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Communicating with Cancer Patients

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In a prospective study, 100 cancer patients and their relatives were separately interviewed using a structured interview to examine whether the diagnosis of cancer should be communicated to patients and relatives; the reasons for doing so or not, the emotional reactions of patients and families; any change in the attitude of relatives; behaviour of patients and patient's expectation, on diagnosis, of the course of their illness. The majority of patients, who knew their diagnosis (71%), wanted to be told the truth. The majority of relatives wanted to know the truth themselves (81%) without the patients being told (77%). Patients did show immediate emotional reactions like anxiety and dejection, however they appeared to accept the diagnosis. Findings suggest that in an Indian setting the attitude of family members is more positive. The role played by sociocultural factors in the acceptance of the truth is discussed.

The word 'cancer' connotes an incurable disease followed by a distressing and inevitable death which is an ultimate challenge to the knowledge and skills of physicians, and a disturbing reminder of their limitations. Some doctors experience their failure to save the patient as a personal defeat and humiliation. They may respond with feelings of guilt, shame and resentment. To cope with his own emotions, the doctor may simply avoid the patient or become awkward or detached when they meet. The doctor's withdrawal tends to increase the patient's sense of helplessness and loneliness. Often the patient, his family and the doctor, attempt to maintain the denial of impending dissolution and an awkward game of mutual deception and avoidance of facing the facts takes the place of open communication.

The issue to be faced and settled by all concerned is that of communication of the diagnosis and its consequences. The perennially controversial question is whether or not to tell the truth. It is remarkable that extensive studies conducted among physicians and layman, respectively, reveal almost diametrically opposing views on this issue: 80–90% of healthy subjects questioned as well as cancer patients, responded that they wished to be told that they had cancer or another fatal illness (Cappon, 1962; Kelly & Friesen, 1950). However, 40% of dying patients who were asked if they wanted to be told when they would die, responded that they did not (Cappon, 1962).

Of 219 physicians questioned by Oken (1961), 90% said that they did not disclose diagnosis of cancer as a usual policy. In a general poll of 5000 American doctors, 22% said that they never told patients that they had cancer. Yet doctors usually affirm that they would personally want to be told if they were critically ill (Oken, 1961).

Whether or not the patient is told that he has cancer, he sooner or later guesses the truth from non-verbal clues. How this problem should be handled is a difficult issue often confronted by psychiatrists. The question is not only whether to tell, but who should do it, how, when and what should be told. Practical difficulties such as these, led to the present investigation.

Aims of the study

A prospective study was carried out at SMS Hospital Jaipur (India) to find out:

(a) whether diagnosis of cancer should be communicated to patients and relatives
(b) why the diagnosis of cancer should be revealed or not to patients and relatives
(c) the emotional reaction of patients and their relatives when patients know that they are suffering from cancer
(d) if patients perceive a change in their own behaviour after they know the diagnosis
(e) whether there is any change in the attitude of relatives towards the cancer patients on knowledge of diagnosis and if so, what is the change
(f) whether knowledge of having cancer is related to the patient's expectation of the course of the illness.

Method

In a prospective study, 100 consecutive patients, with an established diagnosis of cancer, attending the radiotherapy

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out-patient department of SMS Hospital, Jaipur, were included. The assessment of patients was done any time within 2 to 4 weeks of establishment of the diagnosis. The patients and their relatives were interviewed separately. Out of 100 patients included in the study, 33 had cancer of the head and neck organs, 32 had involvement of the genitourinary system, and 35 had cancer of sites other than those mentioned above.

All the available 77 relatives were interviewed, using a semi-structured interview schedule. This was designed to elicit the responses of relatives on disclosure of diagnosis both to them and the patients and their emotional reactions towards patients on knowledge of diagnosis (Appendix 1). All 100 patients were interviewed using another interview schedule. This was designed to elicit from patients a) what they thought they were suffering from; b) how they knew about it; c) their emotional reactions to their diagnosis; d) any change in their behaviour (as perceived by themselves) after the onset of illness; e) any change in the behaviour of others towards them; and f) their own expectation of outcome to treatment (Appendix 2). Special care was taken to see that at no time during the interview with the patients, were the words 'cancer', or, 'malignancy' used – or any indirect clue given to indicate their diagnosis. However, 48 patients already knew that they were suffering from cancer – either from the treating physician – or from the case files where diagnosis of malignancy/cancer was written – or they guessed from the fact that they were being treated at the cancer out-patient department – or they guessed it from behaviour towards them. These 48 patients were asked whether they thought their diagnosis should be revealed to them or not – and the reasons for their answers.

We designed the semi-structured interview schedules used for this study in a pilot study for interview of patients and relatives separately. Both of us were well versed with the technique of administering the interview schedule. Rates of literacy were judged according to the educational status of the informant; a person who had no schooling and did not know how to read and write was rated as 'illiterate', while those who had primary education were rated as 'low literate'. A rating of 'moderately literate' was given to those who had finished their school education (12th standard); and those with degree qualifications etc. were rated as 'highly literate'.

The responses were recorded and the results analysed.

Results

Of 100 cancer patients, 51% were ignorant about their illness and only 48% knew about their diagnosis and its outcome, while one patient could not be interviewed since he had a secondary metastasis in the brain (Table I). Of the 48 patients who knew their diagnosis, 23 clearly accepted the fact, while 25 were reluctant and used denial as a defence. It was observed that the majority of the illiterate patients (63%) did not possess the relevant knowledge, most of the low literate (42%) tended to use denial more frequently, while moderately and highly literate patients expressed their knowledge, and denial was infrequently used.

An enquiry into the immediate emotional reactions of patients on knowledge of their diagnosis, revealed that anxiety was the predominant immediate emotional reaction (77%), followed by feelings of dejection (42%); 8% did not initially accept the diagnosis, 4% felt that their anxiety was relieved and 6% reported no specific change. These emotional reactions were not found to be related to the site of cancer, while they appeared to have some relationship with age. The higher the age-group, the greater percentage of patients reported anxiety – while feelings of dejection were found to be maximum in the age-group 30–50 years, and comparatively less common in patients under 30 and over 50 years of age.

When patients were asked whether they perceived any change in their own behaviour after the onset of illness,

TABLE I
Interviews with cancer patients

Patients' knowledge about the illness (distribution according to literacy status)

Responses	*Illiterate* $n=57$	*Low literacy* $n=12$	*Moderately literate* $n=19$	*Highly literate* $n=2$	*Total* $n=100$
No knowledge	42(63%)	3(25%)	6(32%)	—	51
Knowledge	10(15%)	4(33%)	8(42%)	1(50%)	23
Denial of illness	14(21%)	5(42%)	5(26%)	1(50%)	25
Information not available	1	—	—	—	1
Whether truth should be told	$n=24$	$n=9$	$n=43$	$n=2$	$n=48$
Yes	17(71%)	6(67%)	10(77%)	1(50%)	34(71%)
No	2(8%)	1(11%)	2(15%)	—	5(10%)
Undetermined	5(21%)	2(22%)	1(8%)	1(50%)	9(19%)

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57% gave an affirmative answer. Changes included preoccupation with illness (77%), loss of interest in daily routine (51%), irritability (40%), increased/reduced intensity of involvement in family affairs (23%). More than one type of change was reported by many patients.

Patients were also asked how they perceived the attitude of relatives towards them. It was found that 46% of the patients felt no change, while 52% felt it; 48 out of 52 patients (92%) reported that relatives were paying more attention to them.

The subsequent emotional state of patients and their perceptions of the course and outcome of their illness was examined. A comparison of responses in those who knew and those who did not know about their diagnosis showed that the majority (53%) of those who did not know or denied it, were hopeful about the outcome while only 29% of those who know, were hopeful about the outcome; 19% withheld expression of their emotional reaction, 17% expressed helplessness, 12% showed features of depression and 41% were not sure of the course and outcome.

When patients were asked if the truth should be told to them, out of 48 respondents who knew of their illness 71% were of the opinion that they should be told, 10% said the truth should not be told, while 19% were indecisive on this issue. The literacy level of the patients, unlike their knowledge of the disease, did not affect their opinion on this issue.

Of those who wanted the diagnosis revealed to them, 68% were of the opinion that it would increase their sincerity, and co-operation with treatment, 29% said that it would help them accept reality, 6% said that they would be in a position to plan for their dependents, while 3% said they could fulfil their last wishes. (More than one answer was given by some respondents.)

Of the five patients who said that the truth should not be told, 60% felt that the revelation would make them feel depressed and 40% anxious. Two of the respondents could not attribute any specific reasons for what they believed. (Two patients gave more than one response.)

We also explored the relationship between the presence of psychiatric morbidity and duration of illness, and found that higher psychiatric morbidity was found among patients with 1–3 years duration.

Interview with relatives

The majority of relatives of cancer patients were of the opinion that the disease and its outcome should be revealed to the relatives (81%) but should not be revealed to the patient (77%) (Table II). A small percentage (3%) of those who thought that the relatives should be informed, expressed the view that distant relatives should not be informed as this would lead to distancing the patient. Only 12% of the relatives were of the opinion that they should not be told while only 10% were of the opinion that the patient should not be told. A small percentage (10–13%) of relatives were indecisive on this issue. The literacy status of respondents was not found to have any bearing on this question.

Of those 62 relatives who said that the truth should be told to them, 73% felt that it would lead to better patient care in terms of medical facilities, early initiation of treatment and sympathetic attitudes from others, while 18% thought that the truth should be told so that the patient could be separated from others; 13% felt that it would assure the relatives about the progress of disease and 8% thought it would help relatives make financial and social arrangements (if need be) for the patient. One thought that it was his duty to know the truth, while another gave no specific reason for knowing.

The nine relatives who felt that the diagnosis should not be revealed to them, thought that knowing the diagnosis and its outcome would lead to a feeling of helplessness, sadness and thus a lowering of their morale.

The majority of relatives (87%) thought that the diagnosis and its outcome should not be told to the patient because it would make him more worried and restless (71%), apprehensive and fearful (49%) and would lead to an early deterioration of patient's general condition (15%). (Some respondents gave more than one response.)

The small percentage of relatives (13%) who wanted the patient to be informed about his disease and its outcome felt that this should be done to remove the patient's fears,

TABLE II
Interviews with relatives of cancer patients

	Whether truth should be told (responses according to literacy status of respondents)				
Response	*Illiterate n=22*	*Low literacy n=17*	*Moderately literate n=30*	*Highly literate n=8*	*Total n=77*
To the relatives?					
Yes	13(59%)	14(82%)	28(93%)	7(88%)	62(81%)
No	5(23%)	1(6%)	2(7%)	1(22%)	9(12%)
Undetermined	4(18%)	2(12%)	—	—	6(7%)
To the patient?					
Yes	3(14%)	—	4(13%)	1(13%)	8(10%)
No	14(64%)	14(82%)	24(80%)	7(87%)	59(77%)
Undetermined	5(22%)	3(18%)	2(7%)	—	10(13%)

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apprehensions and curiosity (50%) while 25% felt that he should be told so that he himself could take steps to prevent the spread of disease to other family members. Another 25% felt that sooner or later the patient would find out about his disease so one should not hide the facts from him.

An assessment of relatives' emotional reactions towards cancer patients revealed that 86% felt that they should be affectionate and give emotional support to the patient, 10% expressed their helplessness while 9% were indifferent and were just performing their duties towards the patient to meet his daily physical needs.

Discussion

It is evident from the above findings that only 48% of the patient population knew about their illness, which is quite different from those of Albeit (1959) and Peck (1972) who reported that about 80% of their subjects knew their diagnosis. A possible reason could be that these studies were conducted in western countries where the literacy rate of the general population is higher.

When diagnosis is revealed, individuals exhibit different immediate emotional reactions, of which anxiety is predominant. These findings are quite similar to those reported by Bhatt (1963), Bronner-Huszar (1971), Peck (1972), Krant (1972), Hintan (1966), and Patel *et al* (1980). In this study, although a clear depressive reaction was not seen, a feeling of dejection and helplessness was reported by 42.5% of patients. Bhatt (1963) reported such feelings in 15.4% of her patients. It is also interesting to note that other immediate reactions like guilt feelings reported by western authors (Abrams, 1951; Harley *et al*, 1951; Abrams & Finesinger, 1953; Peck, 1972) were not seen so commonly in this sample.

Bhatt (1963) reported that knowledge of illness leads to two different kinds of emotional reactions – immediate as well as delayed, and found that depression and insecurity were the most common (53%) delayed reaction in her sample. Similar results have also been found in the present sample. Possible reasons for similarities in these findings are that patients in both studies came from similar cultural backgrounds and that acceptance of disease is known to be affected by the cultural setting and prevailing attitudes towards the illness.

The attitude of relatives towards patients when they know the diagnosis was found to be most sympathetic and they paid more attention to the patients. No discrepancy was found between patient's perception and relative's expression. These findings were similar in many respects to those reported by Bhatt (1963) where 42% of patients were reportedly treated with deep sympathy by their families and friends. A feeling of being neglected was reported by only two patients in the present study. Although the knowledge of diagnosis made relatives experience anxiety and panic they reported that this did not affect their attitudes towards patients.

Most of the patients (71%) in this series who knew of their diagnosis were of the opinion that truth should be told to them. These findings support the observations of Kelly & Friesen (1950); Aitken Swan & Easson (1959); Albeit (1959); Bo *et al* (1960); Gilbertson & Wangenstten (1962); Hintan (1966); and Peck (1972).

It has also been observed that the maximum number of psychiatric symptoms can be identified in those patients who have suffered from cancer for 1–3 years (94%) or at least for more than 6 months. The frequency of psychiatric symptoms becomes less after 3 years. Probably as the time passes the patient tries to accept his life as such, and makes realistic adjustments to his illness, with altered goals in life.

The above findings indicate that Indian patients tend to accept the diagnosis of cancer rather easily. The authors feel that the concept of death prevalent in Indian culture based on the philosophy of 'Geeta' where the soul is accepted as immortal and it is believed to transfer through death from one to another human/species (Bhagwat Geeta translated by Swami Adidevanand, 1973) plays a significant role in the easy acceptance of the diagnosis and planning of the rest of life. It is probably the cultural background, close emotional family ties and the tendency in the Indian population to come together at times of crisis which cause these responses about why the truth should be told.

Concerning the questions who should reveal the diagnosis, and how and when, we subscribe to the view of Krant (1972) that communication should be the responsibility of someone close to the patient and his family. Time must be allowed for the facts to be absorbed and questions to be raised. The patient should not be told that there is nothing more than can be done for him. The way the news is broken should depend upon patient's personality, intelligence, religion and the indirect clues he provides about how he is likely to deal with the disclosure. Some patients should not be told until a strong relationship with a member of the therapeutic team has developed. Clearly a general rule of thumb has no place here.

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Appendix 1
Questionnaire for the relatives of cancer patients

Question 1 What do you know about cancer?

2 Suppose one person in the family has cancer and another person has some other physical illness, will the attitude of the family members be the same towards both?

Yes/No

3 In your opinion what is society's attitude towards a cancer patient?
- a) That he has got an illness which is incurable.
- b) That he needs other people's sympathy
- c) That he has some communicable disease and he should be isolated.
- d) Any other.

4 If someone known to you has cancer what do you think the relatives should be told about it and its seriousness? *Why?*

5 In your opinion should the patient himself be told about the disease and its seriousness?

Yes/No
Why?

6 If someone in your family has cancer what would be your reaction towards him/her?
- a) Show your helplessness
- b) Become indifferent
- c) Just perform duties towards the patient to meet his physical needs.
- d) Give him emotional support/and affection
- e) Any other.

Appendix 2
Questionnaire for patient

Question 1 What do you think you are suffering from?

2

(A) How did you come to know about it?

(B) What was your reaction when you came to know about the diagnosis?
- a) Did you become very serious?
- b) Did you become very anxious?
- c) Was your anxiety relieved?
- d) Did you feel dejected?
- e) Did you accept it?
- f) Was there any other reaction?

3 Did you find any change in your behaviour after the onset of illness? *Yes/No*

If *Yes* –
- a) Do you feel more involved in family affairs?
- b) Do you feel uninvolved in family affairs?
- c) Have you become irritable?
- d) Have you lost interest in daily routine?
- e) Are you mostly preoccupied with your illness?
- f) Is there any other change?

4 Do you find any change in your family member's attitude towards you after the illness?

Yes/No

If *Yes* –
- a) Do they pay more attention to you?
- b) Do they pay less attention than you expect?
- c) Are they rejecting?
- d) Are they indifferent?
- e) Are they hostile?
- f) Is there any other change?

5 Do you feel yourself socially cut off after the onset of illness? *Yes/No*

6 Do you find yourself physically weak after the onset of illness? *Yes/No*

7 How long do you think it should take you to get well?

8 (In case the patient knows the nature of his illness?) Do you think it should be revealed to the patients that they are suffering from cancer?

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