

Original Article

The Frequency of Utilizing the Supportive Web Site by Stroke Patients' Caregivers after Discharge

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Abstract

Aim: The aim of this study is to determine the frequency of stroke patients' caregivers to utilize the supportive web site after their patients are discharged.

Method: This descriptive study was conducted between December 2014 and 2015. Being prepared for caregivers of stroke patients, the web site was introduced at the hospital by delivering brochures. The web site is used without password and accessible for everybody. The caregivers were called three times after the discharge. While the content of the web site was evaluated by the caregivers, the utilization period was assessed over its administrator panel.

Results: It was found that 74% (n=147) of the caregivers examined only the web site and 42% (n=62) of these caregivers completed the questionnaires. 52% (n=32) utilized Internet considerably, the average daily computer use time was 109± 14 minutes, and the rate of using the web site weekly was averagely 60± 78 minutes. 76% (n=47) of the caregivers reported that they used the web site "always and usually." Those using the videos on the web site responded as "I utilized them very much" with the rate of 71% (n=44). According to panel results of the web site, the most viewed videos were the positions used for preventing bedsores, pressure points, and arm and leg exercises. Totally 3235 users accessed to the web site.

Conclusion: This result indicated that the web site achieved its purpose. Many people along with the caregivers of the stroke patients utilized the web site.

Keywords: Stroke, family caregiver, patient care, web education, web site.

Introduction

Stroke is one of the primary causes of death in developed and developing countries. The most important factors leading to stroke are cerebrovascular diseases. Cerebrovascular diseases are among the top leading 10 causes of death in all the age groups (15%) and the second cause of death in people aged 60 years and over (20.7%) in Turkey. In terms of the care burden, cerebrovascular diseases are ranked as the third (5.9%). Incidence of cerebrovascular disease is

69.60/100.000 in total; 67.10/100.000 in men, and 72.10/100.000 in women. Prevalence of stroke is 3.19/1000 in total for both genders (Ministry of Health Turkey, 2010). Requiring a high degree of care due to permanent damage caused by stroke, stroke patients need long-term family support for treatment, care, rehabilitation, and independence. Post-stroke care has numerous difficulties for both patients and their families. Because stroke develops suddenly and unexpectedly, it is difficult for families to get ready for a care-giving role (Brereton & Nolan,

2002). Medical team provides intensive treatment and care to the patients in the hospital in post-acute period of stroke so that they become stable and are discharged. The patients, who are cared by the professional team in the hospital, are cared by their families alone at home after the discharge. The recommended treatment and care for the discharged patients should be continued at home. In this period, generally female members of the family provide care to them (Steiner et al., 2009; Akdemir et al., 2011; Cayir et al., 2013; Cingil, Gozum & Bodur, 2015). Family caregivers may not receive group training on home patient care because of their household roles (Cingil et al., 2015).

While dealing with the acute problems experienced by stroke patients in the hospital, making their families ready for the caregiving role can be neglected. If caregivers of the family do not have special education or experience, home care of the stroke patients is learned by trial and error. On the first few post-discharge days, it is important for family caregivers undertaking home care to have exact and reliable care knowledge for patient safety and supporting the family. Family caregivers need to understand the caregiving training in order to use this training effectively. Any kind of information related to patient care is essential at the transition period. Therefore, the time of discharge is the most appropriate time to provide training for caregivers (Cameron & Gignac, 2008). For this reason, training on patient care starting before discharge should be continued at home. The first days and weeks at home are important for safe care of the patient and preparation of the family for the care-giving role.

In order to increase the rate of utilization of training by caregivers, the current training models should be enriched. Moreover, many opportunities such as easy access and facility of reaching information when needed should be provided to individuals in order to facilitate the training. At the present time, the training model which meets these requirements is the web-assisted health education (Demir & Gozum, 2011). With the help of a computer and internet connection, caregivers can access numerous training modules. It has been determined that caregivers' use of internet, e-mail, and telephone affects their capacities, family support, and care experiences (Chiu & Eysenbach, 2011). In a study, caregivers residing in rural areas used the

web page "caring-web" (Pierce et al., 2004), which was prepared for caregivers of stroke patients, for 3 months and the caregivers were also supported via telephone and e-mail. After these interventions, the caregivers stated that their problem-solving skills improved, they were more hopeful, they managed the disease in a better way, their beliefs regarding recovery of their patients increased, and they balanced the successes and failures in their lives (Pierce et al., 2004). It was found that calls to the emergency services due to cardiology and respiration problems decreased one year after the use of the same web page by the caregivers (Steiner et al., 2009).

In another study conducted by nurses in Korea, the efficiency of the web site prepared for stroke patients and their families to prevent the recurrent stroke was compared using the training provided via a booklet. In the evaluation, it was found that the training provided via internet was more efficient in the adaptation of both the patients and their families to health behaviors (Kim & Park, 2011).

In Turkey, there is a web site designed by the authors of this study for family caregivers of stroke patients. While the quality and content of this web site were evaluated by experts, its efficiency and usability were assessed by 38 caregivers. Videos of bed exercises, postural drainage, oral care, catheter care, and perineal care were added to the web site in order for the caregivers from all the educational levels to understand these issues easily. Assessments of both the stroke specialists and the family caregivers about the web site (<http://www.hastayakini.net/>) was positive (Demir & Gozum, 2015).

The aim of this study is to determine the frequency of stroke patients' caregivers to utilize the supportive web site after their patients are discharged.

Research questions

1. What is the rate of the use of the web site content by the caregivers?
2. What is the rate of the use of the care videos by the caregivers?
3. What is the frequency of visiting the web site out of the sample?

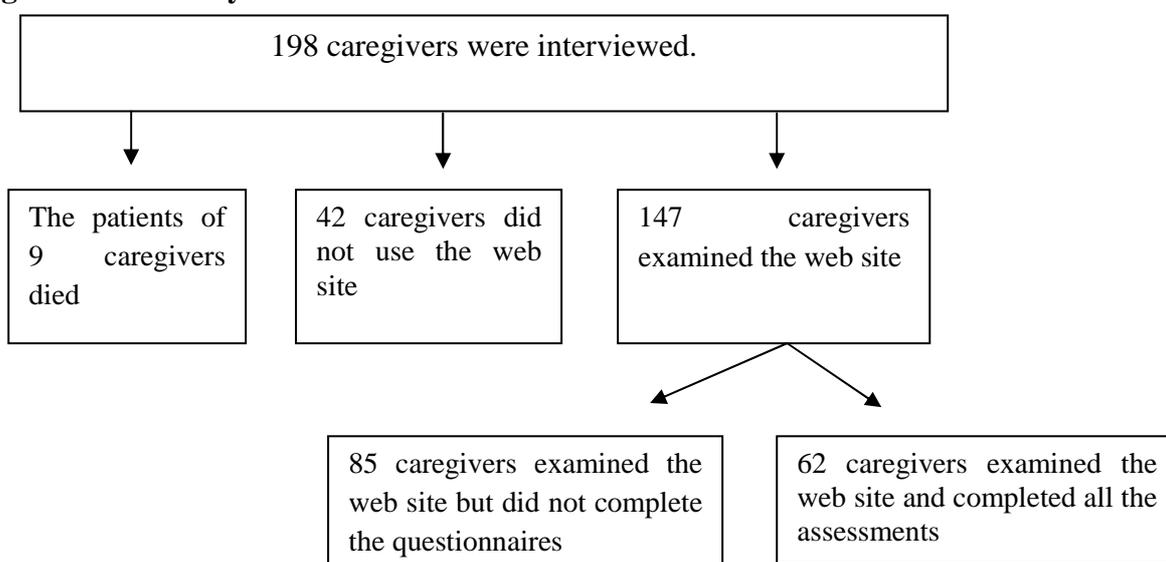
Material and Method

Type of Research and Participants

This descriptive study was conducted between December 2014 and December 2015 in the neurology clinics of two university hospitals. The sample size was not calculated and the caregivers meeting the inclusion criteria in a hospital every week were included in the study by using the purposeful sampling method. In the neurology

clinics of the aforementioned hospitals, 198 caregivers of patients receiving treatment with ICD code G46 or I63 and I64 (stroke, hemorrhage, infarct, CVD and cerebral infarction) were interviewed and handed out with the related brochures and then they were asked to examine the web site and give feedback. 74% (n=147) of all the caregivers, who were included in the study and asked to examine the web site, visited the Web site (Figure 1).

Figure 1: The study chart



The inclusion criteria of the study

For the patients of the caregivers,

- being G46 or I63 and I64 according to the ICD codes

For the caregivers

- Being voluntary to participate in the study
- Having access to the internet
- Using the internet or being accompanied by a person using the internet at home
- Being responsible for the care of the patient after discharge

Procedure

A brochure concerning the web site was prepared. The web site contains information which can be used by the caregivers for the home care of the stroke patients. The information includes definition of stroke, course of stroke, nutrition, respiration, urinary system, bedsores, body hygiene, patient safety, use of drugs, sleeping patterns, pain, communication with patient, and the institutions offering the aid for care of the patient (home care centers and public institutions providing social support). The videos on the web site are related to breathing exercises, postural drainage, oral care, catheter care, perineal care, supine position, side-down position, prone position, passing from supine

position to side-down position, passing from side-down position to prone position, pressure points in side-down position, and arm and leg exercises.

The brochure included the training areas, video subjects, and images illustrating how to access the web site. The web site was introduced by handing out brochures to the caregivers and how to utilize the web site was taught. The caregivers were asked to fill out the information form of the stroke patients and their caregivers as well as the evaluation form on the web site about the utilization of its content 15-30 days after they used the Web site. The caregivers who did not fill out the questionnaires on the web site were called by telephone and they were asked to examine the web site and fill out the evaluation forms.

Telephone call

The caregivers were called three times to remind the use of the web site and complete the questionnaires.

Data Collection Tools

Three assessment forms were used in this study: Information form, Evaluation form for the use of the web site content, and Evaluation form for the use of the care videos. The forms were prepared by the researchers.

Information form

This form included questions on demographic characteristics of the caregivers such as gender, age, education, working status, income level etc., as well as level of competence and duration of computer use. Additionally, the form questioned the presence of previous experiences in patient care and also care of stroke patients. This form included 12 statements.

Evaluation form for the use of the web site content

The evaluation form for the use of the web site content was prepared by the researcher for evaluating the utilization/efficiency of the information on the web site.

The form evaluated different subjects mostly needed by the caregivers such as use of drugs, ensuring safety, maintaining activities of daily living, maintaining the bladder and intestine functions, protecting and continuing the integrity of the skin, swallowing and communication

skills, the use of auxiliary materials, coping with emotional and behavioral reactions of the patient, preventing the development of contracture, the course of the disease, sleep problems, rehabilitation needs, and care of the nasogastric catheter.

This form, evaluating the ability of the caregivers to utilize each section on the web site, consisted of 18 statements and 3 open-ended questions and the participation degree was rated by using options of "always", "usually", and "slightly".

The answer options were arranged in such a way to reveal the utilization as follows: "always for 75% and higher", "usually for 51-74%", "sometimes for 26-50%", "slightly for 25-0%". Additional 3 open-ended questions were used to collect information about the liked or disliked features of the web site and to obtain suggestions.

Evaluation form for the use of the care videos

The evaluation form for the use of the care videos on the web site was prepared by the researchers.

This form evaluated the ability of the caregivers to utilize each of videos on the web site. It consisted of 14 statements and the participation degree was rated by the options: "I utilized very much", "I utilized", "I utilized little", and "I never utilized".

The answer options were arranged in such a way to reveal the utilization as follows: "I utilized very much for 75% and higher", "I utilized for 51-74 %", "I utilized little for 26-50 %", "I never utilized for 25-0%".

Data Analysis

Statistical assessment of the data was carried out using IBM SPSS packaged software (v.20.0; IBM Corporation, Armonk, NY, USA). Descriptive characteristics, the use of the web site content, and use of videos were assessed in number and percentage.

Ethical Principles

Before starting the study, approval from the Non-invasive Clinical Trials Ethics Committee of the Faculty of Medicine at University and written permissions from the hospitals where the study would be conducted were obtained. Informed consent of the caregivers participating in the study was obtained (03.09.2014/403).

Results

It was found that 74% (n=147) of the caregivers participating in the study used the web site and 42% (n=62) of them completed the evaluation forms of the web site. Of the caregivers filling out the questionnaires (n= 62), 63% (n= 39) were female, their average age was 39.08 ± 12.64 and

43.5% (n= 27) were university graduates. The rate of those who considerably used the internet was 51.6% (n=32), the average daily computer use time was 109.35 ± 140.79 minutes, and the rate of using the web site weekly was averagely 60.40 ± 78.41 minutes (Table 1).

Table 1: Descriptive characteristics of the family caregivers (n=62)

		N	%
Gender	Female	39	62.9
	Male	23	37.1
Average ages ($\bar{x} \pm SD$) 39.08 ± 12.64	39↓	29	46.8
	40 (+)	33	53.2
Educational level	Primary school	10	16.1
	Secondary school	6	9.7
	High school	19	30.6
	University	27	43.5
The perceived income level	Low	21	33.9
	Low high	37	59.7
	High	4	06.4
Level of utilizing Internet	Low	8	12.9
	Moderate	22	35.5
	High	32	51.6
Previous experience in patient care	Yes	21	33.9
	No	41	66.1
Previous experience in care of stroke patient	Yes	19	30.9
	No	43	69.4
Daily computer usage time ($\bar{x} \pm SD$) 109.35 ± 140.79 minutes	109 minutes	26	58.5
	110 minutes (+)	34	41.5
Usage time of the Website ($\bar{x} \pm SD$) 60.40 ± 78.41 minutes	60 minutes	50	80.6
	61 minutes (+)	12	19.4

SD, Standard deviation

Table 2: Rates of using the web site

	Number	%	Number	%
	Usually *		Sometimes**	
Caregivers' Use Levels ***				
1.Its effect on me on how to provide the care	45	72.6	17	27.4
2.Effect of my actions on the health of my stroke patient	47	75.8	15	24.2
3. How to perform feeding (swallowing difficulty, naso-gastric catheter, oral care)	40	64.5	22	35.5
4. How to solve respiration problems (difficulty in breathing, coughing)	38	61.3	24	38.7
5. How to perform catheter care	31	50	31	50
6. How to solve excretion problems (constipation, defecation habits)	41	66.1	21	33.9
7. How to prevent pressure ulcers	44	71	18	29
8. How to perform body hygiene	44	71	18	29
9.How to provide the patient safety (falling, fixing the catheter, safety of bed surroundings)	43	69.4	19	30.6
10.Understanding the course of the disease	47	75.8	15	24.2
11. How to use medication	47	75.8	15	24.2
12. How to help perform bed exercises	43	69.4	19	30.9
13. How to regulate sleeping patterns	43	69.4	19	30.9
14. How to relieve pain	41	66.1	21	33.9
15. How to maintain communication	41	66.1	21	33.9
16.Where to get care help (social support, associations, economic and medical care, home care centers)	43	69.4	19	30.6
17 How to reach necessary information for home care	44	73.3	16	26.7
18. How to reach Web-manager nurses on issues relating to home care difficulties	46	74.2	16	25.8

*Always and usually were given together. **Sometimes and rarely were given together.

***The terms were shortened in the table

Table 3: Rates of using care videos

	Utilized*		Less Utilized		Never Utilized	
	N	%	N	%	N	%
Respiratory exercise	30	48.4	25	40.3	7	11.3
Postural drainage	30	48.4	24	38.7	8	12.9
Oral care	32	51.6	22	35.5	8	12.9
Catheter care	28	45.2	18	29	11	17.7
Body hygiene	28	45.2	23	37.1	11	17.7
Supine position	42	67.7	11	17.7	9	14.5
Side-down position	44	71	10	16.1	8	12.9
Prone position	44	71	10	16.1	8	12.9
Passing from supine position to side-down position	44	71	10	16.1	8	12.9
Passing from side-down position to prone position	43	69.4	10	16.1	9	14.5
Passing from side-down position to supine position	43	69.4	11	17.7	8	12.9
Pressure points side-down position	43	69.4	11	17.7	8	12.9
Arm exercises	43	69.4	10	16.1	9	14.5
Leg exercises	43	69.4	10	16.1	9	14.5

*Utilized and significantly utilized were given together.

Table 4: Number of web site users for one year

Months	Numbers of first-time users	Numbers of repeat users	Monthly video usage of users *	Users from Turkey	Users from other countries **			Total Score
					USA **	RU **	GER **	
Dec 2014	194	208	57	413	28	56	3	87
Jan 2015	138	151	48	210	40	74	9	123
Feb 2015	167	196	168	458	37	45	10	92
Mar 2015	197	220	120	413	122	30	27	179
Apr 2015	221	246	168	601	232	29	105	444
May 2015	221	241	93	417	41	36	34	111
Jun 2015	205	240	93	268	83	73	112	268
Jul 2015	185	205	97	324	58	38	13	99
Aug 2015	221	236	69	225	3094	82	423	3599
Sep 2015	241	252	43	249	65	64	12	141
Oct 2015	331	356	76	439	85	196	12	113
Nov 2015	418	441	46	663	420	303	17	757
Dec 2015	496	538	78	748	49	227	16	292
Total Score	3235	3014	1156	5428	4354	1253	793	6305

* Second ** Users from these countries visited the web site most frequently (United States, Russia, Germany)

Of the caregivers who completed the evaluation form for the use of the web site content, 75.8% (n=47) used “always and usually” the web site. 71% stated that they “utilized the videos very much” (n= 44). The most viewed videos were ones related to side-down position, prone, and passing from supine position to side-lying (Table 3).

Table 4 shows the data obtained from the web site administration panel. The Web site www.hastayakini.net was visited several times by numerous persons in addition to those included in the sample group. In December 2015, the Web site was visited by first-time users (496) and also repeat users (538). The videos were viewed mostly in February and April 2015 with an average viewing time of 168 seconds. The Web site was also visited most frequently by users from the United States of America, Russia, and Germany. In August 2015, 3599 entries were made to the Web site by users from the United States of America, Russia, and Germany.

Discussion

The web site www.hastayakini.net, which was prepared for the caregivers of stroke patients, was visited several times by numerous persons in addition to the caregivers to whom the brochure was delivered. Although the web site was visited many times, the rate of completing the questionnaires was found to be low. All the caregivers, who were included in the study and asked to examine the web site, visited the web site, but only one third of them filled out the questionnaires. This low rate of evaluating the questionnaires has been also emphasized as a problem in similar studies (Eyesbach, 2004; Hill & Weinert, 2004; vanGelder & Roeleveld, 2010; Aslan & Yavuz, 2012; Ramathan, 2015). As suggested in the studies by Steiner *et al.*, (2009) and Pierce *et al.*, (2009), the caregivers who did not fill out the questionnaires were called by telephone, and code numbers and necessary information were sent by SMS. Nevertheless, the caregivers stated that they did not fill out the questionnaire due to forgetting, heavy workloads, occasional internet outages at home, and technical problems. It took approximately 20-25 minutes to complete the questionnaires due to many questions, which was the other important reason for not giving feedback. Therefore, the

data to be collected from web site should be short.

In this study, it was determined that three-quarters of the caregivers utilized “always and usually” the web site. The caregivers agreed that they visited usually the web site to understand how to use patient medicines and to access information on the course of the disease and the effect of the practices on the stroke patients (Table 2). Also, the rate of agreeing with statements related to access to the web site administration nurse as well as the needed information was found to be high. In a study examining the training support made for caregivers of stroke patients in a web environment, it was determined that the interaction between the patient and caregiver became stronger and the caregivers provided care to their patient with information obtained from web environment (Steiner *et al.*, 2009).

Stroke patients use anticoagulant drugs such as aspirin (antiplatelet) and coumadin (Krespi, 2009; Mollaoglu *et al.*, 2010; National Health Service, 2017). Administering medicines on time and with the correct dosage and observing their side effects are the responsibilities of the caregiver. Furthermore, the tasks of caregivers involve controlling the dosage of the medicine and possible side effects, adjusting the appropriate dosage, administering medicines, and implementing controls (INR follow-up, bleeding signs, etc.). However, patients and their families are not able to receive sufficient information about medicines at the time of discharge (Knigh *et al.*, 2013; Gilesie, Mullan and Harrison, 2014; Alkan Oz and Enc, 2015). According to Gilesie *et al.*, (2014) the caregivers consider the drug management complex and hardly comprehend it. Therefore, this situation explains the interest in the section related to the use of drugs in the present study.

The open-ended question “Which features did you like on the Web site?” was generally answered as follows: “I reached the necessary information”, “I used the videos”, and “The web site is comprehensible”. One caregiver responded negatively the question related to “disliked features” as “The videos could not be viewed”. Due to a technical problem experienced on the web site, the videos could not be viewed for two weeks. The problem was detected and

subsequently resolved. In the suggestions section, the caregivers wrote the following statements; “Thank you”, “I hope it will continue” and “I have no suggestion.” One caregiver suggested the need for “more comprehensive video support”.

In this study, the mostly viewed videos were on the patient’s lying positions and arm and leg exercises. Both videos contained important information in terms of prevention of pressure ulcers and contractures (Table 3). Viewing those videos suggested that the caregivers were aware of the potential risks in stroke patients. In the literature, it is stated that training, including videos, are efficient in developing the knowledge, attitudes, and beliefs of the patients (Moonanghi et al., 2012; Jensen et al., 2013; Webster, Grene and Grene, 2015). In a study evaluating the efficiency of the watched videos before radiotherapy for reducing the side effects of the radiotherapy experienced by patients with head and neck cancer, it was determined that the rate of understanding of side effects was higher regardless of the educational level of the patients (González-Arriagada et al., 2013). In order to decrease the risk of falling of the hospitalized elderly, video training was found to be more effective than the written material training (Hill et al., 2009). On the other hand, Makarem (2015) states that informative videos can be used efficiently in patient education because they are visual and audial; however, they are not sufficient for behavioral change.

The web site was visited several times every month throughout the study. Additionally, the questionnaires was completed by 62 individuals (Table 4). Since the web site is not encrypted, it was visited by many people. The use of the web site by users from Germany, Russia, and The United States suggested that Turks residing in or foreigners speaking Turkish in these countries might have accessed the web site.

Limitations of the Study

The study has two limitations. The first limitation is that logging in the web site does not require the password. The other limitation is that more participants should fill out the assessment questionnaires to evaluate the level of using the web site in a more proper manner.

Conclusion

Even though the caregivers who filled out the questionnaires in this study used the computer for about two hours a day, they used the web site, prepared for stroke patients, an hour a week. This result indicated that the web site achieved its purpose. Many people along with the caregivers of the stroke patients utilized the web site.

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