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Research Article

PREVALENCE OF EMOTIONAL DISTRESS IN CAREGIVER'S OF CANCER PATIENTS

*Santre Manjeet S¹, Rathod Jyoti², Maidapwad Sainath³

¹Department of Psychiatry, Dr.SC Government Medical College, Nanded, Maharashtra, India

²Department of Psychology, INHS Asvini, Colaba, Mumbai, Maharashtra, India

³Department of Statistics, Dr.SC Government Medical College, Nanded, Maharashtra, India

*Correspondence of Author email: drmanjitsantre@rediffmail.com

ABSTRACT

Background: A diagnosis of cancer is an intensely stressful experience for patients. How much it affects the caregiver's is not apparent as it leads to hidden Co morbidity in the persons involved in the care giving process. Cancer can not only affect the patients, but can equally evoke emotional distress in the caregiver's. **Aims:** We carried out a study to evaluate the prevalence of anxiety and depression as well as effects of socio demographic & cancer characteristics on emotions of caregiver's. **Methods and Material:** This is a cross sectional study of 100 consecutive consenting caregiver's of diagnosed cancer patients attending an oncology department of a tertiary care hospital. Caregiver's are those who have willfully taken the responsibility of care giving to the ailing cancer patients. Hospital Anxiety, Depression Scale (HADS) a well validated questionnaire based scale to evaluate the prevalence of anxiety, depression and emotional distress. It has 14 items 07 related to anxiety & 07 related depressions. **Results:** 100 caregiver's were studied to assess the anxiety and depression levels during their care giving task. The mean anxiety & depression score of subjects were 8.28 (SD-3.45) & 8.79 (SD-3.94) respectively. 34% caregiver's were having score between moderate to severe category with a cutoff of (>10) on both the subscales of HADS. 53% of the subjects showed emotional distress as seen in high score above cutoff of (>15) on total HADS score. The data was compiled, tabulated and analyzed by using SPSS 16 .0 v. P < 0.05 is taken as statistically significant in our study. **Conclusion:** There are multiple factors involved in the emotional distress of the caregiver's. A holistic treatment approach that encompasses both medical and psychological measures for reducing the hidden morbidity in co sufferers of cancer patients to be adapted in treatment of cancer patients.

Keywords: Anxiety, Cancer, Caregivers, Depression, Cancer, Emotional distress.

INTRODUCTION

Cancer is perceived as a serious and chronic disease. The diagnosis of cancer still remains the disease equated with hopelessness, pain, fear, dependency and disfigurement, disruption of key relationships, depression and death in spite of recent advances in management of cancer. Psychological disturbance is not only produced by the diagnosis and treatment of disease but the patient's knowledge of the disease, perception and stigma pertaining to disease.¹⁻²

Cancer diagnosis is not only an individual experience but also brings certain changes in the life of caregiver's of the patients. Caregiver's who witness the pain, sufferings and hopelessness of their beloved ones become tired and unhappy. They have to fulfill the roles of patient in addition to their own role. The individual who takes care of the patients might develop physical, psychological difficulties and

physical diseases due to deterioration of the immune system.³

Emotional distress extends in a continuum ranging from common normal feeling of vulnerability, sadness and fear to problems that can become disabling anxiety, panic, social isolation and depression. Many authors stated that because of social isolation, role conflicts, tiredness, fatigue, financial burden and the attachment of the caregiver to the patients sometimes brings more emotional distress in caregiver's as compared to the patients.⁴

Family members are the first line of emotional support to the cancer patient. Care giving is highly satisfying but the caregiver's are likely to feel under stress when the psychological, physical or both demands of the care giving task exceed the capacity to cope, hence they are called as co sufferers in the treatment of cancer.⁵⁻⁷

Caregiver's can be categorized in formal and informal caregiver's. Formal caregiver's are part of the health care sector and being paid for the care giving services e.g. institutionalized care workers. Informal caregiver's are those who have assumed the task of care giving either willfully or who are highly motivated by a commitment to patients. These informal caregiver's usually are the family members related to the patient who are emotionally attached to them compared to other relatives.⁸

These caregiver's when assume the main responsibility of care giving are called as 'Primary caregivers and they can seek help of 'Secondary caregivers in times when care demands exceeds the carrying capacities of primary caregiver's. A recent trend in shift of cancer management from inpatient hospitalization to home settings & longer survival of patients has increased the number of informal caregiver's.⁹⁻¹¹

Care giving burden is dependent on caregiver's as well as care recipient's characteristics. Socio demographic characteristics like age,¹²⁻¹³ gender,¹⁴⁻¹⁶ socioeconomic status and type of relationship with the care recipient¹⁷⁻¹⁸ of caregiver's cause emotional distress in caregiver's. The care recipient's characteristics such as type of disease, staging of disease, treatment,¹⁹⁻²¹ physical and psychological symptoms and dependency feeling has negative impact on care giving.²²⁻²³ Quality, intensity and different types of care provided²⁴, availability of health resources, preparedness of caregiver's in care

providing process and the period for which the care giving is to be done too have significant impact on the care giving.²⁵

Care giving is demanding and overwhelming and can be a very stressful experience affecting all aspects of caregiver's leading to risk of developing psychological problems which includes anxiety, depression, reduced self esteem and somatic health problems and thus adversely affecting the treatment outcome.²⁶⁻²⁹

Literature review has shown that majority of studies are done in western settings and very few in Indian setting. Considering this geographical differences we conducted the present study to evaluate the prevalence of anxiety and depression in caregiver's and to study the socio demographic and cancer variable factors leading to emotional distress.

METHODS AND MATERIAL

The study a cross sectional & carried out at a large urban tertiary care centre. We undertook the study after an approval from institutional ethical committee. The center provides medical, surgical and radio-therapeutic treatment. Cases included in the study were Caregiver's who were providing care to cancer patients, who were either admitted or attending to oncology department for treatment or follow up. A total 100 caregiver's of cancer patients who had taken the responsibility of care giving willfully were selected by random sampling for the questionnaire based study.

The purpose of the study and questionnaire were explained & verbal consent was obtained from each subject. The subject underwent the following assessments. Socio demographic variables such as age, sex, education, occupation, income, residence, marital status and family type were collected. The age range was 19-60 yrs. Maximum caregiver's were in the age group of 42-49 yrs. In our study male and female subjects were equal in number.

Mental status evaluation by a psychiatrist was carried out. HADS (Hospital Anxiety, Depression Scale) was given to the subjects. HADS scale is designed for assessment of anxiety and depression of the subjects. HADS is originally developed by Zigmond AS and Snaith RP. It has two subscales each consisting seven questions related to anxiety and depression respectively. HADS is brief, easily understandable and acceptable scale and it generates ordinal data.³⁰

Because of these properties it can be used for non cancer patient also.³¹

HADS (A) subscale of Hospital Anxiety & Depression Scale mainly elicit the responses pertaining to frightened feelings, fearfulness, worries and panic attacks while the HADS (D) mainly elicits the responses in regards to subjects feeling of slowness in the activities, inability to enjoy or derive pleasure from pleasurable activities or feeling pessimistic about future course of the life.³²

The subjects were asked to express their responses on a Likert scale ranging from 0 (not at all) to 3 (very often needed / most of the time). Responses are based on the relative frequency of symptoms over the past week. Responses are summed to provide separate scores for anxiety and depression. Subscales score range from 0-21 for anxiety and depression on HADS.

Mykletun A et al studied the factor structure, item analyses, and internal consistency in a large population of HADS.³³

Caregiver's who after explaining the nature of the study and the time the questionnaire will take for them to be replied and willfully agreed were taken in the study. Those who could not understand the questions were not included in the study. All subjects were interviewed by same set of examiners for maintaining the uniformity in the scoring while obtaining the data. Data was compiled, tabulated in Microsoft excel sheet and analyzed with help of statistical software SPSS 16.0 version with help of institutional statistician. The significance level was set at $P < 0.05$.

RESULTS

We did a study of 100 subjects. The mean ages of subjects were 40.4 yrs (SD-9.637). Mean years of schooling of the caregiver's was 9.3 yrs of schooling (SD 2.37). 27% subjects studied beyond 12th standard which includes graduation and post graduation. Out of 100 subjects 92 were married. 47% subjects were from rural background while 67% subjects live in nuclear family. Maximum subjects were home maker by occupation. 4% were unemployed and dependent on the family or patients for their financial needs. 13% of the caregiver's were retired. In cancer variable the frequency of cancer according to the site is shown in Fig 1.

In cancer variable 49% of patients were in stage I of diagnosis and only 1% were in stage IV. 75% of cancer patient were diagnosed more than 6 months prior to their inclusion in the study. 49% patients had received chemotherapy or their cycles of treatment were in process & 8% received radiotherapy. 28% patients were operated cases and were considered for radiotherapy or chemotherapy treatment. Relationship frequency of the caregiver's to the care recipients is shown in Fig 2.

On hospital anxiety, depression scale the mean anxiety scores on HADS (A) were 8.28 (S.D.-3.45). Anxiety score was in range from 3-17 on the scale. 32% cases were having an anxiety score in moderate to severe category. Mean score on HADS (D) was 8.79 (S.D.-3.94). 34% care giver were scored between moderate to severe grade with a cutoff of (>10) on HADS. The range of HADS (Total Score) was 6-33. 53% of the subjects were having emotional distress on cutoff of (>15) on total HADS score. The Correlation of socio demographic, cancer & relationship status variables with HADS (A) & (D) scores were shown in Tables 1, 2 & 3 respectively.

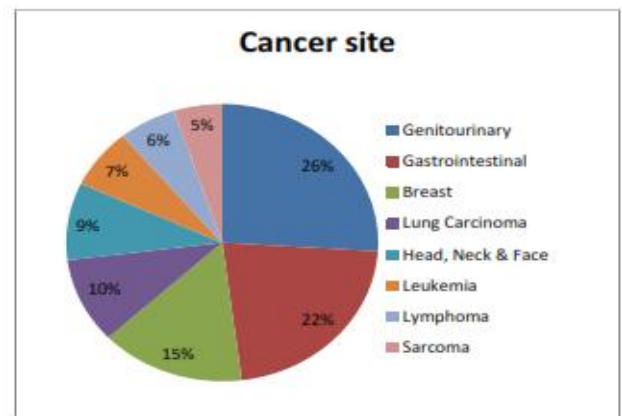


Fig 1: Cancer site

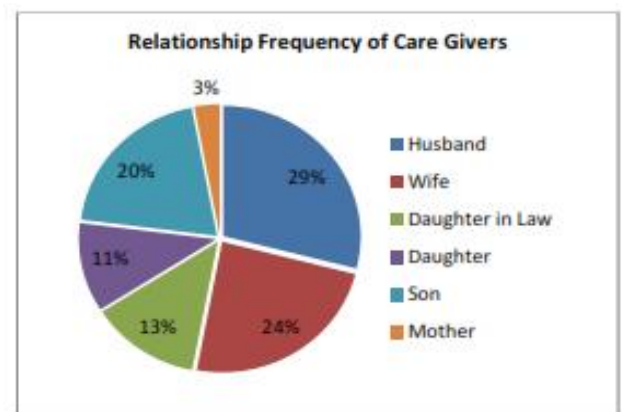


Fig 2: Relationship Frequency of Care Givers

Table 1: Socio Demographic Variables with HADS Score of Cancer Caregiver's

Variables		HADS (A) Score			X ²	HADS(D)Score			X ²
		Mild	Moderate	Severe		Mild	Moderate	Severe	
Age	18-25	01(14.3)	00(0)	01(14.3)	X ² =16.42 p=0.35	02(28.6)	00(0)	01(14.3)	X ² =14.32 p=0.501
	26-33	04(23.5)	04(23.5)	00(0)		03(17.6)	03(17.6)	02(11.8)	
	34-41	04(15.4)	07(26.9)	00(0)		04(15.4)	04(15.4)	02(7.2)	
	42-49	09(27.3)	13(39.4)	02(6.1)		07(21.2)	11(33.3)	05(15.2)	
	50-57	03(25)	03(25)	01(8.3)		01(8.3)	03(25)	03(25)	
	>58	00(0)	01(20)	00(0)		02(40)	00(0)	00(0)	
Gender	Male	07(14)	11(22)	01(2)	X ² =9.40 P=0.024	10(20)	9(18)	3(6)	X ² =5.97 P=0.11
	Female	14(28)	17(34)	03(6)		9(18)	12(24)	10(20)	
Marital	Married	20(21.7)	28(30.4)	3(3.3)	X ² =5.75 P=0.24	17(18.5)	21(22.8)	12(13)	X ² =2.43 P=0.48
	Unmarried	1(12.5)	00(0)	1(12.5)		2(25)	0(0)	1(12.5)	
Education	0-5	3(37.5)	3(37.5)	0(0)	X ² =7.94 P=0.24	3(37.5)	2(25)	1(12.5)	X ² =6.60 P=0.35
	6-11	12(18.5)	22(33.8)	3(4.6)		9(13.8)	13(20)	11(16.9)	
	>12	6(22.2)	3(11.1)	1(3.7)		7(25.9)	6(22.2)	1(3.7)	
Residence	Rural	9(19.1)	17(36.2)	2(4.3)	X ² =3.089 P=9.37	11(23.4)	9(19.1)	7(14.9)	X ² =1.66 P=0.64
	Urban	12(22.6)	11(20.8)	2(3.8)		8(15.7)	12(22.6)	6(11.3)	
Family	Joint	6(18.2)	9(27.3)	1(3.0)	X ² =0.525 P=0.91	8(24.2)	5(15.2)	5(15.2)	X ² =1.71 P=0.63
	Nuclear	15(22.4)	19(28.4)	3(4.5)		11(16.4)	16(23.9)	8(11.9)	
Income (Rs.)	Up to 8000	0(0)	3(42.9)	0(0)	X ² =15.89 P=0.19	1(14.3)	0(0)	1(14.3)	X ² =16.51 P=0.16
	8001-10000	11(26.2)	14(33.3)	4(9.5)		10(23.8)	7(16.7)	10(23.8)	
	10001-12000	7(28)	5(20)	0(0)		3(12)	7(28)	1(4)	
	12001-14000	1(9.1)	2(18.2)	0(0)		1(9.1)	2(18.2)	1(9.1)	
	>140001	2(13.3)	4(26.7)	0(0)		4(26.7)	5(33.3)	0(0)	
Occupation	Dependent	1(100)	0(0)	0(0)	X ² =15.52 P=0.214	2(50)	0(0)	0(0)	X ² =11.74 P=0.46
	Employed	5(13.9)	8(22.2)	1(2.8)		7(19.4)	8(22.2)	2(5.6)	
	Homemaker	13(27.7)	16(34)	3(6.4)		7(14.9)	12(25.5)	9(19.1)	
	Retired	2(15.4)	4(30.8)	0(0)		3(23.1)	1(7.7)	2(15.4)	

(*Read the number in parentheses as percentages)

Table 2: Cancer Variables and HADS Score of Cancer Caregiver's

Cancer Variables		HADS			X ²	HADS			X ²
		Mild	Moderate	Severe		Mild	Moderate	Severe	
Diagnosis	Breast	0(0)	1(6.7)	0(0)	X ² =37.44 P=0.015	2(13.3)	1(6.7)	0(0)	X ² =27.61 P=0.151
	Genitourinary	11(42.3)	6(23.1)	0(0)		5(19.2)	9(34.6)	0(0)	
	Gastrointestinal	3(13.6)	8(36.4)	2(9.1)		2(9.1)	5(22.7)	6(27.3)	
	Lung Cancer	4(40)	3(30)	0(0)		3(30)	1(10)	1(10)	
	Head,Neck & Face	1(11.3)	3(33.3)	0(0)		2(22.2)	1(11.1)	2(22.2)	
	Leukemia	1(14.3)	2(28.6)	0(0)		1(14.3)	2(28.6)	1(14.3)	
	Sarcoma	0(0)	3(60)	1(20)		2(40)	1(20)	2(40)	
	Lymphoma	1(16.7)	2(33.3)	1(16.7)		2(33.3)	1(16.7)	1(16.7)	
Duration	< 6Months	8(32)	6(24)	3(12)	X ² =9.040 P=0.029	3(12)	5(20)	5(20)	X ² =2.13 P=0.544
	>6Months	13(17.3)	22(29.3)	1(1.3)		16(21.3)	16(21.3)	8(10.7)	
Staging	I	11(22.4)	11(22.4)	0(0)	X ² =11.88 P=0.220	10(20.4)	4(8.2)	3(6.1)	X ² =28.89 P=0.001
	II	8(22.9)	9(25.7)	3(8.6)		8(22.9)	11(31.4)	5(14.3)	
	III	2(13.3)	8(53.3)	1(6.7)		0(0)	6(40)	5(33.3)	
	IV	0(0)	0(0)	0(0)		1(100)	0(0)	0(0)	
Treatment	Chemotherapy	9(18.4)	13(26.5)	02(4.1)	X ² =14.29 P=0.282 X ² =8.911 P=0.446	7(14.3)	11(22.4)	5(10.2)	X ² =17.81 P=0.037 X ² =17.81 P=0.037

(*Read the number in parentheses as percentages)

Table 3: Relationship & HADS Score of caregiver's

Relationship	HADS (A) Score			X ²	HADS (D) Score			X ²
	Mild	Moderate	Severe		Mild	Moderate	Severe	
Husband	04(13.8)	08(27.6)	00(0)	x ² =42.90 p=0.000	6(20.7)	5(17.2)	1(3.4)	X ² =17.8 P=0.270
Wife	07(29.2)	09(37.5)	01(4.2)		4(16.7)	7(29.2)	4(16.7)	
Daughter in law	03(23.1)	04(30.8)	00(0)		2(15.4)	0(0)	4(30.8)	
Daughter	04(36.4)	03(27.3)	00(0)		3(27.3)	3(27.3)	1(9.1)	
Mother	00(0)	01(33.3)	02(66.7)		0(0)	2(66.7)	1(33.3)	
Son	03(15)	03(15)	01(5)		4(20)	4(20)	2(10)	

(*Read the number in parentheses as percentages)

DISCUSSION

Recent shifts in care of cancer patients from a hospital setting to home care environment has increased the enrollment of informal caregivers in the care giving process. Caregivers have to cater for the different needs of the patients. These can be in the form of emotional support, financial management, assistance in activities of daily living, maintaining the appointment schedule with oncologist, helping in choosing the treatment option offered by the treating oncologist and even monitoring the schedule & administration of the treatment.

In providing optimum & quality care, caregivers must maintain equilibrium between the previous and current role they are playing so that care giving should not affect their already established roles and turn give rise to conflicts in the process of care giving. Even the caregiver's positive and negative attitude towards diagnosis and progression of the disease has a significant impact on care giving process.³⁴

In our study the possible cases of anxiety and depression were 32% & 34% respectively. These findings are in keeping with those from the previous studies. Michal Braun et al³⁵ in a study of 101 spouse caregiver of mixed cancer patients found to have significant symptoms of depression (BDI-II >15) in 38.9% of cases which is in agreement with our study.

On gender variable scores are statistically significant (p<0.024) and in agreement with prior studies.³⁶⁻³⁸

These studies show that females suffer more care giving burden. This may be due to the dual role of maintaining the home and also caring of the patient. Females as such are more prone to depression in general population.

Caregiver's who are unmarried suffer from increased psychological distress³⁹ as they perceive less of social

support. In our study sample unmarried cases were very less hence could not be commented upon.

On educational status the results of our study show that there were proportionately increased number of patients with anxiety and depression with education between 6-11 standard of schooling. Lower level of education is likely to increase distress due to lack of knowledge of the disease and feeling of ill preparedness for the complex task of care giving.⁴⁰⁻⁴²

The relation to residence and family were not statistically significant with emotional distress but those belonging to the rural background has substantiate proportionate of anxiety and depression as they have to travel frequently from far flung areas to the places where the specialist treatment of cancer is available and eventually exhaust themselves physically, financially and emotionally. Living in nuclear family has increased proportion of anxiety and depression as they have to perform all the tasks and feels a lack of support being alone.

Prior studies have shown that there was an increased emotional distress in people from lower socioeconomic status.^{40,43} Even though our study did not show any significant score on socioeconomic status of the cases may be the caregiver's do not feel the burden of finances for treatment on them as their relatives who were suffering from cancer got treatment free of cost from the hospital.

Care giving in itself is a full time job. Apart from the personal occupation in which the caregiver's were involved they have to perform this task also. Caregivers experience adverse impact of care giving task on their occupation. Different types of occupation have different impact on emotions of the caregiver's.⁴⁴⁻⁴⁶ In our study caregiver's involved in the occupation of the homemaking experiences

proportionately more distress as compared to others, this may be due to the bias of sample.

Zabora et al⁴⁷ studied 4496 cancer patients with 14 different diagnoses. He found that while pancreatic cancer produced highest mean scores on anxiety and depression, while Hodgkin's lymphoma exhibited highest mean score on hostility criteria in patients. Thus the cancer site affected influence quality of life and psychological well being differently of the patients. Similarly there are changes in the emotional distress level of the caregiver's with different types of cancer. Thus in our study on HADS (A) subscale the scores were statistically significant in caregiver's caring for patients with variable cancer site. Our study results were consistent with prior studies in which the distress varies according to the greater illness severity.⁴⁸⁻⁴⁹

As the duration of time period increases in the care giving the emotional fatigue also increases in the caregiver's. Our study result on anxiety subscale is in concurrence to prior study done by Baral et al.⁵⁰

With advanced disease staging there are changes in the physical symptoms of the patients. Dependency feelings & preoccupation of the thoughts of nearing death of the care recipients also increases during advanced staging. Our study results on HADS (D) subscale were in concurrence to prior studies.⁵¹⁻⁵³

Patient's type of treatment, schedule of treatment, side effect of treatment, anxiety regarding the intervention procedures, cost of treatment and final outcome of the treatment all leads to distress in caregiver's as they are the ones who would actively be there with the patient through all this process and also a part of decision making in choosing the treatment option for the patient. Our study in the treatment category found to have statistically significant results (p-0.037) were in agreement with prior studies.⁵⁴⁻⁵⁶ Eva Grunfeld et al⁵⁷ in a study of 89 caregiver's of women with advanced breast cancer found to have mean scores of 8.8 & 5.2 on anxiety and depression scale respectively at the start of palliative period and the score on depression increased in terminal period insignificantly this is again in concurrence to our findings.

Caregiver's relationship to the care recipient is another important factor to the emotional distress they suffer. The level of emotional distress varies with the degree of emotional attachment and the relationship of the caregiver to the care recipient. In

case of spouses who stay with patient, experience more emotional distress as compared to other kinship. Spouses in particular become restricted in their activities and socially isolated in their care giving task. Problems of communication, sexual difficulties, neglect of their children and significant others and also absenteeism in their professional work all leading to emotional stress.⁵⁸⁻⁵⁹ This is in agreement to our study in which the spouses suffered significantly. In a study done by Young RF et al⁶⁰ on care giving of heart patients in 183 caregiver's found significant strain on non spousal caregiver's mainly daughters. In our study also daughters have proportionately more emotional stress than mother, daughter in law and son.

We acknowledge limitations of our study, the studied sample size was small. This study was questionnaire based study and the diagnostic research criteria for psychiatric diagnosis were not applied at the time of categorizing cases as emotionally distressed. Caregiver's emotional distress is influenced by many factors. This factors be related to care recipient or to the caregiver's. Aspects of internal resources playing a role in care giving were not studied.⁶¹ The psychological symptoms, personality traits and traits of dependency of patients were not considered here which too influence the care giving burden. Apart from these there are many more factors which can influence the emotional status of the caregiver's which needs a longitudinal study in a larger sample with consideration of all the factors which affect the caregiver's levels of anxiety and depression.

CONCLUSION

The diagnosis of cancer carries with it a significant amount of emotional distress not only in cancer patients but their caregiver's as well. Optimum care for cancer patients depends largely on optimum care of caregiver's so as to sustain them in the challenging task of care giving. Early evaluation is warranted for management of emotional distress in caregiver's.

Results of the study showed that both anxiety and depression were significantly higher in caregiver's. Their emotional distress level changes with the age, gender, education, economic status, types of cancer, stage of cancer and with different treatment modalities. The relationship status of the caregiver to the cancer survivor also has an impact on the emotional stress experienced by the caregiver's.

There is a need to assist, support and motivate caregiver's in their new and demanding role. In addition to these there is a need to acknowledge the importance of relationships from the point view of caregiver's and patients involved in the cancer treatment.

A psychiatrist can play a very important role in an integrated oncology treatment team, by providing specialized treatment at the earliest which will not only reduce the emotional distress in cancer survivors but also their caregiver's to continue their care giving. This will result in reducing the hidden psychological morbidity of caregiver's and bringing overall improvement in quality of life of cancer patients and their caregiver's as well.

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