Does the cancer patient want to know? Results from a study in an Indian tertiary cancer center

Shekhawat Laxmi, Joad Anjum Khan

Abstract

Objective: The disclosure of the diagnosis of cancer is a distressing and complex issue. Families and doctors still do not tell patients when they have cancer in the belief that the patient does not want to know and telling him would lead to fear and depression. The aim of this survey was to evaluate the information needs of Indian cancer patients. **Materials and Methods:** A cross-sectional survey of 300 patients' views was conducted with the help of an adaptation of Cassileth's Information Needs questionnaire. **Results:** A majority of cancer patients exhibited a strong need for information about illness and treatment. Ninety-four percent wanted to know if their illness was cancer. Most patients also wanted to know the chance of cure (92%). Age, education, and type of treatment significantly affect information preferences. Gender did not have an effect on information needs. **Conclusion:** This study showed that most of the patients wanted to know about their illness, treatment, side-effects, and chances of cure.

Key words: Cancer, Indian, information needs, oncology, patient's preferences

Introduction

The diagnosis of cancer is a stressful experience in life. The disease requires patients to learn about the illness, make decisions regarding treatment, and cope with the illness and therapy. It has been found that having relevant information helps patients understand the disease and facilitates patients' decision-making.^[1] Provision of information can have a positive impact on the patients' attitude. It improves coping ability, reduces anxiety, and mood disturbances and allows the patient to prepare for the future.^[2-4]

There is a growing awareness regarding the importance of information. The challenge for medical professionals is to identify the various reactions from patients with a cancer diagnosis. These range from patients who wish to know everything to those who wish to know nothing. Also, information needs may not remain static but may change throughout the cancer experience.^[5]

In the societies of North America, Northern Europe, and Australasia it may appear appropriate for patients to participate directly in obtaining information, forming an understanding and making decisions regarding their disease process and management.^[6]

In India, the family actively influences consultation by meeting with the doctor beforehand and requesting

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Access this article online				
Quick Response Code:	Website: www.sajc.org			
	DOI: 10.4103/2278-330X.110487			

the doctors to withhold information from patients. We decided to conduct this study to evaluate and explore the information needs of cancer patients in a cancer hospital: How much information would they like to have about their diagnosis, prognosis, treatment benefits, and the adverse effect of therapy?

Materials and Methods

This study was approved by the Hospital Ethics Committee. All the patients were Indians who had cancer and were about to see an oncologist for a consultation about their treatment, prognosis, or for a routine follow-up visit. In the waiting room, the families were asked to indicate if their patient knew the diagnosis. Only patients who knew the diagnoses were administered the questionnaire. Inclusion criteria were adult cancer patients who knew the diagnosis and were willing to complete a questionnaire. A total of 300 cancer patients above the age of 18 years were approached by a member of the research team. The data was collected from November 2010 to June 2011. All the patients gave a written consent for participation.

Patients' views about information were elicited by an adaptation of Cassileth's Information Needs questionnaire.^[7] Specific questions were asked for eliciting the patients' attitudes toward receiving information about: The specific medical name of their illness, whether it was cancer, their progress through treatment, their chances of cure, details of all possible treatment, details of all possible side-effects, and how the treatment worked. The patients were asked to indicate whether they (1) had an absolute need, (2) would like to have or (3) preferred not to have that information. Answers were cross-tabulated according to the patient's age, gender, education, and type of treatment. Statistical significance was assessed using the "Chi-Square test."

Results

Of the 300 patients, 10 forms were incompletely filled and were therefore not included in the analysis. In all, 290

cancer patients were studied. The age of the patients in the study sample ranged from 18 to 80 years. The mean age of patients was 53 years. Forty-nine percent of the patients were female, 51% were male, and 94% of the patients were married. The most common types of cancer were head and neck (24%), breast (18%), and lung (16%). One hundred and seventy six (61%) were receiving curative treatment, 109 (38%) palliative treatment, and in 5 (2%) the intent of treatment was uncertain. Our patients exhibited a strong need for information about illness and treatment. Ninety-four percent of patients needed to know if the illness was cancer [Table 1]. Only 12/290 (4%) did not want to know if they had cancer, 275 (94%) said they absolutely needed to know or would like to know if they had cancer. Fifty-one percent (147/290) of the patients indicated an absolute need to know the specific name of the illness. The patients had a strong desire to know the chances of cure and the side-effects of treatment, with 268 (92%) and 222 (76%), respectively, expressing a need or absolute need to know [Tables 1 and 2].

There was a significant association between the age and the amount of information required by the patient. A majority of patients below 65 years of age wanted as much of information as possible (Chi-Square = 21.078, df = 3, P = 0.00). Patients receiving radical treatment needed more information about all the possible treatments [Table 3]. The patients receiving radical treatment had a greater need for information about side-effects than those on palliative therapy (Chi-Square = 39.361, df = 3, P = 0.00). Literate patients had a higher need for information (Chi-Square = 30.356, df = 3, P = 0.00). There was no significant correlation between patients' need for information about their disease and its treatment and gender (Chi-Square = 7.804, df = 3, P = 0.065). One percent of the sample preferred to leave everything to the doctor [Table 3].

Discussion

The results from our study indicate that cancer patients have a strong need for information about illness and treatment. Ninety-four percent of the patients needed to know that the illness was cancer, 92% wanted to know chance of cure. It is a common belief that the Indian cancer patient adopts a passive role in information needed about their illness. This study does not support these views. Majority of patients wanted to know if they had cancer.

Using the word "cancer" is perceived as stressful for the oncologist and the patient. There are many reasons why doctors avoid communicating bad news. Doctors fear that revealing the diagnosis and prognosis could lead to depression.^[8] The main reason for withholding information about the diagnosis in India and the middle-eastern countries, is that that families equate the diagnosis of cancer with death.^[9] Also, doctors have limited time with each patient and communication may often have lower priority than medical treatment.^[10] However, achieving the

Table 1:	Demographic	characteristics	of	the	study
patients	(<i>n</i> =290/300)				

Variable	No	%
Age (years)		
≤30	23	8
31-50	113	39
51-70	115	40
>70	39	13
Sex		
Male	146	50
Female	144	49
Marital status		
Married	273	94
Single	11	4
Widowed	6	2
Level of education		
Illiterate	102	3:
Primary school	25	9
Intermediate school	69	24
Secondary school	24	8
University	70	24
Type of cancer		
Lymphoma	17	6
Breast cancer	51	18
Lung	48	10
Head and neck	72	24
Gynecological	40	14
Hematological	21	7
Gastro-intestinal	26	10
Others	15	5
Type of treatment		
Radical	176	6
Palliative	109	38
Not specified	5	2

Table 2: Responses of 290 cancer patients to specific questions about need for information. values are numbers (percentages)

Question	Do not want to know	Would like to know	Absolute need to know	Leave up to doctor
Whether the illness is cancer	12 (4)	97 (33)	178 (61)	3 (1)
What is the specific medical name of the illness	52 (18)	90 (31)	147 (51)	1 (0)
What is the week-by-week progress	38 (13)	114 (39)	135 (46)	3 (1)
What are the chances of cure	21 (7)	92 (31)	176 (60)	1 (1)
What are all the possible treatments	36 (12)	102 (35)	144 (50)	8 (3)
What are all the possible side-effects of treatment	65 (22)	110 (38)	112 (39)	3 (1)
Exactly how the treatment works to treat the illness	84 (29)	98 (34)	107 (37)	5 (2)

proper balance between the under-informed and overloaded patient is important because patient dissatisfaction with

	Do not want to know	Would like to know	Absolute need to know	Leave up to doctor	Significance Chi-Square, df, <i>P</i>
Type of treatment					
Radical (n=176)	10 (6)	84 (47)	78 (44)	4 (2)	39.361, 3, 0.000
Palliative (n=109)	26 (23)	18 (16)	66 (60)	4 (1)	
Age (years)					
18-64 (<i>n</i> =184)	12 (6)	61 (33)	106 (57)	5 (2)	21.078, 3, 0.000
65-85 (<i>n</i> =106)	24 (22)	41 (38)	38 (35)	3 (2)	
Gender					
Women (n=144)	24 (16)	50 (34)	64 (44)	6 (4)	7.804, 3, 0.065
Men (<i>n</i> =146)	12 (8)	52 (35)	80 (54)	2 (1)	
Education					
Illiterate (n=102)	23 (22)	45 (44)	30 (29)	4 (3)	30.356, 3, 0.000
Literate (n=188)	13 (6)	57 (30)	114 (60)	4 (2)	

Table 3: Response of 290 cancer patients to the question "what are the treatment option available" by type of treatment, age, gender, and education. values are numbers (percentage)

communication has been linked to non-compliance, "doctor shopping," and general dissatisfaction.^[11]

The desire for information is almost universal even if a patient's degree of active engagement in treatment choices varies: "Most patients want to see the road map, including alternative routes, even if they don't want to take the wheel."^[12]

In India, cultural necessities dictate the decision-making by family members, with the patient being kept in the dark to a greater or lesser degree (depending upon the individual's family).^[13] At present, most patients and their immediate families in South Asian societies, especially in India, are comfortable with the type of family-centric decision-making described above, in which the family may prevail on the patient to refrain from participating in the deliberations. A form of collusion is common between the oncologist and the family with the full knowledge and complete acceptance of the patient.^[14,15] An Indian study demonstrated that the pattern and prevalence of psychiatric morbidity was the same in cancer patients irrespective of their awareness of the diagnosis, however more patients in the "unaware " group refused treatment for psychological distress.^[16] Studies from different cultural backgrounds suggest that awareness of cancer diagnosis and honest disclosure of truth does not worsen any dimension of the quality of life.[17-19] It has also been noticed that patients are aware of the nature and severity of illness and they regularly express their need for open communication.^[20] Research has been performed on the information needs of the Indian cancer patient. A survey of 148 patients in the district of Bangalore who had recovered following hospitalization for a wide variety of health problem found that 94% wanted to know the nature of their illness and 90% needed to know the cause. Thirty percent felt that insufficient information was provided about the nature of their illness.^[21] In another study, Gautam examined the preferences of patients suffering from cancer and their relatives regarding communication of diagnosis. Most patients (who were aware of their diagnosis) felt this was necessary. However, most caregivers wanted to know the truth, while withholding information from the patients.^[22] A survey in a South-Indian teaching hospital examined the preferences of medical undergraduates and faculty about the disclosure of life-threatening illness using two hypothetical questions. The findings indicated that 85% of clinical students and 89% of doctors stated that the diagnosis should be revealed.^[23] Another survey attempted to ascertain the proportion of patients attending radiotherapy services who knew their diagnosis. Sixty-two percent of the respondents were aware of their disease. However, only 46% of the patients said they had received their diagnosis from their doctors.^[24] A study on Asian and white cancer patients in Leicester found that in common with white patients, the majority of Asian patients (majority born outside UK) wanted full information about their illness.^[25]

A Taiwanese study revealed that 92% of patients preferred to be told the truth about their diagnosis, two-thirds preferred that their relatives also be told the truth, 7% voiced a preference to not be told the truth about their own diagnosis, and a third of patients stated that they preferred that their relatives not be told the truth.^[26] Surveys of patients in other countries indicate that the majority of patients prefer to know their diagnosis, treatment options, adverse effects, and prognosis.^[27-29] High levels of information needs and desire for decision involvement were identified, with patients expressing a considerable degree of information satisfaction.^[30]

Results of this study show that age is a significant factor when examining the information required by the patient. Younger patients had a greater need for information about all the possible treatments than elderly cancer patients. This finding is supported by a study from Scotland.^[27] Elderly patients hesitate to ask questions when meeting the doctor. They have been raised in a culture where it is impolite to ask more information from busy doctors.^[29] A systematic review of information needs in cancer patients found that younger patients attribute more importance to information about sexual concerns and physical attractiveness than the elderly.^[30] Our study shows that educated patients had greater information needs than patients with less formal education. The literature suggests that highly educated patients are more likely to employ information-seeking strategies and thus are able to satisfy their information needs.^[31] But, patients with a lower educational attainment may rely on personal sources of information and in their limited time with the doctor, may not be able to satisfy all their information needs. The interaction between educational status and information needs is multifaceted and education affects information needs in different ways. A review by Ankem indicates that highly educated patients may be similar to less-educated patients in the type of information they need. Patients who prefer to be active in decision-making during illness want more information about their illness.^[30]

Cross-sectional analysis of our data showed that patients having radical treatment wanted more information. However, the study done by Jenkins showed no correlation of information needs with intent of treatment.^[29] Patients with a recent diagnosis needed to understand the disease by wanting more information about their illness, but the stage of cancer does not affect the type of information needed.^[30]

There was no significant effect of gender on information needs in our study sample. In a similar study done by Jenkins, there were two areas where the younger women (70 years and under) were significantly different.^[29] They preferred to know the name of the illness, and all the possible available treatments. Younger women also preferred to know the specific name of the illness than men of the same age group. Two recent studies on women with breast cancer gave similar results.^[32,33] A Study conducted in Greece suggested that while women expressed a general desire for as much information as possible about their illness, majority of women play a passive role in treatment decision-making and delegate responsibility of the decision completely to their doctor.^[34]

The specific subsets (patients older than 70, male, Japanese) of patients opt for limited disclosure^[35,27] A study of in-depth interviews with 17 patients with recently diagnosed cancer showed that most patients desired basic knowledge, but they frequently shunned detailed information which was deemed as potentially threatening and unsafe. Their coping strategies (faith, hope, and charity) limited their wish for further information.^[36]

On the other hand, Egyptian families feel that the patient must be dependent and nurtured and not involved in the decision-making. The family makes the decisions because dignity, identity, and security are bounded by belonging to the family. Therefore, disclosure of the exact serious diagnosis to a patient is socially unacceptable. The family is informed of the diagnosis and care plan. This approach is in contrast to modern culture of individualism and patient autonomy which generates quite different approaches to discussing illness.^[37]

Our study had some limitations. The sample size was small. Since the study was done at a single institution, the participants may not be representative of all Indian cancer patients. A multicentre study with a larger sample size would allow for more definite conclusions about the attitude of cancer patients in the country as a whole. Also, all the respondents already knew their diagnosis. Their responses may not represent a population who did not want to know their diagnosis. Their opinions may not reflect patients' unbiased wishes. Patients who did not know the diagnosis were not surveyed. This is because in this group of patients, the family had prevailed upon the treating oncologist to withhold this information. It would not have been ethical for our team to reveal the diagnosis to the patient in order to conduct this study.

These findings probably reflect the change that is occurring over time. In theory, it appears quite logical for a middle-aged patient to know about a dismal prognosis, as this can lead to a realistic decision to finish unfinished business, tie up the loose ends in his or her life, and to take care of the necessary family arrangements, religious, and legal formalities in accordance with his or her preferences. The increasing desire on the part of patients to participate in decision-making may also be seen in other Asian countries, such as Saudi Arabia, Japan, and Pakistan.^[38-41] Nonetheless, the clear disparity between what people would like to be told should they develop cancer, and what patients with cancer know about their disease is brought out by studies done in these countries, as well as in others, such as Nepal, India, and China.^[42-46]

Ankem suggests that consistent and precise measurement of age, education, time, and patients preferred style for involvement in decision-making can provide more accurate and valuable indicators for information provision. With the knowledge of the type of information the patients need and the characteristics of patients who need certain information, better use of limited time during interaction can be made in fulfilling patients' information needs.^[30]

The difficulty is finding a way of providing information that is appropriate for patients who may benefit from knowing something about their illness and its treatment at some stage but may not wish to know everything about their illness at every stage.^[32] The Calman-Hine report recommends that the views and preferences of the patient and the family should be considered.^[47] As Hassan says, the practice of medicine is an art as well as science. It involves compassion and honesty. A good physician will always give a ray of hope as well as discuss the implications of a grave situation.^[48]

Conclusion

In this study, from one centre in India, we observed that most cancer patients want substantial information regarding the cancer, the side-effects, and chances of cure. Gender does not influence the desire to know. Information was sought by a larger proportion of younger patients, literate patients, and patients receiving radical treatment.

Acknowledgments

The authors acknowledge the help and support of Mrs. Sumitra Choudhary and Mrs. Meenakshi Barwar.

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How to cite this article: Laxmi S, Khan JA. Does the cancer patient want to know? Results from a study in an Indian tertiary cancer center. South Asian J Cancer 2013;2:57-61.

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