Health Information Seeking on Behalf of Others: Characteristics of “Surrogate Seekers”

Introduction

During the past few decades, technological advances have greatly altered the way people access health information. Internet and smartphones are among the most notable game changers. These advances have made it relatively easy to access health and medical information on Web sites, databases, and social media. For example, WebMD and the Mayo Clinic make it possible to look up symptoms, prognoses, and treatments for medical conditions. In 2014, the Health Information National Trends Survey found that nearly 70 percent of U.S. adults said they turned to the Internet first when they needed health or medical information.

There are both benefits and drawbacks to the new digital landscape, however. Benefits include reported improvements to quality of life, greater satisfaction with medical decisions, and better communication and engagement with providers and caregivers. Challenges include finding information that is difficult to comprehend, inability to access desirable information, and confusion from conflicting messages online. For example, a 2004 report from the Institute of Medicine found that nearly half of U.S. adults struggled to understand and use health information. According to Pew, an estimated 47 million Americans don’t use the Internet. This group tends to be older, poorer, from a rural area, and non-white.

When it comes to searching for health information, there are “self seekers” – those who go online to find health information for themselves, and there are “surrogate seekers” – those who go online to look for information for others. People who engage in online health information seeking often fall into both categories. When seeking for someone else, surrogate seekers are often responsible for finding health information for people with access or cognitive barriers, children, or people who are emotionally overwhelmed with a new diagnosis. Sometimes, they search without being asked.

Quick Facts

• Surrogate seekers are defined as people who look for health information for other people. They are more likely to be middle aged and to live with others.
• In 2013, nearly 8 in 10 Americans used the Internet to find health information for themselves, while about 7 in 10 went online to find health information for others.
• Half of Americans surveyed in 2013 felt confident they could get health or medical information if they needed it.
• Surrogate seeking is more likely among those who are able to focus on their strengths and values when they feel threatened or anxious.

The most recent time you looked for information about health or medical topics from any source, who was it for?

<table>
<thead>
<tr>
<th>Estimated U.S. Adult Population</th>
<th>Myself</th>
<th>Someone else</th>
<th>Both myself and someone else</th>
</tr>
</thead>
<tbody>
<tr>
<td>56.8%</td>
<td>23.6%</td>
<td>19%</td>
<td></td>
</tr>
</tbody>
</table>

Source: HINTS 4, Cycle 4 data. Data collected in 2014. Percentages do not sum to 100 due to refused or missing responses.

In general, how much would you trust information about health or medical topics from family or friends?

<table>
<thead>
<tr>
<th>Estimated U.S. Adult Population</th>
<th>A lot</th>
<th>Some</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>51.6%</td>
<td>33.6%</td>
<td>8.3%</td>
<td>3.8%</td>
<td></td>
</tr>
</tbody>
</table>

Source: HINTS 4, Cycle 3 data. Data collected in 2013. Percentages do not sum to 100 due to refused or missing responses.

In this HINTS Brief, we identify unique demographic characteristics of surrogate seekers, and describe their satisfaction with the search process.
Surrogate Seekers Are Likely to Be Middle Aged and to Live with Others

In a recently published study using HINTS data, investigators found that two thirds of respondents said they had used the Internet in the past 12 months to look for health information for other people. People between the ages of 35 and 64 were more likely to be surrogate seekers.

There were no significant differences in surrogate seeking by sex, race, education, and income-level, but surrogate seekers were much more likely to live with other people. There were no significant differences in reported satisfaction with online health information seeking experiences among people who sought information only for themselves versus someone else. Self seekers and surrogate seekers reported about the same level of comprehension, effort, frustration, and concern about the quality of information on the Internet. One third of both self and surrogate seekers were frustrated with their searches and felt that they took a lot of effort. More than half were concerned with the quality of what they read.

Surrogate Seekers Are Content Creators

Surrogate seekers are significantly more likely to be involved in online content creation and digital communication. They are more likely to email a doctor’s office, use social media, participate in an online support group, use the web to find a health care provider, track personal health information online, and download health-related information to a smartphone or tablet.

How Can This Inform Your Work?

The Internet has enabled unprecedented access to health information. About 85 percent of surrogate seekers report going online first when they need health or medical information.

Providing health information in accessible formats should be a top priority for content creators of health information. Communication practitioners in public health and health care settings should

• Provide key search terms to patients and surrogate seekers to help with online searching
• Recommend reputable websites
• Provide patients and surrogate seekers printed or digital materials about the patient’s medical condition(s)

Technologies such as electronic health records and personal health records give health care providers and patients more opportunities to communicate outside the appointment encounter. Providers can use these technologies to provide patients with information on diagnoses, treatment plan summaries, next steps, and referral information.

About HINTS

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.

NCI fielded the first HINTS survey in 2002–03 and surveyed 6,369 Americans. Subsequent surveys followed in 2005 (5,586 Americans surveyed), 2008 (7,674 Americans surveyed), and 2011-14 (14,451 Americans surveyed over four cycles).

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. Most 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 http://cancer.gov
• Order NCI publications at https://pubs.cancer.gov/ncipl/home.aspx
• Visit Facebook.com/cancer.gov and http://www.youtube.com/ncigov

References Used in This HINTS Brief

