

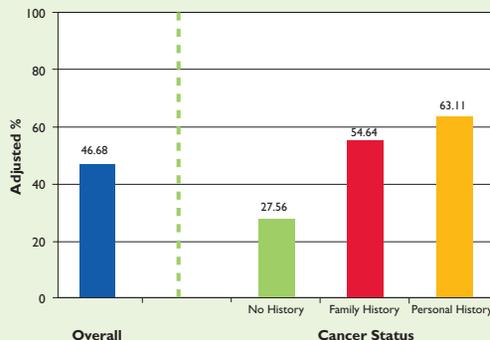
Cancer Survivors and People with a Family History of Cancer Are Most Likely to Seek Cancer Information

Many people who have been touched by cancer actively use available resources (e.g., the Internet, health care providers, newspapers, brochures, and magazines) to seek information about the disease. Compared to the general population of U.S. adults, cancer survivors and people with a family history of the disease are more likely to engage in cancer information seeking. Sixty-three percent of cancer survivors and 54 percent of people with a family history report looking for cancer information, compared to only 27 percent of people with no personal or family history of cancer.

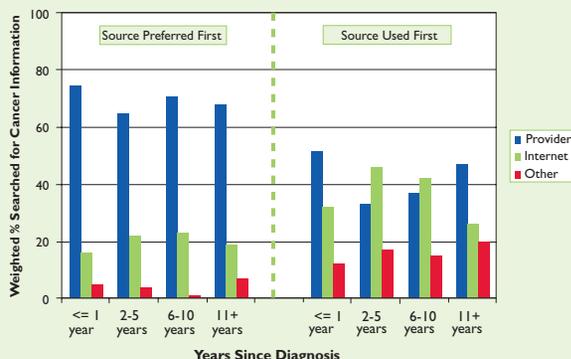
Data from the Health Information National Trends Survey (HINTS) have also shown us that while people say they would prefer to go to a health care provider for health information, most people actually use the Internet first. These patterns are similar among cancer survivors, although usage of health care providers and the Internet as information resources varies with time since diagnosis. During the first year of a cancer diagnosis, patients report going to their health care provider as their first source of information; however, this pattern changes during the time that survivors are in transition (years 2 through 10 post-diagnosis), when Internet usage exceeds health care providers as survivors' first resource for cancer information.

In this *HINTS Brief*, we provide a starting point for improving health communication with cancer survivors. We distinguish the differences between information seekers versus non-seekers in the survivor population, and provide insight on how survivors rate their cancer information seeking experience.

Information Seeking (Ever Searched for Cancer Information by Cancer Status, Compared to Overall Population)
HINTS 2005



Cancer Survivors' Information Source Preferences and Information Source Use*
HINTS 2005



* Weighted percentages are adjusted for gender, age, education, annual income, race/ethnicity, and health insurance status

Quick Facts

- A person is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.
- In 2004 it was estimated that there were 10.8 million cancer survivors in the U.S., representing approximately 3.7% of the population.
- 60% of survivors are currently 65 years of age and older.
- Approximately 14% of the 10.8 million estimated cancer survivors were diagnosed more than 20 years ago.

Survivors' Satisfaction with Seeking Cancer Information

Information Quality Is Biggest Concern

In a HINTS study published in 2008, investigators sought to understand cancer survivors' experience and satisfaction with seeking cancer information. Survivors were asked to recall their last experience with searching specifically for cancer information, and to rate that experience on a satisfaction scale.

Almost half of the survivors in the study (44.6%) said that they were concerned about the quality of the information they found during their last search. Thirty percent of survivors reported that it took a lot of effort to find the information they needed. Twenty-three percent felt frustrated during their last search, and 24% thought that the information they found was difficult to understand.

Information seeking survivors across sociodemographic categories seemed to have similar experiences; there were no significant differences in satisfaction by race/ethnicity, gender, age, education, or income.

Characteristics of Information Seeking Cancer Survivors

A few characteristics differentiate information seekers from non-seekers within the population of cancer survivors in the U.S. According to a recent publication using HINTS 2005 data, information seeking survivors tend to be younger and better educated than non-information seekers.

Age

Compared to survivors aged 75 and older, survivors between ages 35 and 49 are more than twice as likely ever to have searched for cancer information. Survivors between ages 50 and 64 are almost four times more likely than survivors aged 75 and older to have searched for cancer information.

Education

Information seeking among cancer survivors increases steadily with years of education. Compared to survivors who did not complete high school, those with a high school degree are over three times more likely to have searched for cancer information. Survivors with some college or a college degree are over six times more likely than survivors with less than a high school education to have searched for cancer information.

These findings are adjusted for other factors that may be associated with information seeking, including income, race/ethnicity, gender, health insurance status, and time since cancer diagnosis. There appear to be no significant differences in information seeking among survivors by income, race/ethnicity, or gender.

How Can This Inform Your Work?

A cancer diagnosis may present the challenge of sorting through cancer information that is fragmented, uneven, and disparate in quality. Health communication practitioners can be active participants in changing the cancer information environment in order to provide effective support for cancer patients throughout their cancer journey.

- All cancer survivors show a strong interest in going to their provider teams for information first, before looking elsewhere. Provider-patient communication remains paramount, and should be accessible, compassionate, and superior.
- There appears to be an education gradient among survivors who seek out cancer information. Proactive efforts may be

necessary to reach less educated survivors with information that will support their survivorship.

- The Internet is the first resource for many survivors. Because quality of information remains a key concern of cancer survivors, Web-based cancer information must be accurate and usable.
- NCI cancer information resources:
 - NCI's Cancer Information Service offers online *Live Help* Monday through Friday 9 a.m. to 11 p.m. eastern time.
 - NCI's Office of Cancer Survivorship Web site (<http://survivorship.cancer.gov>) provides links to quality resources and institutions offering information and support for cancer survivors and their families.
 - The *Facing Forward: Life after Cancer Treatment* publication series is available online (http://cancercontrol.cancer.gov/ocs/ff_series.html).

About HINTS

<http://hints.cancer.gov>

The National Cancer Institute (NCI) fielded the first Health Information National Trends Survey (HINTS) in 2002-2003, surveying 6,369 Americans. Subsequent surveys followed in 2005 and 2007. HINTS was created to monitor changes in the rapidly-evolving field of health communication. The survey data can be used to understand how adults 18 years and older use different communication channels to obtain health information for themselves and their loved ones, and to create more effective health communication strategies across populations.

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 that are a result of analyzing how age, race, and gender influence specific outcomes. Many *Briefs* summarize research findings from recent peer-reviewed journal articles using HINTS.

For More Information on Cancer

- Call the NCI Cancer Information Service at 1-800-4-CANCER (1-800-422-6237)
- Visit <http://cancer.gov>
- Order NCI publications at <https://cissecure.nci.nih.gov/ncipubs/>

References Used in This HINTS Brief

Hesse BW, Arora NK, Beckjord EB, Finney Rutten LJ. Information support for cancer survivors. *Cancer* 2008 Jun; 112(11):2529-40.

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Hewitt ME, Ganz PA. *From cancer patient to cancer survivor - lost in transition: an American Society of Clinical Oncology and Institute of Medicine symposium*. Washington, D.C.: National Academies Press; 2006. 190 p.

