Information Behaviors of Cancer Patients in the Information Age

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Abstract

Advances in cancer treatments and the increasing availability of information are changing the information behaviors of cancer patients. Many American adults search for health-related information on the Internet and have made decisions based on results from general search engines. Information and health professionals are concerned about the reliability, validity and volume of health information available. Patient usage and preferences are discussed. This article reviews recent literature and research surrounding the information seeking behaviors of cancer patients and provides ideas for future research.

Introduction

Cancer is a major public health problem in the United States. According to the National Cancer Institute's Cancer Trends Progress Report-2007 Update, more than one million people are diagnosed with some form of cancer every year. It is expected that more than half a million people will die of cancer in 2008 (American Cancer Society, 2008). Although the cancer diagnosis and death rates have been in decline since 1993, these statistics are staggering (National Cancer Institute, 2007). Fortunately, cancer patients have the benefits of advanced treatments, prevention techniques, access to clinical trials, and a plethora of information from various sources.

Information is available from healthcare providers, the Internet, libraries, the Cancer Information Services (CIS), friends, and other sources. The Pew Internet & American Life Project: Online Life Report (Fox et al., 2000) states that fifty-two million American adults have looked for health information on the Internet, and more than fourteen million have been influenced by the information they found on the Web. Many patients and physicians are concerned about the reliability of information found from non-moderated sources (Ehrenberger, 2001). More information and misinformation becomes available every day, and cancer patients and their loved ones must decide on sources of information, how to access information about the disease, or who and what to believe. Many patients may become frustrated, confused (Arora et al., 2007), or overwhelmed (Kim, Lustria, Burke & Kwon, 2007) by the available information and sources. Overload can "hinder learning or impair users' ability to make informed decisions" (Kim, Lustria, Burke & Kwon, 2007). The National Cancer Institute's Health Information National Trends Survey (2003) found 48.4% of respondents felt it took a lot of effort to find cancer information and 41.9% became frustrated during the search process. As information becomes increasingly available through different channels, more cancer patients could face information overload, ultimately putting pressure on the health care system to be more involved in information seeking needs and behaviors.

Several studies have investigated information needs and information seeking behaviors of cancer patients. The general research questions include:

- Do cancer patients want information? Which patients seek information and which do not?
- How and why is information used by cancer patients?
- What are differences in information preferences among cancer patients, and what causes these differences?

This paper presents a review of recent literature and research relevant to the information behaviors of cancer patients and provides ideas for future research.

Cancer patients want information but not all seek it out.

A growing trend in cancer treatment is outpatient services. More patients are required to have some basic understanding of self-treatment and knowledge of how to deal with side effects. Over the past twenty years, the medical community has advised health care providers to share information with their patients and has recommended that patients search for medical information so they can participate in their treatment and care. (Czaja, Manfredi & Price, 2003). Several studies have asked the question, "Do cancer patients want information?" Interestingly, there have been some conflicting findings in these studies. However, one main theme in these studies is all cancer patients want information but many do not actively seek additional information beyond what is provided by
their healthcare provider (Czaja, Manfredi & Price, 2003; Leydon et al., 2000; Mayer et al., 2007; Ramanadhan & Viswanath, 2006). The studies have compared information seekers and information non-seekers.

Due to the overwhelming nature of the increase of information accessibility, many cancer patients do not actively seek information but would prefer to let their physicians provide information about their diseases and treatment instead, as well as make medical decisions for them (Czaja, Manfredi & Price, 2003). Cancer information non-seekers were found to be approximately 66 years old, have an annual income of $34,000 or less, had an average of 13 years of education (Mayer et al., 2007; Ramanadhan & Viswanath, 2006), and typically reported a high level of satisfaction and trust in doctors. This group tends to be skeptical of Internet resources and does not seek out second opinions. The difference between these seekers and non-seekers might be caused by the lack of opportunity or ability to find further information. Leydon et al. (2000) found that this group had the belief that the “doctor knows best.” This belief “sometimes negated the perceived value of additional information . . . and that additional information could confuse their situation” (Leydon et al., 2000). Some patients still hold onto the perception that trust in physicians makes them good customers.

Cancer information seekers tend to be younger, more educated, and higher-income patients. On average, the information seeker was approximately 54 years old, had some college experience, and earned more than $34,000 per year (Mayer et al., 2007; Ramanadhan & Viswanath, 2008). A home Internet connection or reliable transportation can enhance the ability to access further information. A high level of stress at diagnosis has also been found to create active information seekers (Czaja, Manfredi & Price, 2003). This group tended to search for information that would help them cope with the disease.

Information is used at different times and stages by cancer patients.

Information is sought by cancer patients in an effort to gather information about screening processes, learn about the disease, understand the diagnosis, find information about treatments, search for clinical trials, reduce stress, learn coping strategies, help make decisions about their care and treatment, learn about living with cancer, and gain support from others (Echlin & Rees, 2002; Shim, Kelly & Hornik, 2006; Ziehland et al., 2004). Cancer patients and those at higher risk of developing cancer have been found to be intermittent information seekers. The different stages can include prevention, early detection, diagnosis, treatment, life after cancer, and end of life (American Cancer Society, 2008). According to LaCosiere, Knofl, and McCorkle (2005), cancer patients search about ten minutes for every clinical encounter with their oncologist.

People with a family history of cancer are seen as having a high risk for developing cancer. This group searches for prevention and early screening information from Internet sites such as the American Cancer Society and the National Cancer Institute. The information obtained during the search process can motivate a person to make decisions regarding lifestyle, such as diet and exercise, and screening opportunities. Many times, they have also spent time searching for information to learn about the disease and assist their loved one(s) diagnosed with cancer.

General and specific information seeking occurs at different stages. Patients normally search for general cancer information before they search for information about their specific needs (James et al., 2002). After the initial shock of diagnosis, cancer patients look for information about general cancer treatments. This information seeking behavior can help newly diagnosed cancer patients reduce anxiety and anger. Patients then begin to gather information about their specific cancer and treatment options, either from their oncologist or other information sources. Those who seek out additional treatment information or second opinions use this information in the decision-making process (Echlin & Rees, 2002). This information also allows people to better prepare themselves for asking questions of their health care provider.

Before, during, and after treatment, cancer patients seek out support from different sources. Some patients rely on their physician and their family or friends as their support system. Others have found email newsgroups, online discussion boards, local cancer association chapters, and health websites. Many groups are geared to a specific type or stage of cancer. Support groups are also available for the family members and friends of cancer patients. Cancer patients, family members, and caregivers can use information found in these resources to help develop and improve coping strategies, influence lifestyle behaviors, and provide support to others facing similar situations.

Differences in information preferences among cancer patients.

The ever-growing need for global accessibility to information is changing the landscape of information-seeking behaviors. As more sources of information become available, people have to make choices on which sources to trust and which to use to make decisions. Cancer patients have many options when looking for more information regarding their disease: healthcare providers, the Internet, the Cancer Information Service (CIS), magazines, newspapers, brochures and pamphlets, television, and friends, family and coworkers. Too much information can cause problems in finding reliable and valid sources as well as present the possibility of cancer information overload (Kim et al., 2007).
Cancer patients want to understand their current situation and prognosis. Many patients look to others such as family members and friends to search for information on their behalf (Hesse et al., 2005; James et al., 2007; Mayer et al., 2007; Meissner, Anderson, & Odenkirchen, 1990). It has been found that the cancer patient caregivers prefer to turn to the Internet and use search engines, community forums, Medscape, and WebMD for cancer information and support. The American Cancer Society, National Cancer Institute, Avon Crusade, and psa-rising.com are also considered favorite sources for content and support.

As discussed earlier, socio-demographic characteristics, gender, health status, health communication, race, age, employment status, type of cancer, and time since diagnosis have all been reported as indicators of information preferences of cancer patients (Ackera et al., 2007; Hesse et al., 2005; Kim et al., 2007; LaCoursiere, Knobf, & McClellan, 2005). Cancer patients who use the Internet as a main source of information typically are women under the age of 65 with higher levels of income and education. Reliance on physicians and other health care providers for cancer information were found to have lower levels of education and income. Overall, the Internet and health care providers are the leading sources patients prefer to use first when searching for cancer information. Active information seekers consulted the Internet more often than physicians "because it was convenient, had a lot of information, and was available when needed (Mayer et al., 2007)." According to the Pew Internet & American Life: Online Life Report (Fox et al., 2000), 70% of health-information seekers went to online sources for information regarding a specific condition or illness and 93% of health information seekers feel it is important to get information when it is convenient for them. However, lack of access to the Internet can hamper some patients' information seeking. Some cancer patients are concerned about the level of reliability in online information. Only about half of online health information seekers checked to see who was providing the information at the Internet sites they visited (Fox et al., 2000). Many Internet users say the search process requires a lot of effort and become frustrated trying to understand the difficult nature of information they found and the number of conflicting and unreliable sources. This uncertainty of reliable information causes some seekers to become non-seekers and rely heavily on information provided by their oncologist (Ramanathan & Viswanath, 2006). When guided by health care providers, Internet searchers were more satisfied with the process in finding and understanding information.

Some researchers are concerned with the amount of information available. This can lead to cancer-related information overload, causing difficulties in absorbing and processing information when a person receives too much information (Ackera et al., 2007, Kim et al., 2007). Level of education has been found to be a strong predictor of cancer information overload. Populations with lower levels of literacy and income may have impaired information navigation abilities. This leads to negative experiences, unsatisfied outcomes, or information overload, hampering the efforts and success of cancer prevention and control programs.

Conclusions

This review suggests that although considerable variation exists among cancer patients’ information behaviors, all patients want information about the disease. Information can be used to help patients cope with this complex and intimidating disease. Many patients have found comfort in understanding cancer and connecting with other people in similar situations. Patients who actively participate in decision-making and treatment options have been found to have less stress, stronger coping mechanisms, ask better questions of their physicians, seek out second opinions, and possibly participate in clinical trials and further research. Many cancer patients rely on their caregivers to be the information seekers and disseminators.

However, not all patients actively search for further information. Some may feel that their physicians provide them with all the information they need. Others may be afraid to learn more due to the overwhelming nature of the Information Age. There have been several studies investigating the differences between cancer information seekers and non-seekers. The research finds distinct socioeconomic barriers that could cause information overload, as well as cancer information non-seeking behavior. Further research is needed to investigate these barriers. Can physicians act as a catalyst to information seeking?

If so, how and when should a physician promote information-seeking? Is there an information gap in health literacy? Do cancer information seekers visit health insurance providers’ websites for information? If not, how can the insurance industry help promote and facilitate health literacy among its members? How can physicians and insurance companies help patients with lower education and income cross the gap, if there is one?

Future research can explore these questions to help devise health information literacy programs and outreach for cancer patients. Greater patient involvement in decision-making can provide more data to help develop cancer prevention and screening communications. By increasing communications, health providers and insurers can help balance health and information inequalities across socioeconomic groups and develop strong intervention programs. As the costs of medical care and insurance rise, information-seeking and effective prevention programs can help provide better health care at lower expense. Paying greater attention to non-seekers can help promote clinical decision-making in our ever-growing information society.
References


