|| ISSN(online): 2589-8698 || ISSN(print): 2589-868X ||
International Journal of Medical and Biomedical Studies
Available Online at www.ijmbs.info
NLM (National Library of Medicine ID: 101738825)
Index Copernicus Value 2019: 79.34
Original Research Article
Volume 5, Issue 2; February: 2021; Page No. 82-89

AWARENESS REGARDING DIFFERENT ASPECTS OF CANCER AND ACCESS TO THE TREATMENTS OF CANCER OF THE PATIENTS ATTENDING AT A PIONEER REGIONAL CANCER CENTRE OF EASTERN INDIA

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Article Info: Received 11 January 2021; Accepted 12 February 2021
DOI: https://doi.org/10.32553/ijmbs.v5i2.1729
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Conflict of interest: No conflict of interest.

Abstract

Cancer patients are prone to be non-compliant to treatment and follow-up. Many studies have been conducted so far regarding knowledge of cancers among the community people. However, not many studies have looked into knowledge of treatments, toxicities due to treatments and importance of follow-up in India. As a result of that no educational intervention programme could be initiated to improve treatment and follow-up compliance among the cancer patients.

Thus the present study aimed at assessing awareness of different aspects of cancer treatments and assessing the accesses to the treatments among the patients attended at regional cancer centre of eastern India.

Methods: The study was conducted on 858 patients selected randomly from 9406 patients attended at Out Patient Door (OPD) of Chittaranjan National Cancer Institute (CNCI) during the period 1st January 2019 – 31st December 2019.

Result: The study aimed at assessing the level of awareness regarding cancer and the access to the treatments of the patients. The mean (mean±s.d.) age of the patients was 50.56±14.94 years with range 2 – 89 years and the median age was 52 years. The sex ratio of the patients was (Male : Female) was 1.0 : 1.3. 71.4% of the patients were with monthly family income ≤ INR 2000. ($p<0.0001$) as a result of that monthly per capita income 56.5% of the patients was ≤ INR 500. ($p<0.0001$). 56.2% of the respondents opined that cancer is curable but 40.7% of them had no idea ($p=0.034$). The mean (mean±s.d.) duration of symptoms of the patients was 8.64±10.23 months with range 0.20 – 96 months and the median was 6 months. The mean (mean±s.d.) time to first consult with any doctor after onset of symptoms of the patients was 11.92±11.22 months with range 0.20 – 96 months and the median was 9 months. The mean (mean±s.d.) distance of residence from CNCI of the patients was 175.14±169.06 km with range 1 – 800 km and the median was 120 km. 70.2% of them had no place to stay with free of cost around CNCI ($p<0.0001$). 70.3% of them had no idea about time to completion of treatments of cancer. 91.7% of them had no idea about type of treatment generally required to treat cancer ($p<0.0001$). 97.8% and 96.7% of them had no knowledge about radiotherapy and chemotherapy respectively ($p<0.0001$). 49.4% of the patients had no idea about requirement of follow-up / check-up after the completion of treatments but 46.5% believed that follow-up / check-up is required after the completion of treatments ($p=0.77$).

Conclusions: From the results of the study it revealed that majority of the cancer patients attending cancer hospitals had no idea about the type of treatments required and its inevitable side effects in most of the cases during treatments which may enforce the patients to be non-compliance of treatments. Moreover, majority of them were reporting late after the onset of symptoms which leads to late presentation by the patients with advancement of disease. Counseling with the patients regarding different aspects of cancer treatments at the very first day of attendance in a cancer hospital will be effective to reduce the drop out during treatments and follow-up.

Keywords: cancer awareness – education interventional programme – access to treatments – late reporting

Introduction

Cancer is a major burden worldwide and a leading cause of mortality in India. Despite progress in reducing mortality rates, changes in the age distribution of the population will mean that cancer incidence will continue to rise.[1] In recent years, the Government of India has developed strategies aimed at reducing cancer incidence and mortality. But not much progress has been found the importance of raising public awareness of early warning signs and risk factors which is reflecting from the increasing incidence of cancers in India.[2-7]

Non-compliance to treatment and follow-up is very common for the patients suffering from cancer. From the medical records of the patients attending Chittaranjan National Cancer Institute (CNCI) hospital it has been observed that nearly 42% of the patients are non-compliant to treatments. Among those who complete treatment, a very low proportion of patients attend the hospital for follow-ups.[8-9]

Not many studies have looked into this very important aspect of cancer care, especially in Indian context. Appropriate counseling and focused education of the patients and relatives can ensure that they understand the

importance of complying with the advice of the physicians. No such structured educational program is available.

The present study aimed at assessing awareness of different aspects of cancer and to assess the accesses to the treatments among the patients attended at CNCI which would aim at the educational invention programme among the patients being attended at CNCI to promote treatment and follow-up compliance among the cancer patients. Thus it was a pioneer study by its nature.

Methods:

During 2019 total number of 9406 patients attended at attending at CNCI for their investigations and treatments. From 9406 patients the 858 patients were selected randomly on the date of first attendance with the help of random number table. The information on awareness and access to cancer treatments were collected with pre-tested well designed proforma in which responses to those statements were recorded by using a Likert scale (Yes, No, and Don't know).[10] The responses were collected by direct interview with the patients and the relatives of the patients in case of patients with aged less than 18 years and patients who were unable to answers due to advanced cancers or throat cancers. There were 15 selective questions to know about the awareness of different aspects of cancer including probable causes for delay in reporting and basic information of the patients in the proforma. The collected information of the patients will be maintained to assess the probable causes of non-compliance to investigations for confirmation to diagnosis, treatments and follow-up after completion of treatments by the patients.

Results:

Statistical Analysis:

Statistical Analysis was performed with help of Epi Info (TM) 7.2.2.2 EPI INFO is a trademark of the Centers for Disease Control and Prevention (CDC).

Descriptive statistical analysis was performed to calculate the means with corresponding standard deviations (s.d.). Test of proportion was used to find the Standard Normal Deviate (Z) to compare the difference proportions. $p<0.05$ was taken to be statistically significant.

Chittaranjan National Cancer Institute (CNCI) is one of the pioneer cancer centres of India which is one of 27 regional cancer centres (RCC) for cancer treatments. Being a tertiary cancer centre most of the patients were referral cases.

Basic information of the respondents:

Being situated in the state of West Bengal of eastern India it caters cancer cares to the patients of eastern India who are mostly from the state of West Bengal (96.6%) ($p<0.0001$).

Among 858 respondents majority were attended the Department of Surgical Oncology (57.3%) which was significantly higher than that of other departments of the institute under study ($p<0.0001$). The mean (mean±s.d.) age of the patients was 50.56±14.94 years with range 2 – 89 years and the median age was 52 years. Thus 69.3% of the patients were with age≥45 years ($p<0.0001$). 1.9% of the patients were with age<15 years.

Ratio of male and female was 1.0:1.3. Proportion of female patients (56.1%) was higher than that of male patients but it was not significant ($p=0.09$). As in the census of India majority of population are Hindu it was reflected in the study Hindu (75.2%) followed by Muslim patients (24.0%) which were significantly higher than the patients with other religion ($p<0.0001$).

Though as per the Census of 2011 the rate of literacy is high in the state of West Bengal, majority of the patients were with primary level of education and illiterate (69.6%) ($p=0.0023$). CNCI is being only government aided cancer treating hospital in the state of West Bengal patients from poor socio-economic background attend the hospital of this institute.

Since female patients were significantly higher in proportion, most of them were home makers (housewife) (48.3%) ($p<0.0001$). As a result of that 71.4% of the patients were with monthly family income ≤ INR 2000. ($p<0.0001$) as a result of that monthly per capita income 56.5% of the patients was ≤ INR 500. ($p<0.0001$). However, though the proportion of joint family (51.3%) was higher than that of nuclear family (48.7%), no significant difference was found between them ($p=0.77$).

Awareness regarding disease of cancer:

56.2% of the respondents opined that cancer is curable but 40.7% of them had no idea ($p=0.034$).

57.1% of the respondents believed that cancer is not an infectious disease in comparison to the answers 'no idea' about it (42.7%) ($p=0.048$). Most of them (95.0%) had no idea that whether cancer should be kept from neighbours or not ($p<0.0001$). However, 1.7% of them answered that it should be secret from neighbours due to social reasons.

Activities earlier to reporting at CNCI:

The time of onset of symptoms of 54.2% of the respondents was between 1 – 6 months ($p<0.0001$). 17.0% of the respondents had the onset of symptoms more than 1 year. The mean (mean±s.d.) duration of symptoms of the patients was 8.64±10.23 months with range 0.20 – 96 months and the median was 6 months.

68.2% of the respondents took more than 6 months to report anywhere with the symptoms ($p<0.0001$). The mean (mean±s.d.) time to first consult with any doctor after onset of symptoms of the patients was 11.92±11.22 months with range 0.20 – 96 months and the median was 9 months.

Thus the mean (mean±s.d.) difference between time of onset of symptoms and first consult with any doctor of the

patients was 3.28±2.49 months with range 0 – 9 months and the median was 3 months.

87.4% of them consulted first either general physician or specialist and rest 12.6% consulted first with the alternative medicine practitioners (p<0.0001). In 54.5% of the cases medical practitioners advised to attend CNCI (p<0.0001).

Access to treatment:

82.8% of the patients were from rural area and only 17.2% of them were from urban area (p<0.0001). 62.2% of the patients had to travel more than 100 km to reach CNCI (p<0.0001). The mean (mean±s.d.) distance of residence from CNCI of the patients was 175.14±169.06 km with range 1 – 800 km and the median was 120 km.

70.2% of them had no place to stay with free of cost around CNCI (p<0.0001) and 82.6% of them were not having capability to bear expenditure to stay around CNCI (p<0.0001).

Awareness regarding treatment of cancer:

70.3% of them had no idea about time to completion of treatments of cancer. 20.4% of the patients believed that surgery causes spread of cancer to other parts of body. However, 61.1% had no idea about it (p<0.0001). 91.7% of them had no idea about type of treatment required to treat cancer (p<0.0001).

97.8% and 96.7% of them had no knowledge about radiotherapy and chemotherapy respectively (p<0.0001).

Awareness regarding follow-up after completion of treatments:

49.4% of the patients had no idea about requirement of follow-up / check-up after the completion of treatments but 46.5% believed that follow-up / check-up is required after the completion of treatments (p=0.77).

Discussion:

Sherin et al. conducted study to access the level of awareness and knowledge about cancers and associated risk factors among 3070 households in six states, West Bengal, Kerala, Madhya Pradesh, Rajasthan and Mizoram. The result revealed that knowledge of cancers of the respondents other than those related to tobacco was very low (prostrate 8%, colon 11%) with a poor awareness of warning signs and the authors concluded that creating awareness among community through educational programs on cancer and Integration of District Cancer Control activities with National Rural Health Mission (NRHM) could be the most cost-effective strategy to prevent cancers and rural population.[2] More or less similar results were found in this study.

Elangovan et al. conducted study on 2981 patients, caregivers, college students and general public with well designed proforma. According to them more than 70% of the study participants were aware that cancer is curable, that cancer is not contagious, and that cancer is not a curse or a death sentence. However, only approximately 50% half believed that surgery or biopsy do not cause cancer to spread to other organs or that radiation therapy does not consist of receiving an electric shock. [3]

In a study conducted by Rai et al. in a hospital setting in Varanasi among patients with breast or cervical cancer, 63.3% of the patients with breast cancer and 41.1% of the patients with cervical cancer considered their disease curable. [4]

In 2004 Mandal et al. reported in their study among the common people of the state of West Bengal that 58% of the respondents believing that most cancers are curable in early stages.[5] In this study 56.2% of the respondents opined that cancer is curable. Thus after time span of one and half decade the situation regarding awareness of cancer prevailing in eastern India is more or less same. However, some improvement was observed in southern part of India.

A qualitative study revealed that although participants expressed profound fear of cancer and perceived cancer as synonymous to death, they acknowledged improved outcomes. Thus similar situation was observed in western countries which indicated that modern researches and treatments of cancer failed to improve confidence among the patients with cancers. [11,15]

A majority of the study participants in the study by Rai et al. had minimal or no formal education, were housewives (87.7%).[4] In this study also majority of the patients were with primary level of education and illiterate (69.6%).

Rai et al. opined that low socio-economic status (64.4%), which could be the reason for the lower level of awareness among those participants.[4] In the similar study by Mandal et al. education, socio-economic status (SES), and social participation were found to be associated with the poor knowledge about cancers. [5] In this study also 71.4% of the patients were with low socio-economic status.

Moreover, in the study by Mandal et al. 21% of the participants answered that cancer is an infectious disease. [5] In the study by Elangovan et al. 30% of the participants reported that cancer is contagious.[3] Present study reported 57.1% of the respondents believed that cancer is not an infectious disease.

Lack of awareness about the onset and prevention of cancer may be the major challenge in cancer control.[16] In a study by Chittem et al. 51% of the patients with cancer were not aware of their diagnosis and treatments.[6] The need for information about the diagnosis and treatment of cancer was expressed by 94% of the patients with cancer, and 92% wanted information about the prognosis, as revealed in a study by Laxmi and Khan. [7]

According to the present study 70.3% of them had no idea about time to completion of treatments of cancer. 91.7% of them had no idea about type of treatment required to treat cancer. 97.8% and 96.7% of them had no knowledge about radiotherapy and chemotherapy respectively. Thus in

overall educational intervention is required to promote the treatment compliance among the patients.

The yardstick for measuring the success of awareness campaigns is achieving down staging of common cancers at presentation for treatment. In India, major proportions of patients with cancer present with advanced-stage disease and do not get the required symptom relief.[18-21]

In a retrospective study by Mandal et al. of the patients registered during 1997 aiming the time taken by the patients from their starting day of symptoms of cancer to reporting i.e. duration of symptoms among a total of 3628 cancer patients registered at CNCI revealed that 19.74% could not remember the duration of symptoms of their diseases at the time of first reporting. Only 2.85% reported within one month of the initial onset of symptoms. However, 97.15% appeared at hospital after several months, contributing to a moderate to advanced stage of their disease at first contact. By that time the mean duration of symptoms was 9.16±8.32 months earlier to the reporting to cancer centre. [9]

The present study revealed that 68.2% of the respondents took more than 6 months to report anywhere with the symptoms ($p<0.0001$). The mean (mean±s.d.) time to first consult with any doctor after onset of symptoms of the patients was 11.92±11.22 months with range 0.20 – 96 months and the median was 9 months. Thus after more than two decades in the same centre the early reporting by the patients remained the common phenomena. This would clearly be expected to lead to poor success in treatment. Late reporting by the patients is most probably due to lack of awareness about the symptoms of cancer. Strategic failure by the Regional Cancer Centres regarding spreading cancer awareness indicates clearly from the study. Thus policy makers have to stress on evidence based cancer awareness to promote early reporting by the patients for down staging.

No study has been conducted on the access to treatments facilities of the cancer patients attending to any cancer centres. However, as per this study 62.2% of the patients had to travel more than 100 km to reach CNCI. The mean (mean±s.d.) distance of residence from CNCI of the patients was 175.14±169.06 km with range 1 – 800 km and the median was 120 km. 70.2% of them had no place to stay with free of cost around CNCI and 82.6% of them were not having capability to bear expenditure to stay around CNCI ($p<0.0001$). With the increasing incidence of cancers and lesser number of cancers treating centres proper strategy may be developed to provide better access to the treatments to the cancer patients.

Conclusions:

From the results of the study it revealed that majority of the cancer patients attending cancer hospitals had no idea about the type of treatments required and its inevitable side effects in most of the cases during treatments which may enforce the patients to be non-compliance of treatments. Moreover, majority of them were reporting late after the onset of symptoms which leads to late presentation by the patients with advancement of disease.

In a government aided hospital mostly poor patients are coming for their treatments. Thus necessary measures need to provide treatments with comparatively low cost. Patients have to travel long distance to reach cancer treating centres from the rural area which indicates that more transport facilities may be provided to the cancer patients and introduction of more night shelters is required for the patients. Thus government and non-government organizations (NGO) must come forward to cope up with the situation.

Majority of the patients are homemakers (house wife) which indicate that accompanying persons are required to support the patients to reach cancer treating centres. NGOs and women welfare organizations can take a vital role to solve this problem keeping in mind that in most of the families accompanying persons are daily wage workers.

Late reporting by the patients put a question about the success of cancer awareness programme in this region. In general most of the awareness programmes of our country are being conducted in special occasions which have adequate impact among the common people. Introduction of Breast Self Examination (BSE) and Self Oral Examination including general cancer awareness programme are required to encourage the patients early reporting. More grants may be available to conduct such programmes which in turn reduce cost of treatments at early stage of cancer and more success in terms of loss of property and loss of life. Even introduction of compulsory chapter in text books of the students may be effective to control increasing burden of cancers in our country including early reporting by the patients.

Counseling with the patients regarding different aspects of cancer treatments at the very first day of attendance in a cancer hospital will be effective to reduce the drop out during treatments and follow-up.

Limitations:

The study was based on only 858 patients attending at a single institution due to financial constraint. Being a government aided hospital mostly patients from poor socio-economic background are attending this kind of cancer treating centres. Thus introduction of multi-centric study may provide better concepts about the existing knowledge of cancers in spite of cancer awareness programme in the community which may provide information to design comparatively better cancer awareness programme in comparison to existing ones. It also helps to design educational intervention programme among the cancer patients to promote treatment and follow-up compliance among the cancer patients.

Acknowledgements:

Authors dully acknowledge Director, CNCI to provide institutional financial grant to conduct the study.

Table1: Basic information of the respondents

Basic Information	Number	%	Z-value	p-value
Department of registration				
Surgical Oncology	492	57.3%	6.02	<0.0001 S
Head & Neck Oncology	134	15.6%		
Radiation Oncology	87	10.1%		
Gynecological Oncology	86	10.0%		
Medical Oncology	59	6.9%		
Age (years)				
<15	16	1.9%	6.67	<0.0001 S
15 - 29	57	6.6%		
30 - 44	190	22.1%		
45 - 59	345	40.2%		
≥60	250	29.1%		
Gender				
Male	377	43.9%	1.69	0.09 NS
Female	481	56.1%		
Religion				
Hindu	645	75.2%	7.21	<0.0001 S
Muslim	206	24.0%		
Christian	5	0.6%		
Sikh	2	0.2%		
Level of education (n=852)				
Illiterate	177	20.8%	3.05	0.0023 S
Primary	415	48.8%		
Middle	239	28.1%		
Secondary	121	14.2%		
Higher Secondary	52	6.1%		
Graduate	25	2.9%		

S-Statistically Significant
NS-Statistically not significant

Table-2: Basic information of the respondents (continued)

Basic information	Number	%	Z-value	p-value
Occupation (n=837)				
Labourer	156	18.6%	4.34	<0.0001 S
Caste Occupation	20	2.4%		
Business	36	4.3%		
Independent profession	33	3.9%		
Agriculture	118	14.1%		
Service	55	6.6%		
Home maker	404	48.3%		
Not disclosed	15	1.8%		
Monthly family income (in Indian Rupees)				
<1000	13	1.5%	8.18	<0.0001 S
1000 - 2000	599	69.8%		
2001 - 5000	115	13.4%		
5001 - 10000	92	10.7%		
≥10000	39	4.5%		
Number of family members				
≤2	86	10.0%	4.89	<0.0001 S
3 - 4	338	39.4%		
5 - 9	380	44.3%		
≥10	54	6.3%		
Monthly per capita income (in Indian Rupees)				
<100	6	0.7%	3.71	0.0002 S
100 - 500	479	55.8%		
501 - 1000	254	29.6%		
>1000	119	13.9%		
Type of family				
Nuclear	418	48.7%	0.28	0.77 NS
Joint	440	51.3%		

Table 3: Awareness regarding disease of cancer of the respondents

Awareness	Number	%	Z-value	p-value
Cancer is curable				
Yes	482	56.2%	2.12	0.034 S
No	27	3.1%		
No idea	349	40.7%		
Cancer is an infectious disease				
Yes	2	0.2%	1.97	0.048 S
No	490	57.1%		
No idea	366	42.7%		
Cancer should be kept from neighbours				
Yes	15	1.7%	13.01	<0.0001 S
No	28	3.3%		
No idea	815	95.0%		

Table 4: Parameters related to activities of the respondents earlier to reporting at CNCI

Activities earlier to reporting at CNCI	Number	%	Z-value	p-value
Time of onset of symptoms (in month)				
<1	33	3.8%	4.19	<0.0001 S
1 - 6	465	54.2%		
7 - 12	214	24.9%		
>12	146	17.0%		
Time of first consult with any doctor after onset of symptoms (in month)				
<1	3	0.3%	5.09	<0.0001 S
1 - 6	270	31.5%		
7 - 12	283	33.0%		
>12	302	35.2%		
Difference between time of onset of symptoms and first consult with any doctor (in month)				
0	161	18.8%	8.48	<0.0001 S
<1	9	1.0%		
1.0 – 6.0	591	68.9%		
6.1 – 10.0	97	11.3%		
Type of doctors for first consultation				
General Physician	446	52.0%	10.46	<0.0001 S
Specialist Doctors	304	35.4%		
Homeopath	61	7.1%		
Ayurvedic	47	5.5%		
To attend CNCI advice given by				
Medical Practitioners	468	54.5%	4.17	<0.0001 S
Self	105	12.2%		
Relative	58	6.8%		
Friend	225	26.2%		
Others (NGO, Social workers and others)	2	0.2%		

Table 5: Parameters related to access to treatment

Access to treatment	Number	%	Z-value	p-value
Place of residence				
Rural	710	82.8%	9.33	<0.0001 S
Urban	148	17.2%		
Residential Status				
West Bengal	829	96.6%	13.29	<0.0001 S
Other States of India	25	2.9%		
Other countries	4	0.5%		
Distance of residence from CNCI (in km)				
<50	188	21.9%	3.39	0.0007 S
50 - 99	136	15.9%		
100 - 149	146	17.0%		
150 - 199	128	14.9%		
200 - 499	209	24.4%		
≥500	51	5.9%		
Place to stay with free of cost around CNCI				
Yes	256	29.8%	5.65	<0.0001 S
No	602	70.2%		
Having capability to bear expenditure to stay around CNCI (n=602)				
Yes	105	17.4%	9.33	<0.0001 S
No	497	82.6%		

Table 6: Awareness regarding treatment of cancer

Awareness regarding treatment of cancer	Number	%	Z-value	p-value
Time to completion of treatments of cancer				
Single Day	0	0.0%	5.65	<0.0001 S
Few days	14	1.6%		
Few weeks	241	28.1%		
No idea	603	70.3%		
Surgery causes spread of cancer to other parts of body				
Yes	175	20.4%	5.90	<0.0001 S
No	159	18.5%		
No idea	524	61.1%		
Knowledge about type of treatment				
Surgery (S)	37	4.3%	11.97	<0.0001 S
Radiotherapy (R)	2	0.2%		
Chemotherapy (C)	6	0.7%		
Hormone (H)	5	0.6%		
S+R	12	1.4%		
S+H	2	0.2%		
R+C	2	0.2%		
S+R+C	5	0.6%		
No idea	787	91.7%		
Knowledge about radiotherapy				
Minimum side effect	8	0.9%	13.57	<0.0001 S
Very distressing	8	0.9%		
Not to be given at all	3	0.3%		
Not known	839	97.8%		
Knowledge about chemotherapy				
Minimum side effect	15	1.7%	13.29	<0.0001 S
Very distressing	10	1.2%		
Not to be given at all	3	0.3%		
Not known	830	96.7%		

Table 7: Awareness regarding follow-up after completion of treatments of cancer

Awareness regarding follow-up	Number	%	Z-value	p-value
Need for check-up (follow-up) after completion of treatments				
Yes	399	46.5%	0.28	0.77 NS
No	35	4.1%		
No idea	424	49.4%		

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