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# BMJ Open

## A mixed-methods investigation of health consumers' perception and experience of participation in patient safety activities

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4 **A mixed-methods investigation of health consumers' perception and experience of**  
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7 **participation in patient safety activities**

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9 Nam-Ju Lee,<sup>1,2</sup> Shinae Ahn,<sup>2</sup> Miseon Lee<sup>1</sup>  
10  
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13  
14 <sup>1</sup> College of Nursing, Seoul National University, Seoul, South Korea  
15

16 <sup>2</sup> The Research Institute of Nursing Science, Seoul National University, Seoul, South Korea  
17  
18  
19  
20

21 **Corresponding author:**  
22

23 Shinae Ahn, RN, PhD, Senior researcher  
24

25  
26 Affiliation: The Research Institute of Nursing Science, Seoul National University, Seoul,  
27  
28 South Korea  
29

30 Address: The Research Institute of Nursing Science, Seoul National University, 103 Daehak-  
31  
32 ro, Jongno-gu, Seoul, 03080, South Korea  
33

34  
35 E-mail: shinae.ahn17@gmail.com  
36

37 Telephone: 82-2-740-8494  
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## Abstract

### Objectives

This study aimed to examine the factors influencing patient safety behaviors and to describe health customers' experiences of patient participation in the healthcare system.

### Design

A mixed-methods sequential explanatory design was employed using a survey and focus group interviews with health consumers.

### Setting

The study was conducted in South Korea using the online survey tool.

### Participants

Survey data were collected from 493 adults, aged 19 years or older, who had visited hospitals within the most recent one year. Focus group interviews were conducted in 2 groups of 6 participants each among those of the survey participants who agreed to participate in interviews.

### Main outcome measures

The survey measured the extent of willingness to participate, recognition of the importance of participation, and experience of engaging in patient safety activities using a 4-point Likert scale.

### Results

The findings demonstrated a relatively strong perception of the importance of participation (Mean±SD;3.27±0.51) and low level of experience of participation (Mean±SD;2.13±0.63). Significant variables which were associated with the experience of participation included the type and frequency of visits to medical institutions, and the participant's willingness to participate. Content analysis of qualitative interview data revealed the following three themes: barriers to patient participation, facilitators of patient participation, and educational

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4 needs for improving patient participation.  
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## 6 7 **Conclusions**

8  
9 Health consumers' perception and experience of participation in patient-safety activities  
10 varied considerably. Our study provides an understanding of the factors affecting actual  
11 patient participation in patient safety activities. To improve patient participation, it is  
12 necessary to create a healthcare environment in which patients can speak comfortably and to  
13 provide an education program reflecting the patients' needs.  
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## 23 **Strengths and limitations of this study**

- 24  
25 ● This study was the first study to examine patient participation in patient safety  
26 activities in South Korea and provided evidence on what factors affect actual patient  
27 safety activities using mixed-methods.  
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- 29  
30 ● Most studies on patient participation were descriptive studies, but this study  
31 performed a regression analysis and a focus group interview to identify factors that  
32 affect patient participation in patient safety activities.  
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36 ● The results of this study can be used to develop the content of patient participation  
37 program and contribute to create a healthcare environment for patient-centered care.  
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41 ● The sample in this study was recruited through websites and social media, so the  
42 generalizability of the findings is limited.  
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## INTRODUCTION

Patient participation in health care is one strategy for improving patient safety. Patients who are more involved in their care tend to experience better health outcomes. Research shows that patients' taking an active role in their health care has positive impacts on patient safety, such as preventing errors,<sup>1</sup> safer medication management,<sup>2</sup> better self-management behavior,<sup>3</sup> and decreased use of healthcare services.<sup>4</sup>

Therefore, several international organizations have emphasized empowering patients as a key factor in ensuring patient safety and have developed educational materials to enhance patient safety and quality of care.<sup>5-9</sup> For example, the Agency for Healthcare Research and Quality has developed guidelines for patients to prevent errors and obtain safer care during hospitalization and surgery, and while taking medications.<sup>7</sup> The Joint Commission launched the Speak Up campaign to help patients and their family caregivers play active roles in care.<sup>8</sup> The National Patient Safety Foundation has created a checklist of actions patients can take to reduce harm.<sup>9</sup>

Despite the growing recognition and encouragement of patients' active role in healthcare, little is known about the factors that influence patient participation in patient safety activities. Several studies have investigated patients' willingness to participate in safety-related behaviors.<sup>10-12</sup> One study assessing patients' comfort level in performing error-prevention behaviors, showed that patients were comfortable asking general questions about medication and medical care but less comfortable asking healthcare providers about handwashing.<sup>13</sup> However, these previous studies focused more on patients' inclination to perform safety practices, and there have been few studies on what factors affect patients' actual participation behaviors and experiences. Moreover, gathering information on the factors facilitating or hindering patient participation is important. Evidence on these factors can reduce the gap between the patients' intention and actual experience of patient

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4 participation in patient safety activities because intention does not necessarily lead to actual  
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6 participation behaviors. To examine the factors influencing actual participation in various  
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8 safety practices or to investigate the relationship between intention and actual behavior, the  
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10 need for a qualitative focus group interview or a mixed method using quantitative and  
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12 qualitative approaches has been suggested<sup>10 11</sup>.  
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16 Thus, we undertook this study to: (1) investigate health consumers' willingness to  
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18 participate in safety activities, their recognition of the importance of their participation, and  
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20 their experience of participating in patient safety activities; (2) examine the factors  
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22 influencing the experience of engaging in healthcare behaviors to improve patient safety; and  
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24 (3) describe healthcare consumers' experience of patient participation in the healthcare  
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26 system.  
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## 32 **METHODS**

### 33 **Study design**

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35 This study used a mixed-methods sequential explanatory design including a survey and  
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37 focus group interviews.  
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### 43 **Participants and data collection**

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45 To investigate health consumers' perception and experience of participation in patient  
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47 safety activities, we conducted an online survey between January 25 and February 3, 2018, in  
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49 South Korea. The target population comprised adults aged 19 years or older who had visited a  
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51 medical institution within the most recent one year. We recruited participants through two  
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53 websites (Korea Alliance of Patients' Organizations (<http://www.koreapatient.com/>), and  
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55 Resources for Enhancing Safety, Competency, and Utilization for Education  
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57 (<http://patientsafety.snu.ac.kr/>) and social media. The websites posted a description of the  
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4 study and the link to the online survey. The survey was implemented using the Qualtrics  
5 online survey tool (<https://www.qualtrics.com>). A total of 493 participants completed the  
6 survey, and we excluded from the analysis the data of 1 respondent who reported being 18  
7 years old. The total sample size exceeded the minimum of 103 required for multiple linear  
8 regression, based on Cohen's statistical method (significance level  $\alpha = 0.05$ ,  $1-\beta = 0.80$ , effect  
9 size 0.15, predictors 7).

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18 Among the survey respondents, with those who agreed to participate in a focus group,  
19 focus group interviews were conducted March 20-22, 2018. The interviews were conducted  
20 in 2 groups of 6 participants each, for 2 hours with each group. The key interview questions  
21 were as follows: "What do you think about patient participation as it relates to patient  
22 safety?", "In your opinion, how important is it to you to participate in your care process and  
23 patient safety activities when you visit the hospital and receive medical care or treatment?",  
24 "To what extent do you think you can participate in patient safety activities as a patient or  
25 their caregiver?", and "How do you think patient involvement in patient safety activities  
26 could affect patient safety?".  
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## 41 **Measures**

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43 Patient participation was measured using a tool developed to measure the inclination to  
44 engage in patient safety practices.<sup>10</sup> We added 3 items from the relevant literature<sup>13 14 15</sup>  
45 (bringing a friend or family member to a doctor's appointment; telling healthcare workers  
46 about any drug allergies; reporting errors to a national reporting system if they notice errors  
47 in the hospital). Thus, the final survey tool comprised 13 items, and the questions included a  
48 list of 13 specific safety-related behaviors through which patients can engage while  
49 undergoing care in medical institutions. The survey questions were grouped into the  
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4 following three sections: the extent of willingness to participate in safety activities,  
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6 recognition of the importance of participation, and experience of engaging in such activities.  
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9 Four-point Likert scales were used to assess the extent of health consumers' willingness  
10 to participate (1=not at all, 2=somewhat likely, 3=likely, 4=very likely) and recognition of  
11 the importance of participation (1=not very important, 2=not important, 3=important, 4=very  
12 important) in patient safety activities.  
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18 Participants were asked to indicate how often they had experienced each patient safety  
19 activity in the hospital using a 4-point Likert scale (1=not at all, 2=sometimes, 3=often,  
20 4=always).  
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25 The reliability of the finalized questionnaire was evaluated using Cronbach's alpha  
26 coefficient. The Cronbach's alpha values of the three sections were 0.814, 0.900, and 0.884.  
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### 32 **Statistical analysis**

33 The quantitative data were analyzed using SPSS 24.0 (IBM Corp., Armonk, NY, USA).  
34 Participants' general characteristics and the scores of participants' willingness to participate,  
35 recognition of the importance of participation, and participation experience were summarized  
36 using descriptive statistics. An independent t-test and one-way ANOVA were used to identify  
37 differences in willingness to participate, recognition of the importance of participation, and  
38 experience of patient participation by general characteristics. For correlations between  
39 willingness to participate, recognition of the importance of participation, and experience of  
40 participation, Pearson's correlation coefficients were used. Multiple linear regression analysis  
41 was performed to identify variables associated with experience of patient participation.  
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54 The qualitative data were analyzed using conventional content analysis.<sup>16</sup> All interviews  
55 were recorded and transcribed. The collected data were written immediately after the  
56 interview, and the field notes were used for analysis. One researcher led the first analysis by  
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4 reading the transcript repeatedly, and two researchers performed a second review. Then they  
5 extracted codes, categories, and themes together during content analysis.  
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## 11 **RESULTS**

### 12 **Participant characteristics**

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15 A total of 492 completed surveys were included in the analysis. The mean age of the  
16 respondents was 31.7 years, 74.8% of respondents were female, most had graduated from  
17 college or above (n=373, 75.8%), and most were unmarried (n=310, 63.0%). The monthly  
18 income of most participants (n=174, 35.4%) was less than 850,000 won. The most frequently  
19 visited medical institutions were clinics or public health centers (n=343, 69.7%), and more  
20 than 60% of the participants had visited medical institutions less than 10 times within the  
21 most recent one year. Most of the participants (n=414, 84.1%) reported going alone when  
22 they visited medical institutions, and 65% of the participants had experienced patient safety  
23 incidents. The vast majority of the participants (n=483, 98.2%) did not know the fact that  
24 they could report patient safety incidents to the national reporting and learning system  
25 themselves (Table 1).  
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### 45 **Participation in patient safety activities**

46 This study's findings on patient safety activities included a relatively high average score  
47 for recognition of the importance of participation (3.27±0.51), but the score for experience of  
48 participation was relatively low (2.13±0.63). Respondents' experience of engaging in patient  
49 safety activities varied considerably. Some respondents reported that they always ask about  
50 the details of a procedure and the reason for a procedure before it is performed (30.5%), ask  
51 for an explanation of care that they were not told about by their doctor or nurse (22.0%), and  
52 call when they have not received the results of a medical test they underwent (23.8%). Fewer  
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4 respondents had the experience of asking healthcare workers if they had washed their hands  
5 (2.7%), bringing a friend or family member to a doctor's appointment (5.1%), or asking for  
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7 healthcare workers to confirm patient identity before performing a procedure (6.3%) (Table  
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14 The scores of respondents' willingness to participate differed significantly by education  
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16 level ( $t=-2.19, p=.029$ ), the type of accompanying caregivers ( $F=2.45, p=.045$ ), and whether  
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18 they had experienced patient safety incidents or not ( $t=-2.19, p=.029$ ). The scores on  
19  
20 recognizing the importance of participation showed significant differences according to  
21  
22 gender ( $t=-3.53, p<.001$ ) and education level ( $t=-2.27, p=.024$ ). The scores of participation  
23  
24 experience differed significantly by gender ( $t=-2.49, p=.013$ ), the type of medical institutions  
25  
26 frequently visited ( $F=5.12, p=.002$ ), the type of accompanying caregivers ( $F=3.29, p=.011$ ),  
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28 and previous experience of patient safety incidents ( $t=-3.34, p=.001$ ) (Table 3).  
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### 34 **Factors influencing experience of patient participation**

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37 The respondents' experience of patient participation showed a significant positive  
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39 correlation with willingness to participate ( $r=.63, p<.001$ ), and their recognition of the  
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41 importance of participation ( $r=.23, p<.001$ ). In addition, participants' recognition of the  
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43 importance of participation showed a significantly positive correlation with willingness to  
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45 participate ( $r=.34, p<.001$ ).  
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49 Multiple linear regression was used to examine the relationship of the experience of  
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51 patient participation with socio-demographic variables (gender, the type of medical  
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53 institution they primarily use, frequency of visits to medical institutions, type of  
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55 accompanying caregivers, and experience of patient safety incidents), recognition of the  
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57 importance of participation, and willingness to participate, with experiences of patient  
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59 participation (Table 4).  
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4 The result of the multiple linear regression showed that the patient who frequently  
5 visited a hospital ( $\beta=0.117$ ,  $p=.001$ ) and a general or advanced general hospital ( $\beta=0.077$ ,  
6  $p=.035$ ) rather than a clinic or public health center, visited medical institutions more than 25  
7 times in the most recent one year ( $\beta=0.095$ ,  $p=.013$ ) rather than less than 5 times, and had a  
8 high score on willingness to participate ( $\beta=0.600$ ,  $p<.001$ ) was expected to have more  
9 experience of participating in patient safety activities.  
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### 21 **Focus group interviews: Health consumers' experience of patient participation in** 22 **hospital care**

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25 Twelve health consumers participated in the interview. Four interviewees were male and  
26 eight were female. The average age was 40 years (range, 29 to 55 years). Ten interviewees  
27 had visited medical institutions more than 5 times in last year and six interviewees had  
28 experienced patient safety incidents. Content analysis produced nine categories extracted  
29 under three themes (Table 5).  
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#### 39 ***Barriers to patient participation***

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41 The first theme involved barriers to patient participation and consisted of three  
42 categories. Patient participation in patient safety behaviors was influenced by various factors,  
43 and they could mainly be classified into three categories: the complexity and professionalism  
44 of the healthcare environment, hierarchical relationship between the patient and medical staff,  
45 and hesitation to participate. All participants stated that the processes and procedures for  
46 receiving care were very complex in hospitals, and the time allocated to see a doctor for  
47 treatment and care is very limited. The participants reported that patients and their caregivers'  
48 access to medical information was very restricted.  
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59 A hierarchy existed between doctors and patients. Focus group members mentioned that  
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4 they felt they had not received satisfactory explanations from health care professionals, but  
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6 they also felt they could not ask a follow-up or repeat question, even if they wanted to. The  
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8 participants felt that most of the medical staff were authoritarian. When a patient asked a  
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10 doctor a question, the doctor was often annoyed and did not explain or share his or her  
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12 treatment plan. Focus group participants reported that their hesitation to participate was also  
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14 related to this hierarchical relationship between the patient and the medical staff.  
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18 The participants were worried about having any disadvantages in their care if they  
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20 pointed out healthcare providers' behaviors which could threaten patient safety. In addition,  
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22 the experience of failing in an attempt to participate undermined their willingness and made  
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24 them reluctant to get involved.  
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### 27 28 29 ***Facilitators of patient participation*** 30

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32 The second theme was related to facilitators of patient participation and consisted of two  
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34 categories: trust and empathy between the patient and healthcare provider, and perception of  
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36 the importance of patient participation. In order to improve patient safety in the care process,  
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38 it was an important step that patients established a trustworthy relationship with healthcare  
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40 providers. Explaining the details of treatment, listening to patients, and paying attention to  
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42 patients were important factors for promoting patient participation.  
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46 Some focus group members reported that patient participation in their care process  
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48 resulted in a different treatment outcome. The participants were actively involved in their  
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50 care process through patient safety behaviors such as asking for information. They reported  
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52 that their previous experience of a patient safety incident and their perception of the  
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54 importance of patient safety activities affected being more active patients. Also, some  
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56 participants perceived that safer care was provided when they participated in their care  
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58 process.  
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### ***Educational needs for improving patient participation***

The third theme we detected in our analysis was the need for education. Participants stated the need for “a variety of information on disease treatment”, “a list of questions they should ask”, “information on patient rights and responsibilities”, and “a smartphone app for patient participation”. There were various topics on which participants wanted to be educated such as disease, diagnosis, treatment, examination, medication, and error reporting. Participants thought it was important to know their rights by being informed about what patients have to do or what patients can do. They also thought it was important for patients to know what questions should be asked. The participants emphasized the necessity of obtaining comprehensible answers when asking questions of healthcare providers. They also thought that helpful information should be given to patients in a comprehensive and timely manner using an efficient medium of communication. In order to actively engage in their treatment process and understand the purpose of treatment while being in the hospital, they emphasized the need to know what is going on.

## **DISCUSSION**

This is the first study to investigate patient participation in patient safety activities in South Korea from the health consumer’s viewpoint. This study provided evidence on what factors affect actual patient safety behaviors.

This study found that the average score for experience of participation in patient safety behaviors was lower than those of willingness to participate and recognition of the importance of participation. The frequency of health consumers’ experience of participation in patient safety activities varied considerably. Among patient safety activities, the most frequently performed were asking general questions such as “the details of surgery” and “an

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4 explanation of what the patient doesn't understand". On the other hand, 'asking health care  
5 workers to wash their hands' was the patient safety behavior with the lowest average scores  
6 for intention and experience. These results were consistent with previous findings.<sup>10</sup>  
7  
8 Specifically, asking healthcare workers wash their hands has been considered a challenging  
9 behavior,<sup>11</sup> with various potential explanations proposed in previous research. Patients  
10 themselves felt uncomfortable with asking about handwashing<sup>13</sup>, and they were worried that  
11 healthcare workers might feel uncomfortable with this question.<sup>11</sup> In addition, patients  
12 thought that questioning healthcare providers about their behavior could imply criticizing  
13 their incompetence, and therefore they were reluctant to do so.<sup>10</sup> These findings might reflect  
14 that patients prefer to passively participate in their care but it also might be related to the  
15 healthcare environment where patients cannot actively communicate or raise questions and  
16 concerns with their clinicians. According to Fisher et al., nearly half of patients (48.6%) in  
17 their study had experienced a problem during hospitalization, and almost one-third (30.5%)  
18 of them reported they were not always comfortable speaking up.<sup>17</sup> Creating a healthcare  
19 environment in which patients can be comfortable raising their concerns may result in safer  
20 care and improved patient participation.<sup>17</sup> Therefore, in order for patients to perform actual  
21 patient participation activities, efforts should be made to create an environment where  
22 patients can comfortably express what they are worried about.

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46 The results of this study showed that patients who were accompanied by caregivers had  
47 experienced more willingness to participate and participation than alone. Patient and family  
48 engagement for patient advocacy has become an important component of the healthcare  
49 system. This is because family members can take on many roles, such as participating in  
50 care coordination, and helping prevent specific unsafe events or medical errors by assessing  
51 care practices in terms of consistency, accuracy, and safety.<sup>18 19</sup> Patient and family  
52 engagement also increases the likelihood that patients can better communicate their  
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4 questions and concerns with the healthcare provider, which in turn can help patients better  
5 understand and follow the treatment plan.<sup>20</sup> Therefore, increased patient and family  
6 engagement is associated with improved patient outcomes and reduced utilization of  
7 healthcare services,<sup>19</sup> and it is recommended that medical institutions also encourage not  
8 only patients but also their family members to participate in safety activities. Thus,  
9 educating patients and their families together on patient participation should be considered.  
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11 This could be a way of increasing the rate of actual patient safety activities in medical  
12 institutions.  
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23 The findings of our study showed that the types and the frequency of visiting medical  
24 institutions affected the experience of patient participation. According to Davis et al.,<sup>21</sup>  
25 severity of the patients' illness, symptoms, and treatment plan were associated with patient  
26 participation. In addition, patients' prior experience of illness led to more willingness to  
27 participate.<sup>21</sup> This may be due to the fact that patients with more experience visiting medical  
28 institutions and those visiting more advanced institutions may have more severe illness and  
29 will be likely to be exposed to higher-risk situations such as testing, drugs, and surgery, all of  
30 which call for patient safety activities. It can also be inferred that patients who have  
31 experienced many hospital visits might perceive themselves as playing a more important role  
32 in the care process.  
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46 The results of the focus group interviews showed that patient participation in medical  
47 institutions appeared to be influenced by three factors: the healthcare environment, the  
48 relationship between the patient and the healthcare provider, and the patient's personal  
49 capacity. A complex care process, time constraints, and restricted access to medical  
50 information were healthcare environmental factors hindering patient participation. A  
51 qualitative study conducted with patients and nursing staff members found similar results:  
52 that patients felt that healthcare providers were too busy asking questions or talking.<sup>22</sup>  
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4 Patients and families may feel overwhelmed by the healthcare system and highly technical  
5 information.<sup>18 23</sup>  
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9 Most patients felt that the relationship between patients and healthcare providers was  
10 hierarchical, which was one of the barriers to participation. Patients can be motivated to  
11 participate in patient safety activities through open communication, empathy, and positive  
12 feedback from healthcare providers. According to Maurer et al.,<sup>18</sup> healthcare providers'  
13 reactions can be a barrier to patient participation, while their active invitation for patients to  
14 participate can be a facilitator. Thus, healthcare providers must support and guide patients to  
15 participate. Even if patients are willing to participate in safety activities, they might be  
16 uncertain about how to be involved. Although patients are on a continuum of care, they  
17 cannot be familiar with all parts of the care process. Therefore, healthcare providers may  
18 better involve patients in their care plan by communicating about care processes such as  
19 diagnosis and treatment with patients.  
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34 Healthcare providers must consider developing and implementing effective education  
35 for patients to increase patients' willingness to ask challenging questions, and to reduce the  
36 gap among perceived importance of participation, willingness to participate, and experience  
37 of patient participation. Patient education can help to increase patients' knowledge and  
38 positively affect their attitude toward safety practices.<sup>24</sup> In this study's findings, health  
39 consumers wanted education programs focusing on "a question list they can ask health  
40 professionals", "patient rights and responsibilities", and "a variety of information related to  
41 treatment including disease and diagnosis, and medication". Thus, to enhance patient  
42 participation in safety activities in medical institutions, development of an education program  
43 reflecting patients' educational needs is suggested. Our findings also suggest intervention  
44 studies educating patients through an easy-to-use mobile app. A mobile app can be a useful  
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4 tool for conveniently providing health consumers with information on patient participation  
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6 and to enhance their knowledge about patient safety.  
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9 This study had several limitations. First, the study was based on health consumers' self-  
10 reports on their participation in patient safety practices, so these self-reported data may not  
11 accurately reflect their actual practices in medical institutions. Second, the sample was  
12 recruited through websites and social media, so the young and well-educated population  
13 might have accounted for a large proportion of the sample. Thus, it may not be generalizable  
14 to all patient groups.  
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## 25 CONCLUSION

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27 Health consumers' patient safety activities in the hospital varied. Participants reported  
28 more experience with patient safety activities aimed to inform themselves, whereas they  
29 expressed less experience with more challenging patient safety actions, such as asking  
30 healthcare providers to wash their hands. There were differences among patients' perceived  
31 importance of their participation, willingness to participate, and their actual experience of  
32 participation in patient safety activities. Future research needs to be conducted to narrow  
33 these gaps using efficient educational methods. The results of this study can be used as a  
34 reference for developing educational content for patients. Healthcare providers may play an  
35 important role in encouraging patients to involve themselves in patient safety practices by  
36 offering education and encouragement to patients. Strategies are needed to give participation  
37 opportunities to patients during their care, and efforts should be made to create a healthcare  
38 environment in which patients and healthcare providers can participate together to improve  
39 patient safety.  
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## Contributors

NL and SA conceived and designed the study. NL, SA and ML performed the cross-section study. NJ and SA carried out the statistical analysis. NJ, SA and ML conducted qualitative research. NL, SA and ML wrote the paper. NL, SA and ML reviewed and edited the manuscript. All authors read and approved the manuscript..

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## Competing interests

None declared

## Data availability statement

No data are available.

## Ethics approval

This study was approved by the Institute Review Board of Seoul National University (No. No. 1801/003-007) and all study participants provided informed consent.

## Patient consent for publication

Not required.

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Table 1. General Characteristics of Participants (N=492)

| Characteristics  | Categories                           | n (%)      |
|--|--------------------------------------|------------|
| Age  | 19-29                                | 270 (54.9) |
|  | 30-39                                | 123 (25.0) |
|  | 40-49                                | 57 (11.6)  |
|  | 50-                                  | 42 (8.5)   |
| Gender   | Female                               | 368 (74.8) |
|  | Male                                 | 124 (25.2) |
| Educational level  | High school diploma or below         | 119 (24.2) |
|  | Bachelor's degree or above           | 373 (75.8) |
| Marital status   | Single                               | 310 (63.0) |
|  | Married                              | 176 (35.8) |
|  | Divorced                             | 5 (1.0)    |
|  | Bereaved                             | 1 (0.2)    |
| Monthly income (KRW)   | <850,000                             | 174 (35.4) |
|  | 850,000-<1500,000                    | 51 (10.3)  |
|  | 1500,000-<2500,000                   | 91 (18.5)  |
|  | 2500,000-<3500,000                   | 77 (15.7)  |
|  | 3500,000-<4500,000                   | 43 (8.7)   |
|  | 4500,000-<5500,000                   | 23 (4.7)   |
|  | 5500,000-<6500,000                   | 7 (1.4)    |
| Types of medical institutions frequently visited   | 6500,000-                            | 26 (5.3)   |
|  | Clinic or public health center       | 343 (69.7) |
|  | Hospital                             | 68 (13.8)  |
|  | General or Advanced general hospital | 79 (16.1)  |
| Number of visits to medical institutions   | Others                               | 2 (0.4)    |
|  | <5                                   | 165 (33.5) |
|  | 5-<10                                | 176 (35.8) |
|  | 10-<15                               | 80 (16.3)  |
|  | 15-<20                               | 40 (8.1)   |
|  | 20-<25                               | 15 (3.0)   |
| Types of accompanying caregivers   | 25-                                  | 16 (3.3)   |
|  | Alone                                | 414 (84.1) |
|  | Spouse                               | 19 (3.9)   |
|  | Children                             | 23 (4.7)   |
|  | Parents (Father or Mother)           | 31 (6.3)   |
| Experience of patient safety incidents   | Others                               | 5 (1.0)    |
|  | Yes                                  | 320 (65.0) |
| Do you know the fact that you can directly report to the patient safety reporting and learning system? | No                                   | 172 (35.0) |
|  | Yes                                  | 9 (1.8)    |
|  | No                                   | 483 (98.2) |



Table 2. Extent of Willingness to Participate, Recognition of Its Importance, and Experience of Participation in Patient Safety Activities

(N=492)

| Patient participation practices  | Engaging in health care behaviors |                           |                             | Frequency of participation |            |            |            |
|--|-----------------------------------|---------------------------|-----------------------------|----------------------------|------------|------------|------------|
|  | Extent of willingness             | Recognition of importance | Experience of participation | Always                     | Often      | Sometimes  | Not at all |
|  | M±SD                              |                           |                             | n (%)                      |            |            |            |
| Seeking a second opinion regarding an important healthcare decision  | 2.70±0.97                         | 3.23±0.71                 | 2.07±0.89                   | 38 (7.7)                   | 98 (19.9)  | 217 (44.1) | 139 (28.3) |
| Asking healthcare workers to explain more fully something they just said that I do not understand  | 3.19±0.80                         | 3.47±0.65                 | 2.58±0.84                   | 73 (14.8)                  | 177 (36.0) | 202 (41.1) | 40 (8.1)   |
| Bringing a friend or family member to a doctor's appointment so that they can help ask questions and understand what the doctor was telling me | 2.19±0.90                         | 2.73±0.84                 | 1.84±0.86                   | 25 (5.1)                   | 75 (15.2)  | 187 (38.0) | 205 (41.7) |
| Asking healthcare workers if they washed their hands   | 1.43±0.76                         | 2.96±0.84                 | 1.37±0.74                   | 13 (2.7)                   | 39 (7.9)   | 64 (13.0)  | 376 (76.4) |
| Telling healthcare workers about any drug allergies when they did not ask for this information   | 3.08±1.02                         | 3.55±0.69                 | 2.22±1.10                   | 82 (16.7)                  | 118 (24.0) | 118 (24.0) | 174 (35.4) |
| Asking healthcare workers to confirm your identity before performing a procedure   | 2.05±1.02                         | 3.20±0.84                 | 1.64±0.94                   | 31 (6.3)                   | 65 (13.2)  | 91 (18.5)  | 305 (62.0) |
| Asking healthcare workers about the details of a procedure and the   | 3.31±0.82                         | 3.55±0.67                 | 2.88±0.95                   | 150 (30.5)                 | 178 (36.2) | 120 (24.4) | 44 (8.9)   |

reason for a procedure before it is performed

|   |           |           |           |            |            |            |            |
|---|-----------|-----------|-----------|------------|------------|------------|------------|
| Asking healthcare workers to explain care, such as an X-ray or drawing blood, that I was not told about by my doctor or nurse | 2.86±0.95 | 3.43±0.72 | 2.50±1.04 | 108 (22.0) | 125 (25.4) | 164 (33.3) | 95 (19.3)  |
| Calling a healthcare worker when I undergo medical tests ordered and no one calls me with the results                         | 3.29±0.83 | 3.40±0.70 | 2.50±1.10 | 117 (23.8) | 129 (26.2) | 127 (25.8) | 119 (24.2) |
| Taking a written list of all the medications I'm currently taking when going to the doctor                                    | 2.34±1.07 | 3.22±0.80 | 2.02±1.03 | 55 (11.2)  | 102 (20.7) | 132 (26.8) | 203 (41.3) |
| Questioning medications or pills if I did not recognize them and never took this medication in the past                       | 2.82±0.98 | 3.33±0.77 | 2.35±1.05 | 85 (17.3)  | 131 (26.6) | 149 (30.3) | 127 (25.8) |
| Checking that I received the right drug and strength before leaving the pharmacy  | 2.30±1.10 | 3.22±0.81 | 2.09±1.09 | 76 (15.5)  | 86 (17.5)  | 134 (27.2) | 196 (39.8) |
| Reporting the errors I noticed had occurred in the hospital to a national reporting system                                    | 2.51±0.96 | 3.20±0.80 | 1.70±0.99 | 40 (8.1)   | 71 (14.4)  | 84 (17.1)  | 297 (60.4) |
| Total   | 2.62±0.52 | 3.27±0.51 | 2.13±0.63 |            |            |            |            |

Table 3. Difference in Extent of Willingness to Participate, Recognition of Its Importance, and Experience of Participation by General Characteristics (N=492)

| Sociodemographic characteristics | Subgroup                     | n (%)      | Extent of Willingness |              | Recognition of Importance |               | Experience of Participation |              |
|----------------------------------|------------------------------|------------|-----------------------|--------------|---------------------------|---------------|-----------------------------|--------------|
|                                  |                              |            | M±SD                  | t or F(p)    | M±SD                      | t or F(p)     | M±SD                        | t or F(p)    |
| Age group                        | 19-29                        | 270 (54.9) | 2.58±0.51             | 1.28 (.281)  | 3.25±0.51                 | 1.23 (.297)   | 2.10±0.63                   | 1.45 (.227)  |
|                                  | 30-39                        | 123 (25.0) | 2.66±0.52             |              | 3.33±0.50                 |               | 2.11±0.59                   |              |
|                                  | 40-49                        | 57 (11.6)  | 2.69±0.52             |              | 3.29±0.43                 |               | 2.25±0.65                   |              |
|                                  | 50-                          | 42 (8.5)   | 2.67±0.59             |              | 3.16±0.65                 |               | 2.25±0.73                   |              |
| Gender                           | Female                       | 368 (74.8) | 2.64±0.52             | -1.72 (.086) | 3.32±0.51                 | -3.53 (<.001) | 2.18±0.64                   | -2.49 (.013) |
|                                  | Male                         | 124 (25.2) | 2.55±0.52             |              | 3.13±0.51                 |               | 2.01±0.59                   |              |
| Educational level                | High school diploma or below | 119 (24.2) | 2.53±0.50             | -2.19 (.029) | 3.18±0.53                 | -2.27 (.024)  | 2.05±0.58                   | -1.80 (.074) |
|                                  | Bachelor's degree or above   | 373 (75.8) | 2.65±0.53             |              | 3.30±0.50                 |               | 2.16±0.65                   |              |
| Marital status                   | Single                       | 310 (63.0) | 2.59±0.51             | 2.05 (.130)  | 3.26±0.50                 | 0.05 (.948)   | 2.10±0.62                   | 1.98 (.139)  |
|                                  | Married                      | 176 (35.8) | 2.68±0.54             |              | 3.28±0.54                 |               | 2.21±0.65                   |              |
|                                  | Divorced & Bereaved          | 6 (1.2)    | 2.37±0.42             |              | 3.27±0.30                 |               | 1.96±0.63                   |              |
| Monthly income (KRW)             | <850,000                     | 174 (35.4) | 2.61±0.51             | 0.77 (.616)  | 3.23±0.51                 | 0.82 (.570)   | 2.10±0.62                   | 0.53 (.811)  |
|                                  | 850,000-<1500,000            | 51 (10.3)  | 2.49±0.53             |              | 3.22±0.63                 |               | 2.09±0.63                   |              |
|                                  | 1500,000-<2500,000           | 91 (18.5)  | 2.66±0.53             |              | 3.31±0.52                 |               | 2.19±0.68                   |              |
|                                  | 2500,000-<3500,000           | 77 (15.7)  | 2.63±0.53             |              | 3.31±0.47                 |               | 2.15±0.62                   |              |
|                                  | 3500,000-<4500,000           | 43 (8.7)   | 2.72±0.51             |              | 3.39±0.43                 |               | 2.18±0.64                   |              |
|                                  | 4500,000-<5500,000           | 23 (4.7)   | 2.62±0.50             |              | 3.21±0.43                 |               | 2.01±0.40                   |              |
|                                  | 5500,000-<6500,000           | 7 (1.4)    | 2.53±0.65             |              | 3.13±0.61                 |               | 2.07±0.86                   |              |
| 6500,000-                        | 26 (5.3)                     | 2.63±0.58  |                       | 3.23±0.50    |                           | 2.26±0.71     |                             |              |

|  |                                      |            |           |              |           |              |           |              |
|--|--------------------------------------|------------|-----------|--------------|-----------|--------------|-----------|--------------|
| Types of medical institutions frequently visited | Clinic or public health center       | 343 (69.7) | 2.60±0.51 | 1.41 (.240)  | 3.27±0.50 | 1.02 (.384)  | 2.06±0.60 | 5.12 (.002)  |
|  | Hospital                             | 68 (13.8)  | 2.59±0.57 |              | 3.19±0.59 |              | 2.27±0.71 |              |
|  | General or advanced general hospital | 79 (16.1)  | 2.73±0.53 |              | 3.32±0.48 |              | 2.32±0.64 |              |
|  | Others                               | 2 (0.4)    | 2.38±0.33 |              | 3.54±0.54 |              | 2.46±0.76 |              |
| Number of visits to medical institutions         | <5                                   | 165 (33.5) | 2.61±0.55 | 0.86 (.509)  | 3.26±0.43 | 0.55 (.738)  | 2.08±0.66 | 1.88 (.096)  |
|  | 5-<10                                | 176 (35.8) | 2.60±0.49 |              | 3.26±0.53 |              | 2.10±0.61 |              |
|  | 10-<15                               | 80 (16.3)  | 2.62±0.57 |              | 3.23±0.57 |              | 2.20±0.62 |              |
|  | 15-<20                               | 40 (8.1)   | 2.67±0.46 |              | 3.39±0.59 |              | 2.20±0.56 |              |
|  | 20-<25                               | 15 (3.0)   | 2.86±0.52 |              | 3.26±0.69 |              | 2.23±0.82 |              |
|  | 25-                                  | 16 (3.3)   | 2.69±0.42 |              | 3.30±0.37 |              | 2.51±0.48 |              |
| Types of accompanying caregivers                 | Alone                                | 414 (84.1) | 2.59±0.52 | 2.45 (.045)  | 3.25±0.52 | 1.09 (.362)  | 2.09±0.63 | 3.29 (.011)  |
|  | Spouse                               | 19 (3.9)   | 2.81±0.54 |              | 3.35±0.55 |              | 2.47±0.61 |              |
|  | Children                             | 23 (4.7)   | 2.88±0.52 |              | 3.45±0.40 |              | 2.32±0.61 |              |
|  | Parents                              | 31 (6.3)   | 2.68±0.48 |              | 3.27±0.51 |              | 2.31±0.57 |              |
|  | Others                               | 5 (1.0)    | 2.72±0.41 |              | 3.45±0.48 |              | 2.46±0.62 |              |
| Experience of patient safety incidents           | No                                   | 320 (65.0) | 2.58±0.54 | -2.19 (.029) | 3.24±0.53 | -1.88 (.061) | 2.07±0.62 | -3.34 (.001) |
|  | Yes                                  | 172 (35.0) | 2.69±0.49 |              | 3.33±0.48 |              | 2.26±0.63 |              |

Table 4. Factors Influencing the Experience of Patient Participation (N=492)

| Variables   | Beta   | t      | p value |
|---|--------|--------|---------|
| (Constant)  |        | -0.110 | 0.913   |
| Willingness to participate                            | 0.600  | 16.413 | <.001   |
| Recognition of importance of patient participation    | 0.020  | 0.527  | .595    |
| Gender  |        |        |         |
| Male  | Ref.   |        |         |
| Female  | 0.037  | 1.021  | .308    |
| Medical institutions frequently visited               |        |        |         |
| Clinic or public health center                        | ref.   |        |         |
| Hospital  | 0.117  | 3.287  | .001    |
| General or advanced general hospital                  | 0.077  | 2.113  | .035    |
| Others  | 0.019  | 0.525  | .600    |
| Number of visits to medical institutions in last year |        |        |         |
| -<5   | Ref.   |        |         |
| 5-<10   | 0.024  | 0.611  | .542    |
| 10-<15  | 0.058  | 1.493  | .136    |
| 15-<20  | 0.018  | 0.492  | .623    |
| 20-<25  | -0.003 | -0.072 | .942    |
| 25-   | 0.095  | 2.498  | .013    |
| Types of accompanying caregivers                      |        |        |         |
| Alone   | ref    |        |         |
| Spouse  | 0.062  | 1.766  | .078    |
| Children  | 0.008  | 0.218  | .827    |
| Parent  | 0.025  | 0.691  | .490    |
| Others  | 0.035  | 0.992  | .322    |
| Experience of patient safety incidents                |        |        |         |
| No  | ref    |        |         |
| Yes   | 0.065  | 1.849  | .065    |

F= 23.19 (p<.001); Adjusted R<sup>2</sup>=0.42.

Table 5. Themes, categories, and codes

| Theme                             | Category  | Code                                    | Quotes   |
|-----------------------------------|---|---|--|
| Barriers to patient participation | Complexity and professionalism of the healthcare environment    | Complex care procedures                 | It was exhausting for a patient to meet new medical staff every 2 or 3 minutes, and it was hard for me to share my problems deliberately. When talking to the final medical staff, a chief surgeon who was charge of my surgery, I was very fatigued so I couldn't think of what to say. (Participant 1, Group 1)        |
|                                   |   | Limited time to see a doctor            | My doctor is too busy. I have almost no chance to talk to him, because usually another patient is waiting when I'm seeing the doctor. So I can't discuss things fully with my doctor though I'd like to ask questions and get answers. (Participant 2, Group 1)  |
|                                   |   |   | We just took it for granted that we only listened to a doctor very briefly in the hospital, because a very limited time was allocated to us. (Participant 6, Group 1)  |
|                                   |   | Limited access to medical information   | Generally speaking, I think the medical system is too closed and patients are restricted from accessing their medical information. (Participant 6, Group 1)  |
|                                   |   |   | The medical system is so professional, and it is not accessible to me. (Participant 4, Group 2)  |
|                                   | Hierarchical relationship between the patient and medical staff | Authoritative attitude of medical staff | When I asked what I didn't understand one more time, the doctor responded with a high and angry tone. After experiencing that, although I didn't catch what he said, I didn't ask him and instead asked other medical staff because I already knew what his response would be if I asked again. (Participant 3, Group 2) |

|                                       |   |   |  |
|---------------------------------------|---|---|--|
|                                       |   | Failure to share treatment plan with the patient            | In the process of my treatment, I didn't feel a sense of care from any doctor or nurse. This is because they only checked over my data and wrote prescriptions, and asked about my current physical state. I had the same experience over and over. (Participant 4, Group 2)   |
|                                       |   | Lack of communication between medical staff and the patient | I haven't felt that I was able to fully ask questions or get satisfactory answers. (Participant 6, Group 1)  |
|                                       | Hesitation to participate                                       | Concerns about having any disadvantages in treatment        | Foremost, I'm afraid of having any disadvantage on my treatment, like snubbing me after I ask questions. (Participant 6, Group 2)<br><br>Feeling on that he doesn't put an effort into, or pay attention during, my treatment. (Participant 4, Group 2)  |
|                                       |   | Experience of failing in an attempt to participate          | When trying to participate in expressing my opinion as a patient, ... If a doctor had explained whether my opinion was right or not, and its reason, even if my opinion was not right, I could have felt a sense of trust in him. Some doctors insisted that their treatment method was definitely right and then I no longer felt willing to participate. (Participant 2, Group 1)  |
| Facilitators of patient participation | Rapport and empathy between a patient and a healthcare provider | Attention on a patient and endeavor to communicate          | It is important for the two of us, a doctor and me, to have mutual trust and discuss my treatment plan together. (Participant 6, Group 1)<br><br>One doctor abrasively listened to me, not my father-in-law, because he couldn't communicate well, and gave only a routine prescription. On the other hand, another doctor tried to talk directly to my father-in-law in detail, and then, to verify, asked me, "He seemed to express such-and-such. Did you find he had the |

|   |   |   |  |
|---|---|---|--|
|   |   |   | same symptoms at home?" and explained his conclusions to me in detail. I was able to trust that doctor more. (Participant 1, Group 1)  |
|   | Perception of the necessity of patient participation    | Perception of the importance of patient participation | The treatment outcome seems to be different depending on whether I participated in patient safety activities or not. (Participant 2, Group 1)  |
|   |   | Previous experience of a patient safety incident      | I really wanted to hear: "Sorry, we made a mistake with the medication for your daughter. So, we took this kind of action after the incident." But they didn't apologize and didn't take any follow-up action. After this incident, I strongly realized the importance of patient safety and the family's participation. (Participant 6, Group 2)  |
| Educational needs for improving patient participation | Providing a variety of information on disease treatment | Contextual information                                | I need information on what I can do and check specifically depending on the situation. (Participant 2, Group 2)  |
|   |   | Disease and diagnosis                                 | I think it would be nice if I could get an app that suggests a potential diagnosis after inputting my age and symptoms and so on. Because I can ask a doctor, "In my opinion, my symptom is A, isn't it?" A doctor may miss the exact diagnosis owing to being busy, right? So, in that case, if I know the information on my symptoms and talk to him, then he can consider the diagnosis and go forward with his treatment plan in the right direction. (Participant 2, Group 1) |
|   |   | Medication  | When I get the medicine at the pharmacy, the information about that medicine is written on the medicine packet, and I think this is very useful for patients. (Participant 2, Group 2)   |
|   | Providing a list of questions                           | List of questions to ask for participation            | I think it's pretty important to know what questions I can ask. If I have a list of things to look out for and   |



|   |  |   |
|---|--|---|
|   |  | check, it is easy for me to get more involved. (Participant 4, Group 1)   |
| Providing information about patients' obligation and rights | Patients' obligation and rights  | It would be great to have some manual or simple reminder on what I have to do in the hospital, informing me: "Oh, I could have done this. I could have asked for this. I should have talked about this to healthcare providers." (Participant 5, Group 1) |
|   |  | I want to know what kinds of rights patients have. (Participant 6, Group 2)   |
| Need for apps enabling patient participation                | App with disease information   | It would be nice if there were an app for obtaining appropriate information after I directly input my information, such as symptoms or diseases in it, instead of asking a nurse on call. (Participant 1, Group 2)  |
|   | App from which patients can find appropriate information by themselves | I thought it would be great if there were apps through which I could participate and get information for myself. (Participant 6, Group 1)   |
|   | App for error reporting  | The most important thing is to report errors. An application should be developed that we can use to report errors. (Participant 2, Group 2)   |

**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

| Section/Topic                | Item # | Recommendation   | Reported on page # |
|------------------------------|--------|--|--------------------|
| <b>Title and abstract</b>    | 1      | (a) Indicate the study's design with a commonly used term in the title or the abstract   | #1-2               |
|                              |        | (b) Provide in the abstract an informative and balanced summary of what was done and what was found  | #2-3               |
| <b>Introduction</b>          |        |  |                    |
| Background/rationale         | 2      | Explain the scientific background and rationale for the investigation being reported   | #4-5               |
| Objectives                   | 3      | State specific objectives, including any prespecified hypotheses   | #5                 |
| <b>Methods</b>               |        |  |                    |
| Study design                 | 4      | Present key elements of study design early in the paper  | #5                 |
| Setting                      | 5      | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection  | #5-6               |
| Participants                 | 6      | (a) Give the eligibility criteria, and the sources and methods of selection of participants  | #5-6               |
| Variables                    | 7      | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable   | #6-7               |
| Data sources/<br>measurement | 8*     | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | #6-7               |
| Bias                         | 9      | Describe any efforts to address potential sources of bias  | NA                 |
| Study size                   | 10     | Explain how the study size was arrived at  | #6                 |
| Quantitative variables       | 11     | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why   | #7-8               |
| Statistical methods          | 12     | (a) Describe all statistical methods, including those used to control for confounding  | #7-8               |
|                              |        | (b) Describe any methods used to examine subgroups and interactions  | #7-8               |
|                              |        | (c) Explain how missing data were addressed  | #6                 |
|                              |        | (d) If applicable, describe analytical methods taking account of sampling strategy   | #5-6               |
|                              |        | (e) Describe any sensitivity analyses  | NA                 |
| <b>Results</b>               |        |  |                    |

|                          |     |  |                |
|--------------------------|-----|--|----------------|
| Participants             | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed            | #8             |
|                          |     | (b) Give reasons for non-participation at each stage   | NA             |
|                          |     | (c) Consider use of a flow diagram   | NA             |
| Descriptive data         | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders   | #8-10          |
|                          |     | (b) Indicate number of participants with missing data for each variable of interest  | #6             |
| Outcome data             | 15* | Report numbers of outcome events or summary measures   | #8-10, #21-26  |
| Main results             | 16  | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | #8-10, #21-26  |
|                          |     | (b) Report category boundaries when continuous variables were categorized  | #8-10, #21-26  |
|                          |     | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period   | NA             |
| Other analyses           | 17  | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses   | #10-12, #27-30 |
| <b>Discussion</b>        |     |  |                |
| Key results              | 18  | Summarise key results with reference to study objectives   | #12-16         |
| Limitations              | 19  | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias   | #16            |
| Interpretation           | 20  | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence                                   | #12-16         |
| Generalisability         | 21  | Discuss the generalisability (external validity) of the study results  | #12-16         |
| <b>Other information</b> |     |  |                |
| Funding                  | 22  | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based  | #17            |

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

# BMJ Open

## A mixed-methods investigation of health consumers' perception and experience of participation in patient safety activities

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6 1 **A mixed-methods investigation of health consumers' perception and experience of**  
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8 2 **participation in patient safety activities**

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10 3 Nam-Ju Lee,<sup>1,2</sup> Shinae Ahn,<sup>2</sup> Miseon Lee<sup>1</sup>

11  
12 4  
13  
14  
15 5 <sup>1</sup> College of Nursing, Seoul National University, Seoul, South Korea

16  
17 6 <sup>2</sup> The Research Institute of Nursing Science, Seoul National University, Seoul, South Korea  
18  
19  
20  
21 7

22 8 **Corresponding author:**

23  
24  
25 9 Shinae Ahn, RN, PhD, Senior researcher

26  
27 10 Affiliation: The Research Institute of Nursing Science, Seoul National University, Seoul,  
28

29  
30 11 South Korea

31  
32 12 Address: The Research Institute of Nursing Science, Seoul National University, 103 Daehak-  
33  
34 13 ro, Jongno-gu, Seoul, 03080, South Korea

35  
36 14 E-mail: shinae.ahn17@gmail.com

37  
38 15 Telephone: 82-2-740-8494  
39  
40  
41 16

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## 1 **Abstract**

### 2 **Objectives**

3 This study aimed to examine the factors influencing patient safety behaviors and to explore  
4 health customers' experiences of patient participation in the healthcare system.

### 5 **Design**

6 A mixed-methods sequential explanatory design was employed using a survey and focus  
7 group interviews with health consumers.

### 8 **Setting**

9 The study was conducted in South Korea using an online survey tool.

### 10 **Participants**

11 Survey data were collected from 493 Korean adults, aged 19 years or older, who had visited  
12 hospitals within the most recent one year. Focus group interviews were conducted in 2 groups  
13 of 6 participants each among those of the survey participants who agreed to participate in  
14 interviews.

### 15 **Main outcome measures**

16 The survey measured the extent of willingness to participate, recognition of the importance of  
17 participation, and experience of engaging in patient safety activities using a 4-point Likert  
18 scale. Qualitative data were collected through focus group interviews to explore health  
19 consumers' experience of patient participation in hospital care, and the data were analyzed  
20 using content analysis.

### 21 **Results**

22 The average score for experience of participation in patient safety behaviors was found to be  
23 lower than those of willingness to participate and recognition of the importance of  
24 participation. By integrating the results of the quantitative and qualitative data analysis, the

1 factors associated with the experience of engaging in healthcare behavior included patient-  
2 related factors, illness-related factors, factors involving relationship between patients and  
3 healthcare providers, and healthcare environment factors.

#### 4 **Conclusions**

5 To improve patient participation, it is necessary to create a healthcare environment in which  
6 patients can speak comfortably and to provide an education program reflecting the patients'  
7 needs. Also, healthcare providers must consider patients as partners for patient safety. Shared  
8 decision-making procedures and patient-centered care and patient safety policies should be  
9 established in hospitals.

#### 11 **Strengths and limitations of this study**

- 12 ● This study was the first to examine patient participation in patient safety activities in  
13 South Korea and provided evidence on what factors affect actual patient safety  
14 activities using mixed methods.
- 15 ● Most studies on patient participation have been descriptive studies, but this study  
16 performed a regression analysis and a focus group interview to identify factors that  
17 affect patient participation in patient safety activities, and finally, integrated the  
18 results of both quantitative and qualitative data.
- 19 ● The results of this study can be used to develop the content of patient participation  
20 programs and contribute to creating a patient-centered healthcare environment.
- 21 ● The sample in this study was recruited through websites and social media, so the  
22 generalizability of the findings is limited.



## 1 INTRODUCTION

2 Patient participation in health care is one strategy for improving patient safety. Patients  
3 who are more involved in their care tend to experience better health outcomes. Research  
4 shows that patients' taking an active role in their health care has positive impacts on patient  
5 safety, such as preventing errors,<sup>1</sup> safer medication management,<sup>2</sup> better self-management  
6 behavior,<sup>3</sup> and decreased use of healthcare services.<sup>4</sup>

7 The concept of patient participation is defined as the desire and capability to actively  
8 participate in care.<sup>5</sup> To enhance patient participation for patient safety, it is important to  
9 encourage patients to participate in patient safety activities while receiving care in medical  
10 institutions. The safety activities that patients could participate in can be classified into four  
11 types (speaking up, asking questions, finding health information, and engaging in the  
12 healthcare process). Patients can speak up if they have questions or concerns about their  
13 needs, preferences, and ideas (eg, asking a healthcare provider whether they have washed  
14 their hands can contribute to a patient's safe treatment).<sup>6,7</sup> Patients should ask questions and  
15 ask about their own health status if anything is unclear in their care process (eg, asking what  
16 the patient's health problem is),<sup>8</sup> seek information about their care (eg, asking for resources  
17 and websites where patients can learn),<sup>6</sup> and participate in all decisions about their treatment  
18 through a shared decision-making process (eg, the patient sharing their needs, symptoms, and  
19 wishes in order to make healthcare decisions together with their healthcare providers).<sup>8,9</sup>

20 Given the growing recognition and encouragement of patients' active role in health care,  
21 several international organizations have developed educational materials to increase patient  
22 participation to promote patient safety and quality of care.<sup>10-14</sup> In the United States, the  
23 Agency for Healthcare Research and Quality has developed guidelines for patients to prevent  
24 errors and obtain safer care,<sup>12</sup> the Joint Commission launched the Speak Up campaign to help

1 patients and their family caregivers play active roles in care,<sup>13</sup> and the National Patient Safety  
2 Foundation has created a checklist of actions patients can take to reduce harm.<sup>14</sup> The  
3 Canadian Patient Safety Institute in Canada has suggested strategies and evidence-based  
4 guidance on engaging patients in patient safety.<sup>6</sup> Also, the Australian Commission on Safety  
5 and Quality in Health care in Australia has developed a booklet to support patients being  
6 actively involved in their care.<sup>11</sup>

7       While the guidelines and materials for patients have been developed, there is a lack of  
8 evidence on the extent of patients' actual experience of participating in patient safety  
9 activities. Several studies have investigated patients' willingness to participate in safety-  
10 related behaviors by quantitative method using surveys.<sup>15-17</sup> However, these previous studies  
11 focused more on patients' inclination to perform safety practices, and there have been few  
12 studies on patients' actual participation experiences using quantitative data. One descriptive  
13 study assessing patients' experience in performing error-prevention behaviors while  
14 hospitalized, showed that patients experienced asking general questions about the purpose of  
15 medication (75.2%) and medical care (85.1%) but had less experience asking healthcare  
16 providers about handwashing (4.6%).<sup>18</sup> Patients who are more comfortable engaging in  
17 safety-related behaviors are more likely to participate in safety activities.<sup>18</sup>

18       Moreover, gathering information on what factors affect patient participation is  
19 important. Some studies have described patients' perception of participation in patient safety  
20 by qualitative method through interviews.<sup>19-21</sup> Some factors were found to negatively affect  
21 patients' participation in their care, such as fear of reprisals from staff, an inability to provide  
22 feedback to staff, and a perception that safety is generally not patients' priority.<sup>19</sup> On the  
23 other hand, feeling connected with their healthcare provider, having an opportunity to provide  
24 feedback on experiences of safety, and sharing responsibility positively affected patient

1 participation.<sup>19-21</sup> Evidence on these factors affecting patient participation can reduce the gap  
2 between the patients' intention and actual experience of patient participation in patient safety  
3 activities because intention does not necessarily lead to actual participation behaviors.

4 A mixed-methods design has the advantage of not only producing a measure of  
5 experience of participation but also deeply exploring patients' perspectives about patient  
6 participation. However, there is a lack of studies focusing on patient participation using  
7 mixed methods. To examine the factors influencing actual participation in various safety  
8 practices or to investigate the relationship between intention and actual behavior, the need for  
9 a qualitative focus group interview or a mixed method using quantitative and qualitative  
10 approaches has been suggested.<sup>15 16</sup>

11 Thus, in this study, we investigated health consumers' extent of willingness to  
12 participate in safety activities, their recognition of the importance of their participation, and  
13 their experience of participating in patient safety activities through a survey. We also  
14 explored healthcare consumers' experience of patient participation and factors influencing  
15 their experience of engaging in healthcare behaviors in depth.

## 17 **METHODS**

### 18 **Study design**

19 This study used a mixed-methods sequential explanatory design including a survey and  
20 focus group interviews. According to this design proposed by Creswell and Zhang,<sup>22</sup> we  
21 gathered and analyzed quantitative data first, and then used qualitative data collection and  
22 analyzed that qualitative data later to help explain the quantitative results.

## 1 **Participants and data collection**

2 To investigate health consumers' perception and experience of participation in patient  
3 safety activities, we conducted an online survey between January 25 and February 3, 2018, in  
4 South Korea. The target population comprised Korean-speaking Korean adults aged 19 years  
5 or older who had visited a medical institution within the most recent one year. We recruited  
6 participants through two websites, the Korea Alliance of Patients' Organizations  
7 (<http://www.koreapatient.com/>) and Resources for Enhancing Safety, Competency, and  
8 Utilization for Education (RESCUE, <http://patientsafety.snu.ac.kr/>), as well as through social  
9 media. The websites are produced by nonprofit organizations. The Korean Alliance of  
10 Patients' Organizations is a patient advocacy organization that claims the rights of patients to  
11 prevent errors and create a patient-centered environment. RESCUE is a health information  
12 website that provides educational materials and resources for patient safety. The websites  
13 posted a description of the study and the link to the online survey. The survey was  
14 implemented using the Qualtrics online survey tool (<https://www.qualtrics.com>). A total of  
15 493 participants completed the survey, and we excluded from the analysis the data of 1  
16 respondent who reported being 18 years old (Supplementary figure 1). The total sample size  
17 exceeded the minimum of 103 required for multiple linear regression, based on Cohen's  
18 statistical method (significance level  $\alpha = 0.05$ ,  $1-\beta = 0.80$ , effect size 0.15, predictors 7).

19 We posted a description of the focus group interview on the website to recruit  
20 participants. Among the survey respondents, with those who agreed to participate in a focus  
21 group, focus group interviews were conducted March 20-22, 2018. The interviews were  
22 conducted in 2 groups of 6 participants each, for 2 hours with each group in a seminar room  
23 at a university. We divided them to the two groups according to their availability, gender, and  
24 ages. Each interview involved all of the researchers. Two researchers (NL or SA) of the

1 research team each facilitated one of the focus group interviews, and one researcher (ML)  
2 played a role as a note taker to produce accurate notes while assisting with the interviews. At  
3 the end of the interview, the interviewer summarized the conversation and repeated key  
4 information to request confirmation for data accuracy. The list of primary interview questions  
5 and safety activities in healthcare settings were sent to participants in advance to inform them  
6 on the areas of discussion to be covered. The key interview questions were as follows: “What  
7 do you think about patient participation as it relates to patient safety?”, “In your opinion, how  
8 important is it to you to participate patient safety activities when you visit the hospital and  
9 receive medical care or treatment?”, “To what extent do you think you can participate in  
10 patient safety activities as a patient or their caregiver?”, “How do you think patient  
11 involvement in patient safety activities could affect patient safety?”, and “Can you tell us  
12 specifically about your experiences in which you participated in the care or treatment  
13 process?”

## 15 **Measures**

16 Patient participation was measured using a tool developed to measure the inclination to  
17 engage in patient safety practices.<sup>15</sup> We added 3 items from the relevant literature<sup>18 23 24</sup>  
18 (bringing a friend or family member to a doctor’s appointment; telling healthcare workers  
19 about any drug allergies; reporting errors to a national reporting system if they notice errors  
20 in the hospital). Thus, the final survey tool comprised 13 items, and the questions included a  
21 list of 13 specific safety-related behaviors through which patients can engage while  
22 undergoing care in medical institutions (Supplementary survey questionnaire). To explore the  
23 factors influencing patient participation, we grouped variables into the following three  
24 categories based on a literature review<sup>15 18 23-25</sup>: patient-related (willingness to participate,

1 recognition of the importance of patient participation, and socio-demographic variables),  
2 illness-related (number of visits to medical institutions and prior experience of patient safety  
3 incidents), and healthcare environment-related (types of medical institutions).

4 Four-point Likert scales were used to assess the extent of health consumers' willingness  
5 to participate (1=not at all, 2=somewhat likely, 3=likely, 4=very likely) and recognition of  
6 the importance of participation (1=not very important, 2=not important, 3=important, 4=very  
7 important) in patient safety activities. Participants were asked to indicate how often they had  
8 experienced each patient safety activity in the hospital using a 4-point Likert scale (1=not at  
9 all, 2=sometimes, 3=often, 4=always). The reliability of the finalized questionnaire was  
10 evaluated using Cronbach's alpha coefficient. The Cronbach's alpha values of the three  
11 sections were 0.814, 0.900, and 0.884.

### 13 **Data analysis**

14 The quantitative data were analyzed using SPSS 24.0 (IBM Corp., Armonk, NY, USA).  
15 Participants' general characteristics and the scores of participants' willingness to participate,  
16 recognition of the importance of participation, and participation experience were summarized  
17 using descriptive statistics. An independent t-test and one-way ANOVA were used to identify  
18 differences in willingness to participate, recognition of the importance of participation, and  
19 experience of patient participation by general characteristics. For correlations between  
20 willingness to participate, recognition of the importance of participation, and experience of  
21 participation, Pearson's correlation coefficients were used. Multiple linear regression analysis  
22 was performed to identify variables associated with experience of patient participation.

23 The qualitative data were analyzed using conventional content analysis.<sup>26</sup> All interviews  
24 were recorded and transcribed. The collected data were written immediately after the

1 interview, and the field notes were used for analysis. One researcher (SA) led the first  
2 analysis by reading the transcript repeatedly, and two researchers (NL, ML) performed a  
3 second review. Emergent themes were discussed in depth, then the researchers extracted  
4 codes, categories, and themes together during content analysis until agreement was reached.

## 6 **Patient and Public involvement**

7 Neither patients nor the public were involved in the design, development of the research  
8 questions, outcome measure, or conduct of this study. To further facilitate the recruitment of  
9 patients, advertisements were posted on the websites.

## 11 **RESULTS**

### 12 **Participant characteristics**

13 A total of 492 completed surveys were included in the analysis. The mean age of the  
14 respondents was 31.7 years (SD: 10.52), 74.8% of respondents were female, most had  
15 graduated from college or above (n=373, 75.8%), and most were unmarried (n=310, 63.0%).  
16 The monthly income of most participants (n=174, 35.4%) was less than 850,000 won. The  
17 most frequently visited medical institutions were clinics or public health centers (n=343,  
18 69.7%), and more than 60% of the participants had visited medical institutions less than 10  
19 times within the most recent one year. Most of the participants (n=414, 84.1%) reported  
20 going alone when they visited medical institutions, and 65% of the participants had  
21 experienced patient safety incidents. The vast majority of the participants (n=483, 98.2%) did  
22 not know the fact that they could report patient safety incidents to the national reporting and  
23 learning system themselves (Table 1).

## 1 **Participation in patient safety activities**

2       Among this study's findings on patient safety activities, average scores were as follows:  
3 recognition of the importance ( $3.27\pm 0.51$ ), the extent of willingness ( $2.62\pm 0.52$ ), and the  
4 experience of participation ( $2.13\pm 0.63$ ). Respondents' experience of engaging in patient  
5 safety activities varied considerably. Some respondents reported that they always ask about  
6 the details of a procedure and the reason for a procedure before it is performed (30.5%), ask  
7 for an explanation of care that they were not told about by their doctor or nurse (22.0%), and  
8 call when they have not received the results of a medical test they underwent (23.8%). Fewer  
9 respondents had the experience of asking healthcare workers if they had washed their hands  
10 (2.7%), bringing a friend or family member to a doctor's appointment (5.1%), or asking for  
11 healthcare workers to confirm patient identity before performing a procedure (6.3%) (Table  
12 2).

13       The scores of respondents' willingness to participate differed significantly by education  
14 level ( $t=-2.19, p=.029$ ), the type of accompanying caregivers ( $F=2.45, p=.045$ ), and whether  
15 they had experienced patient safety incidents or not ( $t=-2.19, p=.029$ ). The scores on  
16 recognizing the importance of participation showed significant differences according to  
17 gender ( $t=-3.53, p<.001$ ) and education level ( $t=-2.27, p=.024$ ). The scores of participation  
18 experience differed significantly by gender ( $t=-2.49, p=.013$ ), the type of medical institutions  
19 frequently visited ( $F=5.12, p=.002$ ), the type of accompanying caregivers ( $F=3.29, p=.011$ ),  
20 and previous experience of patient safety incidents ( $t=-3.34, p=.001$ ) (Table 3).

## 22 **Factors influencing experience of patient participation**

23       The respondents' experience of patient participation showed a significant positive  
24 correlation with willingness to participate ( $r=.63, p<.001$ ), and their recognition of the



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6 1 importance of participation ( $r=.23, p<.001$ ). In addition, participants' recognition of the  
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8 2 importance of participation showed a significantly positive correlation with willingness to  
9  
10 3 participate ( $r=.34, p<.001$ ).

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12 4 Multiple linear regression was used to examine the relationship of the experience of  
13  
14 5 patient participation with three sets of factors: patient-related, illness-related, and healthcare  
15  
16 6 environment-related (Table 4). The result of the multiple linear regression showed that the  
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18 7 patient who frequently visited a hospital ( $\beta=0.117, p=.001$ ) and a general or advanced general  
19  
20 8 hospital ( $\beta=0.077, p=.035$ ) rather than a clinic or public health center, visited medical  
21  
22 9 institutions more than 25 times in the most recent one year ( $\beta=0.095, p=.013$ ) rather than less  
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24 10 than 5 times, and had a high score on willingness to participate ( $\beta=0.600, p<.001$ ) was  
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26 11 expected to have more experience of participating in patient safety activities.  
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### 31 32 33 13 **Focus group interviews: Health consumers' experience of patient participation in** 34 35 14 **hospital care**

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38 15 Twelve health consumers participated in the interview. Four interviewees were male and  
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40 16 eight were female. The average age was 40 years (range, 29 to 55 years). Ten interviewees  
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42 17 had visited medical institutions more than 5 times in last year and six interviewees had  
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44 18 experienced patient safety incidents. Content analysis produced five categories extracted  
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46 19 under three themes (Table 5).

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49 20 The results of the focus group interviews showed that patient participation in medical  
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51 21 institutions appeared to be influenced by three types of factors: patient-related factors, factors  
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53 22 involving the relationship between patients and healthcare providers, and healthcare  
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55 23 environment factors.  
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### 1 *Patient-related factors*

2 Some focus group members reported that patient participation in their care process  
3 resulted in a different treatment outcome. The participants were actively involved in their  
4 care process through patient safety behaviors such as asking for information. Going to the  
5 hospital with family members was a motivating factor for patient participation. Their family  
6 members helped patients to ask questions, check their prescriptions, and remind them of what  
7 they should say to the doctor. In addition, participants reported that their previous experience  
8 of a patient safety incident and their perception of the importance of patient safety activities  
9 made them more active patients. However, the participants were worried about having any  
10 disadvantages in their care if they pointed out healthcare providers' behaviors which could  
11 threaten patient safety. This undermined their willingness to participate.

12 In order to understand the purpose of treatment and actively engage in their treatment  
13 process while being in the hospital, they emphasized the need to know what is going on.  
14 However, they did not have enough knowledge about their health care and felt it was difficult  
15 to understand their care process, including their medication, diagnosis, and treatment plan.  
16 Therefore, they could not share in the development of the treatment plan with their healthcare  
17 providers. Participants thought it was important to understand their health care by being  
18 informed about what patients have to do or what patients can do. There were various topics  
19 on which participants wanted to be educated such as disease, diagnosis, treatment,  
20 examination, and medication. Participants also thought it was important for patients to know  
21 what questions should be asked.

### 23 *Factors involving the relationship between patients and healthcare providers*

24 In order to participate in patient safety activities in the care process, it was important that

1 patients establish a supportive relationship with healthcare providers. Explaining the details  
2 of treatment, listening to patients, and paying attention to patients were important factors for  
3 promoting patient participation.

4 On the other hand, a hierarchy existed between doctors and patients. Focus group  
5 members mentioned that they felt they had not received satisfactory explanations from health  
6 care professionals, but they also felt they could not ask a follow-up or repeat question, even if  
7 they wanted to. When a patient asked a doctor a question, the doctor was often annoyed and  
8 did not explain or share his or her treatment plan. Focus group participants reported that their  
9 hesitation to participate was also related to this hierarchical relationship between patients and  
10 healthcare providers.

### 11 *Healthcare environment factors*

12 All participants stated that the processes and procedures for receiving care were very  
13 complex in hospitals, and the time allocated to see a doctor for treatment and care was very  
14 limited. Also, the type of healthcare delivery system, such as clinic or advanced hospital,  
15 affected the patients' willingness to participate in patient safety activities. Participants were  
16 more prepared with their health information when they visited a higher level of medical  
17 institution, and they also received more information from the medical institution.

18 By integrating the results of the quantitative and qualitative data analysis, this study  
19 showed that the factors influencing patient participation in medical institutions could be  
20 categorized into four factors: patient-related factors, illness-related factors, factors involving  
21 the relationship between patients and healthcare providers, and healthcare environment  
22 factors.

## DISCUSSION

This is the first study to investigate patient participation in patient safety activities in South Korea from the health consumer's viewpoint. This study provided evidence on what factors affect actual patient safety behaviors.

This study found that the average score for experience of participation in patient safety behaviors was lower than those of willingness to participate and recognition of the importance of participation. The frequency of health consumers' experience of participation in patient safety activities varied considerably. Among patient safety activities, the most frequently performed were asking general questions such as "the details of surgery" and "an explanation of what the patient doesn't understand". On the other hand, "asking health care workers to wash their hands" was the patient safety behavior with the lowest average scores for intention and experience. These results were consistent with previous findings.<sup>15</sup> Specifically, asking healthcare workers wash their hands has been considered a challenging behavior,<sup>16</sup> with various potential explanations proposed in previous research. Patients themselves felt uncomfortable with asking about handwashing,<sup>18</sup> and they were worried that healthcare workers might feel uncomfortable with this question.<sup>16</sup> In addition, patients thought that questioning healthcare providers about their behavior could imply criticizing their incompetence, and therefore they were reluctant to do so.<sup>15</sup> In the qualitative interview of our study, we learned that patients worried about encountering any disadvantages in treatment if they were to question a healthcare provider when they found something were not right. These findings might reflect that patients prefer to passively participate in their care, but it also might be related to the healthcare environment where patients cannot actively communicate or raise questions and concerns with their clinicians.

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6 1 The relationships among patients' perception of importance, their willingness, and their  
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8 2 experience of patient participation were found to correlate in the quantitative results of this  
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10 3 study. Likewise, the qualitative results showed that the perception of the importance of  
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12 4 patient participation increased willingness and experience of patient participation. This  
13  
14 5 finding is consistent with a previous study that explored barriers and facilitators to patient  
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16 6 involvement in reporting safety experiences within care transfer.<sup>19</sup> When patients  
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18 7 conceptualized patient safety, they were likely to provide feedback on safety experiences.<sup>19</sup>  
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20 8 Patients who perceived that patient safety was not their responsibility preferred to adopt a  
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22 9 passive role in their care.<sup>19 27 28</sup>

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26 10 Our study found that patients' extent of knowledge on health care was an important  
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28 11 influence on patient participation in safety activities. Patient education can help to increase  
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30 12 patients' knowledge related to their health and positively affect their attitude toward safety  
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32 13 practices.<sup>29</sup> Therefore, healthcare providers must consider developing and implementing  
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34 14 effective education for patients. When healthcare providers develop education program or  
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36 15 strategies to improve patient participation, a patient's abilities, needs, and preferences for  
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38 16 participation must be taken into consideration.<sup>30</sup> In this study's findings, health consumers  
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40 17 wanted education programs focusing on "a question list they can ask health professionals",  
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42 18 "patient rights and responsibilities", and "a variety of information related to treatment  
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44 19 including disease and diagnosis, and medication". Thus, our study's findings suggest  
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46 20 developing an education program reflecting these educational needs.

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51 21 The quantitative and qualitative results of this study showed that patients with caregivers  
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53 22 had more willingness and motivation to participate in patient safety and were more involved  
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55 23 in patient safety activities than unaccompanied patients were. Increased patient and family  
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57 24 engagement is associated with improved patient outcomes and reduced utilization of  
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1 healthcare services,<sup>31 32</sup> and it is recommended that medical institutions also encourage not  
2 only patients but also their family members to participate in safety activities. This could be a  
3 way of increasing the overall frequency of actual patient safety activities and that of specific  
4 activities like “bringing a friend or family member to a doctor’s appointment” in medical  
5 institutions.

6 Most patients felt that the relationship between patients and healthcare providers was  
7 hierarchical, which was one of the barriers to participation. According to a previous  
8 intervention study that developed a prototype consumer reporting system for medical errors,  
9 the contributing factors of medical mistakes included problems with communication and staff  
10 responsiveness to patients.<sup>33</sup> However, patients can be motivated to participate in patient  
11 safety activities through open communication with, positive feedback from, and supportive  
12 relationships with healthcare providers. According to Maurer et al.,<sup>34</sup> healthcare providers’  
13 negative reactions can be a barrier to patient participation, while their active invitation for  
14 patients to participate can be a facilitator. Thus, healthcare providers must support and guide  
15 patients to participate. Even if patients are willing to participate in safety activities, they  
16 might be uncertain about how to be involved. It is important that healthcare providers  
17 consider patients as partners for patient safety<sup>35</sup> and encourage them to speak up if they have  
18 a concern. However, according to Fisher et al., nearly half of patients (48.6%) in their study  
19 had experienced a problem during hospitalization, and almost one-third (30.5%) of them  
20 reported they were not always comfortable speaking up.<sup>36</sup> Creating a healthcare environment  
21 in which patients can be comfortable raising their concerns may result in safer care and  
22 improved patient participation.<sup>36</sup>

23 The findings of our study showed that the frequency of visiting medical institutions  
24 affected the experience of patient participation. According to Davis et al.,<sup>25</sup> severity of the

1 patients' illness, symptoms, and treatment plan were associated with patient participation. In  
2 addition, patients' prior experience of illness led to more willingness to participate.<sup>25</sup> This  
3 may be due to the fact that patients with more experience of visiting medical institutions may  
4 have more severe illness and will be likely to be exposed to higher-risk situations such as  
5 testing, drugs, and surgery, all of which call for patient safety activities. It can also be  
6 inferred that patients who have experienced many hospital visits might perceive themselves  
7 as playing a more important role in the care process.

8 A complex care process, time constraints, and different types of healthcare delivery  
9 systems were healthcare environmental factors influencing patient participation. A qualitative  
10 study conducted with patients and nursing staff members found similar results—that patients  
11 felt that healthcare providers were too busy asking questions or talking.<sup>20</sup> Patients and  
12 families may feel overwhelmed by the healthcare system and highly technical information.<sup>34</sup>  
13 <sup>37</sup> Therefore, the organizational context within hospitals, including workflow processes and  
14 hospital polices, should be changed to be focused on patient-centered care and patient safety.  
15 Then a culture of safety should be established in hospitals.

16 This study had several limitations. First, the study was based on health consumers' self-  
17 reports on their participation in patient safety practices, so these self-reported data may not  
18 accurately reflect their actual practices in medical institutions. Second, convenience sampling  
19 was used to generate the sample, and was drawn from only two websites plus social media, so  
20 people who do not regularly use computers or social network services might not have  
21 participated in this study. Therefore, the young and well-educated population might have  
22 accounted for a large proportion of the sample. Thus, it may not be generalizable to all patient  
23 groups.

## 1 **CONCLUSION**

2       There were differences among patients' perceived importance of their participation,  
3 willingness to participate, and their actual experience of participation in patient safety  
4 activities. Future research needs to be conducted to narrow these gaps using efficient  
5 educational methods. Our study suggests that an education program be developed that reflects  
6 patients' educational needs, such as lists of questions and information on patient safety  
7 activities. The results of this study can be used as a reference for developing educational  
8 content for patients. Also, the findings from our study may be useful for updating patient  
9 participation guidelines.

10       Healthcare providers may play an important role in encouraging patients to involve  
11 themselves in patient safety practices by offering education and encouragement to patients.  
12 Strategies are needed to give participation opportunities to patients during their care. Shared  
13 decision-making procedures and patient-centered policies should be made to create a  
14 healthcare environment in which patients and healthcare providers can participate together to  
15 improve patient safety.

## 17 **Contributors**

18 NL and SA conceived and designed the study. NL, SA and ML performed the cross-section  
19 study. NL and SA carried out the statistical analysis. NL, SA and ML conducted qualitative  
20 research. NL, SA and ML wrote the paper. NL, SA and ML reviewed and edited the  
21 manuscript. All authors read and approved the manuscript.

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1 **Competing interests**

2 None declared

3 **Data availability statement**

4 No data are available.

5 **Ethics approval**

6 This study was approved by the Institute Review Board of Seoul National University (No.  
7 No. 1801/003-007) and all study participants provided informed consent.

8 **Patient consent for publication**

9 Not required.

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1 Table 1. General Characteristics of Participants (N=492)

| Characteristics  | Categories                           | M±SD        | n (%)      |
|--|--------------------------------------|-------------|------------|
| Age  | 19-29                                | 31.72±10.52 | 270 (54.9) |
|  | 30-39                                |             | 123 (25.0) |
|  | 40-49                                |             | 57 (11.6)  |
|  | 50-                                  |             | 42 (8.5)   |
| Gender   | Female                               |             | 368 (74.8) |
|  | Male                                 |             | 124 (25.2) |
| Educational level  | High school diploma or below         |             | 119 (24.2) |
|  | Bachelor's degree or above           |             | 373 (75.8) |
| Marital status   | Single                               |             | 310 (63.0) |
|  | Married                              |             | 176 (35.8) |
|  | Divorced                             |             | 5 (1.0)    |
|  | Bereaved                             |             | 1 (0.2)    |
| Monthly income (KRW)   | <850,000                             |             | 174 (35.4) |
|  | 850,000-<1500,000                    |             | 51 (10.3)  |
|  | 1500,000-<2500,000                   |             | 91 (18.5)  |
|  | 2500,000-<3500,000                   |             | 77 (15.7)  |
|  | 3500,000-<4500,000                   |             | 43 (8.7)   |
|  | 4500,000-<5500,000                   |             | 23 (4.7)   |
|  | 5500,000-<6500,000                   |             | 7 (1.4)    |
| Types of medical institutions frequently visited   | 6500,000-                            |             | 26 (5.3)   |
|  | Clinic or public health center       |             | 343 (69.7) |
|  | Hospital                             |             | 68 (13.8)  |
|  | General or Advanced general hospital |             | 79 (16.1)  |
| Number of visits to medical institutions   | Others                               |             | 2 (0.4)    |
|  | <5                                   |             | 165 (33.5) |
|  | 5-<10                                |             | 176 (35.8) |
|  | 10-<15                               |             | 80 (16.3)  |
|  | 15-<20                               |             | 40 (8.1)   |
|  | 20-<25                               |             | 15 (3.0)   |
| Types of accompanying caregivers   | 25-                                  |             | 16 (3.3)   |
|  | Alone                                |             | 414 (84.1) |
|  | Spouse                               |             | 19 (3.9)   |
|  | Children                             |             | 23 (4.7)   |
|  | Parents (Father or Mother)           |             | 31 (6.3)   |
| Experience of patient safety incidents   | Others                               |             | 5 (1.0)    |
|  | Yes                                  |             | 320 (65.0) |
| Do you know the fact that you can directly report to the patient safety reporting and learning system? | No                                   |             | 172 (35.0) |
|  | Yes                                  |             | 9 (1.8)    |
|  | No                                   |             | 483 (98.2) |

Table 2. Extent of Willingness to Participate, Recognition of Its Importance, and Experience of Participation in Patient Safety Activities  
(N=492)

| Patient participation practices  | Engaging in health care behaviors |                           |                             | Frequency of participation |            |            |            |
|--|-----------------------------------|---------------------------|-----------------------------|----------------------------|------------|------------|------------|
|  | Extent of willingness             | Recognition of importance | Experience of participation | Always                     | Often      | Sometimes  | Not at all |
|  | M±SD                              |                           |                             | n (%)                      |            |            |            |
| Seeking a second opinion regarding an important healthcare decision  | 2.70±0.97                         | 3.23±0.71                 | 2.07±0.89                   | 38 (7.7)                   | 98 (19.9)  | 217 (44.1) | 139 (28.3) |
| Asking healthcare workers to explain more fully something they just said that I do not understand  | 3.19±0.80                         | 3.47±0.65                 | 2.58±0.84                   | 73 (14.8)                  | 177 (36.0) | 202 (41.1) | 40 (8.1)   |
| Bringing a friend or family member to a doctor's appointment so that they can help ask questions and understand what the doctor was telling me | 2.19±0.90                         | 2.73±0.84                 | 1.84±0.86                   | 25 (5.1)                   | 75 (15.2)  | 187 (38.0) | 205 (41.7) |
| Asking healthcare workers if they washed their hands   | 1.43±0.76                         | 2.96±0.84                 | 1.37±0.74                   | 13 (2.7)                   | 39 (7.9)   | 64 (13.0)  | 376 (76.4) |
| Telling healthcare workers about any drug allergies when they did not ask for this information   | 3.08±1.02                         | 3.55±0.69                 | 2.22±1.10                   | 82 (16.7)                  | 118 (24.0) | 118 (24.0) | 174 (35.4) |
| Asking healthcare workers to confirm your identity before performing a procedure   | 2.05±1.02                         | 3.20±0.84                 | 1.64±0.94                   | 31 (6.3)                   | 65 (13.2)  | 91 (18.5)  | 305 (62.0) |
| Asking healthcare workers about the details of a procedure and the   | 3.31±0.82                         | 3.55±0.67                 | 2.88±0.95                   | 150 (30.5)                 | 178 (36.2) | 120 (24.4) | 44 (8.9)   |

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| 3  |                                       |           |           |           |            |            |            |            |
| 4  |                                       |           |           |           |            |            |            |            |
| 5  | reason for a procedure before it is   |           |           |           |            |            |            |            |
| 6  | performed                             |           |           |           |            |            |            |            |
| 7  |                                       |           |           |           |            |            |            |            |
| 8  | Asking healthcare workers to explain  | 2.86±0.95 | 3.43±0.72 | 2.50±1.04 | 108 (22.0) | 125 (25.4) | 164 (33.3) | 95 (19.3)  |
| 9  | care, such as an X-ray or drawing     |           |           |           |            |            |            |            |
| 10 | blood, that I was not told about by   |           |           |           |            |            |            |            |
| 11 | my doctor or nurse                    |           |           |           |            |            |            |            |
| 12 |                                       |           |           |           |            |            |            |            |
| 13 | Calling a healthcare worker when I    | 3.29±0.83 | 3.40±0.70 | 2.50±1.10 | 117 (23.8) | 129 (26.2) | 127 (25.8) | 119 (24.2) |
| 14 | undergo medical tests ordered and     |           |           |           |            |            |            |            |
| 15 | no one calls me with the results      |           |           |           |            |            |            |            |
| 16 |                                       |           |           |           |            |            |            |            |
| 17 | Taking a written list of all the      | 2.34±1.07 | 3.22±0.80 | 2.02±1.03 | 55 (11.2)  | 102 (20.7) | 132 (26.8) | 203 (41.3) |
| 18 | medications I'm currently taking      |           |           |           |            |            |            |            |
| 19 | when going to the doctor              |           |           |           |            |            |            |            |
| 20 |                                       |           |           |           |            |            |            |            |
| 21 | Questioning medications or pills if I | 2.82±0.98 | 3.33±0.77 | 2.35±1.05 | 85 (17.3)  | 131 (26.6) | 149 (30.3) | 127 (25.8) |
| 22 | did not recognize them and never      |           |           |           |            |            |            |            |
| 23 | took this medication in the past      |           |           |           |            |            |            |            |
| 24 |                                       |           |           |           |            |            |            |            |
| 25 | Checking that I received the right    | 2.30±1.10 | 3.22±0.81 | 2.09±1.09 | 76 (15.5)  | 86 (17.5)  | 134 (27.2) | 196 (39.8) |
| 26 | drug and strength before leaving      |           |           |           |            |            |            |            |
| 27 | the pharmacy                          |           |           |           |            |            |            |            |
| 28 |                                       |           |           |           |            |            |            |            |
| 29 | Reporting the errors I noticed had    | 2.51±0.96 | 3.20±0.80 | 1.70±0.99 | 40 (8.1)   | 71 (14.4)  | 84 (17.1)  | 297 (60.4) |
| 30 | occurred in the hospital to a         |           |           |           |            |            |            |            |
| 31 | national reporting system             |           |           |           |            |            |            |            |
| 32 |                                       |           |           |           |            |            |            |            |
| 33 | Total                                 | 2.62±0.52 | 3.27±0.51 | 2.13±0.63 |            |            |            |            |
| 34 |                                       |           |           |           |            |            |            |            |
| 35 |                                       |           |           |           |            |            |            |            |
| 36 |                                       |           |           |           |            |            |            |            |
| 37 |                                       |           |           |           |            |            |            |            |
| 38 |                                       |           |           |           |            |            |            |            |
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| 40 |                                       |           |           |           |            |            |            |            |
| 41 |                                       |           |           |           |            |            |            |            |
| 42 |                                       |           |           |           |            |            |            |            |
| 43 |                                       |           |           |           |            |            |            |            |
| 44 |                                       |           |           |           |            |            |            |            |
| 45 |                                       |           |           |           |            |            |            |            |
| 46 |                                       |           |           |           |            |            |            |            |



Table 3. Difference in Extent of Willingness to Participate, Recognition of Its Importance, and Experience of Participation by General Characteristics (N=492)

| Sociodemographic characteristics | Subgroup                     | n (%)      | Extent of Willingness |              | Recognition of Importance |               | Experience of Participation |              |
|----------------------------------|------------------------------|------------|-----------------------|--------------|---------------------------|---------------|-----------------------------|--------------|
|                                  |                              |            | M±SD                  | t or F(p)    | M±SD                      | t or F(p)     | M±SD                        | t or F(p)    |
| Age group                        | 19-29                        | 270 (54.9) | 2.58±0.51             | 1.28 (.281)  | 3.25±0.51                 | 1.23 (.297)   | 2.10±0.63                   | 1.45 (.227)  |
|                                  | 30-39                        | 123 (25.0) | 2.66±0.52             |              | 3.33±0.50                 |               | 2.11±0.59                   |              |
|                                  | 40-49                        | 57 (11.6)  | 2.69±0.52             |              | 3.29±0.43                 |               | 2.25±0.65                   |              |
|                                  | 50-                          | 42 (8.5)   | 2.67±0.59             |              | 3.16±0.65                 |               | 2.25±0.73                   |              |
| Gender                           | Female                       | 368 (74.8) | 2.64±0.52             | -1.72 (.086) | 3.32±0.51                 | -3.53 (<.001) | 2.18±0.64                   | -2.49 (.013) |
|                                  | Male                         | 124 (25.2) | 2.55±0.52             |              | 3.13±0.51                 |               | 2.01±0.59                   |              |
| Educational level                | High school diploma or below | 119 (24.2) | 2.53±0.50             | -2.19 (.029) | 3.18±0.53                 | -2.27 (.024)  | 2.05±0.58                   | -1.80 (.074) |
|                                  | Bachelor's degree or above   | 373 (75.8) | 2.65±0.53             |              | 3.30±0.50                 |               | 2.16±0.65                   |              |
| Marital status                   | Single                       | 310 (63.0) | 2.59±0.51             | 2.05 (.130)  | 3.26±0.50                 | 0.05 (.948)   | 2.10±0.62                   | 1.98 (.139)  |
|                                  | Married                      | 176 (35.8) | 2.68±0.54             |              | 3.28±0.54                 |               | 2.21±0.65                   |              |
|                                  | Divorced & Bereaved          | 6 (1.2)    | 2.37±0.42             |              | 3.27±0.30                 |               | 1.96±0.63                   |              |
| Monthly income (KRW)             | <850,000                     | 174 (35.4) | 2.61±0.51             | 0.77 (.616)  | 3.23±0.51                 | 0.82 (.570)   | 2.10±0.62                   | 0.53 (.811)  |
|                                  | 850,000-<1500,000            | 51 (10.3)  | 2.49±0.53             |              | 3.22±0.63                 |               | 2.09±0.63                   |              |
|                                  | 1500,000-<2500,000           | 91 (18.5)  | 2.66±0.53             |              | 3.31±0.52                 |               | 2.19±0.68                   |              |
|                                  | 2500,000-<3500,000           | 77 (15.7)  | 2.63±0.53             |              | 3.31±0.47                 |               | 2.15±0.62                   |              |
|                                  | 3500,000-<4500,000           | 43 (8.7)   | 2.72±0.51             |              | 3.39±0.43                 |               | 2.18±0.64                   |              |
|                                  | 4500,000-<5500,000           | 23 (4.7)   | 2.62±0.50             |              | 3.21±0.43                 |               | 2.01±0.40                   |              |
|                                  | 5500,000-<6500,000           | 7 (1.4)    | 2.53±0.65             |              | 3.13±0.61                 |               | 2.07±0.86                   |              |

|  |                                      |            |           |              |           |              |           |              |
|--|--------------------------------------|------------|-----------|--------------|-----------|--------------|-----------|--------------|
|  | 6500,000-                            | 26 (5.3)   | 2.63±0.58 |              | 3.23±0.50 |              | 2.26±0.71 |              |
| Types of medical institutions frequently visited | Clinic or public health center       | 343 (69.7) | 2.60±0.51 | 1.41 (.240)  | 3.27±0.50 | 1.02 (.384)  | 2.06±0.60 | 5.12 (.002)  |
|  | Hospital                             | 68 (13.8)  | 2.59±0.57 |              | 3.19±0.59 |              | 2.27±0.71 |              |
|  | General or advanced general hospital | 79 (16.1)  | 2.73±0.53 |              | 3.32±0.48 |              | 2.32±0.64 |              |
|  | Others                               | 2 (0.4)    | 2.38±0.33 |              | 3.54±0.54 |              | 2.46±0.76 |              |
| Number of visits to medical institutions         | <5                                   | 165 (33.5) | 2.61±0.55 | 0.86 (.509)  | 3.26±0.43 | 0.55 (.738)  | 2.08±0.66 | 1.88 (.096)  |
|  | 5-<10                                | 176 (35.8) | 2.60±0.49 |              | 3.26±0.53 |              | 2.10±0.61 |              |
|  | 10-<15                               | 80 (16.3)  | 2.62±0.57 |              | 3.23±0.57 |              | 2.20±0.62 |              |
|  | 15-<20                               | 40 (8.1)   | 2.67±0.46 |              | 3.39±0.59 |              | 2.20±0.56 |              |
|  | 20-<25                               | 15 (3.0)   | 2.86±0.52 |              | 3.26±0.69 |              | 2.23±0.82 |              |
|  | 25-                                  | 16 (3.3)   | 2.69±0.42 |              | 3.30±0.37 |              | 2.51±0.48 |              |
| Types of accompanying caregivers                 | Alone                                | 414 (84.1) | 2.59±0.52 | 2.45 (.045)  | 3.25±0.52 | 1.09 (.362)  | 2.09±0.63 | 3.29 (.011)  |
|  | Spouse                               | 19 (3.9)   | 2.81±0.54 |              | 3.35±0.55 |              | 2.47±0.61 |              |
|  | Children                             | 23 (4.7)   | 2.88±0.52 |              | 3.45±0.40 |              | 2.32±0.61 |              |
|  | Parents                              | 31 (6.3)   | 2.68±0.48 |              | 3.27±0.51 |              | 2.31±0.57 |              |
|  | Others                               | 5 (1.0)    | 2.72±0.41 |              | 3.45±0.48 |              | 2.46±0.62 |              |
| Experience of patient safety incidents           | No                                   | 320 (65.0) | 2.58±0.54 | -2.19 (.029) | 3.24±0.53 | -1.88 (.061) | 2.07±0.62 | -3.34 (.001) |
|  | Yes                                  | 172 (35.0) | 2.69±0.49 |              | 3.33±0.48 |              | 2.26±0.63 |              |

Table 4. Factors Influencing the Experience of Patient Participation (N=492)

| Variables   | Beta   | t      | p value |
|---|--------|--------|---------|
| (Constant)  |        | -0.110 | 0.913   |
| Willingness to participate                            | 0.600  | 16.413 | <.001   |
| Recognition of importance of patient participation    | 0.020  | 0.527  | .595    |
| Gender  |        |        |         |
| Male  | Ref.   |        |         |
| Female  | 0.037  | 1.021  | .308    |
| Types of accompanying caregivers                      |        |        |         |
| Alone   | Ref.   |        |         |
| Spouse  | 0.062  | 1.766  | .078    |
| Children  | 0.008  | 0.218  | .827    |
| Parent  | 0.025  | 0.691  | .490    |
| Others  | 0.035  | 0.992  | .322    |
| Number of visits to medical institutions in last year |        |        |         |
| -<5   | Ref.   |        |         |
| 5-<10   | 0.024  | 0.611  | .542    |
| 10-<15  | 0.058  | 1.493  | .136    |
| 15-<20  | 0.018  | 0.492  | .623    |
| 20-<25  | -0.003 | -0.072 | .942    |
| 25-   | 0.095  | 2.498  | .013    |
| Experience of patient safety incidents                |        |        |         |
| No  | Ref.   |        |         |
| Yes   | 0.065  | 1.849  | .065    |
| Medical institutions frequently visited               |        |        |         |
| Clinic or public health center                        | Ref.   |        |         |
| Hospital  | 0.117  | 3.287  | .001    |
| General or advanced general hospital                  | 0.077  | 2.113  | .035    |
| Others  | 0.019  | 0.525  | .600    |

F= 23.19 ( $p<.001$ ); Adjusted R<sup>2</sup>=0.42.

Table 5. Themes, Categories, and Codes

| Theme                   | Category                   | Code  | Quotes   |
|-------------------------|----------------------------|---|--|
| Patient-related factors | Willingness and motivation | Perception of the importance of patient participation | The treatment outcome seems to be different depending on whether I participated in patient safety activities or not. (Participant 2, Group 1)  |
|                         |                            |   | As soon as I realize I am speaking up and participating in my care, I feel that I'm an active patient. That changes the degree of participation. (Participant 1, Group 1)  |
|                         |                            | Accompanied by caregiver                              | My grandfather went to several hospitals and took medications from those hospitals which were the same medications he'd gotten from his primary hospital. He had no idea there were duplicates and took them all...After that I told him to get a paper prescription from the pharmacy and to bring medications which he got from other hospitals when he visits his primary hospital. I know that older people need to be accompanied by a family member when they go to the hospital. (Participant 1, Group 1) |
|                         |                            |   | In medical settings, I thought that patient and family participation in the care process as a member of a healthcare team is important. Since my family could be anyone, a patient or a healthcare provider, I thought patient and family participation is necessary. (Participant 2, Group 2)   |
|                         |                            | Previous experience of a patient safety incident      | I really wanted to hear: "Sorry, we made a mistake with the medication for your daughter. So, we took this kind of action after the incident." But they didn't apologize and didn't take any   |

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follow-up action. After this incident, I strongly realized the importance of patient safety and the family's participation. (Participant 6, Group 2)

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Concerns about having any disadvantages in treatment

Foremost, I'm afraid of having any disadvantage on my treatment, like snubbing me after I ask questions. (Participant 6, Group 2)

I had a feeling on that he doesn't put an effort into, or pay attention during, my treatment. (Participant 4, Group 2)

The dentist always doesn't wash his hands. But I've already done my orthodontics and if I move to another dentist, it costs more. If I pointed out that he didn't wash his hands, I thought I would be disadvantaged, so I think I've never been able to tell him. (Participant 3, Group 1)

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Knowledge and skill

Level of health literacy and extent of knowledge

When I asked my doctor about my medication, "I've heard there is this certain drug. Why didn't you prescribe this drug for me before?" And he replied, "The other one that I prescribed is better for your hormone levels." I couldn't understand what he said after that, so I couldn't ask more. (Participant 1, Group 1)

He just explained in terms that he was used to. So, I had no idea about the terminology, if it was a diaphragm or something else. (Participant 6, Group 1)

If I took the drug, my skin became thinner when taking a high dose of an anticancer drug. There were too many side effects. I felt outraged and became sad. "What a fool I am. I should have

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|  |  |  | spoken up." Or I could have asked about the medication at another hospital. But the medical field is too professional for me. So I had no choice but to trust him. (Participant 2, Group 2)  |
|  | Educational needs to participate in their care process |  | I need information on what I can do and check specifically depending on the situation. (Participant 2, Group 2)  |
|  |  |  | I think it would be nice if I could get an app that suggests a potential diagnosis after inputting my age and symptoms and so on. Because I can ask a doctor, "In my opinion, my symptom is A, isn't it?" A doctor may miss the exact diagnosis owing to being busy, right? So, in that case, if I know the information on my symptoms and talk to him, then he can consider the diagnosis and go forward with his treatment plan in the right direction. (Participant 2, Group 1) |
|  |  |  | When I get the medicine at the pharmacy, the information about that medicine is written on the medicine packet, and I think this is very useful for patients. (Participant 2, Group 2)   |
|  |  |  | I think it's pretty important to know what questions I can ask. If I have a list of things to look out for and check, it is easy for me to get more involved. (Participant 4, Group 1)   |
|  |  |  | I want to know what kinds of rights patients have. (Participant 6, Group 2)  |
| Factors involving the relationship between | Supportive relationships                               | Attention on a patient and endeavor to | One doctor abrasively listened to me, not my father-in-law, because he couldn't communicate well, and gave only a routine prescription. On the other   |

|                                   |   |   |
|-----------------------------------|---|---|
| patients and healthcare providers | communicate   | hand, another doctor tried to talk directly to my father-in-law in detail, and then, to verify, asked me, “He seemed to express such-and-such. Did you find he had the same symptoms at home?” and explained his conclusions to me in detail. I was able to trust that doctor more. (Participant 1, Group 1)  |
| No opportunity to participate     | Hierarchical relationship between the patient and healthcare provider | When the nurse simply said, “A certain virus was found. When are you available for your next appointment?”, I was so worried because I had no idea what the virus was. So I asked the nurse to explain about the virus, and the nurse was willing to answer all of my questions. (Participant 1, Group 2)   |
|                                   | Lack of communication between healthcare provider and the patient     | When I asked what I didn’t understand one more time, the doctor responded with a high and angry tone. After experiencing that, although I didn’t catch what he said, I didn’t ask him and instead asked another healthcare provider because I already knew what his response would be if I asked again. (Participant 3, Group 2)  |
|                                   |   | I had a surgery for ovarian tumor removal. My doctor briefly explained that I could choose either laparoscopic surgery or laparotomy. And I was moved to the next room to schedule the surgery. The other doctor told me in the room that “even though laparoscopic surgery is covered by insurance, it is a little more expensive, while laparotomy is cheap.” He just explained it this way. (Participant 1, Group 1) |
|                                   |   | I haven’t felt that I was able to fully ask questions or get satisfactory answers. (Participant 6, Group 1)   |

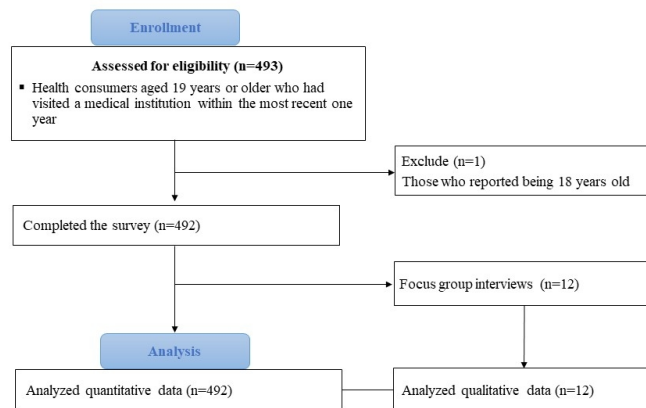
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| 5  |             | Failure to      | In the process of my treatment, I didn't  |
| 6  |             | share treatment | feel a sense of care from any doctor or   |
| 7  |             | plan with the   | nurse. This is because they only          |
| 8  |             | patient         | checked over my data and wrote            |
| 9  |             |                 | prescriptions, and asked about my         |
| 10 |             |                 | current physical state. I had the same    |
| 11 |             |                 | experience over and over. (Participant    |
| 12 |             |                 | 4, Group 2)                               |
| 13 |             |                 |   |
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| 16 |             |                 |   |
| 17 |             |                 | I asked my doctor what the care plan      |
| 18 |             |                 | was. Then the doctor firmly said, rather  |
| 19 |             |                 | than sharing the future treatment plan,   |
| 20 |             |                 | "Do you want to go to another             |
| 21 |             |                 | hospital?" (Participant 5, Group 2)       |
| 22 |             |                 |   |
| 23 |             |                 |   |
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| 25 |             |                 |   |
| 26 |             |                 | When I try to give my opinion to try to   |
| 27 |             |                 | participate from the patient's position,  |
| 28 |             |                 | whether it is right or wrong... There are |
| 29 |             |                 | doctors who insist unconditionally,       |
| 30 |             |                 | saying "No. The treatment that I am       |
| 31 |             |                 | doing is right." In this case, I am not   |
| 32 |             |                 | able to say anything, and I am no longer  |
| 33 |             |                 | willing to participate. (Participant 2,   |
| 34 |             |                 | Group 1)                                  |
| 35 |             |                 |   |
| 36 |             |                 |   |
| 37 | Healthcare  | Complexity      | Complex care                              |
| 38 | environment | of the          | procedures                                |
| 39 | factors     | healthcare      |   |
| 40 |             | environment     | It was exhausting for a patient to meet a |
| 41 |             |                 | new healthcare provider every 2 or 3      |
| 42 |             |                 | minutes, and it was hard for me to share  |
| 43 |             |                 | my problems deliberately. When talking    |
| 44 |             |                 | to the final healthcare provider, a chief |
| 45 |             |                 | surgeon who was charge of my surgery,     |
| 46 |             |                 | I was very fatigued so I couldn't think   |
| 47 |             |                 | of what to say. (Participant 1, Group 1)  |
| 48 |             |                 |   |
| 49 |             | Limited time    | My doctor is too busy. I have almost no   |
| 50 |             | to see a doctor | chance to talk to him, because usually    |
| 51 |             |                 | another patient is waiting when I'm       |
| 52 |             |                 | seeing the doctor. So I can't discuss     |
| 53 |             |                 | things fully with my doctor, though I'd   |
| 54 |             |                 | like to ask questions and get answers.    |
| 55 |             |                 | (Participant 2, Group 1)                  |
| 56 |             |                 |   |
| 57 |             |                 |   |
| 58 |             |                 |   |
| 59 |             |                 |   |
| 60 |             |                 | We just took it for granted that we only  |



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|---|---|
|   | listened to a doctor very briefly in the hospital, because a very limited time was allocated to us. (Participant 6, Group 1)  |
| Difference in patient participation by type of medical institutions | When I visit an advanced hospital for surgery or another examination, people who work there don't know about me. So I started to write down details such as when I was ill or where I had pain, and brought it with me before someone asked me about it. (Participant 5, Group 1) |
|   | When I visited an advanced hospital, they gave me information about what drug it was and what side effect it had. However, the clinic did not give me this information. (Participant 3, Group 2)  |

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Supplementary figure 1

338x190mm (96 x 96 DPI)



1  
2  
3  
4 10. 귀하는 주로 건강관련 정보를 어디서 찾으십니까?  
5

6  인터넷  방송매체(TV, 라디오 등)  신문, 잡지 등의 기사  
7

8  전문가(의사, 간호사, 영양사 등)  주위사람(가족, 친구 등)  기타  
9

10 11. 병원에서 본인과 가족이 의료오류를 경험한 적이 있습니까?  
11

12  있다  없다  
13  
14

## 15 II. 환자안전 보고학습시스템 16 17 18

19 1. 귀하는 환자나 보호자로서 병원에서 의료오류를 발견했을 때, 국가에서 운영하는 환자안전 보  
20 고학습시스템(<http://www.kops.or.kr/portal>)을 통해 직접 보고할 수 있다는 것을 알고 계십니까?  
21

22  알고 있다  모른다  
23  
24

25 2. 귀하는 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오  
26 류를 보고할 것 같습니다?  
27  
28

29 \*환자안전 보고란? 환자안전사고의 예방 및 의료 질 향상을 위해 개별 의료기관의 환자안전 전  
30 담인력 또는 기관의 장, 보건의료인, 환자 및 보호자 등 보건의료서비스를 제공하거나 제공받  
31 는 사람이 인지한 환자안전사고 내용을 보고학습시스템(<http://www.kops.or.kr/portal>) 운영기  
32 관에 보고하는 것입니다.  
33  
34

| 35 전혀<br>36 보고하지 않을 것이다 | 37 가끔<br>38 보고할 것이다 | 39 종종<br>40 보고할 것이다 | 41 항상<br>42 보고할 것이다 |
|-------------------------|---------------------|---------------------|---------------------|
| 43 1                    | 44 2                | 45 3                | 46 4                |

다음은 환자참여에 대한 문항입니다.

설문은 3개 영역, 각 13개 문항으로 구성되어 있습니다.

동일한 문항으로

1) 환자 참여 활동에 대한 의향, 2) 환자 참여 활동의 중요성, 3) 환자 참여 활동 경험을 측정합니다.

1) 환자 참여 활동의 의향은 본인의 건강관리와 관련하여 각 환자 참여 행동을 얼마나 할 것 같은지를 묻는 문항입니다.

2) 환자 참여 활동의 중요성은 각 항목의 환자 참여 행동의 환자 안전을 향상시키기 위해 얼마나 중요하다고 생각하는지를 묻는 문항입니다.

3) 환자 참여 활동의 경험은 각 항목의 환자 참여 행동의 경험 정도를 묻는 문항입니다.

해당하는 곳에 표시하여 주십시오.

### Ⅲ. 환자 참여에 대한 의향

병원에 입원하거나 외래를 방문한 환자로서의 경험을 바탕으로 답하여 주십시오. 그런 경험이 없을 경우는 본인이 환자인 상황을 가정하여 답해 주시기 바랍니다. 귀하는 건강 관리와 관련하여 다음과 같은 행동을 얼마나 할 것 같습니다?

|   | 전혀 그렇지 않을 것이다 | 다소 그럴 것이다 | 종종 그럴 것이다 | 매우 그럴 것이다 |
|---|---------------|-----------|-----------|-----------|
| 1. 치료의 결정을 할 때 추가적인 전문 의견이 듣고 싶은 경우 처음 진료를 받던 의사와 다른 의사에게 의견을 구한다.                    | 1             | 2         | 3         | 4         |
| 2. 보건의료직원(예, 의사, 간호사)이 설명했으나 이해하지 못한 부분에 대해 좀 더 자세하게 설명해 줄 것을 요구한다.                   | 1             | 2         | 3         | 4         |
| 3. 진료를 받으러 갈 때, 보건의료직원(예, 의사, 간호사)이 말하는 내용을 이해하고 질문하는 것을 도와줄 수 있도록 가족이나 친척(친구)을 데려간다. | 1             | 2         | 3         | 4         |
| 4. 보건의료직원(예, 의사, 간호사)에게 진료나 처치 전에 손을 씻었는지 물어본다.                                       | 1             | 2         | 3         | 4         |
| 5. 보건의료직원(예, 의사, 간호사)이 약물 알레르기에 대해 물어보지 않더라도 약물 알레르기가 있으면 말한다.                        | 1             | 2         | 3         | 4         |
| 6. 시술을 받기 전에 보건의료직원(예, 의사, 간호사)이 환자의 신원을 확인하지 않을 경우, 확인하도록 요청한다.                      | 1             | 2         | 3         | 4         |
| 7. 시술(수술)을 받기 전에 시술(수술)의 세부사항(예, 목적, 시간이 얼마나 걸리는지, 회복과정 등)에 대해 물어본다.                  | 1             | 2         | 3         | 4         |
| 8. 의사나 간호사에게 설명 받지 않았던 검사(예, 엑스레이, 혈액검사)를 시행하려고 하면 검사 전 필요성과 자세한 설명을 요구한다.            | 1             | 2         | 3         | 4         |
| 9. 검사를 받고 일정한 시간이 지난 후에도 검사결과를 듣지 못한 경우, 의료진이나 병원에 연락을 한다.                            | 1             | 2         | 3         | 4         |
| 10. 진료를 받으러 갈 때 현재 복용하고 있는 모든 약물의 목록이나 약물을 가져간다.                                      | 1             | 2         | 3         | 4         |
| 11. 무슨 약인지 잘 모르겠고 복용한 적이 없는 약을 설명 없이 받았을 때, 약에 대해 물어본다.                               | 1             | 2         | 3         | 4         |
| 12. 약국에서 나오기 전에 정확한 약물을 받았는지 확인한다.  | 1             | 2         | 3         | 4         |
| 13. 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오류를 보고한다.                              | 1             | 2         | 3         | 4         |

#### IV. 환자 참여의 중요성

환자안전\*을 향상시키기 위해 귀하는 건강 관리와 관련하여 다음의 항목이 얼마나 중요하다고 생각하십니까?

\* 환자안전이란? 환자안전은 의료와 관련된 불필요한 위해의 위험을 최소한으로 낮추는 것을 의미합니다(WHO, 2009).

|   | 매우<br>중요<br>하지<br>않다 | 중요<br>하지<br>않다 | 중요<br>하다 | 매우<br>중요<br>하다 |
|---|----------------------|----------------|----------|----------------|
| 1. 치료의 결정을 할 때 추가적인 전문 의견이 듣고 싶은 경우 처음 진료를 받던 의사와 다른 의사에게 의견을 구한다.                    | 1                    | 2              | 3        | 4              |
| 2. 보건의료직원(예, 의사, 간호사)이 설명했으나 이해하지 못한 부분에 대해 좀 더 자세하게 설명해 줄 것을 요구한다.                   | 1                    | 2              | 3        | 4              |
| 3. 진료를 받으러 갈 때, 보건의료직원(예, 의사, 간호사)이 말하는 내용을 이해하고 질문하는 것을 도와줄 수 있도록 가족이나 친척(친구)을 데려간다. | 1                    | 2              | 3        | 4              |
| 4. 보건의료직원(예, 의사, 간호사)에게 진료나 처치 전에 손을 씻었는지 물어본다.                                       | 1                    | 2              | 3        | 4              |
| 5. 보건의료직원(예, 의사, 간호사)이 약물 알레르기에 대해 물어보지 않더라도 약물 알레르기가 있으면 말한다.                        | 1                    | 2              | 3        | 4              |
| 6. 시술을 받기 전에 보건의료직원(예, 의사, 간호사)이 환자의 신원을 확인하지 않을 경우, 확인하도록 요청한다.                      | 1                    | 2              | 3        | 4              |
| 7. 시술(수술)을 받기 전에 시술(수술)의 세부사항(예, 목적, 시간이 얼마나 걸리는지, 회복과정 등)에 대해 물어본다.                  | 1                    | 2              | 3        | 4              |
| 8. 의사나 간호사에게 설명 받지 않았던 검사(예, 엑스레이, 혈액검사)를 시행하려고 하면 검사 전 필요성과 자세한 설명을 요구한다.            | 1                    | 2              | 3        | 4              |
| 9. 검사를 받고 일정한 시간이 지난 후에도 검사결과를 듣지 못한 경우, 의료진이나 병원에 연락을 한다.                            | 1                    | 2              | 3        | 4              |
| 11. 진료를 받으러 갈 때 현재 복용하고 있는 모든 약물의 목록이나 약물을 가져간다.                                      | 1                    | 2              | 3        | 4              |
| 11. 무슨 약인지 잘 모르겠고 복용한 적이 없는 약을 설명 없이 받았을 때, 약에 대해 물어본다.                               | 1                    | 2              | 3        | 4              |
| 12. 약국에서 나오기 전에 정확한 약물을 받았는지 확인한다.  | 1                    | 2              | 3        | 4              |
| 13. 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오류를 보고한다.                              | 1                    | 2              | 3        | 4              |

## V. 환자 참여 경험

귀하는 건강 관리와 관련하여 다음 활동에 얼마나 자주 참여하십니까?

|   | 전혀 그렇지 않다 | 가끔 그렇다 | 자주 그렇다 | 항상 그렇다 |
|---|-----------|--------|--------|--------|
| 1. 치료의 결정을 할 때 추가적인 전문 의견이 듣고 싶은 경우 처음 진료를 받던 의사와 다른 의사에게 의견을 구한다.                    | 1         | 2      | 3      | 4      |
| 2. 보건의료직원(예, 의사, 간호사)이 설명했으나 이해하지 못한 부분에 대해 좀 더 자세하게 설명해 줄 것을 요구한다.                   | 1         | 2      | 3      | 4      |
| 3. 진료를 받으러 갈 때, 보건의료직원(예, 의사, 간호사)이 말하는 내용을 이해하고 질문하는 것을 도와줄 수 있도록 가족이나 친척(친구)을 데려간다. | 1         | 2      | 3      | 4      |
| 4. 보건의료직원(예, 의사, 간호사)에게 진료나 처치 전에 손을 씻었는지 물어본다.                                       | 1         | 2      | 3      | 4      |
| 5. 보건의료직원(예, 의사, 간호사)이 약물 알레르기에 대해 물어보지 않더라도 약물 알레르기가 있으면 말한다.                        | 1         | 2      | 3      | 4      |
| 6. 시술을 받기 전에 보건의료직원(예, 의사, 간호사)이 환자의 신원을 확인하지 않을 경우, 확인하도록 요청한다.                      | 1         | 2      | 3      | 4      |
| 7. 시술(수술)을 받기 전에 시술(수술)의 세부사항(예, 목적, 시간이 얼마나 걸리는지, 회복과정 등)에 대해 물어본다.                  | 1         | 2      | 3      | 4      |
| 8. 의사나 간호사에게 설명 받지 않았던 검사(예, 엑스레이, 혈액검사)를 시행하려고 하면 검사 전 필요성과 자세한 설명을 요구한다             | 1         | 2      | 3      | 4      |
| 9. 검사를 받고 일정한 시간이 지난 후에도 검사결과를 듣지 못한 경우, 의료진이나 병원에 연락을 한다.                            | 1         | 2      | 3      | 4      |
| 12. 진료를 받으러 갈 때 현재 복용하고 있는 모든 약물의 목록이나 약물을 가져간다.                                      | 1         | 2      | 3      | 4      |
| 11. 무슨 약인지 잘 모르겠고 복용한 적이 없는 약을 설명 없이 받았을 때, 약에 대해 물어본다.                               | 1         | 2      | 3      | 4      |
| 12. 약국에서 나오기 전에 정확한 약물을 받았는지 확인한다.  | 1         | 2      | 3      | 4      |
| 13. 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오류를 보고한다.                              | 1         | 2      | 3      | 4      |

설문이 종료되었습니다.



**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

| Section/Topic                | Item # | Recommendation   | Reported on page # |
|------------------------------|--------|--|--------------------|
| <b>Title and abstract</b>    | 1      | (a) Indicate the study's design with a commonly used term in the title or the abstract   | #1-3               |
|                              |        | (b) Provide in the abstract an informative and balanced summary of what was done and what was found  | #2-3               |
| <b>Introduction</b>          |        |  |                    |
| Background/rationale         | 2      | Explain the scientific background and rationale for the investigation being reported   | #4-5               |
| Objectives                   | 3      | State specific objectives, including any prespecified hypotheses   | #6                 |
| <b>Methods</b>               |        |  |                    |
| Study design                 | 4      | Present key elements of study design early in the paper  | #6                 |
| Setting                      | 5      | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection  | #7-8               |
| Participants                 | 6      | (a) Give the eligibility criteria, and the sources and methods of selection of participants  | #7-8               |
| Variables                    | 7      | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable   | #8-9               |
| Data sources/<br>measurement | 8*     | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | #8-9               |
| Bias                         | 9      | Describe any efforts to address potential sources of bias  | NA                 |
| Study size                   | 10     | Explain how the study size was arrived at  | #7                 |
| Quantitative variables       | 11     | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why   | #8-9               |
| Statistical methods          | 12     | (a) Describe all statistical methods, including those used to control for confounding  | #9-10              |
|                              |        | (b) Describe any methods used to examine subgroups and interactions  | #8-9               |
|                              |        | (c) Explain how missing data were addressed  | #7                 |
|                              |        | (d) If applicable, describe analytical methods taking account of sampling strategy   | #7-8               |
|                              |        | (e) Describe any sensitivity analyses  | NA                 |
| <b>Results</b>               |        |  |                    |

|                          |     |  |                        |
|--------------------------|-----|--|------------------------|
| Participants             | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed            | #10                    |
|                          |     | (b) Give reasons for non-participation at each stage   | NA                     |
|                          |     | (c) Consider use of a flow diagram   | Supplementary figure 1 |
| Descriptive data         | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders   | #10-12                 |
|                          |     | (b) Indicate number of participants with missing data for each variable of interest  | #7                     |
| Outcome data             | 15* | Report numbers of outcome events or summary measures   | #10-12, #25-30         |
| Main results             | 16  | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | #10-12, #25-30         |
|                          |     | (b) Report category boundaries when continuous variables were categorized  | #10-12, #25-30         |
|                          |     | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period   | NA                     |
| Other analyses           | 17  | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses   | #12-14, #31-36         |
| <b>Discussion</b>        |     |  |                        |
| Key results              | 18  | Summarise key results with reference to study objectives   | #15-18                 |
| Limitations              | 19  | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias   | #18                    |
| Interpretation           | 20  | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence                                   | #15-18                 |
| Generalisability         | 21  | Discuss the generalisability (external validity) of the study results  | #15-18                 |
| <b>Other information</b> |     |  |                        |
| Funding                  | 22  | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based  | #19                    |

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

# BMJ Open

## A mixed-methods investigation of health consumers' perception and experience of participation in patient safety activities

|                                 |  |
|---------------------------------|--|
| Journal:                        | <i>BMJ Open</i>  |
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| Complete List of Authors:       | Lee, Nam-Ju; Seoul National University, College of Nursing; Seoul National University, The Research Institute of Nursing Science Ahn, Shinae; Seoul National University, The Research Institute of Nursing Science<br>Lee, Miseon; Seoul National University, College of Nursing |
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6 1 **A mixed-methods investigation of health consumers' perception and experience of**  
7  
8 2 **participation in patient safety activities**

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10 3 Nam-Ju Lee,<sup>1,2</sup> Shinae Ahn,<sup>2</sup> Miseon Lee<sup>1</sup>

11  
12 4  
13  
14  
15 5 <sup>1</sup> College of Nursing, Seoul National University, Seoul, South Korea

16  
17 6 <sup>2</sup> The Research Institute of Nursing Science, Seoul National University, Seoul, South Korea

18  
19  
20  
21  
22 7  
23 8 **Corresponding author:**

24  
25 9 Shinae Ahn, RN, PhD, Senior researcher

26  
27 10 Affiliation: The Research Institute of Nursing Science, Seoul National University, Seoul,

28  
29 11 South Korea

30  
31 12 Address: The Research Institute of Nursing Science, Seoul National University, 103 Daehak-  
32  
33 13 ro, Jongno-gu, Seoul, 03080, South Korea

34  
35 14 E-mail: shinae.ahn17@gmail.com

36  
37 15 Telephone: 82-2-740-8494

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39 16  
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41 17 **Word count:** 4,416 word

## 1 **Abstract**

### 2 **Objectives**

3 This study aimed to examine the factors influencing patient safety behaviors and to explore  
4 health customers' experiences of patient participation in the healthcare system.

### 5 **Design**

6 A mixed-methods sequential explanatory design was employed using a survey and focus  
7 group interviews with health consumers.

### 8 **Setting**

9 The study was conducted in South Korea using an online survey tool.

### 10 **Participants**

11 Survey data were collected from 493 Korean adults, aged 19 years or older, who had visited  
12 hospitals within the most recent one year. Focus group interviews were conducted in 2 groups  
13 of 6 participants each among those of the survey participants who agreed to participate in  
14 focus groups.

### 15 **Main outcome measures**

16 The survey measured the recognition of the importance of participation, extent of willingness  
17 to participate, and experience of engaging in patient safety activities using a 4-point Likert  
18 scale. Qualitative data were collected through focus group interviews to explore health  
19 consumers' experience of patient participation in hospital care, and the data were analyzed  
20 using content analysis.

### 21 **Results**

22 The average score for experience of participation in patient safety behaviors ( $2.13\pm 0.63$ ) was  
23 found to be lower than those of recognition of the importance of participation ( $3.27\pm 0.51$ )  
24 and willingness to participate ( $2.62\pm 0.52$ ). By integrating the results of the quantitative and

1 qualitative data analysis, the factors associated with the experience of engaging in healthcare  
2 behavior included patient-related factors, illness-related factors, factors involving relationship  
3 between patients and healthcare providers, and healthcare environment factors.

#### 4 **Conclusions**

5 To improve patient participation, it is necessary to create a healthcare environment in which  
6 patients can speak comfortably and to provide an education program reflecting the patients'  
7 needs. Also, healthcare providers must consider patients as partners for patient safety. Shared  
8 decision-making procedures and patient-centered care and patient safety policies should be  
9 established in hospitals.

#### 11 **Strengths and limitations of this study**

- 12 ● This study was the first to examine patient participation in patient safety activities in  
13 South Korea and provided evidence on what factors affect actual patient safety  
14 activities using mixed methods.
- 15 ● Most studies on patient participation have been descriptive studies, but this study  
16 performed a regression analysis and focus group interviews to identify factors that  
17 affect patient participation in patient safety activities, and finally, integrated the  
18 results of both quantitative and qualitative data.
- 19 ● The results of this study can be used to develop the content of patient participation  
20 programs and contribute to creating a patient-centered healthcare environment.
- 21 ● The sample in this study was recruited through websites and social media, so the  
22 generalizability of the findings is limited.

## 1 INTRODUCTION

2 Patient participation in health care is one strategy for improving patient safety. Patients  
3 who are more involved in their care tend to experience better health outcomes. Research  
4 shows that patients' taking an active role in their health care has positive impacts on patient  
5 safety, such as preventing errors,<sup>1</sup> safer medication management,<sup>2</sup> better self-management  
6 behavior,<sup>3</sup> and decreased use of healthcare services.<sup>4</sup>

7 The concept of patient participation is defined as the desire and capability to actively  
8 participate in care.<sup>5</sup> To enhance patient participation for patient safety, it is important to  
9 encourage patients to participate in patient safety activities while receiving care in medical  
10 institutions. The safety activities that patients could participate in can be classified into four  
11 types (speaking up, asking questions, finding health information, and engaging in the  
12 healthcare process). Patients can speak up if they have questions or concerns about their  
13 needs, preferences, and ideas (eg, asking a healthcare provider whether they have washed  
14 their hands can contribute to a patient's safe treatment).<sup>6,7</sup> Patients should ask questions and  
15 ask about their own health status if anything is unclear in their care process (eg, asking what  
16 the patient's health problem is),<sup>8</sup> seek information about their care (eg, asking for resources  
17 and websites where patients can learn),<sup>6</sup> and participate in all decisions about their treatment  
18 through a shared decision-making process (eg, the patient sharing their needs, symptoms, and  
19 wishes in order to make healthcare decisions together with their healthcare providers).<sup>8,9</sup>

20 Given the growing recognition and encouragement of patients' active role in health care,  
21 several international organizations have developed educational materials to increase patient  
22 participation to promote patient safety and quality of care.<sup>10-14</sup> In the United States, the  
23 Agency for Healthcare Research and Quality has developed guidelines for patients to prevent  
24 errors and obtain safer care,<sup>12</sup> the Joint Commission launched the Speak Up campaign to help



1 patients and their family caregivers play active roles in care,<sup>13</sup> and the National Patient Safety  
2 Foundation has created a checklist of actions patients can take to reduce harm.<sup>14</sup> The  
3 Canadian Patient Safety Institute in Canada has suggested strategies and evidence-based  
4 guidance on engaging patients in patient safety.<sup>6</sup> Also, the Australian Commission on Safety  
5 and Quality in Health care in Australia has developed a booklet to support patients being  
6 actively involved in their care.<sup>11</sup>

7       While the guidelines and materials for patients have been developed, there is a lack of  
8 evidence on the extent of patients' actual experience of participating in patient safety  
9 activities. Several studies have investigated patients' willingness to participate in safety-  
10 related behaviors by quantitative method using surveys.<sup>15-17</sup> However, these previous studies  
11 focused more on patients' inclination to perform safety practices, and there have been few  
12 studies on patients' actual participation experiences using quantitative data. One descriptive  
13 study assessing patients' experience in performing error-prevention behaviors while  
14 hospitalized, showed that patients experienced asking general questions about the purpose of  
15 medication (75.2%) and medical care (85.1%) but had less experience asking healthcare  
16 providers about handwashing (4.6%).<sup>18</sup> Patients who are more comfortable engaging in  
17 safety-related behaviors are more likely to participate in safety activities.<sup>18</sup>

18       Moreover, gathering information on what factors affect patient participation is  
19 important. Some studies have described patients' perception of participation in patient safety  
20 by qualitative method through interviews.<sup>19-21</sup> Some factors were found to negatively affect  
21 patients' participation in their care, such as fear of reprisals from staff, an inability to provide  
22 feedback to staff, and a perception that safety is generally not patients' priority.<sup>19</sup> On the  
23 other hand, feeling connected with their healthcare provider, having an opportunity to provide  
24 feedback on experiences of safety, and sharing responsibility positively affected patient

1 participation.<sup>19-21</sup> Evidence on these factors affecting patient participation can reduce the gap  
2 between the patients' intention and actual experience of patient participation in patient safety  
3 activities because intention does not necessarily lead to actual participation behaviors.

4 A mixed-methods design has the advantage of not only producing a measure of  
5 experience of participation but also deeply exploring patients' perspectives about patient  
6 participation. However, there is a lack of studies focusing on patient participation using  
7 mixed methods. To examine the factors influencing actual participation in various safety  
8 practices or to investigate the relationship between intention and actual behavior, the need for  
9 a qualitative focus group interview or a mixed method using quantitative and qualitative  
10 approaches has been suggested.<sup>15 16</sup>

11 Thus, in this study, we investigated health consumers' recognition of the importance of  
12 their participation, their extent of willingness to participate in safety activities, and their  
13 experience of participating in patient safety activities through a survey. We also explored  
14 healthcare consumers' experience of patient participation and factors influencing their  
15 experience of engaging in healthcare behaviors in depth.

## 17 **METHODS**

### 18 **Study design**

19 This study used a mixed-methods sequential explanatory design including a survey and  
20 focus group interviews. According to this design proposed by Creswell and Zhang,<sup>22</sup> we  
21 gathered and analyzed quantitative data first, and then used qualitative data collection and  
22 analyzed that qualitative data later to help explain the quantitative results.

## 1 **Participants and data collection**

2 To investigate health consumers' perception and experience of participation in patient  
3 safety activities, we conducted an online survey between January 25 and February 3, 2018, in  
4 South Korea. The target population comprised Korean-speaking Korean adults aged 19 years  
5 or older who had visited a medical institution within the most recent one year. We recruited  
6 participants through two websites, the Korea Alliance of Patients' Organizations  
7 (<http://www.koreapatient.com/>) and Resources for Enhancing Safety, Competency, and  
8 Utilization for Education (RESCUE, <http://patientsafety.snu.ac.kr/>), as well as through social  
9 media. The websites are produced by nonprofit organizations. The Korean Alliance of  
10 Patients' Organizations is a patient advocacy organization that claims the rights of patients to  
11 prevent errors and create a patient-centered environment. RESCUE is a health information  
12 website that provides educational materials and resources for patient safety. The websites  
13 posted a description of the study and the link to the online survey. The survey was  
14 implemented using the Qualtrics online survey tool (<https://www.qualtrics.com>). A total of  
15 493 participants completed the survey, and we excluded from the analysis the data of 1  
16 respondent who reported being 18 years old (Supplementary figure 1). The total sample size  
17 exceeded the minimum of 103 required for multiple linear regression, based on Cohen's  
18 statistical method (significance level  $\alpha = 0.05$ ,  $1-\beta = 0.80$ , effect size 0.15, predictors 7).

19 We posted a description of the focus group interview on the website to recruit  
20 participants. Among the survey respondents, with those who agreed to participate in a focus  
21 group, focus group interviews were conducted March 20-22, 2018. The focus group  
22 interviews were conducted in 2 groups of 6 participants each, for 2 hours with each group in a  
23 seminar room at a university. We divided them to the two groups according to their  
24 availability, gender, and ages. Each interview involved all of the researchers. Two researchers

1 (NL or SA) of the research team each facilitated one of the focus group interviews, and one researcher (ML) played a role as a note taker to produce accurate notes while assisting with the focus groups. At the end of the interview, the interviewer summarized the conversation and repeated key information to request confirmation for data accuracy. The list of primary interview questions and safety activities in healthcare settings were sent to participants in advance to inform them on the areas of discussion to be covered. The key interview questions were as follows: “What do you think about patient participation as it relates to patient safety?”, “In your opinion, how important is it to you to participate patient safety activities when you visit the hospital and receive medical care or treatment?”, “To what extent do you think you can participate in patient safety activities as a patient or their caregiver?”, “How do you think patient involvement in patient safety activities could affect patient safety?”, and “Can you tell us specifically about your experiences in which you participated in the care or treatment process?”

## Measures

16 Patient participation was measured using a tool developed to measure the inclination to engage in patient safety practices.<sup>15</sup> We added 3 items from the relevant literature<sup>18 23 24</sup> (bringing a friend or family member to a doctor’s appointment; telling healthcare workers about any drug allergies; reporting errors to a national reporting system if they notice errors in the hospital). Thus, the final survey tool comprised 13 items, and the questions included a list of 13 specific safety-related behaviors through which patients can engage while undergoing care in medical institutions (Supplementary survey questionnaire). To explore the factors influencing patient participation, we grouped variables into the following three categories based on a literature review<sup>15 18 23-25</sup>: patient-related (recognition of the importance

1 of patient participation, willingness to participate, and socio-demographic variables), illness-  
2 related (number of visits to medical institutions and prior experience of patient safety  
3 incidents), and healthcare environment-related (types of medical institutions).

4 Four-point Likert scales were used to assess the recognition of the importance of  
5 participation (1=not very important, 2=not important, 3=important, 4=very important) in  
6 patient safety activities and extent of health consumers' willingness to participate (1=not at  
7 all, 2=somewhat likely, 3=likely, 4=very likely). Participants were asked to indicate how  
8 often they had experienced each patient safety activity in the hospital using a 4-point Likert  
9 scale (1=not at all, 2=sometimes, 3=often, 4=always). The reliability of the finalized  
10 questionnaire was evaluated using Cronbach's alpha coefficient. The Cronbach's alpha  
11 values of the three sections were 0.814, 0.900, and 0.884.

### 13 **Data analysis**

14 The quantitative data were analyzed using SPSS 24.0 (IBM Corp., Armonk, NY, USA).  
15 Participants' general characteristics and the scores of participants' recognition of the  
16 importance of participation, willingness to participate, and participation experience were  
17 summarized using descriptive statistics. An independent t-test and one-way ANOVA were  
18 used to identify differences in recognition of the importance of participation, willingness to  
19 participate, and experience of patient participation by general characteristics. For correlations  
20 between recognition of the importance of participation, willingness to participate, and  
21 experience of participation, Pearson's correlation coefficients were used. Multiple linear  
22 regression analysis was performed to identify variables associated with experience of patient  
23 participation.

1 The qualitative data were analyzed using conventional content analysis.<sup>26</sup> All focus  
2 group interviews were recorded and transcribed. The collected data were written immediately  
3 after the interview, and the field notes were used for analysis. One researcher (SA) led the  
4 first analysis by reading the transcript repeatedly, and two researchers (NL, ML) performed a  
5 second review. Emergent themes were discussed in depth, then the researchers extracted  
6 codes, categories, and themes together during content analysis until agreement was reached.

## 8 **Patient and Public involvement**

9 Neither patients nor the public were involved in the design, development of the research  
10 questions, outcome measure, or conduct of this study. To further facilitate the recruitment of  
11 patients, advertisements were posted on the websites.

## 13 **RESULTS**

### 14 **Participant characteristics**

15 A total of 492 completed surveys were included in the analysis. The mean age of the  
16 respondents was 31.7 years (SD: 10.52), 74.8% of respondents were female, most had  
17 graduated from college or above (n=373, 75.8%), and most were unmarried (n=310, 63.0%).  
18 The monthly income of most participants (n=174, 35.4%) was less than 850,000 won. The  
19 most frequently visited medical institutions were clinics or public health centers (n=343,  
20 69.7%), and more than 60% of the participants had visited medical institutions less than 10  
21 times within the most recent one year. Most of the participants (n=414, 84.1%) reported  
22 going alone when they visited medical institutions, and 65% of the participants had  
23 experienced patient safety incidents. The vast majority of the participants (n=483, 98.2%) did  
24 not know the fact that they could report patient safety incidents to the national reporting and

1 learning system themselves (Table 1).

### 3 **Participation in patient safety activities**

4 Among this study's findings on patient safety activities, average scores were as follows:  
5 recognition of the importance ( $3.27\pm 0.51$ ), the extent of willingness ( $2.62\pm 0.52$ ), and the  
6 experience of participation ( $2.13\pm 0.63$ ). Respondents' experience of engaging in patient  
7 safety activities varied considerably. Some respondents reported that they always ask about  
8 the details of a procedure and the reason for a procedure before it is performed (30.5%), ask  
9 for an explanation of care that they were not told about by their doctor or nurse (22.0%), and  
10 call when they have not received the results of a medical test they underwent (23.8%). Fewer  
11 respondents had the experience of asking healthcare workers if they had washed their hands  
12 (2.7%), bringing a friend or family member to a doctor's appointment (5.1%), or asking for  
13 healthcare workers to confirm patient identity before performing a procedure (6.3%) (Table  
14 2).

15 The scores on recognizing the importance of participation showed significant differences  
16 according to gender ( $t=-3.53, p<.001$ ) and education level ( $t=-2.27, p=.024$ ). The scores of  
17 respondents' willingness to participate differed significantly by education level ( $t=-2.19,$   
18  $p=.029$ ), the type of accompanying caregivers ( $F=2.45, p=.045$ ), and whether they had  
19 experienced patient safety incidents or not ( $t=-2.19, p=.029$ ). The scores of participation  
20 experience differed significantly by gender ( $t=-2.49, p=.013$ ), the type of medical institutions  
21 frequently visited ( $F=5.12, p=.002$ ), the type of accompanying caregivers ( $F=3.29, p=.011$ ),  
22 and previous experience of patient safety incidents ( $t=-3.34, p=.001$ ) (Table 3).

## 1 **Factors influencing experience of patient participation**

2 The respondents' experience of patient participation showed a significant positive  
3 correlation with recognition of the importance of participation ( $r=.23, p<.001$ ), and their  
4 willingness to participate ( $r=.63, p<.001$ ). In addition, participants' recognition of the  
5 importance of participation showed a significantly positive correlation with willingness to  
6 participate ( $r=.34, p<.001$ ).

7 Multiple linear regression was used to examine the relationship of the experience of  
8 patient participation with three sets of factors: patient-related, illness-related, and healthcare  
9 environment-related (Table 4). The result of the multiple linear regression showed that the  
10 patient who frequently visited a hospital ( $\beta=0.117, p=.001$ ) and a general or advanced general  
11 hospital ( $\beta=0.077, p=.035$ ) rather than a clinic or public health center, visited medical  
12 institutions more than 25 times in the most recent one year ( $\beta=0.095, p=.013$ ) rather than less  
13 than 5 times, and had a high score on willingness to participate ( $\beta=0.600, p<.001$ ) was  
14 expected to have more experience of participating in patient safety activities.

## 16 **Focus group interviews: Health consumers' experience of patient participation in** 17 **hospital care**

18 Twelve health consumers participated in the interview. Four interviewees were male and  
19 eight were female. The average age was 40 years (range, 29 to 55 years). Ten interviewees  
20 had visited medical institutions more than 5 times in last year and six interviewees had  
21 experienced patient safety incidents. Content analysis produced five categories extracted  
22 under three themes (Table 5).

23 The results of the focus group interviews showed that patient participation in medical  
24 institutions appeared to be influenced by three types of factors: patient-related factors, factors



1 involving the relationship between patients and healthcare providers, and healthcare  
2 environment factors.

#### 3 4 ***Patient-related factors***

5 Some focus group members reported that patient participation in their care process  
6 resulted in a different treatment outcome. The participants were actively involved in their  
7 care process through patient safety behaviors such as asking for information. Going to the  
8 hospital with family members was a motivating factor for patient participation. Their family  
9 members helped patients to ask questions, check their prescriptions, and remind them of what  
10 they should say to the doctor. In addition, participants reported that their previous experience  
11 of a patient safety incident and their perception of the importance of patient safety activities  
12 made them more active patients. However, the participants were worried about having any  
13 disadvantages in their care if they pointed out healthcare providers' behaviors which could  
14 threaten patient safety. This undermined their willingness to participate.

15 In order to understand the purpose of treatment and actively engage in their treatment  
16 process while being in the hospital, they emphasized the need to know what is going on.  
17 However, they did not have enough knowledge about their health care and felt it was difficult  
18 to understand their care process, including their medication, diagnosis, and treatment plan.  
19 Therefore, they could not share in the development of the treatment plan with their healthcare  
20 providers. Participants thought it was important to understand their health care by being  
21 informed about what patients have to do or what patients can do. There were various topics  
22 on which participants wanted to be educated such as disease, diagnosis, treatment,  
23 examination, and medication. Participants also thought it was important for patients to know  
24 what questions should be asked.

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### ***Factors involving the relationship between patients and healthcare providers***

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In order to participate in patient safety activities in the care process, it was important that patients establish a supportive relationship with healthcare providers. Explaining the details of treatment, listening to patients, and paying attention to patients were important factors for promoting patient participation.

4

On the other hand, a hierarchy existed between doctors and patients. Focus group members mentioned that they felt they had not received satisfactory explanations from health care professionals, but they also felt they could not ask a follow-up or repeat question, even if they wanted to. When a patient asked a doctor a question, the doctor was often annoyed and did not explain or share his or her treatment plan. Focus group participants reported that their hesitation to participate was also related to this hierarchical relationship between patients and healthcare providers.

5

### ***Healthcare environment factors***

6

All participants stated that the processes and procedures for receiving care were very complex in hospitals, and the time allocated to see a doctor for treatment and care was very limited. Also, the type of healthcare delivery system, such as clinic or advanced hospital, affected the patients' willingness to participate in patient safety activities. Participants were more prepared with their health information when they visited a higher level of medical institution, and they also received more information from the medical institution.

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By integrating the results of the quantitative and qualitative data analysis, this study showed that the factors influencing patient participation in medical institutions could be

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6 1 categorized into four factors: patient-related factors, illness-related factors, factors involving  
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8 2 the relationship between patients and healthcare providers, and healthcare environment  
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10 3 factors.

## 15 5 **DISCUSSION**

17 6 This is the first study to investigate patient participation in patient safety activities in  
18  
19 7 South Korea from the health consumer's viewpoint. This study provided evidence on what  
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21  
22 8 factors affect actual patient safety behaviors.

24 9 This study found that the average score for experience of participation in patient safety  
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26 10 behaviors was lower than those of recognition of the importance of participation and  
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28 11 willingness to participate. The frequency of health consumers' experience of participation in  
29  
30 12 patient safety activities varied considerably. Among patient safety activities, the most  
31  
32 13 frequently performed were asking general questions such as "the details of surgery" and "an  
33  
34 14 explanation of what the patient doesn't understand". On the other hand, "asking health care  
35  
36 15 workers to wash their hands" was the patient safety behavior with the lowest average scores  
37  
38 16 for intention and experience. These results were consistent with previous findings.<sup>15</sup>  
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41 17 Specifically, asking healthcare workers wash their hands has been considered a challenging  
42  
43 18 behavior,<sup>16</sup> with various potential explanations proposed in previous research. Patients  
44  
45 19 themselves felt uncomfortable with asking about handwashing,<sup>18</sup> and they were worried that  
46  
47 20 healthcare workers might feel uncomfortable with this question.<sup>16</sup> In addition, patients  
48  
49 21 thought that questioning healthcare providers about their behavior could imply criticizing  
50  
51 22 their incompetence, and therefore they were reluctant to do so.<sup>15</sup> In the qualitative interview  
52  
53 23 of our study, we learned that patients worried about encountering any disadvantages in  
54  
55 24 treatment if they were to question a healthcare provider when they found something were not  
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1 right. These findings might reflect that patients prefer to passively participate in their care,  
2 but it also might be related to the healthcare environment where patients cannot actively  
3 communicate or raise questions and concerns with their clinicians.

4 The relationships among patients' perception of importance, their willingness, and their  
5 experience of patient participation were found to correlate in the quantitative results of this  
6 study. Likewise, the qualitative results showed that the perception of the importance of  
7 patient participation increased willingness and experience of patient participation. This  
8 finding is consistent with a previous study that explored barriers and facilitators to patient  
9 involvement in reporting safety experiences within care transfer.<sup>19</sup> When patients  
10 conceptualized patient safety, they were likely to provide feedback on safety experiences.<sup>19</sup>  
11 Patients who perceived that patient safety was not their responsibility preferred to adopt a  
12 passive role in their care.<sup>19 27 28</sup>

13 Our study found that patients' extent of knowledge on health care was an important  
14 influence on patient participation in safety activities. Patient education can help to increase  
15 patients' knowledge related to their health and positively affect their attitude toward safety  
16 practices.<sup>29</sup> Therefore, healthcare providers must consider developing and implementing  
17 effective education for patients. When healthcare providers develop education program or  
18 strategies to improve patient participation, a patient's abilities, needs, and preferences for  
19 participation must be taken into consideration.<sup>30</sup> In this study's findings, health consumers  
20 wanted education programs focusing on "a question list they can ask health professionals",  
21 "patient rights and responsibilities", and "a variety of information related to treatment  
22 including disease and diagnosis, and medication". Thus, our study's findings suggest  
23 developing an education program reflecting these educational needs.

1 The quantitative and qualitative results of this study showed that patients with caregivers  
2 had more willingness and motivation to participate in patient safety and were more involved  
3 in patient safety activities than unaccompanied patients were. Increased patient and family  
4 engagement is associated with improved patient outcomes and reduced utilization of  
5 healthcare services,<sup>31 32</sup> and it is recommended that medical institutions also encourage not  
6 only patients but also their family members to participate in safety activities. This could be a  
7 way of increasing the overall frequency of actual patient safety activities and that of specific  
8 activities like “bringing a friend or family member to a doctor’s appointment” in medical  
9 institutions.

10 Most patients felt that the relationship between patients and healthcare providers was  
11 hierarchical, which was one of the barriers to participation. According to a previous  
12 intervention study that developed a prototype consumer reporting system for medical errors,  
13 the contributing factors of medical mistakes included problems with communication and staff  
14 responsiveness to patients.<sup>33</sup> However, patients can be motivated to participate in patient  
15 safety activities through open communication with, positive feedback from, and supportive  
16 relationships with healthcare providers. According to Maurer et al.,<sup>34</sup> healthcare providers’  
17 negative reactions can be a barrier to patient participation, while their active invitation for  
18 patients to participate can be a facilitator. Thus, healthcare providers must support and guide  
19 patients to participate. Even if patients are willing to participate in safety activities, they  
20 might be uncertain about how to be involved. It is important that healthcare providers  
21 consider patients as partners for patient safety<sup>35</sup> and encourage them to speak up if they have  
22 a concern. However, according to Fisher et al., nearly half of patients (48.6%) in their study  
23 had experienced a problem during hospitalization, and almost one-third (30.5%) of them  
24 reported they were not always comfortable speaking up.<sup>36</sup> Creating a healthcare environment

1 in which patients can be comfortable raising their concerns may result in safer care and  
2 improved patient participation.<sup>36</sup>

3       The findings of our study showed that the frequency of visiting medical institutions  
4 affected the experience of patient participation. According to Davis et al.,<sup>25</sup> severity of the  
5 patients' illness, symptoms, and treatment plan were associated with patient participation. In  
6 addition, patients' prior experience of illness led to more willingness to participate.<sup>25</sup> This  
7 may be due to the fact that patients with more experience of visiting medical institutions may  
8 have more severe illness and will be likely to be exposed to higher-risk situations such as  
9 testing, drugs, and surgery, all of which call for patient safety activities. It can also be  
10 inferred that patients who have experienced many hospital visits might perceive themselves  
11 as playing a more important role in the care process. Our study showed that over 60% of  
12 participants had visited medical institutions less than 10 times within the most recent one  
13 year. According to the national data reported by National Health Insurance Statistics,<sup>37</sup> the  
14 annual number of outpatient visits to medical institutions per capita is 17.72, which is  
15 calculated by dividing the number of outpatient visits of all citizens (health insurance  
16 patients) by the average annual population covered by health insurance. Considering this  
17 statistic, the participants of our study may be a relatively healthy population, so these  
18 characteristics of the participants may have affected the outcomes in this study. Therefore,  
19 further research is needed to examine the factors influencing experience of participation  
20 including diverse patients' illness-related characteristics such as health status and prior  
21 experience of illness.

22       A complex care process, time constraints, and different types of healthcare delivery  
23 systems were healthcare environmental factors influencing patient participation. A qualitative  
24 study conducted with patients and nursing staff members found similar results—that patients

1 felt that healthcare providers were too busy asking questions or talking.<sup>20</sup> Patients and  
2 families may feel overwhelmed by the healthcare system and highly technical information.<sup>34</sup>  
3 <sup>38</sup> Therefore, the organizational context within hospitals, including workflow processes and  
4 hospital polices, should be changed to be focused on patient-centered care and patient safety.  
5 Then a culture of safety should be established in hospitals.

6 This study had several limitations. First, the study was based on health consumers' self-  
7 reports on their participation in patient safety practices, so these self-reported data may not  
8 accurately reflect their actual practices in medical institutions. Second, convenience sampling  
9 was used to generate the sample, and was drawn from only two websites plus social media, so  
10 people who do not regularly use computers or social network services might not have  
11 participated in this study. Therefore, the young, relatively healthy, and well-educated  
12 population might have accounted for a large proportion of the sample. Thus, it may not be  
13 generalizable to all patient groups. Future research is suggested to investigate the experience  
14 of participation using national data through a systematic sampling design.

## 16 CONCLUSION

17 There were differences among patients' perceived importance of their participation,  
18 willingness to participate, and their actual experience of participation in patient safety  
19 activities. Future research needs to be conducted to narrow these gaps using efficient  
20 educational methods. Our study suggests that an education program be developed that reflects  
21 patients' educational needs, such as lists of questions and information on patient safety  
22 activities. The results of this study can be used as a reference for developing educational  
23 content for patients. Also, the findings from our study may be useful for updating patient  
24 participation guidelines.

1 Healthcare providers may play an important role in encouraging patients to involve  
2 themselves in patient safety practices by offering education and encouragement to patients.  
3 Strategies are needed to give participation opportunities to patients during their care. Shared  
4 decision-making procedures and patient-centered policies should be made to create a  
5 healthcare environment in which patients and healthcare providers can participate together to  
6 improve patient safety.

### 8 **Contributors**

9 NL and SA conceived and designed the study. NL, SA and ML performed the cross-section  
10 study. NL and SA carried out the statistical analysis. NL, SA and ML conducted qualitative  
11 research. NL, SA and ML wrote the paper. NL, SA and ML reviewed and edited the  
12 manuscript. All authors read and approved the manuscript.

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### 16 **Competing interests**

17 None declared

### 18 **Data availability statement**

19 No data are available.

### 20 **Ethics approval**

21 This study was approved by the Institute Review Board of Seoul National University (No.  
22 No. 1801/003-007) and all study participants provided informed consent.

### 23 **Patient consent for publication**

24 Not required.



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1 Table 1. General Characteristics of Participants (N=492)

| Characteristics  | Categories                           | n (%)                |
|--|--------------------------------------|----------------------|
| Age<br>(M±SD, 31.72±10.52)   | 19-29                                | 270 (54.9)           |
|  | 30-39                                | 123 (25.0)           |
|  | 40-49                                | 57 (11.6)            |
|  | 50-                                  | 42 (8.5)             |
| Gender   | Female                               | 368 (74.8)           |
|  | Male                                 | 124 (25.2)           |
| Educational level  | High school diploma or below         | 119 (24.2)           |
|  | Bachelor's degree or above           | 373 (75.8)           |
| Marital status   | Single                               | 310 (63.0)           |
|  | Married                              | 176 (35.8)           |
|  | Divorced                             | 5 (1.0)              |
|  | Bereaved                             | 1 (0.2)              |
| Monthly income<br>(KRW)  | <850,000                             | 174 (35.4)           |
|  | 850,000-<1500,000                    | 51 (10.3)            |
|  | 1500,000-<2500,000                   | 91 (18.5)            |
|  | 2500,000-<3500,000                   | 77 (15.7)            |
|  | 3500,000-<4500,000                   | 43 (8.7)             |
|  | 4500,000-<5500,000                   | 23 (4.7)             |
|  | 5500,000-<6500,000<br>6500,000-      | 7 (1.4)<br>26 (5.3)  |
| Types of medical<br>institutions frequently<br>visited   | Clinic or public health center       | 343 (69.7)           |
|  | Hospital                             | 68 (13.8)            |
|  | General or Advanced general hospital | 79 (16.1)            |
|  | Others                               | 2 (0.4)              |
| Number of visits to<br>medical institutions  | <5                                   | 165 (33.5)           |
|  | 5-<10                                | 176 (35.8)           |
|  | 10-<15                               | 80 (16.3)            |
|  | 15-<20                               | 40 (8.1)             |
|  | 20-<25<br>25-                        | 15 (3.0)<br>16 (3.3) |
| Types of accompanying<br>caregivers  | Alone                                | 414 (84.1)           |
|  | Spouse                               | 19 (3.9)             |
|  | Children                             | 23 (4.7)             |
|  | Parents (Father or Mother)           | 31 (6.3)             |
|  | Others                               | 5 (1.0)              |
| Experience of patient<br>safety incidents  | Yes                                  | 320 (65.0)           |
|  | No                                   | 172 (35.0)           |
| Do you know the fact<br>that you can directly<br>report to the patient<br>safety reporting and<br>learning system? | Yes                                  | 9 (1.8)              |
|  | No                                   | 483 (98.2)           |

Table 2. Recognition of Importance of Participation, Extent of Willingness to Participate, and Experience of Participation in Patient Safety Activities (N=492)

| Patient participation practices  | Engaging in health care behaviors |                       |                             | Frequency of participation |            |            |            |
|--|-----------------------------------|-----------------------|-----------------------------|----------------------------|------------|------------|------------|
|  | Recognition of importance         | Extent of willingness | Experience of participation | Always                     | Often      | Sometimes  | Not at all |
|  | M±SD                              |                       |                             | n (%)                      |            |            |            |
| Seeking a second opinion regarding an important healthcare decision  | 3.23±0.71                         | 2.70±0.97             | 2.07±0.89                   | 38 (7.7)                   | 98 (19.9)  | 217 (44.1) | 139 (28.3) |
| Asking healthcare workers to explain more fully something they just said that I do not understand  | 3.47±0.65                         | 3.19±0.80             | 2.58±0.84                   | 73 (14.8)                  | 177 (36.0) | 202 (41.1) | 40 (8.1)   |
| Bringing a friend or family member to a doctor's appointment so that they can help ask questions and understand what the doctor was telling me | 2.73±0.84                         | 2.19±0.90             | 1.84±0.86                   | 25 (5.1)                   | 75 (15.2)  | 187 (38.0) | 205 (41.7) |
| Asking healthcare workers if they washed their hands   | 2.96±0.84                         | 1.43±0.76             | 1.37±0.74                   | 13 (2.7)                   | 39 (7.9)   | 64 (13.0)  | 376 (76.4) |
| Telling healthcare workers about any drug allergies when they did not ask for this information   | 3.55±0.69                         | 3.08±1.02             | 2.22±1.10                   | 82 (16.7)                  | 118 (24.0) | 118 (24.0) | 174 (35.4) |
| Asking healthcare workers to confirm your identity before performing a procedure   | 3.20±0.84                         | 2.05±1.02             | 1.64±0.94                   | 31 (6.3)                   | 65 (13.2)  | 91 (18.5)  | 305 (62.0) |
| Asking healthcare workers about the details of a procedure and the   | 3.55±0.67                         | 3.31±0.82             | 2.88±0.95                   | 150 (30.5)                 | 178 (36.2) | 120 (24.4) | 44 (8.9)   |

reason for a procedure before it is performed

|   |           |           |           |            |            |            |            |
|---|-----------|-----------|-----------|------------|------------|------------|------------|
| Asking healthcare workers to explain care, such as an X-ray or drawing blood, that I was not told about by my doctor or nurse | 3.43±0.72 | 2.86±0.95 | 2.50±1.04 | 108 (22.0) | 125 (25.4) | 164 (33.3) | 95 (19.3)  |
| Calling a healthcare worker when I undergo medical tests ordered and no one calls me with the results                         | 3.40±0.70 | 3.29±0.83 | 2.50±1.10 | 117 (23.8) | 129 (26.2) | 127 (25.8) | 119 (24.2) |
| Taking a written list of all the medications I'm currently taking when going to the doctor                                    | 3.22±0.80 | 2.34±1.07 | 2.02±1.03 | 55 (11.2)  | 102 (20.7) | 132 (26.8) | 203 (41.3) |
| Questioning medications or pills if I did not recognize them and never took this medication in the past                       | 3.33±0.77 | 2.82±0.98 | 2.35±1.05 | 85 (17.3)  | 131 (26.6) | 149 (30.3) | 127 (25.8) |
| Checking that I received the right drug and strength before leaving the pharmacy  | 3.22±0.81 | 2.30±1.10 | 2.09±1.09 | 76 (15.5)  | 86 (17.5)  | 134 (27.2) | 196 (39.8) |
| Reporting the errors I noticed had occurred in the hospital to a national reporting system                                    | 3.20±0.80 | 2.51±0.96 | 1.70±0.99 | 40 (8.1)   | 71 (14.4)  | 84 (17.1)  | 297 (60.4) |
| Total   | 3.27±0.51 | 2.62±0.52 | 2.13±0.63 |            |            |            |            |

Table 3. Difference in Recognition of Importance of Participation, Extent of Willingness to Participate, and Experience of Participation by General Characteristics (N=492)

| Sociodemographic characteristics | Subgroup                     | n (%)      | Recognition of Importance |               | Extent of Willingness |              | Experience of Participation |              |
|----------------------------------|------------------------------|------------|---------------------------|---------------|-----------------------|--------------|-----------------------------|--------------|
|                                  |                              |            | M±SD                      | t or F(p)     | M±SD                  | t or F(p)    | M±SD                        | t or F(p)    |
| Age group                        | 19-29                        | 270 (54.9) | 3.25±0.51                 | 1.23 (.297)   | 2.58±0.51             | 1.28 (.281)  | 2.10±0.63                   | 1.45 (.227)  |
|                                  | 30-39                        | 123 (25.0) | 3.33±0.50                 |               | 2.66±0.52             |              | 2.11±0.59                   |              |
|                                  | 40-49                        | 57 (11.6)  | 3.29±0.43                 |               | 2.69±0.52             |              | 2.25±0.65                   |              |
|                                  | 50-                          | 42 (8.5)   | 3.16±0.65                 |               | 2.67±0.59             |              | 2.25±0.73                   |              |
| Gender                           | Female                       | 368 (74.8) | 3.32±0.51                 | -3.53 (<.001) | 2.64±0.52             | -1.72 (.086) | 2.18±0.64                   | -2.49 (.013) |
|                                  | Male                         | 124 (25.2) | 3.13±0.51                 |               | 2.55±0.52             |              | 2.01±0.59                   |              |
| Educational level                | High school diploma or below | 119 (24.2) | 3.18±0.53                 | -2.27 (.024)  | 2.53±0.50             | -2.19 (.029) | 2.05±0.58                   | -1.80 (.074) |
|                                  | Bachelor's degree or above   | 373 (75.8) | 3.30±0.50                 |               | 2.65±0.53             |              | 2.16±0.65                   |              |
| Marital status                   | Single                       | 310 (63.0) | 3.26±0.50                 | 0.05 (.948)   | 2.59±0.51             | 2.05 (.130)  | 2.10±0.62                   | 1.98 (.139)  |
|                                  | Married                      | 176 (35.8) | 3.28±0.54                 |               | 2.68±0.54             |              | 2.21±0.65                   |              |
|                                  | Divorced & Bereaved          | 6 (1.2)    | 3.27±0.30                 |               | 2.37±0.42             |              | 1.96±0.63                   |              |
| Monthly income (KRW)             | <850,000                     | 174 (35.4) | 3.23±0.51                 | 0.82 (.570)   | 2.61±0.51             | 0.77 (.616)  | 2.10±0.62                   | 0.53 (.811)  |
|                                  | 850,000-<1500,000            | 51 (10.3)  | 3.22±0.63                 |               | 2.49±0.53             |              | 2.09±0.63                   |              |
|                                  | 1500,000-<2500,000           | 91 (18.5)  | 3.31±0.52                 |               | 2.66±0.53             |              | 2.19±0.68                   |              |
|                                  | 2500,000-<3500,000           | 77 (15.7)  | 3.31±0.47                 |               | 2.63±0.53             |              | 2.15±0.62                   |              |
|                                  | 3500,000-<4500,000           | 43 (8.7)   | 3.39±0.43                 |               | 2.72±0.51             |              | 2.18±0.64                   |              |
|                                  | 4500,000-<5500,000           | 23 (4.7)   | 3.21±0.43                 |               | 2.62±0.50             |              | 2.01±0.40                   |              |
|                                  | 5500,000-<6500,000           | 7 (1.4)    | 3.13±0.61                 |               | 2.53±0.65             |              | 2.07±0.86                   |              |



|  |                                      |            |           |              |           |              |           |              |
|--|--------------------------------------|------------|-----------|--------------|-----------|--------------|-----------|--------------|
|  | 6500,000-                            | 26 (5.3)   | 3.23±0.50 |              | 2.63±0.58 |              | 2.26±0.71 |              |
| Types of medical institutions frequently visited | Clinic or public health center       | 343 (69.7) | 3.27±0.50 | 1.02 (.384)  | 2.60±0.51 | 1.41 (.240)  | 2.06±0.60 | 5.12 (.002)  |
|  | Hospital                             | 68 (13.8)  | 3.19±0.59 |              | 2.59±0.57 |              | 2.27±0.71 |              |
|  | General or advanced general hospital | 79 (16.1)  | 3.32±0.48 |              | 2.73±0.53 |              | 2.32±0.64 |              |
|  | Others                               | 2 (0.4)    | 3.54±0.54 |              | 2.38±0.33 |              | 2.46±0.76 |              |
| Number of visits to medical institutions         | <5                                   | 165 (33.5) | 3.26±0.43 | 0.55 (.738)  | 2.61±0.55 | 0.86 (.509)  | 2.08±0.66 | 1.88 (.096)  |
|  | 5-<10                                | 176 (35.8) | 3.26±0.53 |              | 2.60±0.49 |              | 2.10±0.61 |              |
|  | 10-<15                               | 80 (16.3)  | 3.23±0.57 |              | 2.62±0.57 |              | 2.20±0.62 |              |
|  | 15-<20                               | 40 (8.1)   | 3.39±0.59 |              | 2.67±0.46 |              | 2.20±0.56 |              |
|  | 20-<25                               | 15 (3.0)   | 3.26±0.69 |              | 2.86±0.52 |              | 2.23±0.82 |              |
|  | 25-                                  | 16 (3.3)   | 3.30±0.37 |              | 2.69±0.42 |              | 2.51±0.48 |              |
| Types of accompanying caregivers                 | Alone                                | 414 (84.1) | 3.25±0.52 | 1.09 (.362)  | 2.59±0.52 | 2.45 (.045)  | 2.09±0.63 | 3.29 (.011)  |
|  | Spouse                               | 19 (3.9)   | 3.35±0.55 |              | 2.81±0.54 |              | 2.47±0.61 |              |
|  | Children                             | 23 (4.7)   | 3.45±0.40 |              | 2.88±0.52 |              | 2.32±0.61 |              |
|  | Parents                              | 31 (6.3)   | 3.27±0.51 |              | 2.68±0.48 |              | 2.31±0.57 |              |
|  | Others                               | 5 (1.0)    | 3.45±0.48 |              | 2.72±0.41 |              | 2.46±0.62 |              |
| Experience of patient safety incidents           | No                                   | 320 (65.0) | 3.24±0.53 | -1.88 (.061) | 2.58±0.54 | -2.19 (.029) | 2.07±0.62 | -3.34 (.001) |
|  | Yes                                  | 172 (35.0) | 3.33±0.48 |              | 2.69±0.49 |              | 2.26±0.63 |              |

Table 4. Factors Influencing the Experience of Patient Participation (N=492)

| Variables   | Beta   | <i>t</i> | <i>p</i> value |
|---|--------|----------|----------------|
| (Constant)  |        | -0.110   | 0.913          |
| Recognition of importance of patient participation    | 0.020  | 0.527    | .595           |
| Willingness to participate                            | 0.600  | 16.413   | <.001          |
| Gender  |        |          |                |
| Male  | Ref.   |          |                |
| Female  | 0.037  | 1.021    | .308           |
| Types of accompanying caregivers                      |        |          |                |
| Alone   | Ref.   |          |                |
| Spouse  | 0.062  | 1.766    | .078           |
| Children  | 0.008  | 0.218    | .827           |
| Parent  | 0.025  | 0.691    | .490           |
| Others  | 0.035  | 0.992    | .322           |
| Number of visits to medical institutions in last year |        |          |                |
| <5  | Ref.   |          |                |
| 5-<10   | 0.024  | 0.611    | .542           |
| 10-<15  | 0.058  | 1.493    | .136           |
| 15-<20  | 0.018  | 0.492    | .623           |
| 20-<25  | -0.003 | -0.072   | .942           |
| 25-   | 0.095  | 2.498    | .013           |
| Experience of patient safety incidents                |        |          |                |
| No  | Ref.   |          |                |
| Yes   | 0.065  | 1.849    | .065           |
| Medical institutions frequently visited               |        |          |                |
| Clinic or public health center                        | Ref.   |          |                |
| Hospital  | 0.117  | 3.287    | .001           |
| General or advanced general hospital                  | 0.077  | 2.113    | .035           |
| Others  | 0.019  | 0.525    | .600           |

F= 23.19 ( $p<.001$ ); Adjusted R<sup>2</sup>=0.42.

Table 5. Themes, Categories, and Codes

| Theme                   | Category                   | Code  | Quotes  |
|-------------------------|----------------------------|---|---|
| Patient-related factors | Willingness and motivation | Perception of the importance of patient participation | The treatment outcome seems to be different depending on whether I participated in patient safety activities or not. (Participant 2, Group 1)   |
|                         |                            |   | As soon as I realize I am speaking up and participating in my care, I feel that I'm an active patient. That changes the degree of participation. (Participant 1, Group 1)   |
|                         |                            | Accompanied by caregiver                              | My grandfather went to several hospitals and took medications from those hospitals which were the same medications he'd gotten from his primary hospital. He had no idea there were duplicates and took them all... After that I told him to get a paper prescription from the pharmacy and to bring medications which he got from other hospitals when he visits his primary hospital. I know that older people need to be accompanied by a family member when they go to the hospital. (Participant 1, Group 1) |
|                         |                            |   | In medical settings, I thought that patient and family participation in the care process as a member of a healthcare team is important. Since my family could be anyone, a patient or a healthcare provider, I thought patient and family participation is necessary. (Participant 2, Group 2)  |
|                         |                            | Previous experience of a patient safety incident      | I really wanted to hear: "Sorry, we made a mistake with the medication for your daughter. So, we took this kind of action after the incident." But they didn't apologize and didn't take any  |

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|                     |  | follow-up action. After this incident, I strongly realized the importance of patient safety and the family's participation. (Participant 6, Group 2)  |
|                     | Concerns about having any disadvantages in treatment | Foremost, I'm afraid of having any disadvantage on my treatment, like snubbing me after I ask questions. (Participant 6, Group 2)   |
|                     |  | I had a feeling on that he doesn't put an effort into, or pay attention during, my treatment. (Participant 4, Group 2)  |
|                     |  | The dentist always doesn't wash his hands. But I've already done my orthodontics and if I move to another dentist, it costs more. If I pointed out that he didn't wash his hands, I thought I would be disadvantaged, so I think I've never been able to tell him. (Participant 3, Group 1)                                 |
| Knowledge and skill | Level of health literacy and extent of knowledge     | When I asked my doctor about my medication, "I've heard there is this certain drug. Why didn't you prescribe this drug for me before?" And he replied, "The other one that I prescribed is better for your hormone levels." I couldn't understand what he said after that, so I couldn't ask more. (Participant 1, Group 1) |
|                     |  | He just explained in terms that he was used to. So, I had no idea about the terminology, if it was a diaphragm or something else. (Participant 6, Group 1)  |
|                     |  | If I took the drug, my skin became thinner when taking a high dose of an anticancer drug. There were too many side effects. I felt outraged and became sad. "What a fool I am. I should have  |

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|  |  |  | spoken up." Or I could have asked about the medication at another hospital. But the medical field is too professional for me. So I had no choice but to trust him. (Participant 2, Group 2)  |
|  | Educational needs to participate in their care process |  | I need information on what I can do and check specifically depending on the situation. (Participant 2, Group 2)  |
|  |  |  | I think it would be nice if I could get an app that suggests a potential diagnosis after inputting my age and symptoms and so on. Because I can ask a doctor, "In my opinion, my symptom is A, isn't it?" A doctor may miss the exact diagnosis owing to being busy, right? So, in that case, if I know the information on my symptoms and talk to him, then he can consider the diagnosis and go forward with his treatment plan in the right direction. (Participant 2, Group 1) |
|  |  |  | When I get the medicine at the pharmacy, the information about that medicine is written on the medicine packet, and I think this is very useful for patients. (Participant 2, Group 2)   |
|  |  |  | I think it's pretty important to know what questions I can ask. If I have a list of things to look out for and check, it is easy for me to get more involved. (Participant 4, Group 1)   |
|  |  |  | I want to know what kinds of rights patients have. (Participant 6, Group 2)  |
| Factors involving the relationship between | Supportive relationships                               | Attention on a patient and endeavor to | One doctor abrasively listened to me, not my father-in-law, because he couldn't communicate well, and gave only a routine prescription. On the other   |

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| 28<br>29<br>30<br>31<br>32<br>33<br>34<br>35<br>36<br>37<br>38<br>39  | No<br>opportunity<br>to participate     | Hierarchical<br>relationship<br>between the<br>patient and<br>healthcare<br>provider | When the nurse simply said, “A certain virus was found. When are you available for your next appointment?”, I was so worried because I had no idea what the virus was. So I asked the nurse to explain about the virus, and the nurse was willing to answer all of my questions. (Participant 1, Group 2)   |
| 40<br>41<br>42<br>43<br>44<br>45<br>46<br>47<br>48<br>49<br>50<br>51<br>52<br>53<br>54<br>55<br>56<br>57<br>58<br>59<br>60                            |   | Lack of<br>communication<br>between<br>healthcare<br>provider and<br>the patient     | I had a surgery for ovarian tumor removal. My doctor briefly explained that I could choose either laparoscopic surgery or laparotomy. And I was moved to the next room to schedule the surgery. The other doctor told me in the room that “even though laparoscopic surgery is covered by insurance, it is a little more expensive, while laparotomy is cheap.” He just explained it this way. (Participant 1, Group 1) |
|   |   |  | I haven’t felt that I was able to fully ask questions or get satisfactory answers. (Participant 6, Group 1)   |

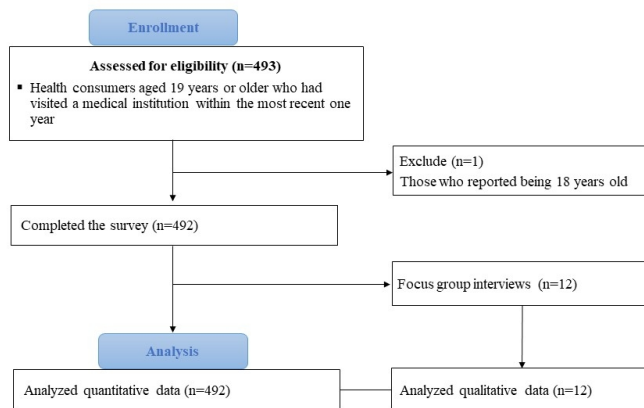
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| 5  |             | Failure to      | In the process of my treatment, I didn't  |
| 6  |             | share treatment | feel a sense of care from any doctor or   |
| 7  |             | plan with the   | nurse. This is because they only          |
| 8  |             | patient         | checked over my data and wrote            |
| 9  |             |                 | prescriptions, and asked about my         |
| 10 |             |                 | current physical state. I had the same    |
| 11 |             |                 | experience over and over. (Participant    |
| 12 |             |                 | 4, Group 2)                               |
| 13 |             |                 |   |
| 14 |             |                 |   |
| 15 |             |                 |   |
| 16 |             |                 |   |
| 17 |             |                 | I asked my doctor what the care plan      |
| 18 |             |                 | was. Then the doctor firmly said, rather  |
| 19 |             |                 | than sharing the future treatment plan,   |
| 20 |             |                 | "Do you want to go to another             |
| 21 |             |                 | hospital?" (Participant 5, Group 2)       |
| 22 |             |                 |   |
| 23 |             |                 |   |
| 24 |             |                 |   |
| 25 |             |                 |   |
| 26 |             |                 | When I try to give my opinion to try to   |
| 27 |             |                 | participate from the patient's position,  |
| 28 |             |                 | whether it is right or wrong... There are |
| 29 |             |                 | doctors who insist unconditionally,       |
| 30 |             |                 | saying "No. The treatment that I am       |
| 31 |             |                 | doing is right." In this case, I am not   |
| 32 |             |                 | able to say anything, and I am no longer  |
| 33 |             |                 | willing to participate. (Participant 2,   |
| 34 |             |                 | Group 1)                                  |
| 35 |             |                 |   |
| 36 |             |                 |   |
| 37 | Healthcare  | Complexity      | Complex care                              |
| 38 | environment | of the          | procedures                                |
| 39 | factors     | healthcare      |   |
| 40 |             | environment     | It was exhausting for a patient to meet a |
| 41 |             |                 | new healthcare provider every 2 or 3      |
| 42 |             |                 | minutes, and it was hard for me to share  |
| 43 |             |                 | my problems deliberately. When talking    |
| 44 |             |                 | to the final healthcare provider, a chief |
| 45 |             |                 | surgeon who was charge of my surgery,     |
| 46 |             |                 | I was very fatigued so I couldn't think   |
| 47 |             |                 | of what to say. (Participant 1, Group 1)  |
| 48 |             |                 |   |
| 49 |             | Limited time    | My doctor is too busy. I have almost no   |
| 50 |             | to see a doctor | chance to talk to him, because usually    |
| 51 |             |                 | another patient is waiting when I'm       |
| 52 |             |                 | seeing the doctor. So I can't discuss     |
| 53 |             |                 | things fully with my doctor, though I'd   |
| 54 |             |                 | like to ask questions and get answers.    |
| 55 |             |                 | (Participant 2, Group 1)                  |
| 56 |             |                 |   |
| 57 |             |                 |   |
| 58 |             |                 |   |
| 59 |             |                 |   |
| 60 |             |                 | We just took it for granted that we only  |

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|   |   |
|---|---|
|   | listened to a doctor very briefly in the hospital, because a very limited time was allocated to us. (Participant 6, Group 1)  |
| Difference in patient participation by type of medical institutions | When I visit an advanced hospital for surgery or another examination, people who work there don't know about me. So I started to write down details such as when I was ill or where I had pain, and brought it with me before someone asked me about it. (Participant 5, Group 1) |
|   | When I visited an advanced hospital, they gave me information about what drug it was and what side effect it had. However, the clinic did not give me this information. (Participant 3, Group 2)  |

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Supplementary figure 1

338x190mm (96 x 96 DPI)



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4 10. 귀하는 주로 건강관련 정보를 어디서 찾으십니까?  
5

6  인터넷  방송매체(TV, 라디오 등)  신문, 잡지 등의 기사

7  전문가(의사, 간호사, 영양사 등)  주위사람(가족, 친구 등)  기타

8  
9  
10 11. 병원에서 본인과 가족이 의료오류를 경험한 적이 있습니까?  
11

12  있다  없다  
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## 15 II. 환자안전 보고학습시스템 16 17 18

19 1. 귀하는 환자나 보호자로서 병원에서 의료오류를 발견했을 때, 국가에서 운영하는 환자안전 보  
20 고학습시스템(<http://www.kops.or.kr/portal>)을 통해 직접 보고할 수 있다는 것을 알고 계십니까?  
21

22  알고 있다  모른다  
23  
24

25 2. 귀하는 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오  
26 류를 보고할 것 같습니다?  
27  
28

29 \*환자안전 보고란? 환자안전사고의 예방 및 의료 질 향상을 위해 개별 의료기관의 환자안전 전  
30 담인력 또는 기관의 장, 보건의료인, 환자 및 보호자 등 보건의료서비스를 제공하거나 제공받  
31 는 사람이 인지한 환자안전사고 내용을 보고학습시스템(<http://www.kops.or.kr/portal>) 운영기  
32 관에 보고하는 것입니다.  
33

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35

| 36 전혀<br>보고하지 않을 것이다 | 37 가끔<br>보고할 것이다 | 38 종종<br>보고할 것이다 | 39 항상<br>보고할 것이다 |
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다음은 환자참여에 대한 문항입니다.

설문은 3개 영역, 각 13개 문항으로 구성되어 있습니다.

동일한 문항으로

1) 환자 참여 활동에 대한 의향, 2) 환자 참여 활동의 중요성, 3) 환자 참여 활동 경험을 측정합니다.

1) 환자 참여 활동의 의향은 본인의 건강관리와 관련하여 각 환자 참여 행동을 얼마나 할 것 같은지를 묻는 문항입니다.

2) 환자 참여 활동의 중요성은 각 항목의 환자 참여 행동의 환자 안전을 향상시키기 위해 얼마나 중요하다고 생각하는지를 묻는 문항입니다.

3) 환자 참여 활동의 경험은 각 항목의 환자 참여 행동의 경험 정도를 묻는 문항입니다.

해당하는 곳에 표시하여 주십시오.

### Ⅲ. 환자 참여에 대한 의향

병원에 입원하거나 외래를 방문한 환자로서의 경험을 바탕으로 답하여 주십시오. 그런 경험이 없을 경우는 본인이 환자인 상황을 가정하여 답해 주시기 바랍니다. 귀하는 건강 관리와 관련하여 다음과 같은 행동을 얼마나 할 것 같습니다?

|   | 전혀 그렇지 않을 것이다 | 다소 그럴 것이다 | 종종 그럴 것이다 | 매우 그럴 것이다 |
|---|---------------|-----------|-----------|-----------|
| 1. 치료의 결정을 할 때 추가적인 전문 의견이 듣고 싶은 경우 처음 진료를 받던 의사와 다른 의사에게 의견을 구한다.                    | 1             | 2         | 3         | 4         |
| 2. 보건의료직원(예, 의사, 간호사)이 설명했으나 이해하지 못한 부분에 대해 좀 더 자세하게 설명해 줄 것을 요구한다.                   | 1             | 2         | 3         | 4         |
| 3. 진료를 받으러 갈 때, 보건의료직원(예, 의사, 간호사)이 말하는 내용을 이해하고 질문하는 것을 도와줄 수 있도록 가족이나 친척(친구)을 데려간다. | 1             | 2         | 3         | 4         |
| 4. 보건의료직원(예, 의사, 간호사)에게 진료나 처치 전에 손을 씻었는지 물어본다.                                       | 1             | 2         | 3         | 4         |
| 5. 보건의료직원(예, 의사, 간호사)이 약물 알레르기에 대해 물어보지 않더라도 약물 알레르기가 있으면 말한다.                        | 1             | 2         | 3         | 4         |
| 6. 시술을 받기 전에 보건의료직원(예, 의사, 간호사)이 환자의 신원을 확인하지 않을 경우, 확인하도록 요청한다.                      | 1             | 2         | 3         | 4         |
| 7. 시술(수술)을 받기 전에 시술(수술)의 세부사항(예, 목적, 시간이 얼마나 걸리는지, 회복과정 등)에 대해 물어본다.                  | 1             | 2         | 3         | 4         |
| 8. 의사나 간호사에게 설명 받지 않았던 검사(예, 엑스레이, 혈액검사)를 시행하려고 하면 검사 전 필요성과 자세한 설명을 요구한다.            | 1             | 2         | 3         | 4         |
| 9. 검사를 받고 일정한 시간이 지난 후에도 검사결과를 듣지 못한 경우, 의료진이나 병원에 연락을 한다.                            | 1             | 2         | 3         | 4         |
| 10. 진료를 받으러 갈 때 현재 복용하고 있는 모든 약물의 목록이나 약물을 가져간다.                                      | 1             | 2         | 3         | 4         |
| 11. 무슨 약인지 잘 모르겠고 복용한 적이 없는 약을 설명 없이 받았을 때, 약에 대해 물어본다.                               | 1             | 2         | 3         | 4         |
| 12. 약국에서 나오기 전에 정확한 약물을 받았는지 확인한다.  | 1             | 2         | 3         | 4         |
| 13. 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오류를 보고한다.                              | 1             | 2         | 3         | 4         |

#### IV. 환자 참여의 중요성

환자안전\*을 향상시키기 위해 귀하는 건강 관리와 관련하여 다음의 항목이 얼마나 중요하다고 생각하십니까?

\* 환자안전이란? 환자안전은 의료와 관련된 불필요한 위해의 위험을 최소한으로 낮추는 것을 의미합니다(WHO, 2009).

|   | 매우<br>중요<br>하지<br>않다 | 중요<br>하지<br>않다 | 중요<br>하다 | 매우<br>중요<br>하다 |
|---|----------------------|----------------|----------|----------------|
| 1. 치료의 결정을 할 때 추가적인 전문 의견이 듣고 싶은 경우 처음 진료를 받던 의사와 다른 의사에게 의견을 구한다.                    | 1                    | 2              | 3        | 4              |
| 2. 보건의료직원(예, 의사, 간호사)이 설명했으나 이해하지 못한 부분에 대해 좀 더 자세하게 설명해 줄 것을 요구한다.                   | 1                    | 2              | 3        | 4              |
| 3. 진료를 받으러 갈 때, 보건의료직원(예, 의사, 간호사)이 말하는 내용을 이해하고 질문하는 것을 도와줄 수 있도록 가족이나 친척(친구)을 데려간다. | 1                    | 2              | 3        | 4              |
| 4. 보건의료직원(예, 의사, 간호사)에게 진료나 처치 전에 손을 씻었는지 물어본다.                                       | 1                    | 2              | 3        | 4              |
| 5. 보건의료직원(예, 의사, 간호사)이 약물 알레르기에 대해 물어보지 않더라도 약물 알레르기가 있으면 말한다.                        | 1                    | 2              | 3        | 4              |
| 6. 시술을 받기 전에 보건의료직원(예, 의사, 간호사)이 환자의 신원을 확인하지 않을 경우, 확인하도록 요청한다.                      | 1                    | 2              | 3        | 4              |
| 7. 시술(수술)을 받기 전에 시술(수술)의 세부사항(예, 목적, 시간이 얼마나 걸리는지, 회복과정 등)에 대해 물어본다.                  | 1                    | 2              | 3        | 4              |
| 8. 의사나 간호사에게 설명 받지 않았던 검사(예, 엑스레이, 혈액검사)를 시행하려고 하면 검사 전 필요성과 자세한 설명을 요구한다.            | 1                    | 2              | 3        | 4              |
| 9. 검사를 받고 일정한 시간이 지난 후에도 검사결과를 듣지 못한 경우, 의료진이나 병원에 연락을 한다.                            | 1                    | 2              | 3        | 4              |
| 11. 진료를 받으러 갈 때 현재 복용하고 있는 모든 약물의 목록이나 약물을 가져간다.                                      | 1                    | 2              | 3        | 4              |
| 11. 무슨 약인지 잘 모르겠고 복용한 적이 없는 약을 설명 없이 받았을 때, 약에 대해 물어본다.                               | 1                    | 2              | 3        | 4              |
| 12. 약국에서 나오기 전에 정확한 약물을 받았는지 확인한다.  | 1                    | 2              | 3        | 4              |
| 13. 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오류를 보고한다.                              | 1                    | 2              | 3        | 4              |

## V. 환자 참여 경험

귀하는 건강 관리와 관련하여 다음 활동에 얼마나 자주 참여하십니까?

|   | 전혀 그렇지 않다 | 가끔 그렇다 | 자주 그렇다 | 항상 그렇다 |
|---|-----------|--------|--------|--------|
| 1. 치료의 결정을 할 때 추가적인 전문 의견이 듣고 싶은 경우 처음 진료를 받던 의사와 다른 의사에게 의견을 구한다.                    | 1         | 2      | 3      | 4      |
| 2. 보건의료직원(예, 의사, 간호사)이 설명했으나 이해하지 못한 부분에 대해 좀 더 자세하게 설명해 줄 것을 요구한다.                   | 1         | 2      | 3      | 4      |
| 3. 진료를 받으러 갈 때, 보건의료직원(예, 의사, 간호사)이 말하는 내용을 이해하고 질문하는 것을 도와줄 수 있도록 가족이나 친척(친구)을 데려간다. | 1         | 2      | 3      | 4      |
| 4. 보건의료직원(예, 의사, 간호사)에게 진료나 처치 전에 손을 씻었는지 물어본다.                                       | 1         | 2      | 3      | 4      |
| 5. 보건의료직원(예, 의사, 간호사)이 약물 알레르기에 대해 물어보지 않더라도 약물 알레르기가 있으면 말한다.                        | 1         | 2      | 3      | 4      |
| 6. 시술을 받기 전에 보건의료직원(예, 의사, 간호사)이 환자의 신원을 확인하지 않을 경우, 확인하도록 요청한다.                      | 1         | 2      | 3      | 4      |
| 7. 시술(수술)을 받기 전에 시술(수술)의 세부사항(예, 목적, 시간이 얼마나 걸리는지, 회복과정 등)에 대해 물어본다.                  | 1         | 2      | 3      | 4      |
| 8. 의사나 간호사에게 설명 받지 않았던 검사(예, 엑스레이, 혈액검사)를 시행하려고 하면 검사 전 필요성과 자세한 설명을 요구한다             | 1         | 2      | 3      | 4      |
| 9. 검사를 받고 일정한 시간이 지난 후에도 검사결과를 듣지 못한 경우, 의료진이나 병원에 연락을 한다.                            | 1         | 2      | 3      | 4      |
| 12. 진료를 받으러 갈 때 현재 복용하고 있는 모든 약물의 목록이나 약물을 가져간다.                                      | 1         | 2      | 3      | 4      |
| 11. 무슨 약인지 잘 모르겠고 복용한 적이 없는 약을 설명 없이 받았을 때, 약에 대해 물어본다.                               | 1         | 2      | 3      | 4      |
| 12. 약국에서 나오기 전에 정확한 약물을 받았는지 확인한다.  | 1         | 2      | 3      | 4      |
| 13. 병원에서 의료오류를 경험하거나 발견한다면, 국가 환자안전 보고학습시스템에 의료오류를 보고한다.                              | 1         | 2      | 3      | 4      |

설문이 종료되었습니다.

**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

| Section/Topic                | Item # | Recommendation   | Reported on page # |
|------------------------------|--------|--|--------------------|
| <b>Title and abstract</b>    | 1      | (a) Indicate the study's design with a commonly used term in the title or the abstract   | #1-3               |
|                              |        | (b) Provide in the abstract an informative and balanced summary of what was done and what was found  | #2-3               |
| <b>Introduction</b>          |        |  |                    |
| Background/rationale         | 2      | Explain the scientific background and rationale for the investigation being reported   | #4-6               |
| Objectives                   | 3      | State specific objectives, including any prespecified hypotheses   | #6                 |
| <b>Methods</b>               |        |  |                    |
| Study design                 | 4      | Present key elements of study design early in the paper  | #6                 |
| Setting                      | 5      | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection  | #7-8               |
| Participants                 | 6      | (a) Give the eligibility criteria, and the sources and methods of selection of participants  | #7-8               |
| Variables                    | 7      | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable   | #8-9               |
| Data sources/<br>measurement | 8*     | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | #8-9               |
| Bias                         | 9      | Describe any efforts to address potential sources of bias  | NA                 |
| Study size                   | 10     | Explain how the study size was arrived at  | #7                 |
| Quantitative variables       | 11     | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why   | #8-9               |
| Statistical methods          | 12     | (a) Describe all statistical methods, including those used to control for confounding  | #9-10              |
|                              |        | (b) Describe any methods used to examine subgroups and interactions  | #8-9               |
|                              |        | (c) Explain how missing data were addressed  | #7                 |
|                              |        | (d) If applicable, describe analytical methods taking account of sampling strategy   | #7-8               |
|                              |        | (e) Describe any sensitivity analyses  | NA                 |
| <b>Results</b>               |        |  |                    |



|                          |     |  |                        |
|--------------------------|-----|--|------------------------|
| Participants             | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed            | #10-11                 |
|                          |     | (b) Give reasons for non-participation at each stage   | NA                     |
|                          |     | (c) Consider use of a flow diagram   | Supplementary figure 1 |
| Descriptive data         | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders   | #10-12                 |
|                          |     | (b) Indicate number of participants with missing data for each variable of interest  | #7                     |
| Outcome data             | 15* | Report numbers of outcome events or summary measures   | #10-12, #25-30         |
| Main results             | 16  | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | #10-12, #25-30         |
|                          |     | (b) Report category boundaries when continuous variables were categorized  | #10-12, #25-30         |
|                          |     | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period   | NA                     |
| Other analyses           | 17  | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses   | #12-15, #31-36         |
| <b>Discussion</b>        |     |  |                        |
| Key results              | 18  | Summarise key results with reference to study objectives   | #15-19                 |
| Limitations              | 19  | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias   | #19                    |
| Interpretation           | 20  | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence                                   | #15-19                 |
| Generalisability         | 21  | Discuss the generalisability (external validity) of the study results  | #15-19                 |
| <b>Other information</b> |     |  |                        |
| Funding                  | 22  | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based  | #20                    |

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).