

Original Paper

Blog Posting After Lung Cancer Notification: Content Analysis of Blogs Written by Patients or Their Families

Akira Sato^{1*}, MD, MPH; Eiji Aramaki^{2*}, PhD; Yumiko Shimamoto², CPsychol; Shiro Tanaka³, PhD; Koji Kawakami³, MD, PhD

¹Department of Respiratory Medicine, Yokohama Municipal Citizen's Hospital, Yokohama, Japan

²Design School, Kyoto University, Kyoto, Japan

³Department of Pharmacoepidemiology, Graduate School of Medicine and Public Health, Kyoto University, Kyoto, Japan

*these authors contributed equally

Corresponding Author:

Eiji Aramaki, PhD

Design School

Kyoto University

5th floor Bldg. #9 Kyoto Research Park 91 Awata-cho, Chudoji, Shimogyo-ku

Kyoto, 600-8813

Japan

Phone: 81 9040335481

Fax: 81 753158981

Email: eiji.aramaki@design.kyoto-u.ac.jp

Abstract

Background: The advent and spread of the Internet has changed the way societies communicate. A portion of information on the Internet may constitute an important source of information concerning the experiences and thoughts of patients and their families. Patients and their families use blogs to obtain updated information, search for alternative treatments, facilitate communication with other patients, and receive emotional support. However, much of this information has yet to be actively utilized by health care professionals.

Objective: We analyzed health-related information in blogs from Japan, focusing on the feelings and satisfaction levels of lung cancer patients or their family members after being notified of their disease.

Methods: We collected 100 blogs written in Japanese by patients (or their families) who had been diagnosed with lung cancer by a physician. These 100 blogs posts were searchable between June 1 and June 30, 2013. We focused on blog posts that addressed the lung cancer notification event. We analyzed the data using two different approaches (Analysis A and Analysis B). Analysis A was blog content analysis in which we analyzed the content addressing the disease notification event in each blog. Analysis B was patient's dissatisfaction and anxiety analysis. Detailed blog content regarding patient's dissatisfaction and anxiety at the individual sentence level was coded and analyzed.

Results: The 100 blog posts were written by 48 men, 46 women, and 6 persons whose sex was undisclosed. The average age of the blog authors was 52.4 years. With regard to cancer staging, there were 5 patients at Stage I, 3 patients at Stage II, 14 patients at Stage III, 21 patients at Stage IV, and 57 patients without a disclosed cancer stage. The results of Analysis A showed that the proportion of patients who were dissatisfied with the level of health care exceeded that of satisfied patients (22% vs 8%). From the 2499 sentences in the 100 blog posts analyzed, we identified expressions of dissatisfaction and anxiety in 495 sentences. Our results showed that there were substantially more posts concerning "Way of living, reasons for living, set of values" and "Relationships with medical staff (own hospital)" than in previous studies (Analysis B).

Conclusions: This study provides insight into the feelings of dissatisfaction and anxieties held by lung cancer patients and their families, including those regarding the "Way of living, reasons for living, set of values" and "Relationship with medical staff (own hospital)," which were inaccessible in previous survey analyses. When comparing information obtained from patients' voluntary records and those from previous surveys conducted by health care institutions, it is likely that the former would be more indicative of patients' actual opinions and feelings. Therefore, it is important to utilize such records as an information resource.

KEYWORDS

blog; lung cancer; notification; content analysis; communication; Internet

Introduction

The advent and spread of the Internet has fundamentally changed the way societies communicate in recent years. In an analysis of websites, blogs, and social networking sites [1], Japan's Ministry of Internal Affairs and Communications reported a surge in the number of online blogs published in Japan between 2004 and 2005. The number of blogs passed the 10 million mark in January 2006, and has since continued to increase steadily. In 2007, blog search engine company Technorati revealed that blog posts written in Japanese were the most prevalent throughout the world, accounting for 37% of the world's total (approximately 70 million blog posts) and surpassing the number of English-language posts (36%) [2]. A portion of these blog posts may constitute an important source of information concerning the experiences and thoughts of patients and their families. Looking into personal articles on social networking sites may indicate particular and specific problems. However, the collection of such particular claims from individuals may be able to provide a broader view of patients' experience. At the same time, the rumors spreading through social networking sites are very effective [3], and it is reasonable to prevent the negative reputation of the hospital by paying attention to such social networking sites' articles.

Approximately 40% of people in the United States have been reported to obtain health-related information through the Internet and email [4]. A similar proportion (39%) was reported in a survey conducted in Japan [5]. According to that survey, many frequent users of the Internet are women, are in good health, are aged in their 20s and 30s, earn annual salaries of US \$30,000 or more, and possess at least a high-school education. Among these Internet users, approximately 68% responded that the information acquired online helped to improve their understanding of symptoms, conditions, and treatments. In addition, more than 60% of Internet users reported an increased sense of assurance after acquiring health-related information. However, almost 84% of respondents reported no attempts to inform health care professionals about their online acquisition of information [5].

An analysis of daily posts regarding common cancers on blogs and discussion forums showed that posts concerning breast cancer were the most frequent, followed by prostate cancer, colon cancer, and lung cancer [6]. Most of these posts (65.8%) were published on media sites, whereas blog posts accounted for approximately 15%. These studies underline the growing trends in acquiring health-related information online, and the Internet is expected to fulfill an increasingly important role as an information source in the future.

The Internet is also garnering attention for its potential applications in accessing and applying information posted by patients or their families as a means of gaining insight into their experiences and thoughts. According to a study by Kim and

Chung [7], patients and their families use blogs to obtain updated information, search for alternative treatments, facilitate communication with other patients, and receive emotional support. However, much of this information has yet to be actively utilized by health care professionals. Recently, there has been an increase in the number of patients who, after receiving treatment, publish their experiences and sentiments online through blogs. This trend represents an important opportunity for health care professionals to become more aware of patients' complaints. Although health-related information acquired online is not a viable replacement for direct communication with a health care professional, this information may fulfill a supplementary role in facilitating patient understanding.

In 2011, a total of 357,305 patients (213,190 men and 144,115 women) in Japan died due to malignant neoplasms, with the prevailing cancers being those of the trachea, bronchi, and lungs (70,293 deaths) [8]. It is no longer unusual for people in Japan to know or to have lost close relatives with cancer. A previous study [9] has shown that diagnosing and notifying patients with cancer did not increase patient pain or feelings of anxiety. However, many cases of lung cancer are already at advanced stages upon detection, and notifying patients of their condition can have an immense effect on their psychological well-being. Therefore, health care professionals should notify their patients about their health status after careful consideration, while also being aware of the sensitivity of the issue. According to a Patient's Behavior Survey conducted by the Japanese Ministry of Health, Labour and Welfare (MHLW) in 2011 [10], 86.1% of outpatient respondents and 92.3% of inpatient respondents reported that they had been briefed by physicians about the medical care and treatment strategies for their disease. In addition, 96.6% of outpatient respondents and 93.7% of inpatient respondents stated that they had understood these briefings. By contrast, the proportions of respondents who felt that they were sufficiently able to communicate their inquiries and opinions about these briefings to their physicians were substantially lower, at 68.7% and 62.8% in outpatients and inpatients, respectively. It is therefore difficult to state that the current level of physician-patient communication in Japan is adequate.

Although numerous papers on doctor-patient relationship or interaction have been published [11], these have mainly focused on their conversation [12], and several studies have pointed out that the authority of the medical staff might have kept the patient rather quiet [13]. This suggests that the patients cannot express their true feelings in front of their medical staff, and thus, their anxiety remains under the surface.

Whereas the positive nature of health care systems makes it difficult to incorporate patient complaints and opinions, clinical trials that include patient-reported outcomes have begun to sporadically appear, such as in cancer chemotherapy trials [14]. This shift reaffirms the necessity of understanding patients' complaints [15], and it is important to provide a channel for

patient opinions to be heard in various settings where physicians and patients would otherwise have limited direct communication.

Although online blog posts are likely to encompass various biases, such as the bias that exaggerates the negative impression of medical care provided, it is important to focus on the fact that there are so much anxieties that patients have to face, but unable to express in front of their medical staff or any other people they deal with. Therefore, it is necessary to reduce as much anxiety of patients as possible for their better quality of life. These blog posts may contain important information such as the preferences, misgivings, and satisfaction levels of patients and their families. This allows health care providers to gain greater insight into previously inaccessible information. In this study, we analyze health-related information in blogs from Japan, focusing on the feelings and satisfaction levels of lung cancer patients or their family members after being notified of their disease.

Methods

Sample Selection

In this study, we focused on blog posts written in Japanese and published by patients (or their families) who had been diagnosed with lung cancer by a physician. The study protocol was approved by the Kyoto University Graduate School and Faculty of Medicine Ethics Committee (No 1070) on January 10, 2014.

Selection Criteria

We analyzed blogs written by lung cancer patients or their families whose blog posts were searchable between June 1 and June 30, 2013. We focused on blog posts that addressed the lung cancer notification event. *Families* were defined as patients' relatives living together with the patient or those within three degrees of kinship.

Exclusion Criteria

Blogs without posts that addressed the lung cancer notification event were excluded from analysis. Determining whether a blog had included a post about disease notification was analyzed by two investigators working independently and blinded to each other's results. Blogs were also excluded if the post addressing disease notification had been published 3 years or more after the notification event.

The *notification event* in this study was regarded as the moment when the patient or his/her family (or both in some cases) was revealed that the patient had malignant tumor. We did *not* consider the notifications by comedical staff and/or those after re-examination.

Data Collection

Overview

Data were collected using two methods, namely, by Internet search and via link-collection website. These methods are described in the following sections.

Method 1: Internet Search

We searched for various permutations of the following terms in Japanese using the Google search engine: "lung cancer," "record of struggle against disease," "blog," and "journal." We collected information from blogs addressing people's struggles with lung cancer within the top 500 search results. However, we excluded sites containing duplicate identical entries with different dates and sites that were not blogs.

Method 2: Link-Collection Website

The TOBYO website [16] hosts a collection of links for Japanese blogs documenting people's struggles with disease. Using this website, we collected information in the order of newest blog entries first. The TOBYO website collects and posts links to blogs that fulfill the following criteria:

- Blogs that contain an adequate amount of information addressing a person's struggle with disease (including 10 screen pages or more of such information).
- Blogs that do not sell health foods or supplements, attempt religious proselytization, or solicit readers to join political/patient advocacy organizations or health care institutions.
- Blog sites that are appropriately constructed (ie, websites do not include excessive advertisements or Web animations).

The number of blogs that we could use in this research filtering by applying Methods 1 and 2 was 150 blogs written by 150 lung cancer patients and/or their family members.

Detection of Notification Event

We extracted the blog entries that indicated the moment of notification. The entries were handpicked, and of the 150 blogs, we obtained 100 articles that contained notification event.

Data Formatting

We broke down the 100 blog articles into multiple sentences, based on punctuation and some specific expressions, such as smiley, which Japanese people considered as the end of the sentence. The average number of sentences per one blog article was 25.

Study Items

Overview

We analyzed the data using the following two approaches: Analysis A, which was conducted using individual blogs as the unit for study; and Analysis B, which was conducted using individual sentences within blog posts as the unit for study.

Analysis A: Blog Content

We analyzed the content addressing the disease notification event in each blog. Qualitative data items (sex, age, date of disease notification) were coded by allocation to a category or assignment of a numerical value. For cases where patient age was ambiguous, age was estimated using the available information. For example, patients who stated that they were in their "mid-30s" were included in analysis as being 35 years of age. Because only the author's information is provided within the posted articles, we completely reviewed the articles and

extracted the necessary information, such as age, gender, stage. The information extracted is presented in [Table 1](#).

Table 1. Results of coding of the blog content (n=100 blogs).

Coding items	Sex			Total
	Men	Women	Undisclosed	
Date of blog post relative to disease notification date				
Not indicated	4	4	2	10
Identical to notification date	10	7	1	18
After notification date	34	35	3	72
Blog author				
Patient	30	24	3	57
Family member	18	22	3	43
Person who received notification				
Not indicated	14	16	3	33
Patient only	20	12	2	34
Family member(s) only	4	4	0	8
Both patient and family member(s)	10	14	1	25
Person who requested notification				
Not indicated	33	33	3	69
Patient only	0	1	0	1
Family member(s) only	0	0	0	0
Both patient and family member(s)	2	3	1	6
Based solely on physician discretion	13	9	2	24
Family history of cancer				
Not indicated	47	44	6	97
Yes	1	2	0	3
No	0	0	0	0
Cancer stage at notification				
Not indicated	26	29	2	57
Stage I	2	3	0	5
Stage II	3	0	0	3
Stage III	6	6	2	14
Stage IV	11	8	2	21
Type of medical treatment				
Not indicated	21	21	4	46
Surgery	5	10	1	16
Radiotherapy	2	2	0	4
Combination of radiotherapy and chemotherapy	4	4	0	8
Chemotherapy	14	9	1	24
Alternative therapies	1	0	0	1
Combination of radiotherapy and alternative therapies	1	0	0	1
Patient actions after notification				
Not indicated	32	33	5	70
Retrieved information from the Internet and books	6	5	0	11
Arranged their personal affairs	1	0	0	1
Informed family members	1	2	0	3

Coding items	Sex			
	Men	Women	Undisclosed	Total
Informed nonfamily members (eg, employer)	0	1	0	1
Started their blog	6	1	0	7
Closed down their blog	1	0	0	1
Commenced treatment approaches different to their physician's recommendation	0	2	0	2
Combination of several of the above actions	1	2	1	4
Satisfaction toward health care				
Not indicated	30	34	5	69
Dissatisfied with physician's treatment	6	7	0	13
Dissatisfied with provided care	4	0	1	5
Dissatisfied with both physician's treatment and provided care	2	2	0	4
Satisfied with physician's treatment	4	1	0	5
Satisfied with provided care	1	0	0	1
Satisfied with both physician's treatment and provided care	1	1	0	2
Dissatisfied with physician's treatment but satisfied with provided care	0	1	0	1

The two coders coded each sentence by hand, and they did not use lexical items. They used the Shizuoka Classification System categories as a reference and labeled every sentence with the category. The Shizuoka Classification System has been built based on the 7885 cancer patients' complaints (made via phone calls) received by the Shizuoka Cancer Center. All complaints were sorted by hand, and were summarized into 20,000 descriptions of the patients' anxieties and burdens. These were then divided into 15 primary categories, 35 secondary categories, 129 tertiary categories, and 623 micro categories.

- First, the coders estimated whether the sentence contained any content regarding dissatisfaction and anxiety (binary classification).
- Second, they classified the sentences with dissatisfaction and anxiety information according to the Shizuoka Classification System (multilabel classification).

The two coders first worked on the material independently using a small dataset (120 sentences) to see how much agreement they could obtain. They obtained a high percentage of agreement (98/120, approximately 82%), and the conflicts were finally resolved by discussion. As mentioned earlier, the coding procedure was performed independently by two individuals, and discrepancies in coding were resolved after obtaining consensus through discussions. In addition, several codes, such as the coding for "satisfaction toward health care," were anticipated to be relatively subjective. We therefore examined the inter-rater agreement before obtaining consensus using the kappa coefficient. Kappa coefficient values were interpreted as follows: <0, No Agreement; .01-.20, Slight Agreement; .21-.40, Fair Agreement; .41-.60, Moderate Agreement; .61-.80, Substantial Agreement; and .81-.99, Almost Perfect Agreement [17].

Analysis B: Patient's Dissatisfaction and Anxiety

Detailed blog content regarding patient's dissatisfaction and anxiety at the individual sentence level was coded and analyzed. First, an analysis was conducted to identify whether dissatisfaction or anxiety was addressed in each of the sentences in the targeted blog posts (2499 sentences in the 100 blog posts). Next, sentences addressing dissatisfaction and anxiety were categorized according to the type of misgiving described. The sentences were categorized according to the Shizuoka Classification System, which was developed by the Shizuoka Cancer Center, Japan. The Shizuoka Classification System is based on the results of a national survey conducted by the Joint Study Group on the Sociology of Cancer. In that survey, the various dissatisfactions and anxieties of 7855 patients were organized and grouped into a structured hierarchy of indicators beginning with 15 primary categories that were further subcategorized [18]. In this study, we only used the 15 primary categories. This coding procedure was performed by a single individual. However, the following five items from the Shizuoka Classification System were expected to include content that could be interpreted in several ways: "Diagnosis/treatment," "Notification, informed consent, second opinion," "Anxiety and other mental problems," "Way of living, reasons for living, sense of values," and "Relationships with family and other people." For these categories, coding was performed by two individuals, and the kappa coefficient was used to analyze inter-rater agreement in 250 sentences among the 2499 sentences (approximately 10% of the data). Discrepancies in coding were resolved after obtaining consensus through discussions by the authors. Because the inter-rater agreement was high (kappa coefficient=.67), the remaining 2259 sentences among the 2499 sentences (approximately 90% of the data) were coded by a single individual.

Results

Overview

Using Method 1, we identified 58 eligible blogs; using Method 2, we identified 92 eligible blogs. However, we excluded 50 blogs that did not have entries addressing disease notification, and thus, a total of 100 blogs were used in the final analysis.

Analysis A: Blog Content

Table 1 shows the results of the final coding, in which nine coding items were used. The 100 blog posts were written by 48 men, 46 women, and 6 persons whose sex was undisclosed. The average age of the blog authors was 52.4 years. A higher proportion of the blogs (57%, 57/100) were written by the patients themselves, with 43% (43/100) written by family members. With regard to cancer staging, there were 5 patients at Stage I, 3 patients at Stage II, 14 patients at Stage III, 21 patients at Stage IV, and 57 patients without a disclosed cancer stage. There was a moderate level of inter-rater agreement in the coding for “satisfaction toward health care” ($\kappa=.58$). The results showed that the proportion of patients who were

dissatisfied with the level of health care exceeded that of satisfied patients (Unclear, 69/100, 69%; Satisfied, 8/100, 8%; Dissatisfied, 22/100, 22%; and Elements of both satisfaction and dissatisfaction, 1/100, 1%).

Analysis B: Patient’s Dissatisfaction and Anxiety

From the 2499 sentences in the 100 blog posts analyzed, we identified expressions of dissatisfaction and anxiety in 495 sentences. The results of this classification are presented in Table 2. In addition, the detailed points of patient’s dissatisfaction and anxiety are presented in Table 3. There was substantial inter-rater agreement for the five possibly ambiguous categories, with an average kappa coefficient of .67 (Table 4). The following expressions of dissatisfaction and anxiety were commonly noted in these 495 sentences: “Way of living, reasons for living, sense of values” (28.1%, 139/495), “Notification, informed consent, second opinion” (25.9%, 128/495), and “Diagnosis/treatment” (17.0%, 84/495). Our results showed that there were substantially more posts concerning “Way of living, reasons for living, sense of values” and “Relationships with medical staff (own hospital)” than in previous studies (Figure 1).

Table 2. Results of classification of patient’s dissatisfaction and anxiety in 495 sentences (n=100 blogs).

Category	Categories and their description	n (%)
1	Outpatient	9 (1.8)
2	Hospitalization/discharge/hospital change	18 (3.6)
3	Diagnosis/treatment ^a	84 (17.0)
4	Palliative care	12 (2.4)
5	Notification, informed consent, second opinion ^a	128 (25.9)
6	Medical coordination	1 (0.2)
7	Home care	3 (0.6)
8	Facility and equipment/access	1 (0.2)
9	Relationships with medical staff (own hospital)	27 (5.5)
10	Relationships with medical staff (other hospitals)	1 (0.2)
11	Symptoms, side-effects, after-effects	26 (5.3)
12	Anxiety and other mental problems	33 (6.7)
13	Way of living, reasons for living, sense of values ^a	139 (28.1)
14	Work, economic burdens	0 (0)
15	Relationships with family and other people	13 (2.6)

^aTop three classifications used in this research

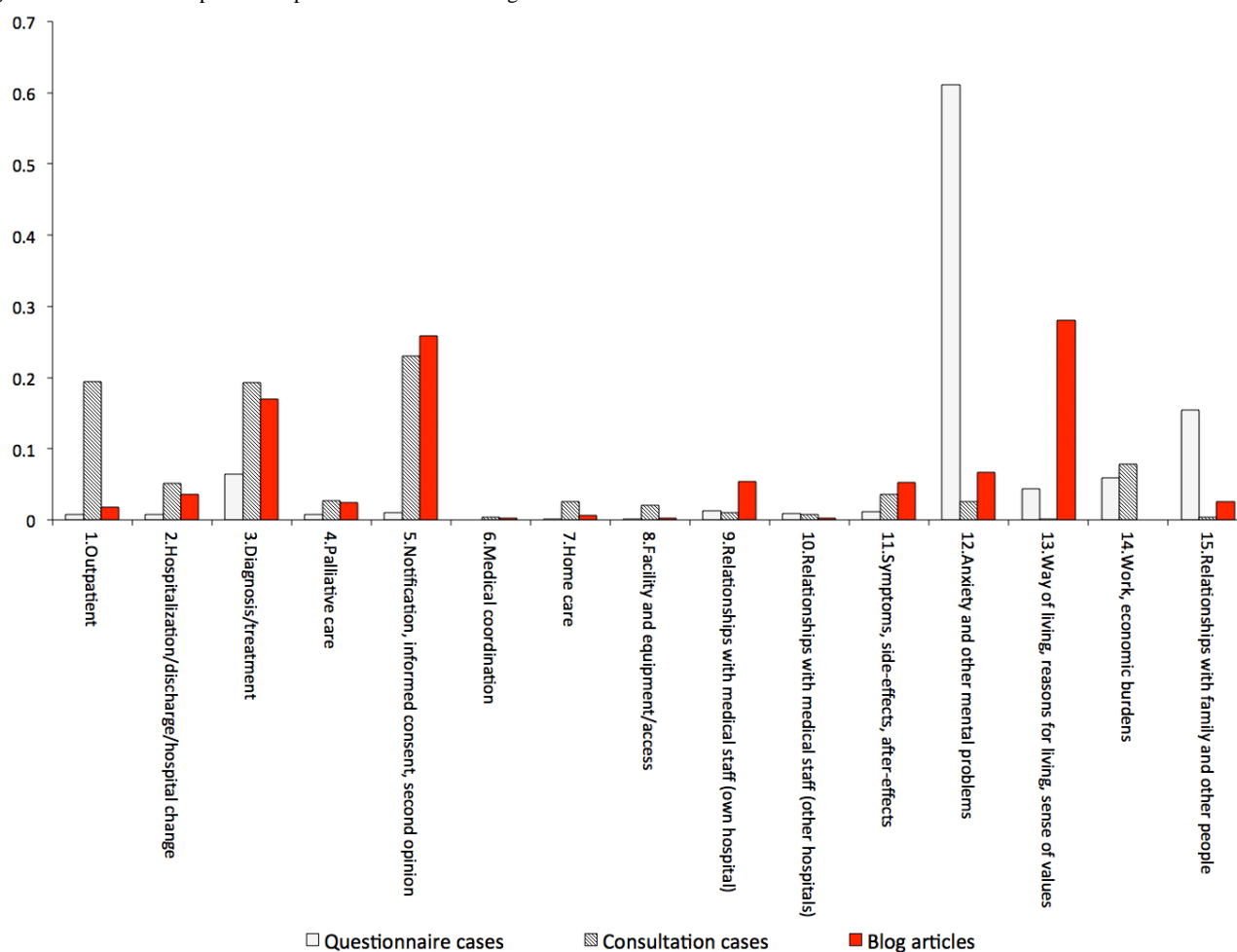
Table 3. Some examples of the actual social networking site posts by patients and their family members (n=100) with Shizuoka Classification System categories.

Shizuoka Classification System category	Posts by the patients
3	“For the first time, I thought I wanted to die...”
3	“I asked what would happen if I left the way as it was, and the answer was I would die within 2 to 3 months, besides, it might be no use even if I had the treatment.”
5	“Mother begged, ‘Please give me a day to think about it’, but the doctor said she did not have much time left for that.”
5	“The doctor told us, ‘I think it is most likely cancer’, and it might have been the notification towards my husband and I. I felt very uncomfortable that he didn’t make it clear that it actually WAS cancer.”
13	“I still have so much I want to do before I die.”
13	“I had a strong will to be cured completely.”
15	“But I pretended I did know nothing in front of my family when I was notified that I only have 1 year left.”
15	“When should I tell my children that I have lung cancer.”

Table 4. Kappa coefficient values of five primary categories in the Shizuoka Classification System.

Category	Description	Statistics ^a	Coefficient value ^a
3	Diagnosis/treatment	.44	Fair agreement
5	Notification, informed consent, second opinion	.71	Moderate agreement
12	Anxiety and other mental problems	.88	Substantial agreement
13	Way of living, reasons for living, sense of values	.69	Moderate agreement
15	Relationships with family and other people	.61	Moderate agreement

^aThe average kappa coefficient obtained was .67, with “moderate agreement” coefficient value.

Figure 1. Results of comparison of previous studies and blog articles.

Discussion

Analysis A: Blog Content

A survey conducted by the MHLW [10] reported that the number of outpatient respondents who were satisfied (49.7%) with the overall care was much higher than those who were dissatisfied (4.4%). By contrast, our analysis—which was not limited to surveys conducted on the day of cancer notification—revealed a large proportion of patients who were dissatisfied with the level of care provided, particularly with regard to their treatment by physicians (13%, 13/100). This proportion of dissatisfied patients was 5 times higher than in the survey conducted by the MHLW. When taking into account the previous discovery that 84% of patients did not share their knowledge of health-related information with health professionals, these findings indicate a lack of active communication between patients and health care providers in Japan. This also suggests the possibility that patients are seeking to voice their opinions through other media. In particular, our study shows the reactions and feelings toward lung cancer notification in middle-aged to senior patients (average age, 52.4 years) who utilize the Internet (with 57%, 57/100, of blog posts written by the patients themselves).

Our analysis focuses only on blog entries that address the lung cancer notification event, where it would be unlikely for patients to express satisfaction toward health care providers. Even among

patients who felt dissatisfied with their treatment by physicians during the notification event, it is possible that the feelings of dissatisfaction would shift to feelings of satisfaction if the patients were surveyed again at a later date. As a result, patients' relationships with health care professionals should be regarded an important determinant of patient's satisfaction level when considering the previously reported high levels of satisfaction.

This study has dealt with the very moment of notification, because it is the point at which the patients' lives have been literally changed, and the articles analyzed were posted not only by the patients themselves but also by their family members, which shows that the cancer notification has a significant impact on the family members as well. This research showed and suggested that after notification, additional supports are required for family members as well.

There are some limitations in this study. Because the prevalence of lung cancer is generally higher in older people, it is likely that the blog authors included in this study are not representative of the overall lung cancer patient population, but instead reflect the feelings of a specific group. The blog post authors represent a group of people who are able to publish such information, and it is therefore necessary for future studies to also include the experiences from patients who are unable to utilize this form of media. A survey regarding the information sources for health-related information in Japan found that approximately 39% of respondents used the Internet or email, with the majority

of these users being in their 20s and 30s [5]. However, as the computer-literate population ages and the use of the Internet continues to spread, there will be a higher proportion of persons in their 50s or older who acquire health-related information online, which subsequently will increase the number of eligible study patients.

Analysis B: Patient's Dissatisfaction and Anxiety

According to a survey conducted by the MHLW [18], patients may or may not seek counseling for a specific disease-related anxiety, depending on the type of concern. For example, patients may actively discuss their treatment options with health care professionals. However, patients may presume that discussions related to symptoms or drug adverse effects would not help to solve these issues, and may therefore choose not to discuss these points with health care professionals despite addressing them in survey responses. Survey items (according to the Shizuoka Classification System) that are not usually discussed include "Symptoms, side-effects, after-effects," "Anxiety and other mental problems," "Way of living, reasons for living, sense of values," and "Relationships with family and other people." In addition, although responses for "Way of living, reasons for living, sense of values" and "Relationships with medical staff (own hospital)" were generally unobtainable in previous studies, our results showed that these important points of anxiety were addressed in blogs. There was a substantially higher number of blog posts that included dissatisfaction and anxieties related to "Way of living, reasons for living, sense of values" after the

lung cancer notification event, indicating that the notification had a considerable effect on patients' approaches to living and their sense of values.

Patients may be unwilling to describe their misgivings in their relationships with current health care providers in surveys conducted by the providers themselves. As a result, when considering patients' efforts to seek alternative treatments or engage in "doctor shopping," voluntary records of patients' opinions are likely to be better indicators of their actual feelings when compared with surveys conducted by health care institutions. In the future, it would be advantageous to develop an automated sampling system that could identify patients concerns regarding their interactions with health care institutions from written content.

Conclusions

This study provides insight into the feelings of dissatisfaction and anxieties held by lung cancer patients and their families, including those regarding the "Way of living, reasons for living, sense of values" and "Relationships with medical staff (own hospital)," which were inaccessible in previous survey analyses. In this analysis, we were able to obtain precise statistics at the point of cancer notification. When comparing information obtained from patients' voluntary records and that from previous surveys conducted by health care institutions, it is likely that the former would be more indicative of patients' actual opinions and feelings, and it is therefore important to utilize such records as an information resource.

Acknowledgments

This study received no external funding. The authors are grateful to the department technical assistants (Mr Kay Kubo and Ms Shuko Shikata) for their contributions to the coding of the blog content.

Authors' Contributions

AS and EA conceived the basic strategies. ST and KK supervised the project. YS performed profile analysis with programs developed with EA. AS and EA designed experiments, analyzed data, and wrote the paper.

Conflicts of Interest

None declared.

References

1. Institute for Information and Communications Policy, Ministry of Internal Affairs and Communications. Research on the Actual Investigation of the Blog. Tokyo: Ministry of Internal Affairs and Communications; 2009. URL: <http://www.soumu.go.jp/iicp/chousakenkyu/data/research/survey/telecom/2009/2009-02.pdf> [accessed 2014-09-23] [WebCite Cache ID 6SnETQeBX]
2. Sifry D. The State of the Live Web. 2007. URL: <http://www.sifry.com/alerts/archives/000493.html> [accessed 2014-08-30] [WebCite Cache ID 6SCjE2ik1]
3. DiFonzo N, Robinson NM, Suls JM, Rini C. Rumors about cancer: Content, sources, coping, transmission, and belief. *J Health Commun* 2012;17(9):1099-1115. [doi: [10.1080/10810730.2012.665417](https://doi.org/10.1080/10810730.2012.665417)] [Medline: [22724591](https://pubmed.ncbi.nlm.nih.gov/22724591/)]
4. Baker L, Wagner TH, Singer S, Bundorf MK. Use of the Internet and e-mail for health care information: Results from a national survey. *JAMA* 2003 May 14;289(18):2400-2406. [doi: [10.1001/jama.289.18.2400](https://doi.org/10.1001/jama.289.18.2400)] [Medline: [12746364](https://pubmed.ncbi.nlm.nih.gov/12746364/)]
5. Takahashi Y, Ohura T, Ishizaki T, Okamoto S, Miki K, Naito M, et al. Internet use for health-related information via personal computers and cell phones in Japan: A cross-sectional population-based survey. *J Med Internet Res* 2011;13(4):e110. [doi: [10.2196/jmir.1796](https://doi.org/10.2196/jmir.1796)] [Medline: [22169526](https://pubmed.ncbi.nlm.nih.gov/22169526/)]
6. Quinn EM, Corrigan MA, McHugh SM, Murphy D, O'Mullane J, Hill AD, et al. Who's talking about breast cancer? Analysis of daily breast cancer posts on the internet. *Breast* 2013 Feb;22(1):24-27. [doi: [10.1016/j.breast.2012.05.001](https://doi.org/10.1016/j.breast.2012.05.001)] [Medline: [22683246](https://pubmed.ncbi.nlm.nih.gov/22683246/)]

7. Kim S, Chung DS. Characteristics of cancer blog users. *J Med Libr Assoc* 2007 Oct;95(4):445-450 [FREE Full text] [doi: [10.3163/1536-5050.95.4.445](https://doi.org/10.3163/1536-5050.95.4.445)] [Medline: [17971894](https://pubmed.ncbi.nlm.nih.gov/17971894/)]
8. Ministry of Health, Labour and Welfare. Summary Report of Vital Statistics of Japan. Tokyo: Ministry of Health, Labour and Welfare; 2013. URL: http://www.mhlw.go.jp/toukei/saikin/hw/jinkou/kakutei13/dl/11_h7.pdf [accessed 2014-09-23] [WebCite Cache ID 6SnF5bY9I]
9. Lundquist G, Rasmussen BH, Axelsson B. Information of imminent death or not: Does it make a difference? *J Clin Oncol* 2011 Oct 10;29(29):3927-3931 [FREE Full text] [doi: [10.1200/JCO.2011.34.6247](https://doi.org/10.1200/JCO.2011.34.6247)] [Medline: [21911715](https://pubmed.ncbi.nlm.nih.gov/21911715/)]
10. Ministry of Health, Labour and Welfare. Patient's Behavior Survey. Tokyo: Ministry of Health, Labour and Welfare; 2011. URL: <http://www.mhlw.go.jp/english/database/db-hss/pbs.html> [accessed 2015-04-22] [WebCite Cache ID 6XyaMsOkY]
11. Teutsch C. Patient-doctor communication. *Med Clin North Am* 2003 Sep;87(5):1115-1145. [Medline: [14621334](https://pubmed.ncbi.nlm.nih.gov/14621334/)]
12. Maynard DW, Heritage J. Conversation analysis, doctor-patient interaction and medical communication. *Med Educ* 2005 Apr;39(4):428-435. [doi: [10.1111/j.1365-2929.2005.02111.x](https://doi.org/10.1111/j.1365-2929.2005.02111.x)] [Medline: [15813766](https://pubmed.ncbi.nlm.nih.gov/15813766/)]
13. Pilnick A, Dingwall R. On the remarkable persistence of asymmetry in doctor/patient interaction: A critical review. *Soc Sci Med* 2011 Apr;72(8):1374-1382. [doi: [10.1016/j.socscimed.2011.02.033](https://doi.org/10.1016/j.socscimed.2011.02.033)] [Medline: [21454003](https://pubmed.ncbi.nlm.nih.gov/21454003/)]
14. Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013 Jan 28;346:f167. [doi: [10.1136/bmj.f167](https://doi.org/10.1136/bmj.f167)] [Medline: [23358487](https://pubmed.ncbi.nlm.nih.gov/23358487/)]
15. Lasch KE, Marquis P, Vigneux M, Abetz L, Arnould B, Bayliss M, et al. PRO development: Rigorous qualitative research as the crucial foundation. *Qual Life Res* 2010 Oct;19(8):1087-1096 [FREE Full text] [doi: [10.1007/s11136-010-9677-6](https://doi.org/10.1007/s11136-010-9677-6)] [Medline: [20512662](https://pubmed.ncbi.nlm.nih.gov/20512662/)]
16. TOBYO. Illness Narrative of Japan 45000. 2014. URL: <http://www.toby.jp/> [accessed 2015-04-22] [WebCite Cache ID 6XyaXPfnT]
17. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977 Mar;33(1):159-174. [Medline: [843571](https://pubmed.ncbi.nlm.nih.gov/843571/)]
18. Yamaguchi K, Joint Study Group on the Sociology of Cancer. A report on research into the anxieties and burdens of cancer sufferers: The views of 7,885 people who faced up to cancer. Shizuoka: Shizuoka Cancer Center; 2004 Jun 01. URL: http://www.scchr.jp/yorozu/pdf/taiken_koe_eng.pdf [accessed 2015-05-04] [WebCite Cache ID 6YGyUzdRS]

Abbreviations

MHLW: Ministry of Health, Labour and Welfare

Edited by G Eysenbach; submitted 30.09.14; peer-reviewed by S Persky, B Davis; comments to author 20.02.15; revised version received 09.04.15; accepted 17.04.15; published 18.05.15

Please cite as:

Sato A, Aramaki E, Shimamoto Y, Tanaka S, Kawakami K

Blog Posting After Lung Cancer Notification: Content Analysis of Blogs Written by Patients or Their Families

JMIR Cancer 2015;1(1):e5

URL: <https://cancer.jmir.org/2015/1/e5/>

doi: [10.2196/cancer.3883](https://doi.org/10.2196/cancer.3883)

PMID: [28410169](https://pubmed.ncbi.nlm.nih.gov/28410169/)

©Akira Sato, Eiji Aramaki, Yumiko Shimamoto, Shiro Tanaka, Koji Kawakami. , 18.05.2015.