

## Multifactorial Etiology Contributes to Disabilities in Individuals with Leprosy at Presentation - A Clinical Study in Dermatology Outdoor of a Tertiary Care Centre

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Among the communicable diseases, leprosy remains the leading cause of peripheral neuropathy and disabilities in the world. Despite extensive efforts to reduce the disease burden, the disease continues to be responsible for stigmatization and rejection in society. It was aimed to study the prevalence, epidemiological profile and associated factors in the occurrence of such disabilities among leprosy patients at presentation attending Dermatology outdoor in a tertiary care centre. This study was conducted at Dermatology outdoor of a tertiary care centre in eastern India. All patients of leprosy (as per inclusion criteria) from February 2016 to June 2017 were recruited in the study. Results show that among total of 451 patients, disability was present in 75.83% (342 patients) of which 261 presented with Grade 1 and 81 with grade 2 disability. Interestingly, grade 2 disability appeared significantly earlier ( $p=0.0212$ ) in patients with a delay in diagnosis of >12 months than patients in whom the diagnosis was made earlier. We have found that 'patient delay' (defined as the time between symptom onset and patients consulting a doctor and receiving appropriate treatment) contributes to disabilities in leprosy. As the study was conducted in a tertiary care centre, it does not perfectly indicate the status in the community. Community based studies should be carried out to understand the situation.

**Keywords :** Disability, Leprosy, Patient Delay

### Introduction

Among the communicable diseases, leprosy remains the leading cause of peripheral neuropathy and disabilities globally despite extensive efforts to reduce the disease burden. These deformities and disabilities may be responsible

for personal and social problems for leprosy patients, stigmatization and rejection in society (Tiendrebeogo et al 1996).

Disabilities in leprosy patients may be due to primary deformities due to direct involvement of tissues and peripheral nerves with *M. leprae*

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causing sensory loss or motor paralysis (anaesthesia, lagophthalmos, claw hand), secondary deformities as a result of damage to the anaesthetic parts of the body (ulcer, loss of toes & fingers) (Srinivasan 1994). Disabilities in leprosy results in reduced opportunities and economic loss both to the patient and community. The social stigma attached to leprosy is still so persistent that even the family members are unwilling to entertain their own leprosy patients in the household and continue to be a major stumbling block in leprosy control measures.

This study is intended to evaluate the epidemiological characteristics of patients with disabilities due to leprosy and relative prevalence of different types of disabilities and to study the factors associated with causing those disabilities among all leprosy patients coming to the Dermatology OPD in a tertiary care centre of BS Medical College, Bankura, West Bengal.

### Material and Methods

The study was Institutional Ethics Committee approved cross-sectional descriptive one and was intended to evaluate the epidemiological characteristics of patients with disabilities due to leprosy, the relative prevalence of different types of disabilities and the causative factors among all leprosy patients coming to the Dermatology outdoor in a tertiary care centre of eastern India.

To determine the magnitude of disease burden, patients were enlisted, and records were maintained about clinical diagnosis of all patients attending Dermatology outdoor. After initial screening, thorough clinical evaluation was done and were recorded, tabulated, analyzed, followed by statistical evaluation.

The study period is of one year duration extending from February 2016 to January 2017. The targeted sample size was 81 patients with grade 2 disability considering previously reported 8.6%

(Sarkar et al 2012) grade 2 disability prevalence of in leprosy patients in Bankura district of West Bengal with 5% allowable error, 95% confidence limit and population size of 250 (considering the annual OPD attendance of leprosy patients) using Rao software® ([http://www.raosoft.com/sample\\_size.html](http://www.raosoft.com/sample_size.html)). Patients of all ages and sex presenting with leprosy with disabilities at presentation were included in the study. Patients with other comorbidities like diabetic neuropathy, traumatic neuropathy, spinal dysgraphism, Refsum's disease that may give rise to such disabilities and those who did not give consent were excluded from the study.

Data regarding age, sex, occupation, socio-economic status (modified Kuppaswamy's socio-economic scale), duration of disease, symptoms pertaining to the disease and onset of disabilities, time gap between onset and diagnosis, time gap between diagnosis and start of treatment and regularity of treatment were collected. The presenting complaints such as skin lesions, tingling and numbness, spontaneous blisters, weakness and deformities of hands and feet, edema of hands and feet, fissures, trophic ulcers, eye and nasal symptoms were noted.

Skin lesions were assessed in individual cases with particular reference to the number, size, shape, margin, trophic changes, supplying nerves, and sensations. All the peripheral nerves were examined, noting thickness, tenderness, consistency and symmetry of involvement. Slit skin smear to calculate bacillary index (BI) was done in all patients.

Thorough clinical examination of the affected parts was done in all the patients, and the grading of disability was done according to the World Health Organisation Disability Grading (WHO 1998) described in Table 1.

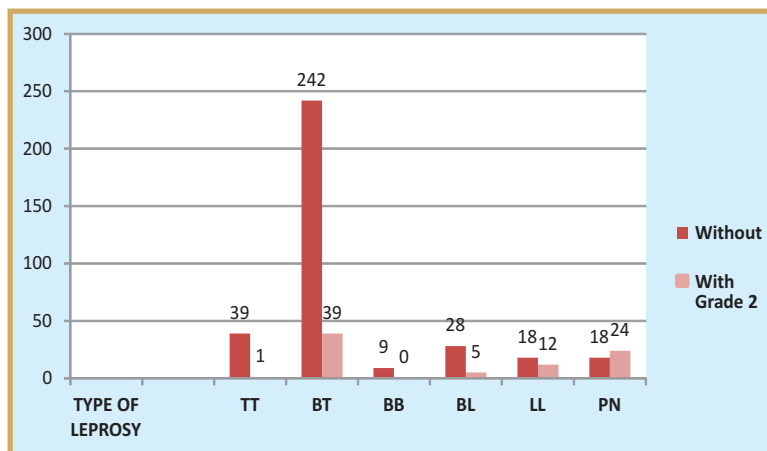
For analytical statistics, numerical data were analyzed using a t-test or Mann Whitney test (as

applicable), and for categorical data chi-square test was used. Medcalc version 14.8.1 was used for statistical analysis, and p-value of less than 0.05 was considered significant.

**Results**

The mean age of our study population was 31.98 ± 13.91, with a male to female ratio of 2.32:1. Most patients were between the 15-30 years age group. 42.2% of patients were illiterate, and 42.35% of patients belonged to the mild manual worker group grade2 disability was most commonly associated with illiteracy and severe manual work.

We have divided our study population into two racial groups (tribal and non-tribal). 59.2% (267 patients) leprosy patients belong to non-tribal group, and 40.8% (184 patients) belong to tribal group. The percentage of patients with grade 1 and grade 2 disability was higher in the tribal group. Chi-square for trend showed significantly (p<0.0001) more disability in the tribal group in comparison to the non tribal group. Grade 2 disabilities more frequently occurred in patients with type 1 lepra reaction than type 2 lepra reaction (Table 2).



**Fig 1: Number of patients with and without Grade 2 disabilities in different clinical types of leprosy.**

**Table 1 : World Health Organization’s grading of disabilities in leprosy 1998**

Grade	Hands and feet	Eyes
0	No anaesthesia, no visible deformity or damage	No eye problem due to leprosy, no evidence of visual loss
1	Anaesthesia present, but no visible deformity or damage	Eye problems due to leprosy present, but vision not severely affected as a result of these (vision 6/60 or better; can count fingers at 6m)
2	visible deformity or damage	Severe visual impairment (vision worse than 6/60; inability to count fingers at 6m) also includes lagophthalmos, iridocyclitis and corneal opacities.

**Table 2 : Clinico demographic profile of patients among different disability groups**

	Without disabilities (n=109)		With Grade 1 disabilities (n=261)		With Grade 2 disabilities (n=81)		
<b>Age</b>							
Mean ± SD	29.73 ± 14.28		31.07 ± 13.37		37.92 ± 13.64		<0.001*
<b>Sex</b>							
	n	%	n	%	n	%	
Male	75	68.81	185	70.88	55	67.71	0.9439
Female	34	39.19	76	29.12	26	32.29	
<b>Education Profile</b>							
Illiterate n=96	37	19.47	102	53.68	52	26.85	Spearman's coefficient of rank correlation (rho -0.147, P=0.0018)
Primary n=145	45	31.03	86	59.31	14	9.66	
Secondary n=96	19	19.79	65	67.71	12	12.5	
Graduate n=19	8	42.1	8	42.1	3	15.8	
<b>Occupation</b>							
Mild physical labour (n=191)	62	56.88	111	42.53	18	22.22	
Moderate physical labour (n=107)	24	22.02	60	22.99	23	28.39	
Severe physical labour (n=151)	23	21.1	90	34.48	40	49.39	
<b>Socioeconomic Status</b>							
BPL n=346	84	24.28	200	57.8	62	17.92	0.9287
APL n=105	25	23.81	61	58.09	19	18.1	
<b>Population</b>							
Non-tribal population (n=267)	83	31.09	150	56.18	34	12.73	<0.0001*
Tribal population (n=184)	26	14.13	111	60.33	47	25.54	
<b>Type of Leprosy</b>							
Paucibacillary (PB) patients (n=144)	42	29.17	84	58.33	18	12.5	
Multibacillary (MB) patients (n=307)	62	21.82	177	57.65	63	20.53	0.0186*
<b>Lepra Reaction</b>							
Type I	6	11.11	20	37.03	28	51.86	<0.0001*
Type II	15	40.54	8	21.62	14	37.84	
No reaction	88	24.44	233	64.72	39	10.84	

Grade 2 disability was most prevalent among pure neuritic (PN) cases, followed by Lepromatous leprosy (LL) and Borderline Tuberculoid (BT) Hansen cases. There was a significantly higher trend of disability among MB cases ( $p=0.0186$ , Chi-square for trend) than Paucibacillary (PB) cases (Fig. 1).

The most common nerve involved in the upper extremity was the right ulnar nerve (23.28%), whereas in the lower extremity, it was the right common peroneal nerve (17.29%). In face and neck supra orbital, great auricular and supra trochlear were equally involved.

Total 81 patients presented with visible deformities in our study. Among the different types of deformities noted (Figure 2), overall most common deformity was clawhand (4.88%), muscle wasting of hand (1.77%) and resorption of toes (1.77%), respectively. Lagophthalmos was seen in 2 patients (Fig. 2). Madarosis was the most common deformity in the face, which is seen in 6 patients. Trophic ulcer was seen in 24 patients.

The major risk factors are known for leprosy disability, and physical deformity is delay in diagnosis and delay in the provision of proper care for the disease. It causes disabilities due to nerve

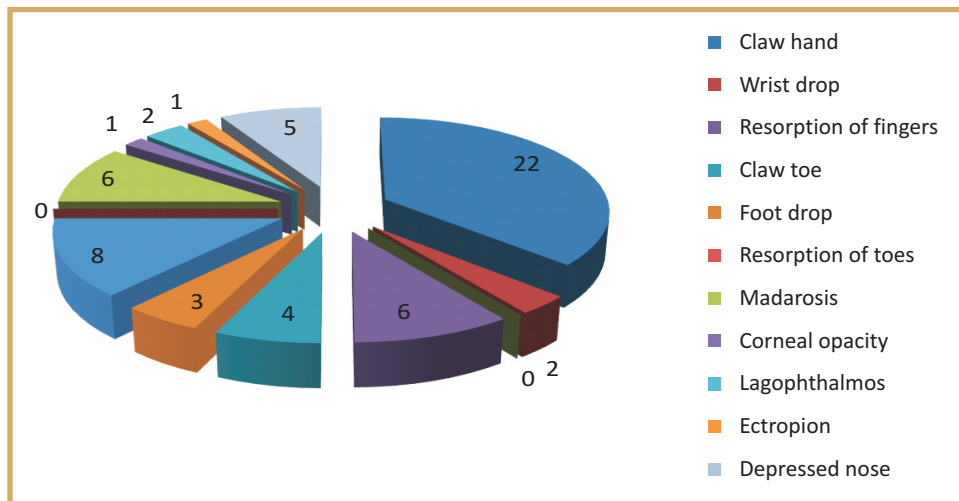
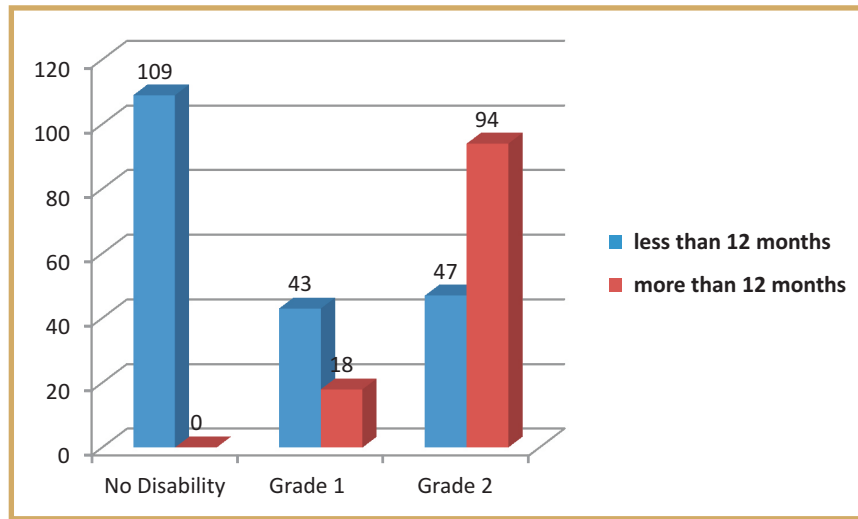


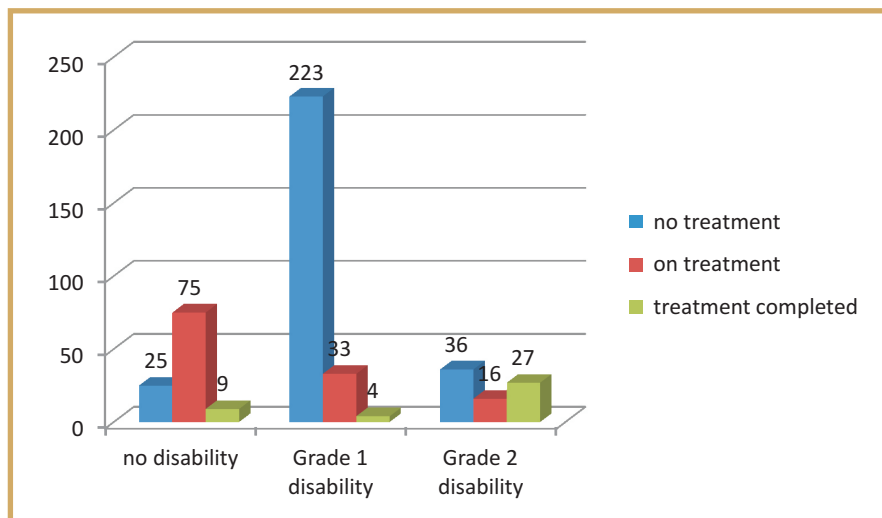
Fig 2 : Prevalence of different types of deformities among all leprosy patients

Table 3 : Bacteriological status of study patients

BI	Grade 1 disability	Grade 2 disability	P value
Mean ±SD	0.3065± 1.0768	0.4691± 1.3237	0.2627
Median, IQR	0	0	
	Non tribal patients	Tribal patients	P value
Mean±SD	0.3258±0.9937	0.6739± 1.6504	0.0055
Median, IQR	0	0	



**Fig. 3 : Comparison of time period for delay in diagnosis among different disability groups**



**Fig. 4 : Treatment status of patients in patients with disabilities**

damage, immunological reactions and bacillary infiltration. There are different factors that contribute to the overall delay in diagnosis of leprosy. Such factors can be divided into two categories: those contributing to 'patient delay' (defined as the time between symptom onset and patients consulting a medical doctor) and those

contributing to 'health-system delay' (defined as the time between first consulting a medical doctor and receiving a diagnosis of leprosy). We have focused mainly on patient delay in this study. It has been obtained mainly from patient's history.

The mean delay in diagnosis in months was also significantly more in patients with grade 2 disability. Fig. 3 shows that among patients with a delay in diagnosis of >24 months, 92.86% of them had grade 2 disability. Interestingly, grade 2 disability appeared significantly earlier ( $p=0.0212$ ) in patients with a delay in diagnosis of >12 months than patients in whom the diagnosis was made earlier.

There was no significant difference in mean BI noted between grade 1 and grade 2 disability patient, but mean BI was significantly more ( $p=0.0055$ , Unpaired t-test) in tribal population than non-tribal population (Table 3).

In our study grade, 1 disability was most commonly present among patients who did not receive any treatment, whereas grade 2 disability was most common in the treatment completed group. Patients who were on treatment showed the least prevalence of grade 2 disability. We found 2 cases of treatment defaulter. Both of them were having a grade 2 disability (Fig. 4).

### Discussion

Deformities in leprosy are the most striking manifestations. It may range from mild degree such as sensory loss over the hands to a very severe degree such as complete claw hand and resorption of fingers. It is the leading cause of morbidity, causing psycho-social and financial impact.

Among a total 451 patients, disability was present in 75.83% (342 patients) of cases of which grade 2 disability was present in 17.96% (81 patients) of cases. This is much more than the global data (7.04%). The higher prevalence rate of grade 2 disabilities in our study might be due to the fact that this study was done in a tertiary care centre where patients with disabilities are referred from other hospitals and health centres. This disturbingly high disability rate, even in the post-

elimination phase, demands immediate focus towards disability preventive measures.

The present study population means age of leprosy patients was  $31.98 \pm 13.91$  years which is similar to a study done by Namrata et al (2015). We have found that the mean age of patients with grade 2 disability ( $37.92 \pm 13.64$ ) is significantly ( $<0.001$ , Unpaired t-test) more than patient with grade 1 disability. This signifies that grade 2 disability occurs at a later age group.

We have found male predominance among leprosy patients similar to studies done by (Rizvi et al 2015, Soomro et al 2008, Jindal et al 2009). This finding may be due to women being reluctant to seek health care services (Lockwood 2010). In studies by Arora et al (2008) and Hussein et al (2010), male to female ratio as high as 3:1 has also been reported.

The overall illiteracy rate in leprosy patients in our study was 42.2 %, and only 4.2% of patients were graduates. Thus lower socio-economic condition, cultural belief and lower treatment-seeking behavior among illiterates, help in the spread of the disease. Other studies by Alam et al (1998) and Guthi et al (2016) showed a prevalence of illiteracy to be 46% and 42.03%, respectively.

We have found a significant positive correlation ( $\rho=0.232$ ,  $P<0.001$ ) by Spearman's coefficient of rank correlation among disability status of patients and their occupation. As the amount of physical labor increased from mild to moderate to severe, the rate of grade 2 disability also increased from 9.25% to 21.5% to 25.17%, respectively. In a similar way percentage of patients with no disability is highest among patients with mild physical labor group. This is because of the nature of outdoor work and more exposure to physical injuries in the form of cuts, pricks, burn etc., in patients with severe manual labor. Further, most patients in that group earned

income on a daily basis, so attending a health centre meant the loss of wages. This led to deliberate negligence of trivial cuts and blisters till they progressed to severe deformities. Similar results have been shown in studies done by (Girdhar 1996, Jain et al 2011, Ghimire 2002).

In accordance with studies done by (Ghimire 2002, Khapre et al 2013, Guthi et al 2016) we have also found that leprosy and its disabilities are more common in the lower socioeconomic group. This may be because of overcrowding, lack of awareness, backward cultural beliefs, and inability to regularly seek healthcare services.

In our study we have found that grade 2 disability was significantly higher among tribal (25.54%) population than non-tribal population (12.73%). The study by Ghimire (2002) also found a higher rate of disability among the tribal population. Access to services thus appears to be an important gap area.

The most common deformity in our study was trophic ulcer (5.32%) followed by claw hand (4.88%). In studies done by Jain et al (2011), Quyum et al (2015) and Nagabhushnam (1967) claw hand was found to be the most common deformity. On the other hand, in accordance with our study, Barua et al (2016) also found trophic ulcer as the most common deformity in their study. Differences are mainly due to differences in the socio-economic and cultural background of the study population.

In the current study most common clinical type of leprosy was BT type. This was in accordance with other studies (Kumaran et al 2015, Jindal et al 2009, Mathan & Devan 2016, Rao & Moodalgiri 2015). Pure neuritic leprosy was seen in 9.31% of cases in the present study.

We have found significantly more cases of disability among patients with multibacillary (MB) type of leprosy. This finding was similar to

studies done by (Sukumar et al 2010, Saha & Das 1993, Schreuder 1998, Richardus et al 1996, Sarkar et al 2012). Concerning the pathogenesis of leprosy, it is very likely that MB patients with more nerve involvement and sensory and motor nerve function impairment will have more disability.

In our study most common nerve involved was the right ulnar nerve (23.28%), followed by the right common peroneal nerve (17.29%), left common peroneal nerve (13.08) and left ulnar nerve (12.19), respectively. Other studies (Brakel & Khawas 1994, Quyum et al 1995) also showed ulnar nerve to be the most commonly involved.

We have found the prevalence of grade 2 disability to be significantly more among patients with type 1 reaction than type 2 reaction. Saunderson et al (2000) has reported a relative risk of 14.7 to develop nerve function impairment in patients with type 1 reaction. Neural impairment is important in the clinical context of type 1 reaction, and it is considered the leading cause of disabilities and deformities (Nery et al 2013).

The major risk factors are known for leprosy disability, and physical deformity is delay in diagnosis, provision of proper treatment and care for the disease. It causes disabilities due to nerve damage, immunological reactions and bacillary infiltration. Different factors contribute to the overall delay in diagnosis of leprosy.

Such factors can be divided into two categories: those contributing to 'patient delay' (defined as the time between onset of symptoms and patients consulting a medical doctor) and those contributing to 'health-system delay' (defined as the time between first consulting a medical doctor and receiving a diagnosis of leprosy). We have focused mainly on patient delay in this study. It has been obtained mainly from patients' history. We found that mean a delay in diagnosis was significantly higher ( $p < 0.001$ , ANOVA)



inpatients with grade 2 disability than grade 1 disability and patients with no disability which signifies that delay in starting treatment increases the chance of nerve damage and grade 2 disability. Sarkar et al (2012), in their study found that the mean delay in diagnosis in months in patients with grade 2 disability is significantly higher ( $p < 0.01$ , ANOVA) than patients with grade 1 disability and no disability. The mean delay in their study ( $19.6 \pm 7.5$  in patients with grade 2 disability) was higher than our study ( $11.95 \pm 8.3$  in patients with grade 2 disability).

Additionally, leprosy patients have been found to prefer visiting traditional healers rather than trained medical doctors (Zhang et al 2009, Choulagai et al 2005, Nicholls et al 2003) which further delays treatment initiation and prevention of severe disability.

In the present study we had found that when there was a delay in diagnosis of  $< 12$  months, there was less propensity to develop disabilities but when there is delay  $> 12$  months the chance of disability increased, which reinforce that early diagnosis and treatment can delay the appearance of disability and is a distinct finding in our study. We found that 54.77% of patients with delay in diagnosis of  $< 12$  months did not develop any disability, whereas only 23.62% of patients had grade 2 disability. But among patients with a delay in diagnosis of  $> 12$  months 83.92% of patients developed grade 2 disability. In their study Chavan & Patel (2011) found that subjects with delayed diagnosis beyond 12 months had significantly excess grade-2 disabilities than diagnosed within 12 months ( $P < 0.05$ ), and similar findings were seen in studies by Sarkar et al (2012) and Kar & Job (2005).

### Conclusion

Thus, to conclude, illiteracy, injury-prone occupation, and delay in diagnosis and multibacillary

leprosy are significant contributory factors in developing disabilities among leprosy patients. In most cases, this delay is because the disease is asymptomatic.

Ignorance and lack of knowledge about the disease may result in failure to recognize the condition early enough to prevent these morbidities. Another very important reason for "delay" is the stigma associated with leprosy, which still continues to be a major problem in leprosy control measures. Fear of being outcast by society and losing economic independence prevent the patient from seeking early medical help.

Proper health education, improving the socio-economic, and providing adequate health care facilities among the tribal population is essential to achieve this goal. Multidrug treatment availability should be regular and easily accessible at health centres. Health workers at primary health care level should be adequately trained so that they can recognize leprosy reactions early enough to prevent deformities. Patient education is also of utmost importance in this regard to prevent the worsening of already developed disabilities. This comprises imparting education about "self-care practices". As the study was conducted in a tertiary care centre, it may not indicate the status of disability problem in the community. It would be worthwhile to use this qualitative information to plan in depth investigations and interventions in the communities served by this tertiary care centre.

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