

## THE FEELINGS OF PARAPLEGIC CLIENTS WITH SPINAL CORD LESION AND THEIR CAREGIVERS: IMPLICATIONS TO THE NURSING CARE<sup>1</sup>

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### ABSTRACT

This study aims to identify and discuss the feelings of both paraplegic clients with spinal cord lesion and their caregivers concerning the trauma and the resulting implications for pedagogic nursing care. The convergent-care method was developed through semi-structured interviews with five paraplegic clients with spinal cord lesion treated in the rehabilitation ward of a public College Hospital in the city of Rio de Janeiro, two paraplegic clients with spinal cord lesion who are residents of a non-government community center in the city of Rio de Janeiro and three caregivers. The data was collected in the period July 1st 2011 to March 1st 2012. To examine the data obtained, this research used a thematic content analysis. The results showed that each individual has their own strategy for dealing with the new condition. Accessing the patient's feelings and exploring their wishes, expectations and emotions is important to Nursing because this will inform a more humanized care system, making the overcoming of this condition less traumatic. A dialogue between the nurse, the client with spinal cord lesion and the caregiver will identify their feelings and facilitate pedagogic care, which is adapted to meet the needs of all concerned.

**Keywords:** Nursing Care. Caregivers. Paraplegia. Feelings.

### INTRODUCTION

Statistics show that spinal cord lesions are occurring more frequently and are intrinsically related to high levels of urban violence, car accidents and gunfights. The victims are predominantly young, male, single and resident in urban areas<sup>(2)</sup>.

The spinal cord lesion is an incapacitating condition that leads to countless alterations in the lives of both the injured person and their relatives. The type of lesion and the effectiveness of emergency care are determining factors that affect the chronicity of the lesion and the motor, sensorial and psychosocial consequences. Thus, after the initial lesion and during the treatment process, a new condition arises that determines changes in lifestyle.

Going back home is an important moment. It is the first contact of the client with the restructured environment that will accommodate

him and with redefined routines dictated by the new limitations. In this context, some feelings emerge that demand relatives and caregivers take a wider view of the treatment of the paraplegic client.

The spinal cord lesion develops an emotional response that, initially, is seen as a series of negative feelings<sup>(3)</sup>. The frustration and the discouragement start from the moment the client feels incapacitated, even if, temporarily, these feelings are followed by the hope of finding a cure. The indignation and the fear of a dark prognosis, the questions regarding sexuality and the uncertainty of going back to the labor market, among others, are feelings that are frequently found in individuals who are affected by a great shock.

The combined participation of the patient's relatives, who assume the role of caregivers, is fundamental to the continuation of the rehabilitation process implemented<sup>(4)</sup>. In this regard, emotional support is offered both to the

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client and to the caregiver, helping them to adapt to the daily changes, either environmental or functional. It is important to mention that a successful rehabilitation contributes to both physical and emotional restoration, avoids or minimizes possible complications and, consequently, reduces the incidence of re-hospitalization.

In order for this process to happen, it is necessary that the health team, especially the nurses, comprehend the reactions and feelings of clients with spinal cord injury. To take care of these clients requires consideration of the creeds, values and experiences inherent to the clients and caregivers, permitting a more humane and effective assistance from the nurses <sup>(4)</sup>.

Effective dialogue and an understanding of reality promote autonomy and demystify situations that interfere negatively in the process of caring. Needless to say, a capacity for listening and for perceiving the signals, gestures and body and facial expressions of the client are fundamental to the whole process, as the specificity of these and the ways in which the caregiver reacts will guide the choice of actions that will contribute to individual adaptation. Meanwhile, it is possible to acquire the subsidies to promote educative care in nursing and to share the understandings and practices inherent to the client and his social circle, which will bring positive consequences to nursing care during rehabilitation.

Based on what was identified regarding the feelings of the client and the caregiver, it is fundamental that the nurse recognizes the phases that the person will experience when acquiring the injury <sup>(5)</sup>. The behavioral characteristics of the client with spinal cord injury can be divided into four well-defined phases. Initially, in the shock phase, there is a state of confusion due to the dramatic changes caused by the trauma; the person cannot comprehend what is really happening. Then, during the denial phase, the person starts to realize what is happening, however he does not accept it and tries to maintain his previous self-image. In the third phase, there is recognition and awareness of the present state. Here, we highlight that the paralysis, the loss of sphincter control, the fear of becoming a burden to relatives and the social restrictions are revealed through many feelings,

including depression. In the last phase, which is adaptation, the client demonstrates a higher awareness of the reality and becomes more cooperative, capable of contributing favorably to the success of the process of rehabilitation in a way that will achieve the goals established <sup>(5)</sup>. The active involvement of the client, motivated by the caregivers and the health team, is crucial to the whole process and it runs through all phases of the process of adaptation.

The theoretical reference that supports this study is Freire's Pedagogy, together with the concepts of the Theory of Self-Care. The problematizing pedagogy <sup>(6)</sup> affirms that man interacts with other human beings, reflecting on and debating reality. A human being abandons the state of ingenuity and passivity to become active, participative, reflexive, critical and questioning and, then, he can build (or rebuild) reality, with an awareness of what must be changed. All the individuals involved must integrate, sharing their experiences. In the Theory of Self-Care, the universal requisites are aimed at keeping physical integrity and organic functionality. The universal requisites are common to all human beings and are adjusted according to age, stage of development, environment and other factors specific to each human being <sup>(7)</sup>.

Based on the above, the subject of this study is the feelings of both paraplegic patients with spinal cord lesion and their caregivers regarding the trauma and the aims are: 1) to identify the feelings of both paraplegic clients with spinal cord lesion and their caregivers regarding the trauma and 2) to discuss the feelings of both paraplegic clients with spinal cord lesion and their caregivers and their implications to educative nursing care.

## METHODOLOGY

This is a qualitative research study, using a convergent-care approach. In this approach, there is a description of the research and the assistance provided, giving some insight to the involvement and inclusion of the research subjects. It aims to resolve or minimize the problems found in practice and/or to improve the performance of some aspects, or to introduce innovations in health practice <sup>(8)</sup>.

Seven paraplegic clients with spinal cord injury, enrolled at the rehabilitation center of a College Hospital or resident in a non-governmental organization (both located in the city of Rio de Janeiro), as well as three caregivers, participated in this study.

The collection of data was performed between July 1<sup>st</sup> 2011 and March 1<sup>st</sup> 2012, with the use of semi-structured individual interviews. The interviews were scheduled in individual meetings, according to each person's availability.

As it is a part of a dissertation project, the focus of this study is centered on the understanding of the clients and caregivers regarding pressure ulcers (PUs) and the care used to prevent and treat them. However, it was necessary to initiate a dialogue on universal topics, in order to establish a link between researchers and subjects. The questions that guided the interview with the clients with spinal cord injury were the following: "Do you know what happened to you?" and "How is your life after the trauma, after the lesion?" To guide the interview with the caregivers, we used the following question: "How is to take care of someone after a trauma, with a spinal cord lesion?" Therefore, it was possible to identify both individual and unanimous feelings and expressions in the testimonies collected.

Following the principles of Convergent-Care Research (CCR), this research was performed in four steps<sup>(8)</sup>: 1) initial contact with the locations where the study took place, aimed at inserting the researcher and choosing the subjects; 2) application of a socio-demographic profile instrument with the clients and caregivers and identification of the actual health status of the paraplegic clients; 3) warm-up and reflection about the topic, performed before the beginning of the interview, in order to provide a stimulus in each subject area to be studied, followed by the sharing of experiences with the subjects using, as a guideline, a semi-structured interview with pre-defined key questions and 4) at the end of the interview, an evaluation form was used, in which the participants (clients and caregivers) stated their considerations in order to evaluate the process of sharing understanding and practices. All steps were recorded in mp3 format and later transcribed. A content analysis by

topics was used, thus generating two categories: the feelings of paraplegic clients with spinal cord injury, regarding the trauma, and the feelings of caregivers regarding the trauma and the conditions that led to them becoming a caregiver.

This project was approved by the Ethics in Research Committee, of the College Hospital São Francisco de Assis/Anna Nery Nursing School, under protocol #047/2011. Authorization was also solicited from all the institutions selected as locations for this research. The clients and caregivers signed a Free and Clear Consent Agreement. The clients were identified by the letter *E* and the caregivers by the letter *C*, followed by the family relationship: i.e. *son*, *brother* and *mother*. After the letters, sequential cardinal numbers were used according to the order of the interviews.

## RESULTS AND DISCUSSION

Seven clients with spinal cord lesion participated in this study, six men and one woman, aged between 36 and 73 years old. The time elapsed since the trauma varied from 5 to 40 years. Regarding the nature of the trauma, four clients were wounded by gun fire, two clients had a fall and one client was the victim of a car accident. With regard to their marital status, four clients were married and three were single. Considering their professional occupation, four clients stated that they were unemployed, two were retired and one mentioned having informal work as a candy-seller.

Three caregivers also participated in this study, two men and one woman, with ages varying from 28 to 65 years old. It is important to mention that all the caregivers had a direct family relationship with the client.

The relationship established between the researcher/nurse and the clients and their caregivers facilitated the discussion regarding their feelings regarding the trauma and this debate was supported by the theoretical basis of this research. Thus, the results collected were organized into two thematic units, which will be presented next.

### Feelings of paraplegic clients with spinal cord injury regarding the trauma

A spinal cord injury brings a series of significant changes in lifestyle due to the limitations imposed on the client. As a result, the client requires assistance from both the health team and their friends and relatives<sup>(9, 10)</sup>. There is no established timeframe for the beginning and end of each stage of adaptation. The individual characteristics of the patient and the degree of complications can determine the period of adaptation, which can take from weeks to years.

In the majority of cases, the clients search for answers in order to understand what has happened and this can make adaptation harder and longer. The testimony of client E1 shows the sadness and the questioning about what happened; observe the feelings that characterize the moment of shock due to the trauma:

My life changed a lot, you know. [...] In the beginning, it wasn't easy... you know, moments of sadness, periods that I didn't know what really happened, why it happened, what was going on [...] I had a great support from my friends and my family, which are fundamental, which helped me to stand up against this new situation. (E1)

The following testimony, from E2, demonstrates what this person feels about retaking control over their movements and the desire to walk without any support again, and the support provided by his faith, friends and family, to confront, accept and overcome the limitations. Moreover, we highlight in this client's testimony, how his way of reacting also affects all the people around him:

I feel like standing up from this chair and walk. Of course that if I want to run away, I will get into more trouble, because if you are by my side, you will start to suffer with me, and in a while you won't be able to give me any support and so and so. [...] It is really hard; only if you could be on my shoes to see the differences [...] God has given me so much strength. (E2)

In fact, the uneasiness of E2 is relevant; it refers to the suffering of relatives and caregivers because of the changes imposed due to the limitations of spinal cord lesion. Support for the paraplegic client requires a restructuring of the family nucleus to deal with the changes and the caregiving required after the lesion. However,

before achieving balance in this relationship, there are reports of anxiety, fear, desperation and the weariness of the client, the relatives and the caregiver.

People who suffer spinal cord injury are often young and sexually active<sup>(2)</sup>. Changes in sexual function depend on the location of the trauma and are a constant worry to the paraplegic client. Client E3 summarizes her feelings about sexual function and sexuality in the following testimony:

Terrible. I feel bad. In all meanings. I am not a woman anymore; I cannot take care of my house. What is the most terrible thing is when you are not a woman anymore and your husband looks at you and he doesn't feel anything about you. My life has become a complete chaos. [...] Sadness, anger, for having that happening with me [...] I don't take care of myself anymore. My problems is all located in these legs that don't have any use anymore. Unfortunately, if I hadn't felt... My marriage is over for a long time already [...] He doesn't have any patience with me anymore. [...] I look to my home and I can't do a thing. [...] God, why? What have I done, my God, to deserve that? [...] You know, he is a guy that used to like me when I was hot, big butt, thick legs. At the moment I felt, that I was feeling bad, he simply discharged me from his life. (E3)

This testimony reports the loss of her femininity and her role as wife and housewife. Yet, it also demonstrates how she is seen by her husband and the decline of the physical relationship of the couple. According to this client, sadness and solitude are frequent feelings in her present life. The marital relationship is conflictive and, in her opinion, her husband neglects the caring she needs, either by lack of his physical presence or by lack of respect and patience. However, her son contributes significantly, despite not having greater availability to provide more care due to his professional life.

Today, client E3 avoids looking at her image in the mirror, because she considers herself unattractive because she cannot perform any of her own self-care activities. This fact is explained by the aesthetical influence on the sexual behavior of men and women; that she considers herself to be unattractive creates feelings of self-prejudice, which leads to a reduction in self-esteem. The emotions of

resentment and anger towards the lesion's consequences call attention to her difficulty in accepting their limitations.

Women who are victims of spinal cord injury tend to lose their partners more frequently than men in similar conditions <sup>(11)</sup>. Men usually receive more attention and care by their partners, due to the fact that maternal instinct is an attribute that strengthens the relationship. Besides the maternal instinct being amplified, the social function of women is also characterized by an intense need to compromise for the family.

The testimony of client E4 expresses how the functional loss and the incapacity to perform previously socially-defined roles are significant:

It is dull, right? It's too hard. My old life compared to now... it is more difficult to have a child, this kind of stuff. I cannot help them now; so it is really hard at this moment. I am not working, I can't. (E4)

In her words, E4 mentions difficulty in having children due to the trauma or, in other words, that there is a barrier to performing her reproductive sexual function. In fact, the level of sexual response, male or female, after the trauma, will depend on the level of the lesion and the rehabilitation, among other factors. In men, the spinal cord lesion affects physiological mechanisms, generating erectile dysfunction and low fertility. Thus, because of the emotional importance attributed to this condition, handling sexual activity requires an approach based on adaptation and the uptake of strategies that generate gratifying sexual intercourse. In this sense, from the moment of understanding the limitations and possibilities of the client's body, it is possible to relearn to feel and provide pleasure and to express love.

Sexual changes in people with spinal cord lesion must be approached through a multi-professional spectrum, considering the different bio-psycho-social aspects encountered. A frequent event in the youngest strata of the population, the acquired spinal cord lesion creates a disruption in the sexual life of a person that did not have deficiency as part of his self-identity <sup>(12)</sup>.

In his testimony, E4 emphasizes that unemployment limits his ability to financially support his family. In this area, it is important to

understand the magnitude of the functional loss to the client and his reaction towards the obstacles that arise and alter his role in life. It is important to mention that, in a patriarchal culture and throughout history, it is the man's responsibility to provide for his family and, therefore, the man who holds the family's economic power <sup>(11)</sup>. During the interview, the researcher/nurse emphasized that many activities can still be done and yet the client demonstrated disbelief in his ability to get a job; he then ended the discussion of this topic. As seen, past experiences did not give scope for future perspectives, which in turn postpones the capacity to adjust.

In the testimony of E5, a rupture emerges between the idealized image and the real social image:

When I sat down in a chair and saw everybody walking, I was so sad! (E5).

This awakening to reality, seen through this reflection on the present situation, observed due to the limitations of the impairment, makes the person feel sad; as a result, the majority of adults will tend to self-isolate, to become depressed, anxious and confused.

Client E5 has lived with the consequences of the trauma for about 40 years. He reports, with an observed plainness, that it is possible to adapt and to have a good quality of life; having not participated in a rehabilitation program before, he taught himself to perform many daily activities. Today, he is socially reintegrated, as seen in the testimony seen here:

I didn't take long to adapt. When I need, I drive my car, go to the mall. I love shopping malls. I usually go near here, at the Norte Shopping mall. I like to lunch there. I like it. Lots of beautiful things, beautiful girls, all the beautiful girls. I like it. There are a lot of people who doesn't like it, but I... But it's their opinion too, right. No one has to enjoy it. But I do. Honestly, I do like it. (E5)

Client E6 views his present condition as a learning situation. His words make a comparison between two moments, attributing to the present moment some positivity and resignation:

It's normal, like before. (...) I always saw it as a positive situation, I do all my things as I always used to. (...) It is a learning situation, a lesson we

must do and that we do without complaining. For me and for many others I am an instrument (E6)

In the testimonies presented, it was possible to identify some of the feelings verbalized by the subjects in relation to the trauma suffered and how these interfere in the process of rehabilitation. In addition, these testimonies make reference to the support from and relationship with family, friends and caregivers, health, education, work, the labor market, transportation and other issues, which correspond to the difficulties faced in the physical, social and emotional environments in which clients live their lives<sup>(13)</sup>.

### Feelings of caregivers regarding the trauma and the condition of being a caregiver

During the dialogue, the caregivers reported what it is like for them to take care of a person with a spinal cord lesion.

Then, based on the caring part, to make dressings, to bath, to take from here to there, it is all fine for me, you know? (C4-brother)

It is not a really easy task. Especially now that I am working, I have to find some more time for her and for my work. (C3-son)

Only the other part, when sometimes I see him bleeding (referring to when there is some bleeding from the lesions) and that's complicated for me. (C4-brother)

In this study, all the caregivers are family-members of the clients with spinal cord lesion and are seen as actively involved in caring; some consider this to be a hard task, as seen in the testimonies of C3 and C4.

When the caregiver is a son, there is a moral duty or filial responsibility, which is based on three ethical principles: reverence, debt of gratitude or reciprocity and friendship and love<sup>(10)</sup>. This responsibility is seen in the testimony of C3:

All people who are in danger, it is the duty of the closest person to the person in danger to take care of this needed individual. (C3-son)

Some tasks performed by the caregivers, started in the period of hospitalization. They report that they learned the procedures to be repeated at home by observing the professionals. Caregiver C7 mentions that such learning is

necessary, as these activities must be done at home in any case:

When he was hospitalized I had to learn a lot of things there, and I had to do it all by myself. [...] So I've been through [...] things that we are forced to do, then we end up learning. If we need to do something, we must do it anyhow. [...] (C7-mother)

This testimony shows that one of the roles of the health team is to guide both the client and the caregiver, preparing them for discharge from hospital. In this area, the nurse performs an educational role to promote health, prevent further damage and to rehabilitate the individual, adjusting the care-plan to the needs of each client. Hence, to achieve the goals necessary for discharge, the nurse will promote involvement between the client and the caregiver, making them participative in the process of caring and ensuring continuity of care. The words of C7 demonstrate how the process of guidance was limited to non-participative observation. During the interview with the researcher, the caregiver showed interest in sharing new information about the general status of her son; however, she also demonstrated tiredness in her testimony:

Today I'm feeling more debilitated, you know? (C7-mother)

According to the Theory of Self-Care, the teaching of another generates an environment that promotes personal development, in order to satisfy the demands of self-care. This principle is highlighted by C7 when she describes the necessity of learning during her son's hospitalization.

The dedication of the caregiver to a person who is completely dependent on them corresponds, according to the Theory of Self-Care, to the method of acting or doing for the other. There is a likelihood of physical and emotional conflicts arising from the overload, according to the testimony of C7. Such overload can be of a concrete nature, such as the economic dependency, change in routine and lack of time for the self, among other things, or of a subjective nature, such as guilt, shame, obligation, low self-esteem and an excessive preoccupation with the relative being taken care of.

The therapeutic demand in self-care (DSC) encompasses the actions needed to maintain life and promote health and well-being. For the clients observed, there is the trauma that directly interferes in their quality of life and self-esteem. On the other hand, the demands of care placed on the caregivers are linked to the conflict generated in doing for the other and the physical and psychological support required. Both the needs of the clients and the needs of the caregivers connect directly to the feelings identified.

The health team, especially the nursing staff, must understand that the family goes through different emotions when performing tasks related to care-giving; the family is rebuilt with new characteristics in self-functioning and with different ethnic, cultural and socio-economic structures<sup>(14)</sup>. Based on the understanding that the family is seen as a caring unit, it is possible to build a care-plan appropriate to the needs of the client and his family/caregivers, in accordance to the social-cultural reality in which they live.

### CONCLUSION

Through the use of convergent-care research it was possible to generate an investigative process of something dynamic, which explores the reality and at the same time intervenes in this same reality. The interaction established between the researcher and the subjects permitted an opportunity for reflection, which revealed the feelings and the strategies used to confront the present condition. It was also found that it is the family that subjects look to, to find physical and

emotional support, which can be crucial to the success of the process of rehabilitation.

The dialogue based on a process of action-reflection with the researcher/nurse permitted the identification of many feelings. From the testimonies given, it is possible to observe clients feeling punished by the situation, anger, sadness, anguish, insecurity, fear and low self-esteem. However, it is important to consider that there were some reports of hope, willpower, the desire to walk again, faith and even resignation.

The identification of the client's feelings, desires, expectations and emotions by nursing staff is relevant because it informs a more humanized care-plan, to manage the spinal cord lesion condition in a less traumatic way. The client is at the center of the nursing care, not forgetting the importance of involving the patient's family in the work of the multi-professional team and respecting the family's reality during the process of rehabilitation.

When self-care is effectively done, it helps to maintain structural and functional integrity, contributing to the process of rehabilitation. The main objective of nursing care is to enable self-care and the maintenance of this self-care in a continuous way, in order to promote life and health, promoting recuperation from the disease or lesion and dealing with its effects. Supporting the ideas of Freire and the principles of the Theory of Self-Care, it was possible to focus on the individual, recognizing the importance of the family in promoting self-care to the client, when generating reflection about the reality on which this study is focused.

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## SENTIMENTOS DE CLIENTES PARAPLÉGICOS COM LESÃO MEDULAR E CUIDADORES: IMPLICAÇÕES PARA O CUIDADO DE ENFERMAGEM

### RESUMO

O estudo objetivou identificar os sentimentos dos clientes paraplégicos com lesão medular e seus cuidadores acerca do trauma; e discutir estes sentimentos e suas implicações para o cuidado educativo de enfermagem. O método foi convergente-assistencial, desenvolvido por meio de entrevistas semiestruturadas com cinco clientes paraplégicos com lesão medular inscritos no atendimento de reabilitação de um hospital escola público do Rio de Janeiro e dois clientes paraplégicos com lesão medular, residentes de um centro de convivência, organização não governamental do Rio de Janeiro e três cuidadores. Os dados foram produzidos no período de 01 de julho de 2011 a 01 de março de 2012. Aplicou-se a análise de conteúdo temática. Os resultados mostraram que cada indivíduo possui sua própria estratégia de enfrentamento à sua nova condição. O acesso aos sentimentos, explorando anseios, expectativas, emoções, por parte da Enfermagem, é relevante, pois esta identificação proporciona uma assistência mais humanizada, tornando o enfrentamento a essa condição, menos traumático. O diálogo estabelecido entre enfermeiro, cliente paraplégico com lesão medular e seus cuidadores identificou os sentimentos dos mesmos, o que proporcionou um cuidado educativo aderente às condições de ambos.

**Palavras-chave:** Cuidados de Enfermagem. Cuidadores. Paraplegia. Emoções.

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## SENTIMIENTOS DE LOS CLIENTES PARAPLÉJICOS CON LESIÓN MEDULAR Y CUIDADORES: IMPLICACIONES PARA LA ATENCIÓN DE ENFERMERÍA

### RESUMEN

El estudio tuvo el objetivo de identificar los sentimientos de los clientes parapléjicos con lesión medular y sus cuidadores acerca del trauma; discutir sobre los sentimientos de los clientes parapléjicos con lesión medular y sus cuidadores acerca del trauma y sus implicaciones para el cuidado educativo de enfermería. El método fue convergente-asistencial, desarrollado por medio de entrevistas semiestructuradas con cinco clientes parapléjicos con lesión medular inscritos en la atención de rehabilitación de un hospital escuela público de Rio de Janeiro y dos clientes parapléjicos con lesión medular, residentes de un centro de convivencia, organización no gubernamental de Rio de Janeiro y tres cuidadores. Los datos fueron producidos en el período de 01 de julio de 2011 a 01 de marzo de 2012. Se aplicó el análisis de contenido temático. Los resultados mostraron que cada individuo posee su propia estrategia de enfrentamiento a su nueva condición. El acceso a los sentimientos, explorando anhelos, expectativas, emociones, por parte de la Enfermería, es relevante, pues esta identificación proporciona una asistencia más humanizada, tornando el enfrentamiento a esa condición menos traumático. El diálogo establecido entre enfermero, cliente parapléjico con lesión medular y sus cuidadores identificó sus sentimientos, lo que proporcionó un cuidado educativo adherente a las condiciones de ambos.

**Palabras clave:** Cuidados de Enfermería. Cuidadores. Paraplejía. Emociones.

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