

## Lost in Transition? Cancer Survivorship and Patient-Centered Communication

### Introduction

As of January 2016, there were an estimated 15.5 million cancer survivors in the United States, and this number is projected to exceed 26 million by 2040 as the population ages and medical advances improve cancer survival rates. Cancer survivors face unique challenges associated with both the long- and short-term physical, psychological, social, and economic consequences of cancer and its treatment. Despite their substantial health care needs, survivors are often left to coordinate their own care across multiple providers in a fragmented system that can make them feel “lost in transition.”

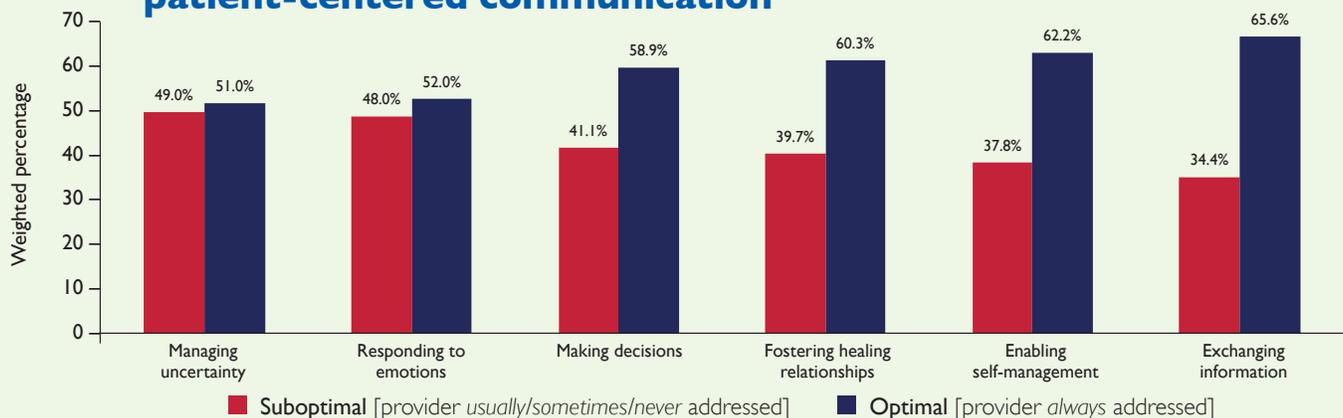
Effective patient-centered communication may enhance quality of life and improve health outcomes for cancer survivors. A 2007 National Cancer Institute monograph describes patient-centered communication as serving six main functions: 1) fostering healing relationships between patients and their providers, 2) exchanging clinical information about the patient’s illness,

### Quick Facts

- In 2016, there were an estimated 15.5 million cancer survivors in the United States.
- Patient-centered communication is essential for delivering quality care to survivors and addressing their complex physical and psychosocial needs.
- Patient-centered communication has six functions: 1) fostering healing relationships, 2) exchanging clinical information, 3) responding to emotional needs, 4) managing uncertainty, 5) facilitating shared decision-making, and 6) enabling patient self-management.
- Many cancer survivors report suboptimal patient-centered communication, particularly in relation to uncertainty management and emotional needs.
- Cancer survivors who report poor health and those who lack a usual source of care are more likely to experience suboptimal levels of patient-centered communication.

3) responding to the emotional needs of the patient, 4) assisting patients in managing uncertainty, 5) engaging patients in shared decision-making, and 6) enabling patient self-management. This HINTS *Brief* examines patterns in cancer survivors’ experiences with patient-centered communication.

### Cancer survivors’ experience with the central functions of patient-centered communication



Data source: Blanch-Hartigan, D., Chawla, N., Moser, R. P., Finney Rutten, L. J., Hesse, B. W., & Arora, N. K. (2016). Trends in cancer survivors’ experience of patient-centered communication: Results from the Health Information National Trends Survey (HINTS). *Journal of Cancer Survivorship*, 10(6), 1067–1077.

## Survivors' Experience With Patient-Centered Communication, 2008–2013

In a 2016 study, investigators pooled data across four administrations of HINTS (2008, 2011, 2012, and 2013) for six survey questions that asked cancer survivors how often their providers engage in the central functions of patient-centered communication. Nearly half of the respondents reported that providers did not always help them deal with their feelings of uncertainty (49 percent) and did not always attend to their emotions (48 percent). Many survivors also reported that their providers did not involve them in decisions as much as they wanted (41 percent), that they could not always rely on their providers to take care of their needs (40 percent), that their providers did not always make sure they fully understood how to care for their health (38 percent), and that providers did not always allow them to ask all the questions they had (34 percent).

Overall, cancer survivors reporting poorer health and survivors without a usual source of care were consistently less likely to report optimal communication. Additionally, female survivors and individuals with incomes below \$50,000 per year were significantly more likely to report optimal communication in the domain of uncertainty management compared to male survivors and those with incomes of \$75,000 or more. Furthermore, while the study found a linear decrease in the percentage of survivors reporting suboptimal care in each of the six core functions over the time period analyzed, this trend remained significant only for the “healing relationship” function in the fully adjusted model, suggesting that trends are emerging differently in certain subgroups.

### How Can This Inform Your Work?

Despite greater attention to the needs of cancer survivors over the past decade, many cancer survivors still experience suboptimal communication with their providers. There are opportunities to improve patient-centered communication, particularly in terms of helping patients manage uncertainty and addressing their emotional needs. Furthermore, because patient-centered communication experiences vary based on sociodemographic characteristics, targeted interventions may be needed for specific groups of survivors, such as male survivors or survivors lacking a usual source of care.

Survivorship care planning is a tool that can be used to enhance patient–provider communication and better address the needs of survivors, especially with managing uncertainty. Although a recently published systematic review reported few significant effects of survivorship care plans, ensuring that all cancer patients receive comprehensive survivorship care plans that are grounded in patient-centered communication might help improve quality of care for survivors.

### About HINTS

[hints.cancer.gov](http://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. It can also help practitioners create more effective health communication strategies.

The HINTS survey has been fielded 10 times to date: HINTS 1 (2003) surveyed 6,369 Americans; HINTS 2 (2005) surveyed 5,586 Americans; HINTS 3 (2008) surveyed 7,674 Americans; HINTS 4 Cycle 1 (2011) surveyed 3,959 Americans; HINTS 4 Cycle 2 (2012) surveyed 3,630 Americans; HINTS 4 Cycle 3 (2013) surveyed 3,185 Americans; HINTS 4 Cycle 4 (2014) surveyed 3,677 Americans; HINTS FDA (2015) surveyed 3,787 Americans; HINTS 5 Cycle 1 (2017) surveyed 3,285 Americans; and HINTS FDA Cycle 2 (2017) surveyed 1,736 Americans.

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 <http://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 <http://www.youtube.com/ncigov>

## References Used in This HINTS Brief

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