

Headache Education by E-Learning Through Social Networking Services (Social Media)

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Introduction: Headache is a common public health problem, but its burden could be avoided by raising headache awareness and the appropriate use of acute medication and prophylactic medication. Few reports on raising headache awareness in the general public have been reported, and there are no reports on headache awareness campaigns through social networking services (SNS), or social media, in Japan. We prospectively performed a headache awareness campaign from March 2022 through 2 SNS, targeting nurse and wind instrumental musicians, because they are with high headache prevalence.

Methods: Through the 2 SNS, the article and video were distributed, respectively. The article and video described the 6 important topics for the general public about headaches, which were described in the Clinical Practice Guideline for Headache Disorders 2021. Just after reading or watching them as e-learning, we performed online questionnaire sheets to investigate the awareness of the 6 topics through the 2 SNS. The awareness of the 6 topics before and after the campaign was evaluated.

Results: In the SNS nurse-senka, we obtained 1191 responses. Women comprised 94.4%, and the median (range) age was 45 (20 to 71) years old. Headache sufferers were 63.8%, but only 35.1% had consulted doctors. In the SNS Creation, we got the response from 134 professional musicians, with 77.3% of women. The largest number of respondents were in their 20s (range 18–60 years old). Headache sufferers were 87.9%. Of them, 36.4% had consulted doctors, 24.2% were medication-overuse headache. The ratios of individuals who were aware of the 6 topics significantly increased from 15.2%–47.0% to 80.4%–98.7% after the online questionnaire in both SNS ($p < 0.001$, all).

Conclusion: E-learning and online survey via SNS can improve headache awareness.

Keywords: awareness, education, medication-overuse headache, migraine, online, prevention, social networking services, social media

Introduction

Migraine is a public health problem^{1–9} in addition to tension-type headache (TTH)^{10–12} and cluster headache,^{13–16} and it is described in the International Classification of Headache Disorders 3rd edition (ICHD-3).¹⁷ Migraine prevalence is 0.9–9.5%.^{8,9,18–25} The economic and social impacts of migraine on productivity are starting to be recognized.^{24,26,27} Presenteeism accounts for 89% of productivity losses associated with migraines. In a four-year study of approximately 8000 employees in the US healthcare system, 22 prevalent health problems were examined for prevalence and their effects on productivity. Migraine was found to be the second most common reason for presenteeism, costing the employer about US\$2 million annually.²⁸ Migraine headaches, a disease with such high economic losses, have become preventable in recent years. Novel drugs, such as calcitonin gene-related peptide (CGRP)-related drugs, for migraine are now widely used.^{4,29–34} They have made migraine a fully preventable disease. Still, there was an unmet need for migraine care: 89.8% of respondents had never taken preventative medicine for headaches, and 36.5% had been hesitant to consult doctors.^{9,35} Most headache sufferers presumably manage the pains by taking over-the-counter (OTC)

medicines.^{36,37} Additionally, when people with headaches consult a doctor, only neuroimaging is done to rule out organic or emergent disorders, and the diagnostic for a detailed primary headache and its treatment is inadequate. Even when diagnosing primary headaches, clinicians lack the necessary treatment understanding, which leaves patients dissatisfied.³⁶ Inappropriately using OTC medications and insufficient headache medical resources may result in chronic migraine and medication-overuse headache (MOH).^{38–41} Before developing chronic migraine and MOH, appropriate preventative drugs can be used,^{14,15,31,32,42–45} but headache patients do not consult doctors.

By promoting headache awareness⁴⁶ and the appropriate use of acute medication and preventative medication, this significant public health issue could be averted. Raising headache awareness not only among headache sufferers who routinely consult doctors but also among the general public, including headache sufferers who never come to the hospital and non-headache sufferers, is important. Many methods have been used to educate the general population about diseases, not just headaches.^{47–49} However, few reports on raising headache awareness of headaches in people without headaches have been reported.^{26,28,38,50,51} In this context, we prospectively ran a headache awareness campaign using social networking sites (SNS) as we call it in Japan, or social media, and assessed the effects of the campaign on SNS users, including both those who already had headaches and those who did not necessarily have them.

Materials and Methods

Campaign Procedure

This headache awareness campaign was held by Itoigawa General Hospital in March 2022, in partnership with SMS Corporation and Regnition. The leading target groups were nurses and wind instrumental musicians because headaches are common in nurses^{25,52–59} and wind instrumental musicians.⁶⁰ About the former, shift workers tend to have migraine due to dysregulation of circadian rhythms.⁶¹ Migraine has a higher prevalence in workers with night shifts.⁶² Regarding the latter, the cultural association between music and migraine has been examined in the past.⁶³ Also, sound hypersensitivity is often comorbid with migraine,⁶⁴ and the relationship between music talent and migraine was also investigated.⁶⁵ There are major SNS for nurses and wind instrumental musicians in Japan. The former one is called “nurse-senka” (<https://knowledge.nurse-senka.jp/>), with 1 million nurse users and 4 million page views per month. The latter one is called “Creatone” (<https://www.creatone.jp/>), on which more than 3000 users and professional musicians can communicate with professional musicians, and they can learn and be taught by professionals online or by e-learning videos.

This campaign emphasizes 6 important topics based on the Clinical Practice Guideline for Headache Disorders 2021³⁶ (Table 1). An article in SNS nurse-senka (<https://knowledge.nurse-senka.jp/500343>) and a video in SNS Creatone (<https://www.youtube.com/watch?v=tkfOALn5vGU>) were created, explaining the 6 topics. The article and video were made available to all users on the two SNS. Immediately after reading or viewing them as e-learning, we conducted online questionnaires to ascertain how well-versed users were in the 6 themes (Table 1) via the 2 SNS. The users read and answered them online of their own free will. We did not force any participation or answers. After a month, we again asked the users to answer the same online survey sheet and measured the awareness ratio of the 6 topics. The users did not acquire any honorarium and responded on a voluntary basis. We also asked, “why most headache sufferers do NOT consult doctors?” as choice questions.

Age and headache characteristics were also collected, and headache and MOH diagnoses were made in the same way in the previous studies.^{18–20} The questionnaire was developed through Google Forms, and the questionnaire sheet consisted of the following items: age, sex, how many days per month a headache occurs in these 3 months or no headaches, whether your headache has been examined and diagnosed by a doctor, what acute medication you use, how many days per month you use the acute medication, use of prophylactic medication for headache, and what prophylactic medication you use. In the valid respondents, cases with headaches within the last 3 months were considered headache sufferers. MOH was defined by referring to the ICHD-3 [2]. A case of MOH was defined as a respondent who had headaches ≥ 15 days per month and reported intake of non-opioid analgesic, such as acetaminophen and loxoprofen, ≥ 15 days per month, combination analgesic (most OTC medicines) or triptan ≥ 10 days per month. These case definitions approximate Criteria A and B of the ICHD-3 diagnostic criteria for MOH (code 8.2).

Google Forms can access the questionnaires. One for Creatone (<https://docs.google.com/forms/d/1052wI3nn7o14dpMVB53tkEpRrdWJxRtu323cfHZ6jQ/edit>) and one for Nurse-Senka cannot be public for the company’s reasons.

Table 1 Topics and Survey Sheet

These are the Medical Facts as Stated in the Clinical Practice Guideline for Headache Disorders 2021. Please Read and Respond to the Following Question.		
Topic Number	Statement	Question (Choose the Answers)
Topic 1	The economic loss caused by headaches, including interference with work, schoolwork, and household chores, has become a social problem.	Yes, I was aware. / No, I was not aware.
Topic 2	The economic loss due to reduced performance in studies and work caused by headaches (presenteeism) is greater than the economic loss due to missed school or work caused by headaches (absenteeism).	Yes, I was aware. / No, I was not aware.
Topic 3	Headache is a symptom; it can be caused by any number of diseases (example: migraine, tension-type headache)	Yes, I was aware. / No, I was not aware.
Topic 4	If you have migraine attacks more than twice a month, if you have strong headaches more than three days a month, or if you take painkillers more than 10 days a month, you should consult doctors.	Yes, I was aware. / No, I was not aware.
Topic 5	There are 2 important treatments for headaches: (1) acute and (2) prophylactic medications.	Yes, I was aware. / No, I was not aware.
Topic 6	There is a “medication-overuse headache”, in which the headache returns and worsens by taking painkillers for more than 10 days a month.	Yes, I was aware. / No, I was not aware.

Notes: Valid responses were those that filled in all the items in the survey sheet. The questionnaire sheets with one or more blank answers were also excluded from this study.

Statistical Methods

Before and after the online questionnaire, the percentage of people who were aware of the six topics was compared using a Chi-square test. Statistical significance was determined as a two-tailed $p < 0.050$. Version 28.0.0 of SPSS was utilized; it was made by IBM in New York, USA. No Bonferroni correction was used.⁶⁶

Ethical Aspects

Itoigawa General Hospital Ethics Committee approved this study (approval number 2022–2, 2022–3). There were no names or other personally identifying information in the anonymous survey. The volunteers were given a copy of the online survey form that detailed the study’s objectives. If they wanted to take part in the study, they had to fill out the survey form. They were allowed not to participate if they did not want to do so by being asked to submit a blank sheet or not to try. The users did not acquire any honorarium and responded on a voluntary basis. All procedures were carried out following the Helsinki Declaration. To protect patient privacy, all identifiable patient data was removed from the database.

Results

We received 1191 responses to the SNS nurse-senka. The median (range) age was 45 (20 to 71) years old, and women made up 94.4% of the population. Only 35.1% of the 63.8% of headache sufferers had seen a doctor. One hundred and thirty-four professional musicians responded to the SNS Creatone survey, with 77.3% of them being female. The majority of responders (range: 18–60 years old) were in their 20s. There were 87.9% headache sufferers. Of them, 36.4% had seen doctors, 24.2% were MOH, and 75.9% reported that their headaches had interfered with their music performance as professionals.

Following the online survey in both SNS, the ratios of people who were aware of the six themes considerably climbed from 15.2% to 47.0% to 80.4 to 98.7% ($p < 0.001$, all) (Table 2). After one month, the nurse-senka group appeared to have a higher level of understanding than the Creatone group.

Table 3 displays the results of the survey question, “Why do most headache sufferers NOT consult doctors?” The results seemed similar in both groups. In nurse-senka, the most answered reasons were because taking time off from work

Table 2 Survey Results Through Social Networking Services for Nurses and Professional Musicians

These are the Medical Facts as Stated in the CLINICAL Practice Guideline for Headache Disorders 2021. Please Read and Respond to the Following Question.					
Users		SNS for Nurses (n=1191)		SNS for Professional Musicians (n=134)	
Topic Number	Statement	Ratio of "I was Aware" Before e-Learning Through SNS	Post 1 month	Ratio of "I was Aware" Before e-Learning Through SNS	Post 1 Month
Topic 1	The economic loss caused by headaches, including interference with work, schoolwork, and household chores, has become a social problem.	27.9%	93.6%	18.2%	84.8%
Topic 2	The economic loss due to reduced performance in studies and work caused by headaches (presenteeism) is greater than the economic loss due to missed school or work caused by headaches (absenteeism).	22.0%	94.8%	15.2%	88.9%
Topic 3	Headache is a treatable disease.	30.3%	98.7%	21.2%	84.8%
Topic 4	If you have migraine attacks more than twice a month, if you have strong headaches more than three days a month, or if you take painkillers more than 10 days a month, you should consult doctors.	41.0%	97.1%	47.0%	80.4%
Topic 5	There are 2 important treatments for headaches: (1) acute and (2) prophylactic medications.	40.1%	95.8%	21.2%	91.8%
Topic 6	There is a "medication-overuse headache", in which the headache returns and worsens by taking painkillers for more than 10 days a month.	36.8%	92.2%	39.4%	90.9%

Notes: The ratios of awareness were improved after 1 month, $p < 0.001$ by chi-square test.

Abbreviation: SNS; social networking services (social media).

Table 3 The Questionnaire Results of “Why Most Headache Sufferers Do NOT Consult Doctors?”

Reasons	Response Rate by Users in SNS for Nurses (n=1191)	Response Rate Users in SNS for Wind Instrumental Musicians (n=134)
Because I do not think headaches are sick enough to go to the hospital.	38.37%	77.3%
Because taking time off from work or school to see a doctor would cause inconvenience to others.	68.84%	45.5%
Because I cannot take time to visit a hospital during the daytime on weekdays.	62.30%	48.5%
Because my headache will go away if I just persevere.	24.43%	50.0%
Because people around me tell me to be patient.	8.14%	12.1%
Because doctors and co-medical staffs will not be kind to me even if I go to the hospital.	17.29%	15.2%
Because over-the-counter medicines are sufficient.	41.22%	62.1%
Because I do not know that there are prophylactic medicines to prevent headaches.	25.77%	40.9%
Because I feel that my headache does not interfere with my daily life.	17.71%	19.7%

Abbreviation: SNS; social networking service (social media).

or school to see a doctor would cause inconvenience to others, because I cannot take time to visit a hospital during the daytime on weekdays, and because over-the-counter medicines are sufficient, in order. Those in Creatone were because I do not think headaches are sick enough to go to the hospital, Because over-the-counter medicines are sufficient, and because my headache will go away if I just persevere, in order.

This awareness-raising led four of the nurses working at Japanese Red Cross Suwa Hospital to visit the headache out patients at the hospital. They are treated with prophylactic medication by our headache specialists.

Discussion

Through two SNSs, we ran this campaign to raise awareness about headaches. After the e-learning and online survey, the ratios of people who were aware of the six themes dramatically rose ($p < 0.001$, all). According to our findings, online surveys and e-learning could increase SNS users' awareness of headaches.

Previous Awareness Campaign

In March 2004, the World Health Organization and the Global Campaign against Headache jointly launched the initiative.⁶⁷ The campaign was conceptualized in 3 steps; 1) Knowledge for awareness, 2) Awareness for action, and 3) Action for change. The details are described in Table 4. This campaign is still well underway around the world, and epidemiological surveys and educational projects for healthcare providers were conducted.^{2,68–71}

Table 4 The Three Strategic Objectives of the Global Campaign Against Headache

Strategic Objective	Purpose	Action
1	Knowledge for awareness	Establish what it is that requires change
2	Awareness for action	Agitate to create desire for change
3	Action for change	Propose and justify the change to be instigated

A national MOH awareness campaign,³⁸ university education,⁵¹ public education,⁵⁰ leaflet distribution at mass vaccinations, and e-learning through schools²⁶ are the only campaigns that have been carried out to inform the general public about headaches, despite the fact that the education program for doctors and headache sufferers has been widely implemented. But not every campaign was successful.

In 2016, a Danish national awareness campaign for MOH was performed. The target audience included the general public, general practitioners, and pharmacists. The campaign achieved significant reach and engagement, with 297,000 views of online videos, distribution of campaign materials to all 400 pharmacies, dissemination of over 28,000 leaflets, radio and television coverage reaching large audiences, publication of numerous print media articles, presence on reputable websites and online news agencies, and scientific paper publications. A survey conducted after the campaign indicated an increase in public awareness of MOH from 31% to 38%. However, this was not statistically significant.³⁸

Here is a report on education at a university. Through social networking sites, Lai et al⁵¹ conducted a study of the University of Birmingham undergraduate students concerning MOH in 2014. A total of 485 respondents, with nearly half having medical training, answered the survey. 372 of the 485 respondents (or 76.7%) were uninformed of the potential for MOH from routine painkiller usage for a headache. After receiving information on MOH, 364 of the 485 respondents (75.1%) said they would use fewer analgesics or seek medical advice. Additionally, 397 out of 485 people (81.8%) said OTC analgesics should have a MOH warning on the label. Although small in scale, this report is an attempt to raise awareness among the general public and is similar to our research in that it uses the Internet.

A system of education for the general public, those who suffer from headaches, and medical personnel was developed in Yekaterinburg, Russia, in 2013. In this situation, the Russian Headache Research Society conducted public education through the media, focusing on the identification of various headache types, their causes and potential preventative measures, appropriate and inappropriate medication use, and when to seek professional assistance. The article does not discuss how education affects the general public, but given that the mass media participated and that the city has a population of more than 1.3 million, we assume it was a significant effort.⁵⁰ Details are not available, but a follow-up report on the effectiveness of this awareness campaign is awaited.

Before this study, we conducted the Itoigawa Headache Awareness Campaign from August 2021 to June 2022, consisting of two main interventions, and assessed their effectiveness. The campaign targeted individuals aged 15–64 in the general public. Two main interventions were implemented, supported by additional smaller interventions. Intervention 1 involved distributing leaflets and administering paper-based questionnaires on headaches during COVID-19 vaccination. Intervention 2 included on-demand e-learning and online surveys conducted through schools. Both interventions focused on six key topics outlined in the Clinical Practice Guideline for Headache Disorders 2021. Data on awareness of the topics were collected before and after each intervention. We obtained 4016 valid responses from 6382 individuals who received vaccinations in intervention 1, and 2577 responses from 594 students and 1983 parents in intervention 2, reaching a total of 6593 participants (32.2% of the working-age population in Itoigawa city). The percentage of individuals aware of the six topics significantly increased after both main interventions, ranging from 6.6% (39/594) - 40.0% (1606/4016) to 64.1% (381/594) - 92.6% (1836/1983) ($p < 0.001$, all). Community-based interventions, particularly during mass vaccination events where residents gather, and school-based e-learning proved to be effective methods for raising headache awareness.²⁶ Even under the coronavirus-2019 pandemic, the awareness campaign could be performed online.

One recent successful awareness campaign is a Japanese information technology company's internal awareness campaign. Sakai and Igarashi et al²⁸ performed a headache education and evaluation program in the workplace of the company from 2019 to 2022. A total of 73,432 employees from the company participated in the program, with 16.7% having migraine, 40.7% experiencing TTH, and 0.5% having cluster headaches. Following the training and education, 82.9% of participants without headaches expressed a change in their attitude towards colleagues with headache disorders, and 72.5% reported an improved understanding of headaches. The educational program increased awareness of the impact of headaches on people's lives, with the proportion of employees recognizing its significance rising from 46.8% to 70.6%. Additionally, 4.1% of participants expressed interest in virtual consultations with headache specialists, and over half of them had not previously sought medical advice for their headaches. The program resulted in an annual productivity gain of approximately 14.7 days per employee with headaches, leading to a cost-saving of \$4531 per employee. These positive outcomes emphasize the value of workplace

programs for migraine across all industries. As these tangible improvements in economic losses are being reported, it is essential to continue to disseminate correct information about headaches.

Thus, there are successful and unsuccessful awareness-raising activities. Further discussion is needed to determine what methods are best in the future. Instead of using mass media, consumer-generated media like weblogs and SNS have been utilized in the current complicated media ecosystem.^{72,73} Due to the possibility that those who do not have headaches are not interested in the burden of headaches, we assume that passively educating the general public through the media has no impact. Therefore, this headache awareness was conducted using the SNS consisting of user groups that would potentially have a high headache prevalence. Our campaigns were not mandatory; we asked for free-will participation on the SNS. We aimed to recruit as many participants as possible by targeting a population with a high headache prevalence and by explaining the 6 topics in a way that was easy to understand for nurses and wind instrumental musicians on each SNS. We may need to devise further ways to increase participation in the future, such as advertisements and point programs.

Importance of Early Medical Consultation

The notion that migraine is a progressive disease is being proposed.^{74,75} It is estimated that episodic migraine progresses to chronic migraine at a rate of 2.5% per year and may be underestimated due to the arbitrary 15-day period according to the migraine criteria.⁷⁶ Key clinical features of migraine progression include progressive increases in the number and intensity of attacks, autonomic disturbance, and allodynia, leading to chronic migraine over time.⁷⁷ Pathophysiologically, changes in hypothalamic activity, as one of the hypothesized generators of migraine,⁷⁸ and diminished brainstem inhibitory process⁷⁹ have been estimated as the main progression mechanisms. The factors related to migraine progression are the high frequency of migraine attacks, medication overuse, comorbid pain syndromes, and obesity.⁷⁴ About 30% of chronic migraine is refractory to both preventive and acute treatment.³⁶ Although CGRP-related agents have been reported to be effective in chronic migraine,^{80–84} their response rate is not comparable to that of episodic migraine. Therefore, early consultation and treatment are needed before the migraine progresses to chronic migraine.

Hirata et al⁸⁵ used epidemiological surveys and questionnaires. They found that 14–38% of headache patients did not visit a hospital because of the effectiveness of OTC medicines. In contrast, some patients first visited a doctor because OTC had become ineffective (48/691, 6.9%) or because their headaches had increased in frequency (55/691, 8.0%). Also, prophylactic treatment is not well performed in Japan,^{9,35} and patients who would make their physicians have thought to prescribe prophylactic treatments aggressively and for whom early prophylactic treatment is prescribed may have already begun to develop chronicity from the initial consultation. If so, further educational efforts^{26,38} should be made, and patients should be seen while they have relatively mild episodic migraine. Also, for such severe patients, the new CGRP-related drugs can perform therapeutic effects.^{80,86–91} Further data accumulation is needed.

In clinical practice, patient education is important, but the long-term perspective is difficult, and patients often drop out and receive multiple medical services.⁹² Patients who consult multiple doctors may lack trust in their doctors and doctor-shop. It will be necessary in the future to build trust between doctors and patients and to plan treatment based on shared decision-making.^{93,94} As a starting point, disseminating information through social networking sites such as this one may be an easy way to spread a little correct knowledge.

Future Plan

We mention future prospects. Under the COVID-19 pandemic, our headache awareness campaign can be performed without face-to-face communication to avoid infection. Also, our materials used for awareness-raising can be installed into smartphone applications of headache diary^{95,96} and further dissemination and spread on SNS, which had a significant impact. Furthermore, with rapid digital transformations such as online telemedicine,^{97,98} treatment devices⁹⁹ and electronic headache diaries as smartphone applications,^{95,96,100} and artificial intelligence diagnosis,¹⁰¹ it should be crucial to raise awareness because it will be more efficient and effective. Considering that migraine sufferers tend to be younger, this awareness campaign may be even more accepted.

Furthermore, the biopsychosocial approach to migraine and headache management will have therapeutic effects.¹⁰² Today, pharmaceutical therapies are the mainstay of migraine and headache treatment. However, because they are complex diseases, it is crucial to adopt a comprehensive strategy to address, in each person, every aspect that affects the disease's effects and

helps to prevent a long-term worsening course. In addition to pharmacological strategies, proper education about headaches, physical therapy, and massage are essential to treatment. These non-pharmacological treatments can be learned through SNS. Finally, SNS can become a place for users suffering from headaches to exchange information and learn from each other, which may lead to social care.¹⁰² Until now, patients have had the opportunity to exchange information with each other in person and to receive education from doctors.⁴⁶ However, with the advancement of digitalization, social care may be created in environments such as SNS and metaverse.¹⁰³

Limitations

We herein described limitations. This campaign was performed in specific SNS, so user demographics are skewed and may be difficult to generalize for all SNSs in Japan as well as other countries. Additionally, because of the data-gathering strategy used, our study may contain responder bias. As a result, the outcomes might not have represented all users. Distributing information through SNS is sometimes difficult because some users are not accustomed to using smartphones or SNS. Also, shown by the low survey collection rate, there is a possibility that some users may have ignored the campaign and survey without engaging in it. The disadvantage is the low participation rate instead of easy dissemination of information. The ratio of headache sufferers seemed high among the responders in this study. However, we did not specify the headache types among the 2 groups since this was a preliminary attempt to provide information for preventing MOH. We should specify the headache types in the next campaign in SNS. Additionally, a significant percentage of those who had no interest in headaches abstained from the e-learning and survey. It may also have been a result of worsening headaches from gazing at the screen of smartphones or computers.^{85,104–108} Furthermore, the review of information retention is very short at one month. We confirmed the educational effect of this campaign but could not confirm that this awareness effect was retained until, for example, 12 months. Lastly, the most important issue is the prevention of medication overuse. If this could be shown, our approach would be one route to tap into an even larger audience and work towards improving and maintaining self-management skills over the longer term. Based on the experience and reflection obtained from this study and our preliminary experience in raising awareness in the community,²⁶ we are currently considering an awareness campaign for hundreds of thousands of people with large municipalities and companies.

Conclusions

This headache awareness campaign was carried out via online surveys and e-learning through two social networking sites. This is so because certain user groups on the SNS may have a high prevalence of headaches. One month after e-learning, the ratios of people who were aware of the six themes related to headaches dramatically increased ($p < 0.001$, all). Our findings imply that online surveys and e-learning can raise headache awareness. The campaign's elements can be added to mobile applications and further disseminated on social media, having a significant impact. Raising awareness will be more efficient and effective in the age of rapid digital innovations, such as online telemedicine and artificial intelligence diagnosis, and it should be a priority.

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