

cumulative survival of women with screening-detected and interval cancer by reference to the Miyagi Prefectural Cancer Registry, one of the oldest and most reliable population-based cancer registries in Japan [11]. As in western countries, RCTs are required for evaluation of the effectiveness of MMG [15], but in Japan this is not realistic because many women have been included in the MMG program through studies to evaluate the efficacy of MMG [4–8] and because of endorsement by the Ministry of Health, Labour and Welfare in 2000. Therefore, this retrospective cohort study is one of the best recent attempts to clarify whether MMG is able to reduce breast cancer mortality in Japan.

Here we found that 5-year survival was over 90 % for women whose cancers had been detected by MMG with CBE, and by CBE alone. Survival of women who had been screened by use of MMG with CBE was significantly better than that of women who had been screened by use of CBE alone, or whose cancers had been self-detected. One possible reason for this better survival was the lower proportion of interval cancers in the group screened by use of MMG with CBE (18.6 %; 80/429) than in the group screened by use of CBE alone (40.0 %; 209/522). A previous study demonstrated that interval cancers tended to be more advanced, less well differentiated, and included a significantly higher proportion of triple-negative cancers, thus resulting a poorer outcome than for screening-detected and self-detected cancers [10]. In this study, the proportion of early, in situ, or localized, breast cancers was higher in the MMG with CBE group (77.6 %; 333/429) than in the CBE alone (64.6 %; 337/522) and self-detection (48.6 %; 1,481/3,047) groups. On the other hand, the proportion of advanced breast cancers, which are thought to be directly related to breast cancer death, was lower in women screened by use of MMG with CBE than in other groups. The proportion of breast cancer deaths was also lower in the MMG with CBE group (4.2 %) than in the CBE alone (10.9 %) and self-detection (18.6 %) groups. In the MMG with CBE group, age tended to be higher and mean observation time shorter than that in the CBE alone and self-detection groups; therefore, there was a possibility that the MMG with CBE group had a higher proportion of deaths from other causes. The proportion of deaths from other cancers and other causes in the MMG with CBE group (4.2 %; 18/429) was similar to that in the CBE alone (3.1 %; 16/522) and self-detection (3.7 %; 113/3,047) groups. Our observation period might have been sufficient because the three Kaplan–Meier curves were parallel at the end of follow-up; therefore, other causes of death might not have distorted the results. Ten-year survival might be almost the same as 8-year survival, because the three survival curves were almost horizontal after 96 months. The different clinical stages and pathological features of

cancers in the MMG with CBE group might have resulted in the lower proportion of breast cancer deaths, which may be the presupposition of the declining mortality.

In the 40 to 49-year age group, the risk of breast cancer death among women screened by use of CBE alone was 2.38-fold higher than that among women screened by use of MMG with CBE, but this was not statistically significant (95 % CI 0.72–7.94, $p = 0.16$). The mortality risk in the self-detection group was significantly higher than that in the MMG with CBE group. In the 50 to 69-year age group, the mortality risk for women screened using CBE alone or self-detection was significantly higher than that in the MMG with CBE group. A meta-analysis of major MMG trials in western countries [2] found that MMG was effective in all age groups, but especially for woman aged 50 years and over. Our findings are consistent with those in that study, indicating that screening using MMG with CBE is more effective than self-detection for reduction of breast cancer mortality among women aged 40–69 years, and especially those aged 50–69 years.

The efficacy of MMG may be lower for women aged 40–49 years, for whom breast density is higher [7]. One approach for overcoming this weakness of MMG was evaluated in the “Japan Strategic Anti-cancer Randomized Trial (J-START)”, which evaluated the effectiveness of MMG with ultrasound for breast cancer screening in comparison with mammography alone for women aged 40–49 years [16].

This study had both limitations and strengths. First, it was vulnerable to a variety of bias because of comparison of survival. Breast cancer screening presumably reduces mortality by detecting breast cancer and thus enabling a patient to be treated appropriately at an earlier stage. Differences in mortality risk between groups screened by use of MMG with CBE, CBE alone, and self-detection were presumably caused by the effect of MMG with CBE in reducing mortality and bias, for example self-selection bias (healthy screenee bias). However, the proportion of deaths from other cancers and other causes in the MMG with CBE group was almost the same as that in the CBE alone group and in the self-detection group, even though age tended to be higher in the MMG with CBE group. Therefore, any such bias might have been too small to distort the results. Second, we speculated whether lead time bias could cause these differences in survival [9]. However, the Kaplan–Meier survival curves for the three groups screened using these methods did not cross over, despite of our long observation period; it is, therefore, assumed that the effect of this bias on survival would have been too small to have affected the results.

One of the strengths of our study was that it was able to evaluate the effectiveness of MMG with CBE for women aged 40–49 years by analysis of mortality risk in different

age groups. Our previous study was unable to evaluate the effectiveness of MMG for women aged 40–49 years, for whom breast cancer incidence and mortality would be high in Japan [1], by analysis of mortality risk by age groups [8], because there were no deaths among patients whose cancers had been detected by MMG with CBE and the number of patients in this age group was small. Second, the quality of CBE and reading of MMG were controlled. The screening program was performed by registered surgeons who were approved by the committee for breast cancer screening of the Miyagi Cancer Society as having sufficient experience in general surgery, including the treatment of breast cancer. Statistically significant differences in survival were observed between self-detection and CBE alone, and between self-detection and MMG (Fig. 1). In comparison with self-detection, survival was significantly better for women whose cancers had been detected by CBE alone or by MMG with CBE. The difference in survival between the self-detection and CBE groups was larger than that between the CBE alone and MMG with CBE groups. This implies that the quality of CBE conducted by registered physicians was well controlled. It can be said that MMG with CBE is better than quality controlled CBE alone, although CBE is, of course, better than self-detection. Third, the Miyagi Prefectural Cancer Registry is one of the earliest and most accurate population-based cancer registries in Japan [11]. Therefore, the quality of the data is regarded as sufficiently reliable.

In conclusion, this analysis, conducted by reference to the population-based cancer registry in Miyagi, Japan and which included screening-detected and interval cancers, revealed that by screening using MMG with CBE it is possible to reduce breast cancer mortality from the perspective of survival and risk of breast cancer death among women aged 40–69 years in Japan. To reduce future breast cancer mortality in Japan, national screening by use of MMG with CBE should be increased. Currently, the prevalence of screening using MMG with CBE is 32.1 % (2005) in Miyagi Prefecture [17], as opposed to 60.8 % (2003) in the United States and 69.5 % (2005) in the United Kingdom [18]. This means there is still a higher proportion of self-detected cases in Japan. The only sure indicator of the effectiveness of MMG screening will be a decline in breast cancer mortality; before this can occur the problem of low screening must be addressed. Invitation to MMG screening for each eligible woman might effectively increase the amount of screening, as reported elsewhere [19].

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Conflict of interest The authors have no conflict of interest.

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RESEARCH ARTICLE

Open Access

Cancer patients on Twitter: a novel patient community on social media

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Abstract

Background: Patients increasingly turn to the Internet for information on medical conditions, including clinical news and treatment options. In recent years, an online patient community has arisen alongside the rapidly expanding world of social media, or “Web 2.0.” Twitter provides real-time dissemination of news, information, personal accounts and other details via a highly interactive form of social media, and has become an important online tool for patients. This medium is now considered to play an important role in the modern social community of online, “wired” cancer patients.

Results: Fifty-one highly influential “power accounts” belonging to cancer patients were extracted from a dataset of 731 Twitter accounts with cancer terminology in their profiles. In accordance with previously established methodology, “power accounts” were defined as those Twitter accounts with 500 or more followers. We extracted data on the cancer patient (female) with the most followers to study the specific relationships that existed between the user and her followers, and found that the majority of the examined tweets focused on greetings, treatment discussions, and other instances of psychological support. These findings went against our hypothesis that cancer patients’ tweets would be centered on the dissemination of medical information and similar “newsy” details.

Conclusions: At present, there exists a rapidly evolving network of cancer patients engaged in information exchange via Twitter. This network is valuable in the sharing of psychological support among the cancer community.

Keywords: Breast cancer, Breast neoplasms, Internet, Leukemia, Social media, Twitter messaging, Web 2.0

Background

Health-focused websites have become an increasingly valuable information source for cancer patients in recent years, with such patients seeking details about treatment options for their specific condition as well as about general cancer information [1-3]. These websites provide a means of communication for patients and their families that is more convenient and less expensive than that provided by traditional face-to-face patient-serving health organizations [2]. In a previous study, we suggested that patient-authored web logs (or “blogs”) represent a unique form of information delivery as they provide useful personal insights about cancer treatment

that are unlike the information often conveyed by healthcare providers through face-to-face interactions and standard media [1]. Such patient-centric sites are also becoming a valuable source of personalized health information for the increasingly “wired” cancer-patient communities across the globe.

Attendant to the continuing rise in social media (“Web 2.0”) participation and the resulting proliferation of user-generated online content, the public can thus potentially play a larger role in all stages of knowledge translation, including information generation, filtering and amplification. As with the Internet itself, social media outlets run the gamut of just about every imaginable scope and size, with Twitter, a free social-networking and micro-blogging service launched in 2006, taking the lead as a method of disseminating exceptionally brief online messages to a potentially global audience; Twitter enables its millions of users to send and read each other’s “tweets,” or short messages limited

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to 140 characters, with the users themselves determining whether their tweets can be read by the general public or restricted to preselected “followers.” Followers of a specific Twitter user can view or respond to tweets online or via smart phones and other handheld devices, allowing for a nearly instantaneous dialogue between the user and his or her followers. The service has more than 190 million registered users worldwide and processes about 55 million tweets per day [4]. The Twitter service started in Japan in 2008; at present, there are more than 10.2 million active Twitter accounts registered in the country [5].

A recent health-focused analysis of the American “Twitter stream” revealed that a substantial proportion of tweets contain general chatter, user-to-user conversations that are only of interest to the parties involved, links to interesting pieces of news or self-promotion or unwanted “junk” messages (i.e., spam) [4]. Yet despite its high level of noise, the Twitter stream does contain useful information. Many recent news events or scientific issues have been documented and discussed via Twitter directly from users at the site in real time [6].

As tweets are often sent on location via smart phones and other handheld platforms, they convey more immediacy with interactivity than other websites or blogs [4]. In addition, healthcare providers and medical researchers are increasingly using Twitter for a variety of purposes related to patient care and treatment, including sharing clinical news with patients and discussing case studies with fellow physicians [7-11]. A recent *JAMA* letter showed that physicians frequently use Twitter to share medical information, with nearly half of the studied tweets being devoted to the discussion of health topics; the authors found that physicians’ rapid and timely dissemination of such information via Twitter could potentially positively influence public health in a variety of ways [12].

Recent research has also shown that Twitter may also be a useful medium for patients, who use Twitter to exchange medical information and discuss various aspects of their individual illness; although detailed information about patients’ use of Twitter for such purposes has yet to be fully studied, it has been shown that some patients with breast cancer, chronic kidney disease, diabetes and inflammatory bowel disease have used Twitter for the purpose of sharing information about these conditions [13-18].

Twitter is an interactive, real-time medium that can be used at a relatively low cost in terms of users’ initial and ongoing monetary investment and in the time, effort and expertise required for use. Furthermore, as has been described above, Twitter has been effectively used in recent years for the dissemination of medical news and advice, as well as the delivery of “personal stories” related

to a number of health topics. As a result, Twitter can be considered to have the potential to play an important role in modern social communities, including online communities consisting of “wired” cancer patients. However, the research conducted to date regarding the role of social media in influencing cancer patients remains very limited. In this study, we examine recent Twitter usage in Japan and evaluate its role in the lives of today’s “wired” cancer patients.

Methods

Search of cancer Patients’ Twitter accounts

A search was conducted of every publicly available user profile on Twitter in Japan. We began this search by reviewing all user accounts in which the names of cancers were described in the user’s Twitter profile. The cancer names used in our search were obtained in accordance with the Foundation for Promotion of Cancer Research’s 2010 report on Japanese cancer rates [19]. The terms searched were: breast cancer, leukemia, colon cancer, rectal cancer, colorectal cancer, cancers of the uterus, malignant lymphoma, brain tumor, stomach cancer, lung cancer, thyroid cancer, ovary cancer, kidney cancer, prostate cancer, esophagus cancer, bladder cancer, liver cancer, oral cancer, pharyngeal cancer, gallbladder cancer, cholangiocarcinoma, laryngeal cancer, skin cancer and multiple myeloma. These names were searched using both the Japanese Katakana writing system and Chinese characters.

The website used for the profile search was the “16 (one-six) Profile Search β Version for Twitter” [20], which enabled us to search, in addition to users’ Twitter profiles, the number of follows, followers, tweets, lists, registered dates and last-posted dates. The search was conducted over a total of 5 days in the spring and summer of 2011: March 27, 28 and 29; April 3; and July 12. Following the methodology used by Chretien et al. (2011) [12], we then extracted from our dataset of cancer profiles only those user accounts that had 500 or more followers; we considered these to be “power accounts,” as they had each developed a relatively robust Twitter following.

Our search of Japanese Twitter profiles that included the cancer terminology noted above yielded a total of 731 user accounts, of which 466 profiles belonged to cancer patients and were included in our initial review. The remaining 265 cancer profiles were excluded from our initial analysis because they belonged to persons and organizations who were not patients themselves (Figure 1).

Among the initial 731 user accounts that included cancer terminology, breast cancer was listed in user profiles most frequently (n=147), followed by leukemia (n=59), colon/rectal/colorectal cancer (n=40) and uterine cancer (n=39). Those patients who listed multiple

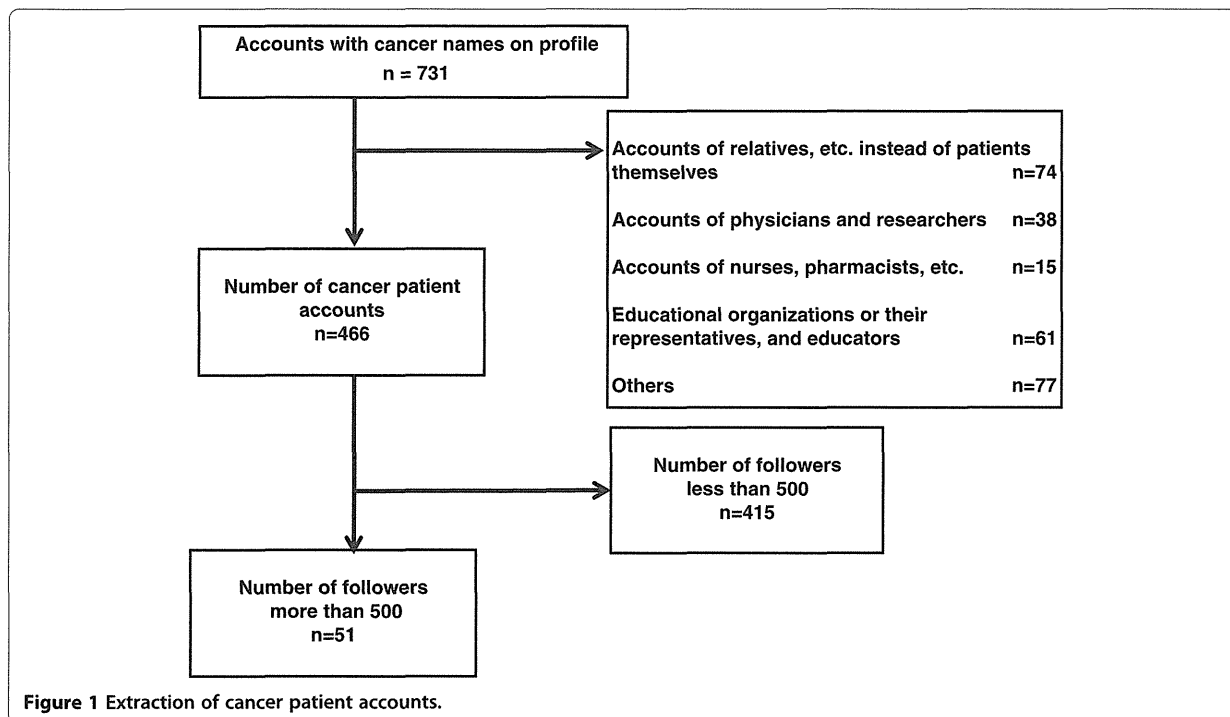


Figure 1 Extraction of cancer patient accounts.

cancers in their Twitter profiles were counted separately (Figure 2).

Fifty-two Twitter accounts with the relevant cancer descriptions in their profiles met the criterion established by Chretien et al. (2011) [12] required for

being “power accounts and were considered by us to be influential accounts because of their wide reach. (The account with the most followers belonged to a comedian with breast cancer; because of the user’s celebrity status, the difficulty of adequately tracking tweets between the

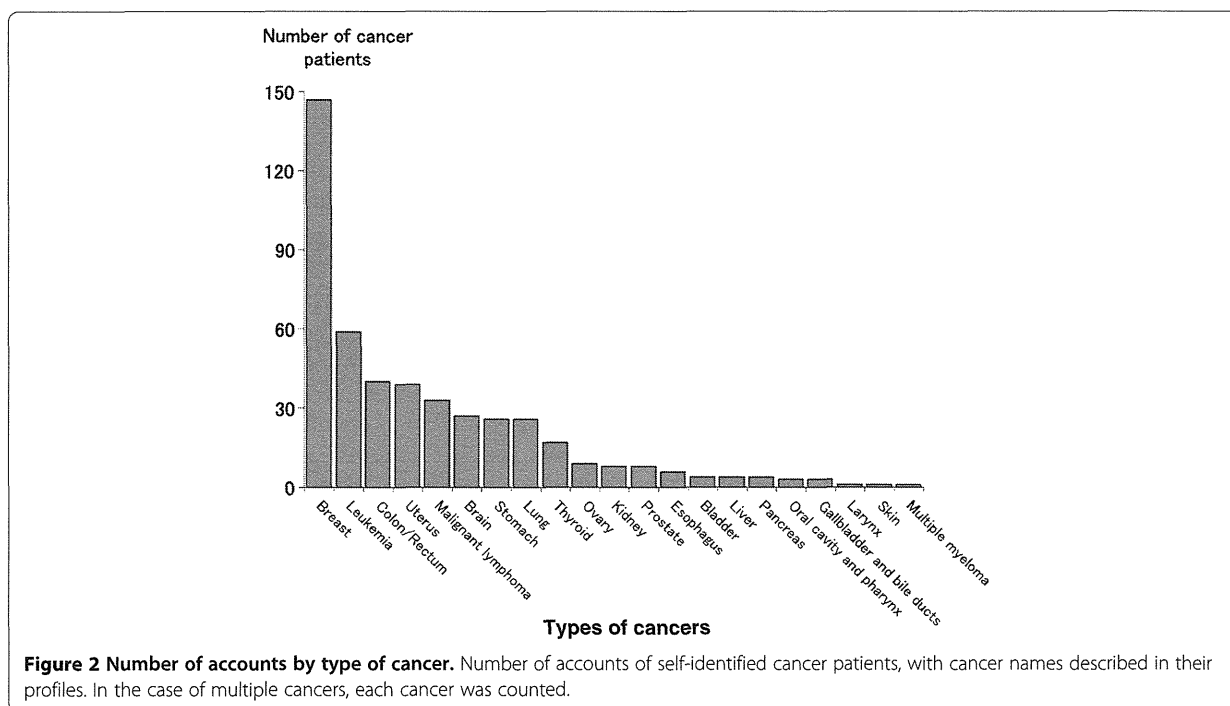


Figure 2 Number of accounts by type of cancer. Number of accounts of self-identified cancer patients, with cancer names described in their profiles. In the case of multiple cancers, each cancer was counted.

user and her followers and the fact that the vast majority of the user's tweets focused on comedy and not on cancer or other medical topics, we excluded this account from our analysis.) A detailed analysis of the remaining 51 accounts was subsequently conducted following their extraction from the dataset.

Review of the relationships between users

Using the mentionapp website [21], which enabled us to search for relationships between users on Twitter, we examined the presence and extent of specific relationships between Twitter users. This site graphically displays the number of tweets created most recently by a specific user prior to a search, as well as the relationship that exists between that user and other users (i.e., referring to sending a reply in the form of "@user name" on Twitter one or more times). This secondary search was conducted on December 4, 2011. As the technical capabilities of this Twitter-centric search engine have yet to be clarified by the site's operators, the period available to send replies that can be detected by a mentionapp search is unknown.

Review of user-generated Twitter content

We extracted from our dataset the user account with the greatest number of followers from the accounts of breast cancer patients, who made up the largest population of Twitter users studied here. We subsequently used mentionapp to extract the Twitter users who had a direct relationship with that primary user. In this way, we were able to extract the user accounts in which a direct relationship was found with the user who had the largest number of followers, as observed by one or more replies being sent. The number of tweets of such accounts per day was analyzed using Whotwi, a tool that displays the number of tweets per day or time zone, as based on an analysis of the most recent 600 tweets of individual accounts [22]. Among these accounts, the account that had the largest number of tweets per day was extracted for further analysis.

The contents of the tweets among the users who tweeted a reply one or more times to the extracted user are described using Bettween, a tool that enables retroactive searching of tweets among users [23]. Furthermore, tweets among cancer patients were also searched in the same manner using the Bettween Search instrument.

The Whotwi and Bettween searches began on December 11, 2011. The Whotwi search was completed this same day, and the Bettween search was carried out over a period of 7 days.

This study was approved by the Ethics Committee at Yamagata University Faculty of Medicine.

Results

Characteristics of user accounts

Characteristics of the extracted 51 "power accounts" that had 500 or more followers are shown in Table 1. As previously noted, the term "breast cancer" appeared more frequently than other cancer term in these users' profiles ($n=13$). The ratio of males to females in the "power accounts" was 1:1. The Kanto region, which includes the Japanese capital of Tokyo and several other major metropolitan areas, was listed as the home location for almost half of the studied user accounts ($n=23$). Of the 51 "power accounts," over half ($n=27$) of users disclosed their real names, while almost half ($n=21$) displayed a personal photograph in their profile. The number of tweets per day for the top 5 types of cancer of user accounts is shown in Figure 3. The median of the average number of tweets per day for breast cancer, leukemia, colon cancer, cancers of the uterus and malignant lymphoma was 2.12, 3.79, 3.21, 3.79 and 2.00, respectively, with corresponding ranges of 0.03–14.6, 0.03–16.2, 0.14–13.1, 0.57–22.3 and 0.13–10.7.

User connectedness

As previously noted, we opted to exclude from our analysis the account of the Twitter user—a celebrity—who had the largest number of followers; the comedian who owned this account had breast cancer, and her Twitter feed was followed by 33,828 other users. The Twitter account of user0 with the second largest number of followers (2,463 followers) was selected for the previously described December 4, 2011, analysis of the relationship between users. The results of this analysis are shown in Figure 4. The 5 accounts with the most followers all belonged to patients with breast cancer; the remaining 3 accounts from the "Top 5" accounts were those with 1,593, 1,518 and 1,241 followers, respectively.

As shown in Figure 4, it was found that there were cancer patients among the followers of user0. Those followers included 3 breast cancer patients, 1 uterine cancer patient and 1 user who was believed to be a cancer patient. It was found that these cancer patients communicated with one another via tweets, revealing real-life examples of information exchanges among cancer patients via Twitter. Among the 5 "power accounts" with the greatest number of followers, the fourth-largest account also had a network of cancer patients on Twitter (data not shown).

Content of tweets

The user accounts of cancer patients among the 6 user accounts that had relationships with user0 (5.5 tweets per day) as shown in Figure 4 were these 5 accounts: user16, user17, user23, user24 and user27, showing tweet numbers of 44, 15, 16, unknown and 5.5, respectively,

Table 1 Characteristics of the accounts (followers > 500)

Variables		Numbers
Sex (male/female/unknown)		24/24/3
Patients (male/female/unknown)	Breast cancer	13 (1/12/0)
	Malignant lymphoma	10 (8/1/1)
	Leukemia	5 (2/3/0)
	Stomach cancer	5 (3/1/1)
	Uterine cancer	4 (0/4/0)
	Brain tumor	4 (4/0/0)
	Colon cancer	4 (2/1/1)
	Renal cancer	1 (1/0/0)
	Prostate cancer	1 (1/0/0)
	Thyroid cancer	1 (0/1/0)
	Lung cancer	1 (1/0/0)
	Bladder cancer	1 (1/0/0)
	Ovarian cancer	10/1/0
Area (male/female/unknown)	Hokkaido, Tohoku	1 (1/0/0)
	Kanto	23 (7/14/2)
	Chubu	11 (6/5/0)
	Kinki	8 (4/4/0)
	Chugoku	0
	Shikoku	0
	Kyushu, Okinawa	2 (1/1/0)
	Unknown	6 (5/0/1)
Identified by full name		27 (12/15/0) (52.9%)
Profile photograph of self		21 (11/10/0) (41.2%)
Contained link to any Web site		14 (9/5/0) (27.5%)
Link to own blog		22 (11/10/1) (43.1%)
Followers	Average	2079
	Median	1077
	Minimum	520
	Maximum	33828
Tweets	Average	5608
	Median	2370
	Minimum	44
	Maximum	44746
Tweets/day	Average	15.2
	Median	5.7
	Minimum	0.1
	Maximum	126.3

when the search was conducted. Because user24 was set as a non-public user, it was not possible to conduct a search of the user's tweets.

As a result of our investigation into the contents of the tweets by user16, who had 44 tweets (the largest number) per day, with another 12 users (who were believed to have a relationship with this user, as shown in Figure 4), the contents were classified into categories such as greetings ("good morning," "good night"); daily conversations or chats ("I did so and so today"); and conversations concerning cancer treatments ("I am going to the hospital today." The total number of tweets for each category was as follows: 176 for greetings, 139 for daily conversations or chats, and 24 for conversations concerning cancer treatments. The contents of the exchanged tweets about cancer treatments through the network shown in Figure 4 are shown in Table 2. These tweets represented psychological encouragement (12 tweets), greetings when visiting the hospital or reports on the outpatient ward (10 tweets), tweets concerning physical condition (6 tweets) and advice for treatment (2 tweets).

Discussion

This study indicated that Twitter could be a valuable medium for sharing information among cancer patients. A total of 51 Japan-based cancer patients with Twitter accounts were determined by our study to be influential Twitter users as based on their having 500 or more Twitter followers. Although this study examined a considerably smaller sample of influential Twitter users (n=51) than did a previous United States-based study of the "power accounts" of influential tweeting physicians (n=260) [12], our research revealed that cancer patients can empower themselves by tweeting information about their own medical condition and treatment and by providing a forum for the discussion of specific topics.

The breakdown of influential accounts was found to be in the order of breast cancer, leukemia, colon cancer, cancer of the uterus and malignant lymphoma; this differs significantly from the order of cancer prevalence in Japan, in which the top 5 types of cancer are, in descending order: stomach cancer, lung cancer, colon cancer, breast cancer and liver cancer [19]. We found it interesting that the cancer prevalence of our influential users and the general population were so dissimilar. We expect that this discrepancy is associated closely with the widespread Internet usage of the younger population, which made up a disproportionate percentage of our studied Twitter users. Compared with other cancers in our study, breast cancer was seen most in women in their late 30s to early 40s. The Internet usage rate of Japanese women in this age range is as high as 95% [24]; we believe that this high Internet literacy confirms our findings.

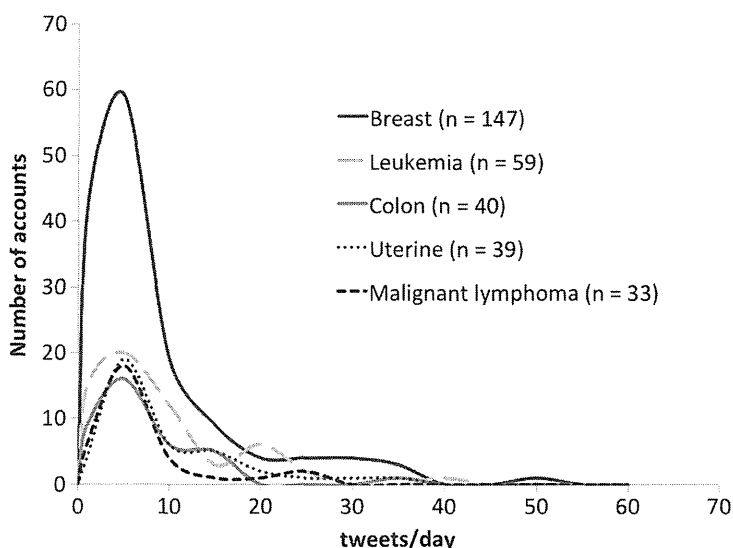


Figure 3 Average number of tweets and number of users per day for Twitter users' 5 most prevalent types of cancer.

Furthermore, while malignant lymphoma or leukemia is a disease with lower numbers of affected people, we found users with these types of cancer to be highly influential in terms of their Twitter connections. This may be a result of the background in which the treatments for leukemia or malignant lymphoma are mainly centered

on chemotherapy, with a long treatment period, indicating that treatment for the disease affects the daily life of these patients for a prolonged period. These patients are thus also more likely to have more opportunities over an extended period of time to engage in timely discourse about their individual conditions and treatment.

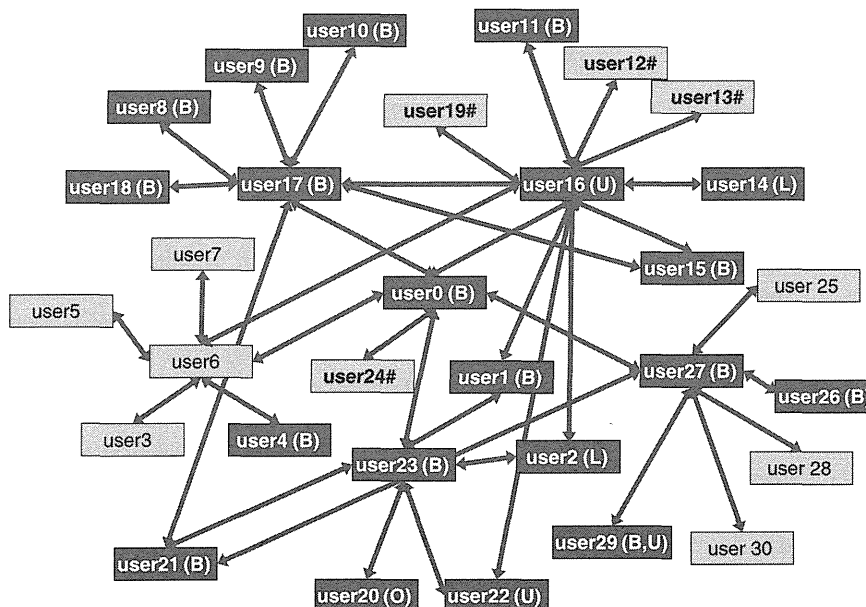


Figure 4 Relationships between users. Correlation diagram centered on user0. The users connected by the arrows mutually sent one or more replies. The search was conducted to incorporate friends' friends. userXX(outlined) : cancer patients. Users who listed their specific type of cancer in their profiles. (B): breast cancer, (L): lung cancer, (O): ovarian cancer, (U): cancer of the uterus. userXX#: Users who are believed to be cancer patients judging from their tweets, although no disease names were described in the profiles (because of descriptions of terms such as anticancer drugs, routine examinations, CT, contrast dyes, bone scintigrams). userXX: Other users.

Table 2 Conversations regarding treatment*

Conversation 1 (psychological encouragement)	user18	I cleared the blood test ♪ but because of a concerning observation above my collarbone (I have had it for 3 years) that I feel has gotten a bit bigger, I had to take an echo test. (>_<)
	user17	Glad to hear that you cleared the test!
	user18	Dear (user17), thank you ♪, now the echo test. . . Wish me luck(^^)
Conversation 2 (psychological encouragement)	user14	Dear (user16), thank you. The medication was effective and I was able to confirm the shrunken CT image. So I think I am ready for chemotherapy. (^^o^)/
	user16	Once it turns out to be effective, we feel we'll be able to take it further. Let's do this!!
Conversation 3 (psychological encouragement)	user16	You don't have to try hard. Just keep yourself in good physical condition for now, so you're ready for the operation next year.After completing treatment, you can come back.
	user16	Dear (user15), keep it up.
	user15	Dear (user16), good morning. (*^~^*)o ♪ I took a day off from work today.~(∇~;)
	user15	Thank you. (^-^)^ I will just take a day off to relax and refresh myself. (*^~^*)o
	user16	Be careful not to catch a cold.
Conversation 4 (report on hospital visit)	user15	Dear (user16), thank you for your kindness as usual. (*∇*)
	user16	Dear (user12), be careful when you visit the hospital.
	user12	Thank you. I am off to the hospital. (*^o^*)
Conversation 5 (conversation regarding physical constitution)	user19	Good morning!! I still have some pain 1 week after the operation. Strangely, my left arm which I broke some years ago hurts. Why?
	user16	Because the weather is terrible today, my scar hurts, too.
	user19	Hi sister, good morning! Well, you, too! It's my first time to experience an old wound hurting. Having various pains here and there is confusing (laughing), ha-ha.
	user16	It also hurts just before it starts to rain. Because I have keloid diathesis and my wound is rather wide and mounted, with adhesion, it really hurts when I have intestinal movements. It is really painful when I have diarrhea, but now I am used to it.
	user17	Dear (user19), good morning (^_^). My cut wound from a year ago has been hurting me since yesterday. Although I can bear the pain if I just moan, apparently there are many people who feel pain from old wounds when the weather gets cold. I hate it. Let's keep ourselves warm.
	user19	Dear (user17), good morning. Wow, you, too, dear (user17)! I guess the cold weather does have an effect, after all. Let's keep ourselves warm so that we can heal, everybody. Keep it up today, too.
Conversation 6 (report on hospital visit)	user11	Dear (user16), good evening. Here is your aunt to talk about nice things. (Laughing) It's nice. I feel like drinking tonight. . . but I will have a gynecological exam tomorrow for the first time in 6 months. Because they will collect my blood as well, I will leave that until tomorrow so I have something to look forward to. d(∩~∩)
	user16	Don't miss it.
	user11	I will meet with my favorite attending physician for the first time in 6 months. I'm really looking forward to it. d(∩~∩)!
	user16	Me, too. With CT and check-up, there will be two hospital visits this month.
Conversation 7 (report on hospital visit)	user11	Just like this year's year-end tax adjustment? For both of us. . . I will have a gynecological exam tomorrow, too, and the year-end lymph care adjustment the day after tomorrow. (laughing)
	user11	Dear (user16), good morning. Today is the last lymph care of the year ♪ I am wearing order-made new stockings and feeling great, ready to leave for the doctor's office. d(∩~∩)!
	user16	Have a nice day.
Conversation 8 (report on hospital visit)	user16	Dearest (user22), good luck with your bone scintigraphy, RT @(user22): Good morning, everybody, today is the day for the bone scintigraphy~~ .
Conversation 9 (psychological encouragement)	user7	Dearest ^△, good morning (^_^)/I totally understand your feelings. Me too, when I was receiving radiotherapy treatment, I really felt depressed whenever I went down the steps, because I felt like I was being told every time "cancer patients are this way?"

Table 2 Conversations regarding treatment* (Continued)

Conversation 10 (advice on treatment)	user17	Dearest (user21), good morning. You are now being treated with Xeroda. It's been just a few days, right? Sorry if I am wrong but it may take some time for the drug to take effect.
	user21	Dear (user17), good morning! Oh, Xeroda. Well, if left for 2-and-a-half months without chemotherapy, that seems rational. (；ω；) Internal medicine apparently works slowly.(；ω；) It will take time, too. (；ω；)

*Japanese conversations were translated into English.

To better understand how cancer patients influence their followers via Twitter, direct investigation involving the use of a survey of cancer patients with Twitter accounts may be necessary in the future. Examining the distribution of user activities did not reveal any significant differences among the different types of cancer noted in users' profiles. On the other hand, our study showed that a smaller number of extremely active accounts existed for each type of cancer examined (Figure 3). Under the hypothesis that such small numbers of active users serve as the center of the patients' networks on social media, we investigated the connections related to the most active users. As a result, we were able to demonstrate that information was exchanged in real time among patients (Figure 4). Based on this finding, we were able to demonstrate for the first time that an information exchange network among patients via social media had already been established.

Of further interest to us is the content of the tweets exchanged among patients. Most of the examined tweets included details of daily life such as greetings or messages concerning treatments, and it was found that almost no medical information concerning cancer was exchanged; this went against our initial expectation that cancer patients would use Twitter to primarily discuss specific cancer-related news and medical information.

Our findings demonstrate that patients use Twitter as a tool of psychological support by being connected among patients, even though it is not a standard or face-to-face method of discussing such information. This observation may support the notion that Twitter plays a unique role that is different from similar-seeming Internet tools such as hospital websites in which patients primarily obtain medical information [2] or blogs in which patients can share their experiences [1]. We expect that as Twitter usage becomes more widespread in the coming years, there will be an attendant rise in the medium's importance to maintaining—and perhaps improving—public health [25]. However, the dissemination of Twitter among patients in the future may generate various methods of usage, making it necessary to continue careful observation in the future.

Twitter can be used not only with real names but also anonymously, which is often controversial. In our study, 53% of the accounts included the users' real names, and 41% of the accounts included personal pictures. In-

vestigation into the Twitter accounts of physicians revealed that 78% of these accounts displayed the users' real names and personal pictures [12], indicating that anonymity is more preferred among patients than physicians. We expect that this discrepancy can be correlated to the fact that information about individuals' medical conditions is considered personal and confidential, and that revealing a Twitter account user's name could lead to the disclosure of potentially private medical details. Many people consider it necessary to maintain anonymity when sharing information through Twitter and other social media; such anonymity may be linked to Twitter's ability to maintain its relevance among the patient populations that use it.

Limitations

While this study demonstrated that a patient network via Twitter is in the process of being established, there remain several issues to be discussed. First, this study targeted only those Twitter users who described "cancer" either in Japanese Hiragana, Katakana or Kanji letters in their profiles. However, this does not mean that all users who were cancer patients included relevant disease names in their profiles; the absence of cancer details in user profiles could potentially exclude an unknown number of cancer patients from analysis.

Second, because of limitations in search tool performance, we were unable to conduct a large-scale comprehensive qualitative analysis. It is expected that the improvement of search-tool performance will enable larger-scale studies in the future.

Finally, future research into this field of study will need to clarify the types of information most often disseminated via social media. It has been reported that social media often include information that is not necessarily beneficial to the health of media users [26]. Furthermore, Chretien et al. (2011), who studied physicians' accounts on Twitter, stated that there existed, although rarely, some ethically problematic content, which could possibly violate the patient privacy [12].

Twitter and other forms of social media can prove quite useful in permitting the rapid and timely dissemination of health-related information. However, as social media continue to evolve, they will need to find ways to provide relevant health information without obstructing patient privacy or delivering inappropriate content.

Overcoming this point will be an important element in the dissemination of medical information via social media.

Conclusions

Twitter users with a variety of types of cancer have proved influential on their followers, as demonstrated through the information exchange engaged in by account owners and their followers. Twitter represents a timely and low-cost medium for cancer patients and others seeking information about specific medical conditions, but our study found that the majority of the tweets posted by the 51 users with “power accounts” focused on conversational details (e.g., greetings, cancer treatments) and psychological support rather than the expected medical news and information. Furthermore, Twitter will need to evolve further in order for patients to fully embrace the power of this social medium, as many people are reluctant to reveal personal details via their Twitter accounts. Our study has demonstrated that Twitter is a powerful medium capable of connecting cancer patients via the establishment of a patient network.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

YS and HN designed the study, provided the study materials, collected and assembled the data and wrote the manuscript. YS, HN, AH, LS, KO and AF analyzed and interpreted the data. All authors reviewed and approved the manuscript.

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Coverage of genomic medicine: information gap between lay public and scientists

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Abstract: The sharing of information between the lay public and medical professionals is crucial to the conduct of personalized medicine using genomic information in the near future. Mass media, such as newspapers, can play an important role in disseminating scientific information. However, studies on the role of newspaper coverage of genome-related articles are highly limited. We investigated the coverage of genomic medicine in five major Japanese newspapers (*Asahi*, *Mainichi*, *Yomiuri*, *Sankei*, and *Nikkei*) using Nikkei Telecom and articles in scientific journals in PubMed from 1995 to 2009. The number of genome-related articles in all five newspapers temporarily increased in 2000, and began continuously decreasing thereafter from 2001 to 2009. Conversely, there was a continuous increasing trend in the number of genome-related articles in PubMed during this period. The numbers of genome-related articles among the five major newspapers from 1995 to 2009 were significantly different ($P = 0.002$). Commentaries, research articles, and articles about companies were the most frequent in 2001 and 2003, when the number of genome-related articles transiently increased in the five newspapers. This study highlights the significant gap between newspaper coverage and scientific articles in scientific journals.

Keywords: coverage, personalized medicine, mass media, newspaper

Introduction

In the wake of the Human Genome Project,^{1,2} which has mapped the entire human DNA sequence, genomic medical research has entered a new era. A working draft of the genome was announced in 2000 and the complete DNA sequence was announced in 2003. In particular, one of the major challenges for medical research in the first half of the 21st century is to develop preventive and therapeutic measures against various diseases by clarifying their relationships with respect to the patterns of human genetic variability.

Personalized medicine using genomic information, which takes into consideration the patient's genetic characteristics and history of environmental factors, is expected to catalyze the next generation of therapy, with the potential to provide preventive and curative interventions specific to each individual.^{3,4} Full-fledged personalized medicine will successfully personalize disease prevention efforts based on the available knowledge of each patient's specific risk factors. It will also adopt patient-specific practices, including the selection of pharmacotherapy tailored to the variations in an individual's pharmacogenetic/pharmacogenomic profile and risk of adverse drug reactions. Thus, personalized medicine is anticipated to reduce disease morbidity and mortality and improve therapeutic effectiveness, as well as impact other aspects of

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medical care.⁵⁻⁷ Since individual genomic information will be essential in fostering personalized medicine, lay people are required to possess accurate knowledge about genomic medicine – so-called “genomic literacy.”⁸

The role of mass media in sharing information about medical sciences is uncertain. Several studies have highlighted the importance of news media as a source of information about medicine and health,⁹⁻²² however, sharing of information about advanced science and medicine between academia and the mass media was reported as being difficult. Although the output of scientific papers increased by 15% between 1990 and 2001, with a total output over 650,000, fewer than 0.013%–0.34% of papers gained attention from the mass media.²³

Given that newspaper coverage can include more information than other mass media such as television or radio, many medical professionals believe that newspapers are a suitable medium to disseminate information about genomic medicine;⁹ however, since studies on newspaper coverage are limited, the role of print media remains uncertain. In Japan, we have a unique and large newspaper database (Nikkei Telecom) that covers all articles in the five major national newspapers. In this study, we investigated newspaper coverage of genomic medicine in Japan.

Methods

Objective of this study

To examine the number of articles related to genomic medicine and their reported contents published by the five major Japanese newspapers within a 15-year time period (from 1995 to 2009), which is the time period covered by the newspaper database.

Target newspapers

This study was directed at the five major newspapers in Japan (*Asahi*, *Mainichi*, *Yomiuri*, *Sankei*, and *Nikkei*). The total number of subscribers to these newspapers was 26 million per day in 2010, indicating that 48% of households subscribed to these five newspapers in Japan.²⁴

Data extraction

We extracted the articles using a keyword search of the database Nikkei Telecom, which is the largest newspaper database in Japan. This database incorporates almost all newspapers issued in Japan, including every article in the five major newspapers since 1995.

First, using a thesaurus search of the Igaku Chuo Zasshi database (Japan Medical Abstracts by NPO Japan Medical Abstracts Society), we extracted Japanese terms related to the word “genome” in order to define the following keywords: genome, human genome, Human Genome Project, genomic medicine, personalized medicine, made-to-order medicine, and tailor-made medicine. The contents of articles from 2001, 2003, and 2009 were analyzed by two researchers who are medical providers (YS and HN). Given the large number of articles, several of them could not be checked to ensure that the content pertained to genomic medicine and other relevant topics. The above-mentioned newspapers were subsequently searched for articles that contained these Japanese keywords, and annual changes in the numbers of such articles and their contents were investigated.

To quantify the number of genome-related research articles in academic journals, we conducted a PubMed search using the same keywords as above in English, and included the term “individualized medicine.” The terms “genome, human,” “Human Genome Project,” and “individualized medicine” were indexed as Medical Subject Headings (MeSH). We also conducted a PubMed search using these MeSH terms.

We defined the terms “genomic medicine,” “personalized medicine,” “made-to-order medicine,” “tailor-made medicine,” and “individualized medicine” as genomic medicine-related keywords. Genomic medicine-related newspaper articles that were published in 2001 and 2003 – when the number of genomic medicine-related articles increased temporarily – and 2009, the most recent year, were extracted and categorized according to their contents.

Statistical analysis

Differences in the numbers of articles among the five newspapers were tested by a two-way ANOVA (newspapers x year), followed by Tukey’s multiple-comparison post hoc test. R version 2.15.0 (R Foundation for Statistical Computing, Vienna, Austria) was used for all statistical analyses.

Results

Total number of articles

The total number of articles published in the five major newspapers in Japan (*Asahi*, *Mainichi*, *Yomiuri*, *Sankei*, and *Nikkei*) averaged 1,140,000 per year, including 280,000 in *Asahi*, 310,000 in *Mainichi*, 280,000 in *Yomiuri*, 130,000 in *Sankei*, and 140,000 in *Nikkei*. Figure 1 shows the change in the total number of articles across the five major newspapers during the study period. While the number of published articles has

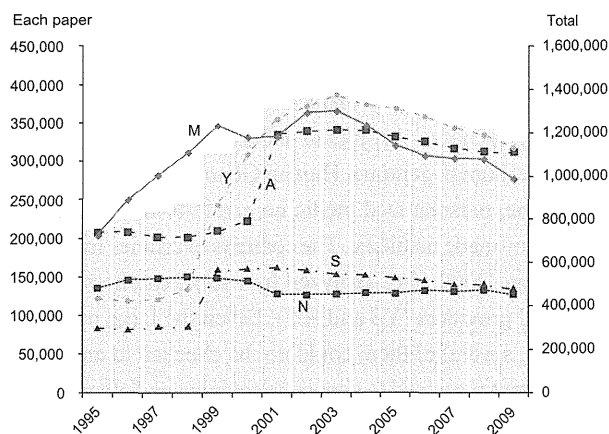


Figure 1 Total number of articles in five major newspapers.
Note: Bar: the five newspapers taken together.
Abbreviations: A, *Asahi*; M, *Mainichi*; Y, *Yomiuri*; S, *Sankei*; N, *Nikkei*.

increased since the early 1990s, there has been almost no change since 2000. Since 2000, the total number of articles published in the *Yomiuri*, *Asahi*, and *Mainichi* newspapers has been approximately three times that in *Nikkei* and *Sankei*.

Number of genome-related articles in the newspapers and genomic medicine-related scientific articles in PubMed

From 1995 to 2009, the total number of genome-related articles published in the five newspapers was 16,735,

including 3019 in *Asahi*, 2583 in *Mainichi*, 3422 in *Yomiuri*, 3299 in *Sankei*, and 4412 in *Nikkei*. The numbers of articles containing the selected keywords in the five newspapers were: genome, n = 7518; human genome, n = 4063; Human Genome Project, n = 4310; made-to-order medicine, n = 425; tailor-made medicine, n = 336; genomic medicine, n = 69; and personalized medicine, n = 14.

Figure 2 shows the change in the number of genome-related articles published in the five major newspapers. The trends in the number of newspaper articles related to the human genome (Figure 2A) and the Human Genome Project (Figure 2B) were almost the same, while the number of articles related to the human genome, the Human Genome Project, and those containing genomic medicine-related keywords, temporarily increased in 2000 across all five major newspapers. Conversely, articles containing genomic-medicine-related keywords (Figure 2C) demonstrated a unique trend: in 2003, the number of genomic-medicine-related articles published in *Nikkei*, *Yomiuri*, and *Mainichi* temporarily increased.

Figure 2 also shows the change in the number of genome-related articles published in PubMed. The trends in the number of human genome- (Figure 2A) and genomic-medicine-related articles in PubMed (Figure 2C) were the same; the number of human genome- and genomic-medicine-

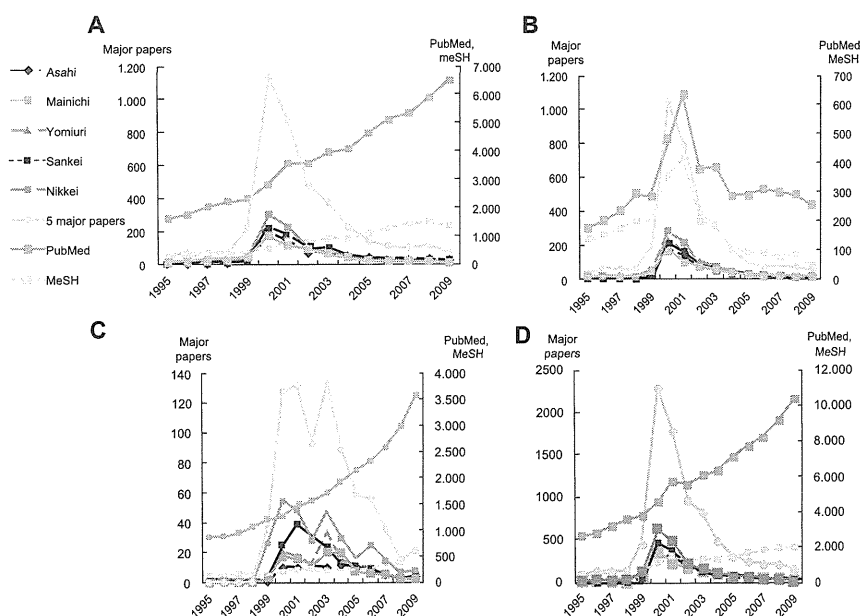


Figure 2 Number of genome-related articles in five major newspapers and genomic-medicine-related scientific articles in PubMed. (A) Articles related to human genome, (B) articles related to Human Genome Project, and (C) articles containing genomic medicine-related keywords in five major newspapers. A PubMed search using the following MeSH terms: “genome, human,” “Human Genome Project,” and “individualized medicine” was conducted in (A–C), respectively. The total number of articles related to (A–C) in the newspapers and PubMed are shown in (D).
Abbreviation: MeSH, Medical Subject Headings.

related articles continuously increased. On the other hand, the number of articles related to the Human Genome Project (Figure 2B) showed a unique trend: the number of articles related to the Human Genome Project increased temporarily in 2001. The total number of articles containing all genome-related keywords are shown in Figure 2D.

The numbers of genome-related articles that were published among the five major newspapers from 1995 to 2009 were significantly different ($P = 0.002$). Table 1 shows the comparison between the newspapers. Differences between *Nikkei* and *Asahi* ($P = 0.04$), and *Nikkei* and *Mainichi* ($P = 0.001$) were statistically significant.

Contents of genomic medicine-related articles published in newspapers

We investigated the contents of articles published in 2000, when the working draft of the genome was announced, and in 2003, when the complete genome was reported. We also investigated the contents of relevant articles published in 2009, the most recent year available in the database. The number of genomic medicine-related articles was 132 in 2001, 133 in 2003, and 21 in 2009. The contents of genomic medicine-related articles in the newspapers and changes in content over the years are shown in Table 2. Commentary articles, articles about research, and articles about companies were most frequently published in 2001 and 2003 (86 articles in 2001 and 88 articles in 2003), when the number of genome-related articles transiently increased across the five newspapers.

Discussion

The present study shows that newspaper coverage about genomic medicine is usually transient. The number of such articles substantially, though temporarily, increased in 2001 (Figure 2). This is probably due to the fact that reports from the Human Genome Project were covered as one of the topics during this time period. In contrast, the rapid decrease after the transient increase in genome-related articles indicated

that detailed information about genomic medicine is not currently reported in newspapers. In contrast, the number of scientific articles about genomes or personalized medicine using genomic information that were found in PubMed has continuously increased, indicating that constant research and advances in genomic medicine have been occurring. This contrast reveals that there has been an information gap about genomic medicine as indicated in the findings noted between the mass media and scientists, and as described in other areas of advanced science.²³ This gap might interfere with the dissemination of knowledge pertaining to genomic medicine, which may affect the conduct of related medical practices in the near future.

As previously reported, one characteristic feature of newspaper reporting on scientific issues is that only part of the subject matter is emphasized due to a poor balance in the number of news reports when compared to the number of scientific articles available.^{9,10} This would appear to be related to the amount of time it takes to discuss medical issues and to the fact that public interest drops when more detailed information or discussions appear. This is believed to be a structural problem inherent to the media, particularly with newspapers, which target the general public and report on a wide range of fields. This structural problem has already been recognized as an “issue attention cycle” in the United States, which was first described by Downs in 1972.¹¹ This cycle has been observed and reported in relation to other medical issues, such as childhood obesity.¹² In this cycle, public attention to a single issue is rarely sustained over an extended period, even in the case of critically important, unresolved problems. Scientists should be aware of this structural problem with mass media when they share information with the public. In this study, we did not investigate how much information is shared about other scientific topics; it would be worthwhile to investigate the newspaper coverage of these topics as well. In addition, the actual newspaper format might also have affected the results. Further, the influence of whether or not the newspaper carries a regular science section or employs science editors also needs to be considered when analyzing our results.

Although this study provided important information on the newspaper coverage of genomic medicine, the following issues still remain to be discussed. First, this study focused only on mass media. These days, the internet plays an increasingly important role in medical practice; information on the adverse effects of an anticancer drug, for example, was shared mainly by internet media such as blogs, homepages, and mail magazines between physicians, patients, pharmaceutical

Table 1 Comparison of the number of genome-related articles in the five major newspapers*

	Asahi	Yomiuri	Nikkei	Mainichi	Sankei
Asahi	NA	–	–	–	–
Yomiuri	0.83	NA	–	–	–
Nikkei	0.04	0.35	NA	–	–
Mainichi	0.71	0.15	0.001	NA	–
Sankei	0.92	1.00	0.24	0.23	NA

Note: *P-values are shown.

Abbreviations: NA, not applicable; P, probability level.

Table 2 Contents of genome-medicine related articles in the five major newspapers in Japan

Classification	Detailed classification 2001	n	Detailed classification 2003	n	Detailed classification 2009	n	
Commentary	Tailor-made medicine	12	Glossary	4	Gender-specific medicine	1	
	Glossary	8	Tailor-made medicine	4	Nanotechnology and new medical devices	1	
	Genes, SNPs, and gene therapy	6	Announcement of sequencing of the complete human genome	2			
	Genomic drug discovery	5	Meaning and benefits of deciphering the human genome	2			
	Regenerative medicine	3	Biochips	2			
	Structural problems in bioscience research	2	Allergy genes	2			
	Post-genome	2	Tailor-made medicine in dentistry	1			
	Personalized drug administration	2	Ten-year general strategy against cancer	1			
	Bioinformatics	1	Amyotrophic lateral sclerosis and tailor-made medicine	1			
	Anticancer drug sensitivity tests	1	Diabetes and tailor-made medicine	1			
	Future predictions	1	“Chronotherapy,” in which adverse effects are decreased with time of day medicine is taken	1			
	Genetic discrimination	1	Advanced cancer screening	1			
	Comparison of accuracy with Celera Genomics	1	Explanation of advanced medicine	1			
	Herceptin	7	Use of genetic information	1			
	Articles on research	Herceptin	7	Gene bank (project to provide medicine suited to individual genetic information)	11	Creation of muscular dystrophy patient genetic information database	2
		DNA chip development	4	Bipolar disorder and tailor-made medicine	5	Development of pathological diagnosis center	1
		ES cells	2	Lecture meeting guide	3	iPS cells	1
		Celera Genomics research	2	International standardization of databases	2	Researcher profile	1
		HIV and tailor-made medicine	2	Cancer society conferences	2	Hepatitis C and tailor-made medicine	1
DNA vaccine		2	Researcher profile	2	New blood concentration analysis methods (theophylline, etc)	1	
Irinotecan		2	Industry-government-academia joint projects	2	Drug design	1	
Discovery of epilepsy gene		2	Completion of genome sequencing and future significance	2	Genes related to hepatitis B	1	
Bronchial asthma and tailor-made medicine		2	Memory and genetic mutations	2			
Human genome SNP identification		1	Predicting efficacy of rheumatism drugs using genes	1			
Genetic diagnosis of chronic fatigue syndrome		1	Predictions of survival following lung cancer surgery	1			
High blood pressure gene		1	Diabetes drugs and SNP	1			
Industry-government-academia collaboration		1	Kazusa Akademia Park, a biotechnology center in Chiba Prefecture	1			
Esophageal cancer and anticancer drugs		1	Bioventures originating at universities	1			
Development of gene analysis systems		1	New drug development and start of clinical trials	1			
Tailor-made medicine for atomic bomb survivors		1	Establishment of specialized courses	1			
Hepatitis C research		1	Regenerative medicine	1			
Methods of detecting individual differences in genetic information		1	Protein analysis	1			

(Continued)

Table 2 (Continued)

Classification	Detailed classification 2001	n	Detailed classification 2003	n	Detailed classification 2009	n
Articles on companies	Biotechnology and genomic medicine	1	Current status of anticancer agent use	1		
	Foundation of translational research centers	1				
	Researcher profile	1				
	Problems in bioscience research	1				
	MDR1 protein gene	1				
	Corporate collaboration and joint research	5	DNA chips	7	Corporate researcher profile	1
	DNA chips	4	Bioventures	3		
	Other businesses enter genome medicine market	2	Development of DNA synthesis and detection devices	2		
	Foreign manufacturers market new anticancer drugs in Japan	2	Business manager lectures	2		
	Establishment of corporate genome research center	2	Corporate restructuring	2		
	Bioventures	2	Research not advancing at genomic medicine information analysis center (Kobe)	2		
	Personnel rotation at Olympus	2	Corporate researcher profile	1		
	Comparison of drug industry in other countries and Japan	1	Gene function analysis system	1		
	Development of new drugs for lifestyle-related diseases	1	Gene analysis for type of leukemia	1		
	Start of gene analysis services	1	Establishment of corporate research organizations	1		
	Sales of genome data by Celera Genomics	1	Protein analyzers	1		
	Development of genetic information databases	1	Establishment of new research centers	1		
Lecture presentations	Tailor-made medicine	8	Tailor-made medicine	13	General science	2
	Bioscience in general	3	Nanotechnology and bioscience	1	Bioscience	1
National strategy	Budget	3	Anti-cancer strategy	3	Medical Engineering Technology Industrial Strategy Consortium (METIS)	1
	Promotion of genomic medicine	2	Budget	2		
	Promotion of cooperation between medicine and engineering	2	Cooperative projects with nanotechnology ministries and agencies	1		
	Key government policies in each country	1				
	Proposed general plan of the Council for Science and Technology Policy, Cabinet Office	1				
	Financial support for advanced technologies	1				
Problems	Bioethics	4	Need for personal information protection in the field of medicine	2	Problems with insurance system	1
	Concerns about human cloning	3	New drug review	1		
	Lack of human cell samples	1	Lack of bioinformatics specialists	1		
	Sharing of genetic information	1	Cancer screening standardization	1		

(Continued)

Table 2 (Continued)

Classification	Detailed classification 2001	n	Detailed classification 2003	n	Detailed classification 2009	n
Book reviews	Differences in way of thinking about bioethics in Japan and Western countries	1				
	Newspaper feature articles	1	Post-genome	1	Hospice	2
	Problems of research in Japan	1	Individual differences in drug effectiveness	1		
	Full explanations of genome research	1				

companies, and governments.²⁵ We are planning future studies to investigate the roles these media play in the public dissemination of medical information. Social media, such as Twitter or Facebook, may also be worth investigating. Second, this study was limited to Japanese media. Media in English or other languages need to be investigated in future studies to determine how Japanese newspapers compare in terms of the reporting of genome-related articles. Third, only newspaper articles were included in this study. Significant differences in the coverage of medical issues have been reported between newspapers and television.¹² This is possibly because different types of media attract different audiences. Genomic medicine is not a major health issue that is on the minds of the general public, especially when compared to issues such as obesity, smoking, or cancers, which have been the subject matter of previous reports.^{12,15,21,26–28} Therefore, highly limited space was probably available for the issue of genomic medicine on television, making it difficult to provide detailed results as to why this discrepancy in news coverage exists. Further investigations about the role of this media are warranted. Additionally, it would be worthwhile to investigate advertising related to genomic medicine in future studies. Fourth, it may actually be appropriate for the media to have reported less upon genomic medicine than scientific journals, given the current stage of this area of research. To date, there are very few health conditions that have shown relevant pharmacogenetic treatment models or preventive medical practices, so it is reasonable that there is a lack of coverage in the press. We could argue that this lack of coverage exhibits appropriate restraint by the press. Fifth, we did not conduct a direct comparison using statistical models due to the difference in methods of detecting articles; however, differences in the trends of newspaper coverage and the number of academic journals itself provided enough useful and important information in this study. Sixth, in the last several years, the rapid expansion of “next-generation”

sequencing is making genomic medicine a true reality. While our data is derived from just before the “next-generation” era, it is extremely likely that another increase in coverage in the press is currently occurring, and this transition may have been occurring beginning in 2010. The revolution that is being wrought by new technologies that make high-throughput sequencing a financial and logistical reality in many contexts may be influencing the coverage by the mass media. This issue is worth investigating in future studies. Seventh, another possible limitation of this study is that journalists may have used more lay language, including words such as “family history” or “risk;” therefore, there may have been some oversight when extracting data from newspaper articles.

The optimal strategy in sharing information on genomic medicine between scientists, physicians, and the lay public via the media is uncertain. Schnoll et al reported that the publication of information regarding the use of spiral computed tomography for early lung cancer detection²⁷ did not increase the level of public awareness and interest, although lung cancer is one of the most important and widely mentioned cancers, with the general public having an intense interest in its prevention and detection.¹¹ In contrast, genomic medicine is less well known than is cancer among the general public, although genetic medicine is expected to play an important role in the future. Thus, it is more difficult to increase the general public’s level of awareness and interest in this topic. Although an optimal strategy of disseminating this information is still unknown, Schnoll et al²⁷ provided an important clue. They showed that greater exposure of health news within magazines is related to greater awareness. Magazines can provide more detailed information in their health-related articles than newspapers. This kind of media can, potentially, also play an important role in communicating findings and information about genomic medicine. Internet media may also be a promising medium through which to present this information because there are no space constraints.

Conclusion

The present study revealed a significant gap in the amount of information being presented about genomic medicine between newspaper coverage and scientific articles in academic journals. Sharing information about genomic medicine is crucial for the facilitation of personalized medicine in the future. Hence, scientists and medical professionals need to be aware of the features and structural characteristics of mass media when they disseminate information to the public.

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Disclosure

The authors report no conflicts of interest in this work.

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