


# A Population-Based Investigation of Health-Care Needs and Preferences in American Adults With Multiple Sclerosis

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## Abstract

**Background:** Comprehensive and effective multiple sclerosis (MS) health care requires understanding of patients' needs, preferences, and priorities. **Objective:** To evaluate priorities of patients with MS for their MS care. **Methods:** Participants included 3003 Americans with MS recruited through the National MS Society and the North American Research Committee on Multiple Sclerosis patient registry. Participants completed a comprehensive questionnaire on aspects of their health-care experiences. **Results:** Participants identified the top 3 health-care priorities as (1) the affordability of MS health care, (2) ensuring that non-MS health-care providers have more education about MS and how it can interact with other conditions, and (3) access to an MS center or specialized MS clinic with MS health-care professionals together in one place. Participants receiving care in an MS center rated the quality and their satisfaction with care higher than those receiving care in other settings. Although having the opportunity to evaluate their health-care quality was important to the participants, only 36.4% had been provided the opportunity in the past year. **Conclusions:** This study identifies health-care priorities and concerns for Americans with MS.

## Keywords

health-care access, health-care delivery, multiple sclerosis, national survey

## Introduction

The Institute of Medicine defined high-quality health care as including services consistent with patient values and preferences and ensuring that decisions reflect patients' needs and preferences (1). Although health care is more effective when consumers are active participants in its design and delivery (1-7), people with multiple sclerosis (MS) have had little involvement in the design of their care or in the development and assessment of health-care outcomes. Rather, clinical guidelines and performance standards for MS care have been almost exclusively derived through the consensus of health-care providers and expert panels (8).

In order to develop a better understanding of the patient's perspective on MS care, this study addressed the following research questions:

1. What are the health-care priorities of Americans with MS?
2. How satisfied are patients with their health care and providers?
3. Are characteristics of health-care interactions related to satisfaction of patients with MS with their care?

4. Do patients with MS have access to the providers and specialists they want to see?
5. Do MS health-care providers ask patients about important health topics?

## Method

### Design and Participants

This descriptive study used a nonexperimental, cross-sectional design. It was approved by the University of Kentucky Institutional Review Board. Participants were adults

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with MS randomly selected from the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry and National Multiple Sclerosis Society (NMSS) members randomly selected from chapters in 5 states in the Midwestern and Southeastern United States. Invitations to participate were distributed to 8619 persons, including 6233 NARCOMS registry participants recruited through e-mailed ( $n = 3586$ ) or mailed ( $n = 2647$ ) invitation letters, and 2500 participants through the NMSS chapter mailing lists recruited through mailed invitation letters. A total of 3003 participants completed the survey, providing an overall response rate of 34.8%, including 1724 completing the questionnaire via mail (57.4%) and 1279 via the Internet (42.6%).

### Survey Instrument

The questionnaire was developed in a multistep iterative process including a comprehensive literature review, focus groups with NMSS members in 5 states, health-care panel reviews (1 panel of MS patients and 1 of MS health-care professionals), and pilot testing, after which the questionnaire was revised and finalized for national dissemination. The questionnaire covered information about participant demographics, MS course and treatment, MS care providers and locations of care, and health-care priorities.

### Data Analysis

Quantitative data were analyzed using SPSS version 23. All statistical tests were 2-tailed, and a  $P$  value  $<.01$  was considered statistically significant.

## Results

### Participants

The sample ( $n = 3003$ ) was primarily female (82.9%), Caucasian (92.0%), followed by African American (3.4%), Hispanic/Latino (1.8%), and multiracial (0.7%), and had a mean age of 58.49 years (standard deviation [SD] = 11.74, range = 18-96). The majority (60.2%) of the participants were married. Most had completed either a 2-year (16.3%) or 4-year (25.1%) college degree or postgraduate studies (24.7%). Only 27% of the sample was employed either full- or part time. Among unemployed respondents, the largest percentage reported their status as being on permanent disability (32.6%), followed by retired (27.6%), homemaker (4.3%), seeking employment (2.3%), unpaid or volunteer employment (2.2%), unemployed but not seeking employment (1.9%), full-time student (0.4%), and nonreporting (1.7%). Participants' annual household income was roughly evenly distributed across income intervals of \$10 000, ranging from  $< \$15$  000 to over \$100 000. Approximately 20% reported an annual household income level below \$25 000 (21.3%), and 23.9% reported over \$85 000. The sample included participants from each US state, with most living in suburban areas (52.6%), followed by rural (25.2%), and urban areas (20%).

The majority (84.4%) had Internet access in their residence. The sample was predominantly English speaking (98.7%), with 0.3% identifying Spanish as their primary language.

The mean age at MS diagnosis was 38.75 years ( $SD = 10.63$ ). Participants self-reported their MS course as relapsing remitting (54.8%) or progressive MS (30%). Most (61.6%) were currently using a disease-modifying therapy (DMT). Co-occurring medical conditions or illnesses were reported by 51.3%. The majority (92.1%) reported that they had health insurance coverage. Most reported either that they did not have any concerns about being able to pay for their MS health care (41.3%) or that they worry "some of the time" (35.3%). Almost 20%, however, reported that they worry "a lot of the time" (13.3%) or "worry constantly" (6.3%) about being able to afford their MS care. There was a significant relationship between annual household income and concern over paying for MS health care ( $\chi^2 = 170.74$ ,  $df = 27$ ,  $P < .001$ ). Among patients reporting that they worry a lot of the time or constantly, 34.2% had an annual household income of \$25 000 or less compared to 16.6% of those with an income of \$75 000 or more.

### Perspectives Concerning MS Care Priorities in Patients With MS

Participants rated the importance of 12 health-care priorities (Table 1) developed through literature review and focus groups. Participants rated each statement on a 4-point Likert-type scale: (1) Not a priority, (2) Low priority, (3) High priority, and (4) Top priority. The top 4 priorities were: (1) the affordability of MS health care; (2) non-MS health-care providers need more education about MS and how it can interact with other conditions; (3) access to an MS Center or specialized MS Clinic with MS health-care professionals together in 1 place; and (4) having a single health-care provider who coordinates MS health care.

### Multiple Sclerosis Health Care Satisfaction

Participants rated the health care they receive from their Primary MS Health-Care Provider (PMSHP) on a 7-point Likert-type scale (from 1 = "Worst health care possible" to 7 = "Best health-care possible"). The distribution of ratings (mode = 7, median [Mdn] = 6, mean (M) = 5.84, standard deviation [SD] = 1.23) indicated that most participants evaluated the quality of their PMSHP care positively. Participants also rated their satisfaction with care: "Overall, how satisfied are you with your MS health care in general (including all MS health care)," based on a 7-point Likert-type scale (from 1 = "Completely unsatisfied" to 7 = "Completely satisfied"). The distribution of ratings (mode = 7, Mdn = 6, M = 5.72, SD = 1.35) suggested that most participants were satisfied with their MS health care.

Only 36.4% of the participants reported that their PMSHP had provided the opportunity to evaluate the quality of their health care in the last 12 months. When asked how important

**Table 1.** Perspectives of Patients with Multiple Sclerosis Concerning Priorities for Their MS Care.<sup>a</sup>

Health-Care Priority	Mean Rating	SD	Percent Rating Topic as a Top Priority
1. The affordability of MS health care.	3.20	0.92	45.9%
2. Non-MS health-care providers need more education about MS and how it can interact with other conditions.	2.92	0.85	31.9%
3. Access to an MS center or specialized MS clinic with MS health-care professionals together in one place.	2.90	0.98	25.9%
4. Having a single health-care provider who coordinates my MS health care.	2.78	0.97	25.4%
5. A resource for helping patients identify good, reliable, and accurate MS information on the Internet.	2.74	0.93	23.6%
6. Health insurance covering more visits for occupational and physical therapy, and speech/language therapies	2.68	1.00	22.8%
7. My MS doctor should communicate better with my other health-care providers.	2.64	0.94	21.2%
8. Naturopathic and homeopathic doctors and diet supplements should be covered by health insurance.	2.63	1.03	17.9%
9. Doctors should pay more attention to the health of the patient's spouse/partner and caregivers.	2.26	0.93	15.0%
10. Transportation for health care.	2.26	1.06	9.9%
11. Better access to MS-care on weekends and after hours.	2.23	0.93	9.7%
12. More options for communicating electronically with health-care providers (e-mail, video, telehealth).	2.22	0.95	8.5%

Abbreviations: MS, multiple sclerosis; SD, standard deviation.

<sup>a</sup>Mean ratings based on a 4-point scale ranging from 1 (not a priority) to 4 (top priority).

it is to have an opportunity to evaluate the quality of their care, based on a 7-point Likert-type scale (from 1 = "Not at all" to 7 = "Extremely"), the responses (mode = 7, Mdn = 5, M = 5.06, SD = 1.81) indicated that most participants consider this opportunity important. Participants who had the opportunity to evaluate their health care rated both the quality and their satisfaction with MS care significantly higher than those who did not have this opportunity ( $t_{(2736.77, 2751.72)} = 17.08$  [99% confidence interval [CI] = 0.62-0.84];  $t_{(2736.77, 2751.72)} = 13.43$  [99% CI = 0.51-0.76], respectively,  $P < .001$ ).

### Multiple Sclerosis Health-Care Providers and Setting

The health-care provider primarily responsible for the participants' MS treatment and follow-up was most often a neurologist (76.4%), followed by a general practice or family physician (7.2%), internist (2.3%), or nurse practitioner (2.1%). Participants primarily received their MS care at an independent medical office (37.9%), at MS Center (28.6%), or a clinic or hospital other than an MS Center (22.3%).

Analysis of variance results indicated that location of MS care was associated with significant between-group differences in both the quality of care received from one's PMSHP ( $F_{(3,2791)} = 34.53$ ,  $P < .001$ ) and overall satisfaction with MS health care ( $F_{(3,2808)} = 24.14$ ,  $P < .001$ ). Specifically, using the Games-Howell procedure for post hoc analysis due to unequal sample sizes and group variances, and controlling the type I error at .001, the post hoc analysis revealed that participants attending an MS center rated the quality of care from their PMSHP significantly higher (M = 6.19, SD = 1.00) than those attending a clinic or hospital (not an MS center; M = 5.78, SD = 1.18;  $t_{(2791)} = 0.41$ ,  $P < .001$ ), an independent medical office (M = 5.67, SD = 1.30;  $t_{(2791)} = 0.53$ ,  $P < .001$ ), or another setting (M = 5.64, SD = 1.41;  $t_{(2791)} = 0.55$ ,  $P < .001$ ).

Participants attending an MS center also rated their satisfaction with MS health care significantly higher (M = 6.05, SD = 1.06) than those attending a clinic or hospital (not an MS Center) (M = 5.70, SD = 1.34;  $t_{(2808)} = 0.35$ ,  $P < .001$ ), an independent medical office (M = 5.57, SD = 1.44;  $t_{(2791)} = 0.47$ ,  $P < .001$ ), or another setting (M = 5.46, SD = 1.52;  $t_{(2791)} = 0.58$ ,  $P < .001$ ). Post hoc analysis revealed no significant differences in either quality or satisfaction with care between non-MS Center settings.

Approximately half (49.7%) of participants reported that there was an MS center or specialized MS care clinic within a 1-hour drive. Alternately, 47.4% of the participants stated that there were not enough MS health-care services in their area. In terms of distance to care, 32.2% reported that they traveled 10 miles or less to get to their MS health-care appointments, 29.4% traveled between 11 and 25 miles, 15.7% traveled between 26 and 50 miles, and 16.7% traveled more than 50 miles. Rural residents traveled significantly farther to appointments than those living in urban or suburban areas ( $\chi^2 = 560.56$ ,  $df = 10$ ,  $P < .001$ ), with 10.6% of residents of rural counties reporting driving over 50 miles to appointments, compared to 1.8% of urban and 5.6% of suburban residents.

Participants reported the frequency of their regular PMSHP follow-up appointments as follows: more than twice a year (18.1%), every 6 months (47.1%), once a year (18.5%), every 1 to 2 years (2.8%), and 8.1% did not have regular follow-up appointments. The majority of participants reported that their appointment schedule was "about right" (81.7%), with only 10.7% reporting that the follow-up visits did not occur often enough, and 2.5% saying they occurred too often.

**Table 2.** Specialists and Other Health-Care Providers.

Provider	I See as Much as Needed, n (%)	I See, but Would Like to See More Often, n (%)	I Need, but Do Not Have Access to This Type of provider, n (%)	Not Needed, n (%)
Ophthalmologist	1396 (46.5)	162 (5.4)	104 (3.5)	850 (28.3)
Urologist	866 (28.8)	136 (4.5)	130 (4.3)	1346 (44.8)
Internist	855 (28.5)	78 (2.6)	62 (2.1)	1420 (47.3)
Physical therapist	661 (22.0)	370 (12.3)	332 (11.1)	1148 (38.2)
Nurse practitioner	648 (21.6)	88 (2.9)	89 (3.0)	1580 (52.6)
Chiropractor	366 (12.2)	126 (4.2)	238 (7.9)	1665 (55.4)
Massage therapist	336 (11.2)	269 (9.0)	627 (20.9)	1224 (40.8)
Mental health counselor	322 (10.7)	112 (3.7)	273 (9.1)	1670 (55.6)
Orthopedist	305 (10.2)	79 (2.6)	161 (5.4)	1806 (60.1)
Occupational therapist	246 (8.2)	120 (4.0)	174 (5.8)	1825 (60.8)
Psychologist	223 (7.4)	73 (2.4)	185 (6.2)	1845 (61.4)
Physiatrist	221 (7.4)	37 (1.2)	138 (4.6)	1916 (63.8)
Neuropsychologist	214 (7.1)	54 (1.8)	266 (8.9)	1794 (59.7)
Nutritionist	192 (6.4)	89 (3.0)	482 (16.1)	1619 (53.9)
Speech/language therapist	120 (4.0)	26 (0.9)	121 (4.0)	2085 (69.4)
Assistive technologist/rehabilitation engineer	77 (2.6)	41 (1.4)	183 (6.1)	1977 (65.8)
Vocational rehabilitation counselor	73 (2.4)	34 (1.1)	125 (4.2)	2075 (69.1)

We asked participants “On average, how many minutes do you spend in regular appointments with your main MS care provider?” with options ranging from under 10 minutes to over 1 hour, in 5-minute intervals. The most frequently reported appointment duration was 16 to 20 minutes (24.8%), followed by 26 to 30 minutes (19.9%). About 20% each reported appointments lasting 15 minutes or less (20.7%) or over 30 minutes (20.6%). Most reported that the amount of time spent in the appointment was “about right” (73.8%). While only 3.1% reported that the amount of time was “more than enough,” 17.1% reported that the amount of time was “not enough” (78% of this group reported appointments lasting 20 minutes or less). Appointment length was associated with ratings of the quality of care ( $F_{(2,2787)} = 123.19, P < .001$ ). Games-Howell post hoc analysis revealed that the quality of care was rated significantly higher by those with a typical appointment length of 26 minutes or more ( $M = 6.16, SD = .99$ ) than by those with shorter appointments, and those with appointments of 16 to 20 minutes ( $M = 5.84, SD = 1.16$ ) rated the quality of care significantly higher than those with appointments of 15 minutes or less ( $M = 5.24, SD = 1.46$ ).

A single health-care professional who coordinated their MS health care was reported by 37.9% of respondents. This professional was most frequently a neurologist (55.7%), followed by primary care physician (33.8%), or nurse (4.6%). Independent samples *t* tests revealed that participants with a single health-care coordinator (any professional) rated both quality of care and satisfaction with care higher than those without a care coordinator ( $t_{(2577.50)} = 6.80, P < .001, 99\% CI [0.19-0.43]$ ;  $t_{(2623.29)} = 5.95, P < .001, 99\% CI [0.17-0.43]$ , respectively,  $P < .001$ ).

### Health-Care Specialist Access and Need

Participants reviewed a list of health-care specialists and allied health providers and indicated whether they (1) see this type of professional as much as needed, (2) see this type of professional but would like to see them more often, (3) need to see, but do not have access to this type of professional, or (4) do not need to see this type of professional. As indicated in Table 2, the health-care professional participants most frequently identified as wanting to see more often was physical therapist. The professional participants most frequently identified as needing to see, but not having access to, was massage therapist.

### Discussion of Health Topics in a Typical Meeting With Primary MS Care Provider

Finally, participants were provided a list of topics, identified through literature review and focus groups as being important to patients with MS, and asked “In a typical meeting with your primary MS care provider, does your provider or anyone in the provider’s office ask you about these things?” Participants also rated the importance of the topics in response to the following: “How important is it to you that your provider should ask you about this?” based on a 4-point Likert-type scale (1 = “Not at all”, 4 = “Extremely”). As shown in Table 3, the topics most important to the participants (scores > 3) included cognitive or memory problems, depression or anxiety, physical activity/exercise, and emotional health. The frequency with which topics were asked about appears generally aligned with the topic’s importance.

We then evaluated the experiences of only those participants who indicated that the topics were either “not at all” or “extremely” important. The results (Table 4) suggest several

**Table 3.** Multiple Sclerosis Care Provider Inquiries about Health Topics.<sup>a</sup>

Health Topics	In a Typical Meeting with Your Primary MS Care Provider, Does Your Provider or Anyone in the Provider's Office Ask You about These Things?		How Important Is It to You That Your Provider Should Ask You About This?
	Yes, n (%) <sup>b</sup>	No, n (%)	Mean Importance Rating (SD)
Cognitive (thinking) or memory problems	1844 (68.8%)	838 (31.2%)	3.29 (0.96)
Depression or anxiety	1794 (67%)	883 (33%)	3.17 (1.00)
Your physical activity/exercise	2051 (76.4%)	635 (23.6%)	3.17 (0.95)
Your emotional health	1757 (65.5%)	926 (34.5%)	3.15 (0.99)
Diet/nutrition	1260 (47.4)	1401 (46.7%)	2.90 (1.06)
Your family's coping	943 (35.7%)	1699 (64.3%)	2.75 (1.11)
Complementary or alternative treatments you are using or interested in learning about	868 (39.1%)	1350 (60.9%)	2.74 (1.13)
Your work	1026 (41%)	1476 (59%)	2.42 (1.23)
Your sexual function	553 (21.3%)	2045 (78.7%)	2.34 (1.19)

Abbreviations: MS, multiple sclerosis; SD, standard deviation.

<sup>a</sup>Importance rating based on a 4-point Likert-type scale ranging from 1 (not at all) to 4 (extremely).

<sup>b</sup>Valid percentage reported (percentage of those responding to this question).

**Table 4.** Relative Importance of Health Topics and Extent Addressed by Primary MS Care Providers.

Health Topic	N = 3003	Asked about Topic in Typical Appointment?	
		Yes	No
Cognitive problems	Not at all important (n = 203, 6.8%)	92 (45.3%)	111 (54.7%)
	Extremely important (n = 1319, 43.9%)	1004 (76.1%)	315 (23.9%)
Depression/anxiety	Not at all important (n = 236, 7.9%)	103 (43.6%)	133 (56.4%)
	Extremely important (n = 1157, 38.5%)	883 (76.3%)	274 (23.7%)
Physical activity	Not at all important (n = 199, 6.6%)	108 (54.3%)	91 (45.7%)
	Extremely important (n = 1100, 36.6%)	903 (82.1%)	197 (17.9%)
Emotional health	Not at all important (n = 238, 7.9%)	92 (38.7%)	146 (61.3%)
	Extremely important (n = 1133, 37.7%)	872 (77.0%)	261 (23.0%)
Work	Not at all important (n = 772, 25.7%)	95 (12.3%)	677 (87.7%)
	Extremely important (n = 605, 20.2%)	394 (65.1%)	211 (34.9%)
Diet/nutrition	Not at all important (n = 335, 11.2%)	258 (77.0%)	77 (23.0%)
	Extremely important (n = 865, 28.8%)	525 (60.7%)	340 (39.3%)
Family coping	Not at all important (n = 439, 14.6%)	77 (17.5%)	362 (82.5%)
	Extremely important (n = 781, 26.0%)	444 (56.9%)	337 (43.1%)
Complementary or alternative treatments	Not at all important (n = 402, 13.4%)	65 (16.2%)	337 (83.8%)
	Extremely important (n = 677, 22.5%)	359 (53.0%)	318 (47.0%)
Sexual function	Not at all important (n = 796, 26.5%)	71 (8.9%)	725 (91.9%)
	Extremely important (n = 536, 17.9%)	206 (38.4%)	330 (61.6%)

Abbreviation: MS, multiple sclerosis.

health topics that a subgroup rated as extremely important that were not being addressed for this group, including sexual function, complementary or alternative treatments, and family coping.

## Discussion

The aim of this study was to expand the limited knowledge about the health-care priorities and preferences of patients with MS. The findings provide important insights to inform

the development and delivery of MS health-care policy and services. Key findings are highlighted in this section.

The affordability of MS health care was a top priority, having the highest mean importance rating and largest number of participants identifying this topic as their top health-care priority. Furthermore, at least 1 in 5 participants worried a lot of the time or constantly about being able to afford to pay for their health care, despite the fact that over 90% of the participants had health-care insurance. Concern about health-care affordability was most prevalent among those

with household incomes under \$25 000; however, this concern was observed across income levels. This priority is consistent with recent studies that demonstrate the high cost of MS care (9-12), which ranges from 2 to 4 times that of the general population (12,13). The largest component in costs appears to be prescription drugs and, specifically, DMTs (14-16). According to the National MS Society, although the last decade has seen an increase in the number of DMTs, the costs have risen substantially higher than medical inflation, with costs for most DMTs exceeding \$70 000 a year (15). Clearly, this priority requires continued attention and advocacy.

Access to comprehensive, coordinated MS care was also a top priority and preference. Having access to an MS center or specialized MS clinic with multiple MS professionals was the third most important health-care priority, rated the top priority by over a quarter of the participants. Similarly, having a health-care coordinator was the fourth highest rated priority and was also a top priority for over a quarter of the participants. There is growing recognition of the health and psychosocial benefits of comprehensive, interdisciplinary MS health care (17-20). As noted by the Consortium of MS Centers, a multidimensional team approach is effective, efficient, and empowering and avoids duplication of services (18). The availability of comprehensive MS care, however, is a concern. Almost half of the participants indicated there were not enough MS health-care services in their area. Rural residence appears to be a critical barrier to accessing MS care, particularly comprehensive care, and about 1 in 10 (primarily rural-dwelling) participants traveled more than 50 miles for their MS care.

Access to specialists and allied providers was also a high priority. Specifically, participants had the highest need for, but limited access to, massage therapists, nutritionists, physical therapists, and mental health counselors. Physical and massage therapists were also identified as professionals that patients wanted to see more often. These results highlight important access gaps. Further analysis of the nature of the barriers to accessing these professionals is required in order to fully understand and effectively address this priority.

Although patients want access to multiple providers, there was frustration evidenced in the second-highest rated health-care priority: that non-MS health-care providers need to have knowledge about MS and how its treatment may impact and interact with other conditions. This priority suggests the need for increased health-care provider education and communication skills.

Finally, prior assessments of MS patients' health-care experiences have demonstrated "a general dissatisfaction" with MS care (21), including dissatisfaction with the management and communication of the diagnosis, availability of care, and accessibility of specialized services (21-27). The present finding of generally high satisfaction with MS care was therefore unexpected. We suggest that the current positive results be viewed with some caution, however, as satisfaction with health care is a complex and multidimensional

construct (27) and was measured here using only broad metrics.

## Limitations

Several limitations are associated with this descriptive, cross-sectional analysis. Multiple sclerosis care consumers are not a homogenous group, and there is no universal approach to health-care delivery that will work for everyone. The health-care priorities of people with MS vary considerably based on individual and group characteristics not accounted for in this analysis. Also, although the characteristics of the sample were generally consistent with other large population-based samples in recent national surveys, the mean age was higher than typically seen, while the number of participants reporting a minority ethnic background and with progressive MS were represented at lower rates than expected.

## Conclusions

This study provides insight into the perspectives and experiences of patients with MS, and the results have important implications. Affordability of care is a top priority among patients with MS, and although it is a particular concern for those with lower incomes, the fact that about 55% of the participants had worried about their ability to pay for their health care suggests the concern is widespread. Patients with MS want coordinated, multidisciplinary care, and many have unmet needs for care from specialists. Although most participants reported relatively high satisfaction with their PMSHP, and with the length and frequency of appointments, many were not provided the opportunity to evaluate their care. Multiple sclerosis health-care providers are encouraged to explore patients' and families' concerns using comprehensive inquiries, and to communicate effectively about these with other providers.

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