Original Research Article

Knowledge, attitude and practices of patients' relatives about cancer: a study from Eastern India

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ABSTRACT

Background: Knowledge, attitude and practice (KAP) about a disease can significantly affect healthcare seeking behaviour and thus, ultimate outcome of a disease. This is particularly true in chronic diseases like cancer. In India, the influence of family members on the treatment decision of an individual is paramount. Hence, KAP of the family about a disease will significantly affect the healthcare pathway of any individual. However, actual data on KAP of common people about cancer are very rare from India. In this Eastern Indian study, we aimed to generate data on this very important aspect.
Methods: In this hospital based study, the relatives of cancer patients were interviewed about their perception about various aspects of cancer. The interview was based on a pre-structured questionnaire modelled after the "Illness Perception Questionnaire".
Results: We had 65 subjects in our study with a mean age of 43.5 years. 32% of the subjects belonged to some profession related to medicine. 44.6% of the subjects thought that cancer was synonymous with tumour. The chief source of information for our respondents was their physician only. Only 5% got their information about cancer from the mass media. The relationship between tobacco and cancer was known to a significant fraction with 21.5% responding that smoking causes cancer and a further 18.5% knowing about other tobacco products as the cause. More than $1/4^{th}$ of the subjects thought that any cancer was a permanent disease. Most (71%) study subjects thought that living with a cancer patient was difficult. 32% believed that cancer meant inevitable death. Almost 2 out of every 5 had used some form of alternative medicine therapy for cancer. Subjects with lower educational status were statistically more likely to use alternative medicine. Regarding the prevention of cancer also, opinions varied widely according to educational level with almost 70% of the subjects in the illiterate subset opining that cancer is non-preventable.
Conclusions: This study shows that the perception about cancer varied widely in the society according to various factors like educational level and/or gender. A significant number of subjects had personal outlook which was quite different from current scientific data. Hence, proper dissemination of information about diseases like cancer in the society is an important need of the hour.

Keywords: Knowledge attitude practice (KAP), Cancer, Family, Illness perception questionnaire

INTRODUCTION

Knowledge, attitude and practice (KAP) about a disease can significantly affect the health-care seeking behaviour

and also the ultimate treatment outcome.[1] For example, lifestyle management is an important part of management of many diseases and KAP of the patient or family influences this significantly. KAP, in turn, is affected by the levels of literacy and awareness.

In many parts of the world, treatment decision for a person is usually a shared decision between the patient and family members and/or friends. This tendency is not unique to any particular country by any means. Some authors have included this as "non-clinical influences" in a treatment protocol.[2] A large qualitative study from a cancer centre in USA found that there was wide disagreement in concerned families about treatment of a patient and this affected various steps of treatment like choice of doctor, hospital, treatment protocol and pathway of care.[3] The level of knowledge, attitude to a disease and religious outlook are some of the factors which may affect the KAP of a person. This is a potential source of conflict between different family members and/or between the patient and his/her family. However, such family influence on treatment is more prominent in certain parts of the world, including Asia.[4]

Such KAP differences can influence not only the decisions of the concerned patient but can also influence treatment decisions by a physician significantly. A study from USA found that physicians often felt pressured by family opinions in prescribing certain drugs.[5] Hence, all concerned stakeholders, including family members must be taken on board while deciding on a particular treatment. For a disease like cancer such inclusive approach is even more important because cancer treatment often requires prolonged follow up. Unless the family is motivated enough to continue such extended therapy, many patients will find it difficult to cope with the therapy on their own.

In India, attitude of other family members can influence treatment decision of a patient to a large extent. While a negative and unscientific attitude may jeopardise a proper care pathway, a positive family attitude may promote quicker healing by various means. The importance of family in effective clinical care in the Indian scenario has been shown for diseases like HIV, eating disorders and alcoholism.[6] Such inclusive care pathway has often been termed "family therapy".[6]

But for such family therapy to be instituted, one needs background data on KAP of people regarding particular diseases. As mentioned earlier, KAP develops from education. Hence, targeted health education may change the KAP in the society in general and this may help in implementing successful treatment protocols for diseases like cancer with the help of family members.

Such KAP studies regarding cancer are almost absent from India. We here have tried to generate some data from Eastern India on this topic. This may be a basis for devising plans to include family members in cancer care in this country.

METHODS

This study was done in a tertiary care Hospital of Eastern India between January and July 2016. Sampling was done opportunistically from the people coming to the radiotherapy and oncology outpatient department. Cancer patients were sampled randomly and explained about the study in their native language. Then, they were asked to identify their next of kin. Only relatives>18 years of age were considered for the study. If that person was present, then he or she was again explained about the study and asked to participate in it. If they agreed, they were taken to a separate room, away from the concerned patient, and interviewed.

Table 1: Questionnaire.

Broad heading	Question no.	The question	Type of response
Identity	1.	What is cancer?	Open ended
	2.	What are the symptoms of cancer?	Open ended
	3.	How did you get information about cancer?	Open ended
	4.	Do you think cancer is preventable?	One of three responses: Yes/no/don't know
Cause	5.	What do you think causes cancer	Open ended
Timeline	6.	What is the duration of cancer?	One of five responses: short/long/permanent/unpredictable/no- idea
Consequences	7.	What do you think of living with a cancer patient?	One of three responses: Easy/difficult/unpredictable
Cure-control	8.	What do you think about effectiveness of cancer treatment?	One of your responses: Effective/partially effective/ineffective/no idea
	9.	What do you think of consequences of cancer?	One of six responses: No idea/curable/partly curable/paralysis/severe suffering/inevitable death
	10.	Have you considered alternative medicine for cancer?	A yes/no response

The interview was based on a pre-structured questionnaire modelled after the "Illness Perception Questionnaire". This questionnaire model has been modified by various authors (Table 1). We modelled our questionnaire keeping the five basic elements of "identity, cause, timeline, consequences and cure-control".[7] The questions were structured in local language. There were 10 questions as shown below.

The term "cancer" was used as it is. No specific type was specified. For question numbers 1, 2, 3 and 5, keywords from the subject's response were noted and recorded.

The interviews were conducted by the same person for all study subjects. In the interview room, no picture or literature or medical paraphernalia related to oncology were visible.

The individual responses were entered in SPSS version 20 data sheet and relevant calculations were done. P value <0.05 was considered significant.

RESULTS

We had a total of 65 subjects in our study with a male: female ratio of 32:33. The mean age of the subjects was 43.5± 11.2 years with a range between 20 to 62 years. As Figure 1 show, only 25% of the subjects were college educated while 12.3% were completely illiterate. Out of 65 subjects, 21 (32.3%) belonged to some profession related to medicine (nurses, paramedics or medical technicians).
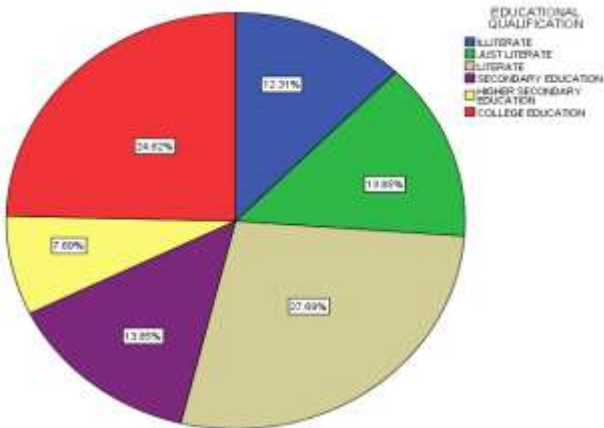

Figure 1: Pie chart showing educational qualification of our study subjects.

As figure 2 shows, 29 out of 65 subjects (44.6%) thought cancer was synonymous with tumour, while 17% thought that cancer was an ulcer. Only 8 persons identified cancer with wasting. Regarding the symptoms of cancer (question 2) the responses were similar with 20 (30.8%) subjects thinking that a tumour or mass was the chief symptom of cancer and 15.4% (n=10) thinking that

weight loss is the chief symptom. Only 13 responses stated that pain was a symptom of cancer.
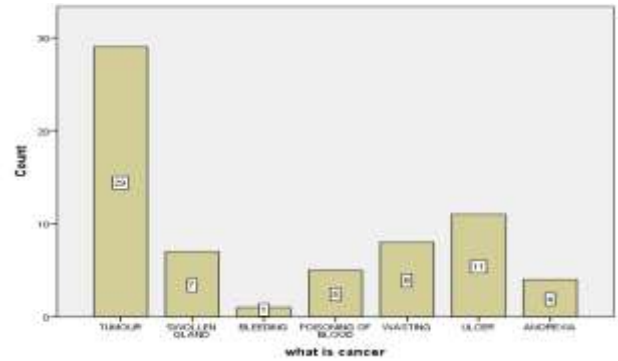

Figure 2: Bar diagram showing the responses to "what is cancer?" question.

In response to question 3, the majority (44.6%) of subjects got their information from their physician and 29% (n=19) got the information as a part of their medical profession (figure 3).
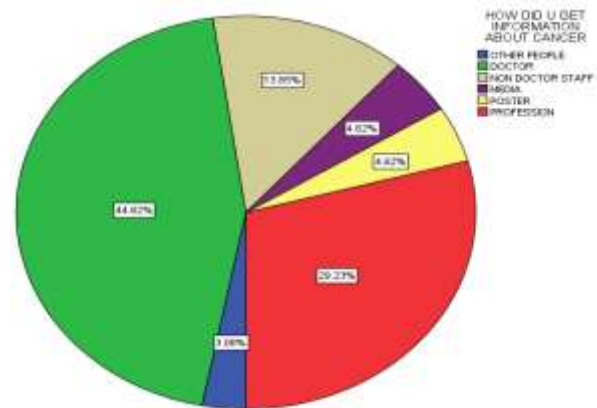

Figure 3: Pie chart showing the source of information about cancer.

Only 4.6% got the information from mass media. As figure 4 shows, 58.5% thought cancer is preventable.
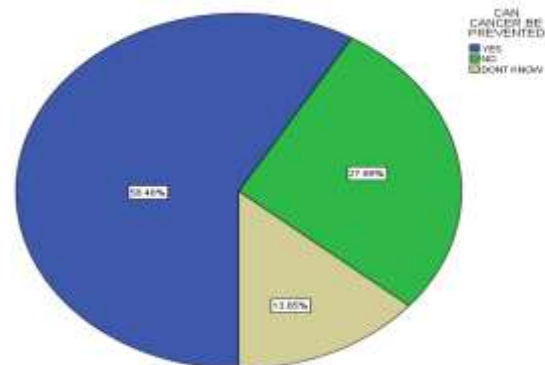

Figure 4: Pie chart showing response to question 4.

Regarding the causes of cancer, the responses were varied. 21.5 % thought that smoking causes cancer while 18.5% thought that any tobacco product causes it (figure 5). Only 10.8% thought that infection causes cancer. Regarding the duration of cancer, 55.4% thought that it was "long" while 26.1% thought that cancer is a permanent disease.
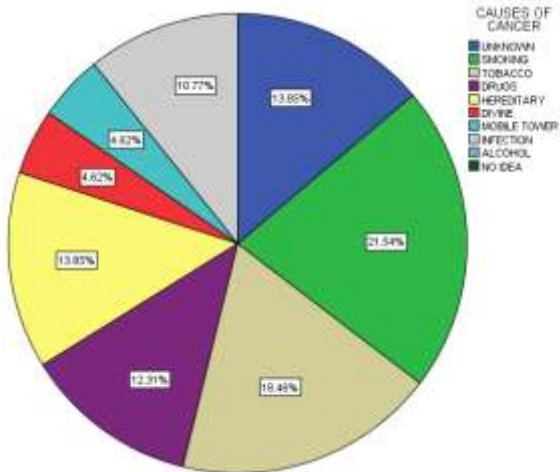

Figure 5: Pie chart showing the perception about causes of cancer.

In response to the question about living with a cancer patient, 71% of the subjects thought that it was difficult (figure 6) while only 23% found it easy.
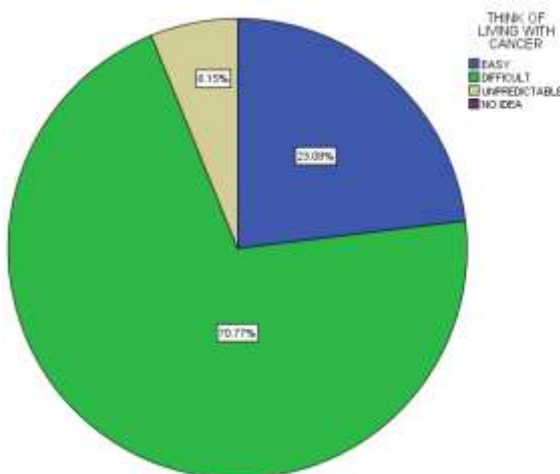

Figure 6: Pie chart showing what the subjects thought about living with a cancer patient.

In response to question 8, 52.3% thought that cancer treatment is only partly effective while 12.3% thought that it is ineffective. However, as figure 7 shows, 32.3% of the subjects thought that cancer means inevitable death. Only 17% thought that cancer is a curable condition.
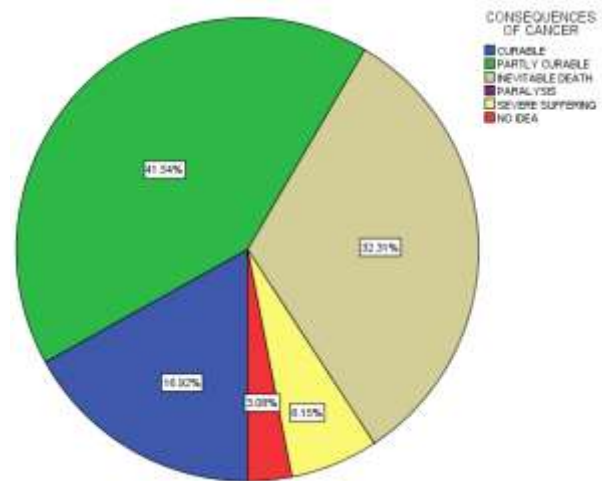

Figure 7: What people thought about consequences of cancer.

37% of the subjects had consulted alternative medicine for cancer treatment. There was no gender difference in this topic. Out of the male subjects, 40.6% (13 out of 32) had consulted it, while in female subset, 33% (11 out of 33) had gone to an alternative practitioner (p=0.826 by Chi square test). However, there was a significant difference based on educational qualification. Out of the 17 subjects who had no school education, 11 (64.7%) had consulted alternative medicine while out of the 48 who had school education or higher, only 13 (27%) went to an alternative medicine specialist (p=0.0086 by Fisher's exact test).

Gender difference was quite prominent in the opinion on living with cancer. Out of 32 male subjects, 37.5% thought living with cancer patient was easy while in the female subset, only 9.1% thought so. In the female subset, 84.6% thought that living with a cancer patient was difficult (p=0.022 by chi square test).

Educational level also affected the perceived effectiveness of cancer therapy. Out of 17 subjects who had no formal education, 4 (23.5%) thought that all cancer treatment was ineffective while out of the 48 subjects with some elementary or higher education, only 8.3% thought so (p=0.19). Similarly, 70.6% of the former group either did not know about cancer prevention or thought that cancer is non-preventable, while only 31% (15 out of 48) of the latter group thought so (p=0.0088 by Fisher's Exact test).

As Table 2 show, the perceived causes of cancer also varied according to the level of literacy. Out of the 16 study subjects who had college education, 50% thought that cancer is hereditary. Only three subjects thought that mobile tower causes cancer and all of them had received only school level education.

Table 2: The perceived causes of cancer in the study subjects according to education level.

		Causes of cancer								Total
		Un-known	Smok-ing	Toba-cco	Drugs	Hered-itary	Divine	Mobile tower	Infection	
Educational qualification	Illiterate	0	0	0	4	1	1	0	2	8
	Just literate	1	4	3	0	0	0	0	1	9
	Literate	3	1	8	2	0	0	2	2	18
	Secondary education	3	2	1	0	0	0	1	2	9
	Higher secondary education	0	1	0	2	0	2	0	0	5
	College education	2	6	0	0	8	0	0	0	16
Total		9	14	12	8	9	3	3	7	65

DISCUSSION

Our small study has shed light on the prevailing KAP about cancer in this part of the country. There are certain salient points which require further attention. For example, only 17% of the study subjects thought that cancer is a curable condition. 71% of the subjects thought that living with a cancer patient was difficult. Such attitudes can affect the level of family support that a patient receives or the motivation for a prolonged treatment protocol that may be needed. If the majority of the family thought that cancer is incurable, then they are unlikely to help the patient financially. In a country like India, most of the cost of treatment is out-of-pocket.[8] Hence, unless family support is available, successful treatment of diseases like cancer is often not feasible. In India, the concepts of community care nurse or McMillan nurse are often rudimentary. Thus, family members form the first line of support at home. If family members have the preconceived notion about difficulty in coping with a cancer patient at home, then this can affect the home care of the patient. Patients may develop a sense of guilt and this may affect their quality of life.[9]

An important aspect of cancer treatment in India is the intrusion of alternative medicine therapy. Use of complementary and alternative medicine (CAM) like Ayurveda and homeopathy is quite common among cancer patients in India.[10] A recent study from north India found that male and female subjects were equally likely to use this form of therapy.[10] Our study came to the same conclusion. The major reason for use of CAM by patients in this study was advice of people close to them. Thus, attitude of family members can influence a cancer patient into trying CAM. Lower socio economic status was linked to the use of CAM significantly.[10] In our study, lower educational level was significantly related to the use of alternative medicine for cancer. These two categories are often strongly related. Hence, this vulnerable group should be targeted for health education. The use of alternative medicine, which has not shown any scientific evidence of benefit, will mean loss of valuable time and money. A study from North India has shown

that people with cancer using CAM were more likely to delay their first visit to a medical facility.[11] Hence, a discussion with the patient and family is a good starting point to find their views about CAM and assess their likelihood of using it in future. However, surveys have shown that doctors are not very likely to discuss alternative medicine during a consultation for any disease.[12] However, lack of discussion may only foster further interest in the alternative therapy. Thus, while on one hand, general public awareness about effective cancer therapies should be raised, on the other hand, doctors should also be encouraged to discuss these topics as a part of inclusive care.

In our study, higher educational levels were linked to better scientific knowledge about cancer and its various aspects like prevention and cure. In a study from Congo, similar results were noted.[13] However, knowledge and practice do not always correlate. In this Congo study, although more than 80% of the subjects knew about cervical cancer, only 9% had ever opted for a Pap smear screening.[13]

In our study, most of the subjects (44%) had received their information about cancer from the physician. The use of mass media as a source of medical information was not significant. In the study from Congo too, a similar trend was observed where people received their information about cancer from other people.[13] However, studies from other countries like Nigeria have shown a different trend with more reliance on mass media.[14] The significantly less influence of mass media in our study subjects may be due to lack of access or low literacy. In our case, although 44% stated that they had received cancer information from a doctor, only 17% thought that cancer is curable and only 29% thought that cancer treatment is effective. Hence, despite consultation with the physician, there were significant lacunae in the knowledge. Thus, the communication about cancer by a doctor to a patient or his/her family also needs modification. Certain information delivery techniques have been found to be more effective in disseminating

proper medical information.[15] Doctors may need training in such techniques.

As Figure 4 shows, more than 40% of our study subjects did not know about cancer prevention or thought that cancer was not preventable. A similar study from South India has shown a very low level of awareness about cancer prevention among well-educated urban subjects.[16] It is often quite difficult to promote preventive medicine in a curative clinical service. When a cancer patient comes to the clinic, there may be little opportunity to discuss prevention with family members. However, the index case in a family may still be used as a focal point to discuss prevention for other family members.

Our study has a lot of limitations. The number of subjects is small and not fully representative of general population as we did opportunistic screening. Also, the number of questions used for the interview is small. Some other aspects of KAP of a disease like effect of religion have not been covered. However, this study throws some light on the prevalent attitudes of our population about cancer. As discussed earlier, the findings are similar to other Indian studies in some respects. This data can be a starting point for future bigger inclusive studies.

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