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FACTORS AFFECTING TREATMENT-SEEKING BEHAVIOUR OF CANCER PATIENTS IN THE NORTH INDIA REGION

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ABSTRACT

Context: Worldwide, the second leading cause of death is cancer. The burden of cancer can be decreased via early detection and right treatment and proper care of cancer patients.
Aims: To know the treatment-seeking behaviour of cancer patients and the factors affecting it.
Settings and Design: A cross-sectional study was conducted from January to December 2021 with 192 cancer-confirmed patients at the cancer registry centre at the civil hospital in Ambala cant, District Ambala.
Methods and Material: Patients were interviewed using a pre-tested semi-structured questionnaire. The data was entered into an Excel sheet and analysed using SPSS.
Statistical analysis: mean and standard deviation were calculated. P value ≤ 0.05 was considered to be statistically significant.
Results: Out of total 192 patients, 95(49.5%) were male and 97(50.5%) were female. The majority (63.5%) were in the 31-60 age group with a mean age of 52.46±13.051 years. (28.1%) cancer patients reported treatment delays for more than 1 month. Reasons /barriers for treatment delay were (79.6%) no idea where to go for treatment, (75.9%) family taking time to decide, etc.
Conclusions: it was observed that treatment delay was significantly associated with the cancer patients' education and occupational status. Private providers need to be sensitized in early screening of cancer and referral of suspected cases of cancer. Factors affecting treatment seeking behaviour of cancer patients in north India region

Key-words: Treatment delay, Treatment seeking behaviour, Cancer, barrier/factors affecting treatment delay.

Background- Cancer is the second leading reason of death in many countries, and its burden and prognosis are highly dependent on disease stage at diagnosis[1].
The burden of cancer can be decrease via early detection and right treatment and proper care of cancer patient. Screening helps in identifying person with specific symptoms and signs, whenever some abnormalities found in screening test, further tests are needed to make a confirm diagnosis and referral if needed for treatment also.

A right and confirm diagnosis of cancer is must for appropriate and effective treatment which usually includes surgery, chemotherapy and radiotherapy used alone or in combination with each other's[2]. Increase cases of various cancer may be likely to the use of various underlying risk factors like high tobacco and other substance uses, inadequate approach to skilled treatment providers, restricted health care resources, underprivileged status, late diagnosis etc. Illness seeking behaviour plays an important role in early diagnosis of cancer which also affects endurance to a noticeable scale, wellbeing and standard of living[3].

Two years into the pandemic, healthcare systems are still facing significant challenges in providing essential health services. Ongoing disruptions have been reported in over 90% of countries surveyed in the third round of WHO's global pulse survey on continuity of essential health services during the covid pandemic. Countries reported disruptions across services for all major health areas including cancer[4]. The covid 19 pandemic has a disastrous effect on medical management system globally due to the profuse infection rate with remarkable morbidness and death. Cancer patients are on high risk of significant complications and dying if they receive the infection with addition to their risk of treatment delay or disturbance which can be harmful to their end result, Actually, the impact of covid 19 on patients with cancer is multi-dimensional and doctors are managing this disease should pay attention to issues that may impact patient end result antagonistically[5].

All framework and human resources in the healthcare system were focused to fight during covid 19 pandemic. Mostly beds in the in-patient clinics and intensive care units in the health institutions were allocated to COVID-19 cases. Regardless of their expertise, most doctors were re-assigned to treatment of with covid 19 patient. However, the number of outpatient clinic admissions was limited. All surgeries, except for emergency or cancer surgeries, were postponed. Citizens were advised through the media and social media not to report to health institutions unless it was compulsory. The perception that hospitals are high-risk areas in terms of covid 19 transmission risk has been initiated in society[6].

Aims and objectives- 1. To study the sociodemographic profile of cancer patients,
2. To study the treatment seeking behaviour of cancer patients in covid 19 pandemic time.
3. To assess the existing barriers, if any towards treatment compliance.

Material and method- It was a cross-sectional study design conducted at cancer clinic of civil hospital Ambala which is a cancer registry centre in District Ambala Haryana. (Facility based study)

Study subjects- study population includes cancer patients coming in cancer out-patient department for seeking treatment/opinion and follow up for any type of cancer/malignancy from last two year of diagnosis.

Inclusion criteria- Cancer patients more than 18 years of age and who gave consent were covered under inclusion criteria.

Exclusion criteria- Cancer patients below 18 years of age and those were not in condition to give information.

Study period-The study will be carried out over a period of one year i.e., January 2021 to December 2021.

Sample size- Sample size was estimated on the basis of number of cancer patients present in District Ambala. Data was provided by cancer registry centre in civil hospital Ambala cantt. and District Ncd cell of District Civil surgeon office of District Ambala with the permission of civil surgeon Ambala. Study was conducted on around 200 cancer patients who were coming to cancer registry centre for treatment and follow up. Finally, a total of 192 cancer patients completed the study.

Study tools- The study was conducted using a self-designed pre-tested questionnaire with two sections:

Section 1: It contains the socio-demographic profile, clinical and treatment related parameters of study subjects.

Sub Section A: Socio-demographic profile of the patient.

Sub Section B**:** Anthropometric details of the patient.

Sub Section C: All clinical details of the patients and factors affecting investigation, treatment and follow up.

Strategy- Personal face to face in depth interview was conducted. Patients were explained about the purpose of study. Written informed consent was taken and complete confidentiality of the person was ensured. To confirm the clinical picture and treatment schedule patient's records available with him/her also was referred. On an average 10-15 minutes were spent for completion of the interview.

Statistical analysis- The data was entered in excel sheet and analysed using SPSS version 28.0. Qualitative variables were expressed as proportions in percentages. Quantitative variables were expressed as mean and standard deviation.

Finally, Chi-square test was used to establish association (if any) among qualitative variables. Association between the various quantitative variables was established using t-test or Anova as per data collected. $P<0.05$ was considered significant at 95% confidence interval.

Ethical consideration- Final approval from the Institutional Ethics Committee was taken. The study didn't impose any financial burden on the patients. Written informed consent was obtained from each participant in their vernacular language. Confidentiality for each patient was maintained throughout the study.

Results- Table 1 shows socio demographic profile and anthropometric information of the cancer patients.

Majority (63.54%) of study participants were in age group 31-60 years, (82.3%) were Hindu by religion, (63.02%) belonged to Rural area, (84.89%) were married, Majority (40.10%) were educated up to below higher secondary level. Majority (44.8%) were living in nuclear family. Majority (30.7%) lies in Upper middle class (II) families as per BG Prasad socio-economic classification. Majority (56.25%) lies with in Normal weight (BMI between 18.0-24.9), Majority (62.0%) did not smoke during their life time, (87%) never used taken tobacco/Guthkha.

Discussion- In our present study, Majority 122(63.54%) of the cancer patients were in age group 31 - 60 years with Mean age of all cancer patients is 52.46±13.051 in years. Similar study results were observed in a study conducted by **Nolte S.et al.(2018)[9]** studied on 15386 patients across 13 countries in Europe results as 8010(52.1%) in 30-59 age group, 3199(40.3%) in above 60 age group and 1177(7.6%) in 18-29 age group. Maximum number of cancer patients belong to middle age group in between 30-60 years. Majority 158(82.29%) of cancer patients in our study belong to Hindu religion. Similar results were seen in study by **Kumar A.et al.(2019)[10].** As In India, Majority of the population were Hindu religion which could be the reason for inclusion of greater number of Hindus in the sample. In our study, 121(63.0%) were belong to rural area while 71(36.97%) belong to Urban area. Similar results by **Kumar A.et al.(2019)[10]** as Rural 133(69.3%) and Urban 69(30.7%). Cancer is more predominant in rural as compare to urban may be because majority of population are living in India in rural setting as compare to urban setting. In our present study,163(84.89%) were found Married with almost similar finding in **Kumar A. et al. (2019)**[10] as 86% married.

In our present study, 77(40.10%) were in below higher secondary level. Similar results were observed in a previous study done by **Gangane N. et al. (2017)[11]** with educational status as 115(55.3%) as below higher secondary level. **Damodar G. et al. (2013)[12]** also shows similar result as 43.89% cancer patients were illiterate while in our study 35.41% were found illiterate. This may be because of different literacy rate of different region across the world.

In our present study, 78(40.6%) were Businessman/Job/Daily wager/Farmer. In **Singh H et al. (2014)[13]** conducted a study in which 2.29% were unemployed, 10.68% were labourer,63.35% were households, 15.2% professionals as different region has different occupation

In our study, Majority 86(44.8%) were living in nuclear family. Similar finding was observed with **Tiwari V.K. et al. (2015)**[14] as 57% as nuclear family. Nuclear family were more than joint and extended family as similar with our study.

In our study, as per **Modified BG Prasad Socio-economic Classification. (Updated- May 2021)[15]**, 59(30.7%) lies in Upper middle class (II). This may be due to as the study was conducted in government hospital and the patients who take treatment from it were usually from low socioeconomic status and also could be due higher occurrence of most common cancers like head and neck, gastrointestinal track, cervical cancer among low socioeconomic status group. Similar results were seen in a study of **Kumar A. et al. (2019)[10]** having modified BG prasad socio economic scale from I to V as I 2(1%), II 14(7.3%), III 46 (24%), IV 77(40.1%) and V 53(27.6%).

In our study, Majority 108(56.25%) were with in Normal weight (BMI between 18.0-24.9), followed by 43(22.39%) Overweight (BMI 25.0-29.9), 31(16.14%) Underweight (BMI<18.0), and 10(5.20%) Obesity (BMI >30) based on **WHO criteria[16]**. Similar finding was observed by study done by **Damodar G. et al. (2013)[12]** on 41 breast cancer patients with 29(70.73%) Normal weight (BMI 18.0-24.9) followed by 9(21.95%) Underweight (BMI <18.0), 2 Overweight (BMI 25.0-29.9), 1(2.43%) Obese BMI >30 was found. A study by **Glade M J et al. (1999)[17]** found that Obesity and lack of physical activity are associated with increased risk at various cancer sites, including breast and endometrial cancer. Energy balance, which includes maintaining ideal weight through physical exercise, has been associated with decreased risk of breast cancer.

In our study, 119(62.0%) cancer patients did not smoke during their life time. Similar finding was observed with **Kumar A et al. (2019)[10]** 260(96.7%) were non-smoker followed by 6(2.25%) were past smoker & 3(1.1%) were current smoker. From various previous studies it was also found that tobacco intake whether in smoking or oral form/ guthkha is associated with head and neck and lung cancer.

Majority of female cancer patients 49(50.5%) were of Breast cancer, followed by 20(20.6%) Genito-urinary type cancer and so on (Figure.1). Similar result with **Globocan 2020 data[18]**, leading cancer in female is breast cancer (26.3%) followed by cervical cancer (18.3%).

While in majority of male cancer patients 41(43.1%) were of Head and neck type cancer, followed by 17(17.9%) Gastro-intestinal track type cancer and so on. Similar result with **Globocan 2020 data[18]**, leading cancer in male is Lip and oral cavity (16.2%) followed by Lung cancer (8%), stomach (6.3%), colorectal (6.3%), oesophagus (6.2%) and so on.

In **Sowmya S K R et al. (2013)[19]** conducted a study 48.57% had gastrointestinal cancer, 28.57% had genitourinary cancer and 21.42% had breast cancer. In **Singh H et al. (2014)[13]** study 26.71% had head and neck cancer, 30.53% had genitourinary cancer, 20.61% had thorax cancer. These different type of cancer in different region may be due to different socio-demographic and cultural factors.

In this present study, 54(28.1%) patients reported Treatment delay. 29(29.8%) female cancer patients and 25(26.3%) male cancer patients reported delay in taking treatment more than 1 month after diagnosis and starting treatment. Treatment delay (TD) is delay in diagnosis and treatment after seeking medical health.

In our study, Majority of cancer patients gave reason /barrier for delay in starting treatment were 43(79.6%) no idea where to go for cancer treatment, 41(75.9%) family takes time to decide, 35(64.8%) money related problems, 26(48.1%) use of alternative system of medicine like ayurveda, homeopathy, Yunani etc.(Figure.2) while in Similar study conducted by **Alexander P J. et al. (1993)[20]** found that psychological shock and arranging money for the treatment/Financial constrains may be the prime reasons for family taking time to decide where to consult for the treatment.

Kumar A. et al. (2019)[10] In Guwahati, India found that treatment delay was 130 (75-258) days. Treatment delay was due to initial visit to, misclassification of disease severity, dissatisfaction with care at public facilities, Money and distance to the nearest health facility were barriers to accessing the health system, fear of treatment and its side effects. While in study by **Tiwari V K et al. (2015)[14]** reported (18%) patients reported delay in initiating treatment. Poor awareness, money problem, using alternative systems of medicine and certain myths and social stigma were the common reason of delay in starting treatment.

Conclusion- Treatment delay is very common despite availability of support from various sector of community and is significantly associated with educational status and occupation of the patients. Lack of awareness about sign and symptoms and availability of health services are also major contributors. Delay in seeking treatment needs to be addressed more importantly because it not only prevents mortality but also affects quality of life of cancer patients. Hence there is strong need for increasing awareness among people through health education approach and involving private health care providers.

Recommendations and suggestions- To Improve awareness about various common symptoms of breast, head and neck & cervical cancer via screening, diagnosis & treatment through multiple channels of communication.

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Table 1. Socio Demographic Characteristics of the participants (N=192)

Characteristics	**Total N=192**	**Percentage 100%**
Gender:		
Male	95	49.4
Female	97	50.6
Age groups/years:		
18-30 years	12	6.24
31-60 years	122	63.54
Above 60 years	58	30.2
Residence location:		
Rural	121	63
Urban	71	37
Religion:		
Hindu	158	82.3
Muslim	23	11.9
Sikh	11	5.7
Marital status:		

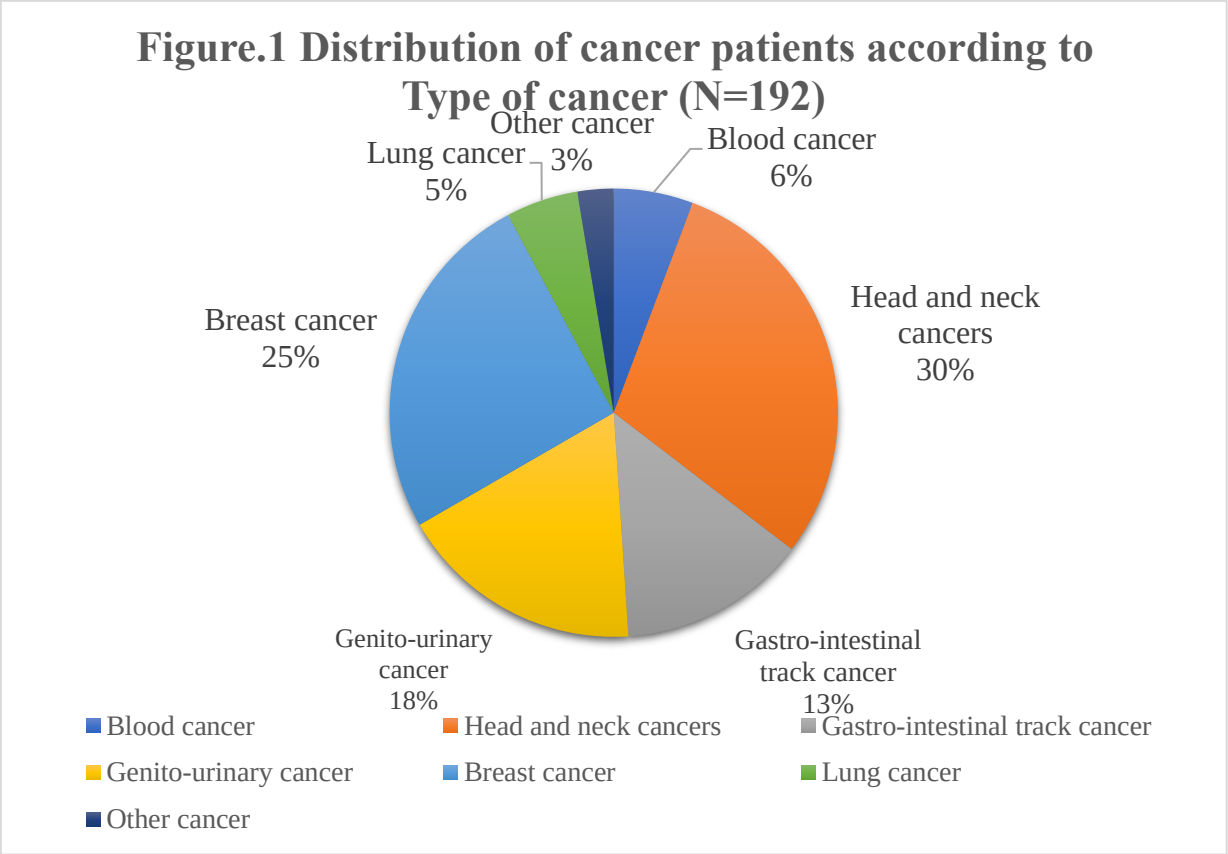
Married	163	84.8
Single	16	8.3
widowed/divorced	13	6.7
Educational status		
Illiterate	68	40.1
Below higher secondary level	77	35.4
Higher secondary and above	47	24.5
Occupation type		
Business/Job/Daily wager/Farmer	78	40.6
Housewife	77	40.1
Retired/Pensioner/Senior citizen	11	5.7
Unemployed	26	13.5
Type of family		
Joint Family	81	44.8
Nuclear Family	86	42.2
Three Generation Family	25	13
Per capita income as per BG prasad scale		
Upper class (I)	27	14
Upper middle class (II)	59	30.7
Middle class (III)	44	23
Lower middle class (IV)	39	20.3
Lower class (V)	23	12
BMI in Kg/meter^2		
Underweight (BMI <18)	31	16.1
Normal weight (BMI 18.0 -24.9	108	56.3
Overweight (BMI 25.0-29.9	43	22.4
Obesity (BMI >30)	10	5.2
History of smoking		
Current smoker	10	5.2
Never smoked	119	62
Past smoker	63	32.8
History of taking oral tobacco/Guthkha		
Current users	5	2.6
Never used	167	87
Past users	20	10.4
History of Alcohol intake		
Currently taking	13	6.7
Never taken	120	62.5
Taken in past	59	30.3
History of any physical activity		
Never	60	31.2
Irregular	6	3.1
Daily	126	65.7

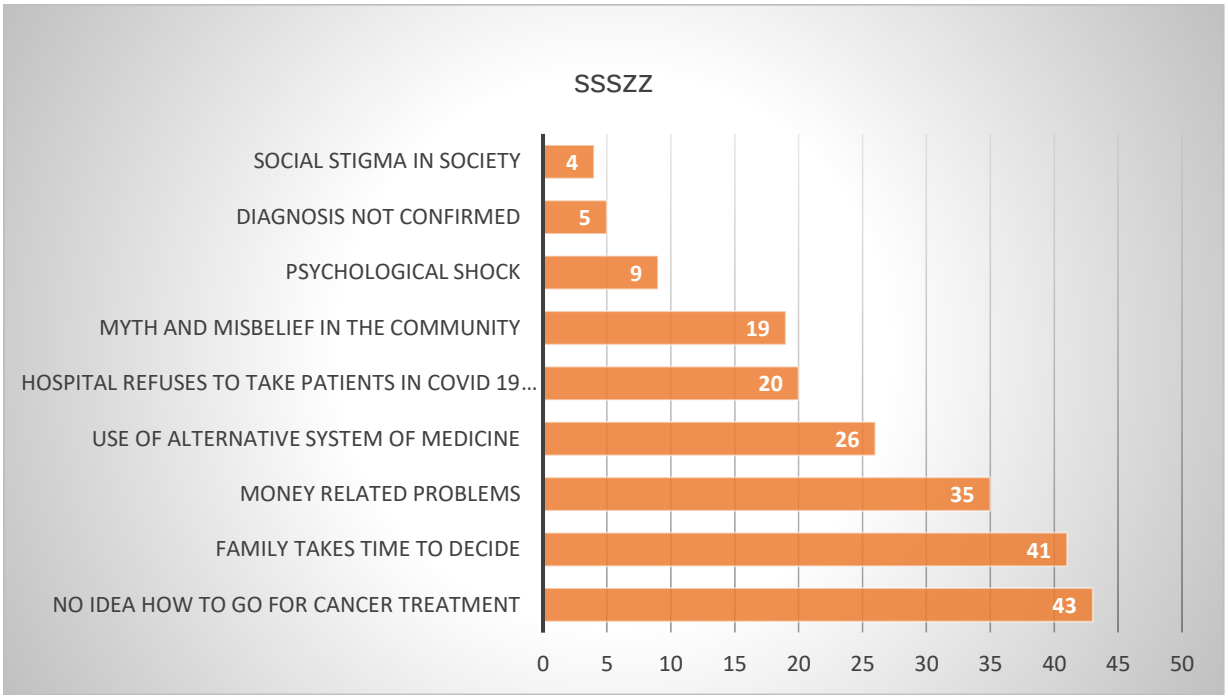
Stage of cancer at the time of diagnosis		
Stage 1	23	12
Stage 2	39	20.3
Stage 3	36	18.7
Stage 4	54	28.1
Not known	40	20.9

Table.2 Distribution of cancer patients according to Treatment delay

Category	**Treatment delay present(n=54)**	**Treatment delay absent(n=138)**	**Total**	**Significance**
Gender				
Male	25(26.3%)	70(73.7%)	95	P value=0.581
Female	29(29.9%)	68(70.1%)	97	
Age groups				
18-30 years	4(33.3%)	8(66.7%)	12	P value=0.917
31-60 years	34(27.9%)	88(72.1%)	122	
Above 60 years	16(27.6%)	42(72.4%)	58	
Occupation				
Business/Job/daily wager/Farmer	17(21.8%)	61(78.2%)	78	**P value<0.001**
Housewife	16(20.8%)	61(79.2%)	77	
Retired/pensioner/senior citizen	4(36.4%)	7(63.6%)	11	
Unemployed/student	17(65.4%)	9(34.6%)	26	
Religion				
Hindu	46(29.1%)	112(70.9%)	158	P value=0.348
Muslim	7(30.4%)	16(69.6%)	23	
Sikh	1(9.1%)	10(90.9%)	11	
Marital status				
Single	6(37.5%)	10(62.5%)	16	P value=0.198
Married	42(25.8%)	121(74.2%)	163	
Widowed/divorced	6(46.2%)	7(53.8%)	13	
Education level				
Illiterate	27(39.7%)	41(60.3%)	68	**P value=0.020**
Below higher secondary level	19(24.7%)	58(75.3%)	77	
Higher secondary and above	8(17.0%)	39(83.0%)	47	
Per capita income BG prasad scale				
Upper class I	11(40.7%)	16(59.3%)	27	P value=0.571
Upper middle class II	16(27.1%)	43(72.9%)	59	
Middle class III	11(25.0%)	33(75.0%)	44	

Lower middle class IV	9(23.1%)	30(76.9%)	39	
Lower class V	7(30.4%)	16(69.6%)	23	
BMI in KG/M2				
Underweight BMI<18	13(41.9%)	18(58.1%)	31	P value=0.295
Normal weight BMI 18.0-24.9	28(25.9%)	80(74.1%)	108	
Overweight BMI 25.0-29.9	10(23.3%)	33(76.7%)	43	
Obesity BMI >30	3(30.0%)	7(70.0%)	10	
Type of Cancer				
Blood cancer	2(18.2%)	9(81.8%)	11	P value=0.703
Breast cancer	15(30.6%)	34(69.4%)	49	
Genito urinary cancer	11(32.4%)	23(67.6%)	34	
Gastro intestinal track cancer	9(34.6%)	17(65.4%)	26	
head and neck cancer	12(21.1%)	45(78.9%)	57	
Lung cancer	4(40.0%)	6(60.0%)	10	
Other cancer	1(20.0%)	4(80.0%)	5	
Distance of treatment centre from home in Km.				
Less than 50	14(17.7%)	65(82.3%)	79(100%)	P value=0.058
Between 50-100	18(37.5%)	30(62.5%)	48(100%)	
Between100-200	20(33.3%)	40(66.7%)	60(100%)	
More than 200	2(40.0%)	3(60.0%)	5(100%)	

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DIAGNOSIS NOT CONFIRMED
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MYTH AND MISBELIEF IN THE COMMUNITY
HOSPITAL REFUSES TO TAKE PATIENTS IN COVID 19...
USE OF ALTERNATIVE SYSTEM OF MEDICINE
MONEY RELATED PROBLEMS
FAMILY TAKES TIME TO DECIDE
NO IDEA HOW TO GO FOR CANCER TREATMENT
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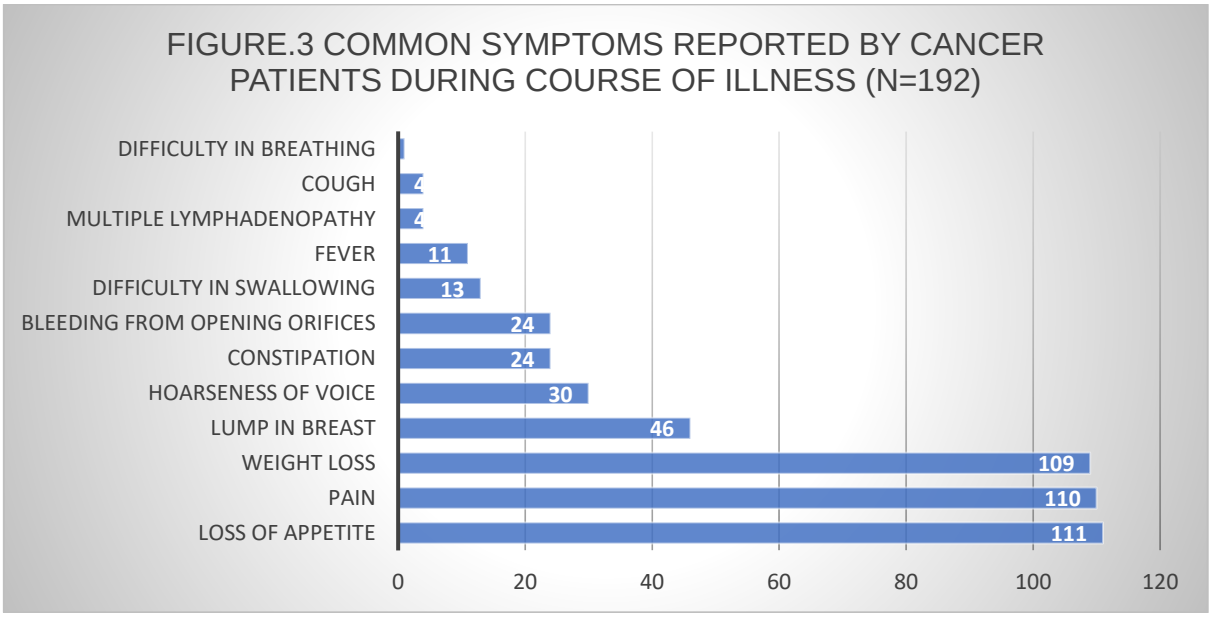
FIGURE.3 COMMON SYMPTOMS REPORTED BY CANCER PATIENTS DURING COURSE OF ILLNESS (N=192)
DIFFICULTY IN BREATHING
COUGH
MULTIPLE LYMPHADENOPATHY
FEVER
DIFFICULTY IN SWALLOWING
BLEEDING FROM OPENING ORIFICES
CONSTIPATION
HOARSENESS OF VOICE
LUMP IN BREAST
WEIGHT LOSS
PAIN
LOSS OF APPETITE
11
13
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