

Awareness among cancer patients about their disease, management and prognosis

S K L A de Silva¹, P M K R de Silva¹, M T D Lakshan², A Patheipan³

¹AL 2000 batch of students, Faculty of Medicine, University of Colombo

²Senior Registrar, Otorhinolaryngology and Head and Neck Surgery, NHSL

³Senior registrar, Oncosurgery, National Cancer Institute, Maharagama

Abstract

Objective: To identify the level of awareness among cancer patients about their disease, management and prognosis.

Methodology: Data was collected using an interviewer administered questionnaire from 126 adult patients at the Cancer Institute, Maharagama

Results: Hundred and sixteen of the study sample were aware that they were having a disease of which fifty six accepted it as a cancer. Local extension was present in twenty seven instances but eleven of these patients believed that their disease has not extended locally. Distant metastasis was present in 21 cases and only one patient was aware of this. Out of 49 patients in whom surgery was not an option, 18 believed that surgery could be done. None of the patients had been given the opportunity to be involved in their management. Thirty eight patients had a general idea about their prognosis. Twenty three derived this from their personal judgment and only three patients had obtained this information from doctors.

Conclusion: A majority (55.56%) was unaware about the existing malignancy. A considerable proportion of patients had inaccurate information of the stage of the disease and its management. Patients' autonomy had been given minimal consideration when planning out the management. The knowledge on prognosis was based on personal judgment and the involvement of a doctor in providing information about the prognosis was poor.

Introduction

Cancer has become a leading cause of mortality around the world. It is usually considered to be a non-curable disease and has a high mortality rate.

The amount of knowledge regarding the disease in these terminally ill patients is questionable, as it is a well known fact that revealing the truth to such patients is an extremely difficult task (1, 2). As a result doctors tend to plan and implement the management quietly and evade the questions of patients. In the rapidly evolving field of medicine, the impact of the patient's involvement in decision-making has become a significant technical and ethical issue. Patients have a right to know about their disease as well as its management and prognosis and also to be involved in the process of decision making (3). Studies done in several countries on this aspect have revealed that a considerable number of patients with cancers are lacking a sound knowledge about their illness (2, 4).

This study was conducted to identify the current level of awareness about the illness, management and prognosis among cancer patients, and to analyze their sources of information.

Methodology

A descriptive cross sectional study was conducted at the National Cancer Institute, Maharagama during a period of one month from 22-05-2006 to 22-06-2006. Permission was obtained from the Hospital Director and all consultants in charge of the wards in which the study was carried out. Ethical clearance was obtained from the ethical review committee of the Faculty of Medicine, Colombo.

All inward adult patients within the study period fulfilling the requirements of the inclusion and exclusion criteria were recruited as the study population and a representative sample from this was selected by systematic sampling. Data was collected using an interviewer administered questionnaire after obtaining verbal consent.

The Bed Head Tickets, Diagnosis cards and other documented material were analyzed to assess the accuracy of data given by the patients. Current medical literature and local guidelines were used to obtain accurate data about the disease, management options and prognosis.

Results

A total of 126 patients were included in the sample of which 54 were males and 72 were females.

Knowledge on the disease

Out of the total sample, 116 accepted that they had a disease, whilst 7 people denied it. Three patients claimed that they were not aware of the existence of a disease. Of the 116 who accepted the presence of a disease, only 56 knew that it was a cancer, 13 denied that they had a cancer and the remaining 47 were not sure of the nature of their disease.

On ethical grounds, the complete questionnaire was administered only to those 56 patients who accepted that they were suffering from a cancer. Forty five patients knew the exact organ of origin of their malignancy. In one case although the patient claimed to know the organ of origin, he was wrong. Out of the remaining 10 patients who were not aware of the organ of origin, seven had at least a vague idea about the area of the body from which the malignancy had originated.

Knowledge on the stage of the disease

When analyzing the knowledge of the stage of the disease only the cases which could be staged by using the TNM classification were considered. Therefore from the sample of 56 patients, 12 patients with leukaemia were excluded from this analysis.

Local extension was present in 27 cases. This was correctly known by 8 patients but 11 believed that their disease had not extended locally. The remaining 8 were unable to comment on the presence of local extension. Of 17 patients without local extension, two wrongly believed that their disease had extended locally beyond the organ of origin. Four were unable to comment and the rest were fully aware that their disease had not invaded the adjacent organs.

Positive lymph nodes were present in 26 instances and only 6 patients were aware of this. Seven patients denied the presence of positive lymph nodes and 13 were unable to comment. In 18 instances, the lymph nodes were negative. This

was known by 10 of the patients. Eight were unable to comment.

Distant metastases were present in 21 cases but only one patient knew that his disease had metastasized to other parts of the body. Five patients denied the presence of metastases, while the other 15 were unable to comment. The patient who knew about the presence of metastases was fully aware of the exact organs of involvement. Distant metastases were absent in 23 instances and only 10 patients were aware of this. One patient believed that his disease had disseminated to other organs as well. The remaining 12 were not sure about the presence/absence of distant metastases.

Sources of information about the disease

The main sources of information about the disease are shown in table 1.

Table 1: Sources of information about the disease

Sources	Number	Percentage (%)
Doctors who diagnosed	23	41.07
Oncologist	18	32.14
Medical student	2	3.57
Other patients	3	5.36
Relatives	7	12.5
Others	3	5.36
Total	56	100

In almost 75 % of cases, doctors had played a major role in giving information about the disease. However in the remaining 25% of patients, medical professionals were not the main source of information. In 11 cases not a single doctor had been involved in the process of giving information. Relatives were the only source of information for 3 of those 11 patients and in the case of one patient, admission to the Cancer Institute was the sole indicator that he had a malignancy.

Irrespective of the sources 49 were satisfied with the amount of information received so far. Seven expressed their disappointment. Five of them felt that the amount of information given by doctors was very little and the other two felt that the doctors did not reveal the truth. All seven wanted to know more details about their disease.

Of the 49 in the satisfied category, three were happy with the existing knowledge and did not want to know more. The remaining 46 wished to know more details about their disease.

Knowledge on the management

The management plan of each patient in the study sample was obtained from the doctors in charge of them led by the consultant oncologist and the patients' knowledge on his or her particular management plan was assessed.

Surgery was a possible management option at the current stage of the disease in only seven cases and four patients were aware of this while the remaining three were unaware of the possibility of surgery as a management option. It was not possible to carry out a surgery as a palliative or a curative measure at the current stage of the disease in 49 cases. Only 12 of those patients were aware of this. Eighteen believed that surgery was still a favourable and the remaining 19 were not sure.

Chemotherapy was a treatment option at the current stage of the disease in 54 cases and in 47 of these instances the patient was aware of it, while seven patients were not sure whether it was possible. Of the two patients in whom chemotherapy was not a management option, one patient believed that it was still favourable and the other was unable to comment. Of 47 who were currently on chemotherapy or knew chemotherapy was a management option, 26 knew that there are side effects associated with chemotherapy. Two patients denied this and 19 were unable to comment on the occurrence of side effects with chemotherapy.

Of 26 who accepted the occurrence of side effects with chemotherapy, 20 correctly knew at least a single side effect. The knowledge on two was inaccurate and the remaining four were not aware on the exact types of side effects which could occur following the initiation of chemotherapy.

It was possible to manage the patient with radiotherapy at the current stage of the disease in 42 cases. In 29 of these instances the patients were aware on this, while three believed it was not possible. The remaining 10 were not sure whether it is possible. Of the 14 patients in whom radiotherapy was not a management option, four believed that it was still favourable, five were not sure, while the remaining five were aware of the exact situation. From the 29 who were currently on

radiotherapy or knew it was a management option, only seven knew that there were associated side effects. Two believed there were no side effects associated with radiotherapy and 20 were not sure.

Of the seven patients who accepted that there were side effects associated with radiotherapy, five correctly knew at least a single side effect. The knowledge of one patient was inaccurate while the other patient was not aware of any side effects.

Majority (49) of the patients were optimistic that the malignancy could be controlled by proper treatment. Only three patients did not believe this and four were not sure about the effectiveness of treatment in controlling the disease. Irrespective of their responses all the patients accepted that being compliant with the management protocol is important for a better outcome.

Fifty four patients accepted the need of regular follow up in the period of treatment and thereafter. One thought that regular follow up was not needed and the other was unable to comment on the importance of follow up and clinic visits. The majority of patients believed that possessing a sound mental state (53/56), good family support (53/56) and proper nutrition (54/56) were important aspects in the management.

Source of information about the management

Main sources of information about the management are shown in table 2

Table 2: Sources of information about the management

Sources	Number	Percentage %
Doctors who diagnosed	3	5.36
Oncologist	31	55.36
Medical student	1	1.79
Nurse	1	1.79
Other patients	1	1.79
Relatives	2	3.57
Friends	1	1.79
Neighbours	1	1.79
Others	15	26.79
Total	56	100

Involvement of a doctor in giving information about the management was seen in 37 instances. In 34 of those cases the doctor was the main source of information. On 19 occasions not a single doctor had been involved in giving information about the management. Fourteen of those patients had got to know about the management, only as he or she was going through a management procedure. Relatives, friends and nurses had been the only source of information in one case each.

Knowledge on the Prognosis

None of the patients knew the statistical data on prognosis. Thirty nine patients had a general idea about their prognosis, which was derived from different sources. The remaining 17 were unable to comment on this issue.

Source of information about prognosis

Sources of information about prognosis are shown in table 3.

Table 3: Sources of information about the prognosis

Source	Number	Percentage (%)
Doctors who diagnosed	1	1.79
Oncologist	2	3.57
Other patients	8	14.29
Relatives	1	1.79
Neighbours	1	1.79
Personal beliefs	23	41.07
Others	3	5.36
None	17	30.36
Total	56	100

Involvement of a doctor in revealing information about the prognosis was seen in only three instances, in two cases by a consultant and only in one by a junior medical officer. Knowledge on prognosis was based on personal judgment in 23 patients. In eight cases other patients were the main source of information regarding prognosis.

Discussion and Conclusions

Cancer Institute, Maharagama is the leading tertiary care institute catering to the cancer patients of Sri Lanka. Although patients with non malignant diseases and pre-malignant conditions are also treated at this institution, there is a general acceptance in the society that if a patient is referred to this hospital, the chances of that patient having a cancer are very high. Therefore, unless specifically enlightened on this issue many people can be misled. On the other hand it is unlikely that a doctor may be reluctant to reveal a non malignant condition to the patient when he or she is referred to the cancer hospital for treatment. Unawareness of an existing malignancy in 55.56% of the total population of the study may be due to denial.

Medical ethics dictate that the patient has the right to know about the disease, treatment options and prognosis (3, 4). The knowledge of the above must be imparted by the most suitable member of the healthcare delivery team and patients should make informed decisions about their management (5). Knowledge about the prognosis helps in the grieving process and enables them to take life decisions in a timely manner.

On analysis of the knowledge of the disease and its stage, a clear finding was that a major proportion of patients had an inaccurate idea about the stage of the disease. In the majority the main source of information about the disease was doctors, with some contribution from medical students. However, the results showed that in a considerable number of patients, information on the disease is derived from non qualified personnel such as relatives and other patients. This may be a significant contributor to the amount of inaccurate information that the patients have. Poor clarification of the information received may be another factor.

The concept of breaking bad news and giving information about the disease and its management and prognosis are important ethical principles in medicine. All doctors should have a sound knowledge in this regard, as it is an important part of their professional practice and has a significant impact on the outcome of patient management (5).

The management plan had been decided by the doctors with minimal patient involvement. The important ethical principles of autonomy and

informed consent had been given minimal respect on these occasions.

Many misconceptions were present among the patients on the feasibility of various management options. This was true for the knowledge on the side effects of those options as well. Even though doctors were involved in giving information about the management to a considerable extent, a large proportion of patients got to know about their management as they went through the procedures.

None of the patients were aware of the current statistical data on prognosis. They had different views on this aspect of the disease, most of which were derived from their personal judgment. Doctors seemed to pay least attention to this aspect of management and their involvement was unsatisfactory. Other patients had contributed to shape the views of the patients on prognosis in a considerable number of cases. The accuracy of the information obtained from other patients is questionable. It is the responsibility of the doctors to pay more attention to this aspect of management, in order to prevent harbouring of inaccurate and unnecessary views by the patient.

Irrespective of the amount of information received so far, most of the patients were happy with their current knowledge. However they expressed a willingness to know more. Their socio-cultural background may have a bearing on this. Sri Lankan patients generally have a great respect for medical professionals and place a lot of confidence in them. They believe the doctors do their best to preserve their lives and improve its quality.

Limitations

A few drawbacks of the method which may have an effect on the results of the study, were identified. The sample size, duration of the study and the exclusion of the floor patients were some of them. Administration of the questionnaire to only the 56 patients who accepted that they have a cancer was a major limitation. As a result, more than 50% of the total sample population was not interviewed, with possible loss of important information from those patients.

References

1. Delvecchio Good MJ, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Culture, Medicine and Psychiatry*. 1990;14(1):59-79. Available from: <http://www.springerlink.com>.
2. Pronzato P, Bertelli G, Losardo P, Landucci M. What do advanced cancer patients know of their disease? A report from Italy. *Supportive Care in Cancer*. 1994;2(4) 242 – 4. Available from: <http://www.springerlink.com>.
3. Beaver K, Luker K, Owens R, Leinster S, Degner L, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing*. 1996;19(1):8-19. Available from: <http://www.cancernursingonline.com>.
4. Eidingen RN, Schapira DV. Cancer patients' insight into their treatment, prognosis, and unconventional therapies. *Cancer*. 1984;53(12):2736-40. Available from: <http://www.ncbi.nlm.nih.gov>.
5. Walter FB, Robert B, Renato L, Gary G, Estela AB, Andrzej P, et al. SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist*. 2000;5(4): 302-11. Available from: <http://theoncologist.alphamedpress.org>.

