# **Original Article**

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# Effects of My Child's Safety Web-Based Program for Caregivers of Children with Cancer in South Korea

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Objectives: The purposes of this study were to develop a Web-based education program, My Child's Safety, which includes patient safety education and information on the diagnosis, treatment, and management for caregivers of children with cancer, and to examine the efficacy of the My Child's Safety program in promoting the caregivers' awareness of patient safety. Methods: A one-group pre- and post-test design was adopted. The participants were the caregivers of children with cancer and were recruited from one pediatric hemato-oncology unit of a tertiary university hospital in a large metropolitan city of South Korea. They were asked to review the Web-based program for patient safety and then complete questionnaires developed to measure the awareness of patient safety among the caregivers. Results: In the study, the total score of the caregivers' awareness of patient safety had increased significantly after Web-based self-learning patient safety education. Also caregivers' awareness of their right to ask and know about procedures and treatments during hospitalization had increased after the program was used. Conclusions: The Web-based patient safety education program effectively improved the awareness of patient safety and the awareness of the right to know and ask about procedures and treatments during hospitalization among the caregivers. Family caregivers were less likely to ask healthcare professionals questions related to safety.

Keywords: Patient Safety, Caregivers, Pediatrics, Neoplasm, Education

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### I. Introduction

The report from the Institute of Medicine, *To Err is Human: Building a Safer Health System* [1], pointed out the fact that up to 98,000 people die annually as the result of medical errors in the healthcare settings of the United States. This report dramatically increased concern regarding medical errors and patient safety; therefore, healthcare professionals, along with organizations, have been making increased efforts to improve patient safety by implementing new approaches and practices [2].

Until now, the healthcare system in the United States received a grade of 'B-' [3] in patient safety and medical errors, which are still prevalent. Many experts in patient safety were not sure whether the previously mentioned efforts actually improved patient safety or not [2]. Changing the system in healthcare

settings and educating healthcare professionals were not effective and had limitations in reducing medical errors [4,5]. Experts in patient safety realized that patients may play a critical role in improving safety by defending themselves [4,5]. However, patients have been traditionally regarded as passive recipients of care and little was known about the role of patients, even though patients' involvement in the healthcare process at any time point can promote their safety [4].

Medical errors in pediatric inpatient setting occurred at similar rates as those observed in adults, but they were more than twice as likely to cause harm [6] due to the susceptibility and vulnerability inherent in pediatric patients. Children diagnosed with cancer face numerous complicated and intensive treatments, including chemotherapy, radiation therapy, and repeated hospitalization for several years. During these processes, family caregivers have to make the most difficult decisions and are fully in charge of their offspring's care both at home and in the hospital. However, Schwappach [5] found that patients or caregivers who perceive their knowledge as insufficient may be less likely to be proactive in patient safety behaviors. Caregivers of children with cancer, thus, require detailed information on diagnosis, treatment, and self-care of cancer, as well as education on patient safety to become active partners.

The number of Internet users in Korea has increased to 78% in 2012 [7]. Among various education approaches, Web-based health education targeting patients and caregivers has several advantages. The advantages of the Web-based approach are that patients and/or caregivers can receive upto-date health information anytime and anywhere [8]. A systematic review on Web-based interventions [9] found that this approach had positive effects on patient empowerment in disease-specific self-efficacy, but still more research is needed to know how the involvement of patients and caregivers could improve safety.

Several studies on patient safety education have been conducted among healthcare providers, such as medical and nursing students, physicians, and nurses [10,11]; however, to our knowledge, there has been no Web-based patient safety program for the caregivers of children with cancer. Therefore, patient safety education using an innovative Web-based approach among caregivers, who can play a critical role as vigilant partners of their child's safety, is necessary.

The aims of this study were 1) to develop a Web-based education program, My Child's Safety, which includes patient safety education and information on the diagnosis, treatment, and management for caregivers of children with cancer, and 2) to examine the efficacy of the My Child's Safety program in promoting the caregivers' awareness of patient safety.

## II. Methods

#### 1. Design, Sample, and Setting

The efficacy of the My Child's Safety program was examined by using a one-group pre- and post-test design. The subjects who participated in the study were the caregivers of children with cancer and were recruited from one pediatric hematooncology unit of a tertiary university hospital in a large metropolitan city of South Korea. The eligibility criteria of caregivers were that they were 1) taking care of a child with cancer, 2) able to read and speak Korean, and 3) able to access Internet. The sample size was calculated using Cohen's formula [12] and G\*Power software [13] based on significance level ( $\alpha = 0.05$ ), effect size (d = 0.5), power ( $1-\beta = 0.8$ ) and paired *t*-test. The estimated total sample size was 27 and the number of participants in the study was 29; therefore, we decided to proceed with the study because it had a large enough sample.

#### 2. Procedure

#### 1) Recruitment and consent process

After we received permission for recruitment from the unit manager and patients' physicians, we posted and distributed flyers to the potential eligible participants (caregivers). When they expressed an interest in participating in the study, we briefly explained the study and scheduled an appointment for the consent process and study orientation. During the consenting, we provided thorough information on the study (e.g., the purpose, procedures, potential benefits and risks, and the participants' rights to withdrawal at any time during research process) to the potential participants.

## 2) Study orientation

After obtaining written informed consent, we provided instruction on how to use the program, including the program link, how to sign-up and log-in, outline of content, and how to submit online questionnaires.

#### 3) Data collection procedure

The data collection period was from April 25, 2010 to May 15, 2010. After the participants signed up for the online program, they completed the online pre-test questionnaire. The pre-test questionnaire included 1) the demographic characteristics of a participant and a patient, 2) the caregivers' awareness of patient safety, and 3) the caregivers' awareness of the right to ask and know about procedures and treatments during hospitalization. Then, they used two modules during two weeks. Once the participants completed the two modules, they submitted the post-test questionnaire, which



included the same items except demographics.

#### 3. Instruments

### 1) Caregivers' awareness of patient safety

The questionnaire was developed to identify how caregivers perceive their children's safety. The instrument was developed based on the contents of the Speak Up module [14] and

literature search. Five experts, who had more than 10 years each of clinical experience in tertiary hospitals, reviewed and validated the questionnaire. Items were measured with a 5-point Likert scale. The discussion and decision on items were based on the characteristics of the study site: a hematooncology unit in a tertiary hospital.

Exploratory factor analysis (EFA) was conducted to see how

Table 1. Exploratory factor analysis of caregivers' awareness of patient safety: scale compositions and item-factor loadings

Item	Asking questions (4 items)	Paying attention (3 items)	Education (4 items)	Asking for help (3 items)	Knowledge on medication (12 items)	Selection of hospital (2 items)	Participation in treatment (5 items)
1	0.771	-0.100	0.201	0.133	-0.235	0.132	-0.333
2	0.838	0.089	-0.139	-0.080	0.342	0.064	-0.126
3	0.871	0.196	-0.229	0.024	-0.073	0.107	0.042
4	0.504	-0.225	-0.017	-0.060	0.130	-0.479	0.053
5	0.311	0.684	0.258	0.183	-0.031	-0.227	0.072
6	-0.168	0.735	0.010	0.007	0.232	0.029	0.041
7	-0.465	0.616	0.023	-0.239	-0.237	0.003	0.110
8	0.124	0.179	0.490	0.094	0.167	-0.133	-0.321
9	-0.115	0.049	0.896	0.203	-0.025	-0.050	-0.090
10	0.126	0.037	0.643	0.300	-0.194	-0.599	0.047
11	-0.071	0.297	0.641	0.101	0.522	-0.173	0.159
12	0.299	0.036	0.230	0.660	0.135	-0.025	-0.147
13	-0.287	-0.357	-0.102	0.442	-0.153	-0.294	-0.315
14	0.224	0.437	-0.069	0.670	-0.098	0.350	-0.204
15	-0.354	0.111	-0.069	-0.700	0.453	-0.195	-0.125
16	-0.068	0.221	0.096	-0.203	0.852	-0.008	0.129
17	0.227	-0.227	-0.385	-0.001	0.532	0.098	0.403
18	0.041	0.050	-0.503	-0.221	0.701	-0.001	0.191
19	0.053	-0.064	-0.024	0.083	0.844	-0.081	0.218
20	-0.409	-0.137	-0.265	0.236	0.593	0.102	0.149
21	0.203	0.140	-0.277	-0.327	0.417	-0.197	0.127
22	0.201	-0.004	-0.084	0.112	0.841	-0.113	0.009
23	-0.065	-0.158	0.083	0.169	0.470	0.122	0.093
24	-0.407	-0.235	0.202	-0.153	0.481	-0.128	0.299
25	-0.127	0.003	-0.225	-0.015	0.462	0.031	0.013
26	-0.089	0.041	0.043	-0.060	0.422	-0.053	-0.035
27	0.022	-0.466	-0.183	-0.357	-0.469	0.546	0.109
28	0.206	-0.062	0.245	0.171	0.118	0.567	-0.085
29	0.308	0.258	-0.312	-0.049	-0.487	0.009	0.444
30	0.309	0.181	0.176	0.080	0.300	0.231	0.788
31	-0.317	0.081	-0.284	-0.171	0.165	0.038	0.796
32	-0.442	0.150	0.159	-0.344	-0.299	0.075	0.491
33	-0.201	-0.070	0.005	-0.013	0.187	-0.072	0.808

many factors are necessary to explain the inter-relationships among a set of indicators of patient safety in the developed questionnaire [15]. The EFA used principal components analysis, followed by varimax rotation, using eigenvalues [16] and scree plot [17] to determine factors that would be independent. Ten components were identified by eigenvalues greater than one rule, and 7 components were identified by scree plot. Items with a factor loading score lower than 0.40 were eliminated. Items with loading higher than 0.40 across multiple dimensions were eliminated. Dimensions with only one or two items were eliminated. After examination of the data, a sevencomponent model was considered as the most suitable solution with 33 items. The extracted dimensions were checked to see if they differed from the conceptual framework that we supposed. The final scale compositions and item factor loadings after an EFA are presented in Table 1.

This measure was found to have acceptable to good internal consistency (0.74), and the subsections also were found to have good to fair internal consistency. The Cronbach's α coefficients for the four subsections were lower than 0.70, which is considered acceptable for new scales [18].

## 2) Caregivers' awareness of the right to ask and know about procedures and treatments during hospitalization

This measure included eight items assessing the level of awareness among caregivers of their right to ask and know about their children's care. This measure is a modified version of the Patient's Right to Know and Self-Determination survey [19]. The original survey has 27 items and five sections, but the patients' awareness of the right to ask and know (8 items) was selected for the study. The items were measured with a 5-point Likert scale, and a higher score indicates that the person has more awareness of the patient's right to know. Cronbach's α was 0.78 in the study of Ahn et al. [19]. This measure has been shown to have good internal consistency in this study (0.73).

#### 4. Description of My Child's Safety Program for Caregivers

Two modules of the My Child's Safety program were developed by system development life cycle (SDLC), such as system analysis, design, development, and evaluation process. Two learning modules were patient safety education for caregivers and pediatric hemato-oncology caregiver education.

## 1) Analysis phase

(1) Module 1: Issues on patient safety and tips to prevent medical errors in children

First, learning objectives and requirements were defined, and then the module was developed based on contents from the Speak Up Initiatives [14] and the Agency for Healthcare Research and Quality's tips for patients & consumers [20]. The researchers selected and modified the contents that were applicable to the target population. Then, the expert panel reviewed the contents and validated the contents in terms of the actual conditions in the Korean hospital setting. The expert panel consisted of eleven experts: one faculty member of the nursing school who has expertise in patient safety and ten registered nurses who were actively involved in hematooncology patients' care for at least three years.

## (2) Module 2: Caregiver education on pediatric hematooncology

The patient and caregiver education materials were originally developed with the input of physicians and nurses working in the designated unit, which included booklets on patient care in hospital and at home. The researchers and the expert panel updated and added relevant contents based on recent literature and publications to match with the program.

#### 2) Design phase

Upon completion of content development, we populated the contents on the website with a Web designer. Each module included specific learning objectives and structured learning content with external Web links to other relevant health sites for further information (Table 2).

Table 2. Overview of My Child'S Safety program

Learning module	Content		
Home	Greetings and purposes of research		
	Program information		
	Associated websites		
Module 1. Speak Up	Speak up		
	20 Tips to help prevent medical errors		
	in children		
Module 2. Pediatric	Tests for diagnosis		
hemato-oncology	Diet and nutrition		
caregiver education	Gargle and sitz bath		
	Vaccination and immunization		
	Central line		
	Transfusion		
	Home care		
Questionnaire	Pretest		
	Posttest		
Bulletin board	Announcement		
	Q&A		



#### 3) Development phase

According to the learning objectives on child's safety issues, all content was developed in Korean and at a 6th grade reading level and reviewed by the same expert panel used to develop the patient safety module. The expert panel revised the first Web-based education program and provided feedback. Based on the feedback, the second version of the Web-based education program was developed.

#### 4) Evaluation phase

To ensure that the program would be usable for the target population, three volunteer caregivers in the hematooncology unit participated in the usability testing of the program. Based on the comments from the usability testing, the content was revised and finalized. Figures 1 through 4 show screen shots of the program.

## III. Results

## 1. Participants

Participants included 29 caregivers (male 17.2%) of children with cancer, such as leukemia (34.5%), neuroblastoma (24.1%), or osteosarcoma (13.8%). Caregivers were an average of 38.0 years of age and patients were an average of 6.9 years. More than half of the caregivers were housewives (55.2%) and only 31.0% of them had received education about patient medica-



Figure 1. Homepage and introduction.

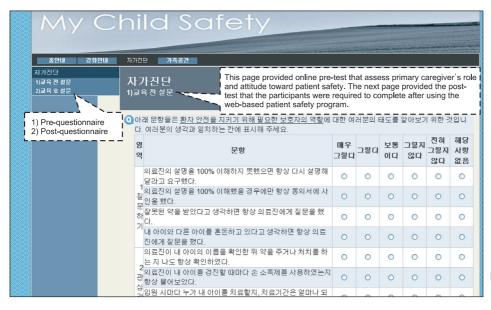


Figure 2. Online survey (pre- and post-questionnaires).

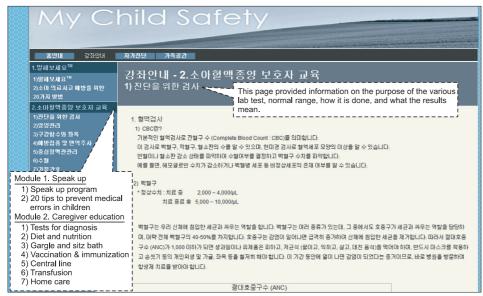


Figure 3. Module 2: Caregiver education on pediatric hematooncology (lab tests).

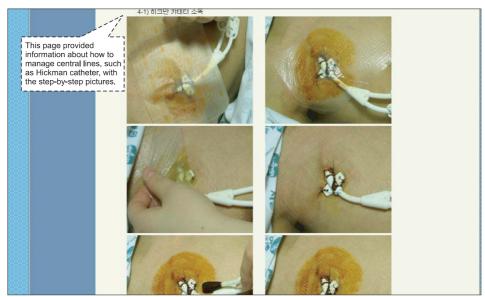


Figure 4. Module 2: Caregiver education on pediatric hematooncology (central line management).

tion and disease from the hospital (Table 3).

#### 2. Improvements in Caregivers' Awareness of Patient Safety

The results suggest that the My Child's Safety program can increase awareness of patient safety and the right to know among caregivers of children with cancer. The total score of caregivers' awareness of patient safety had increased significantly after they had used the patient safety program module (t = 8.51, p = 0.001) (Table 4). Six categories (paying attention, education, asking for help, knowledge on medication, selection of hospital, and participation in treatment) had significantly increased after the program was used. Among the seven categories, only the asking questions category did not show significant improvement (t = 1.957, p = 0.060).

## 3. Improvements in Caregivers' Awareness of Right to Ask and Know about Procedures and Treatments during Hospitalization

Caregivers' awareness of their right to ask and know about procedures and treatments during hospitalization has increased after they had used the program (t = 2.346, p = 0.026) (Table 5). According to the subscale analysis, there were trends for improvement in two items: knowing the results of the medical treatments received (t = 1.797, p = 0.083) and providing health information to build strong relationships between patients and healthcare providers (t = 1.860, p =

Table 3. Characteristics of caregivers and children with cancer

Characteristic	Value			
Caregivers				
Age (yr)	$38.0 \pm 7.8$			
Gender				
Male	5 (17.2)			
Female	24 (82.8)			
Academic background				
<middle school<="" td=""><td>2 (6.9)</td></middle>	2 (6.9)			
High school	13 (44.8)			
College	7 (24.1)			
>University	7 (24.1)			
Occupation				
Housewife	16 (55.2)			
Technical service job	2 (6.9)			
Office worker	5 (17.2)			
Government/non-profit officer	3 (10.3)			
Professional	3 (10.3)			
Relationship to patient				
Parents	20 (69.0)			
Grand parents	6 (20.7)			
Relative	3 (10.3)			
Caring period (yr)	$6.6 \pm 4.1$			
Caring time per day	$15.4 \pm 8.8$			
Received education from hospital about				
patient's medication and disease				
Yes	9 (31.0)			
No	20 (69.0)			
Average monthly income (\$)	2,745 ± 845			
Children with cancer				
Age (yr)	$6.90 \pm 4.08$			
Diagnosis				
Leukemia	10 (34.5)			
Osteosarcoma	4 (13.8)			
Lymphoma	3 (10.3)			
Retinoblastoma	2 (6.9)			
Neuroblastoma	7 (24.1)			
Nephroblastoma	3 (10.3)			
Treatment settings				
Inpatient word	20 (69.0)			
Outpatient word	9 (31.0)			
Frequency of chemotherapy (cycle)	$4.3 \pm 3.2$			
Times of admission	$5.3 \pm 4.5$			
V-1				

Values are presented as mean  $\pm$  standard deviation or number (%).

0.073). One item showed significant improvement: asking about how long the healthcare for my child will take (t = 4.063, p = 0.001). The rest of the five items showed improvement in mean score; however, the changes were not statistically significant.

## **IV.** Discussion

Patient safety has become a major concern among public and healthcare organizations worldwide, including Korea. However, few studies have been conducted regarding patient safety in Korea [21], and the importance of patient and caregiver education has not been emphasized until now. To the best of our knowledge, the My Child's Safety program is the first Web-based program developed for patient safety of children with cancer in South Korea. This study demonstrated that a Web-based program for patient safety effectively improved caregivers' awareness of patient safety and their rights to ask healthcare professionals questions.

Web-based intervention was proven to be a cost-effective method to deliver specific health interventions to patients [22]. Previous studies on patient education using printed materials showed minimal changes related to health-related behaviors [23]. However, patients who have received Web-based educational intervention reported better outcomes than patients who received traditional education, such as face-to-face sessions [24]. Patient-centered patient safety intervention has not been widely studied, but one study on patient safety intervention among patients reported the feasibility and acceptability of face-to-face intervention [25]. Considering the effectiveness of Web-based interventions in previous patient education, utilizing an online program will provide more promising results.

The importance of patients' contributions to their safety and the prevention of errors [25] has been emphasized for more than a decade in other advanced countries. For example, there have been many initiatives in patient safety and regarding patients as partners for patient safety outside of Korea. The representative examples are 1) Speak Up Initiatives, 2) Five Steps to Safer Health Care, 3) Your Role in Making Healthcare Safer, and 4) What You Can Do to Make Healthcare Safer. These initiatives developed various series of brochures and multimedia resources (e.g., video clips) for patients and caregivers. The contents included information on medical conditions and treatments but also encouraged patients and caregivers to challenge the traditional patient roles, such as asking their healthcare providers whether they have washed their hands or if they have double-checked the medications the patient received [14]. In addition, these ini-

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Table 4. Differences on caregivers' awareness of patient safety between pre-test and post-test

Category	Pre-test	Post-test	t (p-value)	Cronbach's α
Asking questions	$3.20 \pm 0.41$	$3.43 \pm 0.44$	1.957 (0.060)	0.71
Paying attention	$2.92 \pm 0.33$	$3.45 \pm 0.46$	4.589 (0.001)	0.66
Education	$2.77 \pm 0.36$	$3.30 \pm 0.37$	5.203 (0.001)	0.66
Asking for help	$2.77 \pm 0.38$	$3.25 \pm 0.34$	4.825 (0.001)	0.60
Knowledge on medication	$2.79 \pm 0.28$	$3.37 \pm 0.48$	5.345 (0.001)	0.67
Selection of hospital	$3.02 \pm 0.49$	$3.40 \pm 0.49$	2.525 (0.018)	0.85
Participation in treatment	$2.77 \pm 0.39$	$3.32 \pm 0.48$	4.441 (0.001)	0.70
Total	$2.86 \pm 0.15$	$3.34 \pm 0.23$	8.513 (0.001)	0.74

Values are presented as mean  $\pm$  standard deviation.

Table 5. Difference on the caregivers' awareness of the right to ask and know between pre-test and post-test

Category	Pre-test	Post-test	t (p-value)
1. I do not always need to know the purpose of medical treatment to my child. <sup>a</sup>	$3.00 \pm 0.60$	$3.24 \pm 0.51$	1.653 (0.109)
2. I do not always need to know the results of medical treatment of my child. <sup>a</sup>	$3.00 \pm 0.70$	$3.31 \pm 0.60$	1.797 (0.083)
3. Since the time taken in each health care for my child varies, I do not need to know how long it will take. <sup>a</sup>	$2.72 \pm 0.65$	$3.45 \pm 0.63$	4.063 (0.001)
4. I do not need to know the likelihood of success in the treatment that my child receives. <sup>a</sup>	$3.14 \pm 0.69$	$3.41 \pm 0.63$	1.684 (0.103)
5. If the health care process meets the patient's and caregiver's right to know, I can understand the results better.	$3.34 \pm 0.86$	$3.41 \pm 0.73$	0.297 (0.769)
6. A patient is the core of health care.	$3.24 \pm 0.91$	$3.59 \pm 0.83$	1.543 (0.134)
7. Proving health information to patients and caregivers will secure the patient's safety and free will and build strong relationship between patients and health care providers.	$3.10 \pm 0.90$	$3.55 \pm 0.78$	1.860 (0.073)
8. Patients who received information from health care providers are more likely to be cooperative and recovered early.	$3.41 \pm 0.68$	$3.48 \pm 0.63$	0.465 (0.646)
Total	$3.12 \pm 0.43$	$3.44 \pm 0.58$	2.346 (0.026)

Values are presented as mean  $\pm$  standard deviation.

tiatives started from the diverse organization level, and there have been many studies or campaigns promoted by hospital or by individual researchers [5].

After using the patient safety modules, six out of seven categories in the caregivers' awareness of patient safety were significantly improved. Consistently with this research, patients who watched an educational patient safety video felt significantly more comfortable talking with their healthcare workers about patient safety issues [26]. Moreover, patients' knowledge level on patient safety and their level of confidence to ask questions increased significantly after watching

the video [26,27].

The category of 'asking questions' in the caregivers' awareness of patient safety was the only domain that did not show significant improvement. Previous studies have also reported similar results that patients felt that asking healthcare providers questions about patient safety was challenging. Patients who watched the patient safety video showed significantly increased confidence; however, they were not comfortable to ask healthcare providers about their medication [27]. In addition, patients were significantly more willing to ask doctors and nurses factual questions (e.g., treatment, recovery,

<sup>&</sup>lt;sup>a</sup>Reverse coding.

and medication) than challenging questions (e.g., washing hands) [28]. However, when they received education from a doctor, patients were more willing to ask healthcare providers challenging questions [26,27]. These results suggest that patient safety education by healthcare professionals could increase patients' intent to participate in activities for preventing medical errors.

In this study, the mean score of the caregivers' awareness of the right to ask and know about procedures and treatment during hospitalization was 3.44 ± 0.58 after using the program. This was lower than the result obtained by Ahn et al. [19] from adult patients (4.14  $\pm$  1.03). The difference in the population may explain the different results of the studies. Only a few studies on the patient's right to know have been conducted in Korea among adult patients [19,29], and there has been no previous study for child patients or their caregivers. While using My Child's Safety program, the participants could learn about their right to know about procedures and treatment but they may not put them into actual actions. One possible reason for the patients' or the caregivers' passive involvement is the relationship between oncology patients and physicians. According to Shin et al. [30], oncology patients have an average consultation time with their physician of about 7 minutes only. Patients or caregivers may be intimated by the healthcare providers' attitudes toward them such they are usually in a hurry and therefore may not have a chance to speak up. Thus, efforts need to be made among healthcare professionals, such as encouraging patients and caregivers to ask if they have any questions or concerns.

The current findings must be understood in the context of several important limitations. Using a convenience sample from one site may limit the generalizability of the study findings. Future research will be necessary to collect data from various geographical regions with larger sample sizes. This study did not control the exact time and frequency to visit the My Child's Safety program by caregivers; thus, future research adopted with a randomized control design is needed.

Despite the limitations we noted, the Web-based patient safety program effectively improved the awareness of patient safety and their right to ask and know among family caregivers. Family caregivers were less likely to ask healthcare professionals questions related to safety. Therefore, specific attention by healthcare professionals is required to increase awareness of patient safety and changing attitudes of family caregivers. Nurses could play an important role by providing positive reinforcement to caregivers to encourage their involvement. In addition, more attention should be paid to healthcare professionals' views on patient safety and caregivers' and patients' roles in preventing medical errors.

## **Conflict of Interest**

No potential conflict of interest relevant to this article was reported.

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