Knowledge and Attitudes Toward Palliative Care Among Cancer Survivors

Palliative care refers to interdisciplinary supportive care focused on improving quality of life for individuals living with serious illness and their families. Palliative care seeks to treat both physical and psychological symptoms, address spiritual concerns, establish goals of care, and assist with complex medical decision making. Palliative care is not synonymous with hospice care, which is a formal system of care for the terminally ill that requires patients to have a survival expectancy of 6 months or less and be willing to forgo curative treatments. In contrast, any patient with a serious illness who would benefit from symptom management and quality-of-life improvement is a candidate for palliative care.

Palliative care can be helpful at any stage of illness and should be initiated at the time of diagnosis and provided concordantly with other disease-directed or curative therapies to ensure that patient needs outside of treatment are met. Research has shown that early integration of palliative care can improve quality of life, symptom control, patient and caregiver satisfaction, survival, and costs of care for cancer patients.

Despite the potential benefits of palliative care for patients with serious illness, awareness and understanding of palliative care remain low in the US. As highlighted in a previous HINTS brief (Brief 41, 2019), more than 70% of Americans have never heard of palliative care. Less work has been done to assess awareness of palliative care among cancer survivors — a population that may be in greater need of this knowledge. Assessing palliative care knowledge among cancer survivors is important because lack of awareness and inaccurate perceptions of palliative care (e.g., conflating it with hospice) can hinder the uptake of these potentially beneficial services. It is also vital to assess whether awareness and perceptions of palliative care vary by sociodemographic or other factors to ensure equitable delivery of care and reduce health disparities among cancer patients. This is especially important given research showing that some groups (e.g., racial minorities, those with lower socioeconomic status) are less likely to receive certain kinds of palliative care services, even though they may have greater need for these services due to higher symptom burden.

Quick Facts

- Palliative care is patient- and family-centered supportive care intended to improve quality of life.
- Research has shown that early integration of palliative care can improve symptom control, satisfaction, survival, and costs of care for cancer patients.
- Lack of awareness and inaccurate perceptions of palliative care can hinder the uptake of palliative care services.
- Sociodemographic characteristics (e.g., race and socioeconomic status) predict both higher symptom burden and lower likelihood of receiving certain kinds of palliative care services among cancer patients.

Palliative Care Awareness Among Cancer Survivors

According to a recent analysis of 2018 HINTS 5 Cycle 2 data in Stal et al. (2022), the following awareness levels were found among cancer survivors:

- 65.6% have never heard of palliative care.
- 17.8% know a little bit about palliative care.
- 16.6% know what palliative care is and could explain it to someone else.

This HINTS® Brief examines knowledge and perceptions of palliative care among cancer survivors in the US.
Prevalence and Correlates of Palliative Care Knowledge Among Cancer Survivors

In a recently published study, researchers analyzed data from HINTS 5 Cycle 2 (2018) to examine knowledge and perceptions of palliative care among cancer survivors. Self-reported knowledge of palliative care was found to be relatively low, with 66% of survivors reporting that they had never heard of palliative care, 18% reporting knowing a little bit about palliative care, and 17% reporting that they know what palliative care is and could explain it to someone else. Regression models showed that male survivors and survivors with lower educational attainment were significantly less likely to report palliative care knowledge.

Most survivors who reported any knowledge of palliative care had accurate perceptions, with a majority agreeing that the goals of palliative care were to manage pain and other physical symptoms (94%), offer social and emotional support (93%), and help friends and family cope with a patient’s illness (91%). A majority also accurately disagreed with the idea that accepting palliative care means giving up (82%) or that accepting palliative care requires stopping other treatments (75%). However, more than a third of survivors (37%) agreed that “palliative care is the same as hospice care,” suggesting that the distinction between these two services may not be well understood among this population. Additionally, 83% of survivors agreed that “it is a doctor’s obligation to inform all patients with cancer about the option of palliative care,” highlighting the important role of providers in informing survivors about these services.

How Can This Inform Your Work?

HINTS data suggest that targeted efforts are needed to increase knowledge of palliative care among cancer survivors. All clinicians who deliver care to cancer survivors, including oncologists and primary care providers, can discuss palliative care with their patients to ensure adequate awareness and understanding of available support services. Initiating these conversations early on, clarifying the goals of palliative care, and explaining the difference between hospice and palliative care could help increase acceptance and uptake of palliative care services when and if they are needed. HINTS data also show that certain groups of cancer survivors (e.g., those with lower levels of educational attainment) are less likely to report knowledge of palliative care and therefore may be less able to take advantage of these potentially beneficial services. To decrease disparities in palliative care provision, clinicians should be aware of the sociodemographic factors that may be associated with palliative care awareness and uptake so they can better identify and counsel patients who may lack knowledge about the goals and benefits of palliative care.

Provider concerns (e.g., about negative reactions from patients) can act as a barrier to initiating palliative care conversations in the clinical setting, suggesting that interventions targeting medical professionals may be needed. Communication training could help clinicians feel more comfortable having difficult conversations, improve patient-centered communication, and enable clinicians to introduce palliative care in a nonthreatening way. Training and education regarding culturally appropriate ways to approach palliative care discussions with underserved populations could be especially helpful, as clinician-patient communication gaps may be particularly pronounced in certain populations, such as racial/ethnic minorities, those of lower socioeconomic status, and immigrant communities.

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 15 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.

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References Used in This Brief