Behavioral Characteristics of Personal Health Information Management among Online Health Community Users: Postprint

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Abstract

[Purpose/Significance] This study aims to analyze the behavioral characteristics of personal health information management among users of online health communities and explore the relationships among elements in the "platform-PHIM-health goals" model. [Method/Process] Users with lupus erythematosus from online health communities were selected as survey subjects. Clustering methods were employed to identify groups with different overall levels of personal health information management behavior, and One-way ANOVA was utilized for comparative studies among different groups. [Results/Conclusion] Personal health information management behaviors conducted via online health communities are defined as health information discovery, health information interaction, and health information sharing. Data analysis reveals that: first, patients with lupus erythematosus in online health communities exhibit significant differences in personal health information management behavior levels; second, users' perceived social support is positively correlated with their personal health information management level; third, a positive correlation exists between personal health information management and users' health goals. This study provides recommendations for online health communities to improve their services and enhance personal health information management levels among chronic disease patients.

Full Text

Abstract

[**Purpose/Significance**] This study aims to analyze the behavioral characteristics of personal health information management among online health community users and explore the relationships among the elements in the "platform-PHIM-health goals" model. [**Method/Process**] Users with lupus erythematosus from online health communities were selected as survey subjects. Clustering methods were employed to identify groups with different overall levels of personal health information management behavior, and One-way ANOVA was used for comparative analysis across different groups. [**Results/Conclusion**] Personal health information management behaviors conducted through online health communities are defined as health information discovery, health information interaction, and health information sharing. The data analysis reveals three key findings: First, lupus patients in online health communities exhibit significant differences in their levels of personal health information management behavior. Second, users' perceived social support is positively correlated with their personal health information management level. Third, personal health information management is positively correlated with users' health goals. This study provides recommendations for online health communities to improve their services and enhance personal health information management capabilities among chronic disease patients.

Keywords: online health community; personal health information management; personal information management; social support; health goals

Introduction

With the development of industrialization, urbanization, population aging, and changes in ecological environments and lifestyles, chronic diseases have become the leading cause of death and disease burden among Chinese residents. The "Healthy China 2030" Planning Outline, issued by the CPC Central Committee and the State Council, proposes goals and tasks for building a healthy China. It emphasizes that guiding people to establish correct health perspectives, strengthening early interventions, and fostering healthy lifestyles, ecological environments, and social environments to promote a shift from disease-centered to health-centered care are crucial measures for improving people's health levels [1]. The Outline advocates the concept that "everyone is the first person responsible for their own health," which requires individuals to actively participate in Healthy China initiatives, enhance personal health literacy, cultivate healthy lifestyles, and achieve personal health goals.

Domestic research in the PHIM field began relatively late but has developed rapidly in recent years. Studies have explored various aspects from different research contexts, including health information needs mining [3-5], health literacy [6-9], health information seeking [10], and health information sharing [11-12]. The importance of personal health information management behavior for improving national health levels has received widespread attention from academia.

Online health communities, as platforms for health information exchange and sharing in the internet environment, have developed rapidly in recent years. With diverse health themes and operational models, these communities can provide customized health information services for different population groups, attracting a large number of users. Online health communities allow members to share health information, particularly experiential information about personal health problems, and encourage interaction among members [13], making them one of the most important platforms for searching and exchanging health information [14]. Consequently, online health communities and their user behaviors have become significant research objects in personal health information management (PHIM) studies.

PHIM is an effective approach to improving personal health levels. Currently, PHIM research based on online health communities generally focuses on independent analysis of users' health information behaviors, with few studies exploring the relationship between online health communities and personal health information management behaviors, or the role of personal information management conducted through online health communities in helping users achieve personal health goals. In short, existing research lacks deeper understanding of the "platform-PHIM-health goals" model. Based on the above discussion, this study attempts to investigate and analyze the behavioral characteristics of personal health information management among online health community users, and explore the relationships among the elements in the "platform-PHIM-health goals" model. Through survey analysis, this research aims to deepen understanding of this model, clarify the connections among its three components, and provide reasonable suggestions for online health communities to improve their services and promote personal health information management capabilities among chronic disease patients.

Theoretical Foundation

2.1 Personal Health Information Management

The concept of personal health information management originates from personal information management. In 1988, M. W. Lansdale first proposed the term personal information management (PIM), defining it as "the methods and processes by which we handle, classify, and retrieve information in our daily lives" [15]. As research has progressed, the core concept and scope of PIM have become increasingly clear. Scholars generally agree that PIM refers to the practices and research involved in acquiring, organizing, maintaining, and retrieving information for daily use [16-18]. PIM encompasses a wide range of activities, including information acquisition, creation, storage, organization, maintenance, retrieval, use, and dissemination, with the goal of helping individuals complete relevant tasks or fulfill responsibilities [19]. W. Jones, a pioneer in PIM research, identifies three types of activities in PIM practice: "finding activities" (from needs to information), "keeping activities" (from information to needs), and "meta-level activities" (focusing on the connection between information and needs) [17-19].

Thus, the PIM process is one of establishing, using, and maintaining a mapping between information and needs [17-19], where creating a connection between needs and information means creating a mapping. Through comprehensive review of domestic and international research, this study defines PHIM as the practice of acquiring, organizing, using, and sharing personal health information to achieve personal health goals [2], and as a process of establishing, using, and maintaining a mapping between health information and health needs through a series of health behaviors. In specific research and practice, PHIM can be considered a collection of personal health information behaviors [2, 32] that manifests differently in various contexts, with the ultimate purpose of achieving personal health goals: health cognition improvement, health action improvement, and health attitude improvement. Health cognition improvement refers to the goal of enhancing health knowledge levels and personal health literacy through health information acquisition and processing. Health action improvement refers to the goal of actively adopting healthy behaviors and cultivating healthy lifestyles based on certain health cognition. Health attitude improvement refers to the goal of developing a psychological tendency to actively participate in healthy living and become the first person responsible for one's own health.

2.2 PHIM in Online Health Communities

An online health community can be defined as a virtual forum where members share common interests or needs regarding health issues [33-34]. Scholars studying online health communities generally agree that these platforms can provide social support to users. Although no universally accepted definition of social support exists, academia consistently views it as a multi-dimensional concept [35]. The social support provided by online health communities 主要包括 information support, emotional support, and instrumental/tangible support [35-37]. This conceptual decomposition indicates that, on one hand, online health communities can provide users with patient-experience-based information, unconventional information, and medical facts through their rich user-generated content [38]. On the other hand, users' empathy can develop and function through shared experiences and social connections in the platform [39], fostering a sense of belonging. Additionally, tangible assistance from online health communities plays a positive role in patients' health activities.

The social support provided by online health communities is crucial for promoting users' health information behaviors. S. Zigron and J. Bronstein's research indicates that online health communities enable patients to obtain multi-source information and reduce fear and shame through personal information disclosure, thereby gaining a sense of belonging [40]. L. Chen et al.'s research suggests that social support in online health communities can influence personal health knowledge and attitudes [41]. Based on a review of previous studies, this study posits that the functional attributes of online health communities make them platforms for personal health information management, and the social support they provide can help users achieve their health goals through personal health information management. According to the behavioral characteristics of online health community users, this study summarizes PHIM behaviors conducted through these platforms as health information discovery, health information interaction, and health information sharing. To explore the relationship between online health communities and PHIM behaviors, and the role of PHIM in helping users achieve health goals, this study investigates the relationships among the elements in the "platform-PHIM-health goals" model.

Research Design

3.1 Research Sample and Questionnaire Design

This study selected users with lupus erythematosus from online health communities as survey subjects. Lupus erythematosus is a chronic autoimmune rheumatic disease most common among women aged 15-40. Because some symptoms are not easily observable to non-patients (e.g., fatigue), it is described as an "invisible disease" [42]. Research shows that lack of understanding from others makes lupus patients more susceptible to negative feedback, such as ineffective social support [43, 44]. Treatment focuses on keeping the disease dormant to reduce harm to the body. Therefore, daily medical care and self-monitoring are crucial for lupus patients, and providing sufficient information can enhance medication adherence [45]. Thus, online health communities that provide effective social support are highly valuable for lupus patients [46].

The reasons for selecting lupus patients as subjects are: (1) they have high personal health information management needs; and (2) lupus patients in online health communities are relatively active, with high incidence rates of information seeking, interaction, and sharing behaviors.

The survey questionnaire consisted of two parts: The first part collected demographic characteristics to verify respondents' identity and understand their basic situations. The second part measured behaviors using scales for personal health information management, social support, and health goals. The questionnaire design referenced studies by R. S. Valdez et al. [47] and S. Kim et al. [2, 32]. Distributed through lupus online health communities and verified for dual identity as "online health community users" and "lupus patients," invalid questionnaires were eliminated, resulting in 550 valid responses.

3.2 Data Analysis Methods

This study first employed K-means clustering to identify groups with different overall levels of personal health information management behavior. After assigning individuals to different groups through clustering, One-way ANOVA with Games-Howell post-hoc tests was used to further explore differences among groups across the social support and health goals dimensions. To enhance the intuitiveness of results, Python was used to create three-dimensional coordinate graphs for visualization.

Data Analysis

4.1 Demographic Characteristics

The demographic characteristics of the research sample are shown in Table 1 . The sample included 350 females (63.6%) and 200 males (36.4%), a reasonable gender distribution given that lupus incidence is higher among females. The age distribution skewed younger, with the largest group aged 21-30 years (270 people), and 92.7% aged 40 or younger. In terms of education, 219 respondents (39.8%) had bachelor's degrees or higher, while 181 (32.9%) had high school education or below. Diagnoses included systemic lupus erythematosus, discoid lupus erythematosus, subacute cutaneous lupus erythematosus, lupus erythematosus profundus, and drug-induced lupus erythematosus, with systemic lupus erythematosus being most common. As lupus exists on a disease spectrum with unclear boundaries between conditions, disease statistics were used only for identity verification. The survey also measured disease duration from diagnosis to survey date, with the largest groups being those diagnosed within 6 months and those between 6-12 months, showing a decreasing trend as duration increased.

4.2 Patient Types

Through K-means cluster analysis, this study identified three distinct user type groups, as shown in Figure 1 [Figure 1: see original paper]. The three groups differed in their levels of personal health information management behavior and were named the active group, intermediate group, and passive group. In Figure 1, the active group (n=249, 45.3%) is shown in red, the intermediate group (n=229, 41.6%) in yellow, and the passive group (n=72, 13.1%) in black. The mean scores and inter-group differences for the three behaviors—health information discovery, health information interaction, and health information sharing—are presented in Table 2 .

4.3 Group Comparisons

4.3.1 Social Support Group Comparison After clustering all survey samples into three groups, this study analyzed differences among the groups across the social support dimension. One-way ANOVA results showed significant differences among the three groups in the three social support sub-dimensions: informational support, emotional support, and instrumental support ($p<0.001$). Mean scores revealed a decreasing trend from the active group to the intermediate group to the passive group across all three sub-dimensions. The distribution of individuals across groups is shown in Figure 2 [Figure 2: see original paper].

4.3.2 Health Goals Group Comparison For the three sub-dimensions of health goals, One-way ANOVA was similarly used to explore group differences. Results showed significant differences among the three groups in health cognition improvement, health action improvement, and health attitude improvement

($p<0.001$). Mean scores again showed a decreasing trend from the active group to the intermediate group to the passive group across all three sub-dimensions. The distribution of individuals across groups is shown in Figure 3 [Figure 3: see original paper].

Results Discussion

5.1 Differences in Users' Personal Health Information Management Levels

This study categorized users into three groups based on their PHIM behavior levels: health information discovery, health information interaction, and health information sharing. The health information interaction dimension included items measuring "commenting on others' posts," "asking questions for answers or help," and "replying to others' comments or questions." The health information discovery and sharing dimensions measured four items each: "disease information," "treatment information," "care information," and "daily life information." The analysis revealed significant differences in PHIM behavior levels among lupus patients in online health communities. Among the 550 respondents, the high-scoring active group comprised 249 individuals, the intermediate group 229, and the low-scoring passive group 72. Score levels reflected users' activity levels in interaction, information seeking, and sharing within online health communities.

This classification aims to clarify that lupus patients in online health communities differ in their reception of platform information services. These differences stem subjectively from users' varying health and information literacy levels, and objectively from the degree to which platform information services meet users' personalized needs. Current information services advocate a user-centered philosophy, which requires first recognizing differences among users. While all respondents shared the condition of lupus and thus had similar health information service needs, their PHIM capabilities showed significant variation when facing the same services, inevitably leading to different user experiences. This phenomenon creates a filtering effect where "services select users," potentially causing the passive group with lower PHIM capabilities to gradually become lost users. Therefore, targeted customized services should be developed to address user differences, such as providing keyword recommendations for users who cannot clearly describe their information needs or formalizing descriptions of user need attributes and their relationships. Customized services can transform "services selecting users" into "users selecting services," representing a viable approach for online health communities to improve service quality.

5.2 Personal Health Information Management and Social Support

This study divided social support provided by online health communities into informational support, emotional support, and instrumental support. Information support items measured the community's provision of "relevant knowledge," "treatment options," and "medical updates." Emotional support items measured support in "stabilizing emotions" and "enhancing confidence." Instrumental support items measured assistance in "health monitoring," "medication adherence," and "health management plan development." While social support has long been a focus of online health community research, this study's exploratory analysis attempted to demonstrate the connection between social support and PHIM. Results showed: (1) groups with different PHIM behavior levels had significantly different social support scores; and (2) scores decreased progressively from the active to intermediate to passive groups.

Regardless of how social support is defined, it is essentially a helping behavior. Previous research has focused on demonstrating whether this "help" is effective. This study argues for a deeper investigation, as the relationship is not simply unidirectional. The data show a positive correlation between perceived social support and PHIM level: higher PHIM capability corresponds to greater social support. This study posits a mutually reinforcing relationship between social support and PHIM. On one hand, patients obtain informational, emotional, and instrumental support from online health communities, thereby improving their PHIM behavior levels. On the other hand, patients with higher PHIM engagement and capability can better extract health-promoting assistance from social support. This conclusion reminds us that individual capability affects the effectiveness of help received. Therefore, emphasizing PHIM behavior and improving PHIM capability not only enhances personal health levels but also improves the utilization effectiveness of public health resources.

5.3 Personal Health Information Management and Health Goals

This study defined health goals for online health community users as health cognition improvement, health action improvement, and health attitude improvement. Health cognition improvement refers to enhanced understanding of one's health status and health knowledge levels, such as better understanding of disease-related knowledge and treatment research progress. Health action improvement refers to patients actively taking practical actions to improve their health status, such as developing personal health plans and enhancing medication adherence. Health attitude improvement refers to improved psychological states regarding their condition, taking more responsibility for personal health, and developing more optimistic emotions. The data analysis revealed: (1) groups with different PHIM behavior levels had significantly different health goal scores; and (2) scores decreased progressively from the active to intermediate to passive groups.

This study proposed that the purpose of PHIM is to achieve personal health goals. The data analysis confirms a positive correlation between PHIM and health goals among online health community users: lupus patients with higher PHIM levels also achieved better health goal outcomes. Conversely, as patients' health cognition, actions, and attitudes improve, their PHIM capabilities also increase, indicating a mutually reinforcing relationship. In practical terms, improving health cognition, practicing health actions, and enhancing health attitudes are crucial for chronic disease patients to stabilize their conditions and gradually improve their quality of life. These goals are achieved through PHIM. The "Healthy China 2030" Planning Outline advocates that everyone is the first person responsible for their own health, requiring individuals to actively participate in Healthy China initiatives by improving health literacy and cultivating healthy lifestyles to achieve personal health goals. Therefore, conducting PHIM is an effective pathway for implementing "Healthy China 2030."

Research Conclusion

Currently, both academic research and social practice of personal health information management in China are in their early stages. Although PHIM plays a positive role in helping chronic disease patients monitor their conditions, patients' PHIM needs, technical support, and policy promotion have not received widespread attention. This study's survey results indicate that chronic disease patients have high PHIM needs and take action accordingly. Therefore, the health service industry should actively identify and respond to these needs by developing appropriate service models to help users effectively manage their personal health information.

To implement the "Healthy China 2030" Planning Outline, it is essential to popularize healthy living concepts and optimize health information services. The significance of PHIM lies in emphasizing the utilization of personal health-related information in daily life and taking effective intervention measures for health issues. Currently, promoting PHIM in China should involve targeted health education based on different population characteristics, improving personal health literacy to make health knowledge, behaviors, and skills universal qualities and capabilities.

This study defined PHIM behaviors through online health communities as health information discovery, health information interaction, and health information sharing. Through investigation, analysis, and discussion of lupus patients using online health communities, this research reveals characteristics of chronic disease patients' PHIM behaviors and proposes a bidirectional, mutually reinforcing relationship among online health communities (platform), personal health information management, and health goals. This study clarifies the relationships among elements in the "platform-PHIM-health goals" model, aiming to deepen understanding of this model and provide reasonable recommendations for online health communities to improve their services and promote PHIM capabilities.

References

[1] State Council. Healthy China Action (2019-2030) [EB/OL]. [2019-07-15]. http://www.gov.cn/xinwen/2019-07/15/content_{5409694}.htm.

[2] KIM S, HUBER JT. Characteristics of personal health information manage-

ment groups: findings from an online survey using Amazon's mTurk [J]. Journal of the Medical Library Association, 2017, 105(4): 361-375.

[3] Shi Jing, Li Chenlu, Qian Yuxing, et al. A comparative study of user health information needs in domestic and international health Q&A communities: an empirical analysis based on thematic and temporal perspectives [J]. Data Analysis and Knowledge Discovery, 2019, 29(5): 1-10.

[4] Qian Yuxing, Zhou Huayang, Zhou Liqin, et al. Research on mining health information needs of elderly online community users [J]. Modern Intelligence, 2019, 39(6): 59-69.

[5] Lu Quan, Zhu Anqi, Zhang Jiyue, et al. Research on mining user information needs in Chinese online health communities: taking tumor board data from Qiuyi Network as an example [J]. Data Analysis and Knowledge Discovery, 2019, 28(4): 22-32.

[6] Song Shijie, Zhao Yuxiang, Han Wenting, et al. Analysis of the inhibitory effect of health literacy on health risks in the internet environment: an empirical study of chronic diseases based on CHNS data [J]. Data Analysis and Knowledge Discovery, 2019, 3(4): 13-21.

[7] Song Shijie, Zhao Yuxiang, Zhu Qinghua. The impact of health information acquisition channels on health literacy cultivation: based on urban-rural heterogeneity perspective [J]. Library and Information, 2018(5): 36-43.

[8] Song Shijie, Zhao Yuxiang, Song Xiaokang, et al. Research on factors influencing credibility judgment of distorted health information in the internet environment [J]. Journal of Library Science in China, 2019, 45(4): 72-85.

[9] KIM S, SYN SY, SINN D. Exploratory study of personal health information management using health literacy model [J]. Aslib Journal of Information Management, 2018, 70(1): 104-122.

[10] Zhou Xiaoying, Cai Wenjuan. College students' online health information seeking behavior patterns and influencing factors [J]. Information and Documentation Services, 2014(4): 50-55.

[11] Chen Xing, Zhang Xing, Xiao Quan. User continuous knowledge sharing intention in online health communities: a model integrating social support and commitment-trust theory [J]. Modern Intelligence, 2019, 39(11): 55-68.

[12] Zhou Tao, Wang Yingying, Deng Shengli. Research on user knowledge sharing behavior in online health communities [J]. Information Science, 2019, 37(04): 72-78.

[13] ZHAO K, YEN J, GREER G, et al. Finding influential users of online health communities: a new metric based on sentiment influence [J]. Computers in human behavior, 2018, 83: 106-118.

[14] ATANASOVA S, KAMIN T, PETRIĆ G. The benefits and challenges of online professional-patient interaction: Comparing views between users and health

professional moderators in an online health community [J]. Journal of medical Internet research, 2014, 21(e2): e212-218.

[15] LANSDALE MW. The psychology of personal information management [J]. Applied ergonomics, 1988, 19(1): 55-66.

[16] HWANG Y, KETTINGER WJ, YI MY. Personal information management effectiveness of knowledge workers: conceptual development and empirical validation [J]. European journal of information systems, 2015, 24(6): 588-606.

[17] JONES W, BRUCE H. A Report on the NSF-sponsored workshop on personal information management [EB/OL]. [2019-12-01]. http://pim.ischool.washington.edu/report%20NSF%20

[18] JONES W. Keeping found things found: the study and practice of personal information management [M]. Burlington: Morgan Kaufmann Publishers, 2008.

[19] JONES W. Personal information management [J]. Annual review of information science and technology, 2007, 41(1): 453-504.

[20] PRATT W, UNRUH K, CIVAN A, et al. Personal health information management [J]. Communications of the ACM, 2006, 49(1): 51-55.

[21] WANG M, LAU C, FREDERICK A. MATSEN I, et al. Personal health information management system and its application in referral management [J]. IEEE transactions on information technology in biomedicine, 2004, 8(3): 287-297.

[22] KIM E-H, STOLYAR A, LOBER WB, et al. Challenges to using an electronic personal health record by a low-income elderly population [J]. Journal of medical Internet research, 2009, 11(4): e44.

[23] MAMYKINA L, LEVINE ME, DAVIDSON PG, et al. Data-driven health management: reasoning about personally generated data in diabetes with information technologies [J]. Journal of the American Medical Informatics Association, 2016, 23(3): 526-531.

[24] HOLDEN RJ, KARANAM YLP, CAVALCANTILH, et al. Health information management practices in informal caregiving: An artifacts analysis and implications for IT design [J]. International journal of medical informatics, 2018, 120: 31-41.

[25] FENG Y, AGOSTO DE. From health to performance: Amateur runners' personal health information management with activity tracking technology [J]. Aslib journal of information management, 2019, 71(2): 217-240.

[26] MOEN A, BRENNAN PF. Health@Home: the work of health information management in the household (HIMH): implications for consumer health IT innovations [J]. Journal of the American Medical Informatics Association, 2005, 12(6): 648-656.

[27] ANCKER JS, WITTEMAN HO, HAFEEZ B, et al. The invisible work of personal health information management among people with multiple chronic

conditions: qualitative interview study among patients and providers [J]. Journal of medical Internet research, 2015, 17(6): e137.

[28] ANCKER JS, WITTEMAN HO, HAFEEZ B, et al. “You get reminded you’re a sick person”: personal data tracking and patients with multiple chronic conditions [J]. Journal of medical Internet research, 2015, 17(8): e202.

[29] HUVILA I, ENWALD H, ERIKSSON-BACKA K, et al. Anticipating ageing: older adults reading their medical records [J]. Information processing & management, 2018, 54(3): 394-407.

[30] TURNER AM, OSTERHAGE KP, LOUGHRAN J, et al. Emergency information management needs and practices of older adults: a descriptive study [J]. International journal of medical informatics, 2018, 111: 149-158.

[31] TAYLOR JO, HARTZLER AL, OSTERHAGE KP, et al. Monitoring for change: the role of family and friends in helping older adults manage personal health information [J]. Journal of the American Medical Informatics Association, 2018, 25(8): 989-999.

[32] KIM S, SINN D, SYN SY. Analysis of college students’ personal health information activities: online survey [J]. Journal of medical Internet research, 2018, 20(4): e132.

[33] RUPERT DJ, MOULTRIE RR, READ JG, et al. Perceived healthcare provider reactions to patient and caregiver use of online health communities [J]. Patient education and counseling, 2014, 96(3): 320-326.

[34] ZHANG S, GRAVEE E, SKLAR E, et al. Longitudinal analysis of discussion topics in an online breast cancer community using convolutional neural networks [J]. Journal of biomedical informatics, 2017, 69: 1-9.

[35] LIN T-C, HSU J S-C, CHENG H-L, et al. Exploring the relationship between receiving and offering online social support: a dual social support model [J]. Information & management, 2015, 52(3): 371-383.

[36] RUBENSTEIN EL. “They are always there for me”: the convergence of social support and information in an online breast cancer community [J]. Journal of the Association for Information Science and Technology, 2015, 66(7): 1418-1430.

[37] ZHANG S, O’CARROLL BANTUM E, OWEN J, et al. Online cancer communities as informatics intervention for social support: conceptualization, characterization, and impact [J]. Journal of the American Medical Informatics Association, 2017, 24(2): 451-459.

[38] CHOI MJ, KIM SH, LEE S, et al. Toward predicting social support needs in online health social networks [J]. Journal of medical Internet research, 2017, 19(8): e272.

[39] HARGREAVES S, BATH PA, DUFFIN S, et al. Sharing and empathy in digital spaces: qualitative study of online health forums for breast cancer

and motor neuron disease (amyotrophic lateral sclerosis) [J]. Journal of medical Internet research, 2018, 20(6): e222.

[40] ZIGRON S, BRONSTEIN J. “Help is where you find it”: the role of weak ties networks as sources of information and support in virtual health communities [J]. Journal of the Association for Information Science and Technology, 2019, 70(2): 130-139.

[41] CHEN L, BAIRD A, STRAUB D. Fostering participant health knowledge and attitudes: an econometric study of a chronic disease-focused online health community [J]. Journal of management information systems, 2019, 36(1): 194-229.

[42] BRENNAN KA, CREAVEN AM. Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus [J]. Quality of life research, 2016, 25(5): 1227-1235.

[43] MAZZONI D, CICOGNANI E. Problematic social support from patients’ perspective: the case of systemic lupus erythematosus [J]. Social work in health care, 2014, 53(5): 435-445.

[44] MAZZONI D, CICOGNANI E. Positive and problematic support, stress and quality of life in patients with systemic lupus erythematosus [J]. Anxiety, stress, and coping, 2016, 29(5): 542-551.

[45] CHEHAB G, SAUER GM, RICHTER JG, et al. Medical adherence in patients with systemic lupus erythematosus in Germany: predictors and reasons for non-adherence—cross-sectional analysis of the LuLa cohort [J]. Lupus, 2018, 27(10): 1652-1660.

[46] MEUNIER B, JOURDE-CHICHE N, MANCINI J, et al. Characteristics and information searched by French patients with systemic lupus erythematosus: a Web-community data-driven online survey [J]. Lupus, 2016, 25(4): 370-375.

[47] VALDEZ RS, GUTERBOCK TM, FITZGIBBON K, et al. From loquacious to reticent: understanding patient health information communication to guide consumer health IT design [J]. Journal of the American Medical Informatics Association, 2017, 24(4): 680-686.

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Note: Figure translations are in progress. See original paper for figures.