Symptoms Experienced by Cancer Patients and Barriers to Symptom Management

Malathi G Nayak, Anice George[1], MS Vidyasagar[2], Stanley Mathew[3], Sudhakar Nayak[4], Baby S Nayak[5], YN Shashidhara[6], Asha Kamath[7]

Departments of Community Health Nursing, [1]Head of the Institution, [5]Child Health Nursing and [6]Departments of Community Health Nursing, Manipal College of Nursing Manipal, [2]Departments of Radiotherapy and Oncology, [3]Surgery, [4]Biochemistry and [7]Community Medicine, Kasturba Medical College Hospital, Manipal University, Manipal, Karnataka, India

Address for correspondence: Ms. Malathi G Nayak; E-mail: malathinayak@yahoo.co.in

ABSTRACT

Background: People living with cancer experience wide variety of symptoms. If symptoms are not managed well, it may hamper an individual's ability to continue his or her activities of daily life. Treatment of symptoms relieves suffering and improves the rate of recovery as well as the quality of life.

Objectives: To assess the symptoms of suffering among cancer patients and to identify the perceived barriers to their symptom management.

Materials and Methods: A cross-sectional study was carried out among 768 cancer patients selected by stratified sampling with a proportionate selection from each stratum. Data were collected from cancer patients by interview technique using structured validated questionnaire.

Results: Majority of the samples (30.2%) belonged to the age group of 51–60 years, most of them were diagnosed with head and neck cancer (40.1%) and 57.7% had stage III disease. The majority of the patients studied had pain (77%), tiredness (96.5%), disturbed sleep (96.4%), weight loss (63.3%), and irritability (85.7%). Most of the patients had lack of appetite (89.4%), feeling of sadness (96.6%), worry (94.5%), and feeling of nervousness (82.8%). Majority of the patients had some misconception regarding symptoms, that is, increasing pain signifies disease progression (92.7%), medicine to control pain may weaken the immune system (89.9%) and pain is inevitable for cancer patients (78.5%). Seventy-seven percent of samples reported that the anxiety or depression is expected after the diagnosis of cancer.

Conclusion: This study provides an overview of symptoms among cancer patients and barriers experienced by them.

Key words: Barriers, Cancer patients, Symptoms

INTRODUCTION

People living with cancer experience a variety of symptoms-such as pain, worry, depression, diarrhea, cough, shortness of breath, nausea, weakness, fatigue, fever, and confusion. Lack of care results in untreated symptoms that hamper an individual's ability to continue his or her activities of daily living. Treatment of symptoms relieves suffering and often improves the rate of recovery and quality of life. Ward and Gatwood (US) identified barriers like fear of addiction, beliefs that "good" patients do not complain about pain, and concerns about side effects[1] Borneman *et al.* (UK) classified barriers into three categories: Patient, professional, and system barriers.[2] Pnina has reported three types of barriers to manage pain; those were an addiction to medication, saving pain medicine to use when the pain gets worse, and pain is a sign that the disease was getting worse.[3] Yeom and Heidrich (2009, USA) identified three

Access this article online

Quick Response Code:

Website: www.jpalliativecare.com

DOI: 10.4103/0973-1075.164893

possible barriers to symptom management; they were: Negative beliefs about managing symptoms, perceived negative attitudes of healthcare providers, and difficulties in communicating about symptoms. Barriers to symptom management may lead to poorer self-care of symptoms that can result in lower levels of psychosocial quality of life.[4]

Objectives of the study

Objectives of the study were to:

- Assess the symptoms among cancer patients
- Identify the perceived barriers to symptom management among cancer patients
- Find the association between perceived barriers and study variables of client such as age, education, income, type of cancer, stage of cancer, duration of illness, and treatment.

Sample size estimation

One of the main objectives was to estimate the barriers perceived by the cancer patients. The sample size for this study was calculated based on the pilot study result. For 95% confidence limits, the allowable error of 1.5% and a design effect of 2 for cluster sampling, a sample size of 768 would be sufficient to estimate the rate at 5% level of significance.

Formula used for the calculation of sample size was:

$$N = \frac{Z\alpha^2 \times \sigma^2}{d^2}$$

N = Sample size

$Z\alpha$ = 95%

σ = 7.8 (Barrier score)

d = 1.5%

Total = 384. 384 × 2 = 768

MATERIALS AND METHODS

An exploratory survey was done among 768 cancer inpatients aged above 30 years and diagnosed to be in third or above stages of cancer of breast/cervix/head and neck/gastro intestinal tract/lung/colorectal cancer and have undergone radiotherapy or chemotherapy or surgery or combination of them in selected reputed cancer hospitals of Karnataka. Patients unable to perform activities and with psychiatric problems were excluded from the study. Reputed cancer hospitals all over Karnataka were selected by purposive sampling, and each hospital was considered as a stratum. Then proportionate sample from each stratum was selected for the study. Data were collected from cancer patients of various hospitals using pre-tested structured interview technique after obtaining permission from the respective hospital administrators. Cancer patients those who have given their consent only were interviewed for the study.

Ethical issues

Reputed cancer hospitals were selected, and permission was obtained from the respective administrators. The hospitals who granted permission to do the study only were included. The objective and study protocol were explained to the study participants, and written consent was taken.

Analysis of data

The obtained data were entered in SPSS version 16.0. Data analysis was performed by using descriptive and inferential statistics.

RESULTS

The data from 768 samples were collected and analyzed based on the objectives of the study. Out of 768, majority of the cancer patients (30.2%) belonged to the age group of 51–60 years, most of them were females (57.2%), belonged to Hindu religion (87.9%) and 94.5% were married [Table 1]. The majority of the cancer patients (39.2%) were primary educated [Figure 1]. Most of the affected patients were housewives (49%), their monthly income was between Rs. 2501 and 5000 (51.3%), and 33.1% of the patients had taken combination therapy [Table 2]. Most of them availed modern medical treatment from the hospital after final diagnosis (80.3%) and 57.7% of the samples were in the third stage of cancer [Table 3]. Around 40% of the patients suffered with head and neck cancer and most (76.2%) of the patients were suffering from the illness for <6 months [Figures 2 and 3].

Self-reported symptoms of suffering

During survey, patients reported various symptoms. Major symptoms are depicted in Figure 4. Majority of the patients (96.5%) had tiredness, 96.4% had disturbed sleep, 94.5% had worry, 90.4% of the patients reported that they lost their appetite after diagnosis, 85.7% patients felt irritable, 83% of patients had feeling of nervousness, 77% had pain and 63.3% of the patients lost their weight after diagnosis, 60.7% had anxiety and 57.6% had depression.

Table 1: Frequency and percentage distribution of cancer patients based on socio-demographic characteristics such as age, gender, marital status, type of family (*n*=768)

Variables	Number of cancer patients (%)
Age in years	
30-40	125 (16.3)
41-50	221 (28.8)
51-60	232 (30.2)
Above 60	190 (24.7)
Gender	
Male	329 (42.8)
Female	439 (57.2)
Religion	
Hindu	675 (87.9)
Christian	40 (5.2)
Muslim	53 (6.9)
Marital status	
Married	726 (94.5)
Unmarried	25 (3.3)
Widow	15 (2)
Divorced	2 (0.3)
Type of family	
Nuclear	747 (97.3)
Joint	18 (2.3)
Extended	3 (0.4)

Table 2: Frequency and percentage distribution of cancer patients based on employment, income, and type of treatment (*n*=768)

Variables	Number of cancer patients (%)
Employment status	
Employed	50 (6.5)
Unemployed	280 (36.5)
Retired	62 (8.0)
House wife	376 (49.0)
Income of the family per month in rupees	
≤2500	22 (2.9)
2501-5000	394 (51.3)
5001-10,000	198 (25.8)
10,001-15,000	84 (10.9)
>15,000	70 (9.1)
Area of living	
Urban	249 (32.4)
Rural	518 (67.4)
Type of treatment taken	
CT	75 (9.8)
RT	112 (14.6)
Surgery	6 (0.8)
RT+surgery	52 (6.8)
CT+surgery	94 (12.2)
RT+CT	254 (33.1)
RT+CT+surgery	175 (22.8)

RT: Radiotherapy; CT: Chemotherapy

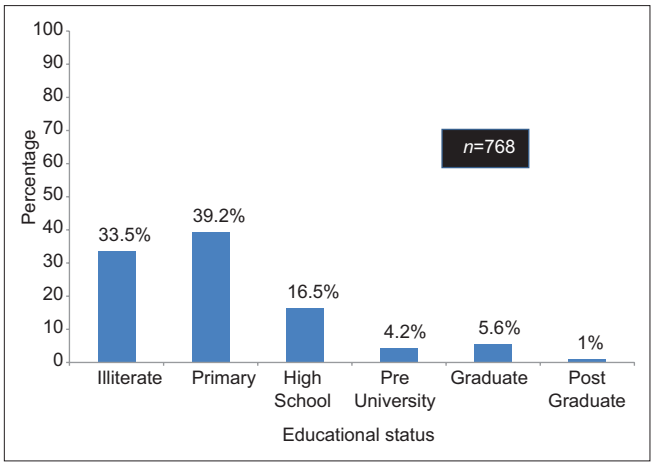

Figure 1: Educational status of cancer patients

Perceived barriers to symptom management among cancer patients

The barriers were categorized into: Communication, personal, professional, financial and misconceptional barriers. The response for all items are graded on a four-point scale (4 = "very much," 3 = "quite a bit," 2 = somewhat, 1 = "a little," and 0 = "not at all"). Major barriers only are shown in the Tables 4-6. Majority of the patients (36.1%) did not know how to express symptoms since the majority had only primary education, they were facing language problems while communicating with the health care personnel (45.8%). 71.4% had worry about side-effects, and 23.1% had fear about addiction. 90.6% had a fear of consequences of treatment, and 96.9% had fear about disease progression. Most (58.8%) of the patients had a fear of further hospitalization, and there were no professional barriers identified except overcrowding in the cancer clinic (50%) [Table 4]. About 89.3% had lack of resources in the family, 99% of the samples expressed that the treatment is very expensive, 72% of samples were not able to afford nutritional supplements, 82.6% of them reported inability to afford the cost of medicine and to pay for health care services (83.1%) [Table 5]. Majority of the samples had some misconception that is, increasing pain signifies disease in progress (92.7%), medicine to control pain may weaken the immune system (89.9%), pain is inevitable for cancer patients (78.5%), and 77.1% of samples reported that the anxiety or depression are expected after diagnosis of cancer [Table 6].

Data further showed that for total barriers score among cancer patients from all categories, the mean was 44.86 and standard deviation 19.38 [Table 7]. Median and interquartile range of each type of barriers identified among cancer patients are presented in Table 8. Financial barriers were

Table 3: Frequency and percentage distribution of cancer patients based on treatment modality, duration of treatment and stage of cancer (*n*=768)

Variables	Number of cancer patients (%)
Treatment modality received before visiting hospital	
Homeopathy	33 (4.3)
Modern medicine	617 (80.3)
Ayurveda	117 (15.2)
Alternative medicine	1 (0.1)
Duration of treatment in months (after diagnosis)	
<6	585 (76.2)
6 - <12	110 (14.3)
12 - <24	37 (4.8)
More than >24	36 (4.7)
Treatment and prognosis	
Yes	489 (63.7)
No	279 (36.3)
Stage of cancer	
Third	443 (57.7)
Fourth	325 (42.3)

affecting symptom management the most among the cancer patients. Central 50% of the samples have a value of 12–24.

Association between mean score of barriers and study variables

One-way ANOVA test was used to test the association between the mean score of barriers perceived by the cancer patients and study variables such as age, gender, education, income, type and duration of illness. Result showed that as education and income increases, barriers score decreases, which is found to be statistically significant (education: $F = 13.556$, $P = 0.001$ and income: $F = 16.338$, $P = 0.001$) [Table 9].

DISCUSSION

The study findings were in conformity with a study done by Naveh *et al*.[3] who reported that 66% of the patients had severe pain and Iyer *et al*. who found that more than 90% of the patients expressed pain, fatigue and loss of appetite. Fatigue, loss of appetite, shortness of breath and pain have a significant negative impact on patient reported disease specific health related quality of life in advanced non-small-cell lung cancer patients.[5] Nilmana *et al*.[6] and Harding *et al*.[7] reported in their study that most of the cancer patients had pain (87.5%), lack of energy (77.7%), feeling sad (75.9%), feeling of drowsiness (72.3%) and worry (69.6%). Yates *et al*.[8] reported some of the symptoms experienced by patients in their study: 48% of cancer patients had pain within the previous 24 h and they were

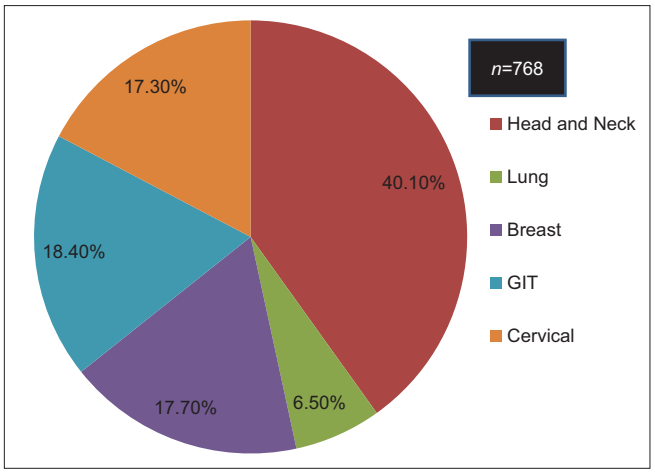

Figure 2: Types of cancers. GIT: Gastro intestinal tract

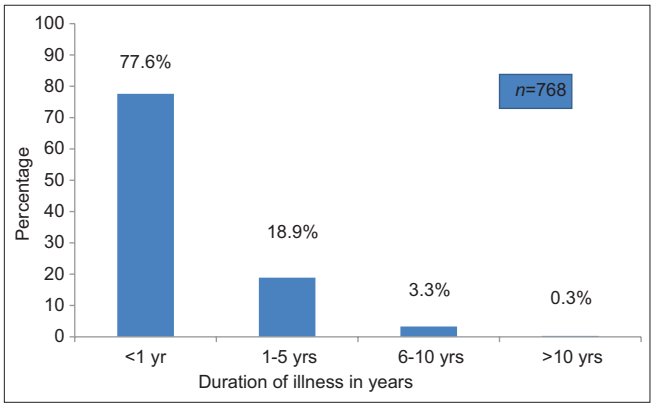

Figure 3: Duration of illness among cancer patients

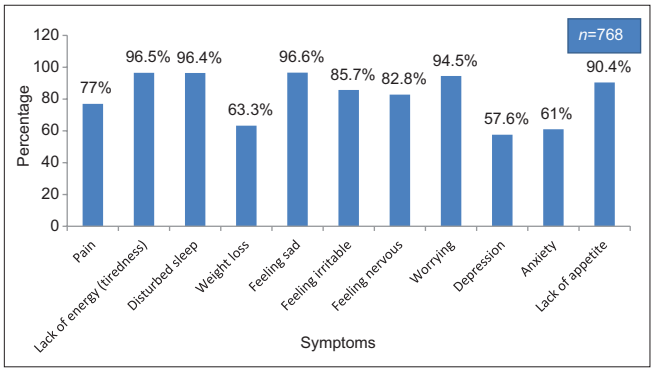

Figure 4: Self-reported symptoms

depressed (41.8%), worried (38.2%), frightened (30.9%) and angry (18.2%) due to disease-related symptoms.

The present study showed that barriers to symptoms management were: Worry about side effect (71.4%), fear of addiction (23.1%) and pain medication harm the immune system (89.0%). Similar findings on barriers were observed by Nilmana *et al*.,[6] Edrington *et al*.[9] and Ward *et al*.[10] in their studies; which were: Concern about medication and its side-effects, fear of addiction and beliefs that "good" patients do not

Table 4: Frequency and percentage on communication, medication, personal and professional barriers as presented by cancer patients (*n*=768)

Barriers	Not at all (0) (%)	A little bit (1) (%)	Somewhat (2) (%)	Quite a bit (3) (%)	Very much (4) (%)
Communication					
Do not know how to express symptoms?	491 (63.9)	83 (10.8)	157 (20.4)	22 (2.9)	15 (2)
Language problems with health care personnel	416 (54.2)	80 (10.4)	150 (19.5)	101 (13.2)	21 (2.7)
Medication					
Worried about side effects	220 (28.6)	10 (1.3)	358 (46.6)	78 (10.2)	102 (13.3)
Fear about addiction	591 (76.9)	1 (0.1)	68 (8.9)	25 (3.3)	83 (10.8)
Personal					
Fear of consequences of treatment	72 (9.4)	16 (2.1)	313 (40.8)	240 (31.2)	127 (16.5)
Fear about disease progression	16 (2.1)	11 (1.4)	253 (32.9)	259 (33.7)	229 (28.9)
Fear about further hospitalization	317 (41.3)	5 (0.7)	97 (12.6)	227 (29.6)	122 (15.9)
Professional					
Overcrowding in the outpatient department	384 (50)	38 (4.9)	135 (17.6)	168 (21.8)	43 (5.6)

Table 5: Frequency and percentage of financial barriers as presented by cancer patients (*n*=768)

Barriers	Not at all (0) (%)	A little bit (1) (%)	Somewhat (2) (%)	Quite a bit (3) (%)	Very much (4) (%)
Financial					
Lack of resources in the family	82 (10.7)	27 (3.5)	88 (11.5)	173 (22.5)	398 (51.8)
Treatment is very expensive	8 (1)		79 (10.3)	229 (29.8)	452 (58.9)
Not able to afford nutritional supplement	215 (28)	13 (1.7)	69 (9)	132 (17.2)	339 (44.1)
Not able to afford the cost of medication	133 (17.3)	11 (1.4)	54 (7)	145 (18.9)	425 (55.3)
No transport facility to access care	184 (24)	5 (0.7)	72 (9.4)	130 (16.9)	377 (49.1)
Lack of financial resources to pay for the health care services	130 (16.9)	11 (1.4)	53 (6.9)	148 (19.3)	426 (55.5)

Table 6: Frequency and percentage of misconceptions among cancer patients (*n*=768)

Misconceptions	Not at all (0) (%)	A little bit (1) (%)	Somewhat (2) (%)	Quite a bit (3) (%)	Very much (4) (%)
Beliefs/misconceptions					
Increasing pain signifies disease progression	56 (7.3)	49 (6.4)	222 (28.9)	278 (36.2)	163 (21.2)
Medicines to control pain may weaken the immune system	78 (10.2)	8 (1)	270 (35.2)	260 (33.9)	152 (19.8)
Pain is inevitable	165 (21.5)	42 (5.5)	215 (28)	203 (26.4)	143 (18.6)
Symptoms of depression or anxiety are expected when the diagnosis is cancer	176 (22.9)	45 (5.9)	186 (24.2)	223 (29)	138 (18)
Cancer patients have to live with pain and other symptoms	622 (81)	24 (3.1)	76 (9.9)	26 (3.4)	28 (2.6)

Table 7: Mean and SD of total score of perceived barriers among cancer patients (*n*=768)

	Mean	SD	Minimum	Maximum
Total score of all types of barriers among cancer patients	44.86	19.38	0	107

SD: Standard deviation

Table 8: Median and IQR of all types of barriers among cancer patients (*n*=768)

Types of barriers	Median	IQR
Communication	3	0-5
Medication	2	0-4
Personal	9	6-10
Financial	20	12-24
Professional	2	0-3
Beliefs/misconceptions	9	6-14

IQR: Interquartile range

complain about pain and disease progression. Gunnarsdottir *et al*.[11] found that pain medications harm the immune system and Yates *et al*. reported that almost 71% believed it is easy to become addicted to pain relieving medication.[8]

Limitations

- Since this study was confined to a single state, the findings cannot be generalized to nationwide
- Cancer patients who gave consent for participation only were interviewed
- Permitted hospitals only were selected for the study.

CONCLUSION

This study revealed that cancer patients experience many symptoms and barriers to symptom management.

Table 9: Comparison of mean barrier scores according to socio-demographic and disease characteristics (*n*=768)

Variables	Category	*n*	Mean	SD	*P*
Age in years	30-40	125	45.70	17.41	0.814
	41-50	221	43.96	18.99	
	51-60	232	44.49	18.66	
	Above 60	190	45.36	19.86	
Educational status	Illiterate	257	49.26	19.94	0.001*
	Primary	301	44.89	16.08	
	High school	127	44.04	20.70	
	PreUniversity	32	37.53	14.40	
	Graduate	43	26.93	15.57	
	Postgraduate	8	30.50	3.77	
Income of the family per month in rupees	<2500	22	48.95	22.59	0.001*
	2501-5000	394	47.92	17.48	
	5001-10,000	198	45.08	17.99	
	10,001-15,000	84	40.40	19.97	
	>15,000	70	29.85	18.32	
Type of cancer	Head and neck	308	44.26	17.70	0.108
	Lung	50	47.08	18.88	
	Breast	136	43.92	19.14	
	GIT	141	42.55	19.70	
	Cervical	133	48.18	19.86	
Duration of illness in years	<1	596	44.79	19.05	0.570
	1-5	145	44.73	17.85	
	6-10	25	42.56	20.05	
	>10	2	62	12.72	
Duration of treatment in months (after diagnosis)	<6	585	44.81	19.11	0.944
	6 - <12	110	44.48	18.83	
	12 - <24	37	45.94	15.47	
	More than >24	36	43.33	18.17	

*Statistically significance, *P*<0.05. *n*: Number of cancer patients, GIT: Gastrointestinal tract, SD: Standard deviation

The management of cancer pain is a critical issue in the care of patients with cancer. All health professionals must ensure that patients receive timely and appropriate education and care. There is a need to develop measures for effective management of symptoms and to reduce the barriers.

REFERENCES

1. Ward S, Gatwood J. Concerns about reporting pain and using analgesics. A comparison of persons with and without cancer. Cancer Nurs 1994;17:200-6.
2. Borneman T, Koczywas M, Sun VC, Piper BF, Uman G, Ferrell B. Reducing patient barriers to pain and fatigue management. J Pain Symptom Manage 2010;39:486-501.
3. Naveh P, Leshem R, Dror YF, Musgrave CF. Pain severity, satisfaction with pain management, and patient-related barriers to pain management in patients with cancer in Israel. Oncol Nurs Forum 2011;38:E305-13.
4. Yeom HE, Heidrich SM. Effect of perceived barriers to symptom management on quality of life in older breast cancer survivors. Cancer Nurs 2009;32:309-16.
5. Iyer S, Taylor-Stokes G, Roughley A. Symptom burden and quality of life in advanced non-small cell lung cancer patients in France and Germany. Lung Cancer 2013;81:288-93.
6. Nilmanat K, Promnoi C, Phungrassami T, Chailungka P, Tulathamkit K, Noo-Urai P. Symptom management and its barriers among patients with terminal advanced cancer in Thailand. BMJ Support Palliat Care 2012; Suppl 1: A49 doi:10.1136/bmjspcare-2012-000196.142
7. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, *et al*. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. Eur J Cancer 2011;47:51-6.
8. Yates PM, Edwards HE, Nash RE, Walsh AM, Fentiman BJ, Skerman HM, *et al*. Barriers to effective cancer pain management: A survey of hospitalized cancer patients in Australia. J Pain Symptom Manage 2002;23:393-405.
9. Edrington J, Sun A, Wong C, Dodd M, Padilla G, Paul S, *et al*. Barriers to pain management in a community sample of Chinese American patients with cancer. J Pain Symptom Manage 2009;37:665-75.
10. Ward SE, Goldberg N, Miller-McCauley V, Mueller C, Nolan A, Pawlik-Plank D, *et al*. Patient-related barriers to management of cancer pain. Pain 1993;52:319-24.
11. Gunnarsdottir S, Donovan HS, Serlin RC, Voge C, Ward S. Patient-related barriers to pain management: The Barriers Questionnaire II (BQ-II). Pain 2002;99:385-96.

How to cite this article: Nayak MG, George A, Vidyasagar MS, Mathew S, Nayak S, Nayak BS, *et al*. Symptoms experienced by cancer patients and barriers to symptom management. Indian J Palliat Care 2015;21:349-54.

Source of Support: Nil. **Conflict of Interest:** None declared.