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A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitudes toward treatment options

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Abstract

Objective: To compare amyotrophic lateral sclerosis (ALS) patients and their caregivers on measures of quality of life (QOL), depression, and their attitudes toward treatment options. *Methods*: Over a 14-month period, we analyzed responses from 27 ALS patients and 19 ALS caregivers as they arrived at the Department of Neurology, Baylor College of Medicine, Vicki Appel MDA, ALS Clinic, and those who completed the study measures. Patients were given the Appel ALS Rating Scale (AALS), the ALS Functional Rating Scale (ALSFRS), McGill Quality of Life Questionnaire Single-Item Scale (MQOL-SIS), and the Beck Depression Inventory-II (BDI-II). An internally generated scale of 1–7 was used to measure perception of emotional support, QOL for others (i.e., the patient's perception of the caregiver's QOL and the caregiver's perception of the patient's QOL), and experience of pain. Attitudes toward treatment options were assessed by yes/no/uncertain responses. Caregivers were administered all of the above measures except the AALS, ALSFRS, and pain scale. Percentage, mean, and standard deviation values were determined. Significance levels were also calculated. *Results*: Twenty-seven patients with a mean age of 57.2 (range 34–81) years and nineteen caregivers with a mean age of 56.9 (range 28–82) years completed the study. The patients were of moderate disease severity with a mean AALS total score of 76.3 (range 39–134) and a mean ALSFRS score of 28.4 (range 12–40). The mean rating of QOL for patients was 5.9 and the mean rating of QOL for caregivers was 5.7 (range 1–7). The patients reported slightly less depression (9.8) than their caregivers (10.7) (range 0–63). There was, however, no significant difference between patients and caregivers on scores of QOL and depression. Patients tended to overestimate caregivers' QOL by a small degree, whereas caregivers tended to underestimate the patients' QOL by a greater degree. Over one-half of both groups would consider percutaneous esophageal gastrostomy (PEG) placement. Patient and caregiver responses to the use of BIPAP differed. Though over half of both groups endorsed the idea of future BIPAP use, more patients (41%) than caregivers (5%) were uncertain. Only 3% of patients responded negatively compared to 32% of caregivers. Both groups were only minimally interested in future invasive ventilation. *Discussion*: Factors contributing to quality of life, depression, and attitudes toward treatment options need to be periodically explored with patients and caregivers throughout the course of the illness. Health care professionals should recognize that the needs and goals of the two groups might differ. For both patients and caregivers, health care professionals should provide education and opportunities for discussion centered on the issues followed by referrals and interventions appropriate to the situation.

Keywords: Amyotrophic lateral sclerosis; Quality of life; Caregiver; Depression; Palliative care; Treatment choices

1. Introduction

The amyotrophic lateral sclerosis (ALS) care team, composed of neurologists, pulmonologists, nurses, occupational therapists, physical therapists, speech pathologists, psychologists, social workers, representatives from the Muscular Dystrophy Association, and community volunteers, can play a significant role in the care not only of the patient with ALS but also of the patient's caregiver. It is important to understand and distinguish between the attitudes, attributes, and psychosocial characteristics of both patients and caregivers to plan and provide effective treatment interventions with the aim of improving the quality of

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life (QOL) for both groups. While studies have addressed the ALS patient's psychological status [1], quality of life [2–5], and attitudes toward treatment options [6], we have found only a few studies that compared patients' and caregivers' viewpoints on these issues.

Rabkin et al. [7] contrasted ALS patients and caregivers on measures of clinical depression, anxiety, and quality of life. Neither group exhibited elevated rates of clinical depression. Gelinas et al. [8] compared quality of life between 7 ventilator-dependent ALS patients and 15 caregivers. The instruments they used were unable to measure patients' quality of life due to the severity of their disability. In comparing ALS patients' and caregivers' ratings of suffering, pain, and quality of life, Ganzini et al. [9] found a greater concordance between the two groups on suffering and pain than on quality of life. In another study, Ganzini et al. [10] compared ALS patients' and caregivers' attitudes toward assisted suicide and found a 73% agreement in opinion between the two groups.

In a qualitative study, Bolmgjö and Hermerèn [11] compared eight ALS patients and eight ALS caregivers on their perceptions and experiences of ALS and found differences in some areas. Jenkinson et al. [12] gathered data on quality of life and caregiver stress from patients in Europe and concluded that any treatment that can reduce the burden of ill health upon patients is likely to have beneficial effects upon caregivers. A study in Germany [13] surveyed ventilated ALS patients and their caregivers and indicated 89% of patients and 80% of caregivers would make the same treatment choice again.

We developed the following study that compared ALS patients and caregiver attitudes on a variety of measures, including quality of life, depression, palliative care, and psychosocial issues.

2. Methods

We analyzed responses from 27 ALS patients and 19 caregivers who arrived at the Department of Neurology, Baylor College of Medicine, Vicki Appel MDA, ALS Clinic, from July 2000 through September 2001 and who completed all of the study measures. All of the caregivers were spouses or family members and were familiar with the patient's functioning. At baseline, two patients used a PEG, four patients used BIPAP, and no patients used invasive ventilation.

Approval for the study was granted by the Baylor College of Medicine Institutional Review Board, and patients' and caregivers' informed consents were obtained. Patients were deemed eligible to participate if they met the criteria for a diagnosis of definite or probable ALS, communicated in English, and were cognitively unimpaired as determined by neuropsychological testing. Two patients and two caregivers did not participate due to time constraints or because they were experiencing unusual stress that day. Not all patients had caregivers present. The caregivers in this study were not matched with the patients. The written instruments took approximately 30 minutes to complete. Patients and caregivers either completed the instruments in the clinic or at home, returning them by mail using stamped, addressed envelopes. A member of our research team distributed and confidentially collected the data and reminded subjects by telephone of unreturned surveys.

Study measures given to patients were (1) the Appel ALS Rating Scale (AALS); (2) ALS Functional Rating Scale (ALSFRS); (3) McGill Quality of Life Single-Item Scale (MQOL-SIS); (4) the Beck Depression Inventory-II (BDI-II); (5) attitudes toward treatment options; (6) QOL for others single-item scale; (7) emotional support attitude scale; (8) pain attitude scale; and (9) internally generated questionnaire (Table 3). Study measures given to caregivers were (1) McGill Quality of Life Single-Item Scale (MQOL-SIS); (2) Beck Depression Inventory-II (BDI-II); (3) attitudes toward treatment options; (4) emotional support attitude scale; and (5) internally generated questionnaire (Table 3).

The Appel ALS Rating Scale (AALS) was used to measure patient's individual function and mean disease severity and progression. The AALS provides a reliable, quantitative estimate of the functional impairment and disease progression in patients with ALS. It includes subjective and objective quantified assessments of bulbar function (speech and swallowing), respiratory function, muscle strength, and muscle function in upper and lower extremities. The AALS total score is the sum of all measurements covering a broad degree of disability ranging from 30 (normal functioning) to 164 (severe impairment) [14].

The ALS Functional Rating Scale (ALSFRS) is a 10-item, 40-point scale that measures bulbar function, upper extremity function, lower extremity function, and respiration. Scores range from 0 (severe impairment) to 40 (normal functioning) [15].

McGill Quality of Life Single-Item Scale (MQOL-SIS) is a single-item, self-report quality of life measure (range 1 = very bad to 7 = excellent) [16].

Beck Depression Inventory-II (BDI-II) is a 21-item, self-report scale that measures depression severity (range from 0 = no depression to 63 = severe depression) [17].

Attitudes toward treatment options are internally generated, self-report questions with choices of yes, no, and uncertain.

Emotional support from others is an internally generated, single-item attitude scale with choices ranging from 1 (not adequate) to 7 (more than adequate).

Pain is an internally generated single-item attitude scale with choices ranging from 1 (no pain) to 7 (severe pain).

Internally generated individual questionnaires were designed separately for patients and caregivers to address demographic, disease characteristics, and psychosocial issues.

Percentage, mean, and standard deviation values were determined. The *t*-test and *p*-values were calculated to

compare the patients and caregivers on QOL and depression.

3. Results

Twenty-seven ALS patients (18 men and 9 women) and nineteen caregivers (9 men and 10 women) participated in the study by completing the written instruments and questionnaires and agreeing to the measurements of physical strength and functioning. The mean age of the patients was 57.2 (range 34–81) years, and the mean age of the caregivers was 56.9 (range 28–82) years (Table 1). Twenty-six percent of the patients and 42% of the caregivers had college or graduate degrees. Seventy percent of patients and 74% of caregivers reported their income as adequate or better, while 30% of patients and 26% of caregivers reported less than adequate income (Table 1).

The mean disease duration for the ALS patients was 2.7 (range 0.2–7.0) years and the total AALS score was 76.3 (range 39–134), indicating a moderate level of disability for the entire group (Table 2). The AALS functional vital capacity subscore was 79.3 (range 38–111) and the bulbar subscore was 11.4 (range 6–30) (Table 2). The ALSFRS mean score for the entire group was 28.4 (range 12–40), corroborating the group's moderate disability level (Table 2). Thirty-three percent of patients reported daily aches and pains (Table 2).

There was no significant difference between ALS patients and caregivers on scores of QOL. Quality of life, as measured by the MQOL-SIS, was rated moderately high, on average, by patients (5.9) and caregivers (5.7) (Table 3). Patients' perception of their caregivers' QOL on a 7-point attitude scale was high (5.8) as was the caregivers' perception of the patients' QOL (5.1). Patients tended to overestimate the caregivers' QOL by a small degree, whereas caregivers tended to underestimate the patients' QOL by a greater degree (Table 3).

Depression, as measured by the BDI-II, was not notable for patients (9.8 = minimal depression) or for caregivers (10.7 = mild depression). Fewer than 20% of both groups reported that they were taking medication for depression (Table 3).

Perception of emotional support as assessed on a 7-point attitude scale was also high, on average, for both patients (6.0) and caregivers (5.7) (Table 3).

Fifty-two percent of patients and 58% of caregivers endorsed the idea of future PEG placement, 22% of patients and 10% of caregivers were uncertain, and 26% of patients and 32% of caregivers responded negatively (Fig. 1). Fifty-six percent of patients and 63% of caregivers favored the use of BIPAP, 41% of patients and 5% of caregivers were uncertain, and 3% of patients and 32% of caregivers responded negatively (Fig. 2). However, only 15% of patients and 5% of caregivers favored invasive ventilation,

Table 1
Patient and caregiver characteristics

Variables	Patients ($n=27$)	Caregivers ($n=19$)
Gender, *n* (%)		
Men	18 (67)	9 (47)
Women	9 (33)	10 (53)
Age (years)		
Mean ± S.D.	57.2 ± 13.7	56.9 ± 13.4
Range	34–81	28–82
Employed, *n* (%)	7 (26)	8 (41)
Education, *n* (%)		
No college	20 (74)	11 (58)
College/graduate degree	7 (26)	8 (42)
Ethnic background, *n* (%)		
Anglo American	23 (85)	18 (95)
African American	1 (4)	0 (0)
Hispanic American	2 (7)	1 (5)
Others	1 (4)	0 (0)
Income, *n* (%)		
Adequate or better	19 (70)	14 (74)
Less than adequate	8 (30)	5 (26)

Table 2
Illness characteristics of ALS patients ($n=27$)

Disease duration (years)	
Mean ± S.D.	2.7 ± 2.2
Range	0.2–7.0
AALS total score	
Mean ± S.D.	76.3 ± 26.2
Range	39–134
Bulbar score	11.4 ± 6.4
Range	6–30
Functional vital capacity (% pred)	
Mean ± S.D.	79.3 ± 22.6
Range	38–111
ALS Functional Rating Scale	
Mean ± S.D.	28.4 ± 6.3
Range	12–40
Suffers daily aches and pains, *n* (%)	9 (33)
Engages in routine exercise program, *n* (%)	8 (30)
Presently uses augmentative communication device, *n* (%)	2 (7)
Presently uses PEG, *n* (%)	2 (7)
Presently uses BIPAP, *n* (%)	4 (15)

Table 3
Patient and caregiver responses

Variables	Patients ($n=27$)	Caregivers ($n=19$)
McGill Quality of Life Single-Item Scale	5.9 ± 1.5	5.7 ± 1.3
Patient perception of caregiver's QOL (mean ± S.D.)	NA	5.8 ± 1.6
Caregiver perception of patient's QOL (mean ± S.D.)	5.1 ± 1.7	NA
Beck Depression Inventory-II (mean ± S.D.)	9.8 ± 6.5	10.7 ± 8.1
Medicated for depression within past 14 days, *n* (%)	5 (19)	3 (16)
Perception of emotional support (mean ± S.D.)	6.01 ± 4	5.7 ± 1.4

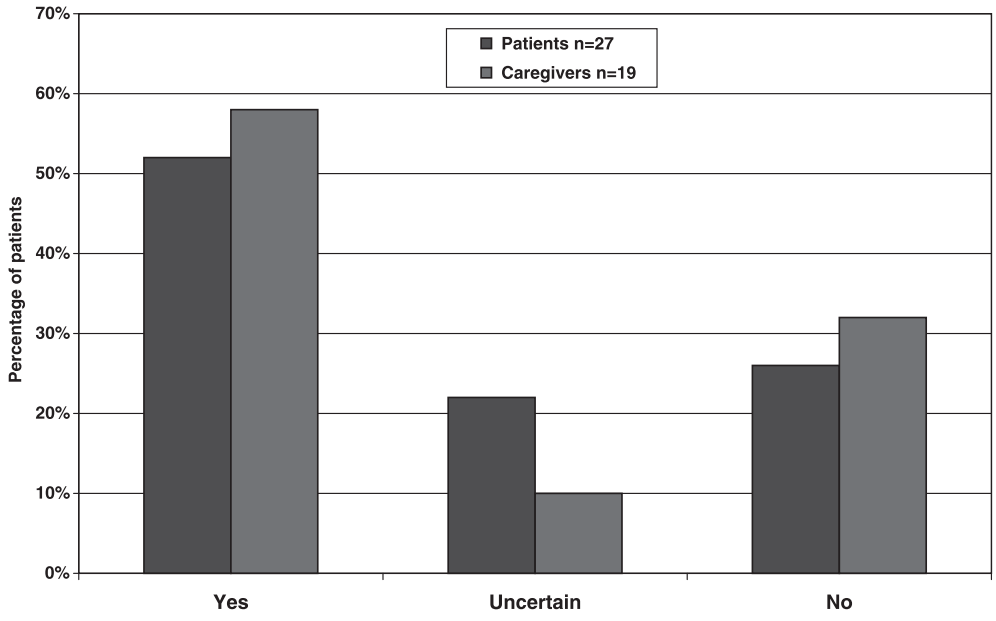

Fig. 1. Patient and caregiver attitudes toward PEG placement.

7% of patients and 10% of caregivers were uncertain, and 77% of patients and 84% of caregivers responded negatively (Fig. 3).

Fifty-eight percent of patients and 63% of caregivers reported that they regularly attended church, and over half of both groups reported church attendance as their primary or sole community activity. Fifty-three percent of caregivers reported negative lifestyle changes due to an ALS diagnosis, but only 16% of caregivers responded that they gave up work outside the home to care for an ALS patient. Over half of the patients (52%) and caregivers (53%) reported negative lifestyle changes such as inability to engage in leisure activities and fewer social contacts.

On self-reported ratings of health, 89% of caregivers rated their health as excellent or good and 11% as fair. Forty-four percent of caregivers spent 0–1 h a day, providing the patient with assistance in activities of daily living,

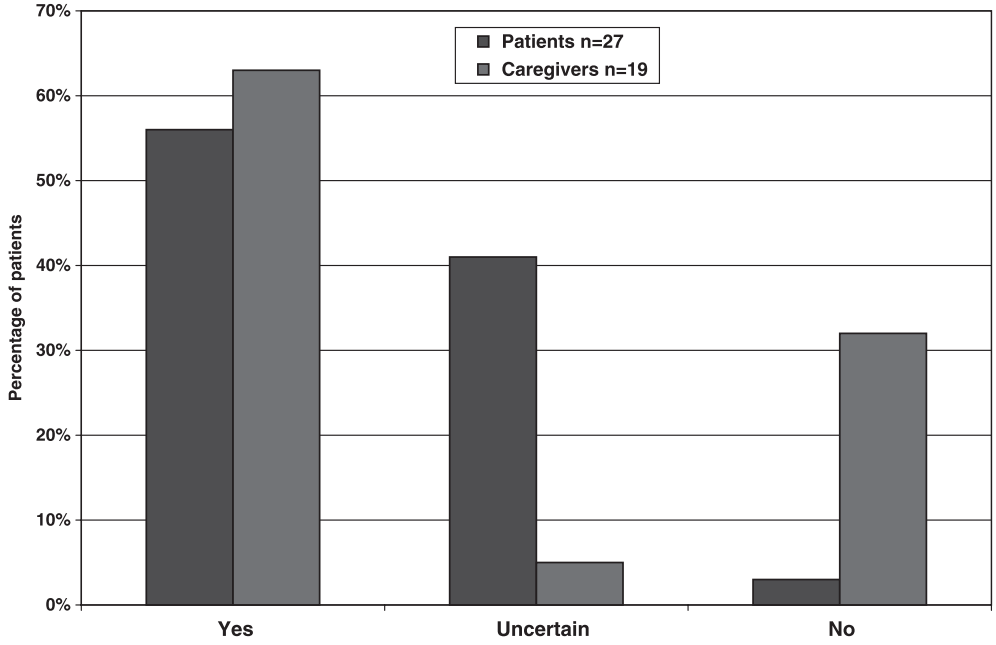

Fig. 2. Patient and caregiver attitudes toward BIPAP.

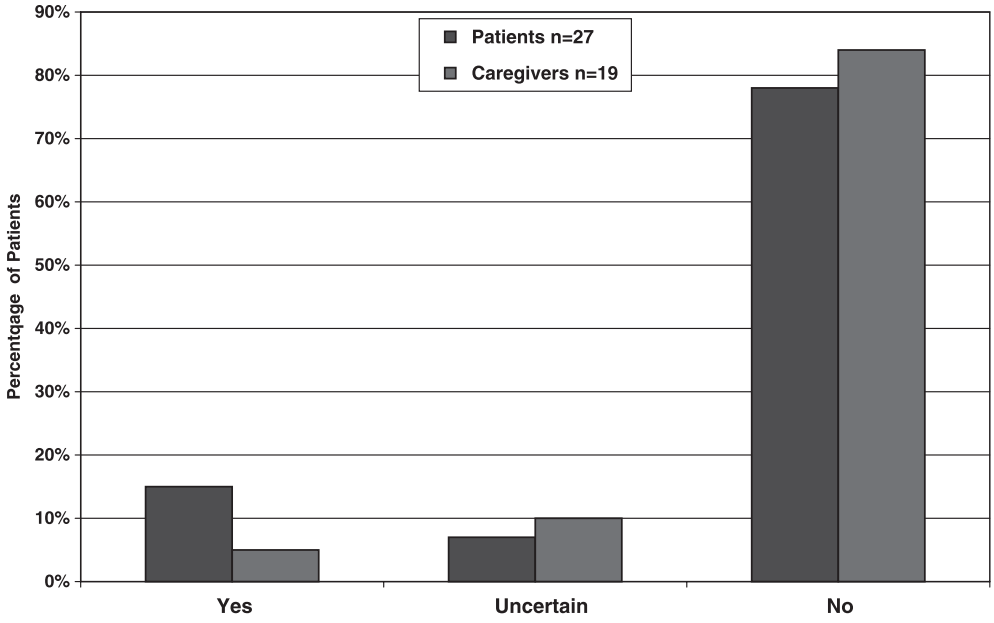

Fig. 3. Patient and caregiver attitudes toward invasive ventilation.

33% gave 2–4 h of direct care a day, and 22% proved 4–8 h or greater of direct patient care each day.

When asked on a 7-point attitude scale how much assistance for daily activities they needed from their caregivers, patients reported a median of 4.5 while caregivers reported a median of 4. Only 30% of patients reported that they engaged in a routine exercise program (Table 2).

The nature of leisure time changed for both patients and caregivers. Seventy-four percent of patients ($n = 23$) reported that they engaged in more active hobbies such as bowling, golfing, and gardening before they developed ALS, while only 26% described sedentary hobbies such as reading, puzzles, and computer activities. After patients developed ALS, only 9% engaged in more active hobbies while 39% reported more passive forms of leisure, 17% reported changes in the nature of their leisure activities, and 35% said they no longer engaged in leisure pursuits. One hundred percent of caregivers reported that they engaged in hobbies before becoming an ALS patient's caregiver, and 44% reported no change in their leisure activities after becoming a caregiver. Examples cited were gardening, reading, and fishing. Thirty-nine percent reported changes in their activities such as "no more camping" while 17% said they had less time for leisure pursuits.

4. Discussion

The assessment of factors contributing to QOL in ALS patients and ALS caregivers needs to be multifaceted and include physical changes, financial and work concerns, social and leisure activities, spirituality/religious issues, and family/friends/community attitudes and behaviors that affect both patients and caregivers.

When we matched patients' AALS scores with scores on the BDI-II, the four patients with severe physical disability were generally not depressed. Their BDI-II scores fell within the mild range. The one patient who was severely depressed scored within the mild disability range on the AALS. The scores indicated that depression was not necessarily related to physical disability, though physicians and other ALS care team members should be alerted to depressive features in both patients and caregivers and make appropriate referrals.

Patient and caregiver preferences for PEG and invasive ventilation were not significantly different. Over one-half of both groups endorsed the future possibility of PEG placement. At the time they completed the surveys, only one-fourth of patients and one-fourth of caregivers expressed a willingness to consider future invasive ventilation. Our findings regarding patients' attitudes are consistent with those of Rabkin et al. [7].

Patient and caregiver response to the use of BIPAP differed. While over half of the patients and caregivers endorsed the idea of future BIPAP use, more patients (41%) than caregivers (5%) were uncertain [1]. Only 3% of patients responded negatively while almost one third of caregivers (32%) answered "no."

The disparity between patients' and caregivers' responses suggests a need for added emphasis upon patient/caregiver education on the use of BIPAP. For example, the patients and caregivers could be jointly instructed in BIPAP and receive a visual demonstration. Patients and caregivers would also benefit from group instruction; for instance, in an ALS support group where

they could confer with others who have experienced BIPAP first hand. Our results indicate that patients and families should receive more in-depth education on BIPAP.

When we compared results on the BDI-II with those of Rabkin et al. [7], the caregivers in our study scored slightly higher than the patients (i.e., more depressed), while the caregivers in their study scored slightly lower than the patients (i.e., less depressed).

Over half of ALS patients and caregivers in our study reported church attendance as their principal community activity. Other studies have linked religiosity and spirituality as sources of support in coping with ALS [2,3,18]. Murphy et al. [19] found that religiosity and spirituality played a role in decision-making about the use of PEG and BIPAP. A lay pastoral counselor, spiritual counselor, or clergy member could play an important role as a member of the multidisciplinary ALS care team [2] by providing interested patients and caregivers the option of spirituality and/or religiosity as an additional means of coping with a catastrophic illness.

ALS patients' transition from more physical leisure to less active leisure is consistent with our findings from a previous study [4]. Patients would benefit from [4] occupational therapy and physical therapy services in early disease to explore ways to modify activities as endurance and muscle strength decline. For instance, patients and caregivers can be educated in advance on how computers can be adapted to accommodate upper extremity weakness, how golfing can be altered to reduce fatigue, and how fishing can be accomplished when generalized weakness is present. Therapists can also help patients and their caregivers find and develop joint leisure pursuits of a more sedentary nature, as meaningful activity exerts a strong influence on quality of life [20–22].

Our data indicate that ALS patients and their families and/or caregivers do not always hold the same attitudes, ideas, and beliefs, or that they always agree on the treatment course and end-of-life decisions. In catastrophic illness, it is difficult for patients and caregivers not only to discuss concerns such as worries about the future and illness progression but also to articulate what the illness means to them. It is important for members of the health care team to provide an environment where these [5] perceptions can be shared, to distinguish between the two groups, and to recognize that their needs and goals might differ. Ideally, the patient and caregiver function as a team, and the caregiver should be included in discussions on treatment and care.

Our study participants were a relatively homogenous group of patients who regularly attend an ALS clinic with a multidisciplinary team. Since our study size was small, larger cross-sectional and longitudinal studies need to be conducted before we can comfortably formulate generalizations about our findings. Treatment options and interventions for both group need to be studied.

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