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Cancer information and the Internet: Benefits and risks

ABSTRACT

The Internet has enormous potential to educate the public about health and medical care, but also can cause tremendous harm through erroneous, misleading, and deceptive information.

A REVOLUTION in communication has occurred over the past several years, as computers and the Internet have made information on an endless number of subjects quickly available to the public. Web sites about health-related topics are growing particularly rapidly, and hospitals, nonprofit and for-profit medical organizations, and private citizen groups are using Internet web sites to communicate with large numbers of people.

Cancer patients often learn about alternative therapies via the Internet

This exciting new technology has enormous potential to inform and educate the public about health and medical care, but it also has the potential to cause tremendous harm through erroneous, misleading, and deceptive information. Cancer information on the Internet is of particular concern. As patients and the general public increasingly look to the Internet as a source of information on cancer and general health, physicians must familiarize themselves with how the available information may benefit or negatively affect the welfare of their patients.

BENEFITS OF CANCER INFORMATION ON THE INTERNET

Therapy for a number of common cancers is not highly effective when they are found in advanced stages, and many antineoplastic treatments can produce considerable toxicity. Therefore, patients and their families often seek alternatives to the treatments recommended by their physicians. The Internet quickly and easily provides them with large quantities of information about cancer and its treatment.

Cancer-related web sites

Many cancer-related health organizations have web sites on the Internet. Examples include the American Cancer Society (http://www.cancer.org) and the National Cancer Institute (http://www.nci.nih.gov). Information available on these web sites includes:

- Descriptions of medical services: eg, unique technology, experimental trials, cancer screening programs, cancer support groups, public lectures on cancer-related topics.
- Data on individual physicians: eg, training, specialization, board certification.
- Descriptions of an institution's focus on cancer: eg, regular multidisciplinary cancer conferences discussing patient management.

Selecting a provider or institution

By examining the available services and physician qualifications, patients may find it easier to select the most appropriate provider and medical institution when cancer is suspected or documented. If an institution has the capacity to communicate with individuals on-line, the patient can ask about the institution's experience with a particular type of cancer. In addition, individuals can obtain information about specialized services for a specific tumor type (eg, stereotactic radiosurgery for brain metastasis, bone marrow transplantation for lymphoma) through direct communication with the provider.

Cancer support groups

Cancer support groups on the Internet can

inform patients about rational alternative treatments. For example, one support group may inform web site visitors that a particular institution or physician advocates or uses a less aggressive surgical procedure for a specific type of cancer, while another support group may offer helpful hints for dealing with specific toxicities of chemotherapy.

RISKS OF CANCER INFORMATION ON THE INTERNET

Unfortunately, the glut of information on the Internet comes with major, potentially harmful drawbacks. Of greatest concern is the complete lack of quality control for any information or advice provided. Well-recognized and highly respected health care organizations and experts in a particular medical discipline have no more inherent authority when viewed on a computer screen than a misinformed member of the public attempting to help others, or than individuals or groups engaged in health care fraud.

Two recent experiences in my practice provide poignant examples of the potential dangers of obtaining cancer information—and misinformation—via the Internet.

Misinformation

A patient with ovarian cancer came to me for a second opinion regarding treatment options. She was visibly upset. She felt her disease had not been diagnosed at an earlier stage because her gynecologist had "failed" to perform yearly screening tests for ovarian cancer, including vaginal ultrasound and serum CA-125 antigen levels. When I inquired why she thought screening for this disease was part of a regular gynecologic examination, or had been demonstrated to be effective in detecting ovarian cancer at an early stage, she said that her on-line support group provided this information. When I pointed out that, in fact, there is currently no reliable evidence to support routine screening for ovarian cancer,[1–3] she seemed quite surprised. "After all," she asked "how can so many people be wrong?"

The answer, of course, is that scientific objectivity has nothing to do with the number of people who claim the information is correct. The shark cartilage cancer-treatment phenomenon is an excellent example of this point.[4] Nevertheless, when people continue to repeat incorrect information, the conclusion may take on a life of its own. After all, how can so many people be wrong?

True information, but misleading conclusions

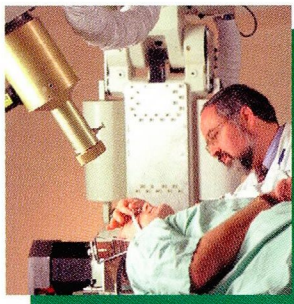
A second, even more troubling example is a man whose wife had been treated for ovarian cancer. Attempting to find the best possible treatment option for his wife, he performed an exhaustive on-line review of the medical literature on second-line chemotherapeutic options for this disease. After examining almost 200 phase-2 (ie, nonrandomized) trials conducted throughout the world over the past several decades, he concluded that more intensive, combined chemotherapy regimens attain higher response rates than single-agent treatment regimens and, therefore, are the best therapeutic option in this situation.

Unfortunately, these conclusions are unjustified and inappropriate. In general, more intensive treatment is reserved for patients in better physical condition, whereas patients in poorer condition receive less intensive, single-agent chemotherapy, because the toxicity of the more intensive strategies cannot be justified in patients with a poor physical status. Further, it has long been known that patients with superior pretherapy clinical characteristics (eg, minimal weight loss, few symptoms, no significant comorbid medical conditions) experience a more favorable outcome independent of specific anticancer therapy.[5]

Seriously ill patients are especially vulnerable to unfounded claims

The on-line databases this man reviewed are available to anyone with access to the Internet, and the impressive amount of clinical information has an air of authority about it, based on the exhaustive efforts to collect the data from trials conducted over several decades. But only well-designed, well-conducted randomized trials can directly compare the effectiveness of one therapeutic strategy with that of another. Comparing the results of small phase-2 trials performed at multiple institutions, with varying entry criteria, patient populations, and pretherapy prognostic factors, is inappropriate and tends to encourage highly misleading conclusions.[5]

The proprietor of this web site apparently did not understand this basic principle of clinical investigation, or simply chose to ignore it.



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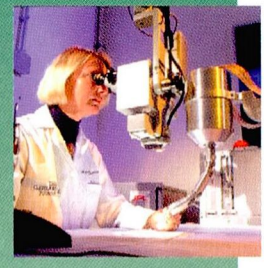

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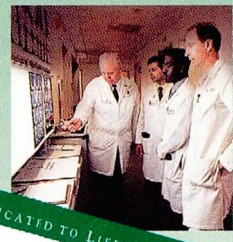

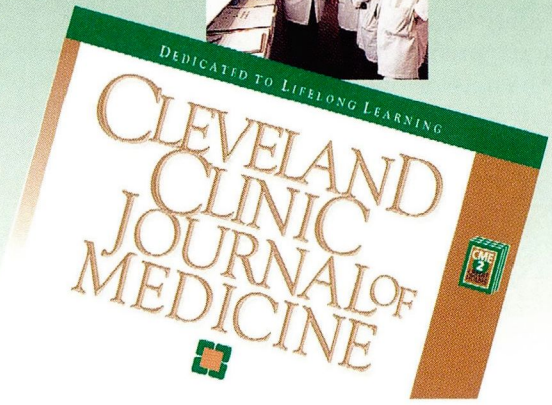

As a result, patients, families, and even physicians risk being misinformed, on the basis of the faulty conclusions from comparing the results of nonrandomized clinical studies. Patients with ovarian cancer who visit this web site are likely to request or even demand treatment that is more toxic, but not more effective.

BALANCING THE GOOD AND THE BAD

The problems with health information on the Internet are many. For example, the quantity of information provided and the technological sophistication of its presentation bear no relationship to the quality of the data and their interpretation. Also, there is no peer review of the scientific and clinical value of the vast quantities of on-line health information, just as there is no requirement for objectivity and balance in the presentation of risks and benefits of cancer treatment options and in claims about their effectiveness. Furthermore, seriously ill people, such as cancer patients, are particularly vulnerable to unsubstantiated claims about less toxic therapies and better overall outcomes.

Ultimately, the balance between benefit and harm from health information on the Internet is determined by how individuals choose to use the data, and by their understanding of the limitations of this mass communication tool. Physicians can help their patients deal with the complexities of this process by encouraging discussion of the information obtained from the Internet and by helping them to gauge the clinical relevance of the material in their particular disease.

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