

Original Research Article

Identification of factors influencing delayed presentation of cancer patients

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ABSTRACT

Background: Delayed presentation of patients of cancer is associated with poorer survival. Early presentation, timely diagnosis and treatment are critical factors in improving long-term survival for patients with cancer. Thus, reducing delays in diagnosis of cancer should be a priority. Against this backdrop this study was conducted to identify factors leading to delayed presentation of patients in advanced stages of cancer at our institute.

Methods: Newly diagnosed patients of cancer coming to radiation oncology, surgery and medical oncology outpatient departments were included in this study. Data was collected in a pre-validated questionnaire format.

Results: 360 patients were included. Majority of patients 212 (58.9%) were male. 66.7% patients were from rural areas. Most of the patient's educational level was upto primary schooling 178 (49.4%) and caregiver educational level was upto primary schooling 153 (42.5%). Reason for alternative treatment correlated significantly with patient awareness about the disease ($p < 0.03$). Most common reason of the time gap given by patients was symptom appraisal 258 (71.7%).

Conclusions: Educational level of patients, symptom appraisal, fear of side effects of treatment and awareness about disease were main reasons for delay in presentation of cancer patients. So, education regarding warning signs of cancer and symptom appraisal are important in reducing delays in presentation.

Keywords: Cancer detection, Delayed, Survival, Awareness

INTRODUCTION

Cancer is one of the leading causes of death in many countries despite the advancement in cancer diagnosis and treatment. According to Globacon 2018 incidence of cancer in India is 11,57,294 annually. Also number of deaths due to cancer in India has increased from 3,82,000 in 1990 to 7,84,821 in 2018.¹ To combat this dreadful disease national cancer control programme was initiated by the government of India in 1975 to equip tertiary care cancer hospitals and institutions to implement systematic,

equitable, and evidence based strategies for prevention, early detection, diagnosis, treatment, and palliation, using available resources. Despite all these efforts most of patients presenting to our hospital are in very advanced stages. How long a cancer patient takes to present may be influenced by several factors, including the nature of the symptoms, awareness of the significance of the symptoms, perception of personal risk of cancer, and physical, social and psychological barriers to health care. Delayed presentation of symptomatic cancer is associated with poorer survival. Early presentation, timely diagnosis and treatments are critical factors in improving long-term

survival for patients with cancer.² During the last 20 years, India has appeared as a fast-growing economy with changes in lifestyle-related behaviour partly accountable for increasing cancer burden and is among top three causes of mortality among adults in both rural and urban India.³ Inequalities in cancer survival may be elucidated by variances in tumour biology, access to effective management and stage at diagnosis. Delay in presentation with symptoms among patients with cancer is likely to contribute to late stage at diagnosis leading to low cure rates and poorer survival.⁴⁻⁶

Studies have done to identify factors leading to advanced stages at presentation. Jenkins et al 2002 studied that patients may not be able to recall nature and duration of symptoms, and therefore did not attend any physician.⁷ Symptoms such as sore throat, cough with sputum, low grade fever and vaginal discharge are underrated by patients and they do not consult doctor unless these symptoms become distressing or affect their day to day life. Rachet et al and Lyratzopoulos et al, mentioned that people of low socioeconomic strata have more advanced cancer at diagnosis and worse survival.^{8,9} Reasons are not clear but meeting the basic needs of life and less awareness about themselves and their health might be a reason. Krishnatreya et al mentioned that literacy rates have also been indirectly related to the socio-economic condition of the patients causing delayed presentations.¹⁰ Factors such as educational levels, availability of treatment resources and knowledge regarding cancer issues to be important factors affecting the delays.^{11,12}

At our institute more than 80% patients of cancer present in very advanced stages when treatment options are limited and most of them are managed by palliative intent. If these patients report early during their malignancy it may help in improving cure rates of these patients. So we aimed to identify risk factors for delay in presentation by analysing socio-demographic characteristics, site of malignancy, symptoms, patient educational status, distance from health care facility and reported reasons for delay in reporting to clinician cancer patients coming to our to inform the development of public health approaches to promote early presentation. Thus, reducing delays in diagnosis of cancer should be a priority. Against this backdrop, this study was conducted to identify factors which are cause of presentation of patients in advanced stages of cancer at our institute.

METHODS

Study setting

This prospective observational study was conducted between April to July 2019 at All India Institute of Medical Sciences Rishikesh. Newly diagnosed patients of cancer coming to radiation oncology, surgery and medical oncology OPD were included in the present study.

Sample size calculation

Assuming the prevalence 9.5%, sample size was calculated to be 260 by keeping relative precision of 5%. Applying a design effect of 1.3, sample size was calculated to be 330. Considering a drop-out rate of 5%, the final sample size was calculated to be 360. Sample size was calculated using the formula $n = \frac{4}{pqL^2}$, where P= assumed prevalence of advanced stage cancer cases, q= 1-p, and L= absolute precision.

Participant selection

Selection criteria included age >18 years, recently diagnosed Stage III and IV all solid tumour patients. Patients who had received previous treatment for cancer, stage I and II patients, disease free patients on follow up and haematological malignancies were excluded from the present study.

Data collection

Complete history and physical examination with reference to duration of symptoms, duration of time to definitive diagnosis were enquired. Staging of each site was done according to 8th AJCC (American joint committee on cancer) classification or FIGO (in gynaecological malignancies). Patients and their care giver were evaluated for their level of education Socioeconomic status will also be assessed. Data was collected in a structured questionnaire format. Questionnaire included sociodemographic profile age, gender, educational status of patient and caregiver, type of family, location of residence and income status. Also, they were interviewed for duration of symptoms, any alternative treatment taken or not, reason for alternative treatment, any investigation done or not, time gap from symptom to diagnosis and reason for delay in diagnosis.

Statistical analysis

Data analysis was done by using SPSS version 19.0. Frequency and percentage value were calculated to explain socio-demographic data, various clinical variables and its risk factors for cancer. P value of <0.05 was considered significant for all tests.

Ethical approval

The study was approved by Institutional Ethical committee. Informed consent was taken from patients before inclusion in study.

RESULTS

Sociodemographic profile

This study was conducted between April to July 2019 and 360 newly diagnosed stage III and IV cancer patients were included. Majority of patients i.e. 106 (29.4%) each

belonged to 51-60 years and >60 years age group. 212 (58.9 %) were male. 66.7% patients were from rural areas and remaining 140 (33.3%) were resident of urban locations. 339 (94.2%) patients were married and 6 (1.7%) were divorced. Most of patient's educational level was up to primary schooling 178 (49.4%) and caregiver educational level was upto primary schooling 153 (42.5%). Only 9.5% and 5.8% of patients and their care givers had received higher education. 192 (53.3%) had nuclear families. 280 (77.8%) patients had their residence distance from health care facility between 10 km to 100 km areas and 62 (17.2%) were residing within 10 km of health care facility. Majority of patients were doing housework (37.5 %) but these were all female patients, followed by agriculture 126 (35%). Majority of patient's

monthly income (in INR) were in Rs. 1000-33000 group (45.5%) followed by Rs. 33001-55000 (44.4%) (Table 1). Cancer site was head and neck region in 104 (28.9 %) followed by gastro-intestinal 89 (24.7 %), lung 70 (19.4 %) and breast 46 (12.8%). Other malignancies included soft tissue sarcoma and melanoma (Figure 1). Most of patients were in Stage IV 231 (64.3 %) and 24 (6.7%) patients did not have diagnosis established so staging was awaited. Histological most of them were squamous cell carcinoma 142 (39.4 %) followed by adenocarcinoma of 30.6% reason being most of the patients belonged to head and neck region. Grade of cancer were grade II in 202 (56.1 %). 94 (26.1%) patients had grade III which rapidly grows and spreads faster than the lower grades.

Table 1: Sociodemographic profile of participants.

S. no.	Variable	Options	Number	%
1.	Age (in years)	>18-30	22	6.1
		31-40	50	13.9
		41-50	76	21.1
		51-60	106	29.4
		>60	106	29.4
2.	Gender	Male	212	58.9
		Female	148	41.1
3.	Residence	Urban	120	33.3
		Rural	240	66.7
4.	Marital status	Married	339	94.2
		Single	14	3.9
		Widowed	1	0.3
		Divorced	6	1.7
5.	Educational level of patient	Illiterate	69	19.2
		Primary schooling	178	49.4
		Complete schooling	79	21.9
		Higher education	34	9.5
6.	Educational level of caregiver	Illiterate	115	34.2
		Primary schooling	153	42.5
		Complete schooling	63	17.5
		Higher education	21	5.8
7.	Type of family	Nuclear	192	53.3
		Joint	168	46.7
8.	Residence (distance from health care facility)	<10 km	62	17.2
		10-100 km	280	77.8
		>100 km	18	5.0
9.	Occupation	Service	69	19.2
		Business	14	3.9
		Agriculture	126	35.0
		House work	135	37.5
		Unemployed	16	4.5
10.	Income (in Rs.)	1000-33000	164	45.5
		33001-55000	160	44.4
		55001-88800	34	9.4
		88801-1,50,000	2	0.55
		>1,50,000	0	0

Table 2: Assessment of patients for reasons of delay and knowledge about cancer.

S. no.	Variable	Options	Number	%
1.	Symptom duration (in months)	<3	89	24.7
		3-6	123	34.2
		6-12	68	18.9
		>12	80	22.2
2.	Any investigation done	Yes	311	86.4
		No	49	13.6
3.	Pattern of presentation	Presenting directly to institute	175	48.6
		Diagnosed outside and then referred to Institute	125	34.7
		Diagnosed and received alternative treatment outside and then came to Institute	60	16.7
4.	Any alternative treatment	Yes	116	32.2
		No	244	67.8
5.	If yes alternative treatment duration (in months)	No treatment taken	244	67.8
		0-3	19	5.3
		3-6	56	15.6
		6-12	21	5.8
6.	Reason of alternative treatment	>12	20	5.5
		No treatment taken	244	67.8
		Faith	37	10.3
		Assurance of cure	73	20.3
7.	Time gap from symptom appearance to diagnosis (in months)	Fear of side effects of chemotherapy/radiation therapy	6	1.6
		<1	17	4.7
		1-3	106	29.4
		>3	220	61.1
8.	Reason of time gap	Diagnosis not yet established	17	4.7
		Symptom appraisal	258	71.7
		Fear and denial	56	15.6
		No nearby health care facility	11	3.1
9.	Patient aware about his/her disease	Investigations were inconclusive	34	9.4
		Yes	298	82.8
		No	62	17.2
10.	Family awareness of cancer	Yes	344	95.6
		No	16	4.2

Majority of patients were having no history of any abuse 156 (43.3 %) and this group had mainly females followed by history of smoking 104 (28.9 %), 43 (11.9%) had habit of smoking, alcohol and tobacco intake. Most of patients were having symptom for 3-6 months 123 (34.2 %), 80 (22.2%) patients had symptoms more than 12 months but still they did not consult clinician. Most of patient were having any investigation done 311 (86.4%) relevant to cancer. Pattern of presentation of cancer among patients were mostly presenting directly to institute 175 (48.6 %), 60 (16.7%) patients were diagnosed and took alternative medication and then reported to institute for treatment.

Reasons for delayed presentation

Most of cancer patients were not taking 244 (67.8 %) any alternative treatment. 116 (32.2 %) took alternative treatment before coming to our institute, among them 56 (15.6 %) were taking alternative treatment since 3- 6 months, 21 (5.8 %) were taking alternative treatment for

6-12 months, 20 (5.5%) were taking it for more than 12 months. Most common reason for taking alternative treatment was assurance of cure of cancer 73 (20.3%), followed by faith in alternative treatment 37 (10.3%) and 6 (1.6%) were taking alternative treatment because of fear of side effects of Surgery, chemotherapy and radiation. Reason of alternative treatment correlated with significantly with patient awareness about disease ($p < 0.03$).

On assessment of time gap between symptom appearance and diagnosis it was more than 3 months in 220 (61.1%) patients, 106 (29.4%) were having a time gap from 1month to 3 months and only 17 (4.7%) patients were diagnosed within 1 month of symptom appearance. Most common reason of time gap given by patients was symptom appraisal by 258 (71.7%), 2nd reason was fear and denial (15.6%), 3rd reason were investigations were inconclusive 34 (9.4%) and 4th reason was no nearby health care facility in 11 (3.1%) patients (Figure 2). 298

(82.8%) patients were aware about his/her disease and 344 (95.6%) family had awareness about cancer (Table 2).

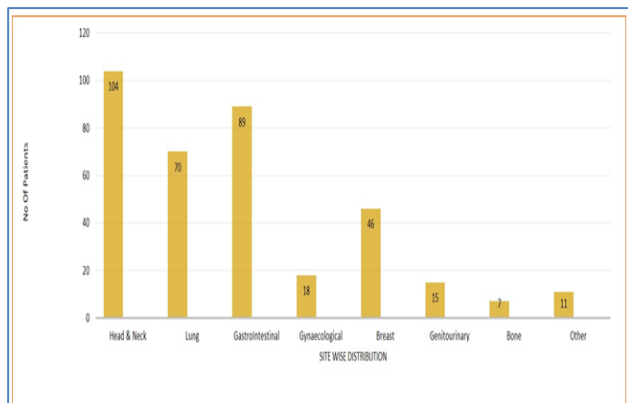


Figure 1: Distribution of patients according to site of malignancy.

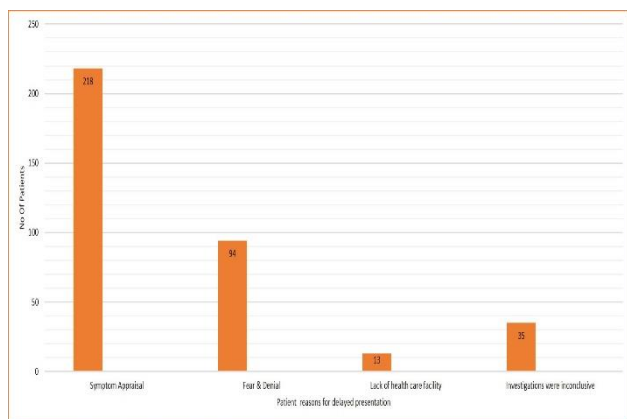


Figure 2: Reasons for delayed presentation of cancer patients.

DISCUSSION

Cancer has become a major public health problem in today’s world. Inequalities in cancer survival may be explained by differences in tumour biology, access to effective treatment and stage at diagnosis. Delay in presentation with symptoms among patients with cancer is likely to contribute to late stage at diagnosis and, thereby, poorer survival.

This study we aimed to identify factors leading to advanced stages of presentation. On analysis it was found that patients and care givers had less education levels so their understanding and symptom appraisal and need to consult physician was late. Literacy rates have also been indirectly linked to the socio-economic condition of the patients causing delayed presentations. Krishnatreya et al has also studied that there was significant difference in educational level of patient and start of treatment in head and neck cancer.¹⁰ Tiwari et al reported that in their study 77.87% of the patients with little or no education

presented in advanced stages of the disease.¹⁵ In present study 50 % of patients had Lyratzopoulos et al, reported that socioeconomic inequalities was associated with delayed in diagnosis.⁹ Similarly in present study 78% of patients presenting in advanced stages had no or upto primary education and also patients mainly belonged to low socioeconomic status had late presentation.

Distance of residence from health care facility was another reason because to commute and transportation to health care was a difficult task. As Uttarakhand is hilly region patients have to travel long distances to receive assistance when required.

Also, patients and care givers stigma about the dreadful disease and acceptability of occurrence is a reason that patients are not willing to consult physician.¹³ Patients in this study mainly belonged to head and neck region followed by gastrointestinal (GI) region and breast. Head and neck are sites where abnormal lesions, ulcer or growth can be identified early but still patients presented to us in advanced stages. Patients of GI cancer may not able to appreciate their symptoms as they are usually nonspecific and patients present only when symptoms are distressing or radiological findings are suggestive of malignancy. Similarly, other studies have also found that site of malignancy also correlated with advanced stages of presentation. Samet et al 1988 reported that patients with prostate cancer were more likely to delay presentation than patients with breast or colorectal cancer.¹⁴

Time gap was also analysed from symptom to diagnosis and 61% of patients had symptoms for more than three months before they were diagnosed to have cancer. When enquired most common reason of time gap was that they were not able to assess symptom 71.7% followed by fear and denial 15.6% that they might be suffering from dreadful disease like cancer, other reason being investigations were inconclusive (9.4%) and lack of nearby health care facility (3.1%). Tiwari et al, in their study reported that most common reasons for delayed hospital presentation included lack of symptom appraisal, consultation with unqualified local practitioners, usage of alternative treatment, poor socio-economic status and lack of a proper referral infrastructure.¹⁵ Also, alternative medication was received by 116 (32.2%) patients for varying duration from 1 to more than 12 months. Out of 116 patients 60 received alternative medication after diagnosis and when there was progression of symptoms then they reported to our institute. Patients’ reasons for opting alternative treatment was that they had faith and assurance of cure was given to them. Patients and care givers education status significantly correlated ($p < 0.03$) with their keenness towards alternative medication.

Use of alternative medication has also been reported in other studies with varying results.¹⁶ More Time gap from symptom to diagnosis significantly correlated with

education level of patients ($p < 0.02$) and education level of care givers ($p < 0.001$) which suggest that we need to educate and more awareness camps are required for symptom assessment and early presentation for diagnosis and management. Also, distance from health care facility significantly correlated with delay in getting investigations done ($p < 0.01$) which also is a factor leading to delayed diagnosis. Site of cancer had a correlation with symptom duration ($p < 0.05$) and patient with GI malignancies though having short duration of symptoms presented with advanced stages reason being GI malignancies have usually nonspecific symptoms so appraisal of symptoms is delayed.

By this study it was analysed that more work needs to be done towards public awareness for symptoms of cancer. Earlier the cancer can be detected, the better the chances for treatment and survival.

CONCLUSION

This study suggests that increasing awareness about early signs and symptoms of cancer through an improved education level may lead to early identification of cancer symptoms. Identifying important factors that can be modifiable through appropriate intervention programs related to delay would not only reduce delays in diagnosis but also minimize time in initiating treatment which can improve cure rates in cancer.

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Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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