

Understanding the Patient Health Information Behavior to Guide Their Health Self-management: Findings from Online Lupus Erythematosus Communities

Completed Research Paper

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Abstract

Online health communities (OHCs) have the potential to empower individuals to develop healthy lifestyles, make better and more informed medical decisions, and improve personal health management. However the relationship between users' health information behavior in OHCs and their health self-management needs further discussion. Our study classified OHCs users into three groups: Positive, Intermediate and Negative by clustering method according to their health information communication. The clustering results showed that there were significant differences in the level of health information exchange among users. The results of one-way ANOVA with Games-Howell test showed that there were also significant differences in the health status, perceived help from OHCs and health self-management among the three groups. And there was a significant correlation between perceived help from OHCs and users' health self-management. Feasible guidance was proposed for stakeholders to improve OHCs' function to help patients with chronic diseases to improve their health.

Keywords: Health information behavior, health self-management, online health communities (OHCs)

Introduction

According to the National Health Commission (NHC, 2017), the chronic disease accounts for 86.6% of the total deaths in China and the burden of the chronic disease has accounted for more than 70% of the total burden of diseases. With the increasing incidence of chronic diseases, the deficiency of medical resources has become a serious problem for China, a country with a large population. How to improve the health outcomes and enhance the well-being of patients with chronic diseases in limited resources has become an important research topic. Empowering patients to accept responsibility for their own health behaviors and engage in health self-management is a feasible method of potential (Nes *et al.*, 2013; Willis and Roynes, 2017). Self-management can improve one's health and reduce healthcare utilization by people with long-term conditions (Joglekar *et al.*, 2018). Previous studies have shown that engaged patients are more willing to seek preventive and routine chronic care, show

stronger adherence to the health behaviors and treatment, so as to improve their health and the quality of life (Menefee *et al.*, 2016; Valdez *et al.*, 2017).

The Internet has empowered patients to share their information and experiences related to their conditions and also have the chance to access to others' information through social media (Antheunis *et al.*, 2013; Hajli, 2014; Zhao *et al.*, 2014). Patients are increasingly accessing online health information and have become more participatory in their engagement with the advent and popularity of social media (Benetoli *et al.*, 2018; McClellan *et al.*, 2017). Online health communities (OHCs), a type of virtual forums based on the Internet where individuals communicate and interact with others about health topics, are the most prominent social media sources for peer-generated health information (Fan and Lederman, 2017; Rupert *et al.*, 2014; Zhang, X. *et al.*, 2017). OHCs promote the sharing, dissemination, and creation of health information of patients at a relatively high level (Goh *et al.*, 2016). People turn to OHCs for different reasons, including easy access of health information, asking for help and learning about other patients' experiences, filling information gaps in patient-provider communication, emotional support and becoming part of a community (Gopalsamy *et al.*, 2017; Huh *et al.*, 2016; Zhang, Y., 2016). Therefore OHCs have become popular platforms for individuals to discuss health challenges, obtain information help and exchange social support with others (Atanasova *et al.*, 2018; Choi *et al.*, 2017; Jung *et al.*, 2018; Park *et al.*, 2018; Petrovčič and Petrič, 2014).

Although previous studies have pointed out that OHCs can help patients with chronic diseases, these studies have either focused on the communication patterns of users (Carron-Arthur *et al.*, 2015; Valdez *et al.*, 2017; Willis and Royne, 2017) or concentrated on analyzing the text generated within OHCs (Fergie *et al.*, 2016; Hartzler *et al.*, 2016; Park *et al.*, 2018; Rupert *et al.*, 2016; Zhang, S *et al.*, 2017). Few studies have focused on the relationship between users' information behavior in OHCs and their health self-management outcomes. In other words, further research is needed on how OHCs help users to improve their health information management. The objective of this exploratory study is to discover the differences between OHCs users with chronic health conditions on the health information behaviors. The further aim is to determine relationships between health information behaviors that typify OHCs users and their health self-management, based on the data from a detailed sample survey.

This study focuses on online lupus erythematosus communities as an example to discuss the above topic. Lupus erythematosus (LE) is a chronic autoimmune rheumatic disease, most commonly seen in women aged 15 to 40 years old. Because LE can involve symptoms that are not physically evident to others (e.g. fatigue), it has been described as an "invisible illness" (Brennan and Creaven, 2016), and sufferers are vulnerable to negative reactions such as disbelief and unwanted or ineffective social support (Mazzoni and Cicognani, 2014, 2016) from social network members. The key to the treatment of LE is "inducer remission", that is, to make the disease keep in dormancy, without harm to the human body. Daily medical care and self-monitoring (Mamykina *et al.*, 2016) are very important for patients with LE, and the provision of sufficient information might enhance their adherence to medication (Chehab *et al.*, 2018). Online patient communities provide original unbiased information that may help improve the provision of information to LE patients (Meunier *et al.*, 2016). We seek to provide insight into the inherent relationship between a patient's health information behaviors and health self-management in OHCs. Then we can give feasible guidance for stakeholders to improve OHCs' function to help patients with chronic diseases to improve their health.

Literature review

Online health community

Online health community (OHC) is considered as a virtual forum where the members share a common interest or need of health topics (Rupert *et al.*, 2014; Zhang, X. *et al.*, 2017). OHC allows members to share their own experience about health issues and encourage interaction (Zhao *et al.*, 2014) that makes it one of the most important sources for searching and exchanging health-related information (Atanasova *et al.*, 2018). Because OHCs enable patients to connect to a large number of people who

suffer from similar health problems with them (Yan and Tan, 2017), OHCs have become valuable resources for people with chronic disease (Willis, 2018).

Previous studies pointed out that online health community had two main functions: informational support and emotional support (Nambisan, 2011; Litchman *et al.*, 2018; Wang *et al.*, 2018; Chen *et al.*, 2019). On the one hand, with the help of the peer-generated content OHCs can provide experience-based information, unconventional information, and medical facts for the chronic disease patients (Choi *et al.*, 2017). Unlike the information provided by regular medical institutions, peer-generated information comes from the actual illness experience or treatment experience of other patients with the same disease (Sinha *et al.*, 2018), which can provide greater reference value for patients. On the other hand, empathy develops and operates through shared experiences and connections in OHCs (Hargreaves *et al.*, 2018) that gives patients a sense of belonging to the community. Emotional support from others plays an active role in health recovery activities of patients with chronic diseases. In general, the widespread use of OHCs plays an important role in the transformation of the experiences of health care and chronic condition management among users (Atanasova *et al.*, 2017).

Personal health information management (PHIM)

Chronic illness places high demands on patients (Nes *et al.*, 2013), their engagement in their health care, or having the knowledge and skills to manage their health, has proven beneficial for improving long-term health outcomes (Menefee *et al.*, 2016). Therefore, personal health information management plays an important role in improving the health status of patients with chronic diseases. There are many definitions of personal health information management. But researchers agree that the tasks involved in collecting and managing personal medical information have been called “personal health information management” (Ancker *et al.*, 2015). We refer to personal health information management as the activities that people perform in order to acquire, organize, maintain, share, retrieve, and use health information items to complete healthcare tasks and fulfill their needs (Zhou *et al.*, 2018). When individuals perform health information management, it emphasizes to engage in the tasks of acquiring, managing, and organizing a diverse set of health information (Moen and Brennan, 2005; Civan *et al.*, 2006).

PHIM requires people to use their personal health information for monitoring and assessing health, making health-related decisions and planning, performing preventive care and delivering treatment (Holden *et al.*, 2018). The increasing volumes of person-generated data open new horizons for promoting self-knowledge and self-awareness. This has a particular significance for individuals with chronic diseases who could potentially use such data to identify beneficial self-management strategies (Mamykina *et al.*, 2016). Due to various suitable attributes OHCs have emerged as an effective platform for self-healthcare management (Zhang, X. *et al.*, 2018). Members of OHCs often acquire disease-related knowledge from the interaction with others and improve their understandings of their conditions. This type of informational support then empowers individuals to strengthen health consciousness, pursue health behaviors, and manage chronic disease (Willis and Royne, 2017). Online communities for people with long-term conditions have the potential to influence health behaviors and the use of healthcare resources; it also facilitates illness self-management (Joglekar *et al.*, 2018; Willis, 2016).

Previous studies have shown that OHCs can help in the fields of smoking cessation intervention (Zhang, M. and Yang, 2015; Zhao *et al.*, 2016), diabetes management (Fergie *et al.*, 2016; Zhang, Y., 2016), arthritis (Willis, 2016), cancer (Zhang, S *et al.*, 2017) and mental health (McClellan *et al.*, 2017; Park *et al.*, 2018; Yan and Tan, 2017). Few studies have focused on the relationship between users' information behavior in OHCs and their health self-management outcomes. In other words, further research is needed on how OHCs help users to improve their health information management. The purpose of this study is to fill in this research gap.

Materials and methods

Sample

This study focuses on individuals with Lupus erythematosus (LE). This chronic condition is selected because it is described as an “invisible illness” that means its symptoms are not physically evident to others. In most cases, only those with the same symptoms can understand each other and help each other. Therefore patients with LE require ongoing interaction and involve significant self-management. Survey data were collected online through ‘Tieba of LE’ subordinate to Baidu Tieba, the largest Chinese online community. The eligible participants came from a nationwide sample of OHCs users who were diagnosed with LE (systemic lupus erythematosus, SLE; discoid lupus erythematosus, DLE; subacute cutaneous lupus erythematosus, SCLE; lupus erythematosus profundus, LEP; and drug-induced lupus, DIL). We initially received a total of 661 cases. Through removing 111 cases in which respondents failed to answer or respondents who gave over consistency options to ensure the reliability and validity of the survey, in a total of 550 cases were available for the analysis.

Measures

The survey instrument contained questions focusing on: (1) eligibility criteria, ensuring participants are LE patients and use an online health community; (2) general use of OHCs, including the login tools, logon frequency, posting frequency, and interaction frequency of users, and the initial reasons and current aims for users to use OHCs; (3) information communication activity in OHCs, (4) health information needs in OHCs, (5) health information sharing in OHCs, (6) perceived help from OHCs, (7) health self-management, and (8) demographics, including gender, age, education, employment, diagnosed illness, and duration of illness of users, and their self-reported health status and attitudes. Questions relevant to the analysis can be found at the end of the Supplementary Appendix.

Data analysis

We aimed to cluster the samples according to their health information behaviors so ‘information communication activity’, ‘health information needs’ and ‘health information sharing’ were selected as the variables for cluster analysis. In order to make data analysis more operable, we created three global measures to yield meaningful and distinct clusters. The global information communication activity measure was created by calculating the average of 10 items of the ‘information communication activity in OHCs’ construct. The global health information needs measure was created by calculating the average of 14 items of the ‘health information needs in OHCs’ construct. The global health information sharing measure was created by calculating the average of 14 items of the ‘health information sharing in OHCs’ construct. As the important variables to reflect user’s health information management, the global measures of ‘perceived help from OHCs’ and ‘health self-management’ were created respectively by calculating the average of 18 items and 16 items.

The K-means clustering technique was used to identify groups of individuals with different levels of the three global measures of health information behaviors. After individuals were assigned to one of the groups via clustering, we tested for the differences among the groups using analysis of variance (ANOVA) and post-hoc pairwise comparisons. To further distinguish groups in terms of their health self-management practices, one-way ANOVA with Games-Howell test was run to compare groups across their self-reported health status and attitudes, perceived help from OHCs and health self-management.

Results

Sample description

Detailed demographics are represented in Table 1. LE is a chronic disease most commonly seen in women just as the data also reflects this characteristic, 63.6% of the participants are female and 36.4% are male. The age of the participants is relatively young and is mainly between the ages of 20 and 40 years old (88.2%). People who are younger than 20 and elder than 40 accounts a small proportion

(11.8%). 1/4 of the participants did not finish high school and more than half of the participants had a college degree or above. The number of people with a bachelor's degree (4-year college degree) is the most. In terms of employment, more than 85% of the individuals have jobs that are either full-time work or freelance. Fewer than 15% of them are unemployed (unemployment, student and retired). In this case, the number of people suffering from SLE, DLE and SCLE is almost the same, accounting about 1/4 respectively. Patients with LEP and DIL account for the remaining 1/4. For the duration of illness, participants who have been diagnosed within 6 months are the most, following by those diagnosed in 6-12 months. Members of illness duration of 1-2 years, 2-5 years and 5-10 years gradually decrease. Only 6 participants have been ill for more than ten years.

Table 1. Participant demographic characteristics

Demographic characteristic	n (%)
Gender	
Male	350 (63.6)
Female	200 (36.4)
Age	
10-20	25 (4.5)
21-30	270 (49.1)
31-40	215 (39.1)
41-50	36 (6.5)
51+	4 (0.7)
Education	
Less than high school diploma	142 (25.8)
High school graduate	39 (7.1)
Higher vocational education	43 (7.8)
Junior college degree	107 (19.5)
4-year college degree	178 (32.4)
Master's degree	32 (5.8)
Doctoral degree	9 (1.6)
Employment	
Full-time work	286 (52.0)
Freelancer	185 (33.6)
Unemployment	70 (12.7)
Student	8 (1.5)
Retired	1 (0.2)
Diagnosed illness	
Systemic lupus erythematosus (SLE)	149 (27.1)
Discoid lupus erythematosus (DLE)	126 (22.9)
Subacute cutaneous lupus erythematosus (SCLE)	144 (26.2)
Lupus erythematosus profundus (LEP)	

Drug-induced lupus (DIL)	49 (8.9)
	82 (14.9)
Duration of illness	
Within 6 months	192 (34.9)
6-12 months	187 (34.0)
1-2 years	93 (16.9)
2-5 years	51 (9.3)
5-10 years	21 (3.8)
10-15 years	3 (0.5)
15-20 years	2 (0.4)
More than 20 years	1 (0.2)

General use of OHCs

General use of OHCs is shown in Table 2, Figure 1, Figure 2 and Figure 3. 29.3% of the participants log in to OHCs once a day and 48.5% of them have a frequent use of OHCs. The general activities of OHCs include posting and interaction. It can be seen from the data that participants' enthusiasm for posting and interaction is relatively high. 48.5% of the individuals claimed that they posted sometimes and 30.0% of them believed they did it frequently. The ones who never or very frequently post are relatively few. Interaction in OHCs means replying to a post or answering a question. More than 1/4 of the participants said they never had interaction with others. But 70% of them have high interaction frequency in the OHCs and 3.5% of them are very active.

Table 2. General use frequency of OHCs

General use of OHCs	n (%)
Frequency of login	
Once a day	161 (29.3)
Frequently but less than once a day	267 (48.5)
A few times a week	95 (17.3)
Less than once a week	17 (3.1)
No fixed frequency(according to the needs)	10 (1.8)
Frequency of posting	
Never	95 (17.3)
Sometimes	267 (48.5)
Frequently	165 (30.0)
Very frequently	23 (4.2)
Frequency of interaction	
Never	146 (26.5)
Sometimes	248 (45.1)
Frequently	137 (24.9)
Very frequently	19 (3.5)

Figure 1 shows the devices for participants to log in to OHCs. The login tools include the mobile phone, laptop, desktop computer, tablet PC and others. This item is a multiple choice question and it can be calculated that there are two ways for each person to log in to the OHCs in average. 489 participants log in to the OHCs with a mobile phone which is the most used tool. Laptop and desktop computer are also particular tools for users. Fewer people use tablets and other tools.

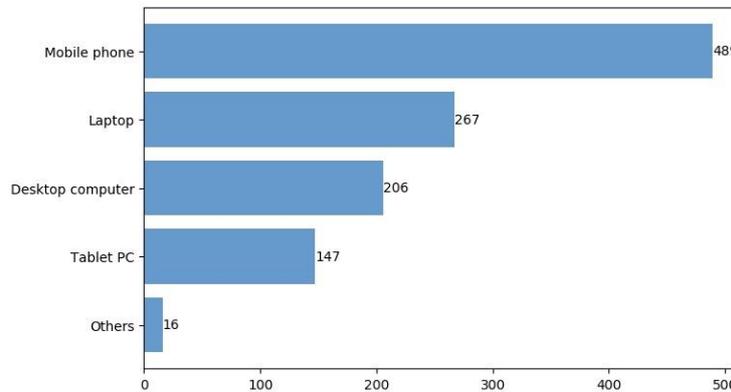


Figure 1. Login devices

Figure 2 shows the initial reasons for participants to use OHCs. The most selected options are ‘getting information about LE’ and ‘searching for treatment’. ‘Seeking spiritual support’, ‘asking for help’ and ‘getting to know those suffering from the same condition’ are also common choices. People who chose ‘accidental cause’ and ‘recommended by others’ are relatively few.

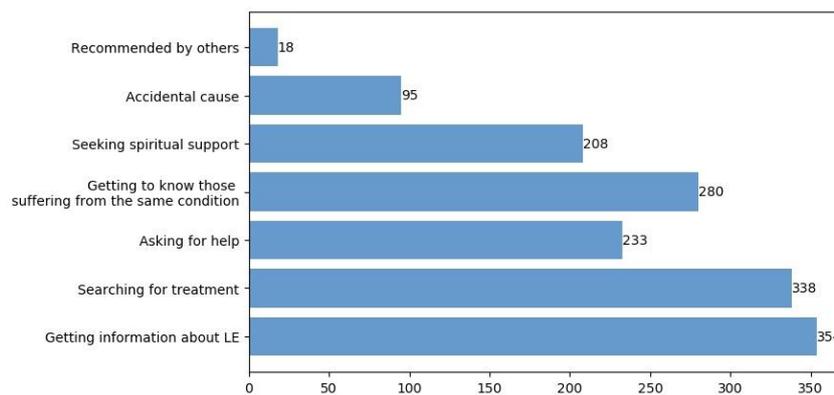


Figure 2. Initial reasons for using OHCs

Figure 3 shows the current aims for participants to use OHCs. People who chose ‘treatment sharing’, ‘information sharing’, ‘getting information from others’ and ‘getting information about LE’ all exceed half of the total. Fewer people chose ‘seeking spiritual support’ and ‘keeping in touch with others’.

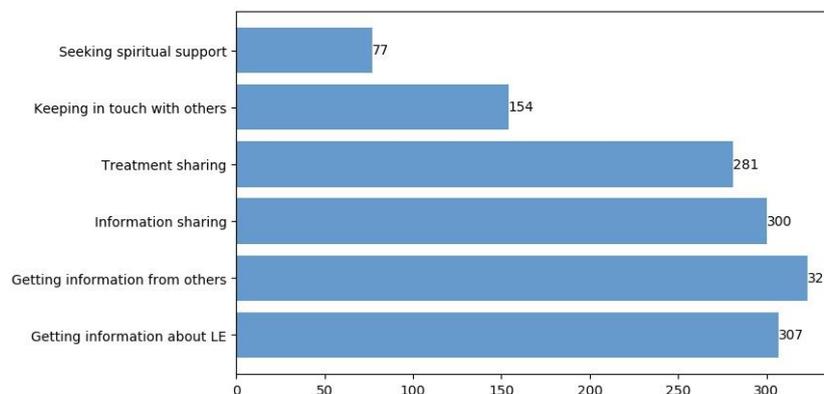


Figure 3. Current aims for using OHCs

User types

Our analysis yielded three distinct user clusters differentiated by the degree of information communication activity, health information needs and health information sharing. According to the levels of the three behaviors, we defined the three groups as Positive, Intermediate and Negative. As shown in Figure 4, the members of the Positive group, Intermediate group and Negative group are respectively in red (n=270, 49.1%), yellow (n=206, 37.5%) and black (n=74, 13.5%).

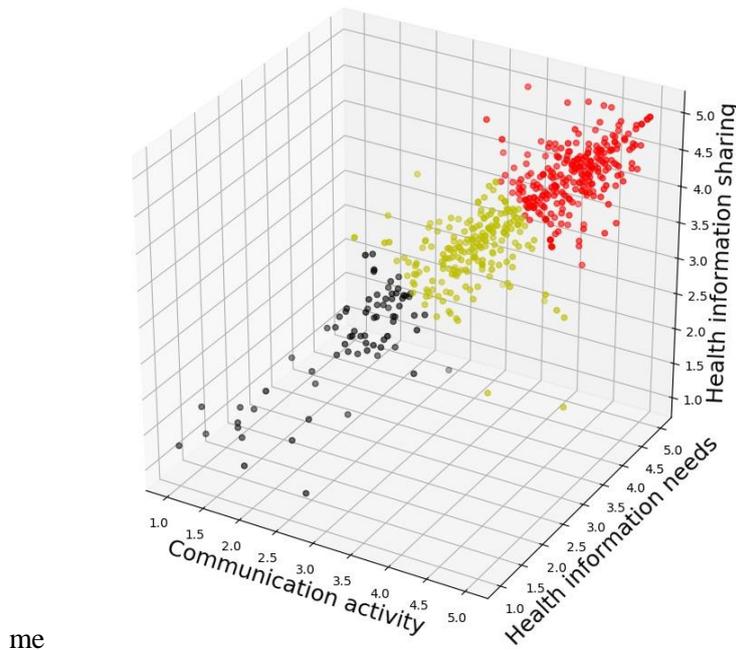


Figure 4. Three clusters of the participants

Cluster comparison

To compare clusters across self-reported health status, attitude towards one's illness, information communication activity in OHCs, health information needs in OHCs, health information sharing in OHCs, perceived help from OHCs, and health self-management, one-way ANOVA with post-hoc pairwise comparisons were run using Games-Howell test to examine the significant differences between the clusters ($p < 0.05$).

Table 3. Comparison of clusters across seven variables

Variables	Positive	Intermediate	Negative	F	p
Self-reported health status	2.15 (0.966)	2.47 (0.882)	2.53 (0.982)	8.818	<0.001
Attitude towards one's illness	1.72 (0.918)	1.81 (0.839)	1.95 (0.992)	1.974	0.140
Information communication activities in OHCs	4.37 (0.365)	3.51 (0.402)	2.47 (0.527)	592.413	<0.001
Health information needs in OHCs	4.33 (0.351)	3.50 (0.421)	2.51 (0.588)	494.876	<0.001
Health information sharing	4.36	3.49 (0.389)	2.44 (0.628)	551.318	<0.001

in OHCs	(0.338)				
Perceived help from OHCs	4.39 (0.378)	3.65 (0.530)	2.73 (0.684)	301.202	<0.001
Health self-management	4.39 (0.379)	3.72 (0.542)	2.81 (0.769)	233.485	<0.001

Note: Data are presented as mean (standard deviation).

As shown in Table 3, there are significant differences between the three clusters in self-reported health status, information communication activity in OHCs, health information needs in OHCs, health information sharing in OHCs, perceived help from OHCs, and health self-management. But there are no significant differences in attitude towards one's illness.

The distribution of the members of each group is shown in Figure 5 with 'Perceived help from OHCs' as the X-axis and 'Health self-management' as the Y-axis. There is a clear correlation between the two variables ($r=0.866$, $p<0.001$) and the distribution of the members of the three groups basically follow the clustering results.

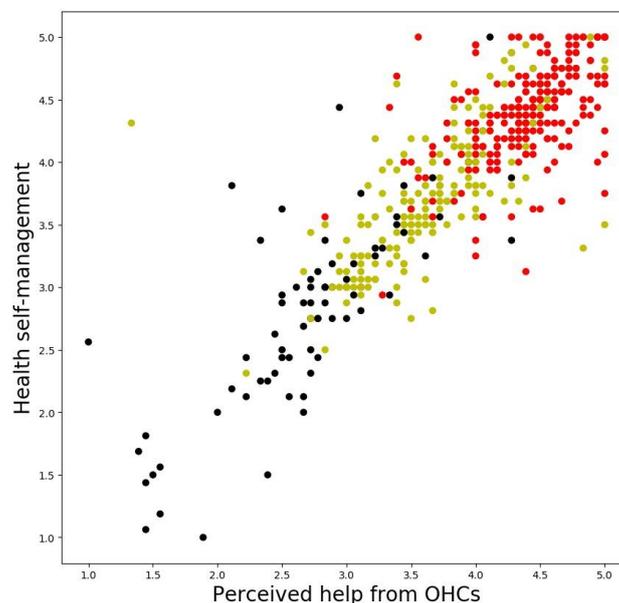


Figure 5. The relationship between 'Perceived help from OHCs' and 'Health self-management'

Discussion

Reasons and aims

The first step in analyzing users' health information behaviors in OHCs is to identify their causes and purposes of using OHCs. Previous researches have suggested that social support contains three specific types: informational support, emotional support, and instrumental support. They are defined as the exchange of information, nurturance, and tangible assistance, respectively (Zhang, S *et al.*, 2017). In our study, 'getting information about LE' and 'searching for treatment' can be categorized as informational support. 'Getting to know those suffering from the same condition' and 'seeking spiritual support' can be categorized as emotional support. Besides 'asking for help' belongs to instrumental support.

As shown in Figure 2, 'getting information about LE' and 'searching for treatment' are the most chosen reasons for users to begin to use OHCs. It can be seen from this that LE is a chronic disease which is not common and it is seldom mentioned in the science popularization of medicine. Therefore, the patients still lack sufficient knowledge of this condition after being diagnosed with LE. Moreover, for chronic diseases that are difficult to eradicate completely, patients tend to seek treatment from

OHCs to prove whether doctors are scientific in their diagnosis and treatment. It is not difficult to know from this situation and the psychological state of users that it is very important to popularize medical science for uncommon chronic diseases. Moreover, strengthening communication between doctors and patients can play an important role in reducing patients' doubts about their own conditions. On the other hand, OHCs have become one of the most popular social media for patients to search for information about diseases; therefore, health information of OHCs has become an important factor influencing patients' health decision-making. Whether the health information of OHCs is scientific should arouse necessary attention. 'Getting to know those suffering from the same condition' and 'seeking spiritual support' are also the reasons for many participants to use OHCs at the beginning. Treatment of chronic diseases is a long and difficult process that patients need to acquire psychological comfort by communicating with each other. Health information communication between patients is not only the method to make up for knowledge loopholes about diseases but also the channels to relieve mental stress. Besides instrumental support is another initial cause of concern for users to turn to OHCs. In most cases, only those with the same symptoms can understand each other and help each other. 'Asking for help' reflects the user's appeal and OHCs can be an important platform for users to seek help.

Figure 3 reflects some interesting changes to the users about their health information behaviors. First of all, access to disease-related information remains the primary goal of users' use of OHCs. 'Getting information about LE' and 'getting information from others' are the current aims selected at most for participants. However 'information sharing' and 'treatment sharing' become the ones that more than half of the participants choose to be their aims of using OHCs. This phenomenon reflects the change of users from passively receiving information to actively sharing information. Altruism has become one of the most important factors that can play a role in the health information behaviors of users. Another change is that the number of people who chose 'seeking spiritual support' decreased from 208 (Figure 2) to 77 (Figure 3). The reason for this change may be that users have come to believe that informational support is more important than emotional support with their user experiences gradually develop. In addition, fewer people chose 'keeping in touch with others', which indicates that OHCs are not very social-functional compared with instant messaging social media.

User type analysis

First of all, there are significant differences between the three groups in health information behaviors as 'information communication activities', 'health information needs' and 'health information sharing'. We set up 10 items including users' reading, reviewing, replying and inquiring in the OHCs to measure 'information communication activities'. This construct represents the frequency of a user's general information communication behaviors. 'Health information needs' and 'health information sharing' include 14 items respectively. 'Health information needs' include one's requirement of the information about symptoms, treatments, healthcare experience, medical expense, and emotional records. This construct reflects the frequency of a user's access to the specific health information. 'Health information sharing' includes one's sharing of the same contents as the 'health information needs'. This construct reflects the frequency of a user's sharing of the specific health information. The scores of three groups: Positive (4.37, 4.33, 4.36; $p < 0.001$), intermediate (3.51, 3.50, 3.49; $p < 0.001$) and Negative (2.47, 2.51, 2.44; $p < 0.001$), decrease successively that shows the members of the three groups are divided into three levels: high, middle and low in the activity of health information behaviors.

The survey also examined the self-reported health status and attitude of the participants toward their illness to further discover the differences between the three groups. For the self-reported health status, Likert scales ranged from 1 (very good) to 5 (very bad). Mean scores of the Positive group, Intermediate group and Negative group are 2.15, 2.47 and 2.53 respectively. Although the scores of the three groups concentrated between "good" and "general", the score of the Positive group is significant 'better' than the Intermediate group ($p = 0.002$) and Negative group ($p < 0.001$). And there are no significant differences between the Intermediate group and the Negative group. The options of 'attitude towards one's illness' ranged from 1 (very optimistic) to 5 (very pessimistic). Scores of the Positive group, Intermediate group and Negative group respectively are 1.72, 1.81 and 1.95 that

concentrated between 'very optimistic' and 'optimistic' and there are no significant differences between the three groups.

Our study classifies OHCs users by clustering method according to their health information communication behaviors. Besides, we further explore the differences in the health status and psychological status among different groups. The results show that members of the Positive group have the highest score of the health status so we think it's possible that the more active the health information behaviors are, the better the health status of the members are. But the psychological status does not show this trend. It can be learned that users acquire and share information, seek help and get spiritual support through OHCs, which is essentially a positive attitude to cope with diseases. Therefore, it can be concluded that users of OHCs have a positive attitude towards disease regardless of their activity in health information communication behaviors. So in terms of mental state, there were no significant differences among the three groups. Because there are significant differences in health information behaviors of OHCs users, it is possible to divide users precisely and formulate corresponding service strategies according to their behavior characteristics. Users with high activity should be encouraged to share personal health information and treatment experience so as to make them become core users with high influence. For users with moderate or low activity, their health information behavior characteristics should be analyzed to meet their health information needs, so as to maximize the functions of OHCs.

Health self-management

To further explore the relationship between user self-health management and health information behaviors in OHCs, we examined the differences of 'perceived help from OHCs' and 'health self-management' between the three groups. Besides in order to make the results more intuitive, we presented the distribution of the members of the three groups with scatter plots (Figure 5). The mean scores of 'perceived help from OHCs' of the Positive group, Intermediate group and Negative group are 4.39, 3.65 and 2.73 respectively and there are significant differences between the three groups ($p < 0.001$). The mean scores of 'health self-management' of the Positive group, Intermediate group and Negative group are 4.39, 3.72 and 2.81 respectively and there are also significant differences between the three groups ($p < 0.001$).

We set up 18 items to measure 'perceived help from OHCs' which include the informational support, emotional support and instrumental support that the users perceive to get when they use OHCs. It reflects the benefits for users after they become a member of the OHCs. As the platform for health information communication, OHCs encourage users to share information and help each other without any material rewards. As we have say above that the altruism has become one of the most important factors that can play a role in the health information communication of users. The score of the Positive group is higher than that of the Intermediate group as well as the Negative group as we can see from the data results. That means users who have the higher activity in health information behaviors perceive the higher helpful assistance from the OHCs. Health self-management means the ability of people to assess their health status and make effort to learn health knowledge, formulate health strategies and implement healthy behaviors. We set up 14 items to measure this construct. The mean scores of the Negative group, Intermediate group and Positive group increase gradually, which shows that with the increase in members' health information behavior activity, the degree of self-health management is also improving. We also tested the Pearson correlation ($r = 0.866$, $p < 0.001$) between 'perceived help from OHCs' and 'health self-management'. The result shows that there is a significant correlation between the two variables.

Previous studies have shown that engaged patients are more willing to seek preventive and routine chronic care, show stronger adherence to the health behaviors and treatment, so as to improve their health and the quality of life (Menefee *et al.*, 2016; Valdez *et al.*, 2017). Our research demonstrated this view and we put forward that the help that users felt and received in the OHCs have improved the level of their self-health management. Besides, the more active the users' information behavior is, the more help they can get in the OHCs, which leads them to strengthen their understanding of their conditions, treatment methods and nursing methods, thus improving the level of self-health management. From this point of view, encouraging patients with chronic diseases to use OHCs and

enhancing their activity and interaction of information communication are conducive to the improvement of their conditions. Most OHCs are decentralized organizations spontaneously organized by users. Therefore, how to effectively organize and improve the participation of users and improve the quality of information on the premise of maintaining the activity of the communities is an important issue in the development of OHCs.

Conclusion

Our study classifies OHCs users into three groups by clustering method according to their health information behaviors. After naming the three groups as the Positive group, Intermediate group and Negative group according to their scores, we explore the differences among the three groups in other variables. The results show that there is a significant correlation between health information behaviors that typify OHCs users and their health self-management. Then we give feasible guidance for stakeholders to improve OHCs' function to help patients with chronic diseases to improve their health.

Our research still has some limitations. Firstly, this paper only discussed the correlation between variables but did not prove the causality. Whether there is a causal relationship between users' health information behavior and health self-management needs further theoretical and data validation support. In addition, the subjects of this study are patients with lupus erythematosus, which is a rare chronic disease. There are also differences in health information behavior and self-health management among patients with different chronic diseases. The research should be further promoted.

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Reference

- Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van de Graaf, M., and Wei, E. 2015. "The invisible work of personal health information management among people with multiple chronic conditions: qualitative interview study among patients and providers," *J Med Internet Res* (17:6), e137.
- Antheunis, M. L., Tates, K., and Nieboer, T. E. 2013. "Patients' and health professionals' use of social media in health care: motives, barriers and expectations," *Patient Educ Couns* (92:3), pp. 426-431.
- Atanasova, S., Kamin, T., and Petric, G. 2017. "Exploring the benefits and challenges of health professionals' participation in online health communities: Emergence of (dis)empowerment processes and outcomes," *Int J Med Inform* (98), pp. 13-21.
- Atanasova, S., Kamin, T., and Petrič, G. 2018. "The benefits and challenges of online professional-patient interaction: Comparing views between users and health professional moderators in an online health community," *Computers in Human Behavior* (83), pp. 106-118.
- Benetoli, A., Chen, T. F., and Aslani, P. 2018. "How patients' use of social media impacts their interactions with healthcare professionals," *Patient Educ Couns* (101:3), pp. 439-444.
- Brennan, K. A., and Creaven, A. M. 2016. "Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus," *Qual Life Res* (25:5), pp. 1227-1235.
- Carron-Arthur, B., Ali, K., Cunningham, J. A., and Griffiths, K. M. 2015. "From Help-Seekers to Influential Users: A Systematic Review of Participation Styles in Online Health Communities," *J Med Internet Res* (17:12), pp. e271.
- Chehab, G., Sauer, G. M., Richter, J. G., Brinks, R., Willers, R., Fischer-Betz, R., . . . Schneider, M. 2018. "Medical adherence in patients with systemic lupus erythematosus in Germany: predictors and reasons for non-adherence — a cross-sectional analysis of the LuLa-cohort," *Lupus* (27), pp. 1652-1660.
- Chen, L., Baird, A., and Straub, D. 2019. "Fostering Participant Health Knowledge and Attitudes: An Econometric Study of a Chronic Disease-Focused Online Health Community," *Journal of Management Information Systems* (36:1), pp. 194-229.
- Choi, M. J., Kim, S. H., Lee, S., Kwon, B. C., Yi, J. S., Choo, J., and Huh, J. 2017. "Toward Predicting Social Support Needs in Online HealthSocial Networks," *J Med Internet Res* (19:8), pp. e272.

- Civan, A., Skeels, M. M., Stolyar, A., and Pratt, W. 2006. "Personal Health Information Management: Consumers' Perspectives," *AMIA Annu Symp Proc*, pp. 156-160.
- Fan, H., and Lederman, R. 2017. "Online health communities: how do community members build the trust required to adopt information and form close relationships?," *European Journal of Information Systems* (27:1), pp. 62-89.
- Fergie, G., Hunt, K., and Hilton, S. 2016. "Social media as a space for support: Young adults' perspectives on producing and consuming user-generated content about diabetes and mental health," *Soc Sci Med* (170), pp. 46-54.
- Goh, J. M., Gao, G., and Agarwal, R. 2016. "The creation of social value: Can an online health community reduce rural-urban health disparities?," *MIS Quarterly* (40:1), pp. 247-263.
- Gopalsamy, R., Semenov, A., Pasilliao, E., McIntosh, S., and Nikolaev, A. 2017. "Engagement as a Driver of Growth of Online Health Forums: Observational Study," *J Med Internet Res* (19:8), pp. e304.
- Hajli, M. N. 2014. "Developing online health communities through digital media," *International Journal of Information Management* (34:2), pp. 311-314.
- Hargreaves, S., Bath, P. A., Duffin, S., and Ellis, J. 2018. "Sharing and Empathy in Digital Spaces: Qualitative Study of Online Health Forums for Breast Cancer and Motor Neuron Disease (Amyotrophic Lateral Sclerosis)," *J Med Internet Res* (20:6), e222.
- Hartzler, A. L., Taylor, M. N., Park, A., Griffiths, T., Backonja, U., McDonald, D. W., . . . Pratt, W. 2016. "Leveraging cues from person-generated health data for peer matching in online communities," *J Am Med Inform Assoc* (23:3), pp. 496-507.
- Holden, R. J., Karanam, Y. L. P., Cavalcanti, L. H., Parmar, T., Kodthala, P., Fowler, N. R., and Bateman, D. R. 2018. "Health information management practices in informal caregiving: An artifacts analysis and implications for IT design," *Int J Med Inform* (120), pp. 31-41.
- Huh, J., Kwon, B. C., Kim, S. H., Lee, S., Choo, J., Kim, J., . . . Yi, J. S. 2016. "Personas in online health communities," *J Biomed Inform* (63), pp. 212-225.
- Joglekar, S., Sastry, N., Coulson, N. S., Taylor, S. J., Patel, A., Duschinsky, R., . . . De Simoni, A. 2018. "How Online Communities of People With Long-Term Conditions Function and Evolve: Network Analysis of the Structure and Dynamics of the Asthma UK and British Lung Foundation Online Communities," *J Med Internet Res* (20:7), pp. e238.
- Jung, W. S., Chung, M. Y., and Rhee, E. S. 2018. "The Effects of Attractiveness and Source Expertise on Online Health Sites," *Health Commun* (33:8), pp. 962-971.
- Litchman, M. L., Rothwell, E., and Edelman, L. S. 2018. "The diabetes online community: Older adults supporting self-care through peer health," *Patient Educ Couns* (101:3), pp. 518-523.
- Mamykina, L., Levine, M. E., Davidson, P. G., Smaldone, A. M., Elhadad, N., and Albers, D. J. 2016. "Data-driven health management: reasoning about personally generated data in diabetes with information technologies," *J Am Med Inform Assoc* (23:3), pp. 526-531.
- Mazzoni, D., and Cicognani, E. 2014. "Problematic social support from patients' perspective: the case of systemic lupus erythematosus," *Soc Work Health Care* (53:5), pp. 435-445.
- Mazzoni, D., and Cicognani, E. 2016. "Positive and problematic support, stress and quality of life in patients with systemic lupus erythematosus," *Anxiety Stress Coping* (29:5), pp. 542-551.
- McClellan, C., Ali, M. M., Mutter, R., Kroutil, L., and Landwehr, J. 2017. "Using social media to monitor mental health discussions - evidence from Twitter," *J Am Med Inform Assoc* (24:3), pp. 496-502.
- Menefee, H. K., Thompson, M. J., Guterbock, T. M., Williams, I. C., and Valdez, R. S. 2016. "Mechanisms of Communicating Health Information Through Facebook: Implications for Consumer Health Information Technology Design," *J Med Internet Res* (18:8), pp. e218.
- Meunier, B., Jourde-Chiche, N., Mancini, J., Chekroun, M., Retornaz, F., and Chiche, L. 2016. "Characteristics and information searched for by French patients with systemic lupus erythematosus: A web-community data-driven online survey," *Lupus* (25), pp. 370-375.
- Moen, A., & Brennan, P. F. 2005. "Health@Home: the work of health information management in the household (HIMH): implications for consumer health informatics (CHI) innovations," *J Am Med Inform Assoc* (12:6), pp. 648-656.
- Nambisan, P. 2011. "Information seeking and social support in online health communities: impact on patients' perceived empathy," *J Am Med Inform Assoc* (18:3), pp. 298-304.
- Nes, A. A., Eide, H., Kristjansdottir, O. B., and van Dulmen, S. 2013. "Web-based, self-management enhancing interventions with e-diaries and personalized feedback for persons with chronic illness: a tale of three studies," *Patient Educ Couns* (93:3), pp.451-458.
- National Health Commission. 2017. "Interpretation of China's medium and long term plan for prevention

- and treatment of chronic diseases (2017-2025 years)," Retrieved from <http://www.nhfpc.gov.cn/zwgk/jdjd/201702/34a1fff908274ef8b776b5a3fa4d364b.shtml>.
- Park, A., Conway, M., and Chen, A. T. 2018. "Examining Thematic Similarity, Difference, and Membership in Three Online Mental Health Communities from Reddit: A Text Mining and Visualization Approach," *Comput Human Behav* (78), pp.98-112.
- Petrovčič, A., and Petrič, G. 2014. "Differences in intrapersonal and interactional empowerment between lurkers and posters in health-related online support communities," *Computers in Human Behavior*(34), pp. 39-48.
- Rupert, D. J., Gard Read, J., Amoozegar, J. B., Moultrie, R. R., Taylor, O. M., O'Donoghue, A. C., and Sullivan, H. W. 2016. "Peer-Generated Health Information: The Role of Online Communities in Patient and Caregiver Health Decisions," *J Health Commun* (21:11), pp. 1187-1197.
- Rupert, D. J., Moultrie, R. R., Read, J. G., Amoozegar, J. B., Bornkessel, A. S., O'Donoghue, A. C., and Sullivan, H. W. 2014. "Perceived healthcare provider reactions to patient and caregiver use of online health communities," *Patient Educ Couns* (96:3), pp. 320-326.
- Sinha, A., Porter, T., and Wilson, A. 2018. "The Use of Online Health Forums by Patients With Chronic Cough: Qualitative Study," *J Med Internet Res*, (20:1), e19.
- Valdez, R. S., Guterbock, T. M., Fitzgibbon, K., Williams, I. C., Wellbeloved-Stone, C. A., Bears, J. E., and Menefee, H. K. 2017. "From loquacious to reticent: understanding patient health information communication to guide consumer health IT design," *J Am Med Inform Assoc* (24:4), pp. 680-696.
- Wang, X., Parameswaran, S., Bagul, D. M., and Kishore, R. 2018. "Can online social support be detrimental in stigmatized chronic diseases? A quadratic model of the effects of informational and emotional support on self-care behavior of HIV patients," *J Am Med Inform Assoc* (25:8), pp. 931-944.
- Willis, E. 2016. "Patients' self-efficacy within online health communities: facilitating chronic disease self-management behaviors through peer education," *Health Commun* (31:3), pp. 299-307.
- Willis, E., and Royne, M. B. 2017. "Online Health Communities and Chronic Disease Self-Management," *Health Commun* (32:3), pp. 269-278.
- Willis, E. 2018. "Applying the Health Belief Model to Medication Adherence: The Role of Online Health Communities and Peer Reviews," *J Health Commun* (23:8), pp. 743-750.
- Yan, L., and Tan, Y. 2017. "The Consensus Effect in Online Health-Care Communities," *Journal of Management Information Systems* (34:1), pp. 11-39.
- Zhang, M., and Yang, C. C. 2015. "Using content and network analysis to understand the social support exchange patterns and user behaviors of an online smoking cessation intervention program," *Journal of the Association for Information Science and Technology* (66:3), pp. 564-575.
- Zhang, S., Grave, E., Sklar, E., and Elhadad, N. 2017. "Longitudinal analysis of discussion topics in an online breast cancer community using convolutional neural networks," *J Biomed Inform* (69), pp. 1-9.
- Zhang, S., O'Carroll Bantum, E., Owen, J., Bakken, S., and Elhadad, N. 2017. "Online cancer communities as informatics intervention for social support: conceptualization, characterization, and impact," *J Am Med Inform Assoc* (24:2), pp. 451-459.
- Zhang, X., Liu, S., Chen, X., Wang, L., Gao, B., and Zhu, Q. 2018. "Health information privacy concerns, antecedents, and information disclosure intention in online health communities," *Information & Management* (55:4), pp. 482-493.
- Zhang, X., Liu, S., Deng, Z., and Chen, X. 2017. "Knowledge sharing motivations in online health communities: A comparative study of health professionals and normal users," *Computers in Human Behavior* (75), pp. 797-810.
- Zhang, Y. 2016. "Understanding the sustained use of online health communities from a self-determination perspective," *Journal of the Association for Information Science and Technology* (67:12), pp. 2842-2857.
- Zhao, K., Wang, X., Cha, S., Cohn, A. M., Papandonatos, G. D., Amato, M. S., . . . Graham, A. L. 2016. "A Multirelational Social Network Analysis of an Online Health Community for Smoking Cessation," *J Med Internet Res* (18:8), pp. e233.
- Zhao, K., Yen, J., Greer, G., Qiu, B., Mitra, P., and Portier, K. 2014. "Finding influential users of online health communities: a new metric based on sentiment influence," *J Am Med Inform Assoc* (21:e2), pp. e212-218.
- Zhou, L., Zhang, D., Yang, C., and Wang, Y. 2018. "Harnessing Social Media for Health Information Management," *Electron Commer Res Appl* (27), pp. 139-151.