

# The Impact of the Internet on Cancer Outcomes

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**ABSTRACT** Each day, more than 12.5 million health-related computer searches are conducted on the World Wide Web. Based on a meta-analysis of 24 published surveys, the author estimates that in the developed world, about 39% of persons with cancer are using the Internet, and approximately 2.3 million persons living with cancer worldwide are online. In addition, 15% to 20% of persons with cancer use the Internet “indirectly” through family and friends. Based on a comprehensive review of the literature, the available evidence on how persons with cancer are using the Internet and the effect of Internet use on persons with cancer is summarized. The author distinguishes four areas of Internet use: communication (electronic mail), community (virtual support groups), content (health information on the World Wide Web), and e-commerce. A conceptual framework summarizing the factors involved in a possible link between Internet use and cancer outcomes is presented, and future areas for research are highlighted. (*CA Cancer J Clin* 2003;53:356–371.) © American Cancer Society, 2003.

## INTRODUCTION

The recent “First International Conference on Cancer and the Internet,” organized by the European School of Oncology and held in New York, had the subtitle “What Is the Impact of the Internet on Cancer Outcomes?” A similar question was posed in a recent news article in this journal.<sup>1</sup>

The current article, an expanded version of the opening keynote speech of that conference, is an attempt to synthesize the available literature published in the realm of “cancer and the Internet” and to put available evidence into a larger context. It is based on a comprehensive review of studies published in the field (for my search strategy, see the Appendix). The aim of this article is to summarize how persons living with cancer are using the Internet, to describe the possible effect on cancer outcomes, and to provide a framework for current and future research in this area.

## WHO USES THE INTERNET?

As of September 2002, one meta-analysis of different global surveys estimates that 606 million persons are online worldwide,<sup>2</sup> which represents approximately 10% of the world population. Although in the past the Internet was used predominantly by North Americans, this has recently changed in terms of absolute numbers: Europeans now constitute the largest user group (191 million), followed by Asian/Pacific (187 million), and Canadian and U.S. (183 million) users. Latin America (33 million), Africa (6 million), and the Middle East (5 million) constitute the developing world when it comes to both the number of absolute users and Internet penetration.

### Persons Living With Cancer

#### *How Many Are Online?*

How many of these millions of Internet users are persons with cancer? One crude way to estimate this number is to multiply the number of persons with cancer worldwide, which is, according to the World Cancer Report,

Based on an opening keynote speech delivered at the first conference on Cancer and the Internet, organized by the European School of Oncology, New York, New York, July 2003.

approximately 22 million,<sup>3</sup> by the global proportion of persons using the Internet (which is, as noted previously, approximately 10%), which would lead to an estimate of about 2.2 million persons with cancer online. However, we know that persons living with cancer are older than the general population, and in this age group Internet use is less common than in a younger population, so this might lead to an overestimate. On the other hand, cancer is more prevalent in the developed world, where people generally have better Internet access, so that taking the global proportion of Internet users of 10% might lead to an underestimate.

A more accurate way may be to focus our discussion on the industrialized world. We can estimate the proportion of persons with cancer who are using the Internet in the industrialized world based on published surveys among persons with cancer, and multiply this by the number of persons with cancer in the developed world. I conducted a systematic review of all studies containing data on the proportion of persons with cancer who are using the Internet (see the appendix for the search strategy).

The Table is a compilation of the 24 identified surveys that contain data on the proportion of persons with cancer who are Internet users.<sup>4-27</sup> Taken together, these studies surveyed 8,697 persons with cancer. The average proportion of Internet users is 39%. Interestingly, this figure corresponds well with what oncologists estimate when asked what proportion of their patients use the Internet: 30%.<sup>11</sup> If we assume that the developed world contains approximately 6 million persons living with cancer, and if we further believe that about 39% of them are online, this would translate into approximately 2.3 million persons with cancer online, an estimate that is not far from our first figure.

The Table also shows that the proportions across studies vary considerably, ranging from 4% to 58%. This partly reflects that these surveys were conducted in different countries over different periods in time. Another reason for the variability is that no standard operational definition of an "Internet user" exists, and different studies may have measured differ-

ent things. Some surveys frame their question as "Do you have access to the Internet," others ask "Do you use the Internet," "Do you use the Internet regularly," "Do you use the Internet for cancer information," or "Which of the following information sources are your primary source of information." How different questions may lead to different answers can be seen in one study, in which 35% of patients said they had access to the Internet, but only 6% said that they had sought cancer information on the Internet.<sup>13</sup>

A further reason for the heterogeneity of results across surveys is that "cancer is not cancer," and significant differences in Internet use according to diagnosis exist. In one study, in which different groups of persons with cancer were surveyed using the same instrument, highly significant differences in utilization of the Internet by diagnosis were observed: 16% of lung patients, 18% of head-and-neck patients, 27% of prostate patients, 34% of breast patients, and 45% of gynecologic patients reported using the Internet to obtain cancer-related information.<sup>20</sup> This partly reflects demographic differences between the cancer types: We know from many studies that women are more active health seekers than men,<sup>28,29</sup> and that younger age<sup>7,9,10,12,14,16,20,21,24</sup> is also associated with greater Internet use. Therefore, age and sex are confounders when comparing Internet use, and it is unclear whether differences between diagnostic groups are mainly a result of demographic differences or whether they remain significant when adjusted for patient age and sex.

In addition, well-known socioeconomic predictors for Internet use or nonuse, that is, factors contributing to the "digital divide,"<sup>30,31</sup> also cut across the population of persons with cancer: those using the Internet are mostly better educated<sup>6,7,14,19,21,24</sup> and have a higher income<sup>6,14,19</sup> than nonusers, and they are more likely white.<sup>6,16</sup> Metz, et al.<sup>20</sup> and Smith, et al.<sup>16</sup> found very large differences in Internet use between a cancer patient population from an academic center (48%) and a VA hospital (8%), which again might be due to differences in socioeconomic status between the hospital populations.

TABLE 1

Published Survey Data About the Proportions of Internet Users Among Persons With Cancer							
Study	Country	Year	%	Proportion Refers to	Setting	n	Response Rate (%)
Chen and Siu, <sup>4</sup> 2001	Canada	2000	50 (7)	Ambulatory cancer patients using the Internet Ambulatory cancer patients citing the Internet as primary information source	Major cancer hospital	191	NR
Jadad, et al. <sup>5</sup> 2001	Canada	1998	47	Cancer patients reporting regular use of Internet	Regional Cancer Centre	1001	74
		1999	51			496	71
		2000	51			501	71
Fogel, et al. <sup>6</sup> 2002	USA	2000	42	Breast cancer patients using the Internet	University hospital	188	74.9
Pereira, et al. <sup>7</sup> 2000	Canada	1999	43	Breast cancer patients having looked for cancer-related information	Cancer care center	107	15
Ranson, et al. <sup>8</sup> 2003	USA	2001/2002	44	Cancer patients (mainly breast cancer) using the Internet	Nearly 100 Community Clinical Oncology Program Facilities	925	91
Norum, et al. <sup>9</sup> 2001	Norway	2001	36	Cancer patients using the Internet	University Hospital (outpatients)	31	NR
Norum, et al. <sup>10</sup> 2003	Norway	2001/2002	33	Cancer patients having searched for medial information to the Internet	University Hospital (outpatients)	127	NR
Helft, et al. <sup>11</sup> 2003	USA	2001	(30)	Median of oncologists estimates on "what percentage of your patients obtain information about cancer from the Internet"	Members of ASCO	266	46.2
Mills and Davidson, <sup>12</sup> 2002	Ireland	NR	10	Colorectal, lung, breast, prostate, gynecological, or gastric cancer patients having used the Internet	NR	430	NR
Carlsson, <sup>13</sup> 2000	Sweden	NR	35 (6)	Cancer patients having access to the Internet Cancer patients having used the Internet as information source	University Hospital	142	74
Satterlund, et al. <sup>14</sup> 2003	USA	1999–2002	49	Breast cancer patients 3 months after diagnosis, using the Internet to gather any information about their disease.	Regional Cancer Centre, in context of clinical trial	224	77
			40	Breast cancer patients 16 months after diagnosis, using the Internet to gather any information about their disease.		217	
Diefenbach, et al. <sup>15</sup> 2002	USA	NR	45 (7)	Early-stage prostate cancer patients having used the Internet as information source Prostate cancer patients reporting Internet as most important reason for making specific treatment decision	Cancer Center	654	72
Smith, et al. <sup>16*</sup> 2003	USA	NR	(32)	Prostate cancer patients using the Internet	Radiation Oncology Centres—Total	295	99
			48		Academic centre	171	
			8		VA Hospital	104	
			20		Community hospital	20	
Brotherton, et al. <sup>17</sup> 2002	Australia	1999	33	Oncology patients having accessed Internet for information related to their illness personally or through proxy	Teaching hospitals	142	59
		2001				153	NR
		2001				153	NR
Raupach and Hiller, <sup>18</sup> 2002	Australia	1999	46 4	Breast cancer patients who received information within the previous 6 months via the Internet	Major tertiary hospital	217	82
Peterson and Fretz, <sup>19</sup> 2003	USA	NR	16	Thoracic oncology patients seeking information on the Internet	Cancer Centre, thoracic oncology clinic	139	76
Metz, et al. <sup>20</sup> 2003*	USA	NR	(29)	Cancer patients (mainly prostate, lung, and breast cancer) using the Internet to find cancer-related information—total	Radiation Oncology Centres—total	921	99
			42		Academic centre	436	
			5		VA Hospital	201	
			25		Community hospital	284	

TABLE 1 (Continued)

Published Survey Data About the Proportions of Internet Users Among Persons With Cancer							
Study	Country	Year	%	Proportion Refers to	Setting	n	Response Rate (%)
Yakren, et al. <sup>21</sup> 2001	USA	NR	44	Cancer patients using the Internet to obtain cancer-related information	Cancer Center	223	71
Vordermark, et al. <sup>22</sup> 2000	Germany	2000	12 (15)	Radiation oncology patients using the Internet directly Radiation oncology patients using the Internet indirectly	University Hospital	139	95
Hellawell, et al. <sup>23</sup> 2000	UK	NR	24	Prostate cancer patients using the Internet	Prostate Cancer Clinic	143	73
Pautler, et al. <sup>24</sup> 2001	Canada	1999	35 (29)	Prostate cancer patients having used the Internet Prostate cancer patients having used the Internet to obtain information about p.c.	Mailed questionnaire	335	68
Fleisher, et al. <sup>25</sup> 2002	USA	2000-2002	44 (21)	Cancer patients being "direct" users of the Internet Cancer patients being "indirect" users (via proxy) of the Internet	Cancer Information Service callers	357	87
Monnier, et al. <sup>26</sup> 2002	USA	NR	58 (80)	Cancer patients having used the Internet Cancer patients reporting that family members had used the Internet	Cancer centre clinics	319	NR
Duffy, et al. <sup>27</sup> 2000	Australia	1998	32	Oncology patients seeking information from the Internet about the diagnosis and management	Radiotherapy Clinic	169	97

Proportions in parentheses were not included in the pooled analysis. NR = not reported.

\*Smith<sup>16</sup> presumably reports a population subset of the study reported by Metz.<sup>20</sup>

### *What Is the Role of the Internet as an Information Source for Patients Compared With Other Media?*

Although in some studies the Internet is cited as the second most important source for cancer information after health professionals,<sup>14,19</sup> it may play a somewhat less important role when it comes to making important treatment decisions in cancer: When asked for the most important factor influencing their treatment decision, men with prostate cancer indicated that physician recommendation (51%), advice from friends and family (19%), and information obtained from books and journals (18%) were more often the most important source, with the Internet cited by only 7%.<sup>15</sup>

Still, for those who use the Internet, information found there certainly influences their decisions, and patients are highly satisfied with the Internet as an information source compared with other media. Raupach and Hiller<sup>18</sup> report that persons with breast cancer were mostly satisfied with information from the Internet

(89%), with lower proportions of patients satisfied with that from television (46%), newspapers (52%), magazines (58%), and radio (60%).

It is also interesting to note that, according to one longitudinal study of persons with breast cancer, the Internet remains an important source of information years after diagnosis, whereas other sources of information such as health professionals or books quickly become less important after the initial phase of diagnosis.<sup>14</sup> It is likely that the ongoing social support provided by Internet communities and the ability to keep up-to-date with recent medical news accounts for this.

### *What About Internet Access of Family Members?*

In addition to the estimated 2.3 million persons with cancer online, an unknown number of friends and relatives of these patients use the Web. Yakren, et al.<sup>21</sup> report that 60% of patient companions used the Internet. An often-neglected phenomenon is that many persons with cancer may not actually use the Internet

themselves (“direct users”), but rather use their companions (eg, husband or wife, children, or friends) to search and retrieve information or to communicate through e-mail (“indirect users”). It can be estimated that 15%<sup>22</sup> to 20%<sup>25</sup> of persons living with cancer are indirect users. With time, indirect users often become direct users.<sup>25</sup>

#### *What Do These Statistics Not Tell Us?*

Approximately 39% of persons with cancer use the Internet directly, and an additional 15% to 20% use it indirectly. However, we realize that this statement may be insufficient to describe the reality, as Internet access or use is not a dichotomous variable, but in fact a quantitative and qualitative continuum.<sup>32</sup> For direct users, conditions of access (physical accessibility at home or in a library, costs, convenience, and filters), computer literacy and search skills, as well as health literacy are factors that influence Internet use quantitatively and qualitatively. If the Internet access is indirect through proxy persons such as family and friends, the degree to which the proxy persons become active and supply information to the patient varies widely, as does the degree to which the information is preselected and filtered through the proxy. Surveys asking dichotomous questions do not capture and reflect these qualitative differences sufficiently. As Internet use becomes more and more common, new measures will have to be found to describe Internet use on meaningful ordinal or continuous scales.

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#### HOW ARE PERSONS WITH CANCER USING THE INTERNET?

To determine what patients and their families are doing on the Internet and what the effect on cancer outcomes might be, it is helpful to distinguish four broad application areas of the Internet.

- **Communication:** e-mail, instant messaging, voice-over-IP (Internet protocol)
- **Content:** health information on the World Wide Web

- **Community:** bulletin board systems, mailing lists, newsgroup/usenet groups, chat-rooms, Web sites with community features
- **e-Commerce:** selling or buying products and services on the Internet

Figure 1 shows a conceptual framework of how these areas are related to each other and depicts hypothesized intermediary steps and factors involved in influencing cancer outcomes (e-commerce was left out).

#### **Communication**

It is e-mail, and not the millions of Web pages on the World Wide Web, that Internet users rank as the number one reason for being online.<sup>33</sup> An astounding 31 billion e-mail messages are exchanged daily world wide,<sup>34</sup> with no data available on what proportion is health related (however, we know that 40% of all e-mail messages exchanged are spam,<sup>34</sup> and most spam messages actually refer to health-related issues such as vitamins, breast augmentation, penis enlargement, weight loss, Viagra, and so forth). For persons with cancer, e-mail communication is important for staying in touch with friends and family, forming new social networks (virtual communities, see below), and communicating with health professionals. Although the former two areas are heavily used, there is a huge gap between demand and supply in electronic physician-patient communication. Survey after survey shows that although patients desperately wish to communicate by e-mail with physicians, in the United States only 6% to 9% of patients have done so.<sup>28,29,35,36</sup> It would, however, be an oversimplification to portray physicians simply as technophobes unwilling or incapable of using e-mail. In fact, most physicians use e-mail to communicate with their colleagues and privately,<sup>37</sup> and one survey shows that as many as 75% of physicians have in fact used e-mail with patients, although only with a very select subset (1% to 5%) of their patients.<sup>38</sup> The reasons why physicians have not yet adopted e-mail on a wider scale to communicate with their patients are more complex than technophobia, and include fear of increased demand on physician time (particularly with overuse of e-mail by



minutes to read and reply to a patient e-mail,<sup>42</sup> 100 patient e-mails per day would easily require an additional staff member who does nothing but reply to e-mails. Would money spent for this additional time be better invested in face-to-face communication, or, for example, in a telephone triage system? As Patt, et al.<sup>39</sup> have noted, the only controlled trial implementing e-mail communication between physicians and patients revealed no significant reduction in the volume of telephone communication,<sup>43</sup> indicating that e-mail is used in addition to existing services, not as a replacement, which may not be cost-effective. Other studies have come to more favorable conclusions about e-mail communication.<sup>44</sup> Much research to evaluate e-mail as a tool for clinical communication remains to be conducted.

#### **Communication With Physicians in the Absence of a Patient-Physician Relationship**

In the absence of any formal e-mail communication channels offered by the traditional health care system, patients have found other ways to satisfy their need to communicate electronically with health professionals. One avenue is to use "cyberdocs," health professionals or other persons offering e-mail advice for money on the Web.<sup>45</sup> Another, perhaps more widely used avenue are unsolicited e-mails sent to physicians.<sup>46</sup> In one study, 50% of physicians were in fact tempted to respond to such an e-mail inquiry from an unknown patient,<sup>47</sup> despite possible liability consequences.<sup>48,49</sup> Guidelines for this so-called "type A" communication (in the absence of a pre-existing patient-physician relationship) have been proposed,<sup>50,51</sup> but this kind of "cybermedicine" remains a gray area. Recently, a woman filed a lawsuit against a radiologist, whose e-mail address she found on a hospital Web site and whom she asked a seemingly casual question via e-mail. The radiologist responded with a quick e-mail trying to help. The woman later turned out to have cancer and claimed to have been harmed by the advice she received, and she sued the radiologist.<sup>52</sup>

In summary, physician-patient e-mail communication is a challenging area in health communication, with many unresolved questions,

most significantly the cost-effectiveness of introducing electronic physician-patient communication into routine clinical practice. E-mail is likely to be useful and cost-effective only for a quite narrow set of scenarios and conditions, which could be covered by health and social insurance plans. For the remaining situations, e-mail is going to be offered by physicians as an additional service for which patients may have to pay or co-pay for out of their own pockets. Electronic communication might also become an integral part of the "e-end" of health services, with a hospital providing Web-based medical records online and patients having the chance to review them, supply additional information, or enter the communication module to ask questions.

#### **Community**

##### *What Are Virtual Communities?*

Virtual communities are "social aggregations that emerge from the Net when enough people carry on ... public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace."<sup>53</sup> Virtual communities are therefore social networks formed or facilitated through electronic media.<sup>54</sup> In the health context, they may also be referred to as electronic support groups (ESGs). As of August 2003, Yahoo!Groups lists 22,000 support groups in the Health & Wellness section, among them at least 280 cancer groups. Although most ESGs are actually mailing lists, other synchronous (real-time) community venues exist. For example, on Web sites such as cancerpage.com, online support groups meet on designated days and at designated times in chat rooms. Although most ESGs are unmoderated, some are facilitated by trained professionals, either oncology nurses, counselors, or cancer survivors involved in offline support.

Among the most comprehensive online resource for electronic cancer support groups is the Association of Cancer Online Resources (ACOR), founded by Gilles Frydman. After his wife was diagnosed with breast cancer, Frydman used a breast cancer mailing list, which eventually led him to the conclusion that his wife's physician

was recommending a far too radical course of treatment, and he sought a second opinion. He was so impressed with the information he found on mailing lists that he tried to create a clearing-house for mailing lists.<sup>55</sup> As of March 2003, the Web site (<http://www.acor.org>) hosts 235 cancer mailing lists, with 115,000 messages exchanged per day.

#### *What Kinds of Messages Are Exchanged in These Virtual Communities?*

According to a content analysis study of an electronic cancer support group, 80% of messages contain information giving or seeking personal opinions, encouragement and support, and personal experiences, whereas the remaining 20% contained thanks, humor, and prayers.<sup>56</sup> An emphasis on the two pillars "information" and "support" was also found in other content analysis studies,<sup>57,58</sup> mirroring findings from the literature on face-to-face self-help support groups.<sup>59</sup> Klemm notes interesting gender differences in the content of the messages, with women engaging in supportive messages more frequently than men, who used the electronic community primarily for information exchange,<sup>60</sup> which again is similar to findings from face-to-face groups.<sup>59</sup>

It has been suggested that virtual communities present an excellent opportunity for researchers to learn about preferences and experiences of patients, provided that the material it is obtained in an ethical manner.<sup>61</sup> Content analysis of these messages can be a rich source for researchers interested in understanding the experiences and views of interested persons and patients, and it is a largely untapped opportunity for health researchers to analyze where and why gaps exist between evidence-based medicine and consumer behavior and expectations. Such research may elicit a wealth of valuable data that may inform priorities for research, health communication, and education.<sup>61</sup>

#### *What Are the Advantages and Disadvantages of ESGs Over Face-to-Face Groups?*

The advantages of virtual communities over face-to-face groups include absence of geo-

graphic and transport barriers; anonymity for stigmatizing, embarrassing, or sensitive issues; increasing self-disclosure; encouraging honesty and intimacy; and that even patients with rare diseases can find peers online. Electronic support groups seem to attract more men than traditional face-to-face support groups, where women outnumber men four to one.<sup>59</sup> The anonymity of virtual communities may facilitate the participation of men, who may be culturally and socially conditioned not to ask for help and support.

The disadvantages of virtual communities include a large volume of mail with a considerable amount of "noise," negative emotions ("flaming"), and lack of physical contact and proximity.<sup>62</sup> As with content on the Web, there have been concerns over inaccurate or "non-evidence-based" information exchanged in virtual communities.<sup>63,64</sup> A recent topic analysis of messages from a mailing list for brain tumor patients found that alternative treatments were the most frequently discussed topics (15%), followed by debates about therapeutic strategy and symptoms.<sup>65</sup>

#### *What Is the Effect of Virtual Communities on Well-being and Health Outcomes?*

I believe virtual communities are probably the one Internet application area with the greatest effect on persons with cancer. Anecdotal reports from patients support the notion that they can benefit enormously from these interactions.<sup>55,66,67</sup>

There is an ongoing debate on whether electronic communities in fact lead to social isolation and reduced well-being rather than a strengthening of social support. These concerns are based mainly on the controversial "Internet paradox" publication reporting results from a longitudinal study of the effect of the HomeNet project at Carnegie Mellon University, where 169 persons were provided free computers and Internet access and followed for a period of 1 to 2 years. The study provided alarming evidence of the possible harmful effects of Internet use.<sup>68</sup> The paradox was that a "social technology" (e-mail, newsgroups, and chatrooms) used primarily for interpersonal interaction apparently increased social



isolation and decreased mental health and psychological well being among its users. Heavy Internet use was associated with increases in loneliness and depression and tended to increase stress. To explain the paradox, the researchers reasoned that superficial relationships (weak ties) formed online displaced meaningful relationships (strong ties) in the real world.

It should be noted that the HomeNet study was conducted with healthy participants and not with persons with cancer. However, in a cross-sectional study looking at persons living with cancer in an ESG (14 men with prostate cancer, 2 of whom were receiving active treatment) and a face-to-face group (26 men and women with “different cancer diagnoses,” 14 of whom were undergoing active treatment), Klemm and Hardie<sup>69</sup> noted a significant higher proportion of depressed persons with cancer in ESGs (92%) compared with no depressed participants in face-to-face cancer support groups. Does this mean that ESG participation causes depression? Or that face-to-face groups reduce depression, whereas ESGs do not? Or only that depressed persons are turning primarily to electronic groups while staying away from face-to-face groups? Obviously, an association does not tell us anything about the causation sequence, and the latter explanation (selection bias of the study participants) might be the most plausible explanation for this finding. Longitudinal studies or randomized trials are needed to investigate this question further.

Conversely, there are many patient narratives<sup>55,66,67</sup> and studies reporting benefits for persons with cancer that are incompatible with the notion that Internet use leads to depression. Fogel, et al.<sup>70,71</sup> reports that Internet use in persons with breast cancer is associated with increased perceived social support and decreased loneliness. The most impressive study to date, a randomized controlled trial with recipients of a breast cancer mailing list, suggests that a Web-based support group can be useful in reducing depression and cancer-related trauma as well as perceived stress.<sup>72</sup>

In summary, the overall “net benefits” of virtual communities, in particular in the health context and even more specifically for persons with cancer, are unclear, and there is a lack of

high-quality controlled trials addressing these questions.<sup>59</sup> It is likely that most persons with cancer benefit from virtual communities, whereas a minority may prefer local face-to-face support and might not feel comfortable using computers to build social relationships. In fact, when the authors of the original Internet paradox publication recently revisited their HomeNet study population after three years, which is now more experienced with Internet and computers, higher Internet use was associated with lower depression, and no significant association with loneliness was observed. The authors speculate that the negative findings from the early study phase might have been only a result of the novelty of the Internet and due to the fact that the nature of the Internet in these early years of the Web was different. The authors have also expanded their analysis and now argue that Internet use has positive effects on well-being for extraverted, highly sociable persons, who have existing social support in “real life,” whereas the opposite is true for introverted persons, where the Web might interfere in real life relationships.<sup>73</sup> Persons living with cancer participate more in online communities when they perceive that support received from a face-to-face partner is low.<sup>74</sup> In this situation, it is unlikely that time spent to build a virtual support network compromises local support, in particular as some ESGs actually lead to face-to-face meetings and “virtual” interactions can turn into strong and long-lasting social and emotional support relationships.

### Content

The third pillar of the Internet is provision of information (“content”), most notably on the Web, but, as noted before, also through communities.

#### *Why Are Patients Turning to Web Information?*

Most patients seek explanatory information about their cancer or treatment, especially just after their diagnosis and before starting treatment.<sup>75</sup> However, health professionals frequently

fail to meet their patients' information needs fully. In one study, 48% of persons with cancer reported that they had insufficient information;<sup>76</sup> in another survey, 20% were not satisfied with the information given.<sup>77</sup> Two surveys reported that 87% of patients stated that they want as much information as possible,<sup>4,78</sup> and almost 54% of these patients did not feel that their physicians and other health care workers provided them with adequate information.<sup>4</sup> In another study, 39% of persons with breast cancer indicated that they "wished that they had help with knowing what questions to ask."<sup>79</sup>

Is it this degree of dissatisfaction with insufficient information received from health care professionals that makes patients turn to the Web? Indeed, persons with breast cancer who had used the Internet were less satisfied with the amount of treatment-related information they received from caregivers than were those patients who had not used the Internet.<sup>7</sup> Although this could indicate that dissatisfied patients are more likely to turn to the Internet, it may also mean that the expectations of Internet patients have changed in a sense that they become more dissatisfied than non-Internet users when they realize how much information is out there that they *should* have received.

Dissatisfaction with information is not the only reason why patients turn to the Web: Searching for information has also been described as a coping strategy.<sup>80</sup> Persons living with cancer may be completely happy with the amount of information they received but still wish to reassure themselves that they have every bit of information available.

#### *What Is the Prevalence of Health-Related Searches on the Web?*

This enormous thirst for information translates into millions of Web searches conducted every day on the Internet. Based on my research with Kohler, we estimate that approximately 4.5% of all searches on the Web might be health related.<sup>81</sup> Although this appears to be a relatively small proportion, the absolute numbers are still impressive: Google, a search engine with a usage share of 54%,<sup>82</sup> reports 150 million searches per day on all regional partner

sites combined. Based on this, we estimate that on a global level, 278 million Internet searches are being conducted every day, of which approximately 12.5 million searches are health related. No data are available on how many of these are cancer related.

#### *What Is the Effect of Information on Persons With Cancer?*

Provision of information to persons with cancer has been shown to help patients gain control, reduce anxiety, improve compliance, create realistic expectations, promote self-care and participation, and generate feelings of safety and security.<sup>83,84</sup> Satisfaction with information has been shown to correlate with quality of life,<sup>85</sup> and patients who feel satisfied with the adequacy of information given are more likely to feel happy with their level of participation in the overall process of decision making.<sup>76</sup>

Although more than 15 randomized trials have evaluated interventions to provide information to persons with cancer,<sup>86</sup> most focus on evaluating the effect of providing printed patient education pamphlets or computer-based personalized<sup>87</sup> information to patients. Relatively little is known about the effects of general undirected "chaotic" Internet information on persons with cancer.

Fleisher<sup>25</sup> reports a strong relationship between Internet use and both self-efficacy (confidence in remaining independent and being able to make treatment decisions) and patient task behavior. Most persons (92%) believed that getting Internet health information made them feel empowered to make decisions about their health. Most (91%) also believed that the information helped them talk to their physicians about their health. Having access to Internet health information has a direct relation to having the confidence to ask questions to a physician and to a perceived "partnership" relation with a physician. Despite these perceived positive aspects of using Internet health information, some users also felt that getting the information could be overwhelming (31%), that information on the Web made them aware of conflicting medical information about their

cancer (76%), and that getting Internet health information made them confused about the right course of cancer treatment (27%).

Although most oncologists agree that in general Internet information increases the level of understanding of patients,<sup>11</sup> they also warn that patients' understanding of information is only "sometimes" or even "rarely" correct,<sup>4</sup> and that Internet information also increases the patients' level of confusion and anxiety.<sup>11</sup>

Most physicians embrace the accessibility of health information on the Web as a positive development,<sup>4,11,88</sup> but an important minority (9%, in one study) felt that it has, in fact, worsened the patient-physician relationship because patients challenge their physicians' authority, patients' requests are not always appropriate for their health, and patients bring information to consultations and interfere with the physicians' time efficiency.<sup>89</sup> Nearly all (95%) oncologists agree that time spent discussing Internet information has increased in the past 5 years; almost one half admit that they sometimes (38%), most of the time (5%), or always (1%) had difficulty discussing Internet information, with 9% of oncologists sometimes or always feeling threatened when patients brought Internet information for discussion.<sup>11</sup>

#### *What Is the Quality of Cancer Information on the Web?*

Most persons with cancer who use the Web have a positive subjective quality experience, especially younger patients.<sup>12</sup> Most consider information on the Web either very reliable (22%) or somewhat reliable (70%).<sup>20</sup> In another survey, 52% from a general (healthy) population who have visited health sites think that "almost all" or "most" health information they see on the Internet is credible.<sup>29</sup> Physicians view the quality of health information on the Web slightly more critically: They report that the last time a patient brought Internet information it was very (8%) or somewhat (66%) accurate, whereas 26% said it was not very or not at all accurate.<sup>88</sup>

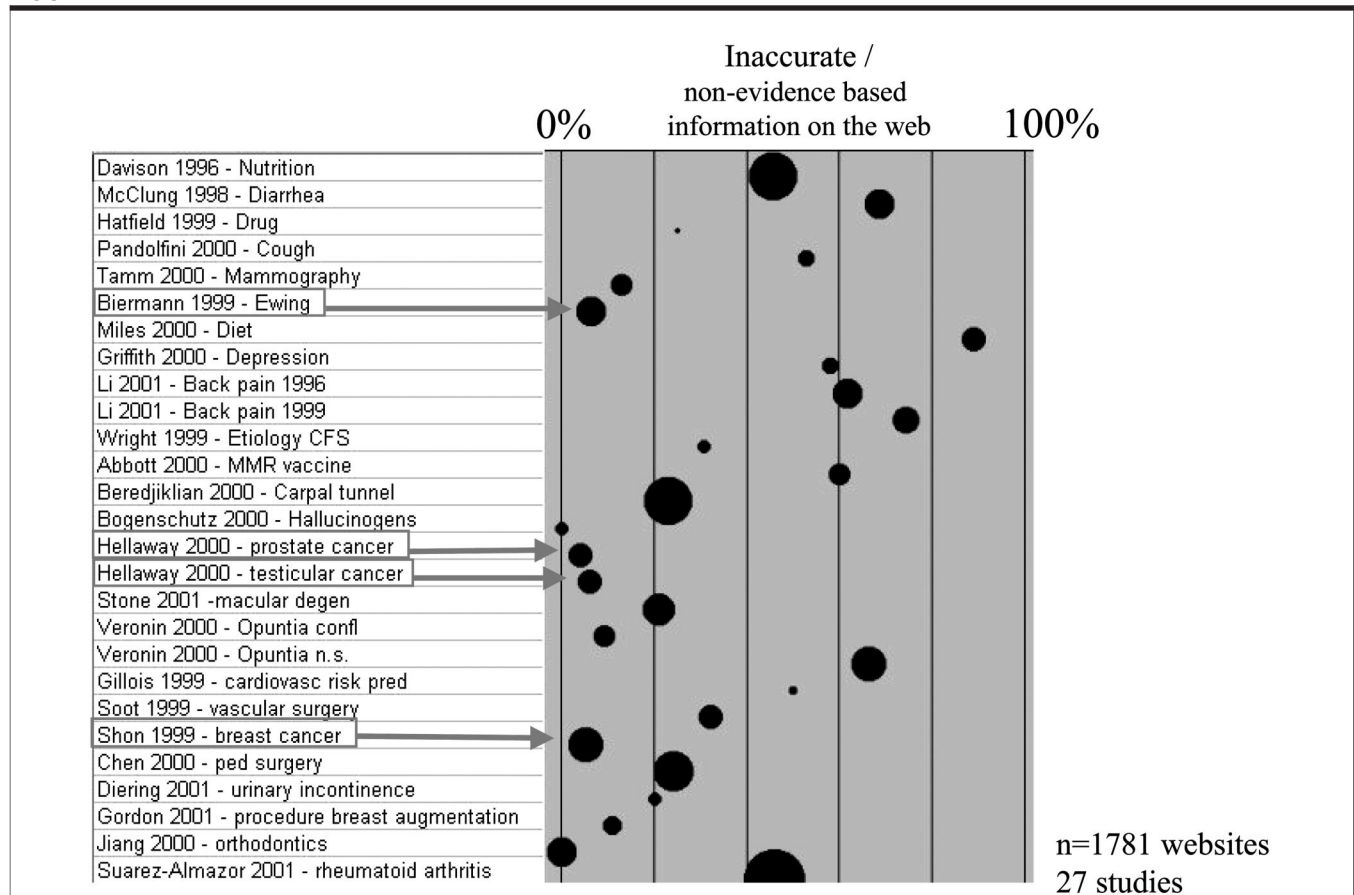
A systematic review of 79 published studies on the quality of health information on the Web revealed that the view of most medical

experts who systematically evaluated information on the Web is even more unfavorable.<sup>90</sup> However, as noted in the review, most study authors did so mainly on grounds of criticizing insufficient disclosure/disclaimer information or other technical criteria (which has little to do with information accuracy), or lack of completeness of information (which is a different concept than "accuracy" and of questionable relevance on the Web). Measuring completeness might make sense for a printed pamphlet, but it is not an appropriate evaluation criterion for Web-based information, because Web sites may deliberately and with good reason focus on a single topic in-depth rather than aim for comprehensiveness, and consumers will usually search across different Web sites when looking for specific health information.<sup>90</sup>

It is also a noteworthy finding from this review that the quality of cancer information on the Web, compared with other topic areas, is not so bad after all. Studies evaluating the accuracy of cancer sites have found inaccuracy rates on the order of 5%: 4% for prostate cancer,<sup>23</sup> 5.1% for breast cancer,<sup>91</sup> 9% English or 4% Spanish breast cancer documents,<sup>92</sup> 6% for testicular cancer,<sup>23</sup> and 6.2% for Ewing sarcoma.<sup>93</sup> Compared with other areas such as diet and nutrition for which authors have found 45.5%<sup>94</sup> or 88.9%<sup>95</sup> inaccurate information, such prevalence figures seem low (Figure 2). Published rates of inaccurate or incomplete information in other media are not less disturbing,<sup>90,96</sup> and little evidence supports the notion that information found on the Web is worse than in other media. For example, two of four inaccuracies found on the Web by Biermann, et al.<sup>93</sup> are in fact inaccuracies that exist in a printed publication as well.<sup>90</sup>

Comparisons of the proportions of inaccurate information across different topic areas, such as presented in Figure 2, must be interpreted carefully, because the search strategy is a major confounder influencing the quality of the retrieved information (for example, entering the key words "rapid and guaranteed cure for cancer" would elicit qualitatively different results than entering "cancer therapy"). For this reason, it is virtually impossible to get a "representative" estimate of the prevalence of inaccurate cancer information,

FIGURE 2



Prevalence figures of inaccurate information on the Web, based on data from a recent systematic review.<sup>90</sup> The size of the dot represents the number of Web sites or Web pages authors evaluated. The four highlighted studies looking at cancer information found comparably low prevalence values of approximately 5%.

because it also depends on the search skills and filtering abilities of the user. In other words, the proportion of low-quality information on the Web is only one factor in the equation that describes the risk for a consumer to encounter low-quality information. The other factor is the search and appraisal skill of the user.<sup>90</sup> Both factors can be influenced by health professionals, the first by publishing high-quality information themselves (CancerNet is a prime example), the second by educating and training patients how to “filter” information. One of the first studies that evaluated how consumers search for and appraise health information on the Web strongly suggests that there is a role for user education and training. For example, none of the Internet users who were given the task to find reliable answers to health questions on the Web were observed to try

to find out who the authors or owners of a Web site were (eg, by checking the “about us” sections).<sup>97</sup> Some institutions have begun to offer Internet training classes to consumers and patients,<sup>98-100</sup> and at Princess Margaret Hospital in Toronto, Canada, we are developing and evaluating an “Internet school” for persons with prostate cancer. In these face-to-face courses, advanced search skills and simple strategies to evaluate health information are taught. For example, we are using the CREDIBLE mnemonic to remind patients what they should look for at a trustworthy Web site,<sup>101</sup> namely:

- Current and frequently updated
- References cited
- Explicit purpose and intentions of the site
- Disclosure of sponsors
- Interests declared and no conflicts of interests

- Balanced content, lists advantages and disadvantages
- Level of Evidence indicated

Another strategy, particularly for cancer information, is to tell patients to watch out for “red flags” indicating questionable information.<sup>102</sup> For example,

- Are patient testimonials available?
- Is the treatment described as a cancer cure?
- Is the treatment described as having no side effects?
- Is online purchasing permitted?

#### E-Commerce

Much of the negative findings from quality evaluation studies can be attributed to the fact that the Web is, in fact, a gigantic marketplace, with most information (83%) being commercial information designed to advertise and sell products and services, with less than 3% nonprofit health information.<sup>103</sup> Limited information is available as to what degree persons with cancer use the Web to purchase health services and products, but at least two studies suggest that about 50%<sup>7,20</sup> of online persons with cancer use the Web to find information about complementary and alternative medicine (CAM), and 12% of persons with cancer who use the Internet actually purchased unconventional medical therapies over the Internet.<sup>20</sup> These numbers are hardly surprising, because we know that the proportion of persons living with cancer using CAM is of the same order,<sup>104,105</sup> and the Internet is just one of many channels through which CAM information and products can be obtained. There has been one reported case of a person with cancer who was severely harmed as a result of ordering CAM on the Web,<sup>106</sup> but to blame the Internet for this would be like blaming telephone books or libraries for similar events that have occurred before. There are no qualitative or quantitative data on whether Internet users are taking more CAM than non-Internet users, and whether this has any effect on outcomes.

In contrast to CAM, the Internet is a less well-established medium to purchase prescription medicines. In a recent U.S. survey, only 5% of those taking prescriptions drugs reported to have ordered them on the Internet, and

fewer than 2% have obtained their prescriptions on the Web.<sup>28</sup>

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#### RECOMMENDATIONS FOR RESEARCH

Much of the discussion around the “quality of information” or the effect of the Internet on persons with cancer<sup>1</sup> has been a debate on whether the glass is half full or half empty. Based on a comprehensive review of the literature, I am convinced that the glass is filled almost to the top with unprecedented opportunities and it would be a mistake to leave them untapped by focusing our attention on the small area that is empty.

One important example that illustrates the degree to which we have been distracted by focusing on the negative aspects of the Internet is the flood of hundreds of publications on the quality of health information on the Web. The time and energy investigators spent on “descriptive infodemiology” (eg, attempting to describe the prevalence of “low quality” health information on the Web<sup>101</sup>) could have been invested in answering more significant questions. Rather, future studies should focus on “analytic infodemiology” and address issues such as the relation of different quality criteria to each other (including which markers of a Web site can be used by a consumer to judge whether the site is trustworthy), or the relation between quality criteria or presentation formats on the one hand and outcomes such as knowledge transfer or satisfaction on the other. One recent example is a usability study conducted by researchers at the National Cancer Institute that considered which Internet presentation format is most effective for knowledge transfer.<sup>107</sup>

Much work also remains to be done to evaluate the opportunities and pitfalls of electronic communication between patients and health professionals, and to integrate these tools into clinical practice if they prove to be effective, without disadvantaging those who have different preferences or those who benefit from more traditional modes of communication.

In addition, we have a long way to go to fully understand the effects and opportunities of

virtual communities on the Web and to devise strategies to maximize their use.

Today the effect of the Internet on cancer outcomes is unknowable and perhaps will never be fully understood. Although we can hypothesize and test that there are associations between Internet use and variables such as self-efficacy, empowerment, coping, decisional conflict, CAM use, anxiety, or depression, questions of causality are more difficult to answer. A myriad of potential confounders, such as education and socioeconomic status, which are both associated with exposure (Internet use) and the outcome variables, may explain the observed associations and must be adjusted for. To do a "clean" randomized trial with "the Internet" as intervention is hardly feasible. Longitudinal studies may help us to understand the interplay and timing of different outcome variables and help us to refine the conceptual framework depicted in Figure 1.

Perhaps the question of whether the Internet affects cancer outcomes should be rephrased. The question of the "Net effect" is largely academic, because the Internet is a permanent fixture in society that is here to stay. The greater task is to develop and evaluate interventions that can maximize the positive effect of the Internet; harness the power of informa-

tion and communication technology for patients who want it, without disadvantaging those who have different preferences; and to evaluate these innovations. In any case, there is an urgent need for research that goes beyond pure descriptive studies.

#### APPENDIX

##### Search Strategy Used

This review is data driven in a sense that I searched (on July 18, 2003) all publications in PubMed using the search terms ["neoplasms" (MeSH term) OR "cancer" (text word)] AND "Internet" (MeSH term) and screened all 489 resulting abstracts.

I conducted further searches to answer specific questions, and I used a personal literature database on Internet literature.

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