

What affects the quality of life in patients with Behcet's disease?

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ABSTRACT

Aim: The aim of this study was to evaluate the possible associations between quality of life (QoL) and sociodemographic features, disease characteristics and the Behcet's Disease (BD) disease activity of the patients with BD.

Patients and Methods: One hundred and seven patients with BD were included in this study. Sociodemographic features including age, gender, education level of the patients and the disease characteristics including disease duration, disease onset age, the history BD clinical involvements were recorded. In patients with BD, the BD Current Activity Form was used for the evaluation of disease activity. The short form-36 (SF-36) QoL scale was used to evaluate the QoL in patients with BD. The Student t test, analysis of variance and Spearman's correlation matrix were used for the statistical analysis.

Results: Men showed higher mean scores of role-physical and bodily pain domains of SF-36 than women did ($p < 0.000$ and 0.001). Patients over 41 years of age had higher mean general health scores and university graduates patients had higher mean mental health scores than the other groups ($p < 0,01$). Patients with a disease duration more than 5 years and patients have a younger disease onset age showed lower general health score than the others ($p < 0,01$). Also patients with an anamnesis of uveitis, genital ulceration, erythema nodosum, thrombophlebitis, joint and gastrointestinal system involvement showed lower QoL than the patients without these complaints ($p < 0,05$ and $p < 0,01$). In the analysis of disease activity physical subscores of SF-36 were found to be correlated with fatigue, oral ul-

ceration and joint involvement ($p < 0,01$). Bodily pain showed a correlation with fatigue, headache and more highly with joint involvement ($p < 0,01$ and $p < 0,001$ respectively). General health was correlated with GIS and eye involvement and vitality was found to be correlated with fatigue, patient's and doctor's impression of disease activity ($p < 0,01$). Mental and emotional scores were correlated with oral- genital ulceration, eye and joint involvements ($p < 0,01$).

Conclusion: In addition to demographic features and clinical involvements, BD disease activity can affect QoL in patients with BD. These results highlight the importance of managing the symptoms and the disease activity effectively in order to improve QoL in BD.

Keywords: Behcet's Disease; Quality of life; Disease activity.

INTRODUCTION

Behçet's disease (BD) is a vasculitis described by Turkish physician Hulusi Behçet in 1937 as a triple-symptom complex consisting of aphthous ulcers of the mouth and genital and relapsing uveitis¹. In addition to the typical triad, BD may involve cardiovascular, pulmonary, neurological, articular, and gastrointestinal systems. As a chronic multisystem disorder, it may cause a variety of clinical problems leading to temporary or permanent functional disability². The symptoms may be separated by long or short intervals, occur simultaneously or in sequence, and exhibit a pattern of exacerbation and remission. They not only affect the physical and mental health of patients negatively, but they also affect their quality of life (QoL) by causing several physical impairments. QoL can be defined as it encompasses being able to satisfy one's own basic needs, being satisfied with life, showing an adequate level of social interaction, allocating time to fun, feeling good emotionally

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and physically, being good at interpersonal relationships, having self-esteem as well as previous experiences³. Evaluations of health related QoL could assist the optimal approach to the patient with a better understanding of the behaviors and the psychological reactions of the patients as well as the difficulties they experience with adjusting to the disease and developing effective coping mechanisms⁴. In recent years, there has been a growing interest in the assessment of QoL, particularly in chronic disabling conditions, including BD. Since BD negatively affects patients physically, mentally and socially, decrease in the QoL significantly may be expected in patients with BD related to these conditions. Previous studies have shown that QoL in patients with BD was negatively affected by the disease itself or by the impact of the symptoms⁴⁻⁸.

The aims of this study were; to evaluate the association between QoL and sociodemographic features of the patients (age, gender, education level); the disease characteristics (disease duration, disease onset age, clinical involvements) and the BD disease activity.

PATIENTS AND METHODS

PATIENTS

One hundred and seven patients with BD who fulfilled the criteria of the International Study Group for BD were included in this study after obtaining the informed consent from all participants⁹. Patients with psychosomatic or psychiatric disorders and any other chronic diseases were excluded from the study. Also dependence on alcohol or other substances and any psychotropic drug usage were considered as exclusion criteria.

CLINICAL ASSESSMENTS

For the evaluation of the sociodemographic features, age, gender, education level of the patients were recorded. Also the disease characteristics including disease duration, disease onset age, the history BD clinical involvements (uveitis, oral-genital ulceration, erythema nodosum, thrombophlebitis, pustules, arthralgia, arthritis, major vessel involvement, gastrointestinal and central nervous system involvement) were investigated. In patients with BD, the BD Current Activity Form (BDCAF), which scores the history of clinical features have been present during the 4 weeks prior to the day of assessment, was used for the evaluation of disease activity¹⁰. With this activity form, fatigue, hea-

dache, oral-genital ulceration, skin lesions, joint involvement, gastrointestinal system involvement, central nervous system involvement, major vessel involvement, patient's impression of disease activity (last 28 days and the same day) and doctor's impression of disease activity were evaluated in our study. A Turkish version of BDCAF has been tested and validated for our population¹¹.

Also, the short form-36 (SF-36) QoL scale was used to evaluate the QoL in patients with BD. This scale is one of the best known and most widely used QoL instruments that have been used in a wide range of diseases. It consists of 8 subcategories: (a) Physical Functioning (10 items), (b) Social Functioning (2 items), (c) Role Physical (4 items), (d) Role Emotional (3 items), (e) Mental Health (5 items), (f) Vitality (4 items), (g) Bodily Pain (2 items), (h) General Health (5 items)¹². The score can range from 0 to 100, where 0 and 100 stood for the lowest and highest QoL respectively. The scale was evaluated taking the last 4 weeks into account. A Turkish version of the scale has been validated for our population¹³.

STATISTICAL ANALYSIS

All statistical analysis was performed using the SPSS 20.0 software package program. The Student t test, analysis of variance and Spearman's correlation matrix were used to compare the data and to evaluate the possible correlations between the scores of disease activity and QoL. Statistical significance was determined at $p < 0.05$.

RESULTS

After exclusion of five patients due to thyroid dysfunction and antidepressant usage, one hundred and two patients with BD were evaluated in this study.

The QoL scores of the patients were investigated and the means and standard deviations for the SF-36 QoL subscales were calculated as follows: physical function $60,22 \pm 18,26$; role-physical $44,70 \pm 17,79$; bodily pain $47,70 \pm 24,12$; general health $47,74 \pm 21,27$; vitality/fatigue $39,98 \pm 21,28$; social function $62,24 \pm 24,26$; role-emotional $32,02 \pm 18,42$ and mental health $49,92 \pm 13,22$.

SOCIODEMOGRAPHIC FEATURES

The age, gender and education level were analyzed as sociodemographic features of the patients. There were

48 female and 54 male patients. Men showed higher mean scores of role-physical and bodily pain than women did ($p < 0.000$ and 0.001 respectively). The age range of the patients was 20 and 51 years ($35,01 \pm 7,85$ year \pm SD). 32 patients were between 20 and 30 years of age, 40 patients were between 31-40 years of age and 30 were 41 or older. Patients over 41 years of age had a higher mean general health score than other age groups ($p < 0.01$). The education levels were primary school for 33 patients, secondary school for 45 and university for 23 patients. University graduates had a higher mean mental health score than the other groups while other groups had similar scores ($p < 0, 01$). The sociodemographic features and SF-36 QoL scores of the patients were showed in Table I.

DISEASE CHARACTERISTICS

The disease characteristics including disease duration, disease onset age, and the history BD clinical involvements were investigated. The disease duration of the patients was $84, 20 \pm 48, 37$ months with a range 24 and 240 months. Patients with disease duration more than 5 years showed significantly lower general health scores than the other patients ($p < 0,01$). Also disease onset age of the patients was ranged from 17 to 40 year-old ($28,15 \pm 5,63$ year-old) and patients have a younger disease onset age showed lower general health score than the others ($p < 0.05$). The history of previous BD clinical involvements was investigated by yes or no questions. With this evaluation, all patients had current oral ulcers or previous oral ulceration history due to the classification criteria used. 32 patients had genital ulceration, 30 patients had uveitis, 50 patients erythema nodosum, 44 patients had thrombophlebitis, 50 patients had pustules, 28 patients had joint involvement, 13 patients had gastrointestinal system involvement, 5 patients had major vessel involvement, and 5 patients had central nervous system involvement (current or previous involvements). Since oral ulceration history was present in all patients and involvements of major vessels and central nervous system were present only in a few patients, we did not evaluate the significance of QoL in these patients. The other disease characteristics and SF-36 QoL scores of the patients were showed in Table II.

DISEASE ACTIVITY

The disease activity of the patients with BD and its relation with QoL were also evaluated. Physical function and role physical scores were found to be correlated

with fatigue, oral ulceration and joint involvement ($p < 0,01$). Bodily pain component showed a correlation with fatigue, headache and more highly with joint involvement ($p < 0,01$ and $p < 0,001$ respectively). General health was correlated with GIS and eye involvements and vitality was found to be correlated with fatigue, patient's and doctor's impression of disease activity ($p < 0,01$). In addition to mental health and eye involvement correlation, role emotion and mental health scores were also showed a correlation with oral- genital ulceration and joint involvement ($p < 0,01$). Since there were only a few patients with major vessel involvement and central nervous system involvement in our study, they were not included in analysis. The relation with the other scores of BDCAF and SF-36 subscores were shown in Table III.

DISCUSSION

In recent years, QoL assessment has become a valuable component of the evaluation process of a patient especially in chronic disabling conditions. To determine the factors impair the QoL of a patient with a chronic condition may help in the management of the disease. Most previous studies have shown that BD may decrease the QoL of the patients by affecting them physically, mentally and socially⁴⁻⁷. These investigations have revealed the impact of several features of BD on QoL. In this study, we investigated the factors affect the QoL in patients with BD. As possible related factors to QoL in BD, we analysed the sociodemographic features, disease characteristics and disease activity of the patients.

In sociodemographic features we found significant differences in groups created according to gender, age and education levels of the patients. Role physical and bodily pain subscores of SF-36 QoL scale were significantly lower in female patients than the male ones. These results found to be similar with previous studies showing more impaired pain and physical QoL subscores in female patients with BD^{4,6,14}. This difference between men and women could be attributed to the different gender roles, physiological and hormonal differences or different coping strategies for living with BD^{2,15}. Patients more than 41 years of age were found to have higher scores of general health than the younger groups in our study. This result may contribute the previous studies indicate that BD may be less severe as the age of the patient increases^{2,3,16,17}. Also we found

TABLE I. SOCIODEMOGRAPHIC FEATURES OF THE PATIENTS WITH BD AND SF-36 QOL SCORES (MEAN± STANDARD DEVIATION)

Sociodemographic features	n	%	SF-36 QoL subscales mean±SD									
			Physical function	Role physical	Bodily Pain	General health	Vitality/fatigue	Social function	Role emotional	Mental health		
Gender												
Female	48	47	62,85±12,42	43,95±12,67	44,43±12,52	42,38±18,57	35,76±18,79	63,32±22,03	29,48±15,68	50,15±12,30		
Male	54	53	65,38±23,27	61,79±10,05	53,09±12,22	40,03±19,19	37,75±21,42	60,68±24,25	35,83±19,44	55,30±12,40		
P			NS	0,000	0,001	NS	NS	NS	NS	NS		NS
Age (year)												
20-30	32	31,3	61,50±26,27	30,76±42,01	46,98±15,54	34,31±12,13	37,75±14,52	71,12±12,12	33,33±13,42	47,14±16,04		
31-40	40	39,2	62,85±21,12	29,76±21,12	51,14±14,48	38,61±12,49	30,02±24,36	68,45±25,42	32,22±12,34	50,28±14,20		
≥41	30	29,4	65,27±20,70	32,66±12,25	54,47±12,21	46,86±18,02	33,57±20,14	70,98±14,12	29,18±12,12	51,14±12,42		
P			NS	NS	NS	0,01	NS	NS	NS	NS		NS
Education level												
Primary	33	32,3	59,16±24,55	25,36±12,44	51,14±12,14	54,72±23,44	37,48±18,44	60,18±22,18	29,23±10,08	33,50±5,52		
Secondary	45	44,1	68,88±22,74	28,12±10,22	46,64±20,12	52,18±10,96	30,18±14,46	64,32±21,29	30,24±11,46	34,96±7,63		
University	23	22,5	65,11±20,16	32,44±11,36	50,18±18,36	47,18±24,66	32,48±16,99	59,88±18,87	32,12±14,99	47,90±12,40		
P			NS	NS	NS	NS	NS	NS	NS	NS		0,01

NS: not significant

significantly higher mental health scores in university graduates patients than the others similar with another study's results about QoL in patients with BD⁴. It might be due to be more aware about the disease course or higher socioeconomical status.

We also analysed the disease characteristics itself as possible factors related to QoL in BD. Due to the younger disease onset age and longer disease duration parameters related to lower general health score, it may be thought that chronicity in BD may contribute the impairment of QoL. Also we investigated the current or previous BD clinical involvements as possible related factors in QoL in patient with BD. In several previous studies QoL in BD was found to be affected by oro-genital ulcers especially in emotional and social aspects^{4,18,19}. We could not compare the patients with or without oral lesion history in our study since all patients had oral ulceration anamnesis due to the diagnosis criteria. However, similar to previous studies we also found impaired emotional and mental scores in patients with current or previous genital ulceration. Although there was no significant difference between QoL subscores of patients with or without pustular lesions, we also determined lower social function scores in patients with erythema nodosum and lower physical function scores in patients with thrombophlebitis. Parallel with our results, previous studies investigating the cutaneous manifestations of BD indicated that oral and genital ulcers not only cause deterioration in personal relationships but also have an important impact in the limitation of QoL in patients^{6,8,18,20}. This may be due to the negative effect of oral lesions on motor functions such as speaking, swallowing and chewing, and negative effect of genital lesions on extension of pain, perception of self-image and diminished sexuality^{6,21}.

In our study we also demonstrated lower scores of physical function, social function and bodily pain in patients with articular involvement. Previous studies also showed that joint involvement in BD affects considerably patients' QoL due to pain, swelling and movement difficulties^{4,6,7,22}. Uveitis as one of the most serious involvement of BD, can also be

TABLE II. DISEASE CHARACTERISTICS AND SF-36 QOL SCORES OF THE PATIENTS

Disease characteristics	n	%	SF-36 QoL subscales M±SD										
			Physical function	Role physical	Bodily Pain	General health	Vitality/fatigue	Social function	Role emotional	Mental health			
Disease duration													
0-5 year	30	29,4	33,57±24,34	70,10±24,59	55,56±26,37	44,36±17,17	37,23±21,25	65,38±24,85	29,36±15,23	47,23±16,33			
6-10 year	29	28,4	35,76±18,74	66,57±22,13	49,23±24,21	38,10±15,11	30,21±23,34	62,45±22,14	33,33±19,44	50,42±24,12			
11-15 year	18	17,6	37,35±20,14	60,68±32,03	52,12±22,14	33,55±11,84	35,56±18,76	60,12±21,16	30,14±15,87	49,23±26,12			
16-20 year	25	24,5	32,14±12,25	68,22±22,12	54,23±14,35	33,08±10,11	33,24±20,15	64,45±23,58	31,15±24,12	52,13±14,12			
p			NS	NS	NS	0,01	NS	NS	NS	NS			
Disease onset age													
≤20 year-old	18	17,6	65,21±24,12	65,45±29,23	48,88±22,15	28,22±10,19	31,18±22,14	60,12±22,14	33,42±11,15	56,23±22,18			
21-30 year-old	44	43,1	63,47±23,88	60,12±23,98	46,64±18,41	36,72±14,20	33,65±21,18	64,42±21,48	29,12±10,09	50,19±19,95			
≥31 year-old	38	37,2	67,32±20,19	59,86±22,18	51,12±12,44	39,18±15,49	30,19±22,22	62,12±19,15	31,14±14,54	54,52±21,16			
p			NS	NS	NS	0,05	NS	NS	NS	NS			
Genital ulceration													
(+)	32	31,4	59,82±26,24	47,74±15,82	49,12±12,44	42,18±24,45	34,18±21,14	59,97±24,12	38,79±18,20	36,40±12,96			
(-)	70	70,6	62,76±24,19	51,18±11,14	52,17±21,17	44,78±19,48	39,45±19,98	61,14±19,49	46,93±20,52	43,11±15,30			
p			NS	NS	NS	NS	NS	NS	0,05	0,05			
Uveitis													
(+)	30	29,4	49,97±12,25	38,87±24,72	39,94±21,16	43,28±19,92	32,18±19,08	56,26±18,12	32,14±21,06	33,96±12,64			
(-)	72	70,6	51,14±10,09	41,14±21,14	41,18±19,92	46,72±20,02	41,16±20,16	59,47±20,02	41,18±19,48	43,94±14,83			
p			NS	NS	NS	NS	NS	NS	NS	0,01			
Erythema nodosum													
(+)	50	49,0	58,12	49,92±24,16	50,26±24,16	48,42±12,24	42,24±18,82	59,66±24,23	32,24±12,24	52,14±19,92			
(-)	52	50,9	61,16	52,21±19,92	53,04±18,82	51,18±14,42	39,38±14,98	69,97±12,65	36,54±18,51	49,98±20,09			
p			NS	NS	NS	NS	NS	0,05	NS	NS			
Thrombophlebitis													
(+)	44	43,1	57,48±21,15	51,14±18,92	40,24±17,82	37,10±11,11	37,56±19,76	63,42±19,48	33,12±18,44	48,83±22,12			
(-)	58	56,8	67,17±22,19	48,98±21,09	41,38±17,98	36,55±14,87	34,24±21,15	60,12±17,15	29,14±15,27	52,03±14,18			
p			0,05	NS	NS	NS	NS	NS	NS	NS			
Pustules													
(+)	50	49,0	48,97±13,25	38,47±23,72	50,22±23,16	40,18±20,45	31,18±19,88	55,26±17,12	32,42±12,15	50,19±20,95			
(-)	52	50,9	51,56±10,99	41,44±21,18	53,24±18,92	43,78±18,48	41,02±20,66	58,47±21,02	29,82±11,09	53,52±21,19			
p			NS	NS	NS	NS	NS	NS	NS	NS			

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TABLE II. CONTINUATION

SF-36 QoL subscales M±SD										
Disease characteristics	n	%	Physical function	Role physical	Bodily Pain	General health	Vitality/fatigue	Social function	Role emotional	Mental health
Joint involvement										
(+)	28	27,4	58,16±14,13	48,82±23,16	43,22±15,24	42,28±18,92	35,18±20,14	56,45±15,15	38,14±22,06	51,14±19,42
(-)	74	72,5	70,97±22,65	52,11±18,92	49,12±12,15	46,02±20,12	38,45±21,98	66,17±19,19	41,78±19,18	48,98±21,09
P			0,05	NS	0,05	NS	NS	0,05	NS	NS
Gastrointestinal involvement										
(+)	13	12,74	35,35±21,14	59,12±13,98	49,26±22,16	39,16±11,19	37,18±19,14	57,26±12,12	33,42±14,15	51,19±19,95
(-)	89	87,2	32,54±11,25	57,86±21,18	51,04±12,82	45,86±17,52	39,12±20,08	59,47±20,02	30,88±12,39	53,02±20,02
P			NS	NS	NS	0,01	NS	NS	NS	NS

NS: not significant

expected to affect the QoL in patients. It has been shown that general health is more affected than visual functioning in patients with Behcet uveitis²³. Also scores of mental health domain of SF-36 was found to be significantly worse in BD patients with eye involvement in a previous study²². Similar with these results, we found lower mental health scores in patients with eye involvement anamnesis in our study. Systemic involvement may be a major factor associated with impaired QoL patients with BD as it may lead, not only to severe morbidity but also to increased mortality in the disease. Since there were only a few patients with major vessel involvement and central nervous system involvement in our study, we could not evaluate the QoL in these patients. However, we demonstrated lower scores of general health domain of SF-36 in patients with GIS involvement similar with previous studies⁵.

We also investigated the relation between disease activity and QoL in BD. The heterogeneous nature of the disease expression of BD makes it difficult to achieve a single score for disease activity. Because BDCAF does not have an overall activity score, i.e. a composite index, deduced from the individual scores for different organ systems, we evaluated the possible correlations for each parameter of the scale²⁴. With this evaluation disease activity in fatigue subscore was found to be related with physical function, role physical, bodily pain, and vitality/fatigue subscores of SF-36. In a previous study Gilworth et al demonstrated that more than 80 % of the patients with BD think that they do not have enough energy to perform daily activities⁸. In another study, fatigue was found to be one of the most related factors to physical domains of QoL in patients with BD⁶. Also patients with BD suffering from fatigue was shown to have lower QoL scores related to hindered performance in daily activities, decreases in physical performance, incompetence in completing routine tasks⁴. It can be concluded that fatigue is one of the most common symptoms related to lower QoL scores in patients with BD. Headache component of BDCAF showed a correlation with impaired QoL score in bodily pain domain of SF-36 in our study. Similar with our result, headache was found to be a factor affecting QoL in previous studies^{5,6}.

In the analysis of possible relations between BD disease activity and QoL domains, we demonstrated important correlations. In these aspects, we found correlations between disease activity scores of skin lesions, GIS, eye and joint involvements and QoL scores. Al-

TABLE III. THE CORRELATIONS BETWEEN BDCAF AND SF-36 SUBSCORES

SF-36 QoL subscales M±SD

	Physical function (r)	Role physical (r)	Bodily Pain (r)	General health (r)	Vitality/ Fatigue (r)	Social function (r)	Role emotional (r)	Mental health (r)
BDCAF								
Fatigue	-0,360*	-0,328*	-0,219*	0,09	-0,312*	0,13	0,16	0,26
Headache	-0,11	0,21	-0,283*	-0,12	0,27	0,21	0,15	0,25
Oral ulceration	-0,246*	-0,243*	0,28	0,13	0,12	0,17	-0,240*	-0,238*
Genital ulceration	0,09	0,13	0,21	0,16	-0,17	0,007	-0,288*	-0,277*
Erythema nodosum/superficial thrombophlebitis	-0,28	0,01	0,18	0,09	0,13	0,29	0,21	0,07
Pustules	0,28	0,16	0,23	0,16	0,10	0,17	0,13	0,21
Arthralgia	-0,314*	-0,382**	-0,388**	0,23	0,19	0,09	-0,304*	-0,312*
Arthritis	-0,302*	-0,372**	-0,366**	0,13	-0,12	0,09	-0,288*	-0,302*
GIS involvement I	0,09	0,21	0,13	-0,302*	0,17	0,19	0,13	0,07
GIS involvement II	0,28	0,09	0,12	-0,355*	0,17	0,11	0,21	0,09
Eye involvement	0,21	0,07	-0,22	-0,311*	0,10	0,21	0,12	-0,309*
Patient's impression of disease activity last 28 days	0,28	0,13	-0,21	0,12	-0,320*	0,07	0,09	0,17
Patient's impression of disease activity (today)	0,17	0,15	0,11	0,15	-0,302*	0,16	0,08	0,09
Doctor's impression of disease activity	0,19	0,18	0,11	0,09	-0,288*	0,11	0,21	0,17

GIS involvement I: nausea or vomiting or abdominal pain

GIS involvement II: diarrhea with altered or frank blood

*p<0,01; ** p<0,001

though other systemic involvements couldn't be evaluated in our study, disease activity scores of GIS involvement had a correlation with impaired QoL. Disease activity scores of joint involvement was the most related factor to physical domains and pain in our study. This result can support the previous studies⁶. Also doctor's and patient's impression of disease activity scores showed correlations with vitality. It can be concluded that not only the clinical involvement in the disease course, but also the disease activity of the involvement affect the QoL in patients with BD. As mentioned above BD manifestations have been indicated as important related factors to QoL in BD. However, data on the BD disease activity and its correlation with QoL are extremely limited. Our results indicating correlations between disease activity scores and QoL in BD may contribute the importance of our study. The main weakness of our study was the inability of the evaluation of QoL in patients with large vessel and several systemic involvements due to inadequate number of the cases although it is reasonable to expect important impact of systemic involvement on QoL. However the indication of a correlation between disease activity score in GIS involvement and QoL might

suggest similar relations with other systemic involvements. Further studies evaluating such cases will clarify the relationships between QoL and disease activity of systemic involvements in patients with BD.

In conclusion; in addition to demographic features and clinical involvements, BD disease activity can affect QoL in patients with BD. These results highlight the importance of managing the symptoms and the disease activity effectively in order to improve QoL in BD.

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