

Patients cannot Keep up Posting Blog Articles without Responses

Tetsuaki Nakamura

Center for the Promotion of
Interdisciplinary Education and Research
Kyoto University
Kyoto, Japan
tetsuakinakamura8@gmail.com

Kay Kubo

Center for Japanese Language and Culture
Osaka University
Osaka, Japan
kaykubo.ktu@gmail.com

Yasuyuki Usuda

Graduate School of Human and
Environmental Studies
Kyoto University
Kyoto, Japan
usuda.yasuyuki.23n@st.kyoto-u.ac.jp

Shuko Shikata

Center for the Promotion of
Interdisciplinary Education and Research
Kyoto University
Kyoto, Japan
shukoshikata@gmail.com

Eiji Aramaki

Center for the Promotion of
Interdisciplinary Education and Research
Kyoto University
Kyoto, Japan
eiji.aramaki@design.kyoto-u.ac.jp

Abstract—Due to the development of Internet, many patients are now displaying their subjective opinions. Also, several reports have convinced that the social network users maintain, or sometimes improve their quality of life (QOL) by actively using social networking services. However, preceding research has not paid much attention to the question of what keeps the patients' motivation of using of the social networks. This research is to investigate the factors that influence the patients' motivation to maintain their active participations in the social networks. We used 18,917 blog articles to explore the factors that brought the blog posting to a halt. These articles were posted on the *LifePalette*, one of the biggest Japanese online social networking services for patients. We investigated on the following three conditions: disease-based condition, gender-based condition, and socially-supported-based condition. In order to capture the image of how long it took for the *LifePalette* users to stop posting the blog articles, we used the Kaplan-Meier methods to estimate the ratio of the actively posting users over time, as an analogy of blog's life. Our investigations showed that the factor which influenced the continuation of the user's article posting was whether the user received comments or not, instead of the other factors, such as the disease types or the gender differences. The result of our research suggests the importance of receiving comments for the social network users.

Keywords—social networking service; social media; natural language processing; medical information

I. INTRODUCTION

There are reports convincing that using of online social networks increases the quality of life (QOL) of the patients, and due to the development of Internet and of social networks, many patients are now displaying their subjective opinions. However, there are not many researches that explore what makes it possible to keep the patients' continuous use of the social networks. This research is to investigate the factors that influence the patients' motivation to maintain their active participations in the social networks.

The mainstream of the medical decision has been made based on the scientific evidences reported by doctors or any other academic specialists, and such decision has traditionally excluded the patients' subjective information.

The conventional medical research has been mainly focusing on the clinical evidences by doctors or any other academic specialists. On the other hand, such research has not given much attention to the patients' subjective information.

These days, however, with the development of information and communication technology, collecting data of patient's self-descriptions and their self-reports has become much easier, and the enormous amount of information from such data, so-called the Big Data, is now actively used for medical analysis [1], [2], [3].

Generally speaking, there are several approaches taken for such medical analysis by using patients' self-data, such as the approach for practical medical studies. One of the most famous attempts is the *PatientsLikeMe* [4]. This world-famous social network allows the patients who are suffering rare diseases (e.g. ALS, MS, Parkinson's Disease, HIV/AIDS) to interact each other to share their actual experiences. Their experiences as the patients' subjective data have now become a new evidence for the further scientific researches [5], [6], [7].

Patients who are suffering chronic diseases, such as cancer or depression, are also actively committed to social networks, for there are numbers of patients who are sharing the experiences of the same diseases. Such patients are supporting each other through social networking services, and such activities are sometimes called the Internet Support Groups (ISGs) [8], [9], [10], [11], [12], [13], [14], [15], [16], [17], [18], [19], [20], [21], [22], [23], [24], [25], [25], [26].

Also in Japan, patient supporter groups are starting up new social networking services [27], [28], [29]. There are networks that are not limited to particular diseases. One of such social

networks is the *LifePalette* [27], originated from a cancer ISG, which we have used for this research.

The advantages of sharing patients’ experiences by using such online communities or any other social networks are functioning as exchanging information, as getting social supports and as regaining their personal empowerment [8], [10], [11]. Especially, the increase of the patients’ QOL is investigated in variety of reports [16], [17], [19], [14], [15], [30]. Winzelberg, et al. reported that the peer support through an online support group is as effective as a face-to-face group support [19]. There are reports that claim that participating in online communities helps patients to overcome their loneliness and to be fulfilled in their lives [31], [32]. However, there are a number of patients who do not actively commit to such online communities [33], [34]. Especially, in Japan, even though the Internet penetration rate is as high as Western countries, there are much less online communities available [35].

Such studies were focusing on the practical outcome of the social networks. However, according to the previous studies, only few researches have been done on the specific factors which benefit the users of online communities [18], [36].

In any cases, it is shown that patients should actively commit to the social networks and share their information to increase their QOL. However, it is also true that many patients cannot keep up with participating in the communities, and they eventually stop participating at all, or some participants are not active at all from the first place [33]. Considering that the active participants are benefited more [36], it is important to keep the participants’ motivation.

This research is to investigate the cause that influences the continuous participation of social networks, and to try revealing the conditions for keeping their motivation to actively participate in the online communities.

II. MATERIALS AND METHODS

We used 18,917 blog articles to explore the factors that brought the blog posting to a halt. These articles were those posted on the *LifePalette*, which is one of the biggest Japanese online social networking services for patients. As of this report, the *LifePalette* has 185 registered users (53 males, 78 females, and 54 unknowns) and 18,917 posted articles (11,202 blog articles and 7,715 comments), and each user averages 0.88 comments¹. All users of this social network are patients, and the top 10 diseases that the users have are shown in Table I. It shows the most common disease that the users afflicted with is cancer, and amongst all the types, the users are most often suffering from breast cancer.

This research is to investigate the factors that are related to maintain the social network user’s article posting. We investigated as long as 36 months span (the posting lasted longer than 36 months were also considered as 36 months of posting). For those users with blank period of posting articles, we investigated from the beginning of the article posting until the posting stopped for more than 13 months, but no later. As a result, the average duration of the user’s posting was 4.76 months.

TABLE I. THE TOP 10 DISEASES THAT THE *LifePalette* USERS HAVE. NOTE THAT A SINGLE USER MAY HAVE ONE OR MORE DISEASES. “UNKNOWN” DENOTES THAT WE COULD NOT FIND ANYTHING THAT INDICATES THE USER’S DISEASE FROM HIS/HER BLOG. “CANCER” DENOTES THAT THERE ARE INDICATIONS THAT THE USER HAS CANCER, BUT COULD NOT FIND THE INDICATION OF THE CANCER TYPES. THE MOST COMMON DISEASE AMONG THE USERS IS CANCER, ESPECIALLY BREAST CANCER.

Disease	Patients
breast cancer	29
unknown	18
malignant lymphoma	12
leukemia	12
lung cancer	10
uterine cancer	9
stomach cancer	9
prostate cancer	7
brain tumor	5
diabetes	4
depression	4
cancer	4

We made this investigation on the following 3 conditions: disease-based condition, gender-based condition, and socially-supported-based condition. (Hereafter, we call each condition, disease condition, gender condition, and sociality condition.)

Disease Condition: As shown in Table I, we first investigated according to the users’ diseases. We used the most common 8 diseases of the *LifePalette* users (at least 5 users are afflicted with each disease), that are: breast cancer, malignant lymphoma, leukemia, lung cancer, uterine cancer, stomach cancer, prostate cancer, and brain tumor. We investigated the relationship between the each disease type and the duration of the user’s posting. The total number of the users we investigated was 93, as shown in Table I.

Gender Condition: We secondly investigated according to the gender differences. This was to find the relationship between the gender differences and the continuous posting term. We eliminated the users whose gender could not be identified from the articles. The total number of the male users was 53, and that of the female users was 78.

Sociality Condition: We thirdly investigated the relationship between receiving comments and the duration of the user’s posting. The maximum value of the number of comments received was 10.44, the minimum value was 0, and the median value was 0. Since the median was 0, in this report, we divided the users into two groups: the user group that had received one or more comments, and the other that had never received a comment. We investigated the relationship between these two groups and the continuous posting term.

III. RESULTS

Our first step was to explore the factors that bring the blog posting to a halt.

In order to capture the image of how long it took for the *LifePalette* patients to stop posting the blog articles, we used the Kaplan-Meier methods to estimate the ratio of the actively posting users over time, as an analogy of blog’s life. The following figures (Fig.1-3) indicate disease-based, gender-

¹including comments by nonregistered users

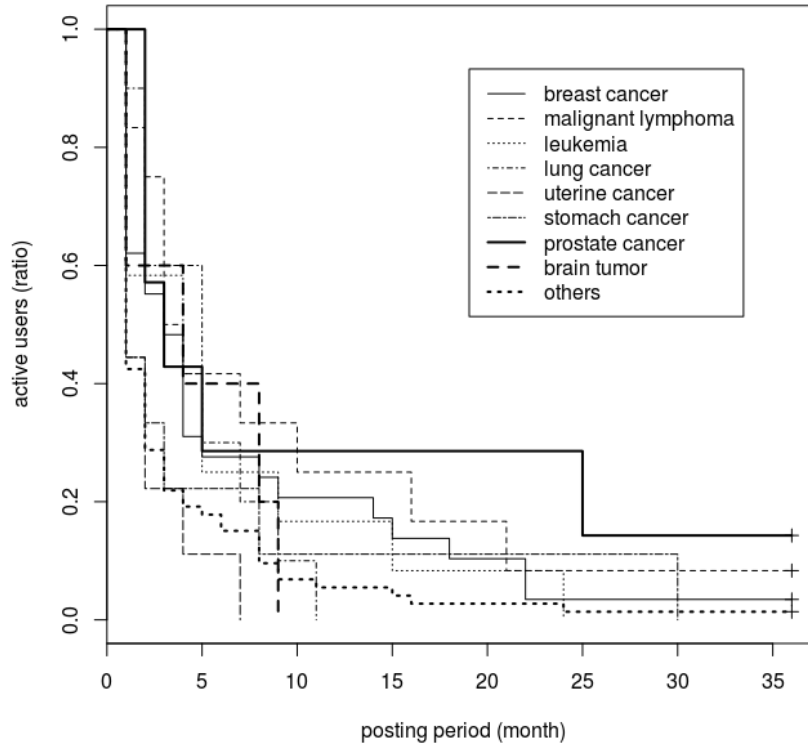


Fig. 1. The Kaplan-Meier curves according to disease-types. The vertical-axis represents the user rates of the blog posting. The user rates indicate the rates of the users who continued the article posting. The horizontal-axis represents the months passed since the first posting of the each user (1 - 36 months). All curves showed the exponential decreases over time.

based, and socially-supported-based Kaplan-Meier curves of the active user analysis.

Fig.1 indicates the disease-based estimation. We used 9 disease-types (which more than 5 users of the *LifePalette* are afflicted with), including the disease-type unknown (meaning, the patient's disease was not indicated in the article). As shown in Fig.1, all disease-types showed exponential decreases over time. The drastic decrease continued until 6 months after the first post, and 50% of all the users stopped posting articles by their first 6th month. After 12 months, 30% of the prostate cancer patients still continued their posting, whereas all the uterine cancer, brain tumor and lung cancer patients quitted posting. After 3 years (36 months), even the active user ratio of the prostate cancer patients decreased to 20%. Among all the diseases we investigated, prostate cancer patients showed least decrease in blog posting.

Fig.2 indicates the gender-based investigation. As shown in Fig.2, both male's and female's Kaplan-Meier curves decreased exponentially over time, just as of the disease-based investigation. This tendency was again obvious by the 6th month after their first article postings, and 50% of both male and female users stopped posting their articles. After one year (12 months), both male and female users' rate decreased to approximately 10%, and after 3 years (36 months), the ratio of both genders decreased to less than 10%.

Fig.3 indicates the socially-supported-based investigation. The socially-supported group was consisted of the users who had gotten one or more comments throughout their posting, and the not-socially-supported group was consisted of those

who had never gotten any comments. As shown in Fig.3, with or without comments, the rate exponentially dropped over time. However, this tendency was more conspicuous for the not-socially-supported group. When the user did not receive any comment, 80% of them stopped posting any articles by 6 months since their first posting, and after 24 months, 100% of them stopped posting articles. On the other hand, less than 70% of the socially-supported group stopped posting articles by 6 months, and even after 24 months, approximately 10% users kept posting their articles.

IV. DISCUSSION AND CONCLUSION

Fig.1 shows that the user rate of the prostate cancer was relatively high. We divided the users into two groups: those afflicted with prostate cancer, and those with other diseases. We used the generalized Wilcoxon test on the above two groups, and there was not a significant difference between the two ($p = 0.08$). However, this time, the number of users who had prostate cancer was small ($n = 7$), and further investigations with greater samples were required for verification.

Fig.4 shows the relationship between the five-year relative survival rates of each disease and the active user rates, as well as the duration of posting articles depends on the user's disease. There was no significant correlation between the relative survival rates and the duration (Pearson's product-moment correlation coefficient: $r = 0.26, df = 6, p = 0.54$). When taking into consideration that the five-year relative survival rate is one factor of measuring the seriousness of diseases, the

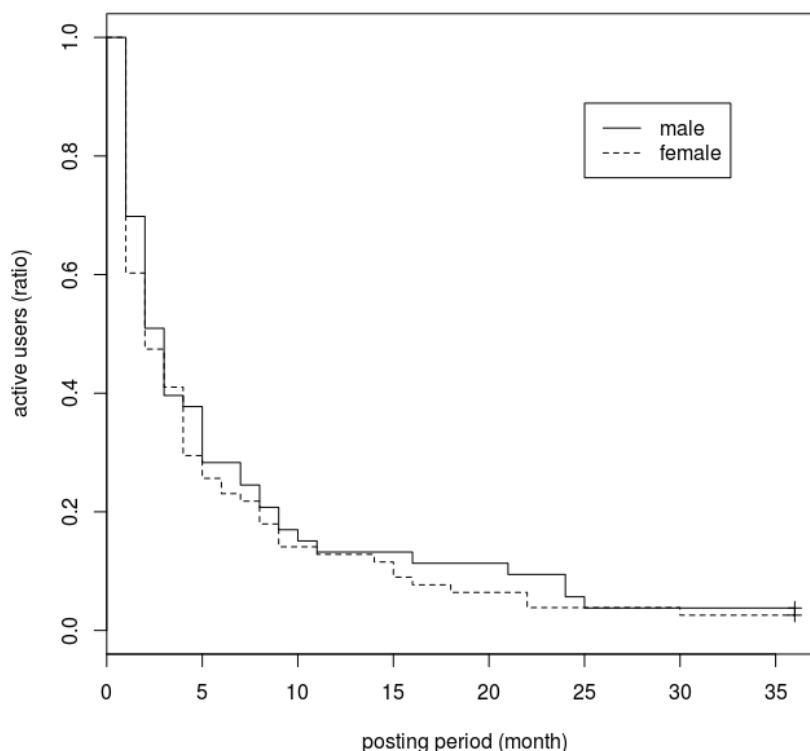


Fig. 2. The Kaplan-Meier curves according to the gender-types. The vertical-axis represents the user rates of the blog posting. The user rates indicate the rates of the users who continue the article posting. The horizontal-axis represents the months passed since the first posting of the each user (1 - 36 months). The gender difference did not show differences of the curves, and both male's and female's curves decreased over time.

seriousness of diseases had little influence on the continuation of article posting.

Japanese blogs comprise approximately 37% of the all blogs of the world in 2006 [38], which suggests that Japanese people are quite familiar with posting blog articles. However, Fig. 2 indicates that more than 50% of whole *LifePalette* users stopped posting articles. We used the generalized Wilcoxon test on this result, and there was no significant difference between male and female users ($p = 0.42$). This showed that even for Japanese people who should be familiar with posting blog articles have difficulty maintaining the long-term blog posting, while they are afflicted with diseases.

On the other hand, the generalized Wilcoxon test score between the users with comments and the users without comments showed significant difference ($p = 0.0067$). This result indicated that the users who had received comments tended to maintain their article posting for longer term, compared to those who had never received comments. However, this research did not investigate as far as whether receiving comments became the motivation of maintaining the continuation of article posting, or the continuous posting functioned as pump-priming to receive comments. To verify this relation between cause and effect, further study warranted.

From above investigations, it could be said that one of the factors associated with the continuation of the user's article posting was whether the user received comments or not, instead of the other factors we had investigated, such as the disease types or the gender differences. The result of

our research suggests the importance of receiving comments for the social network users. Some social networking services such as *J-RARE.net*[28] is taking the conflicts between users into consideration, and is disabling the commenting function. However, such conduct towards the social network function may possibly weaken user's volition for being an active user, for patients may likely stop posting blog articles without responses.

ACKNOWLEDGMENT

This study was supported in part by JST PRESTO. The authors wish to thank "Mediaid Corporation" for providing blog articles on the SNS "Life Palette."

REFERENCES

- [1] V. Lamos and N. Cristianini, "Tracking the flu pandemic by monitoring the social web," in *Cognitive Information Processing (CIP) 2010 2nd International Workshop on*, 2010, pp. 411–416.
- [2] M. J. Paul and M. Dredze, "You are what you tweet: Analysing twitter for public health," in *Processing of the Fifth International AAAI Conference on Weblogs and Social Media (ICWSM)*, 2011.
- [3] E. Aramaki, S. Maskawa, and M. Morita, "Twitter catches the flu: Detecting influenza epidemics using twitter," in *Proceedings of the Conference on Empirical Methods in Natural Language Processing (EMNLP2011)*, 2011, pp. 1568–1576.
- [4] PatientsLikeMe. (2004) PatientsLikeMe. [Online]. Available: <http://www.patientslikeme.com/>

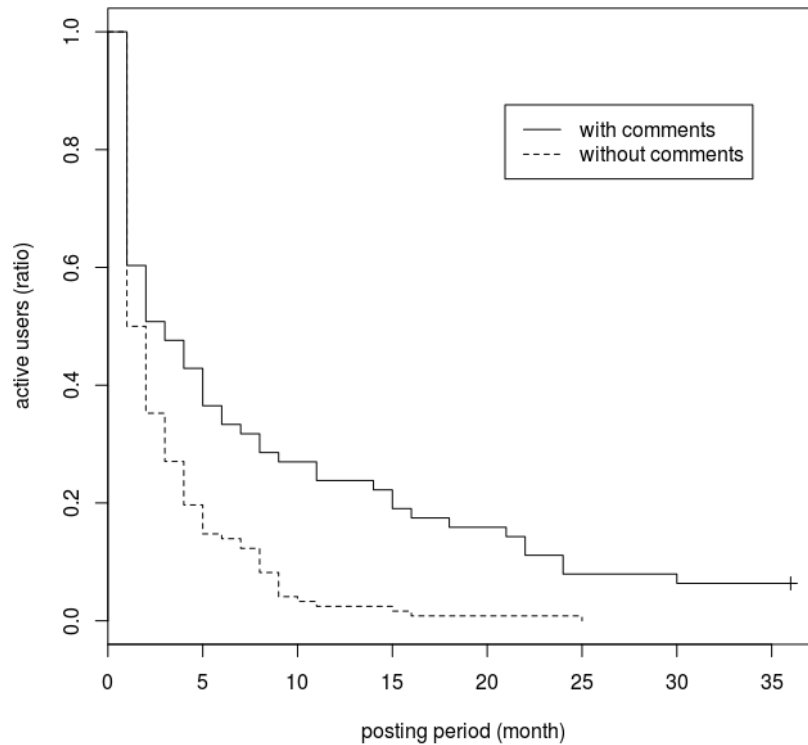


Fig. 3. The Kaplan-Meier curves associated with receiving comments. The vertical-axis represents the user rates of the blog posting. The user rates indicate the rates of the users who continued the article posting. The horizontal-axis represents the months passed since the first posting of the each user (1 - 36 months). All curves showed the exponential decrease over time, but the group of the users who were getting one or more comments showed moderate decrease, whereas the group without comments showed acute decrease and eventually extinguished after 24 months.

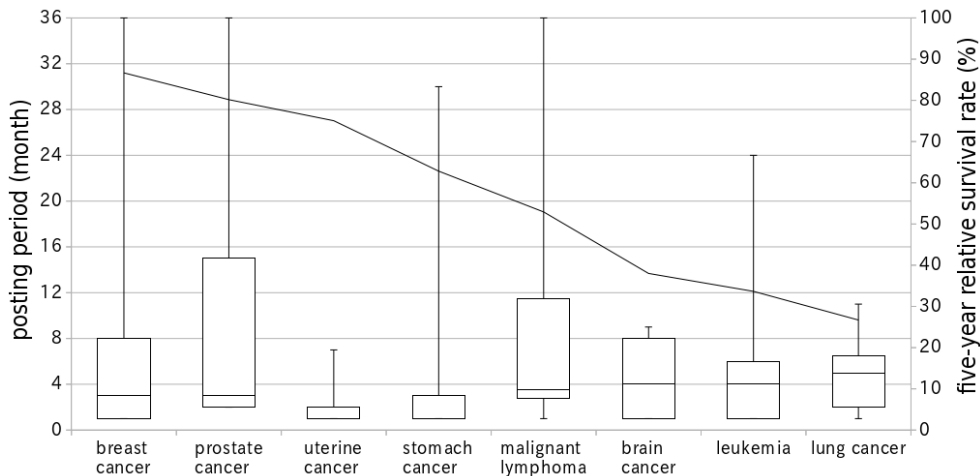


Fig. 4. The relationship between the five-year relative survival rates of each disease (0-100%: line chart) and the duration of user's posting (1-36 months: box plot). We used the public data distributed by National Cancer Center in Japan for the five-year relative survival rates [37]. The left vertical axis represents the period of writing (months), and the right vertical axis represents the active user rate (%). There was not a significant correlation between the period of writing and the active user rate.

[5] E. A. Bayliss, D. E. Bonds, C. M. Boyd, M. M. Davis, B. Finke, M. H. Fox, R. E. Glasgow, R. A. Goodman, S. Heurtin-Roberts, S. Lachenmayr, C. Lind, E. A. Madigan, D. S. Meyers, S. Mintz, W. J. Nilsen, S. Okun, S. Ruiz, M. E. Salive, and K. C. Stange, "Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters," *Annals of Family Medicine*, vol. 12, no. 3, pp. 260-269, 5-6 2014.

[6] C. A. Brownstein and P. Wicks, "The potential research impact of patient reported outcomes on osteogenesis imperfecta," *Clinical Orthopaedics and Related Research*, vol. 468, no. 10, pp. 2581-2585, 10 2010.

[7] J. Frost and M. Massagli, "Patientslikeme the case for a data-centered patient community and how als patients use the community to inform treatment decisions and manage pulmonary health," *Chronic Respiratory Disease*, vol. 6, no. 4, pp. 225-229, 2009.

[8] B. F. Sharf, "Communicating breast cancer on-line: support and empow-

- erment on the internet," *Women & Health*, vol. 26, no. 1, pp. 65–84, 1997.
- [9] A. M. Napoles-Springer, C. Ortiz, H. O'Brien, M. Diaz-Mendez, and E. J. Perez-Stable, "Use of cancer support groups among latina breast cancer survivors," *Journal of Cancer Survivorship*, vol. 1, no. 3, pp. 193–204, 9 2007.
- [10] L. Bonniface and L. Green, "Finding a new kind of knowledge on the heartnet website," *Health Information & Libraries Journal*, vol. 24, no. Supplement s1, pp. 67–76, 12 2007.
- [11] N. S. Coulson, H. Buchana, and A. Aubeeluck, "Social support in cyberspace: a content analysis of communication within a huntington's disease online support group," *Patient Education and Counseling*, vol. 68, no. 2, pp. 173–178, 10 2007.
- [12] L. M. Hoey, S. C. Ieropoli, V. M. White, and M. Jefford, "Systematic review of peer-support programs for people with cancer," *Patient Education and Counseling*, vol. 70, no. 3, pp. 315–337, 11 2008.
- [13] K. P. Davison, J. W. Pennebaker, and S. S. Dickerson, "Who talks? the social psychology of illness support groups," *American Psychologist*, vol. 55, no. 2, pp. 205–217, 2 2000.
- [14] P. Radin, "To me, it's my life: medial communication, trust, and activism in cyberspace," *Social Science & Medicine*, vol. 62, no. 3, pp. 591–601, 6 2005.
- [15] T. K. Houston, L. A. Cooper, and D. E. Ford, "Internet support groups for depression: a 1-year prospective cohort study," *American Journal of Psychiatry*, vol. 159, no. 12, pp. 2062–2068, 12 2002.
- [16] M. A. Lieberman and B. A. Goldstein, "Self-help on-line: an outcome evaluation of breast cancer bulletin boards," *Journal of Health Psychology*, vol. 10, no. 6, pp. 855–862, 11 2005.
- [17] K. M. Griffiths, A. L. Calear, and M. Banfield, "Systematic review on internet support groups (isgs) and depression (1): Do isgs reduce depressive symptoms?" *Journal of Medical Internet Research*, vol. 11, no. 3, p. e40, 7-9 2009.
- [18] K. M. Griffiths, A. Calear, M. Banfield, and A. Tam, "Systematic review on internet support groups (isgs) and depression (2): What is known about depression isgs?" *Journal of Medical Internet Research*, vol. 11, no. 3, p. e41, 7-9 2009.
- [19] A. J. Winzelberg, C. Classen, G. W. Alpers, H. Roberts, C. Koopman, R. E. Adams, H. Ernst, P. Dev, and C. B. Taylor, "Evaluation of an internet support group for women with primary breast cancer," *Cancer*, vol. 97, no. 5, pp. 1164–1173, 3 2003.
- [20] G. Anderson, J. Bergstorm, F. Hollandare, P. Carlbring, V. Kaldø, and L. Ekselius, "Internet-based self-help for depression: randomised controlled trial," *The British Journal of Psychiatry*, vol. 187, no. 5, pp. 456–461, 11 2005.
- [21] S. Murner, R. Burrows, N. Please, B. Loader, and S. Nettleton, "Births, deaths, sex and marriage ... but very few presents? a case study of social support in cyberspace," *Critical Public Health*, vol. 10, no. 1, pp. 1–18, 2000.
- [22] S. Muncer, B. Loader, R. Burrows, N. Please, and S. Nettleton, "Form and structure of newsgroups giving social support: A network approach," *CyberPsychology & Behavior*, vol. 3, no. 6, pp. 1017–1029, 7 2000.
- [23] D. A. Salem, G. A. Bogat, and C. Reid, "Mutual help goes on-line," *Journal of Community Psychology*, vol. 25, no. 2, pp. 189–207, 3 1997.
- [24] S. Fekete, "The internet - a new source of data on suicide, depression and anxiety: a preliminary study," *Archives of Suicide Research*, vol. 6, no. 4, pp. 351–361, 2002.
- [25] W. Macial, L. S. Lewis, and T. L. Smith, "Health-related message boards/chat rooms on the web: discussion content and implications for pharmaceutical sponsorships," *Journal of Health Communication*, vol. 10, no. 3, pp. 209–223, 2005.
- [26] S. C. Alexander, J. L. Peterson, and A. B. Hollingshead, *Help is at your keyboard: support groups on the Internet*. London, UK: Lawrence Erlbaum Associates, 2003, pp. 309–334.
- [27] Mediaid Corporation. (2008) LifePalette. [Online]. Available: <http://lifepalette.jp/>
- [28] J-RARE.net. (2013) J-RARE.net. [Online]. Available: <https://j-rare.net/>
- [29] National Center of Neurology and Psychiatry. (2010) Remudy. [Online]. Available: <http://www.remudy.jp/index.html>
- [30] T. Nakamura, K. Kubo, Y. Usuda, and E. Aramaki, "Defining patients with depressive disorder by using textual information," in *the AAAI Spring Symposium Technical Report SS-14-01: Big Data Becomes Personal: Knowledge into Meaning*, 3 2014, pp. 39–44.
- [31] W. G. Hill and C. Weinert, "An evaluation of an online intervention to provide social support and health education," *Computers Informatics Nursing*, vol. 22, no. 5, pp. 282–288, 2004.
- [32] C. F. van Uden-Kraan, C. H. Drossaert, E. Taal, E. R. Seydel, and M. A. van de Laar, "Self-reported differences in empowerment between lurkers and posters in online patient support groups," *Journal of Medical Internet Research*, vol. 2008, no. 10, p. e18, 2.
- [33] B. Nonnecke and J. Preece, "Lurker demographics: counting the silent," in *CHI '00: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 4 2000, pp. 73–80.
- [34] J. Preece, B. Nonnecke, and D. Andrews, "The top five reasons for lurking: improving community experiences for everyone," *Computers in Human Behavior*, vol. 2004, no. 20, pp. 201–223, 2.
- [35] M. T. Høybye, C. Johansen, and T. Tjørnhøj-Thomsen, "Online interaction: effects of storytelling in an internet breast cancer support group," *Psychooncology*, vol. 14, no. 3, pp. 211–220, 3 2005.
- [36] Y. Setoyama, Y. Yamazaki, and K. Namayama, "Benefits of peer support in online japanese breast cancer communities: differences between lurkers and posters," *Journal of Medical Internet Research*, vol. 13, no. 4, p. e122, 12 2011.
- [37] National Cancer Center. (2014) Download of spreadsheets (in Japanese). [Online]. Available: <http://ganjoho.jp/professional/statistics/statistics.html>
- [38] D. Sifry. (2006) Sifry's alerts: State of the blogosphere, april 2006 part 2: On language and tagging. [Online]. Available: <http://www.sifry.com/alerts/archives/000433.html>