


PAPER

Perceived needs for the information communication technology (ICT)-based personalized health management program, and its association with information provision, health-related quality of life (HRQOL), and decisional conflict in cancer patients

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Abstract

Objective The use of information communication technology (ICT)-based tailored health management program can have significant health impacts for cancer patients. Information provision, health-related quality of life (HRQOL), and decision conflicts were analyzed for their relationship with need for an ICT-based personalized health management program in Korean cancer survivors.

Methods The health program needs of 625 cancer survivors from two Korean hospitals were analyzed in this cross-sectional study. Multivariate logistic regression was used to identify factors related to the need for an ICT-based tailored health management system. Association of the highest such need with medical information experience, HRQOL, and decision conflicts was determined. Furthermore, patient intentions and expectations for a web- or smartphone-based tailored health management program were investigated.

Results Cancer survivors indicated high personalized health management program needs. Patients reporting the highest need included those with higher income (adjusted odds ratio [aOR], 1.70; 95% [confidence interval] CI, 1.10-2.63), those who had received enough information regarding helping themselves (aOR, 1.71; 95% CI, 1.09-2.66), and those who wished to receive more information (aOR, 1.59; 95% CI, 0.97-2.61). Participants with cognitive functioning problems (aOR, 2.87; 95%CI, 1.34-6.17) or appetite loss (aOR, 1.77; 95% CI, 1.07-2.93) indicated need for a tailored health care program. Patients who perceived greater support from the decision-making process also showed the highest need for an ICT-based program (aOR, 0.49; 95% CI, 0.30-0.82).

Conclusions We found that higher income, information provision experience, problematic HRQOL, and decisional conflicts are significantly associated with the need for an ICT-based tailored self-management program.

KEYWORDS

cancer, HRQOL, ICT, oncology, perceived need, self-management

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1 | BACKGROUND

Over the last 2 decades in Korea, substantial advances have been made in cancer-related technology.^{1,2} This progress implies that more and more patients may be freed of their cancer, yet in many cases, cancer still needs to be managed as a chronic illness requiring long-term surveillance.³ Given this need for long-term management of cancer patients, not only the continuity of clinical care but also support systems for self-management and independent living are demanding issues among cancer patients.^{4–6}

Recently, with the increased use of the Internet and smartphones, numerous information and communication technology (ICT)-based self-management programs have been developed to assist cancer patients with personalized health care,^{7,8} and these programs are expected to substantially improve health outcomes.^{9–11} However, the implementation of these web- and smartphone-based self-management programs in clinical practice and their practical use by cancer patients has been very poor.^{12–14}

According to a previous study, the attitudes and medical experiences of patients appear to predict their actual online program engagement.¹² Cancer survivors' needs and preferences for programs can be differentiated on the basis of their medical experience (ie, experience with ICT technologies, positive relationship with medical doctors, sufficient satisfaction with treatment information, decisional conflicts during shared decision making) and individual characteristics.^{15,16} Therefore, identifying the relationship between patient needs and their medical experience can be considered in the development of ICT-based cancer care platforms to improve user adherence rates.^{6,16}

Finally, the aim of this study was to investigate the perceived need of cancer patients for ICT-based self-management programs and the association of this need with several sociodemographic variables and medical experience including information provision, decisional conflicts, and health-related quality of life (HRQOL).

2 | METHODS

2.1 | Participants

We contacted 766 consecutive cancer outpatients from 2 hospitals in South Korea (the National Cancer Center and Seoul National

University Cancer Hospital) between July 1, 2012, and November 30, 2012. Cancer patients were considered eligible if they (1) had been diagnosed with cancer, (2) knew they were undergoing cancer treatment, (3) were more than 18 years old, and (4) understood the intention of the study and agreed to participate. Individuals who consented to participate were given information about the study and completed a consent form and patient-reported questionnaire. Of the potential pool of 766 cancer patients for whom contact information was available, 625 daytime cancer outpatients completed the survey. The entire study process was approved by the institutional review boards of the 2 hospitals.

2.2 | Selection of the items included in the survey

2.2.1 | Information provision

We investigated the information provision score to identify the relationship between information provision and increased need for a tailored program. To determine the patients' self-administered status as related to the information about their condition and treatments, we used the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Information 26, which has been validated in the Korean population.¹⁷ Scores greater than 66 were used as an indicator to determine clinically meaningful "perceived adequate information provision" in cancer patients, based on the results of a previous study.¹⁸ The internal consistency reliability was estimated with Cronbach's α coefficient of .902 for all variables.

2.2.2 | Health-related quality of life

To assess the impact of perceived needs on HRQOL, we examined the Korean version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30).^{19,20} The EORTC QLQ-C30 is a 30-item cancer-specific questionnaire used to assess HRQOL of cancer patients. The questionnaire includes 5 functional domains (physical role, cognitive role, emotional role, social role, and global health) and 9 symptom scales (fatigue, pain, dyspnea, appetite loss, nausea and vomiting, insomnia, constipation, diarrhea, and financial difficulties). We created binary variables for each of the HRQOL functions and symptom scales with a problematic cutoff point according to the EORTC QLQ-C30 scoring manual²¹ to screen for clinically meaningful associations between HRQOL and

the perceived need for the program. The internal consistency reliability was estimated with Cronbach's α coefficient of .82 for all variables.

2.2.3 | Decisional conflict scale

To assess and measure decisional conflict of cancer patients, we used the Korean version of the decisional conflict scale (DCS) already used in a prior Korean study.²² Decisional conflict scale presented the perceived level of uncertainty, how well-informed cancer patients felt about their choice, the clarity of personal values, and the support they experienced in the decision-making process.^{23,24} We used a 5-point Likert scale of the DCS to assess the cancer patients' satisfaction with decision making, using the higher scores reflected lower levels of satisfaction.^{23,24} Internal consistency reliability of DCS was estimated with Cronbach's α of .83 for all variables

2.2.4 | Needs assessment for web- and mobile-based tailored health management program

Because our goal was to develop an ICT-based tailored self-management program to reflect the comprehensive needs of cancer patients, we evaluated the medical perception and attitudes of cancer patients toward the need for such a program. A simple questionnaire about ICT-based health management program needs was used to assess the comprehensive needs of patients and limit the burden on the respondents. With this questionnaire, study participants answered questions about several other aspects (eg, use intensity for the program and expectations in using an ICT-based self-management health care program).

The survey asked "What was your level of needs for web- or smartphone-based tailored health management program after treatment of cancer? If we develop the personalized health management program, are you going to use it?" The response scale was 1 for "not at all," 2 for "a little," 3 for "quite well," and 4 for "very much," determining the level of needs. To identify the most pressing needs among the patient population, we classified the responses into 2 groups: very much and others. We also asked patients about their expectations in using such a program.

2.2.5 | Data analysis

We conducted descriptive statistical analyses to characterize the overall study sample and to examine the levels of overall needs for web- and mobile-based tailored programs. We dichotomized the score distributions of all the questionnaire items based on the distribution of each item. We used the chi-square test to determine the relationship of each independent variable with the need for the program. In addition, when potential covariate factors were significantly associated in univariate analysis, we used logistic multivariate analyses to examine predictors of perceived need from sociodemographic variables and information provision, HRQOL, and DCS parameters. For the final selection, we used a backward-selection method with a minimum of 0.05 and a maximum of 0.10. Both first-entered and final-selected models showed good calibration (Hosmer-Lemeshow *P* values of .162 and .101, respectively). We set the significance level at $P < .05$ and used the SAS statistical package, version 9.3.

2.3 | Results

2.3.1 | Participant's characteristics

The sociodemographic and clinical characteristics of the participants are shown in Table 1. The mean age was 61.8 years, and more females participated than males (58.4% versus 41.1%, respectively). About a third (31.3%) of cancer patients were finished with cancer treatment and about half (52%) were in the treatment stage.

2.3.2 | Overall levels of perceived need

About 32% of participants reported that they needed and wanted to use a web- or mobile-based tailored program very much, and more than half of respondents showed a positive need for the program (63%). In using a web- or mobile-based tailored health care program, 179 (29%) cancer patients expected acquisition of effective information related to cancer, 288 (48%) expected efficacy of health care service, and 131 (22%) expected convenient communication with the medical team.

2.3.3 | Factors associated with items of perceived need for the web- or mobile-based health tailored program

For sociodemographics, patients who were younger than 65 years had a monthly income of >\$3000 and who had graduated from a university showed much higher need for the program (Table 1). Cancer patients who had been provided the information related to cancer treatment and services reported that they need and are willing to use the web- or mobile-based tailored program.

In the domain of information experience, information about other services ($P = .025$) and information about things you can do to help yourself ($P = .038$) were significant factors. At the same time, cancer patients responded that they wished to receive both more and less information. This result literally means that they wanted to get much more help but also hoped to get an appropriate level of cancer information ($P < .001$; Table 2).

For the DCS, all 5 subscores had critical impacts on the perceived need of an ICT-based tailored self-management program (Table 2). With respect to the domain of HRQOL functions and symptoms, 4 problematic functions and 3 symptoms were related to this need: Physical function ($P = .014$), emotional function ($P = .018$), cognitive function ($P = .001$), social function ($p = .021$), appetite loss ($P = .042$), constipation ($P = .035$), and diarrhea ($P = .036$) were significant (Table 3).

2.3.4 | Predictors of items for the perceived need for an ICT-based health program

The highest need for personalized web or mobile health management program was predicted by income level: Need was significantly higher in participants of high income status (aOR [adjusted odds ratio], 1.70; 95% [confidence interval] CI, 1.10-2.63). The highest need for the web- or mobile-based health personalized program was significantly greater in participants who had received information about things they could do to help themselves (aOR, 1.71; 95% CI, 1.09-2.66). Patients who wished to receive more information (aOR, 1.59; 95% CI, 0.97-2.61) were a significant factor associated with the need for a program. Interestingly, patients who wished to receive less information also

TABLE 1 Univariate analysis of correlation of patient needs for a tailored health management program with demographic and clinical variables

		Cancer Patients (N = 625)		Tailored Program Needs				P value
				Strong Needs		Others		
				No.	%	N = 195	31.2%	
Sex	Male	257	41.1	73	29.3	176	70.7	.216
	Female	365	58.4	122	34.3	234	65.7	
Age (years) Mean ± SD: 61.77 ± 76.19	>65	129	20.6	29	23.8	93	76.2	.024
	≤65	491	78.6	166	34.6	315	65.5	
Marital status	Married	524	83.8	163	32	346	68	.752
	Not married	93	14.9	31	33.7	61	66.3	
Education	≤middle school graduates	359	57.4	98	28.2	250	71.8	.012
	High school graduates	253	40.5	94	37.9	154	62.1	
Monthly income (US, \$)	<3,000	343	54.9	96	28.9	236	71.1	.043
	≥3,000	268	42.9	97	36.9	166	63.1	
Cancer type	Breast cancer	208	33.3	73	35.4	133	64.6	.085
	Stomach cancer	105	16.8	29	28.2	74	71.8	
	Lung cancer	95	15.2	25	27.2	67	72.8	
	Colon cancer	79	12.6	17	23.3	56	76.7	
	Others	134	21.4	51	38.9	80	61.1	

Bold *P* values indicate significance (*P* < .05).

showed a positive relation (aOR, 1.70; 95% CI, 1.04-2.78). Finally, the highest need for the program was in cancer survivors who had problematic HRQOL function and symptoms (ie, cognitive function [aOR, 2.87; 95% CI, 1.34-6.17] and appetite loss [aOR, 1.77; 95% CI, 1.07-2.93,]) and those who felt much more support from the decision-making process (aOR, 0.49; 95% CI, 0.30-0.82) (Table 4).

3 | DISCUSSION

The goal of this study was to measure the perceived need for an ICT-based tailored self-management program among cancer patients, and its association with patient experience regarding information provision and the decision-making process, HRQOL measuring overall functioning and symptoms in patients, as well as regular socioeconomic status (SES), regardless of cancer type or treatment status.

There are several possible explanations for these findings. First, these findings are consistent with previous studies, which reported that the majority of cancer survivors were interested in supportive care and had a positive attitude toward self-management through online programs.^{25,26} With the fast development of the Internet and lasting mobile technology, these high needs for ICT-based personalized health care will be accelerated within the medical setting.^{25,26}

Second, perceived information provision and positive medical experience accurately predicted the need of cancer patients for ICT-based self-management programs. In our study, patients who received information about other services and ways to provide self-care showed the highest need for the ICT-based tailored program. In addition, more than one-third of the study participants expected the ICT-based self-management program to be an effective cancer-related information acquisition tool; thus, the experience of information satisfaction was connected to the real need for an ICT-based self-management program.

Because a broad range of psychological problems can exist within the decision-making process, such as anxiety and fear of cancer recurrence, effective communication with medical support may provide a

positive impact on those with the highest need for ICT-based self-management. Previous studies of the affects of social interactions and support on the acceptance of ICT technologies also demonstrated a positive relationship between decisional support and need for ICT-based programs.^{27,28} In our analysis, patients who had positive clinical experiences with the process of decision making expressed the highest need for the ICT-based tailored program^{29,30}; this suggests convincingly that patients who say they need the program very much might have had experience in receiving active medical information and greater benefits through medical treatment or services.

Third, SES could be an entry barrier to this new paradigm of self-management or to engagement in the cancer care system.¹³ In prior studies, characteristics of internet-using information seekers showed they were likely to be of a younger age and have a higher SES.^{31,32} In our study, both education status and economic status were related to having the highest need for an ICT-based health care program. This revealed a trend in ICT-based health care use and barriers,¹³ namely, patients with a much higher SES could contribute to the transition in the role of patients from passive recipients to active medical consumers of the health care market. As many mobile apps or web-based self-management have emerged as possible solutions for lowering health care costs,³³ we suggest policies that lower the barriers using ICT tools; reducing these barriers and improving the accessibility of these tools is of importance.

Finally, we observe that poor HRQOL of cancer patients can also predict the highest need for the program. From the previous study,¹² the group with a higher quality of life score, compared to the group with a lower quality of life score, was associated with a less positive attitude regarding the ICT-based self-management program. Several programs based on ICT have allowed patients to access all components of optimal factors, including immediate accessibility to patient assessment, online education, a tailored action plan, patient status monitoring, and social supports aiming at HRQOL improvement. With the development of such an ICT-based self-management program, patients can expect an improvement in their health status and HRQOL.^{8,34}

TABLE 2 Univariate analysis of correlation of patient needs for the tailored health management program with the perceived level of information provision (EORTC QLQ-INFO 26), decisional conflicts scale (DCS)

	Needs for Tailored Program						P value
	N (%)	Others		Strong Needs		OR (95% CI)	
		N = 410	65.6%	N = 195	31.2%		
EORTC QLQ-INFO 26							
Information about disease							
<66.67	345 (55.2)	227	67.8	108	32.2	1 (ref)	.916
≥66.67	276 (44.2)	182	68.2	85	31.8	0.98 (0.70-1.39)	
Information about medical tests							
<66.67	258 (41.3)	170	68.3	79	31.7	1 (ref)	.944
≥66.67	359 (57.4)	238	68.0	112	32.0	1.01 (0.71-1.44)	
Information about treatments							
<66.67	450 (72.0)	307	70.3	130	29.7	1 (ref)	.053
≥66.67	168 (26.9)	101	62.0	62	38.0	1.45 (0.99-2.11)	
Information about other services							
<66.67	513 (82.1)	348.0	69.9	150.0	30.1	1 (ref)	.033
≥66.67	103 (16.5)	59	59.0	41	41.0	1.61 (1.04-2.51)	
Information about things you can do to help yourself							
<66.67	270 (43.2)	188.0	72	73.0	28.0	1 (ref)	.075
≥66.67	355 (56.8)	222	64.5	122	35.5	1.38 (0.97-1.97)	
Wish to receive more information							
Yes	192 (30.7)	148	79.1	39	20.9	1 (ref)	<.001
No	396 (63.4)	239	62.2	145	37.8	2.30 (1.53-3.47)	
Wish you have received less information							
Yes	401(64.2)	262	74.7	99	25.3	1 (ref)	<.001
No	138 (22.1)	76	57.6	56	42.4	2.17 (1.44-3.33)	
DCS							
DCS_ uncertainty							
<25.00	113 (18.1)	64	58.2	46	41.8	1 (ref)	.024
≥25.00	497 (79.5)	338	69.5	148	30.5	0.61 (0.40-0.93)	
DCS_informed							
<25.00	82 (13.1)	46	57.5	34	42.5	1 (ref)	.039
≥25.00	531 (85.0)	360	69.6	157	30.4	0.49 (0.37-0.96)	
DCS_values clarity							
<25.00	82 (13.1)	45	55.6	36	44.4	1 (ref)	.015
≥25.00	531 (85.0)	359	69.4	158	30.6	0.55 (0.34-0.89)	
DCS_support							
<25.00	134 (21.4)	73	56.2	57	43.8	1 (ref)	.002
≥25.00	478 (76.5)	330	70.7	137	29.3	0.53 (0.36-0.79)	
DCS_effective decision							
<25.00	126 (20.2)	54	43.9	69	56.1	1 (ref)	.003
≥25.00	483 (77.3)	140	29.7	332	70.3	0.54 (0.36-0.81)	

Abbreviation: EORTC QLQ-INFO 26, the European Organization for Research and Treatment of Cancer Quality of Life Group information 26 questionnaire. In DCS of 0-100, scores lower than 25 are associated with implementing decisions.

Bold P values indicate significance ($P < .05$).

Several limitations of our study can be noted. First, there could be a selection bias. Because only 2 academic centers participated in this study, meaning that the generalization of our finding to similar groups of cancer patients may be restricted. Second, because this study is a cross-sectional study, we could not identify the actual causality. Therefore, further cohort studies or randomized controlled trials are needed

to clarify the order of the event. Third, the needs assessment questionnaire did not necessarily determine whether patients had any current experience with using web- or smartphone-based technologies and was, therefore, somewhat vague. In this study, other aspects of personality that have been or can be related to use of the Internet, with the exception of patients' personal SES, were not considered in the

TABLE 3 Univariate analysis of correlation of patients' needs for the tailored health management program with the HRQOL of EORTC QLQ-C30

	N (%)	Needs for the Tailored Program					
		Others		Strong Needs		OR (95% CI)	P value
		N = 410	65.6%	N = 195	31.2%		
Physical functioning							
>33.33	566 (90.6)	382	69.3	169	30.7	1 (ref)	
≤33.33	57 (9.1)	28	51.9	26	48.1	2.10 (1.20-3.69)	.014
Role functioning							
>33.33	497 (79.5)	334	68.7	152	31.3	1 (ref)	
≤33.33	125 (20.0)	75	63.6	43	36.4	1.26 (0.83-1.92)	.323
Emotional functioning							
>33.33	528 (85.2)	360	69.8	156	30.2	1 (ref)	
≤33.33	92 (14.8)	49	56.3	38	43.7	1.79 (1.13-2.85)	.018
Cognitive functioning							
>33.33	564 (90.2)	385	70.0	165	30.0	1 (ref)	
≤33.33	56 (9.0)	24	45.3	29	54.7	2.82 (1.59-4.98)	.001
Social functioning							
>33.33	464 (74.2)	318	70.4	134	29.6	1 (ref)	
≤33.33	155 (24.8)	90	60.0	60	40.0	1.58 (1.08-2.32)	.021
Fatigue							
<66.67	442 (70.7)	108	62.4	65	37.6	1 (ref)	.084
≥66.67	180 (28.8)	301	69.8	130	30.2	1.39 (0.96-2.02)	
Nausea and vomiting							
<66.67	561 (89.8)	373	68.4	172	31.6	1 (ref)	.245
≥66.67	61 (9.8)	36	61.0	23	39.0	1.39 (0.80-2.41)	
Pain							
<66.67	524 (83.8)	351	68.6	161	31.4	1 (ref)	.333
≥66.67	98 (15.7)	58	63.0	34	37.0	1.28 (0.81-2.03)	
Dyspnea							
<66.67	522 (83.5)	344	68.0	162	32.0	1 (ref)	.811
≥66.67	97 (15.5)	63	66.3	32	33.7	1.08 (0.68-1.72)	
Insomnia							
<66.67	444 (71.0)	303	69.7	132	30.3	1 (ref)	.118
≥66.67	175 (28.0)	104	62.7	62	37.3	1.37 (0.94-1.99)	
Appetite lose							
<66.67	468 (74.9)	320	70.2	136	29.8	1 (ref)	.042
≥66.67	152 (24.3)	89	61.0	57	39.0	1.51 (1.02-2.22)	
Constipation							
<66.67	514 (82.2)	350	69.7	152	30.3	1 (ref)	.035
≥66.67	105 (16.8)	59	58.4	42	41.6	1.64 (1.06-2.54)	
Diarrhea							
<66.67	540 (86.4)	365	69.5	160	30.5	1 (ref)	.036
≥66.67	79 (12.6)	44	57.1	33	42.9	1.71 (1.05-2.79)	
Financial difficulties							
<66.67	452 (72.3)	302	68.3	140	31.7	1 (ref)	.623
≥66.67	167 (26.7)	106	66.2	54	33.8	1.10 (0.75-1.61)	

Abbreviations: EORTC QLQ-C30, European Organization Research and Treatment of Cancer Core Quality-of-Life Questionnaire scale of 0-100, problematic functioning is indicated by a score of ≤33.33, and problematic symptoms are indicated by a score ≥ 66.67; CI, confidence interval; HRQOL, health-related quality of life; OR, odds ratio.

Bold P values indicate significance ($P < .05$) by 2-sided chi-square test

questionnaire. In the future studies, we should add more concrete questions that measure aspects related to the practical use of web-based programs and the prior experiences of patients with ICT.

In conclusion, our study provides evidence that there is a substantial perceived need for ICT-based health management programs, and patients possess diverse expectations, including acquisition of

TABLE 4 Adjusted odds ratio of the highest needs for the program by each of the independent variables from backward multiple logistic regression analysis^{a,b}

Predictors	n (%)	Highest Needs for the Program aOR ^a (95% CI)
Monthly income(USD)		
<3000	343 (54.9)	1
≥3000	268 (42.9)	1.70 (1.10-2.63)
(Info26) Information about things you can do to help yourself		
<66.66	192 (30.7)	1
≥66.67	396 (63.4)	1.71 (1.09-2.66)
(Info26) Wish to receive more information		
No	192(30.7)	1
Yes	396(63.4)	1.59 (0.97-2.61)
(Info26) Wish you have received less information		
No	401(64.2)	1
Yes	138(22.1)	1.70 (1.04-2.78)
(EQLQ-C30) Cognitive functioning		
>33.33	564 (90.2)	1
≤33.33	56 (9.0)	2.87 (1.34-6.17)
(EQLQ-C30) Appetite lost		
<66.67	468 (74.9)	1
≥66.67	152 (24.3)	1.77 (1.07-2.93)
(DCS) Support		
<25.00	134 (21.4)	1
≥25.00	478 (76.5)	0.49 (0.30-0.82)

Abbreviation: Info 26, the European Organization for Research and Treatment of Cancer Quality of Life Group information 26 questionnaire scale of 0-100; EOTRC-QLQ-30, European Organization Research and Treatment of Cancer Core Quality of Life Questionnaire scale of 0-100; DCS, decisional conflict scale of 0-100.

^aMultiple logistic regression analysis including variables identified as independent predictors that showed statistical significance in univariate analysis of correlates of needs for tailored health management program.

^bThe backward-selected multiple logistic regression model identified with stay level (sl) entry = 0.05 and sl stay = 0.10.

effective information related to cancer, improved efficacy of health care services, and convenient communication between cancer survivors and members of the medical team. Because our results highlighted personal variations in program needs and expectations among cancer patients, a tailored approach for investigating the predictive values of ICT-based self-management program needs is warranted for designing and developing a high-quality ICT-based self-management program that focuses on the engagement of cancer patients.

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CONFLICT OF INTEREST

The authors have declared no conflict of interest.

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