



Acta Paulista de Enfermagem

ISSN: 0103-2100

ISSN: 1982-0194

Escola Paulista de Enfermagem, Universidade Federal de São Paulo

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Acta Paulista de Enfermagem, vol. 35, eAPE03661, 2022
Escola Paulista de Enfermagem, Universidade Federal de São Paulo

DOI: <https://doi.org/10.37689/acta-ape/2022AO03661>

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Perceptions of people with tuberculosis/HIV regarding treatment adherence

Percepções de pessoas com tuberculose/HIV em relação à adesão ao tratamento
 Percepción de personas con tuberculosis/VIH con relación a la adherencia al tratamiento

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How to cite:

Silva AR, Hino P, Bertolozzi MR, Oliveira JC, Carvalho MV, Fernandes H, et al. Perceptions of people with tuberculosis/HIV regarding treatment adherence. Acta Paul Enferm. 2022;35:eAPE03661.

DOI

<http://dx.doi.org/10.37689/acta-ape/2022A003661>



Keywords

Medication adherence; Coinfection; HIV; Tuberculosis

Descritores

Adesão à medicação; Coinfecção; HIV; Tuberculose

Descriptores

Cumplimiento de la medicación; Coinfección; VIH; Tuberculosis

Submitted

December 5, 2020

Accepted

March 25, 2021

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Abstract

Objective: To analyze aspects related to adherence to tuberculosis treatment in people living with tuberculosis/human immunodeficiency virus coinfection.

Methods: This is an exploratory, descriptive, qualitative study on adherence to tuberculosis treatment among people with tuberculosis/human immunodeficiency virus coinfection. The study setting was a reference center for human immunodeficiency virus/acquired immunodeficiency syndrome located in the capital of the state of São Paulo. The data collection instrument contained socio-demographic and health profile related questions. The discourse analysis method was used for the analysis of the empirical material, which allowed the comprehension of thematic phrases.

Results: Sixteen people were interviewed. Most were male, mixed race, in the age group of 30-39 years, with 9-12 years of study, living alone, single and declared themselves homosexuals. Three categories of analysis emerged from the analysis of testimonies: Health-disease process: the impact of the diagnosis and the meanings of living with coinfection; Drug treatment: reasons for follow-up, facilities and difficulties involved; and Care in the health service: embracement and support networks that favor treatment adherence.

Conclusion: Adherence to treatment in the tuberculosis/human immunodeficiency virus coinfection has shown a relation to the way people are inserted in society, their living and working conditions. The fact that care in health services interferes with adherence is also noteworthy, given the importance of the bond between the health professional and the user.

Resumo

Objetivo: Analisar aspectos relacionados à adesão ao tratamento da tuberculose em pessoas que vivem com coinfeção tuberculose/vírus da imunodeficiência humana.

Métodos: Trata-se de um estudo exploratório, do tipo descritivo, com abordagem qualitativa sobre a adesão ao tratamento da tuberculose entre pessoas que apresentam a coinfeção tuberculose/vírus da imunodeficiência humana. O cenário do estudo foi um centro de referência para vírus da imunodeficiência humana/síndrome da imunodeficiência adquirida do estado de São Paulo, localizado na capital. O instrumento de coleta de dados continha questões relacionadas ao perfil sócio demográfico e de saúde. Para a análise do material empírico foi utilizado o método de análise de discurso que permitiu a apreensão de frases temáticas.

Resultados: Foram entrevistadas 16 pessoas, sendo a maioria do sexo masculino, da cor parda, na faixa etária entre 30 a 39 anos, com 9 a 12 anos de estudo, que moravam sozinhos, solteiros e que se declararam homossexuais. Da análise dos depoimentos emergiram três categorias de análise: Processo saúde doença: o impacto do diagnóstico e os significados de viver a coinfeção; Tratamento

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Conflicts of interest: none to declare.

medicamentoso: motivos para o seguimento, facilidades e dificuldades envolvidas; e Cuidado no serviço de saúde: acolhimento e redes de apoio que favorecem a adesão ao tratamento.

Conclusão: A adesão ao tratamento na coinfeção tuberculose/vírus da imunodeficiência humana mostrou-se relacionada à forma como a pessoa está inserida na sociedade, suas condições de vida e trabalho. Ressalta-se também que o cuidado nos serviços de saúde interfere na adesão, dada a importância do vínculo entre o profissional de saúde e o usuário.

Resumen

Objetivo: Analizar los aspectos relacionados con la adherencia al tratamiento de tuberculosis en personas que viven con la coinfección tuberculosis/virus de la inmunodeficiencia humana.

Métodos: Se trata de un estudio exploratorio, tipo descriptivo, con enfoque cualitativo, sobre la adherencia al tratamiento de tuberculosis en personas que presentan la coinfección tuberculosis/virus de la inmunodeficiencia humana. El escenario de estudio fue un centro de referencia del virus de la inmunodeficiencia humana/síndrome de inmunodeficiencia adquirida del estado de São Paulo, ubicado en la capital. El instrumento de recopilación de datos contenía preguntas relacionadas con el perfil sociodemográfico y de salud. Para analizar el material empírico se utilizó el método de análisis de discurso que permitió extraer frases temáticas.

Resultados: Se entrevistaron 16 personas, de las cuales la mayoría era de sexo masculino, de color pardo, del grupo de edad entre 30 y 39 años, con 9 a 12 años de estudios, que vivían solos, solteros y que se declararon homosexuales. Del análisis de los relatos surgieron tres categorías de análisis: Proceso de salud y enfermedad: el impacto del diagnóstico y los significados de vivir la coinfección; Tratamiento farmacológico: motivos para el acompañamiento, facilidades y dificultades relacionadas, y Cuidado en el servicio sanitario: contención y redes de apoyo que favorecen la adherencia al tratamiento.

Conclusión: La adherencia al tratamiento de la coinfección tuberculosis/virus de la inmunodeficiencia humana demostró estar relacionada con la forma como la persona está insertada en la sociedad, su condición de vida y trabajo. También se observó que el cuidado en los servicios de salud interfiere en la adherencia, debido a la importancia del vínculo entre los profesionales de la salud y los usuarios.

Introduction

The epidemiological magnitude of tuberculosis (TB) represents a global health threat.⁽¹⁾ The disease is among the top ten causes of death caused by infectious diseases and is the leading cause of death among people living with HIV and AIDS (PLWHA). In 2019, 10 million people worldwide fell ill with TB, of which 8.2% were coinfecting with HIV. Of the total number of TB cases, 1.2 million people died, and of these, 208,000 deaths occurred among PLWHA.⁽²⁾

The United Nations (UN) and the World Health Organization (WHO) have long proposed strategies for ending TB. Tuberculosis is highlighted in the Sustainable Development Goals (SDGs). The WHO End of TB Strategy, launched in 2014, aims to eliminate TB, as well as the suffering and deaths resulting from it by 2035.⁽²⁾ In consonance with this plan, the Brazilian Ministry of Health established, as of 2017, the National Plan for the End of Tuberculosis, also targeting to reduce the TB incidence rate to less than 10 cases per 100 thousand inhabitants and the TB mortality rate to less than 1 death per 100 thousand inhabitants by 2035.⁽¹⁾

Among the countries with higher TB burden, Brazil ranks 19th on TB/HIV coinfection. In Brazil, rates for treatment default were 11.6%, with 71.9%

cure in 2019.⁽¹⁾ Such rates are still far from the target established at 5% for death and greater than 85% cure rates.⁽³⁾

The unfavorable outcomes (abandonment and death) and failures in the success of TB treatment among people with TB-HIV coinfection call attention and show the need for studies seeking to identify the determinants of non-adherence to treatment.⁽⁴⁾

Tuberculosis treatment drug interactions with antiretrovirals, drug resistance and long lasting therapy pose difficulties in the management of TB in PLWHA.⁽⁵⁾ In addition, as a result of immunosuppression, PLWHA are at a higher risk of developing TB compared to the general population. Social and health inequities add extra challenge in the control of both TB and TB/HIV coinfection.⁽⁶⁾

HIV/AIDS implications go beyond clinical aspects and may impact on mental and social status, with all these being intrinsically interdependent. TB/HIV coinfection can increase stigma and may cause rejection by family members and other people of the social circle. In addition, non-adherence to treatment contributes to clinical worsening with impact on the quality of life (QoL).⁽⁷⁾

While the TB treatment is performed for a period of at least six months, with the possibility of cure in almost all cases, the treatment of HIV/AIDS

is continuous throughout life. In this perspective, it is assumed that PLWHA who undergo TB treatment may represent a group of greater vulnerability to not following treatment, mainly due to the potential adverse effects of antituberculosis drugs and antiretroviral therapy (ART). The intolerance, in addition to other aspects related to the evolution of coinfection, can lead to treatment abandonment and impact the patients' QoL.^(4,8)

Recognizing the importance of adherence to treatment in people living with TB/HIV coinfection, the present investigation was guided by the following question: According to the perception of PLWHA undergoing TB treatment, what are the aspects involved in adherence to treatment? Thus, the objective of the study was to analyze the aspects related to adherence to tuberculosis treatment in people living with tuberculosis/HIV coinfection.

Methods

This is an exploratory, descriptive, qualitative study on adherence to TB treatment among people with TB/HIV coinfection. The study took place at CRT DST Aids, a Brazilian HIV/AIDS treatment reference center in the capital of São Paulo state. This is a normative reference unit for evaluation and coordination of the State Program for the Prevention, Control, Diagnosis and Treatment of Sexually Transmitted Infections and Acquired Immunodeficiency Syndrome (AIDS) that attends users residing in the municipality and surroundings. The service is an outpatient and hospital complex with approximately 800 employees, including doctors of different specialties, nurses, dentists, pharmacists, nutritionists, psychologists, social workers, laboratory and nursing technicians and administrative officers

The study inclusion criteria were people aged 18 years or over, regardless of sex, who had an HIV-positive serology result, were prescribed TB treatment and antiretrovirals (ART) for at least a month, and with cognitive and physical conditions to participate in the study.

During the data collection period, there were 18 people with TB/HIV coinfection on TB treatment.

Convenience sampling was used, and all patients were invited to participate in the study at the moment of the medical appointment or when receiving directly observed treatment at the reference center. Data collection took place from April to August 2019 and was performed by an undergraduate Nursing student duly trained to interview the study participants. The interviews were performed individually in a private environment on the premises of the health service in order to guarantee privacy.

The data collection instrument contained socio-demographic and health related questions and the following guiding questions: 1) "Tell me about the start of your TB event. 2) Has the TB and HIV treatment brought needs that you did not have before? and 3) What are the easy and difficult issues in your treatment? Each interview lasted an average of 25 minutes; the testimonies were recorded and fully transcribed by the same interviewer. Then, testimonies were identified by a letter (I) followed by an Arabic number in order to guarantee anonymity. In-depth and exhaustive reading of the interviews was performed to apprehend the meanings of adherence to treatment of people who experience TB/HIV coinfection.

In this study, a concept of adherence involving three plans was used: 1) the health-disease concept of the person being treated, which can mean greater passivity or proactivity in coping with the health-disease process; 2) the social place occupied by the sick person, understanding that insertion in society determines access to life with dignity and the potential for coping with the processes that lead to strain while conducting life; and 3) the plan that addresses the health production process, that is, the way health services are organized to offer and provide health care. These constituent elements of the concept of adherence contribute to broaden the understanding of the health-disease process.⁽⁹⁾

For the analysis of empirical material, the discourse analysis method was used, allowing the comprehension of thematic phrases. Ideas and speeches are expressions of real life, containing people's worldviews that materialize in representations of elements of objective reality.⁽¹⁰⁾ The analysis of speeches was performed in the light of the social determination of the health-disease process.

The project was approved by the Research Ethics Committee (opinion number: 3.732.087) (CAAE: 91820618.0.0000.5505) and by the Research Ethics Committee of the health service where interviews were held (opinion number: 3.806.049) (CAAE: 91820618.0.3001.5375). Respondents who participated in the study signed the Informed Consent form.

Results

Two out of the 18 people invited to participate in the study refused, which was justified by the impossibility of remaining in the service for a longer period of time. Sixteen people were interviewed, most were male (n=12), mixed race (n=9), predominant age group was 30-39 years (n=6), with 9-12 years of study (n=10), living alone (n=7), single (n=14) and declared themselves as men who have sex with men (n=10). Table 1 presents the description of work, life and health-disease process conditions.

Table 1. Sociodemographic and health characteristics of people living with HIV/AIDS undergoing tuberculosis treatment

Variables	n(%)
Characteristics of working conditions	
Works	5(31.3)
Does not work	9(56.2)
Retired	2(12.5)
Characteristics of living conditions	
Income (minimum wage)	
Up to 1	6(37.5)
2 to 3	5(31.3)
>3	5(31.3)
HIV exposure	
Sexual	14(87.5)
Other	2(12.5)
HIV diagnosis time (years)	
>10	9(56.3)
1 to 9	2(12.5)
<1	5(31.2)
Viral load (copies/mL)	
<50 (undetectable)	7(43.7)
50 to 20.000	9(56.3)
CD4+ T cell count	
>350	3(18.8)
200 to 350	6(37.5)
<200	7(43.7)
Clinical form of tuberculosis	
Pulmonary	12(75)
Extrapulmonary	1(6.2)
Extrapulmonary + pulmonary	3(18.8)
Tuberculosis treatment time (days)	
31 to 90	10(62.5)
91 to 360	5(31.2)
>360	1(6.2)

*User on second treatment attempt in the same year

The analysis of testimonies showed that adherence to treatment is perceived as something complex that involves aspects transcending those related to disease clinical aspects, involving social issues. Three analysis categories emerged from the analysis process: Health-disease process, Drug treatment and Care in health services. Chart 1 presents the analytical categories and their respective constituent elements.

Chart 1. Categories of analysis and constituent elements of adherence to tuberculosis treatment among people living with HIV/AIDS

Health-disease process: the impact of the diagnosis and the meanings of living with coinfection	Drug treatment: reasons for follow-up, facilities and difficulties involved	Care in the health service: embracement and support networks that favor treatment adherence
- Impact of diagnosis - Meanings of living with TB/HIV coinfection - Health conditions	- Reasons to undertake treatment - Facilities and difficulties in treatment	- Care offered - User embracement - Support network

Regarding the category Health-disease process, the analysis of testimonies showed that experiencing TB/HIV coinfection is a multifaceted process. For some interviewees, TB represented an alert to resume HIV treatment, demystifying the false feeling of *“I have nothing”* (I2). For others, the search for care was motivated by a flu-like condition that intensified with *“fever and a lot of lung pain”* (I12), which led to the diagnosis of both TB and HIV. As a result, changes in daily life occurred as a way of adapting to the diseases. The most cited were not being able to go out as often, having to prioritize health care, in addition to the search for knowledge about HIV, TB and other opportunistic diseases.

Feelings of surprise and fear were common when receiving the diagnosis of TB and HIV, as illustrated by the following statement: *“when I discovered HIV, it was a shock, I wanted to kill myself, because I did not know the disease”* (I6). With the diagnosis of TB, feelings of fear and panic were mentioned, in addition to the intensification of symptoms of the disease: *“I couldn’t sleep at night, I sweated a lot, and had a cough that would not go away”* (I10), *“a lot of fever, that sweating, lack of appetite”* (I11).

Some participants who had not undergone ART reported that their health condition became compromised with HIV infection: *“I was weakened”*

(I11), *“I did not feel the movements of my legs”* (I3), *“I had a headache, drowsiness”* (I10).

Regarding changes in life, one of the interviewees reported that because he was infected with HIV while still in adolescence (I2), he did not remember his life before that period. Furthermore, some interviewees (I4, I5) who reported having been diagnosed with HIV at a time when ART were not available, considered that, as they were asymptomatic, they worried about the disease only after experiencing the death of close people. Others also mentioned that TB or HIV diagnosis had implications on mental health, such as suicidal ideation (I6, I8).

Social issues arising from the diagnosis of TB/HIV coinfection were also mentioned. Respondents reported that disclosing treatment and serological status directly affected daily life and interpersonal relationships: *“I think I have a lot of difficulty in socializing, in my social life, you know”* (I2). *“I am no longer able to have relationships with anyone”* (I10).

In relation to the category Drug treatment, the search for quality of life and the fear of dying were mentioned among the reasons for taking the treatment. Experiencing TB/HIV coinfection was reflected in the commitment to undertake drug treatment. According to an interviewee, the TB diagnosis determined that he should try to resume ART: *“it is a good time, because this panic makes me stick to treatment”* (I2).

On the other hand, the treatment goes beyond taking medications and involves moral, religious and sexual issues: *“it goes a little beyond that, these situations I am dealing with now, I was abused as a child, sexual hyperstimulation, religious repression”* (I2).

Family support revealed itself in different ways that directly interfere in the continuation of therapy. Family's acceptance of sexual orientation and serological status were perceived as positive and strengthened the continuation of treatment *“She [mother] is my support for everything, she is my life, my everything, nowadays, she is the one who makes me live”* (I11). The opposite occurs when family members showed attitudes of denial or even exclusion, such as: *“yesterday my father told me to leave the house, I don't know if because of TB too, he no longer accepts me”* (I1).

TB/HIV coinfection seemed to be an incentive for treatment adherence. Some users reported that the state of physical weakness made them feel obliged to continue treatment: *“I put it in my head: there is only one way, either to die or to be treated”* (I6); *“Ah, I set a goal in my mind that I want it to come out of me, then, I think about taking the medicine every day”* (I3).

Regarding to the incentives to stick to the therapeutic scheme, participants reported that the bond established with the health service favored treatment adherence, mainly because they felt embraced and free from prejudice *“I felt embraced, was well treated, in four days I got out of bed, I have the confidence to get here and open myself up”* (I11). The provision of medicines and food incentives by the public service, free of charge, the easy access to the health unit and the bond with the health care team were also mentioned as facilitators for the continuation of treatment.

On the other hand, social stigma has a negative impact on the lives of people who experience TB/HIV coinfection, making treatment adherence difficult: *“I spent a year in retreat, I didn't want to see nor talk to anyone, I only knew how to keep my distance, I isolated myself for a year, either because of my prejudice in relation to the disease, or because of the prejudice of others”* (I9).

In addition, some reports mentioned that health care makes the treatment routine stressful: *“my life is only doctor”* (I10), which leads the user to reflect: *“I will have to take the medicines every day for the rest of my life, it's something I didn't want for myself”* (I7).

Finally, the category “Care in the health service”, revealed that user embracement represents one of the main pillars for adherence to treatment of TB/HIV coinfection (*“the staff is highly concerned about the person as a whole, aren't they?”* (I8), since it constitutes a support network. The bond with the health team and the provision of food assistance (monthly food parcel) is highlighted. Most interviewees reported that the availability of free medicines and food supplements, the possibility of carrying out laboratory tests and multidisciplinary follow-up in the service were essential to continue the clinical management of coinfection. Due to the

above mentioned, despite the fact of living far from CRT DST Aids, users chose to be treated there.

Discussion

The testimonies showed that adherence is not limited to an act of personal volition and individual nature exclusively, but is associated with other dimensions, such as user embracement in the health unit and family support.⁽¹¹⁾ Adherence to treatment is not reduced to the acceptance of drug therapy, but a multi-faceted process involving the multidisciplinary team and co-responsibility of the user. A study conducted in the city of Campinas with people on TB treatment showed the importance of health education when offering information and guidance on the disease and treatment as a way to improve treatment adherence.⁽¹²⁾

The testimonies were explicit in showing that adherence to treatment is strongly related to the way the health service receives the user by offering quality and humanized care

The importance of the bond between the multidisciplinary team and the user was highlighted in the testimonies and constitutes a facilitator of treatment adherence, especially if the care is centered in the user, with attention to individual health needs. Shared decisions when making the therapeutic plan brings users closer to the healthcare team, and encourages the patient to reach for help when in need. This finding corroborates a study that brings user-centered care and based on monitoring and counseling that encourage self-management of health care as elements of success to the treatment.⁽¹³⁾

Likewise, testimonies reported that the incentives received contributed to strengthen treatment adherence, especially for the more socially vulnerable. Some authors advocate that even if not being the solution to health problems and needs, incentives minimize the suffering of the affected ones, and more than that, social protection must be an structural part of society.⁽¹¹⁾

A study was conducted in Ukraine to identify TB treatment adherence challenges from the patients' perspective showed that the time and cost of the

journey to reach treatment was an obstacle to adherence, as well as the lack of qualified listening and user embracement.⁽¹⁴⁾ The analysis of testimonies of the present study showed that despite the time spent in the journey, the cost and the waiting time at the service, users chose to continue treatment in this health unit, because of the quality of care and the bond established with the healthcare team. This service was understood by participants as a place that meets the health needs in both HIV and TB treatment.

In another line, social stigma resulting from HIV and TB can affect treatment adherence. When prejudice occurs within the family and social spheres, the odds of non-adherence seem to be higher. The present study findings corroborate the ones of an investigation performed in two South African provinces, in which simultaneous adherence to treatment for TB and ART was evaluated to identify the risk factors for non-adherence to both treatments. The results showed better adherence and health care in those who disclosed their serological status to family and friends and could count on their support to remind them to take the medications.⁽¹⁵⁾

The findings of this study are in line with a national study in which the desire to live of people with TB/HIV coinfection was essential for treatment adherence, because it allows overcoming barriers imposed by health conditions.⁽¹⁶⁾ In fact, interviewees reported that the search for quality of life and the fear of dying were reasons for seeking health services and adhering to treatment.

The testimonies revealed that quality of care is decisive for the continuity of treatment, and also mentioned accessibility, a good relationship with the multidisciplinary team, as well as availability of medications and food incentives. It is known that dissatisfaction with the health service and long wait for care can negatively influence adherence to treatment, discouraging treatment. Therefore, when the health promotion process involves the individual, treatment commitment is enhanced.⁽¹⁷⁾

In the context of therapeutic management of coinfection treatment, participants reported that falling ill with TB brought up the need to resume ART and health care, representing one of the reasons for treatment adherence. A study conducted in Rio de

Janeiro showed that the impact of TB diagnosis is directly associated with acceptance of the serological condition, since the diagnosis of coinfection was a result of deficient care with one's health, with TB being a coinfection that worsens life with HIV. ⁽¹⁸⁾

The user's behavior may not be the same for each therapeutic regimen, given the specific intrinsic complexity. Like the reports observed in interviews, this study revealed that adverse effects, social isolation, and stigmatization of coinfection negatively influenced adherence to treatment. Therefore, the need for a care model focused on the therapeutic management of coinfection and its particularities is confirmed. ⁽¹⁹⁾

A study conducted in Ceará state aimed to evaluate ART adherence in TB treatment found that adherence to treatment was lower in patients coinfecting with TB/HIV. ⁽²⁰⁾ The population of the present study is similar to interviewees of the Ceará study, since most were male and in the 30-39 age group, which represents economically active individuals. This particular aspect may suggest that the therapeutic plan may demand adjustments to accommodate this need.

Since TB/HIV coinfection remains a challenge for the control of both TB and HIV, the results of this study reinforce the need to implement collaborative actions between both diseases coordinating the health care networks in order to offer comprehensive and qualified care to adequately fulfil the needs of PLWHA on TB treatment.

A possible limitation of this study was the fact it was restricted to only one reference service for the care of PLWHA. However, given the richness of testimonies, we believe the information enables a reflection with regard to adherence to treatment in the perception of PLWHA undergoing TB treatment.

Conclusion

The present study investigated issues related to adherence to treatment of TB/HIV coinfection, including the health-disease process, drug treatment and care in health services. In this sense, we highlight that the establishment of a bond between the user and the healthcare team favors adherence, as

well as the support networks and incentives provision. On the other hand, social stigma and prejudice involving both conditions may negatively interfere with treatment adherence. The findings of this study corroborate WHO End of TB Strategy pillars, since they demonstrate the importance of patient-centered, integrated care, in close connection with bold policies that promote access to treatment at good quality healthcare services, where a stable bond with the user can be maintained.

Acknowledgements

To the São Paulo Research Support Foundation (FAPESP) for granting a Scientific Initiation scholarship (Process 2018/02915-0).

Collaborations

Silva ARS, Hino P, Bertolozzi MR, Oliveira JC, Carvalho MVE, Fernandes H and Sakabe S declare that they contributed to the design of the project, analysis and interpretation of data, writing of the article, critical review of the intellectual content and final approval of the version to be published.

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