sheets, and short videos could also be effective tools for increasing palliative care knowledge, especially if they are culturally sensitive and written at an appropriate literacy level.

### About HINTS

[hints.cancer.gov](https://hints.cancer.gov)

The National Cancer Institute (NCI) created the Health Information National Trends Survey (HINTS) to monitor changes in the rapidly evolving field of health communication. The survey data can be used to understand how adults use communication channels to obtain health information for themselves and their loved ones. HINTS data can also help practitioners create more effective health communication strategies. The HINTS survey has been fielded 11 times to date.

HINTS *Briefs* provide a snapshot of noteworthy, data-driven research findings. They introduce population-level estimates for specific questions in the survey and summarize significant research findings resulting from analyses of how certain demographic characteristics influence specific outcomes.

Many *Briefs* summarize research findings from recent peer-reviewed journal articles that have used HINTS data.

### For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER
- Visit <https://www.cancer.gov>
- Order NCI publications at <https://pubs.cancer.gov/ncipl/home.aspx>
- Visit [Facebook.com/cancer.gov](https://www.facebook.com/cancer.gov) and <https://www.youtube.com/ncigov>

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