ORIGINAL ARTICLE

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A study of cancer information for cancer patients on the internet

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Abstract

Background. There have been few studies of the information provided for cancer patients on the internet.

Methods. Using the Japanese language, we searched for cancer-related web pages, using the Google search engine, and evaluated the characteristics of the 150 top-ranked search results. We collected information on the operators of the websites, number of links, existence of a search function, and advertisements on the site. According to their contents, the 150 websites were classified into seven categories, of which five (numbers 1, 2, 3, 4, and 6) each accounted for 20% of the websites. The categories were: (1) mediarelated websites (e.g., newspapers and publishers), and portal sites; (2) patient association websites, patient's diaries, blogs by patients and/or their families (n = 33); (3) websites of medical institutions (e.g., hospitals; n = 27); (4) websites of research institutions (e.g., universities; n = 35);

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(5) websites of pharmaceutical companies; (6) other websites providing medical information (n = 32); and (7) other websites that did not belong to categories 1-6. Outgoing links were common in websites created by media-related organizations (median, 13) or patients and their families (median, 15), but such links were not common in the other types of websites (median, 0-4). Eight of the 13 cancer based hospitals in Japan, as well as the National Cancer Center were publishing general cancer information on their websites. Of the 13 cancer based hospitals, 12 included a link to the National Cancer Center. The National Cancer Center had the largest amount of information (736575 words), exceeding the amount provided by the other cancer based hospitals (1622-155515 words). Two of the 7 websites of academic associations (included in category 6) had cancer information for patients, but the document sizes were small (3230-44091 words).

Conclusion. The website of the National Cancer Center is the most prominent source of general cancer information for patients, but it still has room for improvement in its usability.

Key words Google · Cancer patients · Links · Cancer care facilities · Advertisement

Background

The amount of information available on the internet has grown rapidly in recent years. According to the *White paper on information and communications* published by the Japanese Ministry of Internal Affairs and Communications¹ in 2006, the number of internet users in Japan had reached 85.29 million, and the penetration rate was 67%. Information sources for cancer patients used to be limited to medical professionals such as doctors and nurses, but today patients can obtain a wide variety of medical information on the internet.^{2-4,5} However, as the amount of available information is increasing exponentially, it is becoming increasingly difficult for patients to efficiently extract relevant information.

Cancer information on the internet is a valuable resource for cancer patients.⁵ Many cancer patients, however, are elderly and are not used to browsing the internet using a personal computer. In many cases, the patients' children and other family members access the internet instead. Because patients' family members do not often receive explanations directly from the doctors, they tend to seek information about common cancer treatment plans on the internet.⁶ On the other hand, when patients themselves use the internet regularly, they often seek information on a more personal level, such as "listening to other people's experiences" and "reducing anxiety about the disease and treatments," in addition to searching for common medical information. A variety of information is thus in demand, but few studies have investigated the content of cancer information on the internet in detail.

In this study, we collected cancer information available on the Internet, examined how information is currently provided to patients and their families on the internet, and identified some problems with this information.

Methods

Information extraction from the internet

We searched for cancer-related web pages, using the Google search engine. We used Google because it is the world's largest search engine. PageRank (Google, CA, USA) is an algorithm used to evaluate the importance and significance of web pages on the internet. Rankings of the pages were calculated using this algorithm. Rankings of the pages could be affected by "search engine optimization," which is the process of improving the volume and quality of traffic to a website from search engines.

For each of the 150 top-ranked search results, we examined the entire website to which the result page belonged (most of the top-ranked result pages were the home pages of the associated websites). We determined the organization that operates the website, the targeted readers of the website, the update frequency, the date of the last update, the main content, whether a search function existed, the destinations of outgoing links, whether the site carried advertisements, the number of backlinks (links pointing to the website), ¹⁰ and the page rank of the website. This study was conducted using the Japanese language only.

We also compared the 50 top-ranked search results from July 19, 2006 and from December 22, 2006, to examine how the information changed over time.

Classification of websites, link destinations, and advertisers

The websites, their outgoing link destinations, and their advertisers were classified into the following seven categories:

A. Media-related websites (e.g., newspapers and publishers), and portal sites

- B. Patient association websites, patient's diaries, blogs by patients and/or their families
- C. Websites of medical institutions (e.g., hospitals)
- D. Websites of research institutions (e.g., universities)
- E. Websites of pharmaceutical companies
- F. Other websites providing medical information
- G. Other

Category F contained websites providing medical information on cancer that did not belong to categories A through E. Category G contained websites that did not belong to categories A through F.

Investigation of websites of the National Cancer Center, other cancer based hospitals, and academic associations

We collected the websites of the National Cancer Center, other cancer based hospitals, and academic associations from the 150 top-ranked search results. We then checked whether they included a search function, their number of outgoing links, their number of backlinks (links pointing to the website), the amount of information published for patients, and the date of the last update (as of December 22, 2006).

Purpose of this study

The purpose of this study was to examine the characteristics of cancer information published on the internet, and to evaluate the usefulness of different cancer-related websites. In particular, we examined the relationship between usability for patients, and the organization operating the website.

Results

Classification of the websites and their characteristics

We classified the 150 websites into seven categories, as noted above (Table 1). Each of categories A, B, C, D, and F accounted for 20% of the content of the websites; category B: patient association websites, patients' diaries, blogs by patients and/or their families; category C, descriptions of medical institutions; category D, descriptions of research institutions; and category F, other websites presenting medical information. A search function was provided in 43% of the media-related websites and 100% of the pharmaceutical company websites, but in only 14% of the other categories. The median number of outgoing links for the media-related websites was 13, and that for the websites created by patients and their families was 15. There were few outgoing links in the other websites (median, 0-4). Advertisements were generally scarce, and the median number of advertisements across all the categories was 0. As for advertisements within different categories, approximately 30% of the media-related and patient-created websites carried some advertisements, while only 10% of the other categories did so.

Table 1. Classification and characteristics of websites

	Number of	Websites with a	Outgoing links		Advertisements	
	websites	search function	Number of websites with links	Number of links per website; median (range)	Number of websites with advertisements	Number of advertisements per website; median (range)
A	14	6 (43%)	12 (86%)	13 (0–111)	4 (29%)	0 (0–20)
В	33	4 (12%)	29 (88%)	15 (0–158)	12 (36%)	0 (0–76)
C	27	4 (15%)	19 (70%)	2 (0–17)	4 (15%)	0 (0-4)
D	35	2 (6%)	27 (77%)	3 (0–198)	4 (11%)	0 (0–20)
E	4	4 (100%)	1 (25%)	0 (0-5)	0 (0%)	0 (0–1)
F	32	6 (19%)	18 (56%)	4 (0–109)	1 (3%)	0 (0–26)
G	5	2 (40%)	2 (40%)	1.5 (0–6)	1 (20%)	0 (0-0)

- A, Media-related websites (newspapers, publishers) and portal sites
- B, Patient association websites-patients' diaries, blogs by patients and/or their families
- C, Websites of medical institutions
- D, Websites of research institutions
- E, Websites of pharmaceutical companies
- F, Other websites that provide medical information^a
- G. Other

Table 2. Total number of outgoing link destinations by website category

	Number of sites in the category	Links to category A	Links to category B	Links to category C	Links to category D	Links to category E	Links to category F	Links to category G
Category A	14	1	103	22	15	0	67	27
Category B	34	49	443	28	66	23	127	62
Categories C	102	31	93	213	381	45	95	128
through G								

- A, Media-related websites (newspapers, publishers) and portal sites
- B, Patient association websites-patients' diaries, blogs by patients and/or their families
- C, Websites of medical institutions
- D, Websites of research institutions
- E, Websites of pharmaceutical companies
- F, Other websites that provide medical information
- G, Other

Table 2 shows the destinations of the outgoing links from the websites in each category. Both of the categories with a larger number of outgoing links (category A, media-related websites, and category B, patient-created websites) included links to patient associations, patients' diaries, and blogs by patients and/or their families (category B), and links to medical information sites (category F).

The single website receiving the most incoming links was the site of the National Cancer Center. Forty websites had a link to the site of the National Cancer Center, and 25 of these did not have any other outgoing links.

Characteristics of the websites of the National Cancer Center and the websites of other cancer based hospitals

As of December 2006, 179 hospitals in Japan had been certified as cancer based hospitals. 11 Of these hospitals, 13 had websites in the top 150 search results that we included in this study. We examined the characteristics of these 13 cancer based hospital websites plus the site of the National Cancer Center (Table 3). Seven of these hospitals are

located in the Kanto area, 2 in Tokai, 2 each in Chugoku and Shikoku, 1 in Tohoku, 1 each in Hokuriku and Shin'etsu, and 1 in Kyushu.

The median number of outgoing links for each of the 14 websites was 19.5 (range, 4 to 72). The proportion of the outgoing links that pointed to other cancer based hospital sites was over 40% from 6 of the 14 hospital sites, while it was less than 10% from the other hospital sites. Aichi Cancer Center¹² was the only 1 of the 13 cancer based hospitals whose website did not include a link to the site of the National Cancer Center. The number of backlinks to the site of National Cancer Center was the highest regardless of which search engine was used to measure the number of backlinks.

Eight of the cancer based hospital sites were publishing their own cancer information. Two of these websites included a search function. The Kyushu Cancer Center website¹³ instead included a link to the information service section of the site of the National Cancer Center.¹⁴ The published information was categorized as information on solid cancer (43.0%), blood and lymph node cancer (22.1%), treatments (27.3%), palliative care (3.4%), examinations (1.8%), and other (2.4%).

^a Organizations that operate these websites: corporations 8, foundations 6, patients and their families 6, doctors 2, medical institutions 3, academic or research organizations 2, medical association 1, nonprofit organizations 1, municipality 1, unknown 2

Table 3. Characteristics of the websites of the National Cancer Center and the based hospitals for diagnosis and treatment of cancers^a

Rank in	Name of	Search	Date of last Outgoing links	Outgoin	g links		Number of	Number of backlinks ^b				Cancer inform	Cancer information the site provides ^c	te provides	0	
Google search results		function	update	Total number of links	Number of links to based hospitals	Link to National Cancer Center	Indicated by Google	Indicated by Yahoo!	Indicated 'by MSN	Total	Solid	Blood or lymph node cancer	Treatments	Palliative care	Examination	Other
	National Cancer Yes	Yes	12, 12, 2006	21	10	NA	551	17600	5553	736575	268764	171 551	243840	33899	5664	12857
7	Center Aichi Cancer	No	18, 12, 2006	9	0	No	150	1210	786	92284	92284	0	0	0	0	0
∞	Center Shizuoka	No	13, 06, 2006	99	29	Yes	41	735	1166	0	0	0	0	0	0	0
12	Cancer Center Chiba Cancer	No	07, 12, 2006 19	19	11	Yes	24	394	482	0	0	0	0	0	0	0
14	Center Kanagawa Cancer	No	19, 12, 2006	4	0	Yes	42	364	909	0	0	0	0	0	0	0
18	Center National Kyushu Cancer	N _o	13, 12, 2006	13	0	Yes	30	436	965	_P 0	0	0	0	0	0	0
21	Center Shikoku Cancer	No	21, 12, 2006	20	2	Yes	21	267	603	111145	0	0	11145	0	0	0
22	Center Tochigi Cancer	Yes	15, 12, 2006	13	0	Yes	40	437	629	40383	22108	1 933	1 620	1483	5373	7866
28	Miyagi Cancer	No	01, 12, 2006	21	11	Yes	25	355	533	0	0	0	0	0	0	0
29	Center National Hospital	No	20, 05, 2004	6	0	Yes	18	399	578	9819	8782	0	1 037	0	0	0
	Organization Hokkaido Cancer															
30	Center Niigata Cancer	No	13, 12, 2006	25	10	Yes	70	384	1283	155 515	71121	962 296	17861	0	0	3737
31	Center Gunma Cancer	No	20, 11, 2006	17	1	Yes	26	241	421	1622	0	0	399	0	1223	0
32	Saitama Cancer	Yes	21, 12, 2006	32	21	Yes	6	255	909	29028	0	1549	18 077	750	6793	1859
65	National Hospital	No	21, 12, 2006	72	7	Yes	16	360	(662	0	0	0	0	0	0	0
	Organization Kure Medical															
	Center and Chugoku															
	Cancer Center															

^aData collected on December 21, 2006
^bNumber of backlinks was obtained using http://system.webtrigger.jp/backlink.php
^cNumber of words in the pages providing cancer information on the website
^dThe website had a link to the information service at the National Cancer Center

Table 4. Amount of information contained in the websites for academic associations

Association name	Number	of words of	Number of words of cancer information				Number of	Date of	Number of backlinks	acklinks	
	Total	Solid	Blood or lymph node cancer	Treatments	Palliative care	Examinations	outgoing links	last update	Indicated by Google	Indicated by Yahoo!	Indicated by MSN
Japanese Cancer Association	0	0	0	0	0	0	2	20, 12, 2006	107	4140	1948
Japanese Society of Pediatric Oncology	0	0	0	0	0	0	24	01, 04, 2004	0	89	166
The Japanese Association for Metastasis Research	0	0	0	0	0	0	9	05, 12, 2006	0	87	101
Japanese Association for Cancer Detection	0	0	0	0	0	0	4	05, 07, 2006	∞	82	128
The Japanese Society of Gastroenterological	3 230	0	0	0	0	3230	12	20, 12, 2006	11	171	129
The Japan Society of Hepatology	44091	44 091	0	0	0	0	19	21, 11, 2006	69	732	1482
Japanese Society of Cancer Nursing	0	0	0	0	0	0	5	08, 11, 2006	0	83	91

Characteristics of academic association websites

Seven of the 150 websites included in the study were operated by academic associations. Table 4 shows the characteristics of these seven academic association websites. The median number of outgoing links for these websites was 6 (range, 2 to 24). Two of the websites presented cancer information for patients in the form of documents. The academic association sites had a smaller number of backlinks than the cancer based hospital websites. Three of the sites had no backlinks at all (as indicated by the Google search engine).

Top-ranked search results compared between findings on July 19, 2006 and December 22, 2006

When the two lists of 50 top-ranked search results collected on July 19 and on December 22, 2006 were compared, 47 search results had different ranks (Table 5). Fifteen of the 50 top-ranked search results on December 22, 2006 were not in the July 19 list. There was one search result whose rank moved more than five places within the top 10 list between July and December, but there were 12 such search results in the top 50 list. The site of the National Cancer Center remained at the top both times.

Discussion

This study illuminates what cancer information is currently available on the internet. It also provides valuable information regarding the obstacles in creating websites that are useful from the patients' viewpoint.

Determining which organizations operate cancer-related websites is essential for understanding the current situation of cancer information on the internet. Table 1 shows the types of organizations operating the 150 websites investigated in this study. The fact that each of the four categories, B, C, D, and F operate approximately 20% of the websites indicates that patients, doctors, and researchers provide information from their viewpoints with equal frequency. The top 10 sites ranked by the Google search, however, are operated by four medical institutions, two foundations, two media-related organizations, and two corporations (Table 5). The top 10 list did not include any of the sites where patients can share their experiences. The top 10 list also did not contain any sites of government organization such as the Ministry of Health, Labour, and Welfare, or sites of any academic associations. This suggests a possible bias in the information currently available on the internet.

Many cancer-related websites are used by patients and other nonmedical experts. Certain efforts are required to create a website that is easy to use for people without medical expertise. First, a search function can contribute to the efficiency with which users can obtain relevant information. While 56% of the websites owned by media-related organizations and pharmaceutical companies contained a search function, only 14% of the other websites did (Table

Operating institution Aichi Cancer Center Kenko Shinbun, Inc. Information Desk Kanpo Gan Center, Toyo Kanpo Kenkyujo, Inc. Center, Cancer Shizuoka Cancer Human Balance, National Cancer Nikkei BP, Inc. Information Informatics International Franslational Medicalall Research Center Center LLC. NHK http://www.imic.or.jp/cancer/index.html http://www.pref.aichi.jp/cancer-center/ http://www.sinbun.co.jp/kenkou/link/ http://cancernavi.nikkeibp.co.jp/ http://www.nhk.or.jp/support/ http://www.y-assist.com/ http://cancerinfo.tri-kobe.org/ http://www.ncc.go.jp/jp/ http://www.gan3.com/ http://www.scchr.jp/ linkcan.html Address Symptoms, Chinese Medicine, Aichi Cancer Center, top page National Cancer Center home Traditional Chinese Medicine Fowards Improving Patients' Cancer Center for Cancer Link Collection for Cancer Unapproved Anticancer Quality of Life - Cancer Cancer Support Campaign Cancer Information Japan IMIC Cancer Information Shizuoka Cancer Center Drugs, Integrative Cancer Super Link^a Medicine ... Navigation Conquest 23, 12, 2006 Page title page Translational Research Human Balance, LLC Cancer Information International Medical Information Center Informatics Center, Chiba Cancer Center Operating institution Aichi Cancer Center Kanpo Gan Center, Kenkyujo, Inc. Shizuoka Cancer National Cancer Nikkei BP, Inc. Toyo Kanpo Center Desk NHK http://cancernavi.nikkeibp.co.jp/ http://www.pref.chiba.jp/byouin/ http://www.pref.aichi.jp/cancerhttp://www.gan3.com/ http://cancerinfo.tri-kobe.org/ http://www.nhk.or.jp/support/ http://www.imic.or.jp/cancer/ http://www.y-assist.com/ http://www.ncc.go.jp/jp/ http://www.scchr.jp/ index.html **Fable 5.** Changes in the top ten search results center/ Address gan/ treatment of cancer, Patients' Quality of Aichi Cancer Center, Colon cancer, Liver Chiba Cancer Center Center home page New possibilities for Cancer Super Linka Towards improving Cancer Information Chinese Medicine Cancer Center, Shizuoka Cancer National Cancer Life - Cancer Cancer Support Information IMIC Cancer Traditional cancer,... Navigation Campaign top page Page title 5, 8, 2006 Rank 0 € 4 S 9 _ ∞ 6 10

^aGan Gan Super-links, in Japanese

1). The National Cancer Center did not include a search function on the home page of its website, but it did include a search function on the pages of the Cancer Information Service section that is operated by its Cancer Information Service division. Considering that a lot of users access the home page of the National Cancer Center site, the National Cancer Center should reevaluate the placement of the search function. Furthermore, it is necessary to pay close attention to the orthographic representation of cancerrelated terms. For example, search results differed significantly when searching for different orthographic representations for the word "cancer" in Japanese ("gan" [hiragana character], "gan" [katakana character], and "gan" [kanji character]). The search rank of the National Cancer Center site decreased when the kanji (Chinese character) representation ("gan") was used as a search term. In contrast, a website owned by a private corporation was titled "gan · gan · gan Super-links (Cancer Super-links)," including all three orthographic representations.

Outgoing links and advertisements provide the users with opportunities to obtain related information. By following links, users can find websites that are related to the original site. In this study, we found that media-related websites and websites created by patients and/or their families contained many links. The median number of links was 13 for the media-related websites, and 15 for the websites created by patients and/or their families (Table 1). The websites created by patients and/or their families contained links to similar websites. This suggests that cancer patients are forming communities on the internet. We assume that the media-related websites have many links because they intend to develop into portal sites. The other websites had a median number of 0-4 outgoing links (Table 1). These sites primarily seemed to be interested in publishing their own information. Advertisements indicate the sponsors for a website, and examining the advertisements carried on a website might make it possible to detect certain biases in the website. 15 Most of the websites investigated in this study, however, did not carry any advertisements (Table 1). We conclude that commercial interests currently exert relatively little influence on cancer-related information on the Internet in Japan.

The cancer based hospitals in Japan¹¹ are institutions that are essential for cancer treatment. 16 In this study, 14 of the 150 top-ranked websites were websites for the National Cancer Center and for other cancer based hospitals. It is interesting to note that 7 of these 14 hospitals are located in the Kanto area, which suggests a disparity among different areas in the country. The website of the National Cancer Center had very different characteristics from those of the other cancer based hospital websites (Table 3). It contained by far the largest amount of general cancer information, and it can be considered as a central publishing institution for cancer information. Twelve of the 13 other cancer based hospital sites included a link to the website of the National Cancer Center. Among the 13 cancer based hospitals, the Niigata Cancer Center website¹⁷ and the Aichi Cancer Center website¹² contained a significant amount of general cancer information, but the amount of information

was not reflected in the search results ranking. In other words, users are not evaluating the cancer based hospital websites by the general cancer information available on them. The Shizuoka Cancer Center, which was ranked number 3 among the 14 hospital sites in the search results, did not include any general cancer information, but instead described a consulting service that could be accessed in person, by phone, or by home visit. We assume that such individualized services had popularized the hospital and its website. We expect that, in the future, the cancer based hospital websites will take on a different role from that of the National Cancer Center website, by providing information unique to each hospital, while the site of the National Cancer Center will continue to provide general cancer information.

While the hospital websites contained general cancer information, the websites of academic associations are considered useful in obtaining specialized cancer information. In this study, two of the seven websites for academic associations included some cancer information, but the extent of the information was small. The other five websites for academic associations did not contain any cancer information for patients. This may be due to the nature of academic associations, which are mainly fellowship organizations for facilitating communication among specialists. Cancer patients, however, are increasing their expectations of academic associations. Because academic associations include experts in very specific fields, they can provide information on rare cancers that cannot be treated in sufficient depth by cancer based hospitals. For example, neither pediatric hospitals nor cancer hospitals provide sufficient information on pediatric cancer, because neither type of hospital regards pediatric cancer as its core specialty. In a field such as this, it would be very useful if academic associations took the initiative in providing and publishing relevant information.

This study has shown that there is an abundance of cancer-related information available on the internet. It has also shown that the usability of websites for cancer patients needs to be improved. While the National Cancer Center website is taking the lead in providing general cancer information, the local cancer based hospital websites are expected to provide the individualized information that patients also require. In the future, a system for providing cancer-related information needs to be created that can answer a variety of patient needs.

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