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Clinical profile of patients referred to a palliative care team: integrative review

Perfil clínico de pacientes encaminhados para acompanhamento pela equipe de cuidados paliativos: revisão integrativa

Perfil clínico de los pacientes derivados para seguimiento por el equipo de cuidados paliativos: revisión integrativa

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ABSTRACT

Objectives: To identify in the national and international literature the clinical conditions of patients from different medical specialties referred to the palliative care team. **Methods:** Integrative review carried out in the databases Medical Literature Analysis and Retrieval System Online, Cumulative Index to Nursing and Allied Health Literature, Embase, Scopus, Latin American and Caribbean Literature in Health Sciences and Database in Nursing. **Results:** 15 articles were included. Most patients were characterized by the diagnosis of cancer, low functional capacity and high occurrence of symptoms, with pain being the most prominent symptom, followed by fatigue and dyspnea. **Final remarks:** Patients are referred to the Palliative Care team late, with multiple symptoms and in end-of-life care.

Descriptors: Palliative care; Medicine; Nursing; Referral and consultation; Signs and symptoms.

RESUMO

Objetivos: Identificar na literatura nacional e internacional quais as condições clínicas dos pacientes das diversas especialidades médicas encaminhados para a equipe de cuidados paliativos. **Métodos:** Revisão integrativa realizada nas bases de dados Medical Literature Analysis and Retrieval System Online, Cumulative Index to Nursing and Allied Health Literature, Embase, Scopus, Literatura Latino-Americana e do Caribe em Ciências da Saúde e Banco de Dados em Enfermagem. **Resultados:** Foram incluídos 15 artigos. Os pacientes foram caracterizados, em sua maioria, pelo diagnóstico de câncer, baixa capacidade funcional e alta ocorrência de sintomas, sendo a dor o de maior destaque, seguido da fadiga e dispneia. **Considerações finais:** Os pacientes são encaminhados para a equipe de cuidados paliativos tardiamente, com múltiplos sintomas e em cuidados de fim de vida.

Descritores: Cuidados paliativos; Medicina; Enfermagem; Encaminhamento e consulta; Sinais e sintomas.

RESUMEN

Objetivos: Identificar en la literatura nacional e internacional las condiciones clínicas de los pacientes de diferentes especialidades médicas derivados al equipo de cuidados paliativos. **Métodos:** Revisión integrativa realizada en las bases de datos Medical Literature Analysis and Retrieval System Online, Cumulative Index to Nursing and Allied Health Literature, Embase, Scopus, Latin American and Caribbean Literature in Health Sciences y Database in Nursing. **Resultados:** se incluyeron 15 artículos. La mayoría de los pacientes se caracterizaron por el diagnóstico de cáncer, baja capacidad funcional y alta ocurrencia de síntomas, siendo el dolor el síntoma más destacado, seguido de fatiga y disnea. **Consideraciones finales:** Los pacientes son remitidos al equipo de cuidados paliativos de forma tardía, con plurisintomatología y en cuidados al final de la vida.

Descriptores: Cuidados paliativos; Medicina; Enfermería; Derivación y Consulta; Signos y síntomas.

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INTRODUCTION

Palliative care refers to an approach that improves the quality of life of patients (adults and children) and their families when they face problems associated with potentially fatal diseases. The objective is to prevent and alleviate the suffering they are experiencing through the early identification, correct evaluation and treatment of pain and other problems of physical, psychosocial or spiritual nature(1).

Studies indicate that referring patients to palliative care services immediately after the diagnosis of cancer can promote a better prognosis, increased survival, improved quality of life, lower symptom burden, and greater patient satisfaction(2-4). In addition, it has been reported that in the last six months of life, hospitalization expenses for patients who receive early palliative care are lower compared to those who receive it late(5).

Providing palliative care since the diagnosis of the disease prevents and relieves physical, psychological, spiritual and social suffering at all clinical moments, ensuring greater effectiveness of treatment(2,3).

However, it seems that palliative care is often indicated at a late clinical moment, failing to offer the patient and their family all the comfort and assistance to their needs as they cope with the life-threatening disease. Thus, this study aimed to identify the clinical conditions of patients from various medical specialties referred to palliative care according to national and international literature.

MÉTODOS

This is an integrative review of the literature developed in six stages: definition of the research question; search and selection of primary studies; extraction of data; critical evaluation of the studies included in the integrative review; synthesis of results; presentation of the review(6,7).

In order to locate the best available evidence in each database, we used the "PICO" strategy, described as: "P" Patient/Population (patients from various medical specialties), "I" Intervention (clinical conditions), "C" Comparison (not applicable) and "O" *Outcome* (referral to the palliative care team).

Thus, the following guiding question was established: what are the clinical conditions of patients from various medical specialties referred to the palliative care team?

The search and selection of studies was carried out in February 2021 using controlled and uncontrolled descriptors, according to the equations in the respective databases, as shown in Box 1.

Box 1 – Strategies for the search of primary studies according to the selected database

Information sources	Search strategy	Number of records identified
LILACS and BDENF via VHL	(“Estado Funcional” OR “Sinais e sintomas”) AND (“Doença Crônica” OR “Múltiplas Afecções Crônicas”) AND (“Cuidado Paliativo”) AND (db:(“LILACS” OR “IBECS”))	4
MEDLINE via PubMed	(((“Functional Status”[MeSH Terms] OR “Signs and symptoms”[MeSH Terms]) AND “Chronic disease”[MeSH Terms]) OR “Multiple Chronic Conditions”[MeSH Terms]) AND “Palliative Care”[MeSH Terms]	1366
Scopus	TITLE-ABS-KEY (“Functional Status”) OR TITLE-ABS-KEY (“Signs and symptoms”) AND TITLE-ABS-KEY (“Chronic disease”) OR TITLE-ABS-KEY (“Multiple Chronic Conditions”) AND TITLE-ABS-KEY (“Palliative Care”)	1231
Embase	(‘functional status’/exp OR ‘functional status’ OR ‘signs and symptoms’/exp OR ‘signs and symptoms’) AND (‘chronic disease’/exp OR ‘chronic disease’ OR ‘multiple chronic conditions’/exp OR ‘multiple chronic conditions’) AND (‘palliative care’/exp OR ‘palliative care’) AND [embase]/lim	441
Cinahl	(“Estado Funcional” OR “Sinais e sintomas”) AND (“Doença Crônica” OR “Múltiplas Afecções Crônicas”) AND (“Cuidado Paliativo”)	976

Source: Prepared by the authors.

The following inclusion criteria were established: primary articles published in the Medicine and Nursing areas, published in Portuguese, English and Spanish, without delimitation of time frame, and articles portraying the clinical conditions of patients from various medical specialties referred for first consultation with the palliative care team. The exclusion criteria were: secondary studies, duplicated studies in the selected databases, clinical case reports, editorials, articles without availability of the abstract and/or the full text, and articles that were out the area of human health.

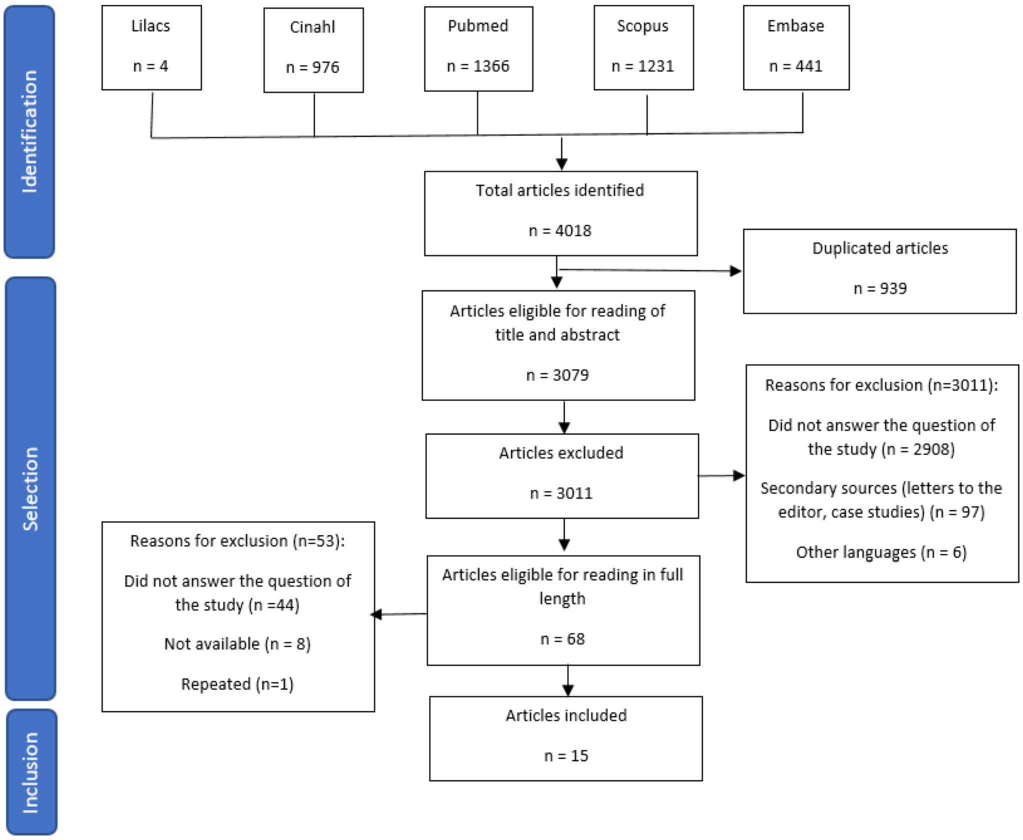
The selection of studies was carried out independently by two researchers using the Rayyan selection application, a free web review program (Rayyan Qatar Computing Research Institute, single version)(8). In the case of divergences regarding the inclusion of studies, a third researcher was called for final consensus. The selection process consisted of two phases: in the first, the selection was made based on the reading of the title and abstract, and the second phase consisted of reading the entire article. At the end of each phase, the consensus among the researchers was implemented.

A data collection instrument adapted from an original version was used to extract data from the studies included in the integrative review(9).

The recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) were used to ensure accuracy in the conduction and reporting of this integrative review(10).

In all, 15 articles were included in the review, as shown in Figure 1.

Figure 1 – Flowchart of the selection process based on the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses*, 2021



*PRISMA
Source: Prepared by the authors.

RESULTS

The results found in each article were described in a synthesized manner and presented in Box 2.

Box 2 – Synthesis of the articles included in the integrative review. Ribeirão Preto, São Paulo, Brazil, 2021

Article	Title	Country/Year	Clinical conditions in the first consultation with the palliative care team
A1	Assessment of pain and Other Symptoms in Mexican Patients With Advanced Illness[11]	Mexico 2014	Mean age of 60.7 years. 71% reported pain with a mean severity of 3.6 assessed by VAS*. Other symptoms highlighted: constipation, dyspnea, drowsiness, weakness, nausea, depression, anxiety and anorexia.
A2	Age, cancer site and gender associations with symptoms and problems in specialised palliative care: a large, nationwide, register-based study[12]	Denmark 2019	Mean age of 69.3 years. High levels of various symptoms, poor physical function and poor quality of life. The highest scores were for fatigue, loss of appetite and pain; other symptoms: constipation, nausea, dyspnea and sleepiness.
A3	Dolor oncológico en una unidad de cuidados paliativos[13]	Spain 2009	Mean age of 57 years. Most patients were referred from the oncology service. The main complaint was pain, followed by asthenia, dry mouth, anorexia, malaise and depression. Mean survival of 60.8 days.
A4	Diferencias en pacientes oncológicos y no oncológicos ingresados en una unidad de cuidados paliativos de reciente creación en un hospital de tercer nivel en la Comunidad Valenciana[14]	Spain 2018	Mean age of 83 years, the majority (55.3%) were classified as non-oncology patients, polypathology patients with irreversible progression of their comorbidities, with advanced chronic organ disease, in the terminal stage and elderly in the final stage of life. Symptom in non-cancer patients receiving palliative care: dyspnea; symptoms in cancer patients receiving palliative care: pain, nausea and vomiting. 46% of patients had more than two limiting symptoms.

A5	Evaluation of symptoms in oncological patients admitted to an exclusive palliative care unit(15)	Brazil 2020	Important functional limitation, great extent of the disease.
A6	Longer duration of Palliative Care in patients with COPD is associated with death outside the hospital(16)	The United States 2019	Only 0.5% to 2% of living patients received palliative care, increased abruptly at death (6%).
A7	Pain characteristics and treatment outcome for advanced cancer patients during the first week of specialized palliative care(17)	Denmark 2004	Mean age of 62.8 years. Most (82.2%) had pain.
A8	Palliative care needs and symptom patterns of hospitalized elders referred for consultation(18)	The United States 2011	Mean age of 66.2 years. Symptoms reported: pain, dyspnea, anxiety, nausea, anorexia and depression.
A9	Patient-reported symptoms and problems at admission to specialized palliative care improved survival prediction in 30,969 cancer patients: A nationwide register-based study(19)	Denmark 2020	Mean age of 68.9. The mean and median survival length were 181 and 67 days, respectively.
A10	Pediatric Palliative Care, Costa Rica's experience(20)	Costa Rica 2010	The majority (73%) were between 1 and 12 years old. Malignant tumor was the main diagnosis at the time of admission (22%). Pain was the most frequent symptom and dyspnea was also common.
A11	Predictors of response to palliative care intervention for chronic nausea in advanced cancer outpatients(21)	United States 2013	Mean age of 59 years, with 11% having brain metastasis. Part of the patients (25%) had moderate to severe chronic nausea and half had constipation.
A12	Referral patterns of non-malignant patients to an Irish specialist palliative medicine service: a retrospective review(22)	Ireland 2012	Mean age of 76.6 years, and 22% were patients with non-malignant diseases. Of these, 31.5% had a diagnosis of pneumonia or exacerbation of chronic obstructive airway disease. Most (60%) of the referrals aimed at end-of-life care, followed by symptom control (25%). Main symptoms: dyspnea, pain, agitation and respiratory secretions. 78.5% of the patients died, among them 12.5% on the day of referral to palliative care and 40% between 1 and 2 days later. And 12% of patients were actively dying at the time of referral.
A13	The Kidney Supportive Care programme: characteristics of patients referred to a new model of care(23)	Australia 2018	Mean age of 74 years. The patients were referred to palliative care in the first year after diagnosis. The main reason for referral was symptom management (37%). The mean number of symptoms reported per patient was ten, of moderate severity. Main symptoms: fatigue, pain, poor mobility and dizziness.
A14	Usefulness of the Palliative Prognostic Index (PPI) in cancer patients(24)	Mexico 2012	The main symptoms were: changes in ingestion, edema, dyspnea at rest and delirium. Severely impaired functional capacity was observed.
A15	Understanding symptoms in patients with advanced chronic kidney disease managed without dialysis: use of a short patient-completed assessment tool(25)	England 2008	Mean age of 82 years. The most prevalent symptoms were: weakness and poor mobility, in addition to lack of appetite, pain, pruritus, and dyspnea.

*Visual Analog Scale
Source: Prepared by the authors.

Regarding the year of publication, a progressive increase of studies was observed over the years, with six (40%) published between 2018 and 2020. There was a predominance of studies in the area of Medicine (14; 93.3%), and only one in Nursing.

The majority (93.3%) of the studies included the adult population (over 18 years of age) in their sample and only one focused on the pediatric public. In the results of the articles, there was a predominance of the elderly population.

The main diagnosis of patients sent for a first consultation with the palliative care team was cancer. Of the 15 studies, seven (46.6%) focused exclusively on cancer patients, and article A3 indicated that most patients (67% of cases) came from the oncology service, 78% of them with metastasis. Two other studies involved only patients with kidney disease (A13 and A15) and one involved only patients with lung disease (A6).

Patients very frequently presented symptoms and problems such as: fatigue, dyspnea, nausea, inappetence, constipation, anorexia, insomnia, poor mobility, low functionality, anxiety and depression, the latter often reported as moderate to severe and limiting/disabling. Articles A13 and A15 indicated an average number of symptoms of 10 and 6.4, respectively, and article A4 indicates that 46% of patients referred for first visit had more than two limiting symptoms.

Pain was a prominent symptom among patients referred from all medical specialties. Pain was cited as the main complaint in A3, A7, A10, with medium to high scores, and present mainly in cancer patients compared to patients with other diseases, as indicated in A4.

Studies indicated that patients referred to palliative care had low functional capacity, which was measured using different scales: Palliative Performance Scale (PPS) and Karnofsky Performance Status (KPS). Articles A5 and A8 indicated mean PPS values of 35.67% and 30% to 40%, respectively; article A7 indicated a mean KPS of 46.4%.

The reasons for referral to the palliative care team were mentioned in two articles: in article A12, 60% of the patients were referred for end-of-life care and 25% for symptom control, and in article A13, 37% of the patients were referred for symptom management.

Late referral was evidenced in article A12, which pointed out that among the 78.5% of the patients referred to palliative care with non-malignant disease and who died, 12.5% died on the day of referral, 40% died between 1 and 2 days later, and 12% were actively dying at the moment of referral. This article also indicates that the mean time between admission to the hospital where the study was conducted and the referral for palliative care was 24.9 days. Articles A3 and A9 indicated a mean survival after referral of 60.8 days and 181 days, respectively. Article A13 indicated a Palliative Prognostic Index (PPI) greater than four in 55% of patients and greater than six in 35% of patients.

Article A6 indicated referral of patients with chronic obstructive pulmonary disease (COPD) only when there was an extension of emphysema, regardless of the burden or time of the disease, revealing the underutilization of the service and late referral. The justification given was the lack of knowledge of the professional team about the indicators of the need to start palliative care.

Only one study (A13) was conducted at an institution in which the palliative care team was integrated into the specialized care team in Nephrology. Patients were referred to the palliative care team in the first year after the diagnosis of chronic kidney disease.

DISCUSSION

It is important to emphasize that a precise medical diagnosis is not necessary for the indication of palliative care. The identification of a threat to life caused by any non-reversible condition or complication is enough, complemented by the multidimensional view of the health professional through the evaluation of perceived needs, parameters of severity and progression, geriatric syndromes, emotional aspects, comorbidities and use of resources(26).

This integrative review identified the predominance of cancer over other health conditions among patients referred for a first consultation with the palliative care team, a result that is in line with the findings of a cohort study(27). This result attests to the historical trajectory of palliative care, initially defined in 1990 by the World Health Organization as comprehensive care aimed at patients with cancer, especially those in the final stages of life. This concept was revised and expanded only in 2002 and now encompasses patients affected by other diseases that also threaten the continuity of life and cause important suffering(28).

As a consequence of this trajectory, palliative care is still almost restricted to cancer patients, as shown in the results of this integrative review, in which only 10.1% of non-oncology patients were receiving palliative care at the time of referral to the palliative care team while 48.4% of cancer patients were receiving it. This shows a failure to offer relief of suffering to patients with health conditions other than cancer.

There are other chronic diseases or conditions that have specific indicators that point to the benefit of the timely provision of palliative care. They include chronic lung disease, chronic heart disease, dementia, frailty and degenerative or non-degenerative neurological disease (amyotrophic lateral sclerosis, multiple sclerosis and Parkinson's)(26). However, the lack of knowledge about the indicators of need for palliative care and the consequent mistaken, absent or late referral are a present reality and a challenge to be overcome(28).

Delayed referral of COPD patients to palliative care team is exemplified and justified. The main indicator for referral is the extent of the emphysema, a condition that indicate the advanced stage of the disease and late referral (26).

This inequity in the referral of COPD patients is explained by the unpredictable and unknown course of the disease, the frequent exacerbations, the difficulty in defining the terminal phase and the lack of knowledge about the indicators for need of palliative care(29). As a consequence, these patients are less often sent to palliative care, or they are sent too late compared to patients with other progressive chronic diseases(30).

In this study, pain was the most prominent symptom among patients from all medical specialties, but fatigue and dyspnea also stood out. A systematic review of the literature(31) portrays and confirms these findings, indicating that these three symptoms are universally predominant among patients with advanced cancer, acquired immunodeficiency syndrome (AIDS), heart disease, COPD and kidney disease, suggesting that palliative care is relevant to all of these conditions, although there is still under-evaluation and under-treatment.

Pain, the main symptom reported by patients, can be aggravated by psychosocial and spiritual problems, aspects that should be taken into account when diagnosing the benefit of the palliative approach. This is pointed out by the instrument Palliative Needs (NECPAL)(26), used internationally as an indicator for referral to palliative care.

Considering that in oncology, functional capacity is directly related to prognosis(32), the studies analyzed here indicated late referral to palliative care and the patients showed very compromised functional capacity right in the first consultation. Mean KPS values lower than 50% are associated with severe dependence, survival of less than eight weeks and the need for referral to palliative care(26). Likewise, mean PPS values between 30 and 40% indicate low functional capacity, in which the patient is most of the time bedridden or fully bedridden, unable to perform most or any activity, with extensive disease and is nearly or completely dependent on the assistance of others(33), and average survival is between five and 36 days(34).

The short survival time was also evidenced by the predominance of patients with PPI greater than four and six, values that indicate survival time less than six and three weeks, respectively, after referral to the specialized team (35). Also, it was shown in the significant number of patients who died at the time of referral or up to two days after referral. The findings show, once again, the underutilization of palliative care services, failing to offer comfort and greater quality of life to patients and family members in a longitudinal, progressive way, since the diagnosis of a life-threatening condition that generates important suffering.

It was observed in this study that 60% of the referrals were made with the goal of providing end-of-life care. This indicates the underutilization of the palliative care service as an approach to prevent suffering and that can be reconciled with the modifying treatment of the disease. A descriptive and exploratory study also indicated that the care offered by the palliative care service of the host institution of the study was related to the end of life and death was the main outcome, and showed that care was requested late in the course of the disease(36). Other study showed that the palliative care team was most often requested by oncologists at the end of the course of the disease, to manage uncontrolled symptoms(37).

Early referral to palliative care can be promoted by the integration of palliative care service into the medical specialty. This was the case in only one study, in which there was a specialized and integrated program of palliative care and nephrology. A randomized clinical trial showed the beneficial effect of early and systematic integration of palliative and oncological care on the quality of life of patients with advanced cancer, reinforcing the need for integration between the specific care team (disease modifiers) and the palliative care team [38].

There are several reasons why many patients eligible for palliative care fail to receive this care or receive it too late in the course of the disease. They include the lack of knowledge or disbelief of health professionals about the palliative approach and its principles and indications; the failure of physicians to predict prognosis and the lack of knowledge about the patient's suffering; barriers related to the patient and family such as ineffective knowledge of their health conditions and prognosis; taboos around palliative care and refusal of this care; social barriers such as the lack of public policies; barriers linked to language, ethnicity and accessibility(39,40).

There is an urgent need to include the palliative care approach as a mandatory subject in courses of the health area, as well as to train professionals already working in the health sector, particularly with regard to the criteria for indication of palliative care and the use of instruments to help in the early identification of this approach.

This study may contribute to advances in the health area. The results may call the attention of professionals regarding the urgency of structural changes in the system to facilitate the early identification of the patients' needs and the adoption of appropriate interventions, which can only occur with the timely referral of patients from different specialties to palliative care.

This review has limitations. Most of the eligible articles presented data from retrospective studies, data collected from secondary sources, and this may have weakened the analyses due to the lack of information about the clinical condition of the patients. Another limitation is the possibility that patients referred to palliative care already were very symptomatic and/or had very low functional capacity and/or lowered level of consciousness, making them unable to provide the necessary information and, therefore, being excluded from the studies, which compromises the quality of data collection and the definition of the clinical profile of these patients because an unreliable and unrealistic profile may be portrayed. Further, the search strategies used and the limitation with respect to language may have favored the exclusion of eligible articles.

FINAL CONCLUSIONS

The findings of this review revealed that most of the patients referred to the palliative care team were older adults, diagnosed with cancer, with many symptoms and low functional capacity. Pain, fatigue and dyspnea were the most frequent, which allowed us to identify that palliative care was provided too late in most cases.

The evidence of late referral may awaken the eye to the need for changes in this scenario and the creation of new public policies supporting the principles of palliative care in order to prevent and soften the suffering in the course of the disease and enable patients and families to live in the best and most active way until the end of life.

More studies are necessary to define the clinical profile of patients referred for the first time to palliative care, exploring not only the physical dimension, but also the psychosocial and spiritual dimensions of the patients. Furthermore, more studies are needed in the area of pediatrics.

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