Awareness of Sources of Peer-Reviewed Research Evidence on the Internet

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Evidence-based decision making (EBDM) is an initiative that seeks to facilitate the judicious, systematic, explicit, and conscientious consideration of the current best evidence from research to guide health-related decisions. This initiative is facing a series of barriers that hinder its implementation. Some of these barriers are associated with the decision makers (eg, lack of awareness or understanding of EBDM, lack of time), the evidence per se (eg, abundance, bias, imprecision, irrelevance), and the health care system (eg, poor infrastructure, lack of financial incentives, ineffective training programs).1

Since the introduction of the World Wide Web, many organizations promoting EBDM have used Internet-based resources to facilitate the dissemination, access, and use of the best available research evidence by anyone interested in health-related decisions.2 To our knowledge, there have been no systematic efforts to examine decision makers’ awareness of such resources and the organizations that sponsor them. We searched MEDLINE in January 1998 and October 2001, using the terms Internet, awareness (or survey), and evidence, and found no published study that addressed this issue.

The main objective of this study was to estimate and compare the levels of awareness of important sources of research evidence that can be found on the Internet by patients with cancer, their family physicians, oncologists, and oncology nurses. Cancer was selected as the focus for this study because it is a highly prevalent disease; has high mortality, morbidity, stress, and costs; and has been the focus of efforts to promote effective dissemination of treatment information through the Internet.

Methods

The study was based at the Hamilton Regional Cancer Centre (HRCC), a tertiary-level institution in Hamilton, Ontario, affiliated with the faculty of health sciences at McMaster University—the place where the term evidence-based medicine was coined, and the host of the Canadian Cochrane Centre and the Program in Evidence-Based Care (PEBC) of Cancer Care Ontario.

Three groups of patients attending the HRCC were randomly selected and surveyed at 6-month intervals from July 1998 through January 2000. Individual exclusions included if they were unable to speak or read English, if they were too ill to answer, or if they died within 2 weeks of the mailings. Eligible patients were assured that their participation was voluntary and that they would not be identified individually.

The survey was also administered during the first 12 months of the study to all clinical oncologists and oncology nurses affiliated with the institution. At each period, the questionnaire was offered to all family physicians listed as involved in the care of the study patients.

We selected 2 initiatives that provide information about the whole spectrum of health care (the Cochrane Collaboration, PubMed/MEDLINE) and 3 organizations that focus on cancer and...
its treatment (CancerNet, CancerLit, and the PEBC\(^3\)).

The questionnaire was developed with input from health professionals, researchers, and patients, with slight modifications to address each of the groups. The questionnaire asked for information on use of the Internet to find health information and awareness of initiatives promoting EBDM that have produced Internet-based resources to facilitate access to research evidence (TABLE). Participants were asked if they had heard of these sources, not if they had used them. The survey followed a modified Dillman method.\(^4\) Questionnaires were sent to oncologists and nurses through internal institutional mail and to patients and family physicians by post. All data gathering was completed on January 31, 2000.

Relevant comparisons of descriptive statistics were made between and within groups (Table) using \(\chi^2\) and Fisher exact tests (2-sided). \(P<.05\) was considered statistically significant. The statistical analysis was conducted using SAS v8.02 (SAS Institute Inc, Cary, NC).

### RESULTS

Response rates were 72%, 44%, 97%, and 84% for patients, family physicians, oncologists, and nurses, respectively; 47% of patients, 64% of family physicians, 72% of nurses, and 100% of oncologists reported using the Internet.

Of the Internet users, 63% of the patients were female, 67% were older than 50 years, and 51% (204/403) had education beyond high school; 22% of family physicians were women and 28% were older than 50 years; all nurses and 14% of oncologists were women, whereas both groups had similar proportions of people older than 50 years (15% and 11%, respectively).

Significantly fewer patients than clinicians reported that they looked for health information on the Internet (Table). Few patients were aware of the existence of the Cochrane Collaboration (1%), MEDLINE (13%), or the PEBC (3%). Among the health care professionals, oncologists had the highest reported levels of awareness of the sources of evidence on the Internet. As expected, oncology clinicians were significantly more aware about the existence of cancer-specific sources than family physicians. The only significant difference between oncologists and nurses was related to awareness of the Cochrane Collaboration and PubMed.

### COMMENT

This study shows that efforts to make research evidence available on the Internet remain unknown to many people involved in health-related decisions, regardless of their background. The results also suggest that there are major differences across groups, even within the same institution. The gap in Internet use between patients and health care professionals is wide.\(^5\)

Our findings could have at least a couple of explanations. First, it is possible that organizations promoting EBDM are not placing enough emphasis on efforts to make people aware of their existence. Second, most decision makers may not be interested in research evidence at all, being less prone to notice and remember organizations promoting EBDM.

Although the results of the study seem plausible, their validity may have been compromised by the small sample size for oncologists and nurses and by the relatively low response rate of family physicians. The response rate from the family physicians, although low, is typical of other surveys.\(^6\) The focus on a specialized cancer treatment facility also limits the generalizability of the results. We have initiated similar studies in other regions of Ontario, focusing on other health conditions. We encourage similar efforts by research groups in other parts of the world.

### Table. Response Rate, Use of the Internet, and Awareness of Research Evidence*

<table>
<thead>
<tr>
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<th>No. (%)</th>
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<tbody>
<tr>
<td></td>
<td>Patients</td>
</tr>
<tr>
<td>Response rate</td>
<td>1448/1998 (72)</td>
</tr>
<tr>
<td>Internet users</td>
<td>NA</td>
</tr>
<tr>
<td>Total</td>
<td>403/859 (47)</td>
</tr>
<tr>
<td>Women</td>
<td>252 (63)</td>
</tr>
<tr>
<td>Older than 50 y</td>
<td>271 (67)</td>
</tr>
<tr>
<td>Look for health info</td>
<td>134 (33)</td>
</tr>
<tr>
<td>Specific sources used</td>
<td></td>
</tr>
<tr>
<td>Cochrane Collaboration</td>
<td>6 (1)</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>52 (13)</td>
</tr>
<tr>
<td>PubMed</td>
<td>NA</td>
</tr>
<tr>
<td>Program in Evidence-Based Care, Cancer Care Ontario</td>
<td>13 (3)</td>
</tr>
<tr>
<td>CancerLit</td>
<td>NA</td>
</tr>
<tr>
<td>CancerNet</td>
<td>NA</td>
</tr>
</tbody>
</table>

*NA indicates not applicable.
†For comparison of family physicians, nurses, and oncologists.
‡For comparison of nurses and oncologists.
§By 2-sided Fisher exact test.
other limitation of this study is that it focused on awareness, not use, of the information produced by organizations promoting EBDM through Internet-based resources.

In summary, our findings suggest that the potential for the Internet to promote inexpensive, fast, and efficient access to the most up-to-date, valid, and relevant knowledge has not been realized. Unless organizations promoting EBDM make stronger and more effective efforts to help their target audiences become aware of their existence, the Internet may become a missed opportunity to help decision makers access evidence.

Author Contributions: Study concept and design: Jadad. Acquisition of data: Jadad, Sigouin. Analysis and interpretation of data: Jadad, Sigouin. Drafting of the manuscript: Jadad, Sigouin.

REFERENCES

Analysis of Cases of Harm Associated With Use of Health Information on the Internet

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The Internet has spawned a plethora of publications warning of potential harm, particularly regarding the inappropriate use of the Internet by patients and families. Potential risks can emanate from the use of irrelevant or inaccurate information1,2 or from misunderstanding relevant and valid information.3 In these cases, harm can be physical (eg, due to inappropriate treatments, adverse effects, or untreated disease), emotional (eg, from false hope or anxiety regarding unfounded diagnostic, prognostic, or therapeutic information), or financial (eg, expenses associated with unnecessary second opinions and purchase of inappropriate services or products).

Our objective was to conduct a systematic review to examine the number and characteristics of cases of harm associated with the use of health information available on the Internet.

Context There is concern about the potential harm associated with the use of poor quality health information on the Internet. To date, there have been no systematic attempts to examine reported cases of such harm.

Methods We conducted a systematic review of the peer-reviewed literature, to evaluate the number and characteristics of reported cases of harm associated with the use of health information obtained on the Internet. Using a refined strategy, we searched MEDLINE (from 1966 to February 2001), CINAHL (from 1982 to March 2001), HealthStar (from 1975 to December 2000), PsycINFO (from 1967 to March 2001), and EMBASE (from 1980 to March 2001). This was complemented with searches of reference lists. Two authors separately reviewed the abstracts to identify articles that describe at least 1 case of harm associated with the use of health information found on the Internet. Articles of any format and in any language deemed possibly relevant by either researcher were obtained and reviewed by both researchers.

Results The search yielded 1512 abstracts. Of these 186 papers were reviewed in full text. Of these, 3 articles satisfied the selection criteria. One article described 2 cases in which improper Internet searches led to emotional harm. The second article described dogs being poisoned because of misinformation obtained on the Internet. The third article described hepatorenal failure in an oncology patient who obtained misinformation about the use of medication on the Internet.

Conclusions Despite the popularity of publications warning of the potential harm associated with using health information from the Internet, our search found few reported cases of harm. This may be due to an actual low risk for harm associated with the use of information available on the Internet, to underreporting of cases, or to bias.