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### **Original Research Article**

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# Assessment of quality of life in parents of epileptic children and its associated factors

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#### **ABSTRACT**

**Background:** Aim of the study was to assess quality of life (QOL) of parents of epileptic child and its association with various factors like demographic, clinical, therapeutic and behavioral factors.

**Methods:** Consenting parents of 160 epileptic children were enrolled after finishing child's visit to the pediatrician. Parents were enquired on baseline demographic variables like age, gender, socio-economic status, parental education; clinical details like type of epilepsy, duration of seizure, seizure frequency and co-morbidity and therapeutic factors like treatment of epilepsy and adverse drug reactions. QOL was evaluated using QOLCE questionnaire and Childhood Illness-related Parenting Stress Inventory and analysed.

**Results:** Out of 160 parents, 85% belong to 30-40 years of age and 62.5% were male. Deteriorated quality of life was reported by parents as mean score 63.46±7.69. QOL was significantly poor (p<0.05) in parents of younger child (<6 yrs), education status (upto primary school only), employment status of parent (unemployed) and lower socioeconomic status. Assessment of disease related parameters revealed that type of seizure, seizure frequency, duration and co-morbidity were factors significantly affecting quality of life of parents with lower QOL scores(p<0.05). QOL of parents of child with epilepsy undergoing polytherapy with multiple AEDs treatment, particle seizure control and having adverse drug reaction were associated with poor scores of health and well being (p<0.05). It was found that parents of epileptic child had deteriorated QOL score with respect to behaviour patterns irrespective to conditions of epilepsy due to constant stress and anxiety and poor state of mind.

**Conclusions:** QOL of parents was compromised in Indian children with epilepsy. Demographic factors like age of child, parental education, socio-economic status and clinical factors like type of seizure, frequency & duration of seizure and co-morbid conditions significantly affect the QOL of parents. Significantly poor QOL scores was also due to therapeutic factors like treatment with polytherapy and adverse drug reactions with poor behavioral patterns which was observed in parents that should be taken care and should not be overlooked.

**Keywords:** Childhood illness-related parenting stress inventory, Epilepsy, Parental quality of life, Parent's stress and anxiety, QOLCE questionnaire

#### INTRODUCTION

Epilepsy is one of the most common and chronic neurological disorders which can occur in any age, race and social class. This disease, as one of the common brain disorders, is a type of periodic and severe disorder in nervous system which is caused by abnormal discharge of brain cells. It is estimated that there are nearly 50 million individuals with epilepsy around the world which around two thirds of these people live in third world countries. Despite abundant progresses are achieved in medicine science about epilepsy, but the negative semantic load accompanied with the word "epilepsy" still

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effects the patient more than the disease itself or drug side effects in some societies. Epilepsy can effect specifically on life quality. This subject not only is because of chronicity of the disease or the common drug consumed or its side effects, but also because of bigotries, prejudices, and social problems which still surrounds it.<sup>1,2</sup>

Epilepsy is one of the most significant and prevalent neurological conditions in children in the recent years where child experiences a wide range of cognitive, psychiatric, and behavioural comorbidities that often go under-recognized and untreated.<sup>3,4</sup> Several studies indicate that childhood epilepsy is a high risk factor for poor psychosocial outcomes, including depression and anxiety, low self esteem, behavioural problems, not only in children but is also regarded as unpleasant experience generating range of negative emotions in their parents and all members of family especially mothers which are the main caregiver of the child.<sup>5-8</sup> Even families of children with epilepsy (CWE) have been found to experience greater stress, poorer quality of parent-child relationships, lower parenting confidence, and more problems in family functioning, adaptation, and relationships, relative to other families.<sup>9</sup>

Diagnosis of epilepsy in a child brings with it a series of consequences for the parents and family, and most parents are negatively affected by it. The bliss of a perfect child and the realization that the child might always be different from other children because of their illness will be a constant thought and concern among parents of epileptic children's. 10 Child with epilepsy proves to have a persistent long-term impact, and a compromise in health-related quality of life (HRQOL) is observed in children with epilepsy and their parents. Parents of children with epilepsy have been reported to have significantly lower QOL scores than parents of healthy children. A substantial reduction in QOL of parents of children with epilepsy is observed and are at risk of increased symptoms of depression and anxiety compared with parents of children who do not have epilepsy. Previous research focusing on quality of life or symptoms of depression and anxiety in parents of children revealed that mothers of such children are always associated with extreme levels of clinical depression and anxiety. 11,12

Assessment of quality of life of parents is an important health outcome to assess health of children with epilepsy because they are a high risk group and in critical development period during which many cognitive and social skills have to be learned. Health-related QOL is an important construct in understanding how parents respond, adapt, and cope with the challenges of childhood-onset epilepsy and other stressors. Despite its importance, there is relative lack of research on quality of life among parents with epileptic child. There is also little evidence about the parent's view on the effects of epilepsy on their functioning and management of their children. Literature review also demonstrates lack of

detailed study on impact of child's epilepsy on QOL of parents with respect to type, duration and severity of symptoms, medication, long term behaviour towards child and childcare. Keeping this in view the aim of this study was to evaluate the QOL in parents of epileptic child and its associated factors in Indian population.

#### **METHODS**

#### Study design and setting

This was a prospective observational questionnaire based study carried with the primary objective of to assess QOL of parents with epileptic child and the secondary objectives were to assess the demographic factors and clinical factors which influence the QOL of parents of children with epilepsy. The entire study was conducted in the outpatient consultation in the paediatric department of a tertiary care teaching hospital in western India. The centre is a Government run centre, which caters to heterogeneous population representing both urban and rural patients. Permission from the ethical committee was obtained and informed consent form was obtained from the parents prior to enrolment in the study.

#### Study participants

In present study, consenting parents of 160 children aged 0-14 years, suffering from epilepsy were enrolled who had undergone a comprehensive clinical evaluation for epilepsy. Children with presence of two or more unprovoked seizures at least 24 h apart and were receiving prophylactic antiepileptic drug (AEDs) for a minimum of 6-month duration were included in the study. Electroencephalography and neuroimaging were used as comprehensive clinical evaluation method for determination of epilepsy for selecting a child. The eligible consenting parents had to be older than 18 years of age and capable of answering the oral administration of the instruments. Children with chronic medical condition (asthma, hypertension, chronic renal failure, chronic lung disease, thalassemia, hypothyroidism, etc.) along with epilepsy were excluded from the study. Even parents of children who were not available to answer the questionnaire were excluded from the study. In addition, the parents of epileptic children who were considered for alternate therapies including dietary therapy or epilepsy surgery were also excluded from the study.

#### Study procedure in detail with data collection

Parents of eligible children who consented to participate were assessed for demographic and clinical factors which could influence the QOL among enrolled children. Because of the low socioeconomic and educational level of the participants in this study, the questions were read to them, and their oral responses were scored by the interviewer. The following demographic factors were recorded in performa: gender, age of child and parent, parental education and employment status, economic

status, primary care taken and marital status. Clinical factors were determined and recorded in terms of seizure type, duration of seizure, seizure frequency over preceding 1 year, seizure control, family history and comorbidity. Also various therapeutic factors were simultaneously determined and recorded as treatment with monotherapy or polytherapy, type of AEDs whether recent AEDs or old AEDs including ADR monitoring. Patient's seizure type was classified broadly as generalized seizures, partial seizures and partial seizures with secondary generalization. Diagnosis of the syndrome classification of epilepsy was attempted based on seizure semiology, electroencephalographic and neuroimaging findings. Seizure frequency per month was determined by the mean monthly seizure frequency for at least 1 year prior to enrolment. Seizure frequency was determined as per the history recalled by parents or from the records if they were maintaining a seizure diary. The seizure frequency was categorized as number of seizures observed during weekly, monthly, quarterly and yearly duration. Duration of seizure was categorized as less than 5 seconds, 5 to 10 seconds and more than 10 seconds. Treatment with drugs were classified into three categories as individual treatment with old drugs, individual treatment with recent drugs and treatment with combination of both type of drugs. Even numbers of AEDs in the last 6 months were classified as 1 AED and more than 1 AED along with determination of ADR.

## QOL assessment (quality of life of parents with epileptic child)

QOL was evaluated by the QOLCE questionnaire.4 The instrument was translated by professional translators in Gujarati and Hindi and was piloted on 10 parents prior to initiation of the study. All precautions were exercised to retain the meaning, grammar and simplicity of the original version as the reliability and validity of QOLCE. Father and/or mother were given self-administered version of QOLCE questionnaire in vernacular language. Original QOLCE contains 91 items, which fell into five quality-of-life domains with 13 multi-item and three single item subscales: Physical function domain (12 items), cognitive function domain (23 items), emotional well-being domain (19 items), social-function domain (12 items) and behavioral function domain hub scale (23 items). Total score was also calculated and lower score denoted poor quality of life.

Parental stress was also assessed using the Childhood Illness-related Parenting Stress Inventory.<sup>5</sup> It was also translated in the local language for the ease of administration. Principle investigator assisted parents in filling the questionnaire wherever required.

#### Statistical analysis

The data were entered into Microsoft Excel and statistical analysis was performed using the Epi-info software. Categorical variables like demographic and clinical

factors were expressed as numbers and proportions; whereas, QOL scores was expressed as mean and standard deviation. The mean QOL scores were compared among the demographic and clinical variables using a Student's *t*-test and p value less than 0.05 was considered significant.

#### **RESULTS**

Parents of 160 children with epilepsy belonging to age group of 0-14 years were evaluated for QOL.

Table 1: Socio-demographic profile of parents with epileptic child and its association with QOL scores as evaluated by QOLCE questionnaire.

a .	-		
Socio-	<b>NT</b> (0/)	QOL score	
demographic	N (%)	(SD)	P value
profile	-		
Gender of child			
Male	100 (62.50)	54.46 (4.67)	>0.05
Female	60 (37.50)	58.75 (8.63)	(NS)
Age of child in			
0-6	35 (21.88)	32.35 (6.69)	
6 to 9	72 (45.00)	48.88 (7.83)	< 0.05
9 to 12	42 (26.25)	47.83 (7.92)	(significant)
12 to 14	11 (6.88)	62.35 (9.03)	
Age of parent in	ı years		
20-30	58 (36.25)	54.34 (6.92)	. 0.05
30-40	85 (53.13)	57.03 (7.93)	>0.05
40-50	17 (10.13)	62.77 (10.33)	(NS)
Level of educati	ion		
Primary school	25 (15.63)	42.33 (7.93)	
Secondary		64.04.(10.04)	
School	14 (8.75)	64.24 (12.94)	< 0.05
High school	40 (25.00)	55.35 (11.47)	(significant)
Collage and	91 (50 (2)	(0.26 (12.50)	
more	81 (50.63)	69.36 (13.58)	
Employment sta	atus		
Unemployed	22 (13.75)	48.04 (4.89)	.0.05
Unskilled	39 (24.38)	49.03 (5.72)	<0.05
semi-skilled	62 (38.75)	55.34 (10.38)	(significant)
Skilled	37 (23.13)	68.83 (10.47)	
Economic status	- ' '	. , , ,	
Lower	39 (24.38)	51.43 (9.36)	
Middle	82 (51.25)	55.44 (10.36)	<0.05 (significant)
Upper	39 (24.38)	65.25 (8.03)	
Primary care ta			
Father	35 (21.88)	53.46 (5.29)	>0.05
Mother	125 (78.13)	69.46 (7.82)	(NS)
Marital status	123 (70.13)	07.10 (7.02)	(210)
Married	145 (90.63)	71.22 (8.58)	>0.05
Divorced	15 (9.38)	61.35 (6.92)	(NS)
OOI - Quality of			(140)

QOL= Quality of Life; SD= Standard Deviation

As shown in Table 1, among the total number of children, 100 (62.50%) children were male and 60 (37.50%) were females, majority of which (45%) belonged to an age group of 6-9 years. Majority of parents (53.13%) were of

median age with age of 30-40 years. Deteriorated QOL scores was observed among parents with children of age 0-6 years suffering from childhood epilepsy and was found to be significant (p<0.05). Majority of parents (50%) had college level education which was having a significant impact on QOL scores. Poor education was associated with lower QOL scores (p<0.05). Unemployed (13.75%) and unskilled (24.38%) parents with poor socio-economic status were associated with significantly lower QOL scores compared to parents with higher education (p<0.05).

Table 2: Clinical profile and epilepsy related parameters of children and its association with parental QOL scores as evaluated by QOLCE questionnaire.

Parameters	N (%)	QOL (SD)	P value
Type of seizure			
Generalized tonic	27 (16.88)	46.63 (6.72)	
Generalized tonic-clonic	34 (21.25)	54.66 (7.83)	<0.05
Simple partial	66 (41.25)	65.92 (8.92)	(significant)
Complex partial	33 (20.63)	59.75 (7.84)	
<b>Duration of seiz</b>	ure		
Less than 5s	78 (48.75)	63.52 (4.63)	-0.05
5 to 10s	59 (36.88)	59.33 (10.93)	<0.05
More than 10s	23 (14.38)	51.29 (8.28)	(significant)
Seizure frequen	cy		
Weekly	42 (26.25)	44.09 (6.72)	
Monthly	64 (40.00)	50.35 (7.91)	< 0.05
Quaterly	12 (7.50)	58.47 (7.82)	(significant)
Yearly	42 (26.25)	66.75 (9.04)	
Seizure control			
Controlled	102 (63.75)	61.44 (10.92)	< 0.05
Poorly controlled	58 (36.25)	52.33 (8.83)	(significant)
Family history			
Yes	34 (21.25)	66.35 (9.10)	>0.05
No	126 (78.75)	58.82 (12.36)	(NS)
Co-morbidity			
Yes	58 (36.25)	49.25 (8.03)	< 0.05
No	102 (63.75)	61.33 (10.92)	(significant)

QOL= Quality of Life; SD= Standard Deviation

Analysis of clinical parameter related to epilepsy and its association with parental QOL has been shown in Table 2. It was observed that simple partial seizure is the most common type of prevailing seizure (41.25%). Parents of child with simple partial seizure (41.25%) were associated with higher QOL scores compared to parents with child suffering from generalized tonic clonic seizure (21.25%) due to its severity and complexity (p<0.05). As generalized clonic tonic seizure was associated with more severe symptoms with higher frequency, QOL of parents of child with such epilepsy was significantly influenced. Higher frequency and longer duration of seizure was associated with significant lower QOL scores with

majority of children had monthly frequency of seizure (40%). In this study, 63.75% children were suffering from controlled seizure with better parents QOL (p<0.05). Significantly low QOL scores was reported for those patients with co-morbidity (36.25%, p<0.05).

Table 3: Drug therapy related parameters of children and its association with parental QOL scores as evaluated by QOLCE questionnaire.

Parameters	N (%)	QOL (SD)	P value
Treatment			•
Monotherapy	92 (57.50)	64.51 (9.92)	< 0.05
Polytherapy	68 (42.50)	57.88 (8.27)	(NS)
Class of antiepileptic drug			
Old	58 (36.25)	55.57 (7.82)	0.05
Newer	79 (49.38)	58.92 (5.52)	>0.05 (NS)
Combined	23 (14.38)	51.55 (6.03)	(143)
ADR			
Yes	48 (30.00)	55.24 (7.01)	< 0.05
No	112 (70.00)	69.02 (9.03)	(Significant)

QOL= Quality of Life; SD= Standard Deviation; ADR= adverse drug reactions.

Table 4: Overall QOL scores of the subscales of QOLCE questionnaire.

Subscales	QOL scores mean (SD)
Physical restrictions	56.23 (8.92)
Energy/fatigue	51.25 (9.48)
Attention/concentration	59.02 (11.25)
Memory	72.36 (13.52)
Language	78.92 (7.92)
Cognition	62.36 (13.24)
Depression	55.62 (10.38)
Anxiety	80.91 (12.36)
Control/helplessness	60.92 (8.92)
Self esteem	56.79 (10.82)
Social interactions	72.45 (13.46)
Social activities	77.03 (11.03)
Stigma	82.36 (12.63)
Behaviour	52.28 (6.73)
General health	55.49 (7.92)
QOL	58.37 (15.79)
Overall QOL	63.46 (7.69)

QOL= Quality of Life; SD= Standard Deviation

Drug therapy related parameters and its association with parental QOL has been shown in Table 3. Majority (57.50%) children were treated through monotherapy while (42.50%) children were on polytherapy treatment. During the study it was found that 79 (49.38%) patients were prescribed with newer anti-epileptic agents (49.38%) and 23 (14.38%) patients were treated with combined drug therapy which was not significantly affecting QOL of parents (p>0.05). Out of total patients 48 (30%) patients suffered from ADR with different severity with was associated with significantly lower

QOL scores compared to parents of child with no ADR (70%; p<0.05).

The overall QOL score was 63.46 (7.69) showing deteriorated quality of life among parents of epileptic children. Table 4 outlines the QOL scores in each subscale. Lowest scores were observed Energy/Fatigue (51.25 [9.48]) subscale and subscales with higher QOL scores included in Anxiety (80.91 [12.36]), language (78.92 [7.92]) and social stigma (82.36 [12.63]).

Table 5: Parenteral behaviour for epileptic children as evaluated by childhood illness-related parenting stress inventory.

Parameters	Frequency (%)
Role of function	
financial trouble	74 (46.25)
Little time for family needs	62 (38.75)
Little time for own needs	69 (43.13)
Missing important events	42 (26.25)
Being unable to go to work	39 (24.38)
Change in the relationship with other family members	51 (31.88)
Being in the hospital	29 (18.33)
Communication	
Arguing	65 (40.63)
Annoying	49 (30.63)
Feeling confused	92 (57.50)
Disagreeing	32 (20.00)
Less time to speak with family	49 (30.63)
Emotional disturbance	
Difficulty in sleeping	93 (58.13)
Feeing numb inside	45 (28.13)
Feeling isolated	63 (39.38)
Feeling helpless	59 (36.88)
Feeling uncertain	42 (26.25)
Seeing mood changes	74 (46.25)
Seeing child sad	69 (43.13)
Family difficulties	52 (32.50)
Medical care	
Watching trouble eating	35 (21.88)
Trouble in decision making	82 (51.25)
Constant visit to clinic	73 (45.63)
Trouble in maintaining the hygiene needs	64 (40.00)
Trouble in helping procedures	66 (41.25)
Handling charges	59 (36.88)

The parent stigma was accessed by childhood illness-related parenting stress inventory and was reported in Table 5. An average no. of parents was experiencing financial troubles in daily life (46.25%) sparing minimum duration for their own needs (43.13%). Almost (24.38%) parents due to sensitive situation of child were unable to go to work and also missing important events in their social life (26.25%). Most of times parents feels confused

regarding their child health (57.50%). They also felt that they were arguing (40.63%) and annoying (30.63%) with co-workers and family members. Many of the times parents were emotionally disturbed even half of the parents were facing difficulty in sleeping (58.13%). They were also feeling numb inside (28.13%) and feeling helpless in certain cases (36.88%).

#### **DISCUSSION**

Epilepsy is a common neurological disorder of childhood which has complex ramifications. Epilepsy is characterized by seizures and epilepsy-like febrile seizures and drug-induced seizures. Because of seizures and other co-existing health conditions that can significantly affect a child's physical health as well as psychological and social well-being; quality of life of the children and parents of epileptic child deteriorates many times. This scenario has been different and more difficult in India because of prevalent stigma associated with epilepsy in population. This study was performed to evaluate the QOL of parents of children with epilepsy.

In the present study, parents of children with epilepsy were associated with much lower QOL with considerable emotional burden and higher levels of stress due to range of cognitive and behavioural difficulties faced by child with epilepsy compared to than that of parents of healthy children coinciding with results of other similar studies. <sup>14,15</sup>

Diverse demographic factors such as age of epileptic child, gender of child, age of parents, level of education of parents, employment status, economic status and marital status were assessed to evaluate the effect of demographic factors on QOL of parents. It was identified that age of child, level of education of parents and employment status were prominent demographic factors which has significant impact on QOL of parents of epileptic child (p<0.05). Multiple studies have shown that parents with lower education with child of small age and financial instability tends spend most of their income, time, and effort on child's treatment and care. This results in exhaustion of existing economic and social resources which negatively affects a parent's quality of life. 16,17

Parents of children whose seizures are not well controlled characterized by generalized tonic clonic seizure and complex seizure reported reduced QOL as they were always associated with continuous stress and anxiety due to disability of child to learn and grow normally compared to those children who have well controlled epilepsy which was well demonstrated by other similar studies. As noticed in the previous studies, in this study also it was also observed that eplipsy related factors like duration of seizure, seizure frequency and seizure control also poses negative impact on QOL of caregivers among which seizure frequency substantially has significant effect on the QOL score of parents. If It was studied that parents of children in the present study who had co-

morbid conditions like cerebral palsy and intellectual developmental delay need to have constant supervision and assistance in activities of daily living like feeding, bathing, giving medication, and mobility, thus increasing physical and emotional attachment which resulted into a high level of parental stress and lower QOL.<sup>20,21</sup>

In present study several indicators were identified to gauge the influence of drug therapy on the QOL of parents with epileptic child. It was found that compared to parents of children undergoing treatment with monotherapy using old antiepileptic drugs, parents of children with polytherapy following use of combination drugs reported greater impairment in different aspects of QOL due to poor Disease management issues, confusion related to drug administration, taking decisions related to medical tests and frequent change in medication. This confirms the findings reported in several other studies.<sup>22</sup>-<sup>24</sup> In present study it was also observed that parents of child with more adverse drug reaction were associated with higher stigma which was characterized by intense worry, negative mood. These factors had an adverse impact on parent's life which was associated with significant lower QOL and which coincides with results obtained from other studies.<sup>25-27</sup>

In general, a negative attitude toward the epileptic condition of the child was manifested by about threequarters of parents of the study. Although parents of children with epilepsies of low severity showed less negative attitudes than parents of children with more severe disease, more than one-third of them showed concerns that did not seem justified in view of the favourable prognosis of the disease. This could be explained by changes taking place in routine life of the parents and inadequate information about the disease condition of the child but, for the most part, by insufficient understanding of the nature of the disorder, resulting in excessive emotional reactions. In fact, this negative attitude was correlated to an increased apprehensiveness, appearing significant also in lowseverity varieties of epilepsy and followed by a change of family's life. An increase of "parent's apprehensiveness" was reported in about three-fourths of cases and was a source of tensions and conflicts in one-third. This shows how emotional factors play a role in worsening QoL, in accordance with reports who found a significant correlation between parental anxiety and stress, fear and concern due to lack of communication or emotional disturbance. It should also be noted that, in the parents' of epileptic child struggle to spare time for work, needs and leisure activities which were affected in about one-fourth of cases, an aspect of QoL not frequently evaluated. Studies including lack of communication with family and friends and constant annoyed behaviour also have a substantial impact on QOL which commonly is unrecognized in majority of studies evaluating QOL of parents of epileptic child. Moreover, deterioration of normal sleep routine, extra-familial relationships, economic problems and constant medical care with

respect to visit to hospital, maintaining hygiene or feeding the child were claimed to be important factors by parents affecting QOL, although in a low percentage.<sup>28-30</sup>

Significant strengths of the current study include that an enough sample of parents from both urban and rural area responded using standardized measures of QOL and emotional well-being. Furthermore, because both parents responded to the questionnaire and detailed evaluation of QOL was performed. There are a number of significant limitations that also need to be considered. We had no information on size of the family, detailed child comorbid conditions or child cognition and behavioural functioning. We did not have information on who the primary caregiver was in the families, how many children were there in family and how many parents of the children who had been referred for alternate therapy.

#### **CONCLUSION**

QOL of the parents of epileptic children found to be deteriorated in Indian population. It was found to be significantly associated with demographic parameters like age of child, parents education, employment and socioeconomic status; clinical parameters like type, duration and seizure frequency and presence of comorbidity; and drug therapy related parameters like number of antiepileptic drugs prescribed, seizure control achieved and adverse drug reactions. The present study provides a deep insight towards QOL of parents with epileptic child which is frequently found unsatisfactory and disturbing. Excessive parental apprehensiveness appears to be frequently associated with QOL deterioration. It is recommended that information facilitating the understanding of the family's and child's condition and needs should be given by the treating doctor and more empathetic approach with the parents can help them in coping the situation well. Also treating team should be more sensitive and spend more time with the parents before making any treatment-related changes, and attention can be given to parent's involvement in the child's management. Such small changes in the treatment pattern can improve the scenario of epilepsy and stigma associated with it in countries like India.

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