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Câncer da primeira infância notificados no integrador do registro hospitalar de câncer do Brasil

Cancer de la primera infancia notificado en el registro integrador de cancer hospitalario de Brasil

RESUMO

Objetivo: Identificar a prevalência do câncer na primeira infância no registro hospitalar de câncer brasileiro. Metodologia: Estudo quantitativo, descritivo e retrospectivo, realizado com dados secundários do Registro Hospitalar de Câncer, no período de janeiro de 2012 a dezembro de 2022, com crianças na faixa etária de zero a seis anos. A análise de dados realizado pelo percentual de completude, frequência absoluta e relativa. Resultados: Analisados 19.612 (98,6%) dos casos, com índice de completude considerado excelente. A prevalência foi do sexo feminino 10.778 (55%), com dois anos de idade 3.331 (17%), da raça branca 4.783 (24,4%), ocorridos principalmente no Estado de São Paulo (n= 4961; 25,3%). Os cânceres infantis notificados foram dos sistemas hematopoiéticos (n= 6.709; 34,2%) e neoplasia maligna do encéfalo (n= 795; 4,1%). Conclusão: Percebe-se a necessidade de implementar uma rede de atenção para prevenção e rastreio dos tumores infantis, para diminuir o diagnóstico tardio.

DESCRITORES: Câncer infantil; Sistemas de Informação em Saúde; Epidemiologia; Oncologia.

ABSTRACT

Objective: To identify the prevalence of cancer in early childhood in the Brazilian hospital cancer registry. Methodology: Quantitative, descriptive and retrospective study, carried out with secondary data from the Hospital Cancer Registry, from January 2012 to December 2022, with children aged zero to six years. Data analysis was performed by percentage of completeness, absolute and relative frequency. Results: 19,612 (98.6%) of the cases were analyzed, with a completeness rate considered excellent. The prevalence was females 10,778 (55%), two years old 3,331 (17%), white 4,783 (24.4%), occurring mainly in the State of São Paulo (n= 4961; 25.3%). The reported childhood cancers were of the hematopoietic systems (n= 6,709; 34.2%) and malignant neoplasia of the brain (n= 795; 4.1%). Conclusion: There is a perceived need to implement a care network for the prevention and screening of childhood tumors, to reduce late diagnosis.

DESCRIPTORS: Childhood cancer; Health Information Systems; Epidemiology; Oncology

RESUMEN

Objetivo: Identificar la prevalencia de cáncer en la primera infancia en el registro de cáncer hospitalario brasileño. Metodología: Estudio cuantitativo, descriptivo y retrospectivo, realizado con datos secundarios del Registro Hospitalario de Cáncer, de enero de 2012 a diciembre de 2022, con niños de cero a seis años. Análisis de datos realizado por porcentaje de completitud, frecuencia absoluta y relativa. Resultados: Se analizaron 19.612 (98,6%) de los casos, con un índice de completitud considerado excelente. La prevalencia fue del sexo femenino 10.778 (55%), dos años 3.331 (17%), blanca 4.783 (24,4%), ocurriendo principalmente en el Estado de São Paulo (n= 4.961; 25,3%). Los cánceres infantiles notificados fueron del sistema hematopoyético (n= 6.709; 34,2%) y neoplasia maligna del cerebro (n= 795; 4,1%). Conclusión: Se percibe la necesidad de implementar una red de atención para la prevención y tamizaje de tumores infantiles, para reducir el diagnóstico tardío.

PALABRAS CLAVE: Cáncer infantil; Sistemas de Información en Salud; Epidemiología; Oncología.

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INTRODUÇÃO

Childhood cancer affects children and adolescents aged 0-19 years, corresponding to 1 to 4% of all malignant tumors in most populations (Brazil, 2017), and childhood cancer in early childhood occurs in the first six years of life , being relevant to the health and development of human beings, resulting from the psychological, physiological and social changes caused. [1]

The World Health Organization has set a global survival target of 60% for all children with cancer, with the aim of saving more than a million lives by 2030. [2] Technological health advances in the diagnosis and treatment of cancer have dramatically improved the survival rate of children with cancer over a five-year period, which has reached approximately 80% in high-income countries. [3]

However, low- and middle-income countries have difficulty accessing supportive care and insurance coverage and establishing a national cancer control system, resulting in a lower survival rate and higher burden of childhood cancer. According to Lancet Oncology estimates, 13.7 million cases will be diagnosed and 11.1 million children will die from childhood cancers in the next 30 years. [4]

Epidemiologically, the Brazilian incidence predicted for the year 2023 by the National Cancer Institute was 7,930 thousand cases of childhood cancer, representing great importance in the mortality rate of this population. However, 80% of these patients may have a recurrence of the disease, if discovered early. [5]

However, the mortality or survival rate for childhood cancer varies depending on the region in which these patients live, with 80% survival in high-income countries and 20% in low- and middle-income countries. [3] And, as pointed out by the Cancer Mortality Atlas, there were 2,425 child and adolescent deaths in Brazil. [6]

Infant mortality can be evidenced by the lack of programmed territorial planning actions, especially planning based on agreement policies, as is the case of the Unified Health System, which require broad, consistent and comprehensive assessment instruments, capable of integrating the complex nature of problems. [7]

The main types of cancer that affect children and adolescents are leukemias and tumors of the Central Nervous System, Lymphatic System, Wilms', neuroblastomas, sarcomas, osteosarcoma, germ cell tumors and retinoblastomas, with leukemias being the most common cancers in this age group. [8]

The histological variety of childhood cancers arises from the similarity of fetal tissues at different stages of embryonic development. [1] This similarity generates great morphological diversity, resulting from constant cellular transformations, and there may be a varying degree of cellular differentiation. For this reason, the classifications used in pediatric cancers differ from those used in adults, with morphology being the main aspect to be considered. [1]

According to the classifications used, the treatment of childhood cancers can vary into four modalities (surgery, chemotherapy, radiotherapy and hematopoietic stem cell transplantation), being applied in a rational and individualized manner for each specific type of cancer and according to the extent of the disease and the treatment protocol approved by the Ministry of Health. [1]

In order to carry out studies, it is essential that bodies from national institutions provide notifications and statistical data relating to the incidence of the disease in this population, revealing its incidence, mortality and survival rates, age range and specificities of cancers, evaluating therapeutic actions with the objective of improved survival. [9] This evidence therefore provides information about the impact on the health of this population, allowing health professionals and competent bodies to optimize health prevention, promotion and protection measures, as guaranteed by the Unified Health System. [5]

The institution of health policies, such as the United Nations International Emergency Fund for Children, recommends the implementation of plans, actions and expanded public policies that take into account contexts, ways of life, health care and nutrition, protection against harm and a sense of security, such as providing early learning

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opportunities for all children, which can be monitored by the Child Health Index to measure the state of children's health and the conditions of their development. 10

In view of the above, the question arises: What is the prevalence of early childhood cancer cases reported in the Brazilian hospital cancer registry between 2012 and 2022? Therefore, this study aims to identify the prevalence of cancers in early childhood, reported in the Brazilian cancer hospital registry, as cancer notification is extremely important for carrying out new studies, helping in the effectiveness of therapeutic measures, identifying risk factors, and estimating new survival rates for these patients.

METHOD

This is a descriptive, retrospective study with a quantitative approach, carried out with secondary data obtained from the Integrator of the Hospital Cancer Registry (IRHC - Integrador de Registro Hospitalar de Câncer), reported from January 2012 to December 2022. The temporal choice was made over the last ten years of data available in full on the platform.

IRHC is a system developed by INCA to group hospital data from all over Brazil, providing information data produced by this system that allows monitoring of the care provided 11, being a resource used to monitor and evaluate the quality of the work carried out in cancer treatment centers. 5

The study included children aged between zero and six years old, of both sexes, as its target population. The following were excluded: records that were incomplete regarding age, sex, race and location of the cancer. The data were obtained from IRHC and were coded in the Microsoft Excel spreadsheet with the help of the Cancer Prevention and Surveillance Manual: Routines and Procedures, published in 2010.

The selected variables were categorized into three groups: 1) sociodemographic: sex, age and race; 2) clinical profile: ICD-10 location; and 3) form of treatment: type of treatment performed, reason for not tre-

ating and patient's condition after the first treatment performed.

After extracting the variables of interest for the study, an analysis of the percentage of completeness was carried out, and descriptive statistics methods were applied. To analyze the completeness of the records, four parameters were established according to the percentage of incompleteness of the records, that is, those with less than 5% incomplete were excellent; good, when 5 to 10% of the records were incomplete; regular 10 to 20%; bad from 20 to 50% and very bad when incomplete completion was greater than 50% of the record. 12 This study was not submitted to the Ethics and Research Committee, in accordance with CNS Resolution No. 510, of 2016, due to the use of pre-existing aggregated data banks, without individual identification.

RESULTS

Foram identificadas 19.888 notificações de câncer em crianças menores de seis anos de idade entre os anos 2012 a 2022 nos registros hospitalares no contexto brasileiro. Entretanto, foram excluídas 216 (1,4%) notificações devido à falta de informação sobre o local do nascimento, totalizando 19.612 (98,6%) notificações, com um índice de completude considerado excelente.

Das notificações analisadas (Tabela 1), evidencia-se que o pico de notificações foi em 2016 com 2743 (14%) dos casos, a maioria do sexo feminino 10778 (55%), com dois anos de idade 3331 (17%) e da raça parda 5490 (28%). Destaca-se que a completude para raça foi considerada ruim, devido a ausência de informação em 8791 (44,8%) notificações.

Table 1 - Sociodemographic characteristics of childhood cancer cases reported at IRHC from 2012 to 2022. Brazil, 2023.

NOTIFICATION FEATURES		N	%
Year of Registration	2013	199	1
	2022	212	1,1
	2012	336	1,7
	2021	930	4,7
	2020	2183	11,1
	2015	2534	12,9
	2019	2571	13,1
	2017	2577	13,1
	2014	2595	13,2
	2018	2732	13,9
	2016	2743	14
Gender	Male	8834	45
	Female	10778	55
Age	0	3158	16,1
	1	3079	15,7
	2	3331	17
	3	3078	15,7
	4	2631	13,4
	5	2266	11,6
	6	2069	10,5

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Race / Color	Yellow	53	0,3
	White	4783	24.4
	Indigenous	65	0,3
	Brown	5490	28
	Black	430	2,2
	No information	8791	44,8
Total		19612	100

Source: IRHC (2023).

Of the notifications in the Brazilian context (Table 2), the highest prevalence occurred in the states of São Paulo (n= 4961; 25.3%), Minas Gerais (n=1731; 8.83%) and Paraná (n= 1369; 6.98%).

Table 2 - Distribution of pediatric cancer cases by federal state			
BRAZILIAN REGION - FEDERATIVE STATE		**N**	**%**
North	Roraima	70	0,36
	Amapá	106	0,54
	Acre	112	0,57
	Tocantins	155	0,79
	Rondônia	207	1,06
	Amazonas	436	2,22
Northeast	Piauí	128	0,65
	Sergipe	155	0,79
	Alagoas	157	0,8
	Paraíba	364	1,86
	Rio grande de Norte	391	1,99
	Maranhão	619	3,16
	Ceará	806	4,11
	Pernambuco	812	4,14
	Bahia	1328	6,77
Mid West	Mato Grosso	211	1,08
	Goiás	230	1,17
	Mato Grosso do Sul	269	1,37
	Distrito Federal	442	2,25
Southeast	Espirito Santo	321	1,64
	Pará	395	2,01
	Minas Gerais	1731	8,83
	São Paulo	4961	25,3
	Rio de Janeiro	1010	5,15

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South	Rio Grande do Sul	854	4,35
	Santa Catarina	940	4,79
	Paraná	1369	6,98
No information		1033	5,27
Total		19612	100

Source: IRHC (2023).

Of the cases reported in the IRHC (Table 3), the 15 most prevalent types were presented, the three main ones being Neoplasms of the hematopoietic system (n=6463; 33%), malignant neoplasm of the kidney (n=2046; 10.4%) and malignant neoplasm of the retina (n=1356; 6.9%), with the female sex being the most predominant, except in malignant neoplasm of the kidney.

Table 3 – Location of childhood cancer cases reported at IRHC from 2012 to 2022. Brazil, 2023.

LOCATION OF THE PRIMARY TUMOR	FEMININO		MASCULINO		TOTAL GERAL	
	N	%	N	%	N	%
Tumors of hematopoietic and reticuloendothelial systems	3626	18,5	2841	14,5	6463	33
Malignant neoplasm of the kidney, other than renal pelvis, unspecified	992	5,1	1054	5,4	2046	10,4
Malignant neoplasm of the retina	737	3,8	619	3,2	1356	6,9
Malignant neoplasm of the brain, unspecified	428	2,2	367	1,9	795	4,1
Malignant neoplasm of the adrenal gland, unspecified	389	2	333	1,7	722	3,7
Malignant neoplasm of the cerebellum	402	2,1	263	1,3	665	3,4
Malignant neoplasm of the brain, except lobes and ventricles	256	1,3	213	1,1	469	2,4
Malignant neoplasm of the brain stem	227	1,2	225	1,1	452	2,3
Liver cell carcinoma	255	1,3	155	0,8	410	2,1
Malignant neoplasm of the retroperitoneum	198	1	188	1	386	2
Other neoplasms	3268	16,7	2576	13,1	5844	29,8

Source: IRHC (2023).

In relation to the clinical profile and the forms of treatment (Table 4) carried out in children aged zero to six years old with a diagnosis of cancer reported to the IRHC, it was observed that 17,490 (89.2%) did not apply, it was observed that 455 (2.3%) died before starting any treatment modality. Of the treatments performed (surgery, chemotherapy, radiotherapy and transplant), 12,555 (64%) used monotherapy, and 2,327 (11.9%) had stable disease after the first treatment.

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Tabela 4 - Notifications, by IRHC, of childhood cancer cases by clinical profile and form of treatment, from 2012 to 2022. Brazil, 2023.

CHARACTERISTICS OF THERAPEUTICS		N	%
Reason for not treating	Treatment abandonment	43	0,2
	Treatment complications	15	0,1
	Advanced disease, lack of clinical conditions	501	2,6
	Does not apply	17490	89,2
	Death	455	2,3
	Other associated diseases	133	0,7
	Others	568	2,9
	Patient refusal	24	0,1
	No information	383	2
Mode of therapy used	Monotherapy	12555	64
	None	1436	7,3
	Polytherapy	5545	3
	No information	76	0,4
Final state after the first treatment	Progressing disease	738	3,8
	Stable disease	2327	11,9
	Out of therapeutic possibility	267	1,4
	Not applicable	1482	7,6
	Death	1523	7,8
	Partial remission	1088	5,5
	No evidence of disease	2541	13
	No information	9646	49,2
Total		19612	100

Fonte: IRHC (2023).

DISCUSSION

The public availability of data through national health information systems has increased substantially, especially in major diseases such as cancer, expanding opportunities for concrete analysis of information. However, concerns about the quality of this information have been an obstacle to its use in evaluation studies. Therefore, this study aimed to identify the quality and profile of information on reported early childhood cases in the Brazilian Cancer Hospital Registry Integrator, as the quality of information in hospital records is aligned with the perception of cancer registrars, as

per This is evident in the qualitative study carried out in Rio de Janeiro, which highlights the need to deepen epidemiological studies related to information systems and monitoring of oncological diseases. 13 The importance of recording cancer cases helps in the effectiveness of therapeutic measures, identifying risk factors, and estimating new survival rates for cancer patients. 9

Thus, in this study, the prevalence of cases in females was highlighted, however, the study carried out in a reference hospital in Piauí, had a 52% higher incidence of cancers in males, being justified by the constitutional fragility of this sex, or due to changes linked to the X chromosome. 14 It

shows that the prevalence of cases occurred in the two-year-old age group (17%), but there is no evidence to justify this fact, but there may be a relationship between the disease and environmental or genetic factors. 1 And the study carried out in the State of Piauí highlights that the main types of cancer affected in the age groups from zero to five years are leukemia, kidney tumor, abdominal and pelvic tumors, central nervous system tumor and soft tissue tumor. 14

When analyzing the quality of information in hospital cancer records, the expression "no information" is observed, which in this study observed in the race/color variable, presented the highest rate with 44.8%

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of records, in this case the records fit that were not filled out correctly. Subsequently, the brown race/color presented 28% of the records, being the second highest number, and this fact is justified by the fact that Brazil has 58.3% of its brown population, due to the miscegenation of the original peoples. 15

The geographic distribution of early childhood cancer cases was high in the State of São Paulo, due to the inspection that institutions such as the Population-Based Cancer Registries (RCBP - Registros de Câncer de Base Populacional) carry out in these reference states and with large population numbers, with the aim of promoting greater epidemiological surveillance, improving the quality of information in records. 16

In the study on the completeness of data on cancer patients in the State of Mato Grosso, the incompleteness of the patient identification block was highlighted, mainly in cities in the interior of the state compared to the capital Cuiabá, and there was an improvement in filling out the relevant fields diagnosis and treatment of patients, compared to data on socioeconomic information. 17

There is a greater number of records in the state of São Paulo and this may be due to the inspection that institutions such as the RCBP carry out in these reference states and with a large population, with the aim of promoting greater epidemiological surveillance, improving the quality of information of records. 16

The primary location of cancer reported in the Brazilian Cancer Hospital Registry Integrator was mainly malignant neoplasms of the hematopoietic system and brain, corroborated in the Brazilian study that mainly cites acute leukemias, diseases of the central nervous system and lymphomas, in addition to abdominal masses and bone tumors. 1 Of these, leukemia is seen as the main cause of the disease and of child and adolescent deaths in relation to tumors of the central nervous system, which present numerous non-specific symptoms and make early and adequate diagnosis difficult, delaying treatment. 1

Research carried out in Santa Catarina highlighted two commonly found types of cancer (leukemia and central nervous system cancer), highlighting those of a lymphatic nature. 18 In this scenario, in a study carried out within the oncohematology sector of a public hospital with 63 children and adolescents diagnosed with cancer, it was observed that there was a predominance of leukemias and lymphomas (36.5%), followed by sarcomas (28.6%). 19 In the study carried out in a hospital institution, with a population of 12 children and adolescents, the diagnosis presented was 33.3% for a Central Nervous System tumor and 25% for osteosarcoma. 20

Another important study carried out analyzing cases of childhood cancer diagnosed between 2013 and 2019 and which included a population of 39,711 cases of children and adolescents, having identified the main cancers of neoplasia of the lymphatic and hematopoietic tissue, with 43.6% of totality, the brain or other part of the central nervous system with 12.6% and bones and joints with 7.63%. 21

Similar findings were found in a documentary epidemiological study in an analysis of hospitalizations for cancer, considering a total sample of 7,536 patients, showing that 50.3% of these cases occurred due to the diagnosis of leukemia, corroborating the findings in the literature, which point out this as one of the most common types of malignant neoplasms found in the child and adolescent population. 22 Finally, also demonstrated in the study carried out in Minas Gerais, based on an analysis of 2,645 hospital records of children and adolescents, it was highlighted that there was a high prevalence of cancer of the hematopoietic system, central nervous system, lymph nodes, bone and thyroid. 23

However, due to the difficulties in early detection of childhood cancer, there is a long delay and lack of early and accurate diagnoses, as more complete, complex exams and more coherent analyzes are often necessary. In many cases, for example, numerous symptoms go unnoticed, and the patient ends up receiving incorrect or inaccurate diagnoses, which ends up de-

laying treatment. 18 And it highlights the findings of this study regarding possible reasons for not treating cancer, situations such as advanced diseases or lack of clinical conditions, death and other associated diseases were observed.

One of the main reasons for not treating the neoplasia is associated with the discovery of the disease in more advanced stages, as pointed out in the study carried out which showed that around 55% of cancer patients discover the disease only when there is no longer any possibility of remission (stages III and IV), causing the treatment to be rejected or even unfeasible to improve the health condition and, in many of these cases, the treatment no longer becomes more effective due to the great extent and severity, with only palliative treatment being optimized. 24

The same is pointed out in the exploratory study of hospitals certified by the Ministry of Health, which showed that the diagnosis of cancer in many children and adolescents is in more advanced stages, with the possibility of offering palliative treatment, which makes this one of the reasons so that family members and the individual themselves do not opt for more advanced treatments. 13 Still for the authors, in these cases, the assistance provided by the health team is now only valid with regard to the signs and symptoms of the disease, no longer seeking curative treatment, but rather palliative treatment that can provide basic and assistance care. for a better quality of life for the patient, during their survival. 13

It is seen that one of the main reasons for not treating these complications is the continuity of treatment, since cancer often requires years of treatment in the search for remission, and in many cases, patients begin to disbelieve in the improvement when there is prolongation treatment time, also enhancing the signs and symptoms of the disease itself. 25

Another reason that can be highlighted is social vulnerability and the lack of economic conditions, since many patients do not understand their own rights relating to Public Health, reception and treatment locations, Public Policies, or even due to ba-

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sic economic needs being insufficient, such as in the transportation itself between the residence and the treatment hospital, with little resource to add in the search for these better conditions. 18

Regarding the forms of treatment, the greatest predominance indicated in this study was monotherapy with 64%, followed by polytherapy with 28% and no therapy used, with 7.3%. These findings corroborate a study carried out that reported that, regarding treatment, there are currently specialized and advanced treatments, specific for each type of cancer and its stages, generally involving chemotherapy, radiotherapy, combined treatments and surgeries, with polytherapies presenting better chance of disease regression. 17

Chemotherapy is one of the most popular treatments for the treatment of cancer, generally being the first reference when it comes to the search for the best health prognosis and remission of the disease, becoming part of the routine of these individuals.14 However, despite being essential, it generates numerous complications of symptoms such as nausea, vomiting, malaise, pain, tiredness and irritability, as this procedure attacks not only sick cells, but also healthy ones, causing generalized and acute actions, generating stressors to these individuals. 25

In the study carried out with 63 children and adolescents with cancer, it was observed that the treatment was predominantly chemotherapy with 57.1%, surgical procedures combined with chemotherapy with 15.5%, 9.5% of patients underwent a combination of chemotherapy, radiotherapy and surgery, and only 7.9% underwent exclusively surgical treatment. 19

In another research with 12 individuals from the same population and diagnosed with malignant neoplasms, it was shown that 75% underwent treatment essentially consisting of chemotherapy combined with resection surgery or chemotherapy with placement of an endoprosthesis. 20 And in the study, 25% were also subjected to radiotherapy, which observed in a statistical sample of 39,711 patients, that only 21.1% were subjected to surgical procedures, given the need for resection of the neoplasm. 21

By knowing and describing the epidemiological and clinical configuration of cancer in this population, it was evaluated in an exploratory study in Minas Gerais, relating to the case of 2,645 individuals from the child and youth population, showing that there was a higher prevalence for chemotherapy (42.56%) followed by 13.26% underwent surgical procedures and 12.4% who underwent radiotherapy and points out the main findings of the final state after the first treatment, was the stability of the disease in 27.82% of cases, complete remission in 11.55 %, death in 8.9%, partial remission in 7.77% and progressive disease in 6.7%. 23

It is important to highlight that both in stages in which there is remission, stability of the disease or even death of the patient, all family dynamics are altered, generating impacts in different spheres of the life of the child or adolescent, their family members and the individuals around them. 25 Thus, several individual and collective adaptations are necessary that involve all these individuals and the care environment, generating impacts for everyone. 17

However, this study has some limitations, such as: the lack of completeness of reported cases from 2023 available in the secondary database; the fragility of filling out the identification data for the reported case, as it highlights the "no information" response; and the lack of information regarding the survival rate of reported cases.

CONCLUSION

The IRHC notifications of cancer in early childhood highlight the need for a care plan for patients affected by leukemia and malignant tumors of the kidney and retina, with the implementation of prevention strategies and early cancer screening, starting with further guidance in prenatal care. Also, the importance of adopting family guidance tools to identify the signs and symptoms of the main childhood tumors is highlighted. The findings showed that completeness is adequate for basic identification data, but for specific data such as race, this commitment to completion is not the same. Greater encouragement and adequate training are needed to adequately complete the form.

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