Tuberculosis/HIV/AIDS coinfection in Porto Alegre, RS/Brazil - invisibility and silencing of the most affected groups

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Tuberculosis/HIV/AIDS coinfection in Porto Alegre, RS/Brazil - invisibility and silencing of the most affected groups

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OBJECTIVE: To analyze how belonging to certain social groups contributes to constituting the vulnerabilities associated with illnesses due to tuberculosis/HIV/AIDS coinfection.

METHOD: This is a qualitative study carried out in the city of Porto Alegre, state of Rio Grande do Sul, in regions of high social vulnerability. Twenty coinfected people were interviewed in specialized health services between August and December 2016. The analysis was based on the frameworks The Sound of Silence and Vulnerability and Human Rights.

RESULTS: Socioeconomic conditions were decisive for the constitution of the vulnerability conditions. Processes of invisibilization, and the silencing of their voices, in a scenario marked by economic, racial and gender inequalities, contributed for their health needs not to be understood and effectively taken into account in the services actions.

FINAL CONSIDERATIONS: The more effective strategies are to legitimize voices and to understand the needs of those affected by coinfection, the greater the chances that programmatic responses to the problem will be successful.


ABSTRACT
Objective: To analyze how belonging to certain social groups contributes to constituting the vulnerabilities associated with illnesses due to tuberculosis/HIV/AIDS coinfection.

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Final considerations: The more effective strategies are to legitimize voices and to understand the needs of those affected by coinfection, the greater the chances that programmatic responses to the problem will be successful.

Keywords: Coinfection. Tuberculosis. Acquired immunodeficiency syndrome. Health vulnerability.

RESUMO
Objetivo: Analisar como o pertencimento a certos grupos sociais contribui para a constituição das vulnerabilidades associadas ao adoecimento pela coinfecção tuberculose/HIV/aids.


Resultados: Condições socioeconômicas foram decisivas para constituição das condições de vulnerabilidade. Processos de invisibilização das pessoas e silenciamento de suas vozes, em um cenário marcado por desigualdades econômicas, raciais e de gênero contribuíram para que suas necessidades de saúde não fossem compreendidas e efetivamente levadas em consideração nas ações dos serviços.

Considerações finais: Quanto mais efetivas forem as estratégias para legitimar as vozes e compreender as necessidades das pessoas afetadas pela coinfecção, maiores serão as chances de que as respostas programáticas para o problema sejam exitosas.


RESUMEN
Objetivo: Analizar cómo la pertenencia a ciertos grupos sociales contribuye a la constitución de las vulnerabilidades asociadas al padecimiento de coinfeción tuberculosis/HIV/AIDS.


Resultados: Las condiciones socioeconómicas resultaron decisivas para constituir las condiciones de vulnerabilidad. Los procesos de invisibilización de las personas y el silenciamiento de sus voces contribuyan a que sus necesidades de salud no fueran comprendidas y efectivamente consideradas en las acciones de los servicios.

Consideraciones finales: Cuanto más efectivas sean las estrategias para legitimar las voces y comprender las necesidades de los afectados por la coinfeción, mayores serán las posibilidades para que las respuestas programáticas al problema resulten exitosas.

INTRODUCTION

The population groups that are most affected by tuberculosis/HIV/AIDS coinfection have in common the fact that they have conditions and life situations that increase health risks. Research that traces socio-epidemiological profiles related to tuberculosis (TB) and HIV/AIDS mentions groups and characteristics associated with these diseases, with frequent occurrence of coinfection in men between 30 and 59 years of age, low educational level, harmful use of alcohol and other drugs, people living in the street or in prison, history of abandonment of drug treatment, and multidrug resistance to tuberculosis (MDR)(1-2).

In order to understand how and why, in the context of tuberculosis and AIDS, certain people are sicker than others, the study has incorporated the referential of the determinants of the health and disease process in the analysis, to examine environmental, behavioral, cultural and social factors related to vulnerability to these diseases(3-4).

The use of The Sound of Silence methodology allowed us to overcome the view that people should adopt behaviors regarding the use of methods of protection or drug ingestion, pointing out the existence of other social, cultural and economic influences in the process of becoming ill due to coinfection.

The awareness of the importance of socio-structural elements in the health-disease process, elicited by the framework in question, leveraged the scientific production in health and the corresponding actions of the sector. However, it is becoming increasingly apparent that the influence of these aspects needs to be understood from perspectives that capture the unique stories of those living with diseases such as HIV/AIDS and tuberculosis. It is an understanding that, besides showing the material disadvantages and those of access to services and consumer goods, allows us to focus on the symbolic processes involved in illness, such as the effect of stigmas, prejudice and discriminations in a cultural scenario marked by a social class structure, racism and gender inequality(5-6). The disclosure of these processes can favor the establishment of relationships and forms of communication with these groups to favor the recognition of their health needs. These needs are neglected in political and cultural systems with the potential to silence the voices of people who are morally rejected because of their social belonging. Hence, “silence” may reflect non-shared aspects of how beliefs, values, and experiences of some groups influence their health(7).

The appreciation of these aspects can facilitate the understanding of how people attribute meaning to the actions they perform and to the behaviors they adopt in their life contexts. In the health area, it is very important, for instance, to understand the abandonment of certain therapies or the failure to follow medical guidelines and practices that are harmful to health. When providing elements for this understanding, the social and structural perspective helps us to recognize that people are constituted in different ways in the various spaces they occupy, and therefore need to be understood “in a context”, in the expression of their behaviors, habits, beliefs, and cultures(7).

Considering these premises, and to deepen analysis of the scenarios in which the people who are most affected by TB/HIV/AIDS coinfection are inserted, we seek support within the theoretical framework of Vulnerability and Human Rights (HR). The notion of vulnerability adopted here refers to the set of individual and collective aspects related to susceptibility to health problems, while noting that, in this context, few resources are made available to people for their protection.

In order to propose health actions that are consistent with the needs of these groups, we argue, from this theoretical framework, that it is important to reinterpret the epidemiological categories that classify the types of people who are most susceptible to illness. Mobilized by criticism to the use of risk factors as a hegemonic parameter for health actions, the authors who disseminate the Vulnerability and HR(5-6) framework question the positioning of individuals in contrast to society, the group, the environment, that is, to be removed from its social, cultural and political context. According to the theoretical framework of Vulnerability and HR, the problematization of the notion of the individual conceived as a set of biopsychic-behavioral factors proposes an awareness of real people. In their daily lives, they come across normativeness and social powers supported by political organization, economic structure, cultural traditions, religious beliefs, gender relations, race relations, etc. Based on this awareness we defend, along with other authors, that, in contexts of vulnerability, health actions be associated with the notion of the right-holder, and not that of the biopsychic-behavioral individual(8).

In 2016, in Porto Alegre, to contribute to the knowledge of these themes, a study was developed to analyze social processes that silence the voices of certain groups affected by coinfection(9). Porto Alegre is the second Brazilian capital with the highest incidence of TB, the first in HIV/AIDS incidence, and the highest proportion of coinfection in the country, with 25% of cases of TB diagnosed in people living with HIV(10).

Considering that there are already elements showing the sites and cases of tuberculosis/HIV/AIDS that deserve greater attention, this research was initiated in an attempt
to answer how and why individuals from certain population groups continue to develop coinfection and die so often. This exercise led to the problematization of the results regarding the following objective: to analyze how belonging to certain social groups contributes to constituting the vulnerabilities associated with illness due to TB/HIV/AIDS coinfection.

**METHODOLOGY**

This article originated from the doctoral thesis “Estudo epidemiológico sobre coinfecção TB/HIV/AIDS e fatores de risco para a internação e mortalidade em Porto Alegre” (Epidemiological study on TB/HIV/AIDS coinfection and risk factors for hospitalization and mortality in Porto Alegre) (8).

The research was developed through the methodology of The Sound of Silence, in four different stages (3-7). In the first, a literature review was carried out to delimit the research object. In the second, we sought to explore which groups were silenced through the profile and the District Administration Health Units (DAHU) where the cases of coinfection were located. In the third stage, qualitative data were produced about the research participants with TB/HIV/AIDS who live in situations of vulnerability. The fourth stage consisted of data analysis.

The scenarios were selected through the calculation of the prevalence rate of coinfection by gender, race/color and DAHU (second stage). Porto Alegre has its territory divided into eight DMs: Center (CEN), North/Eixo Baltazar (NEB), East/Northeast (LENO), Gloria/Cruzeiro/Cristal (GCC), Southern/Center-Southern (SCS), Partenon/Lomba do Pinheiro (PLP), Restinga/Extremo Sul (RES), Northwest/Humaitá/Navegantes/Ilhas (NHNI).

After analyzing the coinfection rate by the DAHU, gender, and race and color, the managements CEN (because they had a greater non-white coinfected population), LENO (because they had a greater coinfected female population), and PLP (because they had a higher prevalence of cases of coinfection) were selected. The reference centers for treatment of tuberculosis of each management were used to perform data collection. The inclusion criteria were: being treated for coinfection and being over 18 years old.

Data collection took place between August and December 2016, in reference centers for the treatment of tuberculosis linked to each DAHU. Twenty interviews were conducted with open questions about how the TB/HIV coinfection process developed. The script contained questions such as: Tell us how you found out you were coinfected with TB/HIV. Discuss how treatment is being performed for both diseases. Is there any difficulty in performing the treatment for coinfection? The questions enabled the research participants to describe how their illness course was, listing aspects of their diagnosis and treatment for coinfection. The sample size was delimited by the data saturation criterion.

Data analysis (fourth stage) followed the guidelines proposed in the theoretical framework of The Sound of Silence methodology (3-7). The interviews were transcribed and read with the desire to find units of analysis (words or phrases) that could be grouped into common units, referring to the objective of analyzing how belonging to certain social groups contributed to constituting the vulnerabilities associated with TB/HIV/AIDS coinfection.

The study followed the guidelines of Resolution 466/2012 of the National Health Council. The project was approved by the Research Ethics Committee of the Federal University of Rio Grande do Sul (UFRGS) and by the Ethics Committee of the Municipal Health Department of Porto Alegre, under reports no. 952.907 and 939.250, respectively. To ensure anonymity, participants were identified with the letter P and a number from 1 to 20.

**RESULTS AND DISCUSSION**

The results were debated in the light of The Sound of Silence theory (3-7), which supports the methodology used, coupled with the theoretical framework of Vulnerability and HR (3-6). Regarding the methodology of The Sound of Silence, it is worth mentioning that it is a theoretical framework that allowed the use of new methodological paths, contributing to the delimitation of the research problem, data obtainment, and analysis, problematizing the existence of silenced groups in the studies. As discussed above, considering the theoretical framework of Vulnerability and HR, some criticism to the use of risk factors as hegemonic parameters for health actions, pointing out that such actions should adhere to the notion of right-holder, and not that of the biopsychic-behavioral individual.

The process of getting TB/HIV/AIDS in Porto Alegre occurred in scenarios of extreme social vulnerability, which was closely related to the denial of citizenship and non-respect of people as right-holders.

According to what was revealed in the research, some of the conditions experienced during the process of sickness had an important role in increasing vulnerabilities to HIV and TB infections, and worsening of people's health. As described in Chart 1, these conditions include: being black, using drugs, living on the street, being a sex worker, having a history of imprisonment in the penal system, having a low education level and not having a formal job.
The study advanced towards deepening the comprehension of these conditions, revealing their naturalization, and the invisibilization of groups affected by TB/HIV/AIDS coinfection. This process resulted in difficulties in communicating and recognizing their needs, including health needs. It is, therefore, a process of silencing or even oppression of the voices that could, depending on the opportunities of communication, express anxieties, values and difficult experiences along their illness course.

Some lines suggest that, sometimes, in communication with health professionals, guidelines that could aid in the recovery/rehabilitation process were omitted, and people’s symptoms and complaints were neglected. Some professionals also assumed a position of custody of the users, as it is possible to observe in the following:

*I took a lot of medicine that I do not even know what for.*

(P9)
Then the doctor doubted what I said. I said that the lung itself was hurting, but he thinks it’s because I do not take the medicine, but I take it. (P20)

I escaped from there (hospital). There is a rule to leave, a rule to enter, a rule for everything. If you are late, you have to ask the doctor. To go out, you have to get your doctor’s permission. (P4)

According to the information in Chart 1, it is possible to identify that, in general, people who developed coinfection had conditions such as informal employment, volatile income, with restricted access to education; in addition, many of them lived on the streets, and had experiences of imprisonment in the prison system. The participants’ statements show that their lives are marked by successive material and moral problems, ranging from no guarantee of living conditions, to abuse, violence, and little resolution in healthcare facilities.

Illnesses from coinfection were not always due to a linear sequence of events: HIV infection - immunological deficiency - non-adherence to treatment - tuberculosis infection. To a certain extent, data revealed that several medical diagnoses and facts of daily life occurred simultaneously, with the discovery of HIV infection and coinfection with diseases such as tuberculosis, syphilis, toxoplasmosis, herpes, among others, being frequent during a hospital stay or medical consultation for another reason. The succession of events and the difficulties of diagnosis and treatment may have been aggravated by the social situation in which the research participants were (homelessness, sex work, imprisonment). The timing of infection transmission, especially of HIV, has been described by the study participants, so it is not possible to precisely delimit this period. The following statements indicate that, many times, the diagnosis of coinfection was made under some circumstances:

Oh! It was in life. It was an involvement with a prostitute, and drug... And, these things, I got from life itself, I can’t say correctly when it was. (P14)

Exactly, because I had tuberculosis, I discovered that I had HIV because I was coughing too much. (P1)

I had it all together, it was in the hospital that I discovered. I was admitted to hospital because I didn’t walk, I got the disease from a cat. I had six illnesses when I went to the hospital. (P10)

The participants express a relational dynamics in the health services that makes these people and their needs invisible. Some reports also point to the precariousness of the users’ link with services, a context that took them away from the chances of having the right to a timely diagnosis and treatment and disease control, as follows:

I went to the community health center, and the woman told me to go to hospital, I went home. Then, on Monday I went to the hospital, I was sick, I was hospitalized. On Tuesday I took the exams and stayed in hospital. Then, after a few days I went to see the result. I knew I had the thing [HIV], so they told me to take all the medication here. (P4)

I was all marked, I went to the ground three times ... it took time in the health center to know what it was. (P7)

Silence existed because, very often, these individuals’ complexity of life circumstances was not taken into account. They were people who lived in conditions of extreme vulnerability, and who were often liable and blamed for being in these conditions. Studies with persons serving a sentence in the prison system have shown that these research participants are often stigmatized by health professionals and that former offenders could be better cared for if the services could understand their health and structural needs better.

Another relevant issue concerns the right to education as opposed to the precarious access to education of the interviewees. Only two had completed high school, and the others stated they only knew how to read and write. Education precariousness is a piece of information that may reveal other deficiencies related to their socioeconomic condition; it is known that the lower the level of education, the greater the difficulties to find a job with a fair salary, and to have an income that supplies essential life needs will be.

The participants’ low level of education may have a direct influence on how they get sick. According to the statements below, they had informal jobs and difficulties to remain employed due to their physical conditions and lack of resources for housing and food:

When possible, I work at a bar on the weekend to get the rent money. Anyway, we eat there and get organized. (P8)

You can see the chart there, I stopped treatment three or four times. Some days I worked at night, took the medicine and slept for a few hours, took the medicine, left home at eleven pm, and spent the night working. I needed. (P16)
The difficulty of adhering to treatment is a problem reported in several studies. In Porto Alegre, the dropout rate for coinfection treatment reaches 40%[12]. Thus, understanding treatment discontinuation requires considering the social condition of those who become ill. As shown in their words, a person with a low educational level, linked to the informal labor market, exposed to poor housing and insufficient food, first needs to fight for their immediate survival needs and then for their health, as referred to below:

Then, today I explained to the doctor there, because he asked me: “why I sometimes didn’t take the medicine”. And I said: “What is the use of taking the medicine if you are hungry?” Then, you take the medicine, get anxious, it makes you hungry, then I said “no, we have to eat.” (P16)

Oh! I have no ticket, I have no money. I bought some things to eat, the money I brought today was already spent. (P7)

It’s very difficult, a bad life on the street. Not having anywhere to sleep, not having anywhere to wash, not having anything to feed me. (P9)

The simplification of the therapeutic approach, which is focused only on the availability of drugs, seems to be revealing of the silencing and invisibilization of the life situation of those who become ill. Criticism about health interventions based exclusively on criteria of technical success has been intensified. Such interventions become selective, iniquitous and fragmented, reiterating the notion of the person as an object, whose life should be organized and disciplined. In a substitutive perspective, it is possible to propose care approaches expressly guided by a spontaneous and creative sympathy between health professionals and users under their care. These approaches have the potential to disclose neglected, oppressed, or unfamiliar voices and subjective perspectives that are common in contexts marked by deep social inequalities[13].

A publication analyzing social inequalities at the global level shows that three of the ten main causes of death are infectious diseases. These also account for 16% of deaths each year. Most of these deaths occur in poor and developing countries and are attributable to preventable or treatable diseases such as diarrhea, respiratory infections, HIV/AIDS, tuberculosis and malaria[14]. In these contexts, most of the diseases are neglected, including TB and HIV/AIDS. Although there have been significant advances in the discovery of interventions to prevent and treat them, such interventions are not always available to the populations that most need them[13].

Other problems that mark illnesses due to coinfection are situations of violence and drug use, life scenarios marked by social, cultural, material and political adversities. These situations are not always the focus of attention in health services, and their effects on the clinical picture of people living with TB/HIV/AIDS are often not considered. The statements show that cases of murder, abuse and domestic violence associated with drug use are frequent where the participants lived. The following statements illustrate some of these events and how they are trivialized:

I was not well because I spent all night using drugs. Then, we began falling in disagreement, she killed herself, got soaked in alcohol and committed suicide. That’s why I was arrested. (P5)

Due to robbery, I did not kill anyone or anything, the difficulty found me in this: stealing. Then I went to semi-open prison and ran away. They caught me stealing again, I came back again. (P20)

And this amputation here was the result of shooting. (P14)

Here was a stab. He woke up and said he was going to kill me. But I also broke him. (P10)

Drug use and violence and splitting in crime and incarceration have been identified in other publications[16-17] as events related to greater susceptibility to coinfection and worsening of health status. In one study, the use of alcohol and other drugs was also reported as influential in episodes of discontinuation of tuberculosis treatment[12].

The social process involved in silencing people and their health needs is the same that silences them in the justice and security system. The most criminalized people, and the most exposed to violence in Brazil are black, poor and with low levels of education[18]. Like in health, it can be said that these sectors, with their traditional practices, do not contribute to the formation of critical awareness that associates racism and contempt for poverty to social exclusion. Being socially excluded, these people have reduced power to transform the context in which they are inserted and little chance of accessing resources that would prevent them from situations of violence, crime, and drugs.

Among the symbolic elements that are determinant of the health and disease process, gender issues were also significant in the researched scenario. This was evidenced in the ways in which people became infected by HIV/AIDS, being different in men and women. It was clear that the vulnerability to infection is closely related to protection/ex-
Exposure behaviors manifested in consonance with belonging to a particular gender category:

- I got HIV from a husband I had. He’s dead, his ex-wives died, the only one alive is me. (P9)

- The other one got from me. He never wanted to wear a condom. He would say, “Oh, I won’t wear a condom, no way!” (P10)

- I think I went out with all the crazy women around. I went to the whorehouse, went out with the sluts and had sex with three of them. (P4)

- In a cabaret. I had sex without a condom for more money. I worked there and they paid more without a condom. I accepted. My poor mother never explained to me what a condom is, she never explained to me what it is to have sex, all this I learned on my own when I went to work in the cabaret at the age of 13. (P7)

- I got HIV because I went out at night a lot and then the nice one [sic] deceived me ... The handsome guy can have it and the pretty woman can have it. A flirt wannabe and such, he drank and smoked. That’s where all this led to. (P15)

A previous study demonstrated the influence of gender on behaviors that increase sexual transmission of HIV. The predominant female reliance on stable relationships and the typical male rejection to condoms pointed out in this study could also be noted by the statements by P9 and P10. Measurement of risk may be different for men and women. For men, the way they dealt with the risk for sexually transmitted infections could be manifested in words such as those by P15 – “was a flirt wannabe” - and P4 – “I even got to have sex with three at the same night”. Among women, the most expressive statement of this experience with the risk was that of P7: “I had sex without a condom for more money”. In this case, the risk was related to a submission that resulted from the opportunity to increase the gains from prostitution.

In health services, gender relations and the way men and women are socially seen often interfere in the approaches of professionals who, by naturalizing male and female behaviors, stop working with protective measures to avoid coinfection. This is because they believe that certain behaviors are common to ‘being a man’ and ‘being a woman’ in a particular culture or social class.

Analysis of the information indicates that the most significant aspects in the constitution of vulnerability to TB/HIV/AIDS coinfection of the research participants refer to social situations produced in contexts of material and symbolic disadvantages. From the material point of view, precarious access to goods and services that are essential to the maintenance of existence are observed, triggering a clear violation of the most important and fundamental human right: life. From the symbolic point of view, oppression, prejudice, and discrimination can be observed in a cultural scenario marked by inequalities of gender and social class.

The restricted expressiveness of these people’s needs and demands, the result of their constant silencing, potentiates their condition of research participants with little chance of exercising citizenship. This situation strains the responses offered by the health services, usually not referenced by a psycho-social health approach. The use of this approach, coupled with the notion of human rights, would lead to innovations in the way care is provided, and greater effectiveness of actions, by demonstrating who is at a disadvantage, how these disparities determine the worst health outcomes for certain groups, and how much these outcomes are the result of injustice.

Investing in active listening to uncover the social specificities of groups most affected by TB/HIV/AIDS co-infection would not only increase the expectation of technical success in health (cure and disease control), but also contribute to mitigating vulnerabilities that hinder projects of a just and egalitarian society.

**FINAL CONSIDERATIONS**

In this study, coinfectioned people/participants were from disadvantaged sections of the population, marked by poverty and the violation of fundamental rights for achieving a dignified human condition. Information analysis allows to conclude that, in the context studied, the limitations related to level of education have repercussions on access to better working conditions and on the offer of a fair remuneration, social security and protection against occupational risks. Situations of use of alcohol, drugs, and violence are frequent and may be related to the places where people live, areas of the city known to be dominated by drug trafficking and constant police intervention. Gender also appears to have influenced HIV infection and the development of coinfection with tuberculosis and other diseases, because the research participants, both men and women, made use of sexual practices considering that the risks of infection did not exist or were lower in relation to others risks they were exposed to.

It was concluded that the experiences of coinfectioned research participants are marked by a process of invisibili-
zation and silencing that interferes negatively in their conditions to recover health. Silence exist because these individuals are not seen as right holders, that is, they are people who are not in a position to exercise their citizenship, as far as political, social and economic rights are concerned. Lacking a legitimate voice, they lack the power or political recognition to participate in the debate in order to influence change, which limits their ability to advocate for their needs and their social inclusion.

In health vulnerability processes, this logic needs to be revoked and its repercussions need to be addressed for health actions to be effective. This way, the perspectives are widened when health care is based on the notion of human rights. We learned from the Vulnerability and HR framework to recognize people’s singularities - their subjectivity and their sociability - from the possibilities of exercising their rights, thus being conceived as right holders, and no longer as a generic sample of a person, defined according to epidemiological criteria. In this sense, the notion of Vulnerability and HR is fundamental for the person to be made visible stemming from the complexity of his/her existence in a world marked by inequalities.

The relevance of this study to the health field in general and to nursing in particular has to do with its potential to indicate the programmatic failures that occur in the study scenario and to express the urgency of a resizing of direct health actions to coinfected individuals, beyond the biomedical perspective, still hegemonic in the health services. Caring for coinfected people requires a look that seeks to assimilate the difficulties of each subject regarding treatment compliance and maintenance, understanding the contexts that make them invisible and silence their voices.

The study allows recommending, to health professionals, especially of the nursing area, an extension of the traditional ways of caring, of intervention possibilities that value the research participants’ singularities, and contribute to ensure access to fundamental human rights. The recognition of the importance of these singularities in the health-disease process of coinfected individuals can influence changes in the teaching of these professionals, as well as to base research proposals and university extension that contribute to promoting education that overcomes the traditional biomedical bias. Health actions that may not only be more effective in promoting adherence to treatments but also, and above all, consciously investing in improving health conditions of stigmatized and vulnerable populations.

A limitation of this study stands on the difficulty to identify the coinfected research participants in the health services, because there is no integrated registry system with data on the health problems of each user, with a manual review of several records and systems being necessary.

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