

Health Information Sharing on the Web: The Influences of Age and Gender

인터넷에서의 건강정보공유: 성별과 나이의 영향을 중심으로

Ji-Hyun Kim(김지현)*

Jung A Lee(이정아)**

ABSTRACT

This study investigated what web users share on a health website and how the demographic characteristics of users reflect health information sharing behavior. By using a content analysis method, this study analyzed 1,042 randomly chosen messages in the discussion board of a health website. The results revealed that the health website users emotionally supported other users, provided health information, and built relationships between them. Two third of the health website users shared his/her thoughts or feelings about ALS (Lou Gehrig's Disease) on the health website and one fourth of the health website users connected with others who had ALS. A half of the users actively provided information as a direct response to a question. No significant differences were discerned with regard to total posting frequency by age and gender effect. However, the male users in the 50s answered questions to others more actively and tried to manage their life better than the other age groups.

초 록

이 연구는 인터넷 사용자들의 건강정보 웹사이트에서 정보공유내용과 인구통계학적인 특징이 건강정보 공유행동에 미치는 영향을 조사하였다. 건강정보 웹사이트 토론방에 있는 메시지 중에서 1,042개를 임의로 선택하여 내용분석한 결과, 건강정보 웹사이트 회원들은 서로간 감정적인 공감과 정보제공, 그리고 관계형성에 적극적인 것으로 나타났다. 건강정보 웹사이트 회원 중 2/3는 루게릭병에 대한 자신들의 생각과 감정을 나누었고, 루게릭병을 가진 타인과의 관계형성에 노력한 회원은 1/4 정도였다. 절반 정도의 회원들은 적극적으로 다른 회원의 질문에 답하였다. 이 연구는 전체적으로 분석했을 때 나이와 성별에 의한 정보공유의 효과는 없었지만, 50대 남성의 경우 다른 사람들에게 대한 질문에 대한 대답이나 자신의 삶에 대한 관리에 다른 연령대 그룹보다 더욱 적극적인 모습을 보였다.

Keywords: health information sharing, web users, age effect, gender effect, content analysis, health websites
건강정보공유, 인터넷 사용자, 성별과 나이의 영향, 내용분석, 건강사이트

* Department of Library and Information Science, Chung-Ang University, Instructor (jhkim0099@nate.com) (제1저자)

** College of Sciences in Education, Yonsei University, Instructor(jal12@yonsei.ac.kr) (공동저자)

■ 논문접수일자 : 2012년 5월 19일 ■ 최초심사일자 : 2012년 5월 27일 ■ 게재확정일자 : 2012년 9월 12일
■ 정보관리학회지, 29(3), 61-77, 2012. [http://dx.doi.org/10.3743/KOSIM.2012.29.3.061]

The Internet plays a key role in the way that individuals manage their health care. Approximately 80% of web users or 59% of Americans have reported seeking medical information online (Fox, 2012). The Internet has been regarded as one of the most important resources for individuals seeking health related information (Fox, 2012; Ybarra & Suman, 2008; Woo, 2007). People can get information beyond time and spatial limitations using the Internet, and health care professionals can provide patients with highly customized information and services through the Internet. 18% of web users or 13% of Americans have used the Internet to find others who might have health concerns similar to theirs (Fox, 2012). Health information websites have revolutionized “how individuals access and share health information and resources” (Keith et al., 2009, p. 1033). Therefore, understanding how patients and caregivers access informative resources, and then share that information, is crucial to improving overall disease management (Keith et al., 2009).

There are various types of health information sharing websites that help people find health resources and manage their health behaviors. One good example of a health care website that addresses a wide range of health information topics is the PatientsLikeMe website (PatientsLikeMe, 2012). PatientsLikeMe (PLM) is a health information communication website that has been built upon the concept of sharing of a health data. At this site, not only can patients manage their health condition, but health care organizations can participate to promote new treatments for improved patient care and provide a venue for

the broader release of content related to patient care research. The PLM website is free for patients and supports more than 145,000 patients with chronic diseases like ALS (Lou Gehrig’s Disease), Multiple Sclerosis (MS), and Parkinson’s Disease. Members of the PatientsLikeMe (PLM) Amyotrophic Lateral Sclerosis (ALS) online support community share social support, but also exchange knowledge within their discussion forum (Wicks et al., 2010). There are a wide range of health care issues discussed on the site. Site participants have identified more than 1,000 health conditions, sharing details of their health conditions and communicating their personal knowledge, experience, and feelings. PLM is a website that allows its members to share not only social support, but also information with other members on their symptomatology, treatments, medications, and outcomes (Wicks et al., 2010). The popularity of the PLM website indicates that it provides a medium for study that will yield a better understanding of patients’ health information sharing.

To understand patients’ health information sharing on websites, the research focuses on questions relating to how PLM users acquire and share health information. The four purposes of this study are to: (1) describe the demographic characteristics of PLM users; (2) investigate how PLM users share on the PLM website; (3) investigate what types of information is shared by PLM users; and (4) determine how the demographic characteristics of PLM users reflect health information sharing on the PLM website.

1. Literature Review

1.1 Health Information on the Web

When health is the topic of concern, people use various sources to meet their information needs. As information needs arise out of “situations pertaining to a specific task” (Leckie et al., 1996, p. 82), much health related information seeking has great personal relevance and specificity. Web based health-sharing sites offer individuals the opportunity to connect with others, share information, and relate personal experiences. The Internet is one of the most popular ways to share health information and to help web users maintain and improve their health (Veinot, 2009).

In this technology driven society, more and more people seek and share health information via web sites. There is vast amount health information available across numerous websites. The diverse topics or applied range of the Internet health information is as broad and complex as the topic of medicine itself (Sonnenberg, 1999). In their quest for health related information on the web, individuals may connect with health websites that assist in diagnosing or otherwise determining their health issues. Health information seeking is defined as searching for content or an informative message that helps reduce uncertainty regarding health status, or provides a personal sense of health or wellbeing (Goldsmith, 2000). Increasingly, patients seek to obtain health information from sources other than their primary physician. Thus, the health information seekers are deciding

their health care treatment based on their personal health knowledge and their physician’s advice (Fox & Rainie, 2000). In expanding their personal health knowledge, health information seekers pursue searching for health information using web based resources and by participating in social support groups.

Health information seekers who seek detailed content about their health care concerns are motivated by a desire for a diagnosis of symptoms, or to determine an appropriate treatment plan. They seek online health information because they can save time, expense, and can readily increase their awareness of issues relating to health prevention, self-care, aging, and medicine (Cotton, 2001). Searching for health related information leads to more informed medical care and can significantly influence an individual’s medical decision making. Health information seekers can have a chance to select their health care providers, evaluate treatment options, and research specialized care systems. In a larger context, internet health information could be used to design more effective health intervention programs. These programs could be adapted as web-based and tailored health intervention programs for improving public health in schools, hospitals, and health related organizations (Goldsmith, 2000). The Internet provides easy to access health information that can support improved teaching, informing, and connecting providers and consumers. In this way Internet based health resources can offer content that is more current, supports high volume, and promotes rapid and widespread dissemination by overcoming traditional information seeking processes’ limitations, including

space and time barriers. Key benefits of Internet based health resources include more effectively reaching key underserved populations, offering 24 hours per day access to hard-to-reach audiences such as rural populations. These unique features make the Internet an efficient and effective tool for the health information seeker.

Over seventy percent of health information seekers engage in social support groups via the Internet (Keith et al., 2009). Goldsmith (2000, p. 148) indicates that since the late 1990's, the Internet has emerged to be "a powerful new social institution". Various online tools exist for consumers to access health information resources such as websites, chat rooms, instant messaging, online support groups, discussion boards, and e-mail. While these social supports are now available online, they have been a successful part of the shared-experience social functions in an offline world. These offline opportunities are exemplified by venues as club meetings, written correspondence, newsletters, or group bulletin boards. The Internet social support groups, much like offline support groups, commonly involve discussions relating to professional care, health information, and testimonials. In these groups, individuals can share their concerns, fears, discuss financial pressures, and get emotional support from other online members. These social support groups have evolved to be communities consisting of empowered participants, which can provide positive effects on health behavior changes (Keith et al., 2009). These groups are wide ranging in composition, diverse in age, race, ethnicity, and gender, so that their needs for health information

are dramatically different. Any effort to tailor information content would require a better understanding of the demographic characteristics of these information seekers, with the goal being to help provide more targeted and useful health information for the participants.

1.2 The Effects of Age and Gender

Recent research suggests age and gender affect the health seeking and sharing experience on the web (Ybarra & Suman, 2008). Scholars suggest that younger people tend to seek information more actively than older people (Mayer et al., 2007; Rutten et al., 2005). The frequency of older adults' internet usage for health information is lower relative to younger users (Ayers & Kronenfeld, 2007). One study reveals that 60% of older adults use the Internet to find health care information, compared to 70% for middle-aged and younger (Miller & Bell, 2012). However, Ybarra and Suman (2008) report that there are no differences in using the Internet as a health care information sources between older adults and adolescents. For the individuals who have the same medical condition, middle-aged people are more likely to use the Internet as a health information resource than younger people (Sabel et al., 2005).

Men and women differ in their health information seeking and sharing (Ybarra & Suman, 2008). Male users are more likely to use the Internet than female users (Dryburgh, 1999). However, females indicate that health information found online would be more influential in helping them cope with their illness

compared to males (Fox & Rainie, 2002). Females have consistently sought health information more frequently than males (Fox & Rainie, 2002; Huber & Cruz, 2000; Rutten et al., 2005). Females are more highly sensitive to stressful medical information than males, and try to avoid or minimize obtaining stressful medical information (Lee, 2007).

As the Internet's influence on health care information increases, it becomes more important to understand how health website users' demographic characteristics mediate the online health information seeking behavior. Such findings will help health information professionals to better understand what health information seekers share, and will reveal how these demographic characteristics relate to different information sharing practices of online information seekers.

2. Method

The current study focuses on the quantitative and qualitative analyses of the ALS (Lou Gehrig's Disease) community within PLM. This research used a content analysis method to analyze posts from the discussion board in PLM. The analyzed data include 1042 randomly chosen messages by web masters.

2.1 Data Collection and Analysis

This study generated descriptive categories that reflected the PLM users' information sharing. An inductive thematic analysis method was used to ana-

lyze 1042 messages posted to the ALS discussion forum on the PatientsLikeMe website. An initial codebook was developed by the PLM project team through an inductive analysis of randomly selected posts, without pre-determined categories. This codebook included explicit directions for coding procedures, as well detailed sets of codes to be used to assess the purpose of an individual post (e.g., the post was made to help the poster, to help others, or to benefit the site); to delineate the content of the post (including factual matters, emotional tone, etc.); and the poster's textual practices (e.g., the use of signatures or emoticons). The researchers tested and modified this codebook through an iterative process of coding. To develop the final codebook, the researchers closely followed the procedures developed by Dickey et al. (2007). For example, a randomly selected set of 25 posts was assigned to each of the researchers. Then, the researchers examined those and discussed discrepancies in their coding in depth. The researchers made changes to the codebook in light of these discussions. This process continued until an acceptable level of inter-coder agreement was reached. When the researchers agreed that their coding practices were in sync, the codebook was finalized and the full dataset was divided up between the researchers for individual coding.

As the results of those processes, the researchers developed a list of codes that was used to guide coding of the full set of posts. The final categories and code list included demographic information, purpose categories (15 codes), miscellaneous categories (18 codes), and contents categories (84 codes). The

full lists of 117 codes were produced for the further analysis of the PLM users' posts.

However, this study needs to take into account the specific codes that were applicable to the qualitative analysis. The concepts associated with online health information sharing suggested an approach to the coded data with a focus on interactions; where web users share their feelings about ALS and connect with others; where web users are asking or answering questions to each other; where different posters share information sources; where interactions occur about topics that was previously undiscovered. Therefore, further examination was made of posts that were related to the purpose of the qualitative analysis. Such codes included: ask a question answer a question; connect with others express thoughts and feelings; supply factual information direct users to other resources; statements of advocacy; conversation related with drugs; communication issues; breathing problems; mobility issues; activities; policy; treatments experience with ALS; emotions; web users' coping mechanisms.

The quantitative analyses were conducted with 31 codes in two categories (purpose and content), because the numbers of posts of other categories and codes were not enough to be analyzed in a statistical program (see Appendix). Quantitative analysis of data was performed using SPSS for Windows 18.0. Frequencies and percentages for demographic variables were calculated. Means and standard deviations for all scales were also reported. Data were analyzed using Two-way ANOVA to determine if differences exist by age and gender.

3. Findings

This study investigates what PLM users share on the PLM website and how the demographic characteristics of PLM users reflect health information sharing behavior on PLM.

3.1 Demographic Characteristic and Posts

The total number of posts was 1042. The number of posts per individual ranged from a minimum of 1 to a maximum of 76, with a median number of posts per individual of 2 and a mean number of posts per individual of 4.3. The total number of posts made by males was 613 and by females was 328. The total number of unique discussion threads was 85. The number of posts per thread ranged from a minimum of 3 to a maximum of 48, with a median number of posts per thread of 7 and a mean number of posts per thread of 12.2.

The total number of individual participants in these posts was 238. Demographic statistics were collected about each participant's gender and age. Posters consisted of 112 men (47.1%) and 98 women (41.2%). 28 posters (11.8%) did not indicate their gender. The mean age of posters was 52 and 90% of posters were over 40s. Most PLM users were patients (80%) and caregivers (14%) with four staffs, a researcher, and a guest. 37 posters (15.5%) did not reveal their role in the PLM website (see Table 1).

The correlations among all posts, age, and gender are analyzed. Male users more actively ask questions

〈Table 1〉 Demographic characteristics of posters

Variable code	Type	Male		Female		Total		
Age	Under 39	16	14.3%	10	10.8%	26	10.9%	
	40s	30	26.7%	23	25.1%	53	22.3%	
	50s	28	25.0%	27	29.6%	57	23.9%	
	60s	31	27.7%	29	31.8%	60	25.2%	
	70s	7	6.3%	9	9.7%	9	3.8%	
	missing					33	13.9%	
Role	Under 39	patient	11	9.8%	4	4.3%	15	6.3%
		caregiver	2	1.7%	6	6.6%	8	3.3%
		staff	3	2.6%			3	1.2%
	40s	patients	27	24.1%	20	21.9%	47	19.7%
		caregiver	0		2	2.2%	2	0.8%
		researcher	1	0.9%	0		1	0.4%
	50s	patients	27	22.3%	25	27.4%	52	21.8%
		caregiver	1	0.9%	2	2.2%	3	1.2%
		staff	1	0.9%			1	0.4%
	60s	patients	29	25.9%	24	26.3%	53	22.2%
		caregiver	1	0.9%	3	3.2%	4	1.6%
		guest	1	0.9%			1	0.4%
	70s	patients	2	1.7%	9	9.8%	11	4.6%
	missing					37	15.5%	
	Total		112	100%	91	100%	238	100%

〈Table 2〉 Correlation analysis of posts, age and gender

Codes	Age	Gender
Ask questions posting	-.138	-.256*
Humor posting	-.155	-.325*
Direct address to another user posting	-.275**	-.186
Total posts	.157	.522

(*p<.05, **p<.01)

to other users compared to female users, and male users post more humorous contents compared to female users. Older posters more directly address another website than younger posters to online health in-

formation seekers in overall. However, there is no significant correlation among age, gender, and total posts (see Table 2).

3.2 Information Sharing between PLM users

Sharing health information via the Internet is a good method to help web users maintain and improve their health. Patients connect with the health websites that may determine their health issues and actively seek to obtain health information. One of popular subject of PLM users is just to share their health conditions or illness. This study finds that the 164 users (569 posts) shared his/her thoughts or feelings about ALS on the PLM website and the 58 users (90 posts) intended to engage or connect with others who have ALS (e.g., to talk, empathize, sympathize or commune with). One user posted his experience with ALS with others; the initial post goes on to say:

“After a few years of experiencing them, I have learned to ignore my fasciculation for the most part ~ as they don't hurt its not been too difficult. I have recently developed specific 'new' areas where they are intensely constant over a period of days and at times have become annoying. The current regions are in my right forearm and elbow and my right cheek (the one I sit on!). As I say I have them all over the place but they are usually fairly transient, coming and going and for the most part I am almost unaware of them.”

Health information seekers pursue searching health information and participating in online health communities. The PLM users also provide unique

information that patients are not able to obtain on their own. This study finds that many PLM users actively ask questions and answer those to improve their situation. However, as we know, non-expert users are not always sufficient for users seeking in-depth information about complex medical issues. In order to respond appropriately to advanced information needs, a professional-level search, either on the Internet or in subscription-based databases, is required (Volk, 2007). The 60 users (211 posts) asked a question to other posters and the 101 users (96 posts) provided information as a direct response to a question. For example one user asked about wheelchair:

“Can anyone offer advice on what type of pwr'd wheelchair to get? I will have to use medicare to help pay for it and I know they are critical on options. I know I need tilt and a comfortable seat. I also will need to get the chair into a minivan. So any advice will be helpful.”

For this question, one user provided an answer to the original poster immediately:

“ER" Episode Highlights Assistive Technology for ALS, view the article here. For more information about the motorized wheelchair being auctioned, visit Permobil Inc. online. <http://www.cmarket.com/catalog/landingPage.do?vhost=alsa>”

Health information seekers who seek material of their disease are triggered by desire for treatment

disease from a diagnosis. Searching health information leads to help consumer's medical care and influence their medical decision. One of the interesting finding of this study is that, PLM users share unique information they are not able to obtain on their own. The PLM users also have updated information in an interactive way. The 47 posters (121 posts) told users about other resources where they could find help, such as organizations, websites, books, etc. This user provided the useful information about wheelchair clothing:

“Some more tips for fashionable (!) wheelchair clothing options for women... <http://beautyability.com/2.0/category/fashion-advice/>Note the guys might appreciate some of the photos on this site too so use your best judgment when viewing at work, or around children, within eyesight of home bound ALS patients, etc.” ;)

The health information seekers can decide their health care treatment based on their health knowledge and physicians' advice (Fox & Rainie, 2000). Information and medical professionals have begun to question the accuracy and credibility of health information on website (Wright, 1998). Therefore web users offer authorized information or an expert opinion regarding a host of topics. Even though the PLM users are not authored by medical professionals, they try to provide credible content on the website. The 54 users (121 posts) provided factual information to help others. For example, one user cited many resources:

“Pot may hold Alzheimer's promise Sharon Kirkey, CanWest News ServicePublished: Monday, October 09, 2006 THC, the active component in marijuana, may protect the brain from the ravages of Alzheimer's disease, U.S. scientists reported. In lab experiments, investigators from Scripps Research Institute in La Jolla, Calif., found THC appears to block an enzyme in the brain that causes plaques to form better than currently approved drugs.”

Examining the PLM posts from the perspective of information sharing raises the importance of health information behavior on the web. Many PLM users frequently shared information that they learned from other people. Information sharing behavior of PLM users involves personal reasons for seeking information and the resources for solving problems. They also share information through behavior such as forwarding authorized information or an expert opinion.

3.3 The influence of age and gender on information sharing behavior

Table 3 reports the mediated effect of age and gender on information sharing behavior. The test results are analyzed by using a two-way Analysis of Variance (ANOVA) procedure. No significant differences are discerned with regard to total posting frequency by age and gender effect. However, the test in the two codes (*answer questions to others* and *manage life*) shows a significant interaction effect

between age and gender, indicating age and gender effect on how the PLM users answer questions to other (F (4, 91) = 2.60, p = .041) and manage their life (F (4, 91) = 10.4, p = .000). Age also has a significant main effect on how the PLM users manage their life (F (4, 91) = 6.93, p = .001) (see Table 3). This result indicates that the older PLM users post more messages related to manage life compared to the younger PLM users.

Since the test results of ANOVA demonstrate a significant interaction effect, the follow-up test (simple main effect) is conducted because the interaction effect indicates that the scores on the dependent variable (*answer questions to others* and *manage life*) are affected by the particular combination of the levels of the independent variables (*age* and *gender*). The simple main effects isolate the levels of a variable and compare the means of those groups in order to investigate where the differences among the inter-

actions are. The simple main effects were acquired using the SPSS option with ANOVA.

Simple main effect analysis shows that the male users in 50s answer questions to others more actively than other ages and female users (F (1, 31) = 8.039, p = .006). The male users in 50s and the female users in 60s try to manage their life better than other age groups (F (1, 31) = 22.547, p = .000; F (1, 31) = 7.41, p = .011) (see Table 4).

In addition, the male users reveal their name on the posts more frequently than the female users (F (1, 95) = 4.434, p = .038). The male users also significantly address other users by name on the posts compared to the female users (F (1, 80) = 3.966, p = .050) (see Table 5).

In summary of the results, the total number of posts made by males was 613 and by females was 328. The PLM users between 40s and 60s consisted of the fully 80% of users. They share his/her thoughts

<Table 3> Effect of age and gender on information sharing

Variable	Source of Variance	Sum of Squares	df	Mean Squares	F	Sig.
Answer questions to others	Age	33,503	4	8,376	1,465	.219
	Gender	2,089	1	2,089	.365	.547
	Age*Gender	59,470	4	14,867	2,600	.041
Manage life	Age	4,332	3	1,444	6,935	.001
	Gender	.001	1	.001	.003	.956
	Age*Gender	6,497	3	2,166	10,402	.000

<Table 4> The results of simple main effect

Variable	Age	Gender	Mean	Std. Error	F	Sig.
Answer questions to others	50s	Male	4,556	.797	8,039	.006
	60s	Female	2,000	.263	7,410	.011

〈Table 5〉 The gender differences

Variable	Gender	Mean	Df	F	Sig.
Name on posts	Male	3.58	1	4.434	.038
	Female	2.00			
Address others by name	Male	4.02	1	3.966	.050
	Female	1.98			

or feelings about ALS on the PLM website and connect with others who have ALS. Many PLM users also actively ask questions, and answer those to improve their situation. Age and gender partially have the mediated effect on health information sharing. The PLM male users in 50s answer questions more actively than other ages and female users. The PLM male users in 50s and the female users in 60s try to manage their life better than other age groups.

4. Discussion

This study investigates what PLM users share on the PLM website and how the demographic characteristics of the PLM users reflect health information sharing behavior. Interestingly, PLM users emotionally support other users and build relationships between them. Two third of the PLM users shared his/her thoughts or feelings about ALS on the PLM website and one fourth of the PLM users connected with others who have ALS. Sharing health information may help ill people and support their caregivers to build relationships. Also, emotional supports between health website users become definitely important (Salander, 2002). Therefore, health in-

formation professionals may need to provide patients and caregivers potential sources of emotional support as well as health information.

The Internet social support groups, much like off-line support groups, commonly involve discussions relating to professional care, health information, and testimonials. In these groups, individuals can share their concerns, fears, discuss financial pressures, and get emotional support from other online members. The findings suggest that the PLM users share health information spontaneously and actively with each other. One fourth of the PLM users asked a question to other posters and half of users provided information as a direct response to a question. PLM users also share unique and factual information they are not able to obtain on their own. They also share information through behavior such as forwarding authorized information or an expert opinion.

The influence of age and gender on health information sharing is analyzed. Scholars suggest older people may be less likely to access the Internet for health information seeking (Ayers & Kronenfeld, 2007; Czaja et al., 2006; Miller & Bell, 2012). The results reveal that the male users in 50s answer questions to others more actively and try to manage their life better than other age groups. Ybarra and Summan

(2008) explained that middle age groups have responsibility to take care of their parents as well as their children (Ybarra & Suman, 2008). Thus, these age groups need health information not only for their family but also for themselves. Similarly, Sabel et al. (2005) argue that, in the same medical condition, middle-aged people are more likely to use the Internet as a health information resource than younger people. The results partially support that web users in 50s appear to value the role of health websites in supporting their health. However, middle aged people in 40s and 50s complain they do not have enough time to seek all health information and the search takes too much effort (Ybarra & Suman, 2008). Therefore, health websites designed for middle aged or older group should pay more attention on easy navigation and in-detailed direction on health websites.

Even though younger people tend to seek information more actively than older age groups, they may not have a significant health risk factor in general. In this study, only 10% of PLM users were under 39. One of reasons why younger people have not actively participated in the PLM websites is that younger people may be less influenced by ALS (Lou Gehrig's Disease) compared to older people. People are not active to find helpful health information on the web without typical health status and disease risk (Ybarra & Suman, 2008). However, it is also important to point out that both younger and older adults highly consider the quality of online information when seeking health information (Miller & Bell, 2012; Ream et al., 2009). Non-professional resources are not always sufficient for users seeking

in-depth information about complex medical issues, because unreliable health information may reduce the effectiveness of health websites (Benigeri & Pluye, 2003; Kim, 2010; Miller & Bell, 2012). To improve the quality of online information, health information seekers and providers need to consider credibility and access issues.

There were two times as many male users as female users who seek and share health information on PLM website. Male users actively asked and answered questions to others, and posted more humorous contents than female users. The results partially support that male users more actively communicate and provide health information than female users. However, this result is not consistent with the expectation based on the gender differences from the previous studies (Fox & Rainie, 2002; Huber & Cruz, 2000; Rutten et al., 2005). This study supports only female users in 60s try to manage their life better than others.

4.1 Implications and Limitations

This study reveals that PLM health community shares their fear of diseases and financial press, and gets emotional supports from each other. The findings of this study may benefit health information professionals to better understand what online health information seekers share, and reveal how these demographic characteristics relate to different information sharing practices of online information seekers. Also, the findings will provide a foundation for understanding how patients and caregivers access informative resources, and help health physicians

to improve their overall disease management. This study confirms that the online social groups include diverse age and gender so that their needs of health information are different. A better understanding of the demographic characteristics of these information seekers will help health information professionals and physicians provide more targeted and useful health information for the participants.

Even though this study reported several useful results, the limitations need to be discussed because understanding the limitations is useful when applying the results to future research. First, the PLM data used for the content analysis were de-identified data to protect PLM users. So, the researchers could not conduct more in-detailed analysis for other variables, such as education or occupation. Second, this study content-analyzed one health website (PLM) to investigate what web users share on the health website and how the demographic characteristics of the users reflect health information sharing behavior. Even though the researchers analyzed large enough posts from PLM website, it is possible for researchers to get more interesting results from other health websites.

4.2 Conclusion

As the Internet's influence on health care information increases, it becomes more important to understand how health website users' demographic characteristics mediate the online health information

seeking behavior. This study focuses on health information sharing of the PLM users and the influence of age and gender on their information behavior. By using a content analysis method, this study captures meaningful results. The PLM users emotionally support other users and build relationships between them. The PLM users share his/her thoughts or feelings about ALS on the PLM website and connect with others who have ALS. The male users in 50s more actively answer questions to others than other age groups. The male users in 50s and the female users in 60s try to manage their life better than other groups. The male users significantly reveal their name more frequently and address other users by name on the posts compared to the female users.

This study supports that adults in 40s, 50s, and 60s are important health seeking groups because they consist of 80% of users. Future research should replicate this study using other research procedures and data from different health websites which treat other health issues.

[Acknowledgements]

I appreciate the PLM project members (Dr. Gary Burnett, Dr. Mia Lustria, Dr. Michelle Kazmer, Dr. Juliann Cortese, Jenny Ma, and Jeana Frost) for their valuable co-works.

References

- Ayers, S. L., & Kronenfeld, J. J. (2007). Chronic illness and health-seeking information on the Internet. *Health, 11*(3), 327-347. <http://dx.doi.org/10.1177/1363459307077547>
- Benigeri, M., & Pluye, P. (2003). Shortcomings of health information on the Internet. *Health Promotion International, 18*(4), 381-386.
- Buckland, M. K. (1991). Information as thing. *Journal of the American Society for Information Science, 42*(5), 351-360.
- Cotton, S. R. (2001). Implications of Internet technology for medical sociology in the new millennium. *Sociological Spectrum: Mid-South Sociological Association, 21*(3), 319-340.
- Czaja, S. J., Charness, N., Fisk, A. D., Hertzog, C., Nair, S. N., Rogers, W. A., & Sharit, J. (2006). Factors predicting the use of technology: Findings from the center for research and education on aging and technology enhancement (create). *Psychology and Aging, 21*(2), 333-352.
- Detlefsen, E. G. (2004). Where am I to go? Use of the Internet for consumer health information by two vulnerable communities. *Library Trends, 53*(2), 283-300.
- Dervin, B. (1983). Information as a user construct: The relevance of perceived information needs to synthesis and interpretation. In S.A.Ward & L.J. Reed (Eds.), *Knowledge structure and use: Implications for synthesis and interpretation* (pp. 155-183). Philadelphia: Temple University Press.
- Dickey, M. H., Burnett, G., Chudoba, K. M., & Kazmer, M. M. (2007). Do you read me?: Perspective making and perspective taking in chat communications. *Journal of the Association for Information Systems, 8*, 47-70.
- Dryburgh, H. (2001). *Changing our ways: Why and how Canadians use the Internet*. Statistics Canada. Retrieved February 02, 2010, from <http://www.statcan.ca/cgi-bin/downpub/listpub.cgi?catno=56F0006XIE>
- Fox, S., & Rainie, L. (2002). *Vital decisions: How internet users decide what information to trust when they or their loved ones are sick*. Washington, DC: Pew Internet & American Life Project.
- Fox, S. (2012). *Pew internet: Health*. Retrieved May 01, 2012, from <http://www.pewinternet.org/Commentary/2011/November/Pew-Internet-Health.aspx>
- Goldsmith, J. (2000). How will the Internet change our health system? *Health Affairs, 19*(1), 148-156.
- Huber, J. T., & Cruz, M. (2000). Information needs and information-seeking of HIV positive men and women. *Medical Reference Services Quarterly, 19*(1), 39-48.
- Keith, J. H., Courtenay-Quirk, C., Harwood, E., Fisher, H., Kachur, R., McFarlane, M., ... Simon, R. (2009). Using the Internet to provide care for persons living with HIV. *Aids Patient Care and STDs, 23*(12), 1033-1041.

- Kim, Yeo-Ra. (2010). Exploring the social and legal issues of Internet medical information: Focusing on the credibility of Internet medical information use and invasion of cyber privacy. *Journal of Korean Communication Science Research*, 10(2), 179-220.
- Kremer, H., & Ironson, G. (2007). People living with HIV: Sources of information on antiretroviral treatment and preferences for involvement in treatment decision-making. *European Journal of Medical Research*, 12(1), 34-42.
- Leckie, G. J., Pettigrew, K. E., & Sylvain, C. (1996). Modeling the information seeking of professionals: A general model derived from research on engineers, health care professionals, and lawyers. *Library Quarterly*, 66(2), 161-193.
- Lee, Dong Suk. (2007). The relationships among gender, information seeking style and high risk behavior in Korean adults. *Korean Journal of Adult Nursing*, 19(2), 127-124.
- McCreadie, M., & Rice, R. (1999). Trends in analyzing access to information. Part I: Crossdisciplinary conceptualizations of access. *Information Processing and Management*, 35(1), 45-76.
- Mayer, D. K., Terrin, N. C., Kreps, G. L., Menon, U., McCance, K., Parsons, S. K., & Mooney, K. H. (2007). Cancer survivors' information seeking behaviors: A comparison of survivors who do and do not seek information about cancer. *Patient Education and Counseling*, 65(3), 342-350.
<http://dx.doi.org/10.1016/j.pec.2006.08.015>
- Miller, L. M., & Bell, R. A. (2012). Online health information seeking: The influence of age, information trustworthiness, and search challenges. *Journal of Aging and Health*, 24(3), 525-541.
<http://dx.doi.org/10.1177/0898264311428167>
- PatientsLikeMe (2012). Retrieved from <http://www.patientslikeme.com/>
- Rutten, L. J. F., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: A systematic review of research (1980-2003). *Patient Education and Counseling*, 57(3), 250-261.
- Sabel, M. S., Stringfield, V. J., Schwartz, J. L., Wang, T. S., Karimipour, D. J., Orringer, J., ... Bichakjian, C. K. (2005). Patterns of Internet use and impact on patients with melanoma. *Journal of the American Academy of Dermatology*, 52(5), 779-785.
- Saracevic, T. (1999). Information science. *Journal of the American Society for Information Science*, 50(12), 1051-1063.
- Salander, P. (2002). Bad news from the patient's perspective: An analysis of the written narratives of newly diagnosed cancer patients. *Social Science and Medicine*, 55(5), 721-732.
- Sonnenberg, F. A. (1997). Health information on the Internet: Opportunities and pitfalls. *Archives of Internal Medicine*, 157, 151-152.

- Veinot, T. C. (2009). Interactive acquisition and sharing: Understanding the dynamics of HIV/AIDS information networks. *Journal of the American Society for Information Science and Technology*, 60(11), 2313-2332.
<http://dx.doi.org/10.1002/asi.21151>
- Volk, R. M. (2007). Expert searching in consumer health: an important role for librarians in the age of the Internet and the web. *Journal of the Medical Library Association*, 92(2), 203-207.
<http://dx.doi.org/10.3163/1536-5050.95.2.203>
- Webster, F. (2002). The idea of an information society. In F. Webster (Ed.), *Theories of the information society* (pp. 8-29). London: Routledge.
- Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., ... Heywood, J. (2010). Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research*, 12(2), e19.
<http://dx.doi.org/10.2196/jmir.1549>
- Woo, Young-Woon, & Cho, Kyoung-Won (2007). Analysis of confidence and satisfaction degrees for Korean health information web-sites. *Journal of Korea Contents Association*, 7(3), 110-117.
- Wright, J. B. (1998). Quality connection on the internet. *Healthcare Executive*, 13(1), 44-45.
- Ybarra, M., & Suman, M. (2008). Reasons, assessments, and actions taken: Sex and age differences in uses of Internet health information. *Health Education Research*, 23(3), 512-521.
<http://dx.doi.org/10.1093/her/cyl062>

Appendix

<Coding Categories and Codes for Quantitative analysis>

Category	Subcategory	Codes
Purpose	Help self	Ask a question
		Connect with others
		Express thoughts and feelings
	Help others	Supply factual information
		Direct users to other resources
		Answer a question
Content	Equipment	Mobility
		Communication
	Drugs	Prescribed drugs
		Alternative medicines/natural remedies
	Activities	Activities they had to give up
		Activities they still do
	Experience with ALS	Diagnosis
		Symptoms
		Other possible causes
	Emotions	Humor
		Thankfulness
		Empathy/Expression of support
		Frustration
		Anger
		Fear of disease
		Mixed emotions
	Coping mechanisms	Rationalizing changes in life
		Avoidance
		Blunting
		Managing lifestyle
	Other Content	Pictures/Images
		Own name
		Direct address to another user by name
		Personal Website
Email address		

