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# Online Discourse on Fibromyalgia: Text-Mining to Identify Clinical Distinction and Patient Concerns

Authors' Contribution:

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Data Collection B  
Statistical Analysis C  
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Manuscript Preparation E  
Literature Search F  
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**Background:** The purpose of this study was to evaluate the possibility of using text-mining to identify clinical distinctions and patient concerns in online memoirs posted by patients with fibromyalgia (FM).


**Material/Methods:** A total of 399 memoirs were collected from an FM group website. The unstructured data of memoirs associated with FM were collected through a crawling process and converted into structured data with a concordance, parts of speech tagging, and word frequency. We also conducted a lexical analysis and phrase pattern identification. After examining the data, a set of FM-related keywords were obtained and phrase net relationships were set through a web-based visualization tool.

**Results:** The clinical distinction of FM was verified. Pain is the biggest issue to the FM patients. The pains were affecting body parts including 'muscles,' 'leg,' 'neck,' 'back,' 'joints,' and 'shoulders' with accompanying symptoms such as 'spasms,' 'stiffness,' and 'aching,' and were described as 'sever,' 'chronic,' and 'constant.' This study also demonstrated that it was possible to understand the interests and concerns of FM patients through text-mining. FM patients wanted to escape from the pain and symptoms, so they were interested in medical treatment and help. Also, they seemed to have interest in their work and occupation, and hope to continue to live life through the relationships with the people around them.

**Conclusions:** This research shows the potential for extracting keywords to confirm the clinical distinction of a certain disease, and text-mining can help objectively understand the concerns of patients by generalizing their large number of subjective illness experiences. However, it is believed that there are limitations to the processes and methods for organizing and classifying large amounts of text, so these limits have to be considered when analyzing the results. The development of research methodology to overcome these limitations is greatly needed.

**MeSH Keywords:** **Text-mining • Fibromyalgia • Online Discourse**

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## Background

Studies of disease experiences have been conducted to understand the various stories of what patients suffer through from specific diseases [1]. The purpose of these studies is to evaluate the sickness by analyzing the patient's physical, psychological, and social conditions over time. Furthermore, the studies can gather generalized knowledge that can be used for diagnosing specific diseases by noting the common aspects among the various personal experiences of different patients. Documents such as memoirs of, and interviews with, patients are the usual sources of the current studies. These sources have been analyzed as stories of their lived experience, but they have a limitation for generalizing the understanding of certain diseases and patients due to the small number of analysis targets.

Recently, more and more people are sharing information on health via the internet [2]. When patients feel a lack of pertinent information available or a need to share their experience with, be heard by, receive help from, and give help to others, they find internet sites where they can be involved in active dialogue with other patients who share the same problems [3]. For these reasons, the internet sites related to diseases are greatly expanding and thus presenting an excellent opportunity for quantitative analyses [4].

An ever-increasing number of memoirs and corresponding comments are being posted online by patients, as well as articles written by professionals. In recent years, this tendency has become more active due to the appearance of blogs, message boards, forums, and SNSs. Numerous stories of illnesses and medication processes are now elicited by, and archived in, various patient-support platforms, and the amount of information thus generated by patients has formed a huge data set, commonly referred to as "big data" [5,6]. To analyze the massive information on the internet, a method called 'text-mining' or 'text data-mining' has been introduced [4,7]. Text-mining is used for classifying and organizing a large amount of text to extract common themes and lexical, phrasal, or sentential tendencies. Recently, an increasing number of researchers dealing with health-related issues have suggested that the text-mining method was found to be more useful for studying massive amounts of data than the traditional, qualitative, ethnographic methods of participant observation and interviews [4,8,9]. The text-mining tasks such as text classification/clustering, word-frequency/content analysis, and phrase net visualization proved efficient in detecting the emerging issues and needs of the patients and in providing portrayals of collective opinions and concerns [3,4,10,11]. Nevertheless, there has been little research on the potential of text-mining in identifying clinical distinctions and patient concerns.

The present study used a text-mining method to analyze memoirs related to a specific disease posted on the internet because

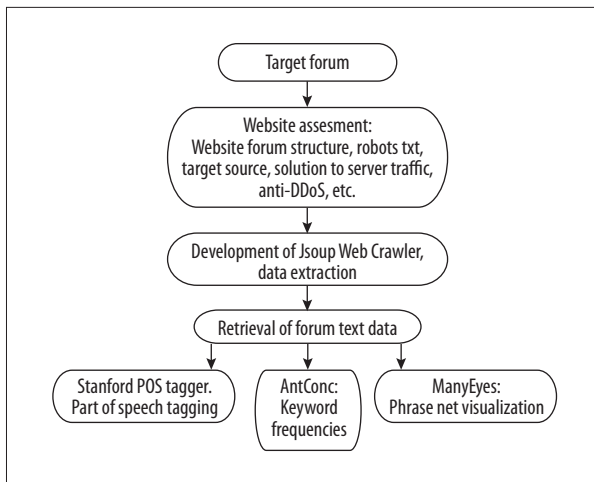
this genre most powerfully captures the patients' experience of the disease. Although this study shares the same object of study as qualitative studies – patients' stories – it differs from the traditional qualitative analyses that are personal and contextual ("at the personal level" and "within the here and now") and particularly from a narrative approach to illness experience that usually aims at finding something that is 'out of average' [12]. In contrast, the text-mining approach transforms the stories into quantitatively estimable data structures and numbers, which generalize the patients' distinctive experiences and conditions a-contextually and collectively. The primary purpose of the present study is to determine whether text-mining the memoirs of patients who have had experiences of a specific disease can form and produce generalized knowledge about a particular disease. As a pilot study for long-term research and an alternative method on massive internet language data, our approach is, by design, focused on a sample of 399 illness stories for the experiment. The secondary purpose of the present study is to discern what interests and concerns have been reflected in the memoirs.

In this study, we used a large sample of on-line memoirs of patients with fibromyalgia (FM) syndrome. The basic reason for focusing on FM is that this disease is often accompanied by a large variety of physical, psychological, and social problems due to the pain of the chronic musculoskeletal disorder [13–15], so we formulated a hypothesis that these peculiarities could be seen in patient memoirs of the disease. The main complaint of FM patients is chronic and systemic musculoskeletal pain that yields difficulties in daily life while they are awake, and the pain is hard to relieve and moderate [11,16–19]. FM patients also suffer from other physical symptoms such as fatigue and sleep disorders, and psychosocial symptoms such as depression, anxiety, and tension [11,12,20–23]. Consequently, these symptoms, as well as the pain, can have a negative effect on the quality of the patients' life [24–28].

To confirm whether the data acquired via text-mining represents the previously mentioned characteristics of FM described in the past studies, we used a method that calculates the frequency of words with the focus on the nouns in a written text. On this basis, we analyzed what types of words were high-frequency nouns, and how these nouns were used in the original text. In many cases, whenever necessary we double-checked the result of the text-mining with the text itself to grasp the usage of words more accurately.

## Material and Methods

Experienceproject.com is a popular online social networking community where 3.8 million personal stories are created and more than 1.5 million participants write and read the



**Figure 1.** Flowchart of text-mining process. The flowchart shows the major steps in the process of text-mining, from the assessment of the website structure, development of the crawler, and extraction to the final analyses of lexical and phrasal distinctions of FM discourse.

stories. Regarding the demographics of the participants of this site, most of them are from the United States (36.8%), India (17.1%), the United Kingdom (7.5%), Canada (4.4%), and Philippines (2.2%) (<http://www.alexa.com/siteinfo/experienceproject.com>). As our data source, we chose the forum under the title of “I Have Fibromyalgia”, where various types of patients share their experience of the disease. At “I Have Fibromyalgia”, the participants are FM patients who voluntarily post their stories to share the illness experience, and receive health-related information and emotional support from others. A total of 399 memoir samples were collected through text-mining tools at <http://www.experienceproject.com/groups/Have-Fibromyalgia/2671?omni>.

To obtain the language data from the forum, we first collected the unstructured data of memoirs associated with fibromyalgia through a crawling process (Figure 1). To obtain the language data from a webpage that uses web-programming languages such as HTML and JSP, JSOUP web crawler was developed to automatically retrieve the “MessageContent” from the target forum. The data thus retrieved were saved into a text file to make a structured and analyzable dataset. After this, we generated information such as word frequency lists, keyword lists, and concordance plots through AntConc, which is a concordancer available on the internet, often used by corpus linguists and social scientists to sort text data [29]. We also made a dataset by categorizing the words of the text file into nouns, verbs, and adjectives by using Stanford POS Tagger, which assigns part of speech tags to individual words [30]. Then we eliminated such unnecessary and functional words as articles (e.g., “a” and “the”), conjunctions (e.g., “and” and “but”), and pronouns (e.g., “I” and “you”) to have

FM-relevant data. Through the process, we obtained a total of 21,929 nouns ready for analysis.

To conduct a lexical analysis and pattern identification, we used ManyEyes, whose distinctive function is to identify phrasal relationships (Figure 1). ManyEyes is a web-based visualization tool created by Fernanda Viégas and Martin Wattenberg [31], which offers a graphic representation of patterns and distinctions of a given dataset. Constructed on a public website, it allows users to upload a set of data, visualize them, and gain new insights into patterns occurring in the data. Particularly, the Phrase Net Visualization offers pattern matching and general views of the words in the data and visualizes any 2 words that frequently associate and appear together.

## Results

### Clinical distinction of FM

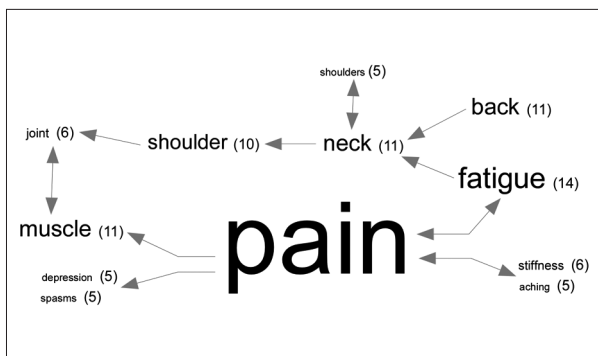
According to the analysis of the frequency of nouns from the memoirs of FM patients, ‘pain’ showed the highest frequency (1<sup>st</sup>) of occurrence (Table 1). This means that pain is the most distinctive issue for FM patients, suggesting it is the most important word characterizing FM. Therefore, by examining how the word ‘pain’ was used in the texts, we were able to extract important information to understand FM.

For more detailed information about the use of ‘pain,’ we conducted 2 additional analyses: 1) keywords that were frequently found in the same sentence as the word ‘pain’ as in “I experience chronic pain, debilitating muscle spasms, joint tenderness and swelling” (see Figures 2 and 3), and keywords that were directly preceding or following the word ‘pain’ as in “It’s so hard to explain to someone that doesn’t have chronic pain,” and “I still am waiting for that elusive pain-free day” (Figure 3). By using the concordance and phrase net visualization, we obtained more concrete information related to the ‘pain’ of FM. Specifically, the pain of FM seems to occur mainly in the body (9<sup>th</sup>), muscles (15<sup>th</sup>), neck (46<sup>th</sup>), back (60<sup>th</sup>), joints (62<sup>nd</sup>), and shoulders (68<sup>th</sup>) (Figures 2 and 3). Fatigue (34<sup>th</sup>) and depression (33<sup>rd</sup>) also seem to be related with pain (Figure 2). The aspects associated with the pain are ‘spasms’, ‘stiffness’, and ‘aching’ (Figure 2), although these nouns were not in the top 100. Overall, the pain is described as being ‘severe,’ ‘chronic,’ and ‘constant’ (Figure 3).

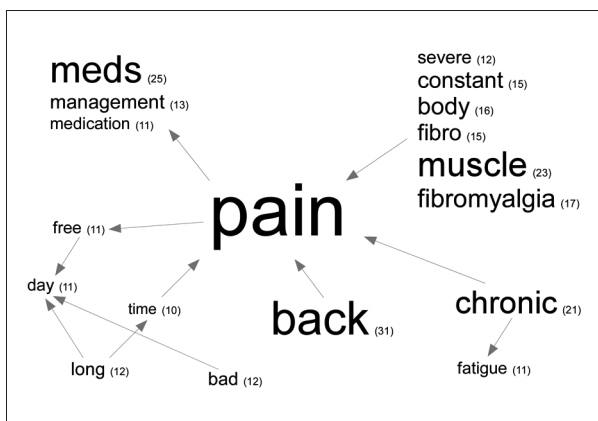
As shown in the analysis of the frequency of nouns (Table 1), ‘fibromyalgia’ is the next most frequent word (2<sup>nd</sup>) after the word ‘pain’ – suggesting that patients are concerned about their pathology. The high frequency of the word ‘symptoms’ (12<sup>th</sup>) indicates that FM patients are interested in their symptoms in the same way (Table 1). Also frequent are the nouns

**Table 1.** Rank of major word frequencies among 21,929 nouns in the online memoirs.

Rank	Noun	Freq	%	Rank	Noun	Freq	%	Rank	Noun	Freq	%
1	Pain, pains	1028	4.69	36	Hours, hour	75	0.34	68	Care	40	0.18
2	Fibro, fibromyalgia, FM	763	3.48	37	Night	74	0.34	72	Condition	39	0.18
3	Years, year, yrs	507	2.31	38	Children, child	73	0.33		Issues	39	0.18
4	Day, days	459	2.09	39	Others	70	0.32		July	39	0.18
5	Time, times	400	1.82	40	Nothing	69	0.31	75	Morning	38	0.17
6	Life	303	1.38		Tests	69	0.31	76	Heart	37	0.17
7	Doctor, doctors, Dr.	276	1.26	42	Head	65	0.30		Syndrome	37	0.17
8	Thing, things	253	1.15		Illness	65	0.30	78	Anxiety	35	0.16
9	Body	199	0.91	44	Disease	63	0.29		Help	35	0.16
10	People	193	0.88	45	Support	60	0.27		Hands	35	0.16
11	Meds, medication, medications	170	0.78	46	Energy	59	0.27		June	35	0.16
12	Symptoms, symptom	156	0.71		Neck	59	0.27		November	35	0.16
13	Months, month	124	0.57	48	School	57	0.26	83	Blood	34	0.16
14	Something	119	0.54		Stress	57	0.26		Weight	34	0.16
15	Muscle, muscles	118	0.54	50	Today	55	0.25	85	Exercise	33	0.15
16	Lot, lots	114	0.52	51	House	54	0.25		Place	33	0.15
17	Way	111	0.51		Story	54	0.25		Kids	33	0.15
18	Mother, mom	107	0.49	53	Person	53	0.24	88	Daughter	32	0.15
19	Week, weeks	105	0.48		Mind	52	0.24		Rest	32	0.15
20	Anything	97	0.44		Point	52	0.24		Side	32	0.15
	Family	97	0.44		Feet	52	0.24		Son	32	0.15
22	Anyone	96	0.44	57	January	50	0.23		April	32	0.15
	Work	96	0.44	58	Brain	49	0.22		December	32	0.15
24	Husband	94	0.43	59	One	48	0.22	94	Couple	31	0.14
25	Job	87	0.40	60	Back	47	0.21		End	31	0.14
	Friends, friend	87	0.40		Feeling	47	0.21		Medicine	31	0.14
27	Sleep	83	0.38	62	Everyone	46	0.21		February	31	0.14
28	Someone	82	0.37		May	46	0.21		March	31	0.14
	Problems, problem	82	0.37		Joints, joint	46	0.21	99	Kind	30	0.14
	Legs, leg	82	0.37	65	Health	45	0.21	100	Arthritis	29	0.13
31	Bed	81	0.37		Relief	45	0.21		Bit	29	0.13
32	Home	79	0.36	67	Diagnosis	43	0.20		Disorder	29	0.13
33	Depression	78	0.36	68	Age	40	0.18	104	Name	28	0.13
34	Everything	77	0.35		Part	40	0.18		Therapy	28	0.13
	Fatigue	77	0.35		Shoulders, shoulder	40	0.18		Type	28	0.13



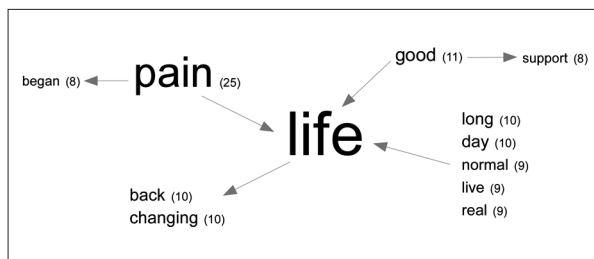
**Figure 2.** The Phrase Net: the keywords related to ‘pain’. The Phrase Net that shows the keywords that were frequently found in the same sentence as the word ‘pain’; the number of occurrence is in parenthesis. The main keyword ‘pain’ is not scaled proportionally here but others are. Each arrow indicates the order of words in a sentence. For instance, “chronic pain” is notated with “chronic → pain”. The original Phrase Net is modified here for better resolution of the view.



**Figure 3.** The Phrase Net: the keywords before/after ‘pain’. The Phrase Net that shows the keywords that were directly preceding or following the word ‘pain’. The main keyword “pain” is not scaled proportionally here but others are. The original Phrase Net is modified here for better resolution of the view.

related to symptoms of FM such as ‘sleep’ (27<sup>th</sup>), ‘depression’ (33<sup>rd</sup>), ‘fatigue’ (34<sup>th</sup>), and ‘stress’ (48<sup>th</sup>) (Table 1). These words in particular directly indicate the symptomatic characteristic of FM. There are terms such as ‘body’ (9<sup>th</sup>), ‘muscles’ (15<sup>th</sup>), ‘leg’ (28<sup>th</sup>), ‘head’ (42<sup>nd</sup>), and ‘neck’ (46<sup>th</sup>) that indicate which parts of the physical body are affected by the pain of FM (Table 1). Overall, the lexically suggested relationship among adjacent words confirms that FM is a disease that causes extensive pain in the musculoskeletal system.

Results also support that patients suffer from FM for a long time because it is a chronic disease. This fact can be seen in the high frequency of the word ‘years’ (3<sup>rd</sup>) that often accompanies



**Figure 4.** The Phrase Net: the keywords related to ‘life’. The Phrase Net that shows the keywords related to ‘life’. The number of occurrence is in parenthesis. The main keyword “life” is not scaled proportionally here but others are. The original Phrase Net is modified here for better resolution of the view.

the description of FM (Table 1). In most cases the word ‘years’ was used with numbers, indicating that FM is a chronic disease.

### Concerns of FM patients

There are various concerns of FM patients. First, FM patients are eager to be free from the pain. As shown in Figure 3, the word ‘free’ (adj.) and ‘relief’ (65<sup>th</sup>) are frequently connected to the word ‘pain’, which reflects the desire of FM patients to have relief from, and be free from, the pain of FM. Also, the word ‘life’ (6<sup>th</sup>) has a high frequency (Table 1) and is still in the top 20 words when combined with modifying adjectives (Figure 4). In other words, the adjectives such as ‘normal’, ‘real’, and ‘good’ were shown frequently modifying the word ‘life’ – meaning that FM patients long for changing their present life and/or going back to a normal life (“hope for a normal life back”). As indicated in Figure 4, the word ‘life’ was connected to the word ‘pain’ representing the painful life of FM patients.

It seems that the cravings and painful life of FM patients are connected to the high-frequency words related to help such as ‘support’ (45<sup>th</sup>), ‘care’ (68<sup>th</sup>), and ‘help’ (78<sup>th</sup>) (Table 1). In many cases, these keywords are used when FM patients are in need of specific help. Furthermore, it has to do with the FM patients’ interest in the treatment of pain. This phenomenon can be confirmed with the words ‘medication’ (11<sup>th</sup>) and ‘management’, which have a connection with the word ‘pain’ (Figure 3) and the high-frequency word ‘medication’ (Table 1). However, the specific treatments, methods, and the names of the drugs were not conclusive in the analysis of the frequency of nouns. This means that from the patients’ point of view these were not important issues; rather, they were only a medical point. Instead, FM patients used everyday language to describe their experiences. Along with the treatment of pain and help against FM, words such as ‘work’ (22<sup>nd</sup>) and ‘job’ (25<sup>th</sup>) showed a high frequency (Table 1), indicating that work/occupation is an important part of FM patients’ concerns (i.e., whether they lost a job or are trying to get one). This is because work/occupation is necessary for living life well, and FM can negatively affect these aspects of life.

Another observation of this study was that there are many words referring to a particular person or group of people, for example, 'doctor' (7<sup>th</sup>), 'mother' (18<sup>th</sup>), 'family' (20<sup>th</sup>), 'husband' (24<sup>th</sup>), 'friend' (25<sup>th</sup>), and 'children' (38<sup>th</sup>) (Table 1). This supports the notion that FM patients continue to live life under the basis of human relations and have concerns related with them.

## Discussion

This study used text-mining methods to analyze 399 samples of only memoirs of the specific disease FM that were posted on the internet. There are 2 important findings in the results of this analysis. First, the clinical distinction of FM was verified. The study confirmed that pain is the biggest issue for the FM patients [11,15–18,20,21]. Through the analysis of keywords used in association with the word 'pain', we obtained the information related to the pains and accompanying symptoms from which the FM patients suffer. The pains were affecting body parts, including 'muscles,' 'leg,' 'neck,' 'back,' 'joints,' and 'shoulders' with accompanying symptoms such as 'spasms,' 'stiffness,' and 'aching,' and were described as being 'severe,' 'chronic,' and 'constant.' The findings were also consistent with the clinical features of FM revealed from previous research [20,22–28]. Besides the FM-related pains, the words with high frequency were found to be the very key words that define the clinical features of FM. For instance, 'sleep' and 'fatigue' were frequently found in the memoirs of the patients, and the high occurrence attests to the significance of sleep deprivation and fatigue severity as issues in their lives – the clinical fact being commonly reported in other studies [11,20,22]. In addition, words such as 'depression' and 'stress' that were ranked high in frequency indicate that the FM patients also go through psychological tribulation [23]. The relationship between the FM-related pains and the clinical features of fatigue and depression were also identified by the Phrase Net Visualization. Through the text-mining method, this study quantitatively confirmed the clinical features of FM that were found by qualitative research, and showed the possibility that the memoirs posted online by people with FM may well describe the clinical features of the disease. Furthermore, the same method can be applied to the memoirs of patients suffering from other diseases.

Second, the study demonstrated that it is possible to understand the interests and concerns of FM patients through text-mining. FM patients wanted to escape from the pain and symptoms [11,18,19,21,26,28], so they were interested in medical treatment and help [11,13,17,21,28]. Also, they seemed to have interest in their work and occupation [28,32–34]. Moreover, it was shown that they hope to continue to live life through relationships with the people around them [28,34,35]. These findings are in accord with the other results from narrative analyses [17,19,20,26,32–35]. The results of this study show the

possibility of recognizing key words from a large database of texts, and even though patient memoirs of illness experiences are personal, the interests of FM patients can be understood by generalizing the patterns of keywords. Consequently, by increasing the understanding of FM patients' interests, medical professionals can increase their effectiveness when dealing with them in a psychological and social way.

It should be noted, however, that the keywords obtained through the text-mining process are not concerned with certain previously known aspects of FM patients' concerns, such as sexual dysfunction related to fatigue and medication [36], psychological need for receiving help from health-related professionals (e.g., nurse, physical therapist, and clinical psychologist) [37], and the struggle to keep up with daily routines or household chores as a coping strategy for pain [17,38,39]. Regarding these concerns, the keywords showed insignificant frequency and were not included as meaningful data. This omission is due to the fact that text-mining represents only dominant patterns and generalizable knowledge. In other words, although the aforementioned concerns are distinctive and important aspects of an individual's experience of FM, those individualized distinctions are averaged and outweighed by the sheer number of more general FM-related verbal phenomena. In that aspect, text-mining fails to focus on qualitative appraisal and assessment of some under-represented concerns, which are otherwise an important aspect of FM patients' inner struggles and personal lives. Therefore, the method and analysis in the present study, which is based on occurrence frequency and phrasal relationship, is only useful for identifying dominant patterns and obtaining generalized knowledge.

There are some other limitations to this study. Firstly, textual analysis of keyword extraction can help researchers understand a large amount of information in a short period time, but it can be unclear how the information can be used in specific contexts. In this study, we have tried to examine how certain keywords were used in context by using the Phrase Net Visualization. In spite of this, there were some cases where the keywords did not occur at a high frequency. In such cases, there was no choice but to find the sentences involving certain keywords to understand the meaning. Finding sentences one by one should not be the goal of such data processing. Therefore, further research is needed to overcome this problem.

Secondly, sometimes the quality of the memoirs of disease experience can change depending on the condition of the patient (e.g., duration and degree of illness and coexistence of other diseases), but this was not addressed in the processing of the data used in this study. In addition, factors such as age, gender, culture, and the social/occupational status of patients were not specified in the memoirs, so these factors were not included. The reason for not controlling these patient features

is that text-mining utilizes large, unspecified amounts of data, which is one of its inherent limitations. Therefore, the limitations should be considered when interpreting the results based on text-mining.

Thirdly, this study was able to grasp the characteristics of FM through a keyword analysis, but extracted keywords may not be the best method for diagnosing diseases. In other words, keywords extracted in the course of medical history can be used by doctors as important information to formulate a hypothesis for the disease of the patients, but this is only a part of the clinical process for making a final diagnosis. To make an accurate diagnosis, clinical check-ups and inferences of doctors are still necessary.

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## Conclusions

To showcase the text-mining method and its performance, this study analyzed 399 patient memoirs of a specific disease (FM) posted on the internet. This research showed that extracting keywords can confirm the clinical distinction of a certain disease, and it can help objectively understand the concerns of patients by generalizing their large number of various, subjective comments. However, it is believed that there are limitations to the processes and methods for organizing and classifying large amounts of text, and these limits have to be considered when analyzing the results. Though text-mining can greatly contribute to the understanding of symptoms and patients' experience of diseases, the development of research methodology to overcome these limitations is greatly needed.