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**The Effect of Training Provided to the Relatives of Stroke Patients  
on the Life Quality, Anxiety and Depressive Symptom Levels of Patients  
and Their Relatives**

**Wpływ szkolenia skierowanego do rodzin pacjentów z udarem mózgu  
na jakość życia, poziom lęku i przejawy depresji u pacjentów oraz ich krewnych**

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**Abstract**

**Introduction.** Stroke is a crisis for the patient relatives who are caregivers of the patient as well. The patients' relatives need training and effective support at the stage of accepting this new responsibility.

**Aim.** The purpose of this study is to determine the effect of the training provided to the relatives of stroke patients on life quality, anxiety, and depressive symptoms of stroke patients and their relatives.

**Material and Methods.** The data were obtained from patients, who received treatment in the Stroke unit of a university hospital in Istanbul as well as from their primary caregiver relatives. While 20 patients whose stroke care/treatment continued and their relatives were assigned to the control group, 20 patients and their relatives that were trained in addition to the care/treatment were assigned to the experimental group. EuroQol Health Questionnaire, State-Trait Anxiety Inventory, and Beck Depression Inventory were used at the beginning of the study and 3 and 6 months after discharge. The data were analysed by descriptive and non-parametric tests.

**Results.** It was determined that there was no significant difference between the experimental and control groups in terms of health-related life quality at admission of hospital and 3 months after the discharge but 6 months after the discharge, health-related life quality of the patients in the experimental group increased statistically compared to the control group ( $p < 0.05$ ). It was observed that the training provided to the patients' relatives in the experimental group had no effect on the perceived health condition, anxiety, and depression by the patients and their relatives; however, in the control group, there was an increase in the anxiety and depressive symptom level of the patients 3 and 6 months after the discharge ( $p < 0.05$ ).

**Conclusions.** The argument stating that the Patients' Relative Training Program may enhance the quality of life following the stroke and may be effective in decreasing the anxiety and depressive symptoms of the patients and their relatives was strengthened. (JNNN 2018;7(2):56–63)

**Key Words:** stroke, quality of life, anxiety, depression, career/caregiver training, nursing

**Streszczenie**

**Wstęp.** Udar wywołuje kryzys, jakiego doświadczają rodziny pacjentów, dla których są oni również opiekunami. Bliskim pacjentów potrzebne są szkolenia oraz skuteczne wsparcie na etapie przejmowania nowej dla nich odpowiedzialności.

**Cel.** Celem niniejszego opracowania jest określenie wpływu szkolenia zapewnianego krewnym pacjentów po udarze mózgu na jakość życia, lęki oraz objawy depresji u pacjentów po udarze i ich krewnych.

**Materiał i metody.** Dane uzyskano od pacjentów, poddanych leczeniu w oddziale udarowym Szpitala Uniwersyteckiego w Stambule, a także od ich krewnych sprawujących nad nimi podstawową opiekę. Podczas, gdy 20. pacjentów kontynuowało leczenie/leczenie udaru, a ich krewni zostali przydzieleni do grupy kontrolnej, 20. pacjentów i ich krewnych, przeszkolonych w dziedzinie opieki uzupełniającej/leczenia, włączono do grupy eksperymentalnej. Kwestionariusz Zdrowia EuroQol, Skalę Stanu Lękowego oraz Skalę Depresji Becka wykorzystano na początku badania oraz 3 i 6 miesięcy po wypisie. Dane analizowano za pomocą testów opisowych i nieparametrycznych.

**Wyniki.** Stwierdzono, że nie ma istotnej różnicy między grupami eksperymentalnymi i kontrolnymi pod względem jakości życia związanej ze zdrowiem przy przyjęciu do szpitala i 3 miesiące po wypisie, jednak 6 miesięcy po wypisie, jakość życia pacjentów związana ze zdrowiem w grupie eksperymentalnej wzrosła statystycznie w porównaniu do grupy kontrolnej ( $p < 0,05$ ). Zaobserwowano, że szkolenie zapewnione krewnym pacjentów w grupie eksperymentalnej nie miało wpływu na postrzegane stanu zdrowia, lęku i depresji przez pacjentów oraz ich krewnych; jednak w grupie kontrolnej nastąpił wzrost poziomu lęku i objawów depresji u pacjentów 3 i 6 miesięcy po wypisaniu ( $p < 0,05$ ).

**Wnioski.** Potwierdzony został argument przemawiający za tym, że Program Szkolenia Rodziny Pacjenta może poprawić jakość życia po udarze i może skutecznie wpływać na zmniejszanie lęku i objawów depresyjnych u pacjentów oraz ich bliskich. (PNN 2018;7(2):56–63)

**Słowa kluczowe:** udar, jakość życia, lęk, depresja, szkolenie opiekuna, opieka pielęgniarska

## Introduction

Stroke was the second most common cause of death in the world in 2013 with 6.5 million deaths according to the report of the American Heart Association [1]. Being the second cause of death with the rate of 15% among the total deaths in Turkey, stroke is ranked as the third with the rate of 5.9% in the calculation of Disability Adjusted Life Years (DALY). In terms of both the cause of death and the disability adjusted life years, stroke constitutes a disease group that becomes gradually more important for community health both in Turkey and in the world [2].

Stroke causes patients to become semi dependent in the performance of life activities by affecting their bio-physiological, psychological and socio-cultural dimensions. Rehabilitation and other professional care practices/support are very limited in care and rehabilitation of the patients following the stroke and the responsibility of the care is often realised at home by the patient's relatives/family members [3]. Since stroke takes place all of a sudden, both the patients and the patients' relatives/family members, who are their primary caregivers, are unprepared for such situation [4]. Physical and mental problems (anxiety and depression) that occur due to stroke, the long-term need for care, and the losses in work and social life significantly impair the quality of life of patients and frequently their caregivers [5].

Lack of anxiety, depressive symptoms and the quality of life at the desired level among caregivers indicates that medical team members should plan and develop interventions for enhancing the quality of life of caregivers [3]. In this sense, it is significant for nurses to plan and implement an effective training program so that nurses could provide adherence to disease and self-care in patients within the scope of their instructional role as well as for patients and patients' relatives to make appropriate decisions regarding the care and to take responsibility together [6]. It is stated in the related studies that training/counselling programs decrease the anxiety, depressive symptom levels and caregiving burden among the patients and patients' relatives, provide to learn proper coping methods, increase care satisfaction,

enhance the quality of life and thus have positive effects on patients' care/treatment outcomes, decrease the length of hospital stay as well as the number of repeated hospitalizations in hospital and rehabilitation units and thus reduce costs [7,8]. It is emphasized, on the other hand, that in particular receiving/providing insufficient information generates significant results such as failing to take secondary measures for the patients and patients' relatives/caregivers and to reach long term psychosocial targets [9]. However, even though in the recent years there has been an increase in the number of studies investigating the effect of practices such as training/counselling provided to the patients/patients' relatives on rehabilitation results, the number of the studies indicating the effectiveness of the training is limited and it is stated that effectiveness of the training alone cannot be exactly revealed in terms of increasing care/treatment outcomes and the quality of life [8,9]. On the other hand, in the related studies, it is stated that there is no consensus on what the most effective training should be like in the context of such subjects as timing, content and duration of the training provided to the stroke patients/patients' relatives and the subject continues to be a significant problem [4,9,10,11].

In Turkey, on the other hand, there is a limited number of studies on stroke patient/patient's relative training and the number of studies evaluating the effectiveness of the patient's relative training on results of both patients and their relatives is small. Accordingly, the study was planned and conducted as quasi-experimental manner in order to determine the effect of the training provided to the relatives of stroke patients on the quality of life, anxiety, and depressive symptoms of the patients and their relatives.

In this process, the aim of the patient's relative training should be to increase the independence of the patients and to protect their own health.

## Material and Methods

### *Population — Sample of the Study*

The population of the study consisted of patients admitted to the stroke unit of one of the largest university hospitals located in Istanbul between November 2007 and May 2008 for the control group and between January and July 2009 for the experimental group; as well as their relatives who were their primary caregivers. The sample included the patients who were within the first week of hospital admission between the study dates, had no total anterior circulation infarct (TACI) based on the ischemic stroke classification suggested by Oxfordshire Community Stroke Project (OCSP); had a Rankin score of  $\leq 4$ ; had a score of National Institute of Health Stroke Scale (NIHSS) of  $\leq 16$ , were awake and had no aphasia; had no history of a psychiatric disorder in their background, and agreed to participate in the study. The inclusion criteria for the patients' relatives were following; being the primary caregiver of the patient; having ability and emotional competence to provide care to the patient; being 18 years old and over; and having no psychiatric history in their background.

### *Data Collection Tools*

The data were collected by conducting the face-to-face interview with the participants through the Information Form, the European Quality Of Life Instrument EQ-5D, the Beck Depression Inventory and State-Trait Anxiety Inventory. In addition, Barthel Index — BI, the validity and reliability of which were conducted in Turkish society, was used to evaluate the functional conditions of the patients when they were staying at hospital and discharged from the hospital [12]. The European Quality of Life Instrument-EQ-5D, on the other hand, is a general purpose quality of life index-type scale the individuals can complete themselves. The instrument has a scale on which individuals assess their health condition between 0 and 100 points (Visual Analog Scales — VAS), where the score ranges from 0 to 100 points [12]. In the assessment of EQ-5D, the methods of percentage distribution of the responses given to the EQ-5D questionnaire (EQ-5D descriptive system), EQVAS mean values, index-based scoring systems (EQ-5DSkor) and time-trade out (TTO) methods are applied [13]. The Turkish validity and reliability study of Beck Depression Inventory-BDI, a 21-item scale measuring emotional, somatic, cognitive and motivation based symptoms in depression, was conducted by Hisli (1989). Each item receives a score gradually increasing between 0 and 3 and the total score ranges between 0 and 63 [14]. The State-Trait Anxiety

Inventory-STAI used in this study was developed by Spielberger et al. [15] in order to determine how individuals feel (state) at certain moments and under certain conditions (state) and how individuals feel independently from the conditions and circumstances (trait). Each of these inventories consists of two separate scales having 20 items in each. The validity and reliability of this inventory for the Turkish society was conducted by Öner and Le Compte. Total score value obtained from both inventories varies between 20 and 80. The high score signifies a high anxiety level [16].

### *Data Collection*

The researcher encountered 117 patients while collecting the data of the control group. Among 33 patients and patients' relatives meeting the inclusion criteria, caregivers of 3 patients were ambiguous, 1 did not understand Turkish; and 4 did not agree to participate in the study. In addition, 3 were not reached after participating in the study; whereas, 2 died. On the other hand, while collecting the data of the experimental group, 166 patients were encountered; among 35 patients and patients' relatives meeting the inclusion criteria, the caregivers of 4 were ambiguous and 4 did not understand Turkish. 5 of the patient's/patients' relatives did not agree to participate in the study and 2 were not reached after participating in the study. Among 40 patients and patients' relatives meeting the inclusion criteria of the study and staying in a stroke unit, those receiving care/treatment constituted the control group (20 patients and patients' relatives), on the other hand, patients and patients' relatives receiving the patient relative training program in addition to the care/treatment (20 patients and patient relatives) constituted the experimental group. There had been no patient's relative training program started previously in the stroke unit in the clinic where this study was conducted. Both groups were evaluated at the beginning of the study and 3 and 6 months after the discharge.

### *Applying the Patient Relative Training Program*

The training manual developed for this study included information that would be the guideline for both patients and their relatives. The training manual prepared in accordance with the nursing model of Roper, Logan and Tierney [17] was used as the effective training material. Accordingly, there was information about stroke, positions, how to prevent infection, pain complication symptoms, medications, creating the safe environment, deep breathing exercises, nutrition, movement, communication problems, problem solving,

coping with anxiety and stress, social support, etc. included in the manual. The training was carried out within the framework of a program specific to needs of the patient's relative by using a laptop computer in 3 to 5 sessions. Follow-up and counselling was provided by the researcher to the patient and patient's relatives through phone/face-to-face interview after the discharge. The effectiveness of training was provided through routine hospital appointments or phone calls 3 and 6 months after the discharge.

### Ethical Considerations

In order to conduct the study, consent was obtained from the Local Ethic Committee of the Deanship of Istanbul Faculty of Medicine Istanbul University, where the study would be conducted. EuroQol group was contacted as it would be used in the study and a written permission was obtained. Consent was also received from Ayşe Küçükdeveci, who adapted the Barthel Index into the Turkish society. Signed informed consent was obtained from all the patients and patient's relatives.

### Data Assessment

Before the data obtained from the study were analysed, their compatibility with the normal distribution had been tested both by applying One Sample Kolmogorow–Smirnow test and drawing their histograms and it was found that they were normally distributed. However, because it was  $n < 25$  in within-group comparisons, the non-parametric significance tests were used. In analyses and assessments, frequency distributions, central and distribution measures as well as Friedman test and Mann–Whitney U tests were applied. The level of the correlation among the variables was accepted as  $p < 0.05$ .

### Limitations of the Study

The insufficient number of samples, the follow-up period limited to 6 months, and the use of the quality of life scale related to general health make us think that time variance were not reflected. Since primary caregivers of the patients were included in the study,

it has been difficult to determine the caregiver in the hospital. Because the relatives of the patients with aphasia, or serious cognitive and speech disorders were not included due to the inclusion criteria, this was thought to be the reason for the failure to address the group in order to benefit from the training more.

## Results

### Demographic and Disease Characteristics

In both groups, most of the patients' relatives were female (N=29, 72.5%). Whereas a great majority of the patients' relatives were the spouses of the patients (N=26, 65%), the remaining ones were the adult children (N=13, 32.5%) and the mothers (N=1, 2.5%). As regards the distribution of the disease-related personal characteristics based on the experimental and control groups, no significant difference was found in terms of "NIHSS score, length of hospital stay, location of stroke, and clinical syndrome" ( $p > 0.05$ ). As arises from Table 1, it was found that implementation of the life activities by the patients independently increased 3 and 6 months

Table 1. Demographics and individual characteristics

	Control	Experimental
Patient's Age (years); Mean (SD)	58.75 (16.36)	57.90 (15.08)
Patient's Sex (male); N (%)	10 (50.0)	12 (60.0)
NIHSS score (days); Mean (SD)	4.89 (1.99)	5.52 (2.67)
Length of hospital stay (days); Mean (SD)	14.20 (4.17)	11.95 (10.58)
The patients' relatives age (years); Mean (SD)	50.35 (15.90)	47.55 (12.08)
Stroke hemisphere N (%)		
Right hemisphere	11 (55.0)	8 (40.0)
Left hemisphere	5 (25.0)	9 (45.0)
Bilateral	4 (20.0)	3 (15.0)
Clinical Syndrome N (%)		
LACI	7 (35.0)	8 (40.0)
PACI	6 (30.0)	4 (20.0)
POCI	6 (30.0)	7 (35.0)
Unclassified	1 (5.0)	1 (5.0)
BI score <sub>(0–100)</sub> Mean (SD)		
Beginnings	65.25 (15.26)	70.00 (17.32)
3 months	73.50 (15.48)	78.75 (15.38)
6 months	77.50 (17.05)	84.00 (16.91)
mRS <sub>(0–4)</sub> Mean (SD)		
Beginnings	2.85 (1.04)	2.45 (0.94)
3 months	2.45 (1.00)	2.15 (0.99)
6 months	2.40 (0.99)	2.05 (1.05)

after the discharge, there was no difference between the experimental and control groups; however, the experimental group was better within itself (Table 1).

### The Quality of Life

As is seen from Table 2, it was found that there was no difference between patient groups in terms of health-related quality of life at beginning of the study and 3 months after the discharge; however, the health-related

quality of life of patients in the experimental group 6 months after the discharge increased. In the patients' relatives, the health-related quality of life did not show difference between the groups. In addition, it was determined that patient's relative training program caused no difference on the perceived health status of the patients and their relatives. However, it was observed that patients and patients' relatives in the experimental group had an increased quality of life concerning health over time (Table 2).

Table 2. Summary of patient and patients' relatives relationship to EQ-5D, SAI, TAI and BDI

		Patient				U	Patients' relatives				
		Control		Experimental			Control		Experimental		
		Mean	SD	Mean	SD		Mean	SD	Mean	SD	U
EQ-5D <sub>Score (0–59.1)</sub>	Beginning	0.29	0.49	0.36	0.44	179.00	0.81	0.22	0.65	0.32	130.00
	3 months	0.41	0.35	0.59	0.36	135.00	0.84	0.15	0.81	0.18	198.50
	6 months	0.44	0.37	0.66	0.39	113.00	0.86	0.14	0.83	0.22	199.50
	$\chi^2$	1.67		8.34			1.88		16.91		
EQVAS <sub>(0–100)</sub>	Beginning	50.50	19.55	52.75	19.41	184.00	68.85	22.31	68.60	20.94	198.50
	3 months	47.20	17.22	53.65	17.61	145.50	66.30	21.45	70.65	15.91	173.00
	6 months	48.25	19.01	55.90	16.84	150.00	67.30	20.55	72.10	14.03	166.00
	$\chi^2$	2.17		2.77			3.97		2.94		
TAI <sub>(20–80)</sub>	Beginning	39.50	8.74	41.90	5.52	151.00	45.40	8.38	40.85	8.83	139.50
SAI <sub>(20–80)</sub>	Beginning	42.65	8.42	43.55	6.43	198.00	42.50	10.41	41.75	10.26	187.00
	3 months	45.50	8.77	44.75	7.06	175.50	44.10	9.73	41.85	8.57	161.00
	6 months	47.40	8.44	43.90	6.65	146.00	43.10	10.30	40.30	8.17	150.00
	$\chi^2$	24.64		4.38			4.85		4.30		
BDI <sub>(0–63)</sub>	Beginning	10.45	4.35	11.40	3.53	181.00	10.20	5.67	9.20	4.03	188.00
	3 months	13.10	4.90	12.80	4.46	191.00	11.70	6.18	9.75	4.52	167.00
	6 months	14.70	4.96	12.95	4.77	153.50	11.50	7.08	9.05	4.94	157.00
	$\chi^2$	28.58		3.39			3.80		2.82		

### Anxiety and Depressive Symptoms

When examining Table 2, it was determined that there was no difference between the groups in terms of anxiety mean scores. In the patient control group, there was a statistically significant increase in SAI over time. There was no difference found between the groups of patients' relatives in terms of the SAI and TAI scores over time. Depressive symptoms increased in the patient control group over time in a statistically significant manner. Between patient relatives in the experimental and control groups and within the groups, no significant change was found in terms of depressive symptoms over time.

### Discussion

#### Quality of Life

In this study, it was found that there was no significant difference in the perceived health status and health-related quality of life (HRQOL) of the patients, whose relatives received training, in the beginning of the study and 3 months after the discharge; on the other hand, HRQOL increased 6 months after the discharge. No difference was found between the patients' relatives in the experimental and control groups in terms of perceived health status and health-related quality of life. In the studies, it was reported that patient's relative training/counselling programs increased the knowledge of stroke patients and patients' relatives regarding stroke, but the

increase in knowledge did not lead to an increase in the functional characteristics of the patients [18], the perceived health status of the patients [19,20], and the quality of life for patients and patients' relatives [21,22]. In this study, the HRQOL and positive health perception of patients' relatives increased in the experimental group; whereas, in the control group, its decrease can be an indicator for a progression toward burnout. There are studies reporting that this increases the patient's quality of life [8], the perceived health status of the patient [8,23], and caregiver's quality of life [24]. However, Forster et al. [4], tested in their TRACS studies the LSTC, a structured training program in the study by Kalra et al. [8], which had been previously found to be effective, through a multicentre randomised controlled approach; and reported that there was no effect on HRQOL, perceived health status, psychological outcomes (anxiety, depression) and the costs of patients and patients' relatives. It is reported that interpreting the effect of training/counselling programs on the quality of life is difficult because of the differences in types (training/psychoeducation, individual/group, support, counselling, etc.) and the content of programs, characteristics of the sample group to whom the programs are applied, place, time and number of applications, as well as the outcome measurements expected in the treatment/care; and that there are differences in the results of the studies, investigating the quality of life [4,8,12,25]. In this study, whether or not the finding of an increase in the quality of life of the patients, whose relatives participated in the patient's relative training program started in the hospital, 6 months later was the contribution of the training as well as its level were not exactly evaluated. However, the increase observed among the patients was thought to be associated with giving importance to how the care of the stroke patient takes place rather than how the patients' relatives provide care in the interventions for both the patient and patient's relative, as stated in the literature review by Bakas et al. [10]. Additionally, this result is considered to be associated with the fact that EQ-5D score used in measuring the quality of life was effective in reflecting the major changes in the health condition [26]. As the British social standards are used in calculating the EQ-5D score, it is reported that the Turkish validity of the index needs to be interpreted carefully [27].

### *Anxiety*

It was found in this study that PRT program had no effect on anxiety symptoms of the patients and their relatives. It was seen in the previous studies that individual/group training and support programs alone had an effect in reducing the anxiety of the patients [28]

and their relatives [19]. In the systematic analysis by Smith et al. [9] that reviewed 17 studies, it was found that although the training provided to the patients/patients' relatives had no significant effect on anxiety scores; in the subgroup analysis the active training programs (training/course sessions, multidisciplinary interview) were found to be more effective in reducing anxiety and depression of the patients and their relatives compared to the passive programs (booklets/brochures and multimedia applications). In this study, it can be considered that the patient control group had an increased state of anxiety over time, and anxiety of the patients' relatives in the experimental group did not increase over time, which might have been associated with the positive effect of the training. Moreover, in this study it can be thought that low dependence level of the patients may cause low prevalence of anxiety and depressive symptoms among the patients' relatives.

### *Depressive Symptoms*

No difference was found between the depressive symptom levels of the patients in this study. Similar to the results of the present study, it was indicated in other studies that patient's relative training/counselling programs had no effect on depressive symptoms [19,20,29]. It was found in the meta-analysis conducted by Smith et al. [9] on the data of 729 patients in 7 studies that the training program had minimal effects on the depression scores of the patients. In the literature, it is stated that since the cognitive incompetence emerging on the patients following a stroke and the organic changes cause not only the misinterpretation of the patient condition, but also by not reporting the depressive symptoms, the problem of identifying the depressive symptoms is observed [30]. In this study, the depressive symptom level remained low in the experimental group over time compared to the control group, whereas the control group showed an increase. In fact, this result suggested that the training of the patients who received patient relative training program was significantly effective in decreasing the depressive symptom levels.

It was found that the BDI mean score of the patients' relatives did not change both between experimental and control groups and as well as within the groups themselves during the admission to hospital and 3 and 6 months after the discharge. Similar to these results, in the literature review by Brevetton et al. [31] it was reported that the training/support programs had no positive effect on a full physical or psychological well-being of the caregiver. In the studies by Clarck et al. [18] and Burton and Gibbon [32] it was found that training/counselling programs were not effective on depression of the patients' relatives. By considering problems related

to application in the individual and group programs, it is reported in the literature that planning of the practices may increase the effectiveness of the practices based on characteristics of patients' relatives [33].

## Conclusions

This study will be a guide for the training programs to be planned and implemented in Turkey concerning stroke patients' relatives and provide data in this matter. Accordingly, the patient/patient's relative training programs need to be initiated in hospitals; to be applied together with individual counselling/support programs and group support programs such as house visits and telephone calls to be made after being discharged from hospital and to be followed up for long terms. It is recommended to establish national, social, and institutional support networks for the stroke patients/patients' relatives in Turkey and to develop rehabilitation nursing and home care nursing practices specific to stroke patients. Additionally, it is recommended to repeat the PRT program in this study, in similar studies or in larger sample groups of studies in which different training methods are used to carry out their long-term follow ups and to compare their results in terms of intercultural differences.

## Implications for Nursing Practice

One of the independent and most important contemporary roles of the nurse is the role of an educator. The nurses need to be aware of the training need of patients and their relatives as from admission to hospital and to make the planning by considering the requirements related to home care. In this process, the aim of the patient's relative training should be to increase the independence of the patients and to protect their own health. Accordingly, the information provided to the patients' relatives should be individualized both for the patient and patient's relatives, as well as being case specific and sufficient. Aside from providing accurate information through the training to be applied to the patients' relatives, nurses would provide the individual, familial, and social adaptation of the individuals to the illness by teaching the ways to cope with problems.

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(A — Concept and design of research, B — Collection and/or compilation of data, C — Analysis and interpretation of data, D — Statistical analysis, E — Writing an article, F — Search of the literature, G — Critical article analysis, H — Approval of the final version of the article, I — Acquisition of assets [eg financial])

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