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The Comparison Analysis of Opinions towards the Concept of Consumer Health Informatics among Korean and American Health Informatics Academic Society Members

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Abstract

Objectives: Consumer Health Informatics is an increasingly important research area within health informatics, however, it is as yet not a well recognized discipline. The purpose of this study was obtaining consensus on a definition and description of Consumer Health Informatics among members of health informatics related society in Korea and the United States. **Design & Measurement:** The Consumer Health Informatics? Working Group's "Survey of Definitions of Consumer Health Informatics" was administered via the World Wide Web in English and Korean. **Results:** Differences found between two groups were opinions on the definition of Consumer Health Informatics and in recognition of importance for related disciplines. **Conclusion:** Visions and recommendations for the future of Consumer Health Informatics are provided. *(Journal of Korean Society of Medical Informatics 11-1,17-25, 2005)*

I. Introduction

A new era of healthcare is emerging. Increasingly educated consumers are demanding conve-

nience in accessing health information, participation in decision-making about treatments, and choice in selection of healthcare, etc. Perhaps the most common healthcare consumer activity today is that of health-information seeking.

These consumers are bringing about changes in the healthcare industry, and in professionals behavior in interacting with consumers[1]. Increasingly, professionals and consumers engage in interactive health communication.

Consumers are defined as individuals whether in good or poor health who are engaged in obtaining or providing health related information to learn about or manage their own, or family's and friends' health. Consumer Health Informatics(CHI) can be defined as the field in health informatics that is concerned with the following activities/issues[2] by International Medical Informatics Association CHI Working Group 2(IMIA CHIWG2):

• Analyzing and modeling consumer preferences, information needs, and information use;

• Developing and evaluating methods and applications to support consumers in obtaining and using health information;

• Developing and evaluating methods and applications to integrate consumer needs and preferences into information management systems in clinical practice, education, and research;

• Investigating determinants, conditions, elements, models, and processes to design, implement, and maximize the effectiveness of computerized information and telecommunication and network systems for consumers;

• Studying the effects of these systems on public health, the patient-professional relationship, and society.

Potential benefits of consumer online health-information seeking are: widespread access to health information, interactivity, tailoring of information, potential to facilitate interpersonal interaction and social support, potential for anonymity.

By contrast, the potential harms and hazards of online health information are: inequitable access to relevant information, navigational difficulties, information overload, disorganization, searching difficulties, inaccessible or overly technical language, lack of user friendliness, lack of permanence, lack of peer review or regulation, inaccurate/misleading/dangerous information, lack of consumers' evaluation skills, risk-promoting messages abound and potential for online pathologic or maladaptive behaviors[3]. Based on these potential but critical factors, there should be definite ways to protect health information consumers on the information superhighways. Concerns about the quality of health information found on the web led to the focus of one *Healthy People 2010's* health communication objective, 'quality of Internet health information sources', as public health officials recognize that 'the potential for harm from inaccurate information...is significant'[4].

The CHIWG became an official IMIA Working Group in 2000. The CHIWG is concerned with electronic information related to healthcare available to the public(e.g. Internet, wireless, standalone electronic media). For its purposes, it defines CHI as "the use of modern computers and telecommunications to support consumers in obtaining information, analyzing unique healthcare needs and helping them make decisions about their own health"[5], in which the consumer interacts with the applications directly with or without the presence of healthcare professionals. The group's interests focus on, but are not limited to, world wide web sites that offer advice about healthy living, research findings, and recommendations on specific disease conditions, descriptions of products, medications, and self-care health programs available to the public. Issues of concern may be the evaluation of the quality of information, education of the public, ethical issues related to the electronic

information, and the effect on a person's healthcare and relationship with healthcare providers.

As such CHI is an increasingly important research area within medical informatics. There are many issues on CHI researches as they are acknowledged as important research subjects. Abelhard and Obst, in grappling with research challenges, indicate that new methods may be required with regard to sampling(as users may vary with amount of use, expertise, nature of use)[6]. Researchers will be challenged to discriminate effects due to the Internet versus other highly accessible health information sources. Controlled studies may include longitudinal investigations(as use and influence may vary over time), retrospective cohort studies and case control studies, as alternatives to traditional studies using control groups[6].

In response to now-common criticisms and concerns regarding health information seeking on the Internet, future research needs to assess the 'net gap' as well as the quality of information. Research needs to address the demographic characteristics of participants, to more precisely identify the underserved, as well as the kinds of information consumers are seeking, what they locate, how they judge the quality of information found, what they learn[7] and how they are influenced behaviorally. Researchers need to compare the processes, outcomes and cost-effectiveness of traditional versus online health information seeking, as well as various types of online information seeking. Future research, practice and public policy need to focus on reducing the 'net gap' both in terms of accessibility and evaluation skills.

Despite abundant speculation regarding the consequences of consumer participation in interactive health communication, little research has investigated these issues; a lack of compelling evidence exists regarding relative *effectiveness*;

perhaps more importantly, little evidence exists regarding *effects*. Critics bemoan absence of research regarding the Internet's *effectiveness*. However, assessing *effectiveness* presumes a consensus regarding websites' goals and objectives. Public health professionals' goals involve enhancing health knowledge, beliefs and behavior. However, taken collectively, health websites do not reflect a monolithic objective; some are created for profit, others for personal benefit and still others to 'validate' views that lack an evidence base. Thus, from the perspective of their creators, some websites may be deemed effective if they are commercially successful, personally confirming, or succeed in disseminating information and gathering support for risk promoting or unhealthy functions. Moreover, given the potential for health websites to 'promote disease' as well as health and to disseminate fiction as well as fact, researchers may do well to think in terms of assessing 'effects' rather than 'effectiveness'[2].

Ultimately interest and research on effects should focus on quality of health and healthcare. Despite observers' contentions, little research has assessed the impact of interactive health communication on the healthcare system[6,7], although healthcare[8], healthcare interaction, and health and medical outcomes[6] likely are affected.

As described above, there are many questions concerned about CHI as it is in the emerging stage, and many research issues to be considered and studied. The purpose of this survey is to define the components of a description of CHI and to understand the relative importance of issues for future study.

Purpose: to define the components and types of CHI and their relative importance, arriving at a quantitative consensus.

Objectives:
1. To identify the working definition of CHI

2. To identify important components of CHI

3. To identify the relative importance of specific issues for a research agenda in CHI

4. To compare the differences of opinions about CHI between Korean and American groups

II. Methods

Based on the purposes mentioned above, a questionnaire was developed by IMIA CHIWG members. The survey questions are: Indicate which of the following subjects should be included in a description of CHI activities. Rate how important each of the following areas of expertise are for development, implementation, and evaluation of CHI interventions(Rate each on a scale from: 1=Very unimportant, 2=Unimportant, 3=Neutral, 4=Important, 5=Very important). Indicate the single most important issue to be incorporated into future CHI research. Are there any ongoing informatics activities(i.e., program development, research, education) at your institution that focus of CHI? Would you recommend that CHI be considered a separate discipline within Health Informatics?, etc. English version questionnaire was translated into Korean by a Korean nursing informatics scholar, and back translated by native and bilingual English speaker. Both English version and Korean version questionnaires were converted into web forms, and uploaded on the Korean professional survey conducting vendor's server to implement the online survey. By obtaining the e-mail lists of Korean and American societies that are concerned with medical and health informatics(Korean Society of Medical Informatics and Capital Area Roundtable on Informatics in NursinG; KOSMI and CARING), survey participation soliciting e-mails were sent to the members. Data were collected from 14th until 22nd December 2002 for Korean members, and from 1st until 8th February 2003 for American members. The reasons of the time lag between two groups were programming and translating issues. Data were analyzed using SAS version 8.1 to identify means, standard deviations and statistical significance of differences between two groups. The Cronbach's Alpha was 0.67 for the reliability testing of the instruments.

III. Results

One hundred and thirty five Koreans out of 566, and 64 Americans out of 767 were responding. The respondents are from academic institution 62 (45.9%), industry 55(40.7%), government 3(2.2%), and clinical institution 11(8.2%) among Koreans; and from academic institution 19(29.7%), industry 17(26.6%), government 4(6.2%), and clinical institution 21(32.8%) among Americans. There were statistical differences for item number 1, 2, 3, 7, and 8. Question No 1(Consumer health information
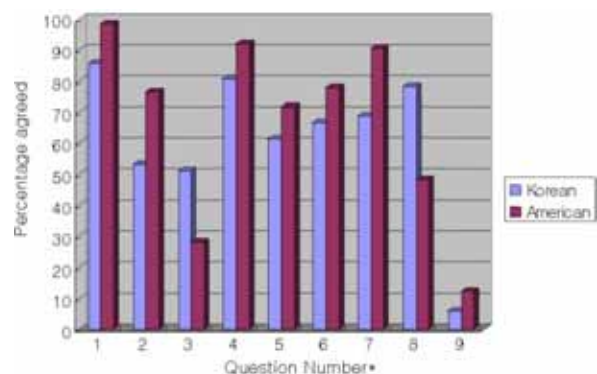
* Question Number descriptions
1. Consumer Health Information – provision of patient education through technology
2. Patient access to their own electronic medical records
3. Consumer Health commerce – advertising for consumer goods
4. Patient Decision Support/Tailoring of information for self-help/ disease management.
5. Patient-to-Patient communication for social support
6. Quality Assessment of Consumer Health Informatics
7. Security/Confidentiality
8. Patient-healthcare provider communication and relationships
9. Other(s)(specify)

Figure 1. Comparison of the opinions on the CHI definition

Table 1. Comparison of the opinions on the Consumer Health Informatics definition

Question No**	Group	Mean	N	SD	Source of Variation	SS	df	MS	F	p
1	Korea	.86	135	.349	Between	.680	1	.680	7.735	.006*
	USA	.98	64	.125	Within	17.310	197	.088		
	Total	.90	199	.301	Total	17.990	198			
2	Korea	.53	135	.501	Between	2.343	1	2.343	10.237	.002*
	USA	.77	64	.427	Within	45.084	197	.229		
	Total	.61	199	.489	Total	47.427	198			
3	Korea	.51	135	.502	Between	2.294	1	2.294	9.683	.002*
	USA	.28	64	.453	Within	46.671	197	.237		
	Total	.44	199	.497	Total	48.965	198			
4	Korea	.81	135	.396	Between	.569	1	.569	4.377	.038
	USA	.92	64	.270	Within	25.602	197	.130		
	Total	.84	199	.364	Total	26.171	198			
5	Korea	.61	135	.488	Between	.469	1	.469	2.057	.153
	USA	.72	64	.453	Within	44.908	197	.228		
	Total	.65	199	.479	Total	45.377	198			
6	Korea	.67	135	.473	Between	.570	1	.570	2.743	.099
	USA	.78	64	.417	Within	40.937	197	.208		
	Total	.70	199	.458	Total	41.508	198			
7	Korea	.69	135	.465	Between	2.051	1	2.051	11.757	.001*
	USA	.91	64	.294	Within	34.371	197	.174		
	Total	.76	199	.429	Total	36.422	198			
8	Korea	.79	135	.412	Between	3.929	1	3.929	19.970	.000*
	USA	.48	64	.504	Within	38.755	197	.197		
	Total	.69	199	.464	Total	42.683	198			
9	Korea	.06	135	.237	Between	.188	1	.188	2.545	.112
	USA	.13	64	.333	Within	14.526	197	.074		
	Total	.08	199	.273	Total	14.714	198			

*P<0.01

**Question Number descriptions

10. Consumer Health Information - provision of patient education through technology

11. Patient access to their own electronic medical records

12. Consumer Health commerce - advertising for consumer goods

13. Patient Decision Support/Tailoring of information for self-help/disease management.

14. Patient-to-Patient communication for social support

15. Quality Assessment of Consumer Health Informatics

16. Security/Confidentiality

17. Patient-healthcare provider communication and relationships

18. Other(s) (specify)

-provision of patient education through technology), question No 2(Patient access to their own electronic medical records), and question No 7 (Security/Confidentiality issues) were agreed higher in Americans than Koreans, whereas question No 3(Consumer health commerce - advertising for consumer goods), and question No 8(Patient-healthcare provider communication and relationships) issues were agreed higher in Koreans than Americans(Fig. 1 and Table 1).

There were statistical differences in recognition of importance for computer science and health education science between 2 groups. Koreans evaluated computer science higher, whereas Americans evaluated health education science (Table 2).

The comparison of order of importance of research issues in CHI showed no statistical difference between 2 groups, even though it seems
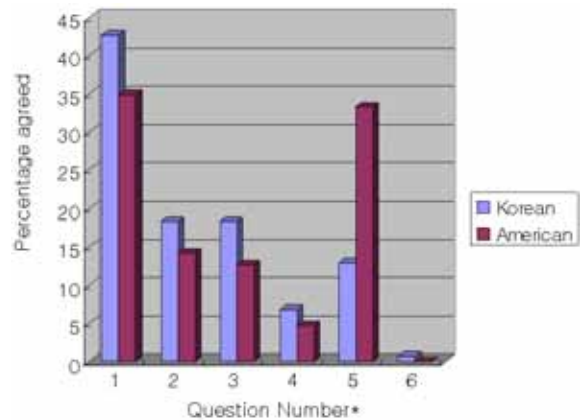
*Question Number descriptions
1. CHI Epidemiology/Needs Assessment(understanding how individuals use, and want to use CHI)
2. CHI program design/implementation
3. CHI Quality Assessment/Quality Assurance(evaluating, creating industry standards, etc)
4. Consumer Health Satisfaction(understanding the perceived value of CHI interventions)
5. Outcomes research for CHI(the impact of CHI on health outcomes, service utilization, etc)
6. Other(s)

Figure 2. Order of importance of research issues in Consumer Health Informatics

Table 2. Comparison of rating of importance among various disciplines

Items	Group	Mean	N	SD	Source of Variation	SS	df	MS	F	p
Computer science	Korea	4.34	130	.710	Between	13.366	1	13.366	18.410	.000*
	USA	3.77	62	1.093	Within	137.946	190	.726		
	Total	4.16	192	.890	Total	151.312	191			
Health science	Korea	4.45	132	.646	Between	1.772	1	1.772	3.679	.057
	USA	4.65	63	.786	Within	92.946	193	.482		
	Total	4.51	195	.699	Total	94.718	194			
Library science	Korea	3.53	129	.811	Between	2.028	1	2.028	2.791	.096
	USA	3.75	63	.933	Within	138.092	190	.727		
	Total	3.60	192	.857	Total	140.120	191			
Health education science	Korea	4.11	130	.770	Between	4.812	1	4.812	8.203	.005*
	USA	4.44	63	.757	Within	112.048	191	.587		
	Total	4.22	193	.780	Total	116.860	192			
Medical science	Korea	3.82	131	.802	Between	.236	1	.236	.328	.568
	USA	3.74	62	.940	Within	137.474	191	.720		
	Total	3.79	193	.847	Total	137.710	192			
Evaluation science	Korea	4.18	130	.734	Between	.130	1	.130	.215	.643
	USA	4.13	62	.859	Within	114.537	190	.603		
	Total	4.17	192	.775	Total	114.667	191			

*P<0.01

Table 3. Comparison of order of importance of research issues in Consumer Health Informatics

Source of Variation	SS	df	MS	F	p
Between	13.343	1	13.343	5.628	.019
Within	455.152	192	2.371		
Total	468.495	193			

that Americans rated outcomes research such as impact of CHI on health outcomes, service utilization and etc very high(Fig. 2 and Table 3).

The comparison of ongoing informatics activities showed no statistical difference between 2 groups. The comparison of degree of agreement on the CHI as an independent discipline showed no statistical difference between 2 groups. Both groups agree modestly that CHI as an independent discipline. There were statistical differences for comparison of percentage of working group participation, as Americans showed much higher participation rate for American Medical Informatics Association (AMIA) that is natural. Other participation rates showed no differences.

Ⅳ. Discussions

In 1990, Shortliffe and Perrault wrote that for health professionals "it is increasingly difficult to practice modern medicine without information technologies" a statement that is more true than ever today[9]. However, these days there is an additional trend: it is also increasingly unlikely that health professionals will encounter patients who have not used information technology to influence their health knowledge, health behavior, perception of symptoms, and illness behavior. Health professionals should, therefore, not only understand consumer health applications but also ensure that these applications are developed, applied, and evaluated properly.

There is another issue to be considered seriously other than consumer health information usage. Although the information society offers tremendous potential for reducing the knowledge gap between professionals and patients, it also brings a risk of a widening of the gap between those who have access to new technology and those who have been excluded[10]. Bridging this digital divide and bringing consumer health informatics to groups that have the greatest need will be particularly challenging. In the industrial age, the inverse care law described the idea that the availability of good medical care tends to vary inversely with the need for medical care in the population served[11]. In the information age, we face an analogous "inverse information law" that is, access to appropriate information is particularly difficult for those who need it most. The vicious circle of low education and low health literacy and low income, poor health, and the inaccessibility of information technology, can only be broken if the field is not left to market forces alone but if public health policy actively brings information technology to those who are underserved.

As such, there are many issues that should be researched to empower consumers of health related information. Several interesting results were found by this survey.

Firstly, it could be reasoned that the reason of low response rate of American members was that the e-mails containing some Korean characters or some meta-statements that made those e-mails be treated as some kind of spam mails and be deleted automatically by the receiving servers. Korean members' low response rate could be conjectured by the fact that some e-mails were returned because of unknown addresses. Conducting international survey using e-mails has some tricky aspect that researchers should be cautious. They need to pay attention to raise the response rate more than usual survey that is conducted in one

country.

Americans seem to have more interests in provision of education, and accessibility at the same time security/confidentiality. Koreans have more interests in advertising online, as Korea's infrastructure for e-commerce has grown up very rapidly to give them more convenience of purchasing products. That could be the reason why Korean health informatics professionals think that consumer health commerce needs attention. The reason of "patient-healthcare provider communication and relationships" issue was rated higher in Koreans than in Americans could be conjectured that patient could not have enough time with their healthcare provider in Korean healthcare delivery system, and it is one of the main complaints of Korean patients. Korean people think it is very important to have close relationships with others, but that could not be the case in patient-healthcare provider. It could be predicted and hoped that the technology and CHI discipline improve the relationships in the near future.

It seems that Koreans have more focus on technology, whereas Americans have more focus on health discipline and health education. Using technology to empower patients as consumers is very brand new notion in Korea, and that makes health informatics professionals have more attention to technology out of computer science.

Other than above mentioned issues, most opinions about CHI showed no remarkable differences between two groups, as there should be some consensus about CHI's role and impact internationally. It would be interesting, however, to find some cultural differences on consumers' status and empowerment through the advancement and adoption of technology in healthcare arena between countries in the future researches.

V. Conclusions

Even though a little differences were found between Koreans and Americans, it could be concluded that CHI is considered as important and essential discipline that needs to be developed and interested in both countries. It is clear that by introducing and utilizing CHI research proactively will empower consumers of health information in this digital age regardless of the region in the world. The greatest contribution of CHI research to the healthcare sector may eventually be found in its attempts to systematize and codify consumers' needs, values, and preferences; in its research into how information is digested and is best presented to consumers; and in its research into how these variables influence outcome measures. Thus, current health informatics research may have greater implications for the practice of medicine than medical informatics ever did before. And also, empowerment of consumers of health related information using CHI researches should be more enlightened, activated and consolidated.

Acknowledgement

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