

# The effect of discharge training on quality of life, self-efficacy and reintegration to normal living in stroke patients and their informal caregivers: A randomized controlled trial

<sup>1</sup>Dilek Baykal, <sup>2</sup>Zeliha Tulek

<sup>1</sup>Department of Nursing, Faculty of Health Sciences, Istanbul Atlas University, Istanbul, Turkey; <sup>2</sup>Florence Nightingale Faculty of Nursing, Istanbul University-Cerrahpasa, Istanbul, Turkey

## Abstract

**Background & Objectives:** This study was carried out to evaluate the effects of discharge training on quality of life and self-efficacy in stroke patients and their informal caregivers; and reintegration to normal living in patients only. **Methods:** In this randomized, controlled trial, 59 patients and their caregivers were randomly allocated to receive discharge with education (via a webpage or booklet) or a standard of care discharge without intervention (i.e. an additional training). The 12-Item Short-Form Health Survey (SF-12), the General Self-Efficacy Scale (GSES) were applied to patients and caregivers and the Reintegration to Normal Living Index (RNLI) were applied to patients only, before discharge and 3 months after discharge. **Results:** It was found that, although the quality of life improved by the trainings in the patient intervention groups, compared with the control group ( $p < 0.05$ ); there was no change in self-efficacy parameter ( $p > 0.05$ ). Both self-efficacy and quality of life of the caregivers improved or maintained by the interventions, compared with the controls ( $p < 0.05$ ). In general, there was no significant difference between training methods (webpage versus booklet) ( $p > 0.05$ ). Lastly, the impact of discharge trainings on reintegration to normal living which was assessed in the patients only, was found to be limited.

**Conclusion:** Although discharge training improved the quality of life in both patients and informal caregivers, its effect on self-efficacy in both populations and reintegration to normal living in patients was found to be limited.

**Keywords:** Caregivers, discharge training, quality of life, self-efficacy, stroke

## INTRODUCTION

Stroke is defined as an episode of neurological dysfunction caused by focal disruption in cerebral, spinal, or retinal function, leading to ischemia or hemorrhage, based on objective evidence of injury in a defined vascular distribution, with symptoms persisting  $\geq 24$  hours or causing death.<sup>1</sup> As the second leading cause of deaths and disability worldwide, stroke is one of the most common and serious global health care problems.<sup>2</sup> It is the third leading cause of death in Turkey and one of the leading causes of disabilities.<sup>3</sup>

Depending on its type, severity, and recurrence, stroke may lead to persistent neurological deficits. These neurological deficits can cause motor, sensational, emotional, mood, and cognitive

disorders, as well as bowel and bladder control issues. Consequently, many patients become functionally dependent on care after a stroke.<sup>4</sup> These problems lead to a decrease in quality of life by impacting not only the patients, but also their informal (family and/or unpaid) caregivers psychologically, socially, and economically.<sup>5</sup> Therefore, to maintain an acceptable quality of life, empowering patients and their caregivers via education programs is critically important.

Stroke education programs are mainly based on helping patients achieve self-efficacy. Self-efficacy can be defined as a person's self confidence in their capability to perform activities required for specific performance achievements. This capability can motivate or demotivate

Address correspondence to: Dilek BAYKAL, RN, PhD, Assistant Professor, Istanbul Atlas University, Faculty of Health Sciences, Department of Nursing, Anadolu Street, No:40, Kagithane \Istanbul\ Türkiye. Tel: +90 212 444 3 439, Email: dilek.baykal@atlas.edu.tr

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the person to take action.<sup>6</sup> As patients begin introducing healthy behaviors into their lives upon being discharged, their self-efficacy in this process is crucial to their success.<sup>7</sup> One of the main goals of stroke education and rehabilitation is the reintegration of patients to a normal life. Studies have reported that stroke survivors encounter enormous difficulties in reintegrating into their social roles. Reintegration to normal living is essential to increasing self-efficacy.<sup>8</sup> It has been reported that patients and caregivers need training to adapt to their new situations that arise as a result of stroke, and this need is not always met.<sup>9</sup> In the literature on stroke, there are studies reporting positive effects of patient education on functional capacity<sup>10</sup>, quality of life<sup>11</sup>, coping skills<sup>12</sup>, and self-efficacy.<sup>13</sup> But these studies mostly have focused on informal family caregivers, and sometimes patient involvement is lacking. However, the guidelines published by the American Heart Association/American Stroke Association (AHA/ASA) recommends a dyadic approach for stroke patients and their family caregivers. Dyadic intervention is defined as a process in which a stroke survivor and his or her caregiver actively participate in the intervention.<sup>14</sup>

One of the dyadic interventions applied to stroke patients and their caregivers is patient education. Due to the motor and cognitive deficits related to stroke, it is recommended that patient education be individualized, applied face-to-face or over the phone, and consist of 5–9 sessions.<sup>15</sup> Although different training methods exist, web-based interventions are currently used extensively.<sup>16</sup> It is reported that these practices increase the efficiency and quality of care during the rehabilitation process.<sup>17</sup> On the other hand, these are not tailored to the specific needs of the individual patient, and this may lead to compliance problems. Therefore, web-based interventions are recommended to be individualized.<sup>18</sup>

Although a growing body of literature and guidelines suggests that interventions for stroke patients should be applied dyadically, it is reported that these studies are generally only published by developed countries.<sup>14</sup> But in developing countries such as Turkey, studies on stroke generally focus only on caregivers, thus not using a dyadic approach.<sup>19</sup>

This study was designed to evaluate the impact of discharge training given to stroke patients and their informal caregivers; on stroke patients' and caregivers' quality of life and self-efficacy, and on reintegration into normal living, in patients only. It also aimed to determine which method of patient

education is more effective. We hypothesized that patients receiving training by booklet or webpage would have improved reintegration to normal living compared with those patients in the control group. Furthermore, we hypothesized that training would result in an improvement in self-efficacy and quality of life not only in patients, but also in their informal caregivers, compared with the control groups.

## METHODS

The current study was a three-arm, randomized controlled trial designed to evaluate the impact of discharge training on stroke patients' quality of life, self-efficacy, and reintegration to normal living and on quality of life and self-efficacy in informal caregivers. Ethics committee approval was obtained from Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty Ethical Committee (11.02.2016, No:395850). Written consents were obtained from all patients and informal caregivers.

The study was conducted in hospitalized stroke patients and their informal caregivers in a university hospital neurology clinic between January and June 2017. Stroke patients over 18 years old, who were literate, ambulatory and with mild to moderate stroke based on National Institutes of Health Stroke Scale (NIHSS) scores were enrolled. Patients were excluded if they have communication problems or any neurological disorders other than stroke. The inclusion criteria for informal caregivers were that they must be over 18 years of age, literate, and have no communication problems. Paid caregivers were excluded. The sample size was calculated as a minimum of 18 patients in each group, and a total of 54 people, using the sample size calculator tool on <https://clincalc.com/stats/samplesize.aspx>. However, we decided to recruit 20 patients in each group considering a drop out rate of 10 %. A total of 60 patients and their informal caregivers were randomized into three arms (training by booklet, training by webpage, and one control group receiving a standard of care discharge) using a non-stratified computer-generated randomization method (<http://www.graphpad.com/quickcalcs/randomize2/>). One of the researchers performed randomization of participants into the intervention groups with a ratio of 2:1, with patients receiving (1) standard of care discharge or (2) an intervention consisting of a stroke education carried out before standard hospital discharge. The other researcher who had

been blinded to the randomization information throughout the data collection period, assessed the results with the blinded statistician.

Participants (patients and their informal caregivers) were randomized to one of the two intervention arms (discharge training by use of either booklet or webpage) or the control group (standard of care discharge for the patients) (Figure 1). Before the research, educational material was prepared based on the literature. The content of the educational material was discussed with stroke specialists, and the clarity and understandability of the material were evaluated by elementary school graduates. The educational material consisted of three chapters (Appendix). The first chapter contained information about stroke. In Chapter 2, stroke rehabilitation was explained. Chapter 3 contained information about reintegration to normal living. This content was available and identical both in the booklet and the webpage. The website was designed by a professional webmaster. There was also a link on the webpage to provide access to the investigator. A forum was created where patients' caregivers could chat with one another and ask questions.

After all preparations were completed, patients

were randomized into three groups. A baseline assessment was made before the intervention. Data collection tools were applied to the patients in the wards while the caregivers were in a separate room. An information form, the General Self-Efficacy Scale (GSES), and the 12-Item Short-Form Health Survey (SF-12) were given to the participants. The patients were also given the Reintegration to Normal Living Index (RNLI). NIHSS scores were obtained from patients' files. This baseline assessment was followed by 45–50 minutes of tailored training, based on the needs of those participants in the intervention groups. Booklets were delivered to, or a webpage address was shared with, the participants in the intervention groups (the webpage address was [www.inmeliyim.com](http://www.inmeliyim.com), which means "I have had a stroke" in Turkish). The investigator's (first author's) contact information was shared with participants, and they were informed that they would be contacted weekly to provide updates, for 3 months. The guidance in the booklets and webpage was related to the problems that stroke patients typically experience in daily life. These problems are generally regarding adaptation struggles resulting from the acute onset of the

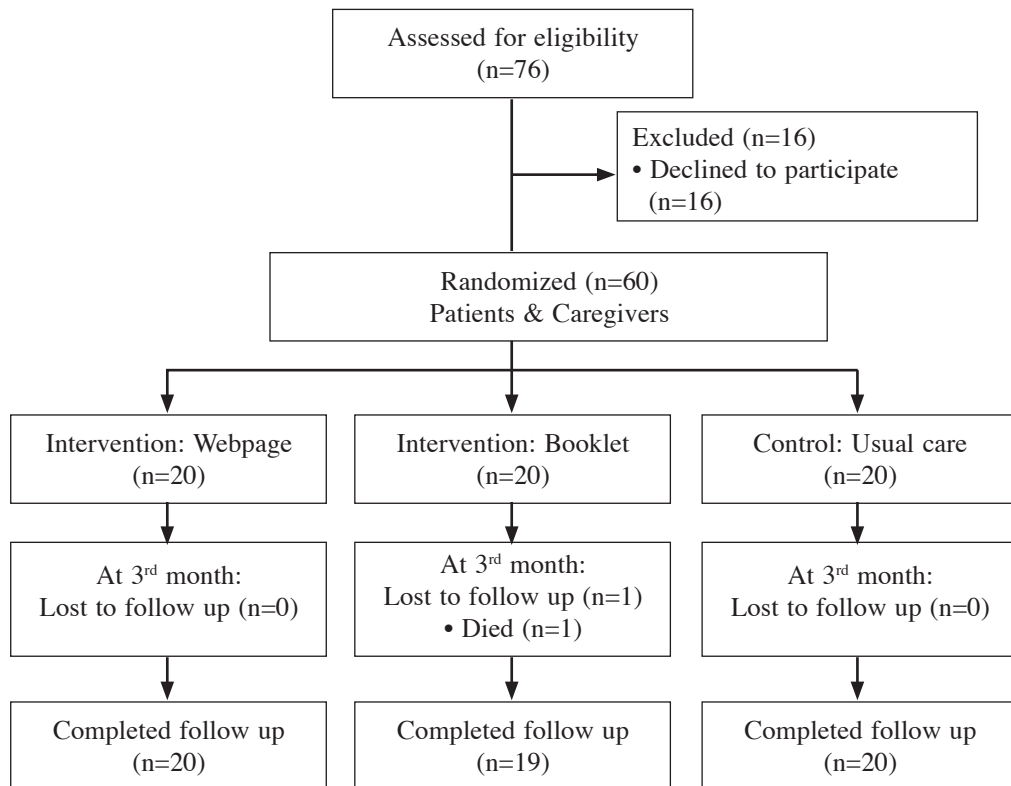


Figure 1. CONSORT flow diagram

disease. The webpage group was encouraged to access the site, and the booklet group was encouraged to refer to their booklets whenever they needed information. No intervention was applied to the control group participants besides standard, routine hospital care and discharge procedures. The hospital's routine discharge procedures included providing patients with a one-page stroke information form, delivered by the nurses. All enrolled participants were called by phone for a follow-up interview at the end of 3 months, and the same data collection tools that were used at baseline (discharge) were applied again. No intervention was applied to the control groups, but according to the ethical standards, the same training was offered to those who were in the control groups, at the end of the study.

In this study, primary outcome measures were the changes in quality of life and self-efficacy in patients and caregivers, and reintegration to normal living in patients, from discharge to 3 months. The SF-12 survey, GSES, and RNLI were used to collect data.

SF-12, developed by Ware *et al.*, consists of two composite scores: physical (PCS) and mental (MCS). It assesses a patient's quality of life, and all scores range between 0 and 100. Higher scores indicate a better quality of life. Cronbach's alpha value of the Turkish SF-12 version is 0.70.<sup>20</sup> GSES is a likert-type scale consisting of 10 items which was developed to measure self-efficacy. The total score ranges between 10 and 40, and a higher score indicates a greater amount of self-efficacy. It was adapted to the Turkish population with a Cronbach's alpha value of 0.80.<sup>21</sup> RNLI was developed by Daneski *et al.* and a higher RNLI score shows a better adaptation to normal living. It was translated into Turkish. Translated version consists of 10 questions and the scores range between 11 and 55. Validity of the Turkish version was performed with a Cronbach's alpha value of 0.89.<sup>22</sup>

The data was analyzed by using the IBM® SPSS® Statistics 21.0 software. The data were presented as the mean and standard deviation or percentage. The chi-square test was used to compare the percentages between the groups. The Kruskal-Wallis test and the Bonferroni-corrected Mann-Whitney U test for post-hoc analysis was used to compare the mean scores of the dependent variables (quality of life, self-efficacy, and reintegration to normal life) in the three groups. The Wilcoxon signed-rank test was

used to compare outcomes before and after the intervention. A  $p$ -value of  $< 0.05$  was considered statistically significant.

## RESULTS

The flow diagram of the study is shown in Figure 1. A total of 76 patient and caregiver dyads met the inclusion criteria during the enrollment period. Of these, 60 were randomized to the intervention and the control groups. One patient died during follow-up. All other patients and caregivers completed the questionnaires at baseline (before discharge) and 3 months after the interventions (trainings). Patient characteristics, including sociodemographic and clinical features (neurological deficits, comorbidity, and duration of stroke), were similar in the 3 groups (Table 1). However, education level tended to be higher in the intervention groups compared with the controls. The percentage of a high-school-or-higher education level was 40% in the webpage group, 31.6% in the booklet group, and 10% in the control group ( $p=0.081$ ).

Regarding caregivers' characteristics, education level and percentage of being single were higher in the webpage group than in the other two groups ( $p=0.002$  and  $p=0.033$ , respectively). Income level was higher in the booklet group compared with the other two groups ( $p=0.035$ ). Other sociodemographic characteristics were similar among caregivers (Table 2).

### Patients

The most widely recognized outcome parameter by the medical community, which we assumed would improve in the patient training groups, was the quality of life. There was no significant difference between QoL-PCS of the three groups at baseline ( $p=0.128$ ), while these scores were significantly higher in the intervention (webpage and booklet) groups at the 3rd month compared to the control group patients ( $p<0.001$ ). When the three groups were compared in terms of difference from baseline to the 3rd month, QoL-PCS decreased by about nine points in the control group and increased by about eight points in both intervention groups ( $p=0.02$ ). Although intervention improved the QoL-PCS results, there was no superiority between the two educational modalities. A positive pattern was also observed for QoL-MCS. The control group reported the worst MCS at the 3rd month ( $p=0.005$ ), but their scores also tended to be worse at baseline ( $p=0.094$ ). Changes in QoL-

**Table 1: Sociodemographic and clinical characteristics of the patients (n=59)**

Variables	Control (n=20)		Web (n=20)		Booklet (n=19)		$\chi^2$	<i>p</i>
	n	%	n	%	n	%		
<b>Gender</b>								
Male	14	70.0	9	45.0	8	42.1	3.731 (SD: 2)	0.155
Female	6	30.0	11	55.0	11	57.9		
<b>Level of Education</b>								
Literate	3	15.0	1	5.0	5	26.3	8.294 (SD: 4)	0.081
Primary education	15	75.0	11	55.0	8	42.1		
Secondary education and higher	2	10.0	8	40.0	6	31.6		
<b>Marital status</b>								
Single/Widowed	3	15.0	6	30.0	4	21.1	1.325 (SD: 2)	0.515
Married	17	85.0	14	70.0	15	78.9		
<b>Work status</b>								
Working	2	10.0	4	20.0	7	36.8	4.159 (SD: 2)	0.125
Not working	18	90.0	16	80.0	12	63.2		
<b>Income (perceived)</b>								
High	4	20.0	3	15.0	5	26.3	0.772 (SD: 2)	0.680
Moderate/Low	16	80.0	17	85.0	14	73.7		
<b>Stroked affected area</b>								
Right hemisphere	11	55.0	11	55.0	10	52.6	0.029 (SD: 2)	0.986
Left hemisphere	9	45.0	9	45.0	9	47.4		
<b>Comorbidities</b>								
Yes	18	90.0	15	75.0	16	84.2	1.625 (SD: 2)	0.444
No	2	10.0	5	25.0	3	15.8		
<b>Age (M±SD)(KW, <i>p</i>)</b>	65.25±14.61		61.00±16.96		59.37±17.89		0.863	0.650
<b>NIHSS (M±SD)(KW, <i>p</i>)</b>	3.30±2.15		2.05±1.79		2.89±2.00		3.611	0.164
<b>Duration of stroke (Day)(M±SD)(KW, <i>p</i>)</b>	7.25±3.71		6.65±4.63		6.47±4.19		1.605	0.448

**NIHSS:** National Institute of Health Stroke Scale

**$\chi^2$ :** Pearson chi-square analysis

**KW:** Kruskal-Wallis test (SD: 2)

MCS from the baseline to the 3rd month were not significant within individual groups or when comparing group scores to one another ( $p=0.404$ ). However, although it was not significant, QoL-MCS decreased in the control group by about nine points, while remained almost the same in the webpage and booklet groups (Table 3).

GSES scores did not change significantly between the baseline and the 3rd month in the groups that received training ( $p=0.156$  for the control group,  $p=0.866$  for the webpage group, and  $p=0.864$  for the booklet group). Moreover, no significant difference was detected in the GSES scores between any of the groups at baseline

( $p=0.953$ ) and the 3rd month ( $p=0.182$ ).

Regarding reintegration to normal living, there was an improvement in in all three patient groups, including the control group, across the study period ( $p=0.082$ ). At the 3<sup>rd</sup> month, RNLI scores were significantly higher in intervention groups compared with the control group ( $p=0.043$ ). However, at baseline, the control group already tended to receive worse scores than the intervention group. Therefore, none of the groups showed a statistically significant increase in RNLI scores, over the other groups, across the time points ( $p=0.326$ ). In other words, analyses within

**Table 2: Sociodemographic characteristics of the caregivers (n=59)**

Variables	Control (n=20)		Web (n=20)		Booklet (n=19)		$\chi^2$	p
	n	%	n	%	n	%		
<b>Gender</b>								
Male	4	20.0	5	25.0	4	21.1	0.161	0.923
Female	16	80.0	15	75.0	15	78.9	(SD: 2)	
<b>Level of Education</b>								
Literate	2	10.0	1	5.0	-	-	12.389	<b>0.002</b>
Primary education	12	60.0	2	10.0	8	42.1	(SD: 2)	
Secondary education and higher	6	30.0	17	85.0	11	57.9		
<b>Marital status</b>								
Single/Widowed	3	15.0	10	50.0	4	21.1	6.795	<b>0.033</b>
Married	17	85.0	10	50.0	15	78.9	(SD: 2)	
<b>Work status</b>								
Working	6	30.0	12	60.0	7	36.8	4.037	0.133
Not working	14	70.0	8	40.0	12	63.2	(SD: 2)	
<b>Income level (perceived)</b>								
High	2	10.0	3	15.0	8	42.1	6.718	<b>0.035</b>
Moderate/Low	18	90.0	17	85.0	11	57.9	(SD: 2)	
<b>Age (M±SD) (KW, p)</b>								
	47.55±11.56		42.35±13.10		45.16±14.89		2.348	0.309

groups showed an increase in RNLI scores from the baseline scores in all three groups, regardless from the intervention.

#### *Informal caregivers*

The QoL-PCS in all the caregiver groups were comparable at baseline ( $p=0.893$ ) but different in the booklet group compared with the webpage and control groups at the 3rd month ( $p=0.004$ ). Within-group analyses indicated a decline in QoL-PCS in the control ( $p=0.005$ ) and webpage ( $p=0.036$ ) groups at the 3rd month compared with the baseline scores. The difference between changes at the 3rd month indicated an increase in quality of life in the booklet group compared with the webpage and control groups ( $p=0.004$ ). Regarding QoL-MCS, although mean QoL-MCS were similar among all the caregiver groups at baseline ( $p=0.712$ ), at the 3rd month the booklet group reported better QoL-MCS than the controls ( $p=0.028$ ). Within-group analyses showed a decrease in mean QoL-MCS in the control group at the 3rd month ( $p=0.005$ ). In general, a comparison of differences between the changes in QoL-MCS across the time points demonstrated a significant decrease in quality of life in the control group, compared with the webpage and booklet groups ( $p=0.042$ ) (Table 4). We can conclude that

interventions had a positive or neutral impact on SF-12 composite scores of caregivers while the controls group's scores worsened.

When we review GSES scores we observe that the caregiver control group reported the worst GSES scores ( $p=0.033$  at the 3rd month, but their scores also tended to be worse at baseline ( $p=0.091$ ). Interestingly, GSES scores decreased both in the control group and in the webpage group at 3 months, whereas remained the same in the booklet group. However, the changes across time were not significantly different between groups ( $p=0.513$ ) that is to say there was no impact of interventions on GSES scores.

#### **DISCUSSION**

The present study demonstrated that discharge training, regardless of the method, was effective in improving not only patients', but also caregivers' quality of life. While self-efficacy did not improve in patients in the intervention groups, it also did not worsen at the 3rd month, unlike in the control group. There was an improvement in reintegration to normal living parameters in all three groups of patients at the 3rd month whose neurological dysfunctions were similar at baseline, but the effect of training on this improvement was unclear. In summary, although discharge training

**Table 3: Comparison of mean scores of patients' quality of life, general self-efficacy, and reintegration to normal living scales**

	Control/C group (n=20)	Web/W group (n=20)	Booklet/B group (n=19)	KW	<i>p</i>
	M±SD	M±SD	M±SD		
<b>QoL-PCS</b>					
Baseline	48.13±21.37	61.56±22.79	53.62±18.90	4.106	0.128
3 months later	38.44±16.13	70.31±18.01	61.18±26.81	18.080	<b>&lt;0.001(C&lt;W,B)</b>
Z	1.713	1.541	1.272		
<i>p</i>	0.087	0.123	0.203		
Difference	-9.68±24.87	8.75±21.40	7.56±28.07	7.796	<b>0.02</b>
<b>QoL-MCS</b>					
Baseline	45.25±23.81	60.88±20.23	56.71±20.54	4.722	0.094
3 months later	36.38±20.35	62.69±23.83	54.67±28.44	10.455	<b>0.005(C&lt;W,B)</b>
Z	1.587	0.414	0.141		
<i>p</i>	0.112	0.679	0.888		
Difference	-8.87±25.22	1.81±30.94	-2.03±38.12	1.811	0.404
<b>GSES</b>					
Baseline	19.45±5.22	20.35±5.26	20.05±5.33	0.097	0.953
3 months later	17.75±3.48	20.60±5.43	19.84±4.05	3.422	0.181
Z	1.418	0.169	0.171		
<i>p</i>	0.156	0.866	0.864		
Difference.	-1.70±4.87	0.25±5.21	-0.21±5.26	1.336	0.513
<b>RNLI</b>					
Baseline	35.95±7.89	40.95±6.81	37.47±6.70	4.993	0.082
3 months later	44.35±5.46	48.85±4.98	48.05±5.90	6.291	<b>0.043</b>
Z	3.326	3.641	3.826		
<i>p</i>	<b>0.001</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>		
Difference	8.40	7.90	10.58	2.240	0.326

**QoL-PCS:** Quality of Life, Physical Composite Score; **QoL-MCS:** Quality of Life, Mental Composite Score; **GSES:** General Self-Efficacy Scale; **RNLI:** Reintegration to Normal Living Scale; **Z:** Wilcoxon signed-rank test; **KW:** Kruskal-Wallis test

improved the quality of life in both patients and caregivers, its effect on reintegration to normal living and self-efficacy was found to be limited.

Physical disabilities may negatively impact stroke patients' reintegration into normal and social living and carrying out of daily activities. Limitations on reintegration into normal living may contribute to depression and anxiety development through loneliness and feelings of abandonment. Further, these factors continue to negatively impact patients for several years post-stroke.<sup>23</sup> It has been reported that discharge training is helpful in identifying patients' and caregivers' needs so that they can develop effective coping methods, leading to enhanced community reintegration and adaptation for patients.<sup>24</sup> However, studies reported that stroke

patients are not willing to reintegration into normal living independently after a stroke but only become active through group exercises. This is attributed to patients being uneager for reintegration to normal living and also their physical impairments and limited self-efficacy. Some obstacles to self-efficacy are the fear of stroke recurrence and the fear of falling. Moreover, the overconcerns of caregivers may influence patients' resume to their normal living before the stroke.

Other obstacles to reintegration and self-efficacy are physical and social environmental factors. Physical barriers are among the factors that negatively impact reintegration to normal living.<sup>25</sup> Substantial access problems among disabled people have been reported even in developed

**Table 4: Comparison of mean scores of caregivers' quality of life and general self-efficacy scales**

	Control/C group (n=20)	Web/W group (n=20)	Booklet/B group (n=19)	KW	p
	M±SD	M±SD	M±SD		
<b>QoL-PCS</b>					
Baseline	69.69±15.35	70.94±15.08	65.79±22.08	0.227	0.893
3 months later	49.38±25.24	57.19±21.77	74.34±19.31	10.921	<b>0.004(C,W&lt;B)</b>
Z	2.816	2.097	1.501		
p	<b>0.005</b>	<b>0.036</b>	0.133		
Difference	-20.31±27.04	-13.75±25.37	8.55±23.40	11.132	<b>0.004(C=W&lt;B)</b>
<b>QoL-MCS</b>					
Baseline	61.50±17.06	58.13±21.67	63.16±26.05	0.679	0.712
3 months later	39.13±29.75	54.13±24.78	62.30±30.46	7.119	<b>0.028(C&lt;B)</b>
Z	2.838	0.785	0.483		
p	<b>0.005</b>	0.433	0.629		
Difference	-22.37±27.62	-4.00±24.96	-0.85±32.48	6.332	<b>0.042(C&lt;W=B)</b>
<b>GSES</b>					
Baseline	21.75±4.23	25.05±4.62	23.16±4.83	4.799	0.091
3 months later	19.55±4.54	22.85±3.57	23.32±3.77	6.840	<b>0.033(C=W&lt;B)</b>
Z	2.472	2.250	0.383		
p	<b>0.013</b>	<b>0.024</b>	0.702		
Difference	-2.20±3.48	-2.20±3.98	0.15±2.73	1.336	0.513

**QoL-PCS:** Quality of Life, Physical Composite Score; **QoL-MCS:** Quality of Life, Mental Composite Score; **GSES:** General Self-Efficacy Scale; **Z:** Wilcoxon signed-rank test; **KW:** Kruskal-Wallis test

countries. Disabled people or physically impaired patients have major difficulties in social participation because of physical barriers in developing countries like Turkey—especially in overcrowded cities like Istanbul, with populations of more than 15 million people.<sup>26</sup>

Our findings, which show the limited impact of discharge training on the improvement of reintegration and self-efficacy of stroke patients, are considered to be the result of those aforementioned factors. The impact of discharge training was found to be limited in caregivers' self-efficacy too. Informal caregivers' self-efficacy and self-concept are important in the management of acute conditions like stroke. Defining individual targets and managing perceptions are required to increase caregivers' self-efficacy.<sup>6</sup> Although caregivers were provided with individualized training and support in the current study, it was reported that caregivers had concerns about their caregiver capabilities, leading to their decision-making mechanisms being impacted.<sup>6</sup> A recent meta-analysis reporting on the difficulties in improving caregivers' self-efficacy due to physical, social and, psychological sequelae of stroke, confirms our findings.<sup>27</sup>

As stated above, in our study, discharge training was found to improve the quality of life in patients and caregivers. Recently, due to increased life expectancy, quality of life has become a popular topic, and efforts to increase quality of life are focused on general wellbeing, rather than being limited to only morbidity and biological functions.<sup>28</sup> Quality of life is particularly important in chronic diseases such as stroke, and studies show a decline in quality of life in the first 3 months after stroke. If early adaptation to acute disease is not achieved, quality of life continues to decrease for several years post-stroke.<sup>17</sup> Low quality of life in patients causes a decrease in caregivers' quality of life too. Spouses of stroke patients—who suffer from psychological, social, and economic burdens of the disease—are especially impacted, and their quality of life decreases.<sup>2</sup> They suffer from social isolation due to diminished self-care and their spending more time at home and not participating in social activities.<sup>30</sup> The burden of caregiving leads to caregivers' negligence of their healthcare needs and a worsening of their current healthcare problems. All these factors result in a higher incidence of cardiovascular diseases and a lower



life expectancy in caregivers<sup>31</sup>, and patient/family education plays an important role in increasing caregivers' quality of life. Effective management of the disease and its complications, as well as improvement of coping skills, can be achieved by patient/family education.<sup>32</sup>

Limitations of the study include single-center research and small sample size which make a generalization of results to a broader population difficult and might not be enough to show a difference between the training methods. On the other hand, this trial was conducted in a major, referral university hospital in the most crowded city in Turkey, and this provided a wide range of variability and diversity in the sample group which can be considered as a representative of the nation. Baseline sociodemographic varieties such as in the educational and income statuses differences among the intervention and control groups, especially in the caregivers, might have influenced the findings. Another limitation is the relatively shorter, 3-months follow-up time point. Longitudinal future investigations are necessary to observe longer-term results in stroke patients and their informal caregivers. The utilization of communication technologies such as smartphones and computers to train patients and caregivers is a relatively newer approach in developing countries. Researchers faced challenges in having participants utilize the webpage, especially in patient groups of advanced age and/or with low educational levels. We may recommend this factor be taken into consideration when future studies are planned in these patient groups. Also, the results cannot be extended to the paid, professional caregivers since they were excluded from the study.

In conclusion, our results showed a beneficial effect of discharge training on quality of life in stroke patients and their informal caregivers and self-efficacy in caregivers only, but it hasn't been determined which training method is more efficient. There was no significant superiority between the two training methods, but more benefits were reported in caregiver parameters in the groups that received the booklet training. We think this result may be explained by sociodemographic differences between caregiver groups at baseline. This research demonstrated that discharge training improved the quality of life in stroke patients and their caregivers. The training also helped participants maintain their self-efficacy. However, no significant superiority between training methods (webpage versus booklet) has been shown.

## DISCLOSURE

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## **Appendix**

### **Overview of the stroke education programme sessions**

#### Section 1: General information about stroke

- Stroke definition
- Risk factors
- Stroke symptoms
- Types of stroke
- Diagnostic methods
- Treatment methods
- Prevention of recurrence of a stroke

#### Section 2: Stroke rehabilitation

- Hygiene practices
- Swallowing difficulties
- Communication difficulties
- Sensory issues
- Excretion problems
- Fatigue
- Sleep problems
- Pain
- Muscle problems
- Cognitive changes
- Psychological and behavioral changes
- Sexuality changes

#### Section 3: Reintegration to normal living

- Providing a safe environment
- Physical activity and exercise
- Participation in work and social life