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The effect of epilepsy education on seizure intervention, knowledge, and stigma levels among high school students: A randomized controlled study

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Abstract

Background & Objective: Misinformation and misconceptions regarding epilepsy in society contribute to the increasing stigma surrounding the condition and its patients. This study aimed to examine the impact of education provided to high school students about epilepsy on their awareness of seizure intervention, knowledge level, and stigma associated with the condition. *Method:* This study, designed as a randomized controlled experimental study with pre-test and post-test measurements, collected data between February and May 2024. To gather data, the Student Information Form, the Epilepsy Knowledge Scale, the Epilepsy Stigma Scale, and the Numerical Rating Scale were utilized. A total of 256 high school students participated in the experimental group, while 201 students were included in the control group. *Results:* The mean total score on the Epilepsy Knowledge Scale in the experimental group increased, indicating a significant improvement compared to the control group ($p<0.001$, Cohens d=1.57, effect size 0.61). A significant decrease was found in all sub-dimensions and total scores of the Epilepsy Stigma Scale in the experimental group. ($p<0.001$, Cohens d= -0.92, effect size -0.41). Both groups' level of competence in seizure intervention was similar before the training ($p=0.531$); however, a significant increase was noted in the experimental group post-education ($p=0.002$, Cohens d= 1.74, effect size 0.65).
Conclusion: Education given to high school students about epilepsy increases their knowledge and seizure intervention competence and reduces the level of stigma. In light of these findings, it is recommended that educational initiatives aimed at reducing stigma against individuals with epilepsy be widely implemented across the community.

Keywords: High school students, epilepsy, knowledge, stigma, epilepsy education

INTRODUCTION

Epilepsy is a neurological disorder characterized by the excessive and abnormal discharge of neurons, leading to seizures. Although epilepsy is a medical condition, it is often regarded as a biopsychosocial disorder that is subject to significant stigma, prejudice, and discrimination.[1] Historically, various misconceptions have surrounded epilepsy, attributing it to divine wrath, punishment for sins, mental illness, psychiatric disorders, and even infectious diseases.[2] Despite significant advancements in treatment, there has been little progress in addressing the widespread misinformation and misconceptions about the condition.[3,4] This issue is particularly pronounced in less developed or developing countries, where the level of stigma faced by patients remains high.[5] As a result, individuals with epilepsy often experience profound impacts on their social lives, particularly in the context of school environments. Children with epilepsy are especially vulnerable to discrimination at school, which can lead to increased feelings of shame, decreased academic performance and self-esteem, social isolation, depression, and a decline in overall quality of life.[6-9] Current studies indicate that students generally possess low levels of awareness and knowledge about epilepsy, often feeling inadequate in responding to seizures and thus reluctant to engage in

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friendships with individuals who have the condition.[10,11] The International League Against Epilepsy (ILAE) has repeatedly emphasized the critical role of education in addressing the challenges faced by individuals with epilepsy in school settings due to societal stigma.[12] Considering that high school students are in their adolescent years, where peer pressure and bullying are prevalent, the importance of educational interventions for this demographic becomes even more pronounced.[13] Therefore, increasing awareness and knowledge about epilepsy among high school students, as well as teaching them how to respond to seizures, can help reduce prejudice and stigma towards patients.[10,14,15] Most studies assessing knowledge levels have been conducted among adult populations, highlighting the limited research involving school-aged children.[16–19] This study aimed to investigate the effects of educational interventions on seizure intervention skills, knowledge, and stigma levels among high school students regarding epilepsy.

METHODS

This study, designed as a randomized controlled trial with a pre-test and post-test design, includes a detailed description of the sample, data collection process, and data collection instruments provided below.

Samples

In Türkiye, formal education spans 12 years, divided into three stages: four years of primary school (ages 6–10), four years of lower secondary school (ages 10–14), and four years of upper secondary (high school) education (ages 14–18).[20] The sample for this study comprised students attending two different high schools in Samsun, Turkiye. Students who voluntarily agreed to participate in the study, had obtained parental consent (as nearly all participants were under 18 years of age), and did not present communication difficulties were included in the research. Conversely, students who were unwilling to participate or whose families did not provide consent were excluded from the study.

Randomization and data collection

To implement the study, a list of high schools located in the two most populous districts of Samsun, identified as the central areas, was compiled. A total of 38 high schools were identified, from which two different schools were randomly selected for the experimental and control groups. It was determined that the A school, which constituted the experimental group, had a total of 986 high school students, while the B school, designated as the control group, had 529 high school students. In accordance with the inclusion criteria for the study, 256 students from A school were placed in the experimental group, and 201 students from B school were included in the control group.

Before data collection, the necessary permissions were obtained, and communication was established with the administration of the selected schools. Initial visits to the A and B high schools were conducted shortly thereafter to facilitate data collection. During the first visit, all students eligible for the study were administered questionnaires to gather pre-test data (T0). Approximately one month later, a follow-up visit was scheduled for the experimental group at A high school, during which the educational intervention was implemented. Immediately after the intervention, the questionnaires were re-administered to gather post-test data (T1). Similarly, students in the control group at B high school were administered the questionnaires during the first visit (T0); however, no educational intervention was conducted for this group. Approximately one month after the initial visit, the students were revisited to gather post-test data (T1) (Figure 1). The data for the study were collected between February and May 2024.

Content of the education on epilepsy

The content of the training provided to the students in the experimental group included information on the definition of epilepsy, its causes, types, seizure classifications, treatment methods, intervention strategies for epilepsy seizures, and the psychosocial aspects of living with epilepsy. The training was conducted face-to-face using a PowerPoint presentation, lasting approximately 45 minutes. Following the training session, an additional 15 minutes were allocated for a question-and-answer segment.

Data collection tools

In the collection of research data, the Student Information Form, Numerical Rating Scale, Epilepsy Knowledge Scale, and Epilepsy Stigma Scale were utilized.

The Student Information Form: The form created by the researcher includes sociodemographic questions regarding the students' age, gender,

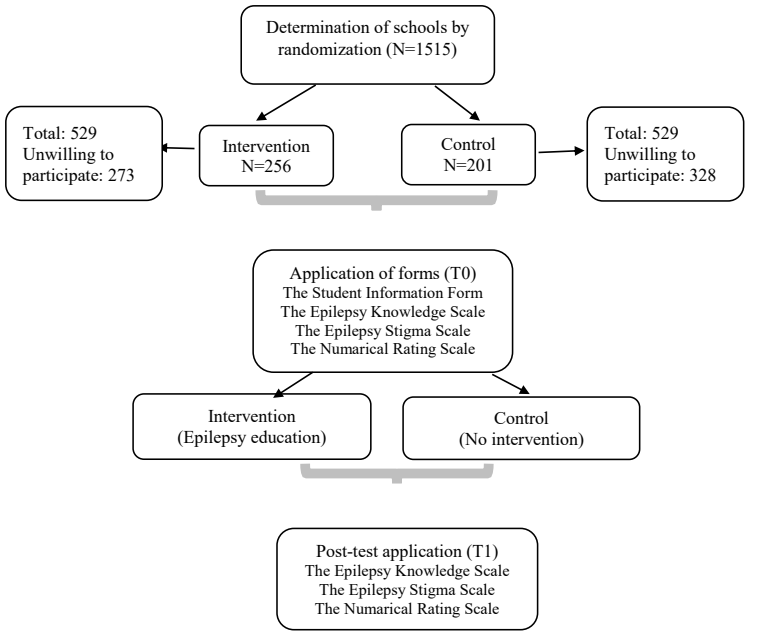

Figure 1. Study flow diagram

grade level, place of residence, and income level. Additionally, it inquires about their familiarity with epilepsy, such as whether they have seen individuals with epilepsy or have family members who are epilepsy patients.

The Numerical Rating Scale: This scale was originally developed by Breivik et al. (2008) to assess pain levels in clinical settings.[21] However, it is now frequently utilized to rate various symptoms or conditions. In this study, students were asked the question, "How competent do you feel in intervening during an epileptic seizure?" and were requested to provide a rating. In this scale, a score of "zero" indicates that the individual feels completely incompetent, whereas a score of "ten" signifies that they feel fully competent.

The Epilepsy Knowledge Scale: Developed by Aydemir (2008), this scale measures the level of knowledge regarding epilepsy within the community. The scale includes general questions about seizures, intervention during seizures, and the causes and treatments of epilepsy. Comprising a total of 16 questions, scores on this scale range from 0 to 16, with higher scores indicating a greater level of knowledge. The scale has been reported to have a Cronbach's alpha coefficient of 0.84.[22]

The Epilepsy Stigma Scale: The scale, originally developed in Turkish by Baybaş et al. (2017), consists of a total of 20 items and three subdimensions. It was designed to determine the levels of misconceptions, prejudices, and discrimination regarding epilepsy among healthy individuals and members of the community. As the scores obtained from the scale increase, it indicates a higher level of stigma associated with epilepsy among individuals. The scale has been reported to have a Cronbach's alpha coefficient of 0.91.[23]

Ethics

To conduct the research, ethical approval was obtained from the Ondokuz Mayıs University Social and Human Sciences Ethics Committee (Ethical No: 2023-870) and institutional permission was granted by the Samsun Provincial Directorate of National Education. Additionally, written consent was obtained from both the students included in the sample and their parents.

Data analyses

The data were analyzed using SPSS 21 (IBM, Amarok, NY). The normality of the data distribution was assessed using the Kolmogorov-Smirnov test, along with skewness and kurtosis

values. Sociodemographic data were presented in terms of frequency and percentage. For the comparison of normally distributed data, the t-test was employed. Chi-square analysis was used for the comparison of categorical variables. The relationships between the scales were evaluated using Pearson correlation coefficients. To assess the effectiveness of the education, a paired sample t-test was conducted. The significance level was set at $p<0.05$.

RESULTS

The study included a total of 457 students, with an average age of 15.1 years (±1.13). The majority of participants were first-year students (37.4%) and second-year students (35.4%). Almost all students (97.6%) resided in urban or district centers, and a significant portion (73.5%) reported their income level as good. Among the students, only one was diagnosed with epilepsy. Additionally, 17.3% of the students reported having a family member with epilepsy, 17.7% had witnessed an epileptic seizure, and 95% had heard of epilepsy (Table 1).

The mean score on the Epilepsy Knowledge Scale for all students included in the study was calculated to be 7.6 (±4.10). The percentages of correct responses to the Epilepsy Knowledge Scale questions are presented in Table 2. Initially, the rates of correct answers among students in both the experimental and control groups were similar ($p>0.05$). However, post-intervention, the experimental group demonstrated a significant increase in the percentage of correct responses for each item compared to the control group ($p<0.001$). The mean total score on the scale before the intervention was 6.9 (±4.1) for the experimental group and 7.3 (±4.0) for the control group, with no significant difference between these means ($p=0.488$). Following the training provided to the experimental group, the average score rose to 13.3 (±2.8), indicating a significant increase in comparison to the control group ($p<0.001$) (Table 2).

The average score on the Epilepsy Stigma Scale for all students included in the study was calculated to be 44.81 (±9.26). The mean scores for the subscales and the total score of the Epilepsy Stigma Scale are presented in Table 3. Prior to the intervention, the scale scores were similar for both groups ($p>0.05$). However, post-intervention, the experimental group exhibited a significant decrease in all subscales and total scores compared to the control group ($p<0.001$).

Before the intervention, both groups reported similar levels of self-efficacy regarding their ability to intervene during a seizure ($p=0.531$). However, post-intervention, the experimental group demonstrated a significant increase in this self-efficacy ($p=0.002$) (Table 4).

When comparing students' knowledge and stigma scores based on sociodemographic characteristics, it was found that female students had significantly better knowledge scores ($p<0.001$) and lower stigma score averages ($p=0.018$) than male students. Additionally, students who had previously heard of epilepsy, witnessed an epileptic seizure, or had a family member with epilepsy also demonstrated better knowledge scores and lower stigma scores ($p<0.005$) (Table 5).

DISCUSSION

Despite being a neurological disorder, epilepsy can impose a significant psychosocial burden on individuals due to the occurrence of seizures. Patients often face stigmatization as a result of the community's insufficient knowledge, misconceptions, biases, and discrimination regarding epilepsy. This is particularly concerning for high school students with epilepsy, who are considered a vulnerable group. They may experience discrimination that undermines their self-confidence, reduces their self-esteem, and negatively impacts their psychosocial well-being.[24] Adolescents, as a demographic group, are susceptible to various stressors, including peer bullying. being one of the most significant factors contributing to their vulnerability. A study conducted by Austin et al. (2002) with a large sample group found that approximately half of high school students (48%) had never heard of epilepsy, and three-quarters reported a high incidence of discrimination and bullying against individuals with epilepsy.[25] In our current study, nearly all students (95%) reported having heard of epilepsy, which can be attributed to the increased accessibility of information facilitated by advancing technology. Nevertheless, it remains evident that misinformation and stigma related to epilepsy persist as ongoing issues. It was noted that students exhibited a particularly low rate of correct responses to many questions within the epilepsy knowledge scale. Common misconceptions include the beliefs that patients may pose a danger during seizures, that epilepsy is an untreatable condition, and that substances such as garlic should be administered during a seizure. However, following educational interventions, there was a significant increase

Table 1: Students' sociodemographic characteristics and familiarity with epilepsy

Characteristics	Intervention (N=256)	Control (N=201)	Total	p
Age (Mean±SD)	15.17±1.29	15.12±0.88	15.19±1.13	0.593
Sex				
Female	138 (53.9)	95 (47.3)	233 (51.0)	
Male	118 (46.1)	106 (52.7)	224 (49.0)	0.187
Class				
1st	94 (36.7)	77 (38.3)	171 (37.4)	
2nd	90 (35.2)	72 (35.8)	162 (35.4)	
3rd	72 (28.1)	52 (25.9)	124 (27.1)	0.354
Where do you live?				
Rural area	6 (2.3)	5 (2.5)	11 (2.4)	0.574
Urban area	250 (97.7)	196 (97.5)	446 (97.6)	
Income*				
Good	189 (73.8)	147 (73.1)	336 (73.5)	
Moderate/bad	67 (14.7)	54 (11.8)	121 (26.5)	0.475
Do you have epilepsy?				
Yes	-	1 (0.5)	1 (0.2)	0.440
No	256 (100.0)	200 (99.5)	456 (99.8)	
Are there patients with epilepsy in your family?				
Yes	35 (13.7)	44 (21.9)	79 (17.3)	**0.025**
No	221 (86.3)	157 (78.1)	378 (82.7)	
Have you heard of epilepsy?				
Yes	244 (95.3)	189 (94.0)	433 (94.7)	0.673
No	12 (4.7)	12 (6.0)	24 (5.3)	
Have you ever witnessed an epileptic seizure?				
Yes	37 (14.5)	44 (21.9)	81 (17.7)	**0.048**
No	219 (85.5)	157 (78.1)	376 (82.3)	

Note: SD: Standard Deviation, * Based on students' subjective self-reports

in correct responses. The mean score on the knowledge scale improved from 6.9 (±4.1) to 13.3 (±2.8). Various studies have also indicated that educational interventions regarding epilepsy significantly impact knowledge and attitudes.[26–31] However, it is important to note that there is a limited number of studies documenting the effectiveness of epilepsy education programs. Furthermore, it is crucial that such programs are not restricted to specific groups and that their continuity is ensured.

In our current study, we determined that the education provided not only improved the students' knowledge levels but also reduced the stigma associated with epilepsy. The average score for the experimental group on the Epilepsy Stigma Scale decreased from 44.6 (±9.7) to 37.5 (±8.5), while no significant changes were observed in the control group. The literature indicates that as knowledge and familiarity with epilepsy increase, attitudes toward the condition improve, leading to a reduction in stigma.[32] It is expected that individuals who perceive epilepsy as a dangerous and contagious disease are likely to advocate for the isolation of patients from society. Those who hold the belief that "epilepsy patients have low intelligence" may argue that these patients should only attend special educational institutions. Similarly, individuals who believe that patients cannot become pregnant or give birth may contend that they should not marry. From this perspective, it can be posited that each piece of misinformation contributes to the development of negative attitudes. Therefore, it is anticipated that as knowledge and familiarity with epilepsy grow, negative attitudes will decline. In our study, we found that individuals who are familiar with epilepsy, have family members with epilepsy, or have witnessed an epileptic seizure scored

Table 2: Comparison of the correct response rates of students to the items of the Epilepsy Knowledge Scale

Items	Intervention n (%)	Control n (%)	p
1. Epilepsy has many different types (T)			
Before	96 (37.5)	64 (31.8)	0.209
After	245 (95.7)	88 (43.8)	**<0.001**
2. Most people with epilepsy can work (T)			
Before	139 (54.3)	116 (57.7)	0.467
After	235 (91.8)	133 (66.2)	**<0.001**
3. Most children with epilepsy can go to public schools (T)			
Before	145 (56.6)	138 (68.7)	0.009
After	229 (89.5)	141 (70.1)	**<0.001**
4. Patients with epilepsy can be dangerous to others during a seizure (F)			
Before	27 (10.5)	38 (18.9)	0.011
After	144 (56.3)	47 (23.4)	**<0.001**
5. Some seizures may last for a matter of seconds (T)			
Before	120 (46.9)	92 (45.8)	0.815
After	177 (69.1)	102 (50.7)	**<0.001**
6. For most patients with epilepsy, seizures can be controlled with drugs (T)			
Before	84 (32.8)	81 (40.3)	0.099
After	179 (69.9)	85 (42.3)	**<0.001**
7. Brain surgery can be used to treat epilepsy in some cases (T)			
Before			
After	45 (17.6)	31 (15.4)	0.540
	166 (64.8)	37 (18.4)	**<0.001**
8. Most people with epilepsy have normal intelligence (T)			
Before	159 (62.1)	134 (66.7)	0.314
After	238 (93.0)	134 (66.7)	**<0.001**
9. Patients with epilepsy can be as successful at work as others (T).			
Before	175 (68.4)	143 (71.1)	0.522
After	232 (90.6)	139 (69.2)	**<0.001**
10. An epileptic seizure is caused by an abnormal function of the nerve cells in the brain (T).			
Before	136 (53.1)	98 (48.8)	0.355
After	224 (87.5)	86 (42.8)	**<0.001**
11. Epilepsy is a kind of incurable disorder (F)			
Before	54 (21.1)	52 (25.9)	0.231
After	213 (83.2)	48 (23.9)	**<0.001**
12. Inadequate sleep, stress, and taking alcohol can cause a seizure (T)			
Before	156 (60.9)	123 (61.2)	0.956
After	228 (89.1)	116 (57.7)	**<0.001**
13. When you see a person having a seizure, you can stop the seizure by giving him/her an onion to smell (F)			
Before	89 (34.8)	76 (37.8)	0.502
After	241 (94.1)	81 (40.3)	**<0.001**

Table 2: (continued)

Items	Intervention n (%)	Control n (%)	p
14. Patients with epilepsy can lead normal lives (T)			
Before	153 (59.8)	138 (68.7)	0.055
After	230 (89.8)	143 (71.1)	**<0.001**
15. Some kinds of seizures can be hardly noticed by others (T)			
Before			
After	107 (41.8)	77 (38.3)	0.451
	187 (73.0)	76 (37.8)	**<0.001**
16. When you see a person having a seizure, you should spill water on his/her face to stop the seizure (F).			
Before	106 (41.4)	83 (41.3)	0.981
After	239 (93.4)	82 (40.8)	<0.001
Total Before	6.99±4.14	7.38±4.04	p=0.488
Total After	13.30±2.87	7.65±4.19	**p<0.001**

Note: T: True, F: False

higher on knowledge assessments and lower on stigma measures, providing evidence to support this relationship. Although not presented in the tables, additional analyses indicate a correlation between knowledge scores and stigma levels, further reinforcing this finding. For all these reasons, educating every individual in society about epilepsy and enhancing their knowledge is crucial for positively influencing the community's perceptions of the condition and its patients.

One of the significant findings of our current study is the change in responses to the question, "Do you feel competent to intervene during an epileptic seizure?" Students were asked to evaluate their sense of competence on a scale from 0 to 10. The average score for students in the experimental group increased from 1.5 (±2.1) to 6.2 (±2.6). Additionally, further analyses revealed that the competence to intervene during a seizure was correlated with both knowledge and stigma levels. In light of these data, providing education to the community about epilepsy and teaching appropriate interventions during seizures can help alleviate unnecessary fears related to the condition. It is anticipated that this improvement will also contribute to reducing negative attitudes and stigma associated with epilepsy.

Among the noteworthy findings of this study was the difference in knowledge and stigma scale scores based on gender. Female

Table 3: Comparison of students' Epilepsy Stigma Scale subscale and total mean scores

Scale	Intervention (N=256)	Control (N=201)	p
Attitude discrimination			
Before	43.91±9.95	44.28±8.88	0.677
After	34.14±10.29	40.73±11.81	**<0.001**
Attitude pre-judgements			
Before	46.58±11.83	47.06±9.64	0.637
After	43.03±8.40	47.81±9.44	**<0.001**
Attitude false beliefs			
Before	48.82±10.40	49.47±9.66	0.495
After	35.44±10.89	47.71±10.01	<0.001
Attitude total			
Before	44.63±9.71	45.04±8.67	0.637
After	37.54±8.56	45.41±8.46	**<0.001**

Table 4: Students' level of feeling competent about intervention to seizure

Characteristic	Intervention (N=256)	Control (N=201)	p
Feeling competent in seizure intervention			
Before	1.54±2.10	1.78±2.19	0.531
After	6.25±2.64	2.07±2.13	**0.002**

students demonstrated higher knowledge levels and lower stigma scores compared to their male counterparts. Similarly, Rho et al. (2010) reported that male students in an adolescent group had higher stigma scores.[33] Furthermore, a recent study on peer bullying indicated that male students exhibited higher levels of being bully/victim compared to females.[34]as well as their relationship with academic performance. To categorize students according to their bullying experiences, the European Bullying Intervention Project (EBIPQ In that same study, students identified as bully/victims were found to have poorer academic performance. The data from this study suggest a parallel to our findings. Therefore, considering the gender factor in future community studies related to epilepsy would be beneficial.

In conclusion, the education provided to high school students has been shown to enhance their knowledge levels and reduce stigma associated with epilepsy. Furthermore, students reported an increased sense of self-efficacy regarding their ability to intervene during epileptic seizures. In light of these findings, it is recommended that epilepsy-related educational programs be more widely and consistently disseminated.

As for limitations, in Turkiye, university entrance examinations are conducted at the end of the fourth year of high school. For this reason, none of the senior students wanted to participate in the study. Therefore, this situation can be shown among the limitations of the research. Additionally, nearly all participants

Table 5: Comparison of epilepsy knowledge and stigma scores with sociodemographic characteristics of students

Characteristics	Knowledge	p	Stigma	p
Sex				
Female	7.86±3.85		43.81±8.16	
Male	6.43±4.22	**<0.001**	45.86±10.20	**0.018**
Age	r=0.066	p=0.160	r=0.096	p=0.040
Class				
1st grade	6.70±4.10		44.60±8.99	
2nd grade	7.40±3.94		44.73±8.80	
3rd grade	7.50±4.27	0.170	45.21±10.24	0.850
Income				
Good	8.08±4.44		42.45±13.66	
Moderate	7.43±3.82		44.75±9.09	
Bad	7.04±4.18	0.514	44.92±9.16	0.662
Have you heard of epilepsy?				
Yes	7.31±3.97		44.45±8.69	
No	4.54±5.34	**0.001**	51.37±15.38	**<0.001**
Do you have patients with epilepsy in your family?				
Yes	8.91±3.40		41.10±7.78	
No	6.80±4.14	**<0.001**	45.59±9.37	<**0.001**
Have you seen an epilepsy seizure?				
Yes	8.75±3.71		42.89±7.64	
No	6.82±4.10	**<0.001**	45.23±9.54	**0.039**

in the study resided in urban centers, which indicates a low representation of students from rural areas, further contributing to the study's limitations. Also, an important methodological limitation concerns the temporal proximity between our educational intervention and post-test administration. This design, while effective for assessing immediate knowledge acquisition, does not permit evaluation of the intervention's longer-term retention effects. The brief interval may have privileged short-term recall over sustained learning, potentially inflating immediate post-test scores. Future studies should incorporate delayed follow-up assessments to distinguish between transient and enduring knowledge gains.

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DISCLOSURE

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Conflict of interest: None

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