

Health Information Seeking Among Caregivers

HINTS data indicate that approximately 15% of Americans care for or make health care decisions on behalf of family members or friends who have a disability or a medical, behavioral, or other condition (including cancer, dementia, and developmental issues). Caregivers often help their loved ones with activities of daily living, administer medications, manage financial and insurance matters, coordinate medical appointments, and communicate with providers. Successfully executing these responsibilities requires caregivers to have information on everything from the trajectory and symptoms of the patient's illness, to medication dosage and side effects, to insurance benefits. Unfortunately, many caregivers report high rates of unmet information needs, and research suggests that unmet information needs are associated with adverse health and psychosocial outcomes among caregivers. Furthermore, the physical and emotional consequences that caregivers experience when they lack adequate resources and support may interfere with their ability to provide their loved ones with optimal care.

As caregivers increasingly turn to the internet to seek answers and get advice from peers in similar situations, assessing caregivers' experiences with using the internet to obtain health information and tracking disparities in information seeking among caregivers is necessary to

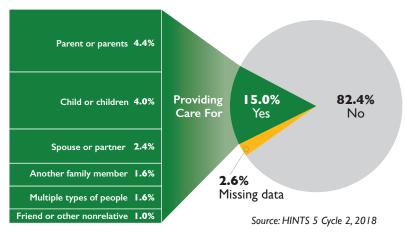
Quick Facts

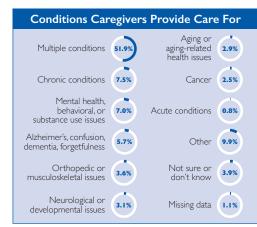
- Fifteen percent of American adults report providing care to someone with a disability or a medical, behavioral, or other condition.
- Caregivers report looking for health information at higher rates than noncaregivers.
- The internet is the most frequently used source of health information among caregivers.
- Caregivers born outside the United States report experiencing greater difficulty in seeking health information than those born in the United States.
- Information-seeking behaviors and perceptions among caregivers vary by racial and socioeconomic characteristics.

ensure that they are getting the information and support they need. Furthermore, although internet-based resources offer a potentially effective way to provide caregivers with information, interventions and materials delivered via the web may not always serve caregivers with different needs, different cultural backgrounds, different levels of comfort with technology, and differing abilities in regard to navigating these online resources.

This HINTS *Brief* looks at health information-seeking behaviors among caregivers, as well as caregiver characteristics that are associated with difficulty or lack of confidence in searching for health information.

Percentage of American Adults Who Report Being Caregivers





Information-Seeking Patterns Among Caregivers

A recently published study used HINTS 5 Cycle I data (2017) to compare the health information-seeking behaviors of caregivers and noncaregivers and to identify disparities among caregivers in their information-seeking experiences. The analysis found that caregivers more frequently reported looking for health information than noncaregivers and that the internet was the most frequently used source of health information for both caregivers and noncaregivers. Caregivers also reported using the internet to find health information for others and to make appointments with health care providers at higher rates than noncaregivers.

In general, both caregivers and noncaregivers reported little difficulty in seeking health information and had moderate levels of confidence in their ability to obtain information about medical topics. However, caregivers born outside the United States reported greater difficulty in seeking health information than those born in the United States, and caregivers who were nonwhite, had lower educational attainment, or lacked a regular care provider reported lower confidence in seeking health information compared to those who were white, had a college degree, or had a regular health care provider, respectively. Similarly, caregivers with higher incomes had greater confidence in their health information seeking than those with lower incomes. These findings suggest that substantial disparities exist in caregivers' health information-seeking experiences and perceptions.

How Can This Inform Your Work?

These HINTS data can inform efforts to meet caregivers' information needs. For instance, caregivers born outside the United States seem to experience greater difficulty in seeking health information—possibly due to language barriers, cultural differences in the ways illness is conceptualized, or a lack of familiarity with the complexities of the U.S. health care system. Practitioners should ensure that caregiver services and interventions (especially those that are internet-based) are appropriate for foreign-born individuals, and providers should be aware that these caregivers may need additional support with navigating health information.

Similarly, caregiving interventions could be better tailored for racial minorities and for individuals with lower education and income levels. Patient portals, educational materials, and other resources should follow plain language best practices and be developed with input from a diverse group of caregivers to ensure that these interventions benefit all individuals, regardless of race or socioeconomic status. Interventions that provide caregivers with the skills needed to successfully navigate online health information might be especially useful for caregivers who report less confidence in their ability to seek health information.

About HINTS 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

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- Visit https://www.cancer.gov
- Order NCI publications at https://pubs.cancer.gov/ncipl/home.aspx
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References Used in This Brief

Bangerter LR, Griffin J, Harden K, Rutten LJ. Health information—seeking behaviors of family caregivers: Analysis of the Health Information National Trends Survey. *JMIR Aging*. 2019;2(1):e11237. doi:10.2196/11237.

Longacre ML. Cancer caregivers information needs and resource preferences. *J Cancer Educ.* 2013;28(2):297-305. doi:10.1007/s13187-013-0472-2.

Chen SC, Chiou SC, Yu CJ, et al. The unmet supportive care needs—what advanced lung cancer patients' caregivers need and related factors. Supportive Care in Cancer. 2016;24(7):2999-3009. doi:10.1007/s00520-016-3096-3.

Oberoi DV, White V, Jefford M, et al. Caregivers' information needs and their 'experiences of care' during treatment are associated with elevated anxiety and depression: a cross-sectional study of the caregivers of renal cancer survivors. Support Care Cancer. 2016;24(10), 4177-4186. doi:10.1007/s00520-016-3245-8.

Thomas LC. Improving caregiver knowledge of support resources. Fed Pract. 2017;34(3), 45.

Chiu TM, Eysenbach G. Theorizing the health service usage behavior of family caregivers: A qualitative study of an internet-based intervention. *Int J Med Inform.* 2011;80(11):754-764. doi:10.1016/j.ijmedinf.2011.08.010.



