Adapting the Content of Cancer Web Sites to the Information Needs of Patients: Reliability and Readability

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Abstract

Background: People who use the Internet to research health topics do not usually find all the information they need and do not trust what they read. This study was designed to assess the reliability, accessibility, readability, and popularity of cancer Web sites in Spanish and to analyze the suitability of Web site content in accordance with the specific information needs of cancer patients. **Materials and Methods:** This was a two-phase, cross-sectional, descriptive study. The first phase involved data gathering through online searches and direct observation. The second phase involved individual structured interviews with 169 patients with breast, prostate, bladder, and kidney cancer. Spearman rank correlations were calculated between variables. **Results:** Most sites belonged to nonprofit organizations, followed by universities or medical centers (14%). Thirty-one percent of the Web sites had quality seals, 59% provided details of authorship, 62% provided references to bibliographic sources, 38% identified their funding sources, and 54% showed the date of their last update. Twenty-one percent of the Web sites did not meet the minimum accessibility criteria. With regard to readability, 24% of the texts were considered to be “quite difficult.” Patients’ information needs vary depending on the type of cancer they have, although all patients want to know about the likelihood of a cure, survival rates, the side effects, and risks of treatment. **Conclusions:** The health information on cancer available on the Internet in Spanish is not very reliable, accessible, or readable and is not necessarily the information that breast, kidney, prostate, and bladder cancer patients require. The content of cancer Web sites needs to be assessed according to the information needs of patients.

Key words: e-health, information management, telemedicine

Background

The general public is using the Internet to look for health information more and more often. Information found on the Internet can complement specialized resources; the Internet becomes a valuable tool for patients and their families, mainly because it is so easily accessible.¹ As it can be assumed that the number of patients who consult the Internet to find health information will continue to rise, the information they find has to be reliable as well as relevant.

Half of the adults in the United Kingdom and up to 75% of the adults in the United States accessed the Internet to source healthcare-related information in 2011.^{2–5} In 2006, 19% of the population of the European Union had gone online to find health information, and in 2010, this figure increased to 40%. In Spain, 41% of Internet users looked for health information on the Web in 2007, and this had increased to 54% in 2009. More women (59.2%) use it for this purpose than men (49%). The most common health topics looked for by Internet users are related to disease diagnosis (80%), followed by nutrition (57%) and medication (45%).⁶

Users use the Internet for this purpose because of the wide range of information available, because of the fact that they are anonymous on the Web, and because it provides an alternative to seeing a medical professional.⁵ A survey carried out in Spain found that most people who use the Internet to research health topics do not usually find all the information they need and do not trust what they read.^{7–10} Sixty-one percent of users feel that finding information on the Internet has helped them to cope with their illness, although 52% felt confused or anxious after their search.^{7,8}

The most searched diseases on the Internet are cancers, followed by muscular problems, dermatology, allergies, gynecology, and sexually transmitted diseases.⁶ Some studies have been carried out among cancer patients to ascertain their information needs during the diagnosis and treatment stage and have found that most Internet users look for information about treatment or alternative treatments and review the information given to them by their doctor.¹¹ However, little is known about whether or not the information included on these Web sites adequately meets these needs.

There is growing concern in the public health sector about the reliability of information available on the Internet. This information is not regulated, and its quality, accuracy, and readability vary.⁹ Few countries impose any restrictions on Internet content. This lack of regulation means that there is a lot of information available and that some of it is incorrect, which could be dangerous to patients.¹² This has led to the development of various tools to help Internet users to

find reliable sites. These tools include quality seals, codes of conduct, accreditations, and recommendations.¹³ In 1997, Hayward et al.¹⁴ looked at various methodologies for measuring healthcare quality on the Internet (the instruments considered authorship, attribution, and disclosure as part of their rating criteria). They identified 47 different ones. In 2002 Gagliardi and Jadad¹⁵ revisited the study and updated it, finding another 51 unvalidated. However, the proliferation of tools for assessing quality continued, fueled by anxieties about patient harm. The current situation is that many countries are trying to develop national quality initiatives. This should hopefully slim down the number of quality control initiatives in use.

With this in mind, the aim of this study is to assess the reliability, accessibility, readability, and popularity of cancer Web sites in Spanish using the tools available. It will also analyze the suitability of Web site content in accordance with the specific information needs of cancer patients.¹¹

The interest in analyzing this information in Spanish stems from the fact that it is the primary language of between 322 and 400 million people in the world, the same population as English in terms of use.¹⁶ Although information provided by Web sites in English can be translated with one click, the translation is always inexact and is very likely not to make sense. Besides, it has been reported that people tend to search for information in their own language.¹⁷

Materials and Methods

A two-phase, cross-sectional, descriptive study was designed. During the first phase of the study, data were gathered using online searches to find out which Web sites contained information in Spanish. Quantitative and qualitative data were then collected using the DISCERN^{18,19} questionnaire as a reference. The Web sites were evaluated, overall, for quality of content by using the validated DISCERN rating instrument and the *Journal of the American Medical Association (JAMA)* benchmarks,²⁰ the Web Accessibility Test (TAW) (www.tawdis.net/taw3/cms/), and the Inflesz scale for Web readability; finally, the existence of the Health on the Net (HON)²¹ seal was also recorded. During the second phase, individual structured interviews based on a survey questionnaire were carried out; the aims of this were to describe the profile of cancer patients who look for health information on the Internet and to analyze the factors related to use of the Internet as a source of health information. The interviews were held in oncology appointments at the Our Lady of the Snobs Hospital in Granada, Spain. The sample group recruited was made up of patients with prostate cancer, breast cancer, bladder cancer, and kidney cancer who had completed at least one stage of treatment and who were attending follow-up and review appointments. These cancers were chosen because of their high incidence and prevalence and because of the effects that the different treatments can have on quality of life. The required sample number was calculated on the basis of an estimated 20% rate of Internet usage to within 6% accuracy and a confidence interval of 95% and with statistical power set at 80%; it was therefore necessary to recruit 169 patients for each type of cancer. Doctors invited all patients who met the inclusion criteria to take part in the study. Patients were excluded

from the study if their doctors felt that their illness was too severe ($n = 31$).

The Google Advanced Search engine was used to identify Web sites about cancer aimed at patients. The searches were carried out in June 2012. This was the only search engine used as it is the most popular one (99% of searches in Spain are carried out using Google).²² The search was carried out using the option to find Web sites with "one or more words," and the search terms (in Spanish) were "cancer" OR "oncology" OR "neoplasia." Only Spanish results were returned. The "related search option" was also used to find other pages similar to the ones found. The first 100 Google search results were sorted and categorized to eliminate any duplicates. In total, 64 Web sites were found.

Once the Web sites had been found, the ones that did not meet the following inclusion criteria were excluded: (1) information in Spanish; (2) aimed at patients; and (3) do not require a password. The following exclusion criteria were applied: (1) contain book reviews or summaries of publications; (2) used only to sell a product; (3) only provide links to other sites or contain broken links; and (4) do not focus on cancer directly. Most of the sites excluded were wikis, news sites, videos, horoscopes, and personal blogs. In the end, in total, 29 Web sites were selected. All of the Web sites were saved for subsequent analysis to avoid any changes during the analysis period. The surveys were used to identify information needs by cancer type. Doctors invited all patients with prostate, kidney, bladder, and breast cancer who attended review and follow-up appointments to take part in the study.

VARIABLES THAT WERE ANALYZED

The following general characteristics were categorized:

- User sex: male/female
- User age: under 45 years/45 years or over
- Level of education (graduate school/school/no college/college graduate)
- Most frequent place of Internet access (home/school)
- Affiliation (commercial/nonprofit organization/university or medical center/government)
- Specialization (exclusively related to cancer/part of the site dedicated to cancer)
- Content type (medical facts/clinical trials/question and answer/human interest stories)

The following reliability standards were assessed:

- *JAMA* benchmarks. The quality of information of the selected Web sites was assessed using criteria known as the *JAMA* benchmarks. *JAMA* benchmarks consisted of the following four concepts: (1) authorship, affiliations, and relevant credentials of author contributors should be provided in the Web sites, (2) attribution, references, and sources for all the contents to be clearly listed and all the relevant copyright information to be noted in the Web sites, (3) disclosure, meaning that the Web site "ownership" should be prominently and fully disclosed, as well as any sponsorship, advertising, underwriting, commercial

funding arrangements or support, and any other potential conflicts of interest, and (4) currency, the dates when the contents were posted or updated on the Web sites.

- Authorship: yes (possible to identify authorship)/no (not possible to identify authorship)
- Attribution: yes (possible to identify authorship)/no (not possible to identify authorship)
- Currency: yes (possible to identify recent date of update)/no (not possible to identify date of update)
- Disclosure: yes (possible to identify source of information and/or bibliography)/no (not possible to identify sources)
- Quality seals: HON Foundation Code of Conduct (HonCode)/other seals/none

Degree of accessibility was defined:

- Priority 1 (A): Web developers *must* satisfy these requirements. Information should be accessible to most groups of disabled users.
- Priority 2 (AA): Web developers *should* satisfy these requirements, to ensure that there are no major obstacles to access to Web content.
- Priority 3 (AAA): Web developers *may* satisfy these requirements, which will facilitate access for certain groups.
- W3C mobileOK Basic Tests 1.0: mobile Web best practices test.

Readability was evaluated as follows:

- The Inflesz readability scale
- The Flesch index, adapted for Spanish texts by Fernández Huerta, was used to assess the Web sites, where <40 was very difficult, 40–55 was quite difficult, 55–65 was normal, 65–80 was quite easy, and >80 was very easy.

Impact or popularity was measured:

- Google PageRank
- The Alexa index (traffic rank)²³ is a rough measure of a Web site's popularity, compared with all the others out there on the Internet, taking into account both the number of visitors and the number of pages viewed on each visit.
- Number of bookmarks in the DELICIOUS bookmarking service
- Sites linking in

Information needs were evaluated:

- A questionnaire based on DISCERN was composed of 23 questions on patients' information needs. The DISCERN instrument, in turn, is a validated rating tool of 16 questions that is freely available online (www.discern.org.uk) and can be used by health consumers or professionals alike.

DATA GATHERING

All instruments were reviewed by the same investigator. The Alexa Web site was used to gather data about age, sex, and level of education. This site provides information about Web site hits and collects information about users who have installed its plug-in. The JAMA

benchmark and quality seal information was assessed by an expert researcher. The accessibility information was assessed using two validation tools, TAW and HERA; the goal is to analyze the level of accessibility in the design and development of Web pages to allow access for all, regardless of their specific characteristics. The TAW is an online (www.tawdis.net/taw3/cms/) tool for the accessibility analysis of Web sites based on the W3C Web Content Accessibility Guidelines 1.0, which provides a useful in-page feedback. The TAW mobile OK Basic mobile Web best practices test was also carried out. In order to assess the readability of the sites, the .htm or .html documents were converted into Word documents so that the statistical indicators could be obtained. Because some of the documents selected were too short to be used as samples, three fragments were randomly selected from each site to produce a document containing an average of 700 words. This means that in total 87 text fragments from 29 Web sites were analyzed. The word count was calculated using the text processing tool Inflesz version 1.0. The Flesch–Huerta grade is based on the Flesch formula but adapted for the Spanish language.^{24,25} The readability formula was $206.84 - 0.60P - 1.02F$, and the Huertas adaptation was $206.84 - (0.6 \times [P]) - (102 \times [F])$, in which P is the number of syllables per 100 words and F is the number of sentences per 100 words. The pages were analyzed using tools designed to measure Web presence: the Alexa Web traffic ranking, the DELICIOUS bookmarking service, and Google PageRank.¹³ Patients' information needs were assessed using a questionnaire based on DISCERN; it was the same that we used in the frame of our study by Valero-Aguilera et al.²⁶

STATISTICAL ANALYSIS

A descriptive analysis was carried out for the variables studied, including the frequencies of the qualitative variables (absolute value and percentage) and the average and range for the quantitative variables, in order to gain an understanding of cancer patients' needs and to assess whether or not those needs are met by the Web sites studied.

The Spearman's rank correlation coefficient (ρ) was used to measure the association or interdependence between two quantitative variables with an abnormal distribution (nonparametric). The data were obtained using SPSS quantitative analysis software (SPSS, Inc., Chicago, IL).

Results

CANCER WEB SITES

The characteristics of the cancer Web sites evaluated are set out in Table 1, which provides details about the country of origin and Web master of each site. The sites found are from the United States (27.6%), Spain (62.0%), and Argentina (10.4%).

Thirty-eight percent of cancer Web sites in Spanish are more frequently visited by women, and 31% of sites are visited by people over 45 years of age. Most of the users of these sites have a high level of education (graduate school, 28%). With regard to the affiliation of the Web sites, 69% belong to nonprofit organizations, 14% to universities, and 10% to or medical centers. Most of the Web sites focus

Table 1. Description of the Web Sites Found

WEB SITE	DESCRIPTION	COUNTRY
1. www.cancer.gov/espanol	Run by the National Cancer Institute. Includes press releases, summaries, fact sheets, clinical studies, and publications on cancer	United States
2. http://es.oncolink.org/es_index.cfm	Web site of the Abramson Cancer Center of the University of Pennsylvania. Provides information about all types of cancer, treatments, new research, ongoing medical training, and prevention	United States
3. www.cdc.gov/spanish/cancer/	Information about the different types of cancer (prevention and control) from the Centers for Disease Control and Prevention. Aimed at the general public	United States
4. www.livestrongespanol.org/site/c.1kLUJ8MKNrH/b.5110051/k.BCF2/Home.htm	The Lance Armstrong Foundation provides useful practical help through its LIVESTRONG Survivor Care program, with personalized support for coping with cancer.	United States
5. www.cancer.net/espanol	The American Society of Clinical Oncology provides information for patients and their families to help them make decisions about their healthcare. The information is approved by oncologists.	United States
6. www.cancer.org/Espanol/index	The American Cancer Society provides information about all cancer types and how to prevent them. The information is provided in guide format, looking at staying healthy, preventing cancer, and diagnosis and treatment.	United States
7. www.nlm.nih.gov/medlineplus/spanish	Health site run by the National Library of Medicine, with information about the different types of cancer, aimed at patients and their families	United States
8. www.y-me.org/espanol/index.php	The National Breast Cancer Organization Web site provides information for anyone affected by breast cancer, from how to deal with a loved one being diagnosed to how to cope with a diagnosis of metastasis.	United States
9. www.seom.org/	The Sociedad Española de Oncología Médica (Spanish Society of Medical Oncology) provides oncology information and training for doctors, the health system, patients, the general public, the pharmaceutical industry, and the media.	Spain
10. www.aecc.es/Paginas/PaginaPrincipal.aspx	The Asociación Española Contra el Cáncer (Spanish Cancer Association) Web site provides information about cancer, early detection, prevention, and health education. Support programs, psychological and social care, advice on health and nutrition, volunteering, and scientific advances. Aimed at the general public	Spain
11. www.cancerinfantil.org/	Web site of the Federación Española de Padres de Niños con Cáncer (Spanish Federation for Parents of Children with Cancer [FEPNC]). Contains information about child cancer produced by the FEPNC and from other sites	Spain
12. www.ayudacancer.com/	Provides information about all types of cancer, treatments, new research, ongoing medical training, and prevention. No information about the Web master is provided.	Spain
13. www.oncosaludable.es/	The Sociedad Española de Oncología Médica (Spanish Society for Medical Oncology) provides advice to help patients with their tolerance of oncology treatments and to understand some aspects of cancer. Information about nutrition and physical exercise aimed at oncology patients	Spain
14. www.paliacclinic.com/index.php	Web site of the Paliacclinic Foundation with information about palliative care for terminal cancer patients, with a specialist team and home palliative care units	Spain
15. www.grupogeis.org/	The Grupo Español de Investigación en Sarcomas (Spanish Sarcoma Research Group) is a nonprofit medical association devoted to improving treatment for sarcoma patients.	Spain
16. www.cancerinfo.es/	Information about tumors, biopsies, and metastasis and diagnostic tests, surgery, radiotherapy, and chemotherapy. No information about the Web master is provided.	Spain
17. www.cancerpulmon.es/	Roche Farma provides up-to-date information for lung cancer patients: about the disease, its symptoms and treatments, and advice from experts.	Spain
18. www.tuotromedico.com/indice_cancer.htm	Health Web site in Spanish produced by PulsoMed. Includes a large medical encyclopedia, frequently asked questions, and a directory of doctors	Spain
19. www.tumoresintraoculares.org/	Introduction to and description of the different types of intraocular tumors and their treatment. Developed by a healthcare professional	Spain

continued →

Table 1. Description of the Web Sites Found *continued*

WEB SITE	DESCRIPTION	COUNTRY
20. www.cancerpiel.es/	Personal Web site on skin cancer, sun protection, melanoma, and similar pathologies. Guide on everything you need to know about skin cancer: prevention, diagnosis, pathology, and treatments	Spain
21. www.oncomeet.com/	The Network of International Cancer Experts provides information about any type of cancer from experts and other patients. Social networking site where users can share their experiences of the disease	Spain
22. www.fefoc.org/	The Fundación para la Educación Pública y la Formación en Cáncer (Cancer Training and Public Education Foundation) provides public education and cancer information and awareness programs and provides support for the ongoing training of healthcare professionals.	Spain
23. www.elmundo.es/elmundosalud/especiales/cancer/introduccion.html	Health site run by Spanish newspaper <i>El Mundo</i> , with information about the different types of cancer	Spain
24. www.cancerpancreas.es/	Roche Farma provides up-to-date information for pancreatic cancer patients: about the disease, its symptoms and treatments, and advice from experts.	Spain
25. www.cancermama.org/index.php	Web site of the Fundación para la Educación Pública y la Formación en Cáncer (Cancer Training and Public Education Foundation) to support breast cancer patients	Spain
26. www.oncologia2000.com/default.asp	Oncology site in Spanish run by the Asociación para la Difusión de la Información en Oncología (Association for the Dissemination of Oncology Information), with information for patients and professionals. Includes up-to-date links to various oncology-related publications	Spain
27. www.cancerdetiroides.com.ar/vn/home.asp	General information for Spanish-speaking doctors and patients developed by a healthcare professional. Includes discussion forums and information about hospitals in Buenos Aires	Argentina
28. www.prevenircancer.com.ar/	Information about the different types of cancer, symptoms, prevention, fight against cancer, diagnosis, treatments, and the latest research. No information about the Web master is provided.	Argentina
29. www.asociacionpaliativa.org.ar/index.php	Paliativa Asociación Civil is a palliative care association for patients with terminal cancer or other terminal illnesses.	Argentina

exclusively on cancer (86%), and the remaining 14% contain some sections on cancer only. With regard to content type, 52% of the information is about medical facts, whereas 24% is on clinical trials or information about ongoing research (Table 2).

With regard to Web site quality, assessed using the JAMA benchmarks, 59% of sites provide information about their authors (affiliation, credentials, etc.), 62% provide references and sources for all their content (clearly listed, along with copyright information), 38% identify their sources of funding and advertisers, and 54% provide the date of the last update. Of the Web sites that meet the JAMA benchmark criteria, 17.24% also have some kind of quality seal. Thirty-one percent of the Web sites have a quality seal. Of these, 24% meet the HONCode requirements, and 28% meet other standardization criteria. Twenty-one percent have another seal or seals in addition to the HON seal, 7% have the HON seal only, and 3% have other seals only. Of the sites with a quality seal, 13.8% meet at least the Priority 1 accessibility requirement (Table 3).

Twenty-one percent of the Web sites analyzed do not meet the basic accessibility criteria (Priority 1). This means that elderly people and those with any kind of disability will not be able to see, understand, browse, or interact with the Web site effectively or to create or contribute content. The Priority 2 requirement, important for eliminating obstacles to Web site access, is only met by 3% of the cancer

Web sites studied. Finally, not one of the Web sites meets the Priority 3 requirement. Forty-eight percent of the sites have a readability score of "normal," 28% are "quite easy," and 24% have scores of between 55 and 65 and are therefore "quite difficult" (Tables 3 and 4).

Table 4 shows the popularity of the different Web sites based on the Alexa ranking, which calculates Web traffic for the sites selected around the world, as well as their impact or importance calculated by the Google PageRank tool. The "Delicious" column shows the number of times that the sites have been added as favorites, and the "Site linking in" column shows the number of links to that site from other sites. The top sites based on these indicators are the ones developed by the National Library of Medicine, the American Cancer Society, the Centers for Disease Control and Prevention, and the National Cancer Institute. It is interesting to note that the *El Mundo* health portal, run by a Spanish newspaper, is the top site based on the Alexa rankings.

PATIENTS' INFORMATION NEEDS VERSUS WEB SITE CONTENT (TABLE 5)

Patients' information needs vary depending on the type of cancer they have, although they all want to know about the likelihood of cure, survival rates, and the side effects and risks of treatment.

Table 2. Web Site Characteristics: Affiliation, Specialization, Age, Sex, Content Type, and Level of Education

VARIABLE	N	%
Sex of users		
Male	2	7
Female	11	38
Not available	16	55
Age (years) of users		
> 45	9	31
< 45	4	14
Not available	16	55
Level of education of users		
Graduate school	8	28
School	2	7
No college	2	7
College graduate	1	35
Information not available	16	55
Place of Internet access		
Home	5	17
School	3	11
Work	5	17
Information not available	16	55
Affiliation		
Commercial	5	17
Nonprofit organization	17	59
University or medical center	4	14
Government	3	10
Specialization		
Exclusively related to cancer	25	86
Part of the site dedicated to cancer	4	14
Content type		
Medical facts	15	52
Clinical trials	7	24
Question and answer	2	7
Human interest stories	5	17

Based on the cancers studied here, patients with breast cancer are the ones with the greatest need for information about their illness. The topics that breast cancer patients access most frequently are related to the likelihood of cure and survival rates (95%), side effects and risks of treatment (95%), and the effects the treatment may have

Table 3. Web Site Content: *Journal of the American Medical Association* Benchmarks, Quality Seals, Readability, and Accessibility

VARIABLE	N	%
JAMA benchmarks		
Authorship	17	59
Attribution	18	62
Currency	13	54
Disclosure	11	38
Quality seals		
Sites with at least one seal	9	31
Sites with more than one seal	6	21
HonCode seal	7	24
Other seals	8	28
HonCode and other seals	6	21
HonCode only	1	3
Other seals only	2	7
Quality seal and JAMA benchmarks	5	17.2
Quality seal and accessibility (Priority 1A)	4	13.8
Accessibility		
Priority 1 (A)	6	21
Priority 2 (AA)	1	3
Priority 3 (AAA)	0	0
W3C mobileOK Basic Tests 1.0	0	0
Readability: InFlesz Scale		
Normal	14	48
Quite easy	8	28
Quite difficult	7	24

HONCode, Health on the Net Code of Conduct; JAMA, *Journal of the American Medical Association*.

on their physical appearance (90.0%). A large proportion of Web sites (69.0%) include information about the likelihood of cure and survival rates, but less than half of them provide details about the side effects of treatment or the effects of the treatment on physical appearance (44.9% and 41.4%, respectively). The correlation coefficient between Web site content and patients' information requirements for breast cancer is not very high (0.663).

For patients with prostate cancer, the most frequently accessed topics are the effects of the disease on sex life (66.2%), risks and side effects of treatment (60.8%), and cure and survival rates (50.2%). Only a quarter of the Web sites studied (27.6%) provide information about the effects that the disease can have on the patient's sex life,

Table 4. Readability, Impact, and Popularity

WEB SITE	DELICIOUS	ALEXA TRAFFIC RANK	PAGE RANK	INFLESZ SCALE	HUERTAS INDEX
www.cancer.gov/espanol	73	14,192	6	Normal	62.92
www.seom.org/	10	1,012,480	5	Quite easy	72.48
https://www.aecc.es/Paginas/PaginaPrincipal.aspx	10	891,164	5	Normal	65.16
www.cancerinfantil.org/index2.html	8	4,300,943	3	Quite easy	71.16
www.ayudacancer.com/	7	1,096,212	3	Quite difficult	55.62
www.oncosaludable.es/	5	5,472,717	0	Quite difficult	54.7
http://es.oncolink.org/es_index.cfm	4	278,174	6	Quite difficult	58.12
www.cdc.gov/spanish/cancer/	4	4075	7	Normal	66.52
www.paliacclinic.com/index.php	4	10,165,449	1	Quite difficult	50.56
www.grupogeis.org/	3	7,454,520	4	Normal	62.83
www.cancerinfo.es/	3	1,107,523	3	Quite difficult	55.27
www.cancerpulmon.es/	2	5,956,720	3	Quite easy	69.77
www.livestrongespanol.org/site/c.lkLUJ8MNMKrH/b.5110051/k.BCF2/Home.htm	2	3,037,400	6	Normal	66.54
www.cancer.net/espanol	2	238,123	6	Quite easy	74.21
www.cancer.org/Espanol/index	2	18,624	0	Quite easy	70.54
www.tuotromedico.com/indice_cancer.htm	0	49,402	4	Normal	66.02
www.tumoresintraoculares.org/	0	14,134,515	3	Normal	66
www.cancerdetiroides.com.ar/vn/home.asp	0	2,082,562	3	Normal	60.26
www.prevenircancer.com.ar/	0	25,737,309	1	Quite easy	70.18
www.asociacionpaliativa.org.ar/index.php	0	9,952,487	3	Quite difficult	54.94
www.cancerpiel.es/	0	5,838,159	4	Quite easy	70.42
www.oncomeet.com/	0	25,735,768	0	Quite difficult	56.7
www.fefoc.org/	6	4,878,607	5	Normal	69.75
www.elmundo.es/elmundosalud/especiales/cancer/introduccion.html	15	436	4	Normal	66.66
www.nlm.nih.gov/medlineplus/spanish/ency/article/001289.htm	7	463	5	Normal	68.09
www.cancerpancreas.es/	3	4,342,245	3	Normal	65.44
www.y-me.org/espanol/index.php	3	5,536,963	5	Normal	63.63
www.cancermama.org/index.php	2	5,626,826	3	Quite easy	75.05
www.oncologia2000.com/default.asp	0	9,599,172	4	Normal	68.11

whereas 69% of sites include sections on the side effects of treatment, and 44.8% include material on the likelihood of cure and survival rates. The correlation coefficient between Web site content and patients' information requirements for this type of cancer is quite high (0.803).

The topics required most frequently by patients with kidney cancer are related to self-care to aid their recovery (66.7%), food and nutrition (66.7%), the likelihood of cure and survival rates (60.0%), and keeping physically well and active (60.0%). More than half of the Web sites studied include information about self-care to aid

Table 5. People Who Have Needed Information About Each Topic Throughout the Course of Their Illness and Web Sites That Include That Information

VARIABLE	PEOPLE WHO HAVE NEEDED INFORMATION ABOUT EACH TOPIC THROUGHOUT THE COURSE OF THEIR ILLNESS								WEB SITES THAT INCLUDE THE INFORMATION	
	BREAST		PROSTATE		KIDNEY		BLADDER			
	N	%	N	%	N	%	N	%	N	%
Estimated recovery time	85	50.0	64	37.7	79	46.7	48	28.6	3	10.3
Information about advance directives	0	0.0	1	0.8	0	0.0	0	0.1	5	17.2
Likelihood of metastasis	59	35.0	38	22.3	90	53.3	38	22.3	7	24.1
Illness' effects on sex life	25	15.0	112	66.2	22	13.3	63	37.1	8	27.6
Risk of other family members developing the disease	127	75.0	49	29.2	34	20	39	22.9	9	31.0
Alternative treatment options	76	45.0	55	32.3	56	33.3	48	28.6	11	37.9
Tests and experiments related to the treatment	8	5.0	10	6.2	34	20	24	14.3	11	37.9
Other patients' treatment experiences	135	80.0	52	30.8	34	20	43	25.7	11	37.9
Effects on physical appearance (hair falling out, etc).	152	90.0	17	10	56	33.3	34	20	12	41.4
Likelihood of cure and survival rates	161	95.0	95	56.2	101	60	106	62.9	13	44.8
Keeping physically healthy or active	135	80.0	101	60	101	60	53	31.4	14	48.3
Alternative options if the initial treatment does not work	17	10.0	27	16.2	22	13.3	29	17.1	15	51.7
Self-care to aid recovery	144	85.0	82	48.5	113	66.7	77	45.7	17	58.6
Food and nutrition	110	65.0	75	44.6	113	66.7	48	28.6	17	58.6
Effects on life plans	17	10.0	18	10.8	34	20	19	11.4	17	58.6
Possible consequences if no treatment is received	76	45.0	40	23.8	45	26.7	34	20	18	62.1
Looking for private healthcare alternatives	8	5.0	6	3.8	0	0.0	10	5.7	18	62.1
Side effects of treatment, risk	161	95.0	103	60.8	79	46.7	82	48.6	20	69.0
Possible causes of cancer	51	30.0	44	26.2	45	26.7	73	42.9	21	72.4
Physical effects of the disease	118	70.0	75	44.6	68	40	58	34.3	21	72.4
Healthcare staff's experience and qualifications	51	30.0	32	19.2	34	20	53	31.4	22	75.9
Spearman's correlation coefficient	0.663		0.803		0.644		0.850			

The three topics patients needed the most have been highlighted in bold for each cancer type.

recovery and food and nutrition (58.6%), whereas topics on the likelihood of cure and survival rates and keeping physically well and active are included in 48.3% and 44.8%, respectively. The correlation coefficient between Web site content and patients' information requirements for this type of cancer is not very high (0.644).

Finally, the topics accessed most frequently by patients with bladder cancer are related to the likelihood of cure and survival

rates (62.9%), side effects and risks of treatment (48.6%), and self-care to aid recovery (45.7%). A large proportion of Web sites (69.0%) include information about the likelihood of cure and survival rates, but less than half of them (44.9%) provide details about the side effects of treatment, and just 41.4% provide information about self-care to aid recovery. The correlation coefficient between Web site content and patients' information

requirements for this type of cancer is the highest of all the cancers studied here (0.850).

Discussion

There are a lot of tools available today that can be used to assess health Web sites,^{12,13,15,27} but the levels of readability and accessibility of Web sites are still largely unknown. Proof of Web site quality would increase users' confidence in the information obtained and minimize exposure to unproven or false information, promoting user autonomy.²⁸

The study carried out here had certain limitations. For example, the search was carried out on one date (June 2012) and may not be representative of matches from other search engines at other. The changes that the Web sites undergo, with regard to content, design, and even services offered, are manifold; they may even change server or even country. This dynamic character may cause a Web site to change radically in very little time. The information available on the Internet is quite dynamic, and the Web sites may have changed over the course of the data-gathering period. Also, our study is limited by the fact that a single reviewer determined the eligibility for inclusion and the number of elements in each quality assessment instrument. Both of these may, in some cases, be subjective. Other limitations include the failure to identify other reputable Web sites; we studied the first 100 sites (top 100), but each search engine decides its own first 100 sites. Furthermore, there are no universally accepted benchmarks, standards, or quality control criteria. This means that the results of this study depend on the criteria selected.

Web site content and information needs are regularly updated and refreshed. The Internet offers rapid access and a wide dissemination of information. The assessment of patient needs is an essential part of Web site development. Health Web sites should be judged not only by the quality, accuracy, reliable, and readability of the information provided, but also by their match with the target audience.

The DISCERN instrument structure for assessing the sites was very helpful in orienting us to the criteria for assessing information's need. The aim of this article is to be the first to analyze the needs of patients with breast, prostate, bladder, and kidney cancer in relation to the reliability of information in Spanish found on cancer Web sites and thus to find out how much these sources can be trusted. It is important to note also that cancer is one of the most searched diseases on the Internet (65.6% of patients have looked for information on the disease at some point²⁹), and 8% of the world population of Internet users speak Spanish.³⁰ The study outlines the profile of breast, kidney, prostate, and bladder cancer patients who use the Internet as a source of health information. Internet use is related to the patient's attitude toward decision-making and level of education. Studies published on this topic so far have looked at Web sites in English from the United States and are therefore not applicable to Spain or Europe because of the digital divide (the Internet usage rate in Spain is currently similar to the U.S. rate in 2001³⁰). Another limitation is that the quantitative/qualitative approach using DISCERN and structured surveys do not mimic how the cancer patients selected for interview go about doing a self-search in reality. The results could

vary because the first-phase analysis is not based on cancer patients. This study provides information of relevance for healthcare professionals specializing in oncology, in that having an awareness of the factors related to use of the Internet as a source of health information will allow them to encourage that use effectively (e.g., by providing details of the best Web sites and explaining how to evaluate information). Doctors could also make available healthcare information of proven quality, taking advantage of the potential benefits that it can offer patients and avoiding the potential adverse effects of incorrect use of the Internet. The results of this study show that Internet use is not linked to a lack of satisfaction with the information received. This suggests that patients who look for information do not do so because they are dissatisfied with the information given to them by healthcare staff, but that they have other motivations or worries that make them want to find out more about their illness.

Numerous studies have assessed the quality of Web sites focusing on a particular disease (breast cancer, depression, neurology, etc.).³¹⁻³³

Some studies have found that the quality of health Web sites is generally high.^{18,19,24} However, other authors have found the opposite, with findings similar to our own. Nevertheless, these studies have used a wide variety of different evaluation criteria, making it difficult to make comparisons.^{8,27}

In this study, the HON label was found to be linked to higher quality. This finding is consistent with those of some studies³⁴ but not with others.³⁵⁻³⁸ These varying results could be because very few sites have the HON label, because of the criteria used for the HON label (related more to ethical considerations than to quality), and because this label is only given if the site's Web master requests it. It is important to note that quality seals are still only used by a limited number of sites, and government sites do not use them. These seals are not used to assess the quality of the information provided by a Web site; they merely guarantee disclosure of the information sources used (not their quality) and the aims pursued by publishing that information. These seals are too much effort given their limited application.²⁹

The results of this study suggest that the health information on cancer available on the Internet in Spanish is not very reliable and often of variable quality. These findings are consistent with those of previous studies on cancer and other health topics for other languages.³⁴⁻³⁹ Generally speaking, the health information found on the Internet is not reliable enough, and it is important to highlight the absence of information provided on the Internet by government bodies.²⁹ Most of the sites evaluated had very limited reliability as a result of factors relating to responsibility for information and readability. The exactness, completeness, and consistency of information also varied a great deal. This in itself illustrates the limited usefulness of Google PageRank and DELICIOUS as a means of classifying Web sites based on their impact or quality, as already discussed by other authors.^{26,33} The results of *Table 4* are inherently unreliable, as page rankings are well known to be easily manipulated by Web masters and advertisers. DELICIOUS linking is inherently subjective ("I liked this site") and does not in any way measure quality of information

because some homeopathy sites are highly linked, for example. Although Alexa, Google PageRank, and DELICIOUS may have met our very loose definition of technical quality criteria, our previous work²⁶ shows that popularity and quality as represented by domain-independent technical quality criteria are not related. Therefore, we do not consider Alexa to be a quality assessment tool that can benefit consumers.

With regard to gender differences, women look for the most health information on the Internet, and they do so more frequently than men. This finding is consistent with those of Red.es,⁴⁰ the Pew Internet & American Life Project,⁴¹ and other studies.^{42–44} Other studies^{34–38,42–44} did not find any differences between information searches by different age groups, but differences were detected here (over 45 years of age). With regard to accessibility, the Spanish Web sites studied were found to have limited accessibility for disabled users. These results are consistent with those of several other studies^{33,45,46} that found that disabled people would find it difficult or impossible to access these sites.

The readability of the sites studied was just as bad as that of sites from the United States, the United Kingdom, and other countries,²⁵ suggesting that readability could limit patients' ability to understand Web content. There was no significant link between Web site size and readability, which suggests that difficulty reading these sites is not linked to word count, and that Web sites with a small number of words had a similar level of readability as sites with more words.

The Internet has improved access to information, but the quality and currency of content are not guaranteed. The accuracy of information is often not guaranteed by any independent and/or public institution. Furthermore, quality seals do not guarantee scientific rigor or the currency of contents, so they provide no solution either. Some authors have suggested the implementation of regulations so that only scientifically proven information is published on the Internet,⁴⁷ but this is a utopian idea, because there will always be countries with more liberal regulations where information can be published in Spanish and will be easily accessible to Spanish users. The best solution would be to create Web sites run by the healthcare authorities containing information for the general public,¹⁰ like the Virtual Health Library, which provides information for healthcare professionals and is endorsed by the Carlos III Health Institute.⁴⁸

Patients' current preferred source of information is their doctor, followed by the Internet. However, because of the changes that have taken place in other countries we can infer that the use of the Internet as a source of health information will increase, becoming the top source, although not necessarily the one that inspires the most confidence.³⁷ So, the Internet aims to become the public's main source of information, with content adapted to patients' needs, which would change patients' habits and their relationship with their doctor. As such, the health services must be aware of Web site content. Web sites should give patients the opportunity to discuss any questions or queries that may arise during their search, to ensure that they interpret the information correctly and to reduce any of the confusion or anxiety that often results. Web sites could also provide a good opportunity to strengthen the doctor–patient rela-

tionship. Furthermore, reliable Web sites should be actively recommended to patients.

Future research could study the effectiveness of interventions that aim to educate patients about effective use of the Internet as a source of health information. These studies should be designed taking into account the factors related to Internet use found in this study, as this would make it possible to consider the peculiarities of each patient and his or her own specific needs.

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