

## **THE EFFECTS OF THE STIGMA OF LEPROSY ON THE INCOME GENERATION OF LEPROSY AFFECTED PEOPLE IN THE TERAJ AREA OF SOUTH EAST NEPAL**

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### **ABSTRACT**

*This study explores the effect of stigma on the income generation of people affected by leprosy in the southeast Terai area of Nepal. Semi-structured interviews were conducted to explore experiences of stigma and the impact on income generation. Results showed a negative effect on income generation – with employment being lost as a direct result of stigma in several cases. The negative physical effects of the disease were for many the main reason for lost income, or employment.*

### **INTRODUCTION**

Leprosy has affected people for thousands of years. It was, and often still is, seen as a contagious, mutilating disease. Today, leprosy can be clinically cured relatively easily, yet the effects that it has on a patient's life can carry on indefinitely. It is a stigmatising condition, and can lead to the person affected being rejected and excluded from society (1). Other examples of social exclusion are available in literature (2,3,4,5). Stigma itself is a complex issue with the capacity to affect all facets of life of a person affected by leprosy. This study has focused primarily on the impact of stigma on income generation. This is an important issue, as a person's sense of self-worth, and how others perceive them, is interwoven with their income level and employment status. Income generation covers employment type and ability to secure employment. The type of employment that a person has, is linked to their status, and well-being.

### **NEPAL**

Nepal is one of the world's poorest and least developed countries, with a Gross Domestic Product per capita of \$1400 (2002 estimate). Most of the population is dependent on agriculture, and 42 per cent are below the poverty line. Life expectancy at birth in 2003, was recorded as

being 59 years (men 59.36 years, women 58.63 years). Nepal is multicultural; the 1991 Census of Nepal recorded 60 caste and ethnic groups and 70 languages and dialects (CIA World Factbook website <http://factbook.wn.com/nepal> World Factbook. Accessed 13th August 2004).

Nepal is the world's only Hindu kingdom. It is a hierarchical society where caste continues to play an important part in dictating a person's position based on Hindu notions of purity and pollution. Furthermore, caste determines an individual's behaviour, obligations, and expectations (6).

The Hindu culture of maintaining purity, and avoiding pollution, is likely to have a bearing on the treatment of people affected by leprosy. This means that such people are thought to be ritually unclean, and contagious.

In a predominantly Hindu country such as Nepal the belief that deformity is a result of divine punishment, is likely to contribute to the stigma experienced by people affected by leprosy. It is perhaps doubtful whether leprosy would be associated with social stigma were it not for the distortions it causes to physical beauty (7).

### **The Maithili people**

One of the ethnic groups of Nepal is the Maithili people, found in the south-eastern Terai region of the country, in Janakpur and the surrounding area. About 10.8 per cent of Nepal's population are Maithili, making them the second largest group in Nepal.

The Maithili are predominantly Hindu, with the remainder made up of Muslims and Christians. The Maithili as a people are known for their religious devotion and are traditional in terms of cultural behaviour. Most Maithili live in isolated rural regions; this isolation has sheltered the majority of the Maithili from the 'modernising' influences of the towns and cities.

Maithili culture is male dominated. Females are restricted in what they can and cannot do. When it comes to income generation, the norm of society is for a woman to remain in the house once married and carry out the housework, paid employment is not common for women. Lower caste women will work in the fields, but this is the exception rather than the rule. This will have a direct influence on the issues involved in this study, because there is no effect on income generation for women who do not have paid work to begin with.

## **Leprosy in Nepal**

Nepal is one of ten remaining countries that have a leprosy prevalence rate greater than 1 per 10 000 population, and at the end of 2003 was ranked fifth in terms of leprosy prevalence rates in the world (8). According to an annual report of the Leprosy Elimination Programme (Nepal) for 2002/2003, the prevalence rate of leprosy was 3.04 per 10 000 population in 2002/2003.

The Maithili as mentioned inhabit the Terai area of South-east Nepal. The Terai is a relatively flat strip of land in southern Nepal which borders India. According to a report of internal leprosy elimination monitoring and evaluation in Nepal, of July-August 2003 (9), more than 80 per cent of leprosy cases in Nepal, and of annual case detection, is contributed to, by 20 endemic districts of the Terai region. This makes the Maithili people an obvious choice for a study of leprosy related matters. This study was undertaken in collaboration with the Nepal Leprosy Trust.

The Nepal Leprosy Trust was founded in 1972, with the purpose of improving the lifestyle of people affected by leprosy and other marginalised people. The Nepal Leprosy Trust is registered as a non-governmental organisation (NGO) in Nepal, and as a Charity in England. The Trust aims to provide medical, social and economic benefits by providing employment and support.

The Trust runs the Lalgadh Leprosy Services Centre (LLSC) in the Southeast Terai near Janakpur. It is here that the data collection took place. The major principle in all of the Trust's activities is to reduce the stigma that wrongfully and unjustly surrounds leprosy. The aim is to promote the full participation in society of all those affected, including family members.

## **Leprosy**

Leprosy (or Hansen's disease) is caused by *Mycobacterium leprae* (*M.leprae*). It is a disease affecting the skin, (where the signs of infection are often first discovered) and other organs, but the involvement of the bacillus in the peripheral nervous system causes the most serious damage to the patient. Leprosy is the only bacterial disease to be characterised by the invasion of peripheral nerves. This invasion and subsequent damage leads to peripheral neuropathy if treatment is delayed (10).

According to Robinson (11), leprosy can be explained in terms of disease (biomedical perception), illness (self-perception) or sickness (social perception). Health workers tell affected persons that they have the disease leprosy according to physical symptoms. The illness leprosy is experienced by the person, and is shaped by cultural and social influences. The sickness leprosy is the problem as perceived and named by society, and it is this that reflects social stigma.

### **STIGMA**

As stated previously, leprosy as a disease has wide reaching impacts beyond the medical impact, most notably stigma. Goffman (12) has provided the most widely accepted definition and description of stigma. According to Goffman, the term 'Stigma' originated with the ancient Greeks. Stigma referred to bodily signs designed to expose something unusual or bad about the moral status of the signifier. The Stigmas were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places. Today, the term is applied more to the disgrace itself than to the bodily evidence of it.

The term stigma will be used in this study to refer to an attribute that is deeply discrediting. Stigma has a double perspective: does the stigmatised individual assume that his/her differentness is known about already, or is evident on the spot, or does he/she assume it is neither known about by those present, or immediately perceivable by them? In the first case one deals with the 'discredited' and in the latter, the 'discreditable'.

Goffman (12) also describes what he calls 'courtesy stigma' as being the extension of a person's stigma to people who are related through the social structure. The relationship leads the wider society to treat both individuals in some respects as one – there is an obligation to share some of the discredit of the stigmatised person.

Hetherington et al. (13) develop Goffman's ideas and point out that stigmatisation, is personally, interpersonally, and socially costly. It is a social construction that involves at least two fundamental components: firstly, the recognition of difference based on some distinguishing characteristic or 'mark', and secondly, a consequent devaluation of the person. Stigmatised individuals are regarded as flawed, compromised and somehow less than fully human.

Bainson and Van den Bourne (7) describe a set of ‘affective dimensions’ that involve the emotional reactions that individuals, groups or communities develop towards leprosy patients. These emotions include pity, anger and fear. With leprosy, it is the element of fear that is most likely to lead to stigmatisation rather than any other affective dimension.

### **Leprosy, Stigma and Income Generation**

A person’s sense of well-being and the level to which they see themselves as useful, is inextricably linked to their income generation, and ability to secure employment. For the spouse or parent, the ability to provide for dependants is linked to a sense of worth and fulfilment in their role.

There are few studies on leprosy, stigma and income generation. However, some researchers have explored the topic. Deepak et al. (14) state that, “even today, social stigmatisation is frequent so that affected persons with clear signs of chronic manifestations are often unable to work, or to marry, they become dependent for care and financial support, leading to insecurity, shame, isolation and consequent economic loss.” While Scott (15), in his study of the psychosocial needs of leprosy patients in South Africa, discovered that all of the subjects were afraid of losing their work, and 17 out of 30 did not mention the name of their disease to their employers. Kaur and Van Brakel (16), in their study of leprosy affected beggars in India, point out that they have found that the combination of leprosy, physical impairments and social stigma leads to ‘dehabilitation’ of the leprosy affected person, which ends with the person becoming a beggar. Dehabilitation in this context, is defined as loss of former place in society or social role, causing loss of dignity, job and/or position leading to physical displacement. Nicholls and Smith (17) comment on the experience of people affected by leprosy, in their set of operational principles for rehabilitation of people affected by leprosy – pointing out that many such people live in extreme poverty and have few opportunities to earn an income. They may be excluded from their former work place or denied access to their former market. They go on to state that the physical impact of leprosy may make it impossible to continue in their former occupation. This is a point that is extremely relevant, it is not simply a matter of stigma being the sole cause of income loss, there are complicating factors involved.

In a study on community behaviour in eastern Nepal towards leprosy affected people, de Stigter et al. (18) show that persons affected by leprosy tried to hide their disease out of fear

for negative community behaviour (stigma). They state that ‘persons affected by leprosy experience exclusion from social life...they have difficulties in gaining employment or they are refused jobs. In general, persons affected by leprosy experience unsympathetic reactions, insults, hate, abandonment or rejection...’ They go on to indicate that the motive for such negative community behaviour is a “fear of infection by germs”, as well as “fear of a curse of God”.

## **METHODOLOGY**

This research was conducted from May to July 2004, at the Lalgadh Leprosy Services Centre, near Janakpur in the Dhanusha District of the Southeast Terai of Nepal.

Semi-structured interviews were conducted with leprosy affected people in Nepal. Nineteen interviews were conducted, nine with men, and ten with women.

The aim was to be illustrative of leprosy affected people, rather than representative of the wider population. Four of the interviews took place at the hospital and fifteen were held either at the meeting locations of the Lalgadh Leprosy Services Centre self-help groups, or in participants’ homes. Interviewees were selected both on the recommendation of Trust staff as well as randomly. The candidates recommended by staff were purposely selected on the basis of their known experiences, in relation to the research. The randomly selected candidates were members of self-help groups, and were therefore not fully ‘random’. However, no information was known about them in advance by the interviewers, unlike the purposely selected candidates.

Given time and resource constraints and the constant threat of imposed strikes by the Maoists, this combination of purposive and random selection was considered to be the most appropriate for the study.

The basic criteria for selection of purposive and randomly selected candidates were:

- Gender,
- Leprosy affected person, or a family member/close friend of a leprosy-affected person.

The interview location (either the candidate’s home village, or on the hospital compound) was not considered relevant to selection.

Prior to the commencement of interviewing, a general interview framework was created – giving a pattern of question themes and areas, to help guide the interview. This framework was reviewed after a number of interviews had been completed and amended, on the basis of that experience.

Due to the difference in language (both Nepali and Maithili are spoken in the area), translators were used for the interviews. Translators were briefed prior to interviewing on appropriate techniques and styles of questioning that were acceptable (i.e. not asking leading, or closed questions, and allowing the participant to speak – not answering for them etc.).

The author undertook the interviews with men (with a male translator), while a female colleague talked to the women with the support of a female translator. The women especially are very reserved around men; so all interviews were undertaken according to a strict gender division.

To aid the translation process, all of the interviews were recorded, with the participant's permission. The transcription and translation of the interview recordings was undertaken by Trust staff and the research team.

For analysis of the data, a simple indexing system was applied to the text of each interview, to allow for easy referencing. Once a significant number of transcripts had been completed and preliminary analysis had been undertaken, common themes were identified and noted.

It was essential for the researchers to recognise their ethical obligation to prevent any harm to the participants, especially as the topics of research are of a sensitive nature. Consent to take part, was gained from all participants. All participants were assured of their anonymity and were free to withdraw from participation at any time. Data protection was of vital importance whilst in Nepal and all data were kept securely, both at the accommodation and whilst out in the field. All translators were briefed on the importance of confidentiality of the interviews they undertook and the texts they dealt with.

## **FINDINGS AND DISCUSSION**

### **Stigma and income loss**

In a developing world context, as found in Nepal, the loss of income is a very serious matter, given the lack of formal safety nets, and the likelihood that relatives and friends may have limited resources themselves, and therefore, may be unable to provide assistance.

Interviews highlighted several incidences of income loss of leprosy-affected people, due to stigma. This was not clear-cut for all cases, as, frequently there are complicating factors involved, most commonly a physical effect of leprosy diminishes income generating capacity, which then works alongside stigma. The interview excerpts are referenced in the following manner: (Male 1) indicates that the quote is taken from interviewee number one, who was male.

The first interview was conducted with a 35–40 year old male from Dharan in Eastern Nepal. He had worked in a restaurant – preparing food and doing other general work (Male 1). He recalled the following situation when he was diagnosed as having leprosy:

... no one was ready to give me work. They all hated me and the restaurant where I was working sacked me telling that I had leprosy and this could be transmitted to others if he stays here. I was in complete destitution, without food, water and shelter. No body allowed me to stay at their place. I had to beg alms for food in Dharan...  
(Male 1)

Begging is an all too common result of leprosy – as pointed out by Kaur and Van Brakel (19).

When asked if the reason for his leaving the restaurant was solely his leprosy he responded:

Yes, this was the only reason, when the customers saw me with leprosy, they stopped coming to the restaurant and the business was almost a flop. So, I was sacked. (Male 1)

This man had been employed for two years in his position, and claimed to have been enjoying the work. To be fired for having leprosy is sadly not an isolated occurrence.

Another case of stigma related income loss is found in interview 15. This was with a 40 year old man whose employment, in his own words, had been:

every work like labour, farming, ploughing, digging and any other farming or labour work. I was able to do any work. (Male 15)

This man developed visible signs of leprosy – wounds on his hands and feet, and as a result of this he was unable to get work. His income suffered as a result of the stigma of both his potential employers and colleagues.

Interviewer – Before this disease were they offering to work? Participant – Yes, they offered me. Interviewer – And after this disease? Participant – No, nobody asked me. (Male 15)

When after I got serious wound, usually they did not want to give me offer to work. But some times they offered me work when no other labourers were available there. (Male 15)

Because there were wounds in my hand and foot they usually told me that I had to work separately, not with them. Other labourers usually told that if I went to anywhere for work they did not want to go there for work (Male 15)

This man obviously felt that he was still physically able to carry out the work, in fact the interview provided background information that shows his physical fitness levels:

I used to play wrestling in my village on any carnival. Some times I taught many boys of my villagers. Still some are very good wrestlers... (Male 15)

A similar case is found with interviewee 17. He was a 35-year-old male who prior to leprosy had been employed to weigh logs and do other work. His situation changed with the onset of the disease, and the associated stigma:

In the beginning I was not accepted to work with other labourers. So, I couldn't earn at that time. I had to take a loan to meet day-to-day expenditures. [...] It was the disease. Because people wouldn't like to work with me, I had less job opportunity. (Male 17).

The subject again has suffered a decrease in his income generation, through the loss of work due to stigma. He claims to be physically able to work:

I don't feel any difficulty in doing work. I soak and scrub my hands and feet every day to remove dead skin and after that I apply oil, and that keeps me fit (Male 17).

But the man does make reference to some negative effects of the medicine taken:

... My work efficiency has considerably deteriorated after this disease. The medicine creates weakness in the months of summer (Male 17).

Another clear example of stigma affecting income generation is found in interview 13. This was with a 65-year-old male, who is currently acting as a facilitator of a self-help group. The participant was previously employed in agriculture. He was required to work on a farm due to an unpaid loan of his fathers:

My father had died when I was a small boy, I survived in my mother's sister's house and I had to pay some loan which was borrowed by my father, to pay that loan I became a servant of the lender. In that period he did not give me any salary, just food (Male 13).

With the onset of leprosy and the appearance of the visible signs of the disease, this man encountered stigma leading to a loss of income generation:

After I developed the wound my owner refused to give me that work, so I lost my job (Male 13).

Interviewer – Ok in that period you lost your job, after that were you able to do work?

Participant – Yes I was able (Male13).

The interview also revealed that the participant developed physical problems inhibiting his income generation at a later date. However, this was after the original stigma related income loss.

### **Income loss due to physical effects of leprosy**

From the interview process, it is clear that the main source of lost income generation is the debilitating physical effects of leprosy. In the majority of cases, there is a physical problem of some degree, even when there is a clear-cut stigma related income loss, there is often a physical problem which also troubles the person.

For some people, the physical effects of leprosy prevent the continuance of physically based employment, which is the main type of employment found amongst the rural population in which the study was carried out.

My dad is unable to work because he has deformity in one hand and one foot ... (Female 2).

We stopped our business for some time, when we got this disease ... Because we were weak. We didn't have power to work (Female 8).

Although we are labourers, due to our physical problem we are not able to work and are sometimes suffering without food for many days (Female 12).

Before that even before I was married, I used to do all kinds of work, household and working in the field. Then I got a wound and then I stopped working (Female 18).

For other people affected by leprosy, the physical effects are less inhibiting of their work activities, and will simply restrict the amount or type of work that they can carry out. The following examples highlight this point...

At that time I was physically normal and strong, but now the disease has affected my hands. I cannot hold things properly with my hands. I can do only easy work now. People have no sympathy with me. No one offers me any job. The previous life was undoubtedly better (Male 1).

The effect of this disease on me is that it made me weak. I can't do work in my full capacity. I don't get appropriate diet. Since there is ulcer in my feet, I am unable to work in the field (Male 9).

I was making more income when I did not have leprosy, but after this disease I became weak and my income was poor. Now I am doing business, which is not physically hard to me, so now it is easy and more beneficial for me. Because it is not necessary for me to go in sunlight or field, it can be done in a room (Female 14).

The issues surrounding leprosy are grounded in the attitudes and emotional reactions of both, the people affected by leprosy and the people with whom he or she comes into contact. The loss of income generation is one part of the overall leprosy related stigma issue, and is itself governed by the attitude of the employer. In the majority of cases, a lack of knowledge and understanding of the facts about leprosy, leads to the assumption that leprosy will be easily caught by anyone coming into contact with an affected person. In the work place this is obviously going to be a highly unwelcome problem, leading to the stigmatisation of the leprosy affected employee – colleagues refuse to work with the person, customers may refuse to be served, or will stop business altogether. This is all amplified by the appearance of visible deformity.

Fear is the route of stigma – fear of exposure to the disease, fear of being infected, and fear of association with a person affected by leprosy and of courtesy stigma. This was highlighted

in the interviews through the attitudes described by the interviewees - of the person with leprosy, of their family and of the community. For example:

When they found out that I have leprosy, the immediate reaction was, they stopped me from entering into the house and they wanted me to stay away from the family. They thought if I am around, I can transmit the disease to them (Male 1).

They became anxious to see the wound. They said that this disease would infect them. Seeing the wound they started to hate me (Female 5).

His son had told him many times in the past – why are you going to Lalgadh? You’ll be found out. The son made him not go for treatment because of fear of stigma. He thinks that he would be in better condition if he had gone for treatment then (Male 10).

The attitudes and emotions of the person affected by leprosy who experienced stigma at home, in the community and in the work place, show some variation, but to generalise, there is an overriding sense of disappointment, anger and sadness at the actions of their former colleagues/employers, and of family and community members.

Towards the general leprosy stigma experience, there is again a mix of emotions and attitudes coming through in the interviews. Some people seem to accept their condition, and are confident in their ability to convince people of their ‘cured’ status – their personality and character cause them to become indignant at the thought of stigma – they’re cured so why should there be any stigma?

Others are less confident/optimistic and are greatly troubled by the anticipated stigma problems that will be experienced/ have already been encountered. The extreme examples of this condition are seen in the few cases of ‘self-stigma’, identified in the study.

The male biased nature of Nepali and more relevantly of the Maithili people, has a bearing on the situation of leprosy affected individuals. As described previously, it is the norm for women to not have paid employment, but to work in the home. The effects of stigma on the income generation of women with leprosy is minimal, as there is no income generation to begin with, however, stigma may prevent them from doing their unpaid work, and may lead to divorce or mistreatment by the spouse or family.

Age, education level, ethnicity, caste, religion, level of visible deformity (Judged according to WHO grading: Grade 0 = No anaesthesia, no visible deformity or damage; Grade 1 = Anaesthesia but no visible deformity or damage; Grade 2 = Visible deformity or damage present) (20) - these factors all have bearing on the income generation of the person with leprosy. The age of the interview participant may limit the opportunities that they would normally have for employment – the very young and the very old have limited earning ability, therefore, the occurrence of leprosy will have a limited impact on their short-term income generation. The poorly educated have less opportunity in the work environment than they otherwise would have – they are limited in the type of work that they can do, and therefore, the income that they can generate. In Nepal, ethnicity, caste and religion have an influence on the type of life that can be led – opportunities are restricted for certain castes. The level of visible deformity, as mentioned previously, will also play a large role in the life of the person affected by leprosy – the more visible the leprosy, the greater the likelihood of stigma and income loss. It is therefore not just a simple matter of leprosy affected people losing income due to stigma – the background situation needs to be considered, as well as the quality of life that would have been available without leprosy, before the full impact of the disease can be determined.

## **CONCLUSION**

Today, leprosy can be clinically cured relatively easily, yet, the effects that it has on a patient's life can carry on indefinitely. It is a stigmatising condition, and can lead to the person affected being rejected and excluded from society. Stigma itself is a complex issue, with the capacity to affect all facets of a leprosy affected person's life.

The question of whether there is a decreased income due to stigma for the person affected by leprosy was addressed in each interview, and as described previously, there were several cases where stigma did indeed account for a decreased income. Although this was not true in all cases, sufficient evidence was discovered to show that this is a current problem faced by people affected by leprosy in Nepal. Where a stigma related problem was present, the consequences for the person affected by leprosy, were extremely negative.

The greater effect of leprosy on income generation was found to be from the physical effects that often come with the disease. In the majority of cases, there is a definite loss in

income, and in income generating ability of the interviewees, or of their leprosy affected family member.

There was however, no evidence from the study to suggest that courtesy stigma of families causes decreased income. In several cases, the person affected by leprosy was separated from the family, thus eliminating the possibility of courtesy stigma.

In many cases, the person is ostracised by their family (to avoid catching leprosy). This has a profound affect on the well-being of a Maithili person affected by leprosy, as, to be cut-off from one's family is unthinkable for most. For a family to be willing to act in this way towards a close relative, shows the degree to which leprosy is feared in the local culture – it overrides the importance of family ties and duties.

The general pattern of events for a person affected by leprosy in the Terai of Nepal, as determined through this study, is for the diagnosis of leprosy and subsequent disclosure about the disease to family and community, to cause stigma against the person. This is manifested in several ways – verbal abuse, ostracism from social functions, enforced isolation and separation from the family, and also in some cases, the loss of income generation and a decreased standard of living. If this particular aspect of stigma is carried through to its conclusion, then the person may be forced into destitution.

In many cases, going forward for treatment is left too late to avoid deformity. This is due to either a lack of knowledge of the symptoms of leprosy (i.e. the person does not recognise that they could have leprosy), or through fear of stigma. Once leprosy has been diagnosed, then it is only a matter of time before people find out and stigma begins. In either case if treatment is not received soon enough, deformities will develop – most commonly of the hands and feet. The act of avoiding stigma by not going forward for treatment, will eventually cause stigma to occur anyway – this is an unfortunate vicious circle.

Stigma is more evident when obvious physical deformity is present; therefore, a job is more likely to be lost due to stigma of a person with visible leprosy, than if the leprosy is invisible. The deformity that causes the stigma, often also inhibits the physical ability to work. It is therefore difficult to separate these two aspects of the problem.

It should be borne in mind, that the interviewees were expressing their personal opinions on issues, from their specific viewpoint. These opinions are subjective, and another person if

asked about the same incident, may well give a different account of events. However, it was not feasible to corroborate the data gathered, due to the restrictions of time, and paucity of other data.

Further study is required focusing on the issues raised by this research, in order to further understand the relationship between leprosy, stigma and income generation. The initial data gathered in the course of this study provides a basis for a more detailed, longer-term research. It is hoped that this study may add something to the stigma elimination efforts of groups such as the Trust. Such work is vital to the long term goal of leprosy elimination, as, until stigma is dealt with, the disease cannot be fully cured.

“The fight is not over yet. But it is winnable. There are enough men and women of goodwill who can spread the word that leprosy is curable, and that leprosy sufferers need not – must not – be shunned... Unless the message reaches every continent, every country, every village, every patient, the disease will prevail in dangerous pockets.” Kofi Annan (21).

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## HELPING CHILDREN WHO ARE BLIND

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