A PILOT STUDY OF FACTORS AFFECTING PATIENT-COMPLIANCE TO CURATIVE TREATMENT OF CANCER

ACKNOWLEDGEMENTS

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INTRODUCTION

What factors adversely affect patient compliance for curative treatment of cancer?

Background

Cancer and other chronic diseases are emerging as major public health problems in developing countries like India. It is estimated that about 9 million new cancer cases are diagnosed every year and over 4.5 million people die from cancer each year in the world. In developed countries it is the second most common cause of death, and epidemiological evidence points to the emergence of a similar trend in developing countries. The estimated number of new cancers in India per year is about seven lakhs and over 3.5 lakhs people die of cancer each year. The state of Kerala has a population of 30 million, with an estimated around 35,000 new cancer patients every year. For the district of Kozhikode alone, the rough estimate will be around 3000 new cancer patients every year. The 'guesstimated' figures for Malabar are more than 15,000 every year.

Up to one half of all cancers are curable if detected early. The commonest cancers in our population are those involving head and neck which generally have a high rate of cure. Treatment involves surgery, radiation, chemotherapy, hormonal therapy or some combinations of these.

The Pain and Palliative Care Clinic and its link clinics in various parts of Kerala generally see patients with advanced incurable cancers. Patients are seen to have explored the possibility of curative treatment in the beginning; but are seen to have not opted out of it, or have had an irregular treatment or discontinued it in between. Patient's compliance with medical advice and procedures is important in treatment. Health care providers have the responsibility not only to prescribe treatment modalities but also to work with patients to increase medication compliance.

Medication compliance is defined as the extent to which a patient takes the medications as prescribed. There are multiple studies in the literature that report noncompliance rates of 30% to 50% or higher based on the class of agents and populations studies. When medication was to be taken over along period, compliance rates dropped dramatically to approximately 50% for either prevention or cure. Loss to follow up is one of the potential problems noticed in follow up of cancer patients. 67% loss to follow up was seen in a five year study in a group of cancer patients at Regional Cancer Centre, Trivandrum. In another study at Cancer Institute (WIA), Madras too, the follow up rate was noted to be low in cancer patients[8].

Though the above studies establish that there is a huge gap between medical advice and compliance, there has been no objective study in the Indian context of the factors that motivate / inspire / compel cancer patients to either take up or give up curative treatment. A retrospective collection of data from hospital records may provide information on the number of patients not completing the full course of treatment, but will not reveal the reasons for this. Obviously, a study of the reasons for non-compliance should point the way to solutions, thereby directly improving cure rate.

Objective

To identify the factors that influence patient's decision not to accept, or withdraw from curative treatment of cancer.

Methodology

This cross-sectional survey was carried out at the Pain and Palliative Care Clinic, Calicut. Volunteers were selected and trained to carry out the interviews to elicit data from the patients. A research assistant made sure that the interview was held in a uniform pattern. Two training sessions were held for training of the volunteers before commencement of the study. These workshops l included role-play so that the procedure is standardized, and so that the volunteer's doubts can be cleared in real life situations.

Inclusion criteria

Patient with a histopathologically proven diagnosis of cancer.

The sample was taken from the list of persons diagnosed to have Cancer from the Department of Pathology, Medical College in 1998

Exclusion criteria

Patient or main carer not willing to reveal information

Patient not giving consent

Informed consent was sought from all patients satisfying the inclusion criteria during the study period.

Assessment and data collection

To obtain a sample eliminating a bias of limiting patients attending pain and Palliative Care Clinic, Calicut, the list of persons diagnosed to have cancer histopathologically in the period 1998, from the Department of Pathology, Medical College, Calicut.

The initial list came up to 272 with a definite diagnosis of cancer. To get their addresses, the hospital records were scrutinized, of which clear addresses were available only for 208 patients.

There were 112 patients belonging to the district of Calicut who were chosen for the pilot study.

To confirm the addresses, a letter was posted on the available address, to the carer, mentioning the study and requesting them to respond. There were responses only from 23 persons.

The next step was involving the volunteer group after training to visit the patients at their respective addresses,

The trained volunteer collected socio demographic data, including the educational status and economic class (appendix 2) from eligible patients (eligibility from appendix 3). There were single interviews with the patient and with the 'decision maker' in the family / main carer. All the patients or carers were asked the same questions (on study form appendix 4). To ensure accuracy, the questions were asked in Malayalam (the local language).

(Note: Main carer / primary carer has been defined as the person who takes major role in patient care, which includes daily care, collecting and giving medicines and regular contact with the doctor)

Duration of study

Six months (From July 2003)

Documentation and Maintenance of data

A research assistant was trained to collect, record and maintain data under the supervision of main researcher. All the records were confidential.

Ethical aspects

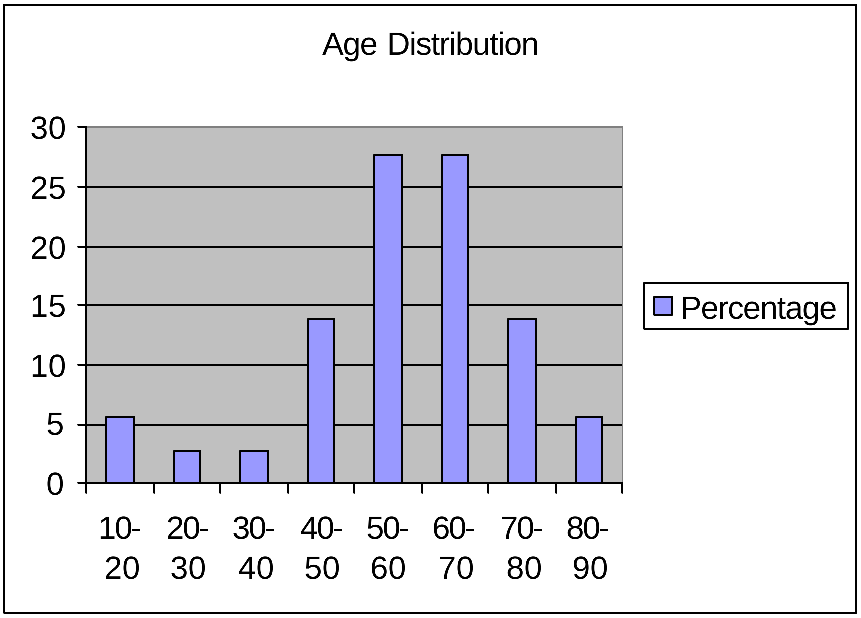
Informed consent was obtained from all patients / carers. The patients right to refuse to participate or to drop out of the study at any time without personal prejudice for the treatment for his or her condition was ensured and the respondents made aware of this. Confidentially of study participants was maintained.

RESULTS

The following observations were made:

Age distribution of patients

Age	*Frequency*	*Percentage*
10-20	2	5.55
20-30	1	2.78
30-40	1	2.78
40-50	5	13.89
50-60	10	27.78
60-70	10	27.78
70-80	5	13.89
80-90	2	5.56



It is observed that the disease is maximum for the age groups 50-60 and 60-70. Also it is noted that the number of persons having the disease increases from 40 years onwards. The mean age was 56.57 years.

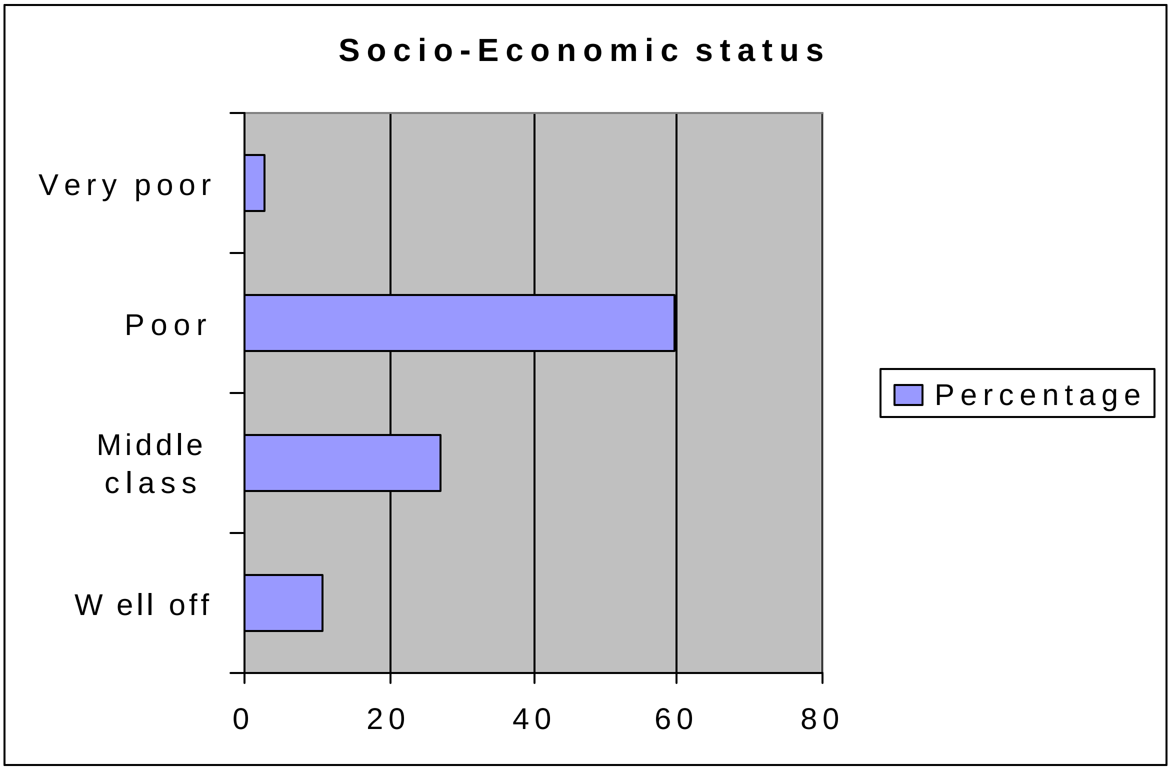
Gender distribution was equal with 18 men and 18 women.

Regarding literacy, 26 (70.27%) were literate and 11 (29.73%) were illiterate. (Literate-knowing to read and write)

Regarding the survival status, the surveyed patients had the disease 1998 or earlier (but diagnosed in 1998) and 14 (37.84%) of the patients were alive during the survey (study) period whereas 23 (62.16%) of them died before the study period. Among the 14 survived of are female (64%) and 5 are males (36%).

The socio economic status of the patients/carers was studied. The distribution of is as given below.

Status	Frequency	Percentage
Well off	4	10.82
Middle class	10	27.03
Poor	22	59.45
Very poor	1	2.70

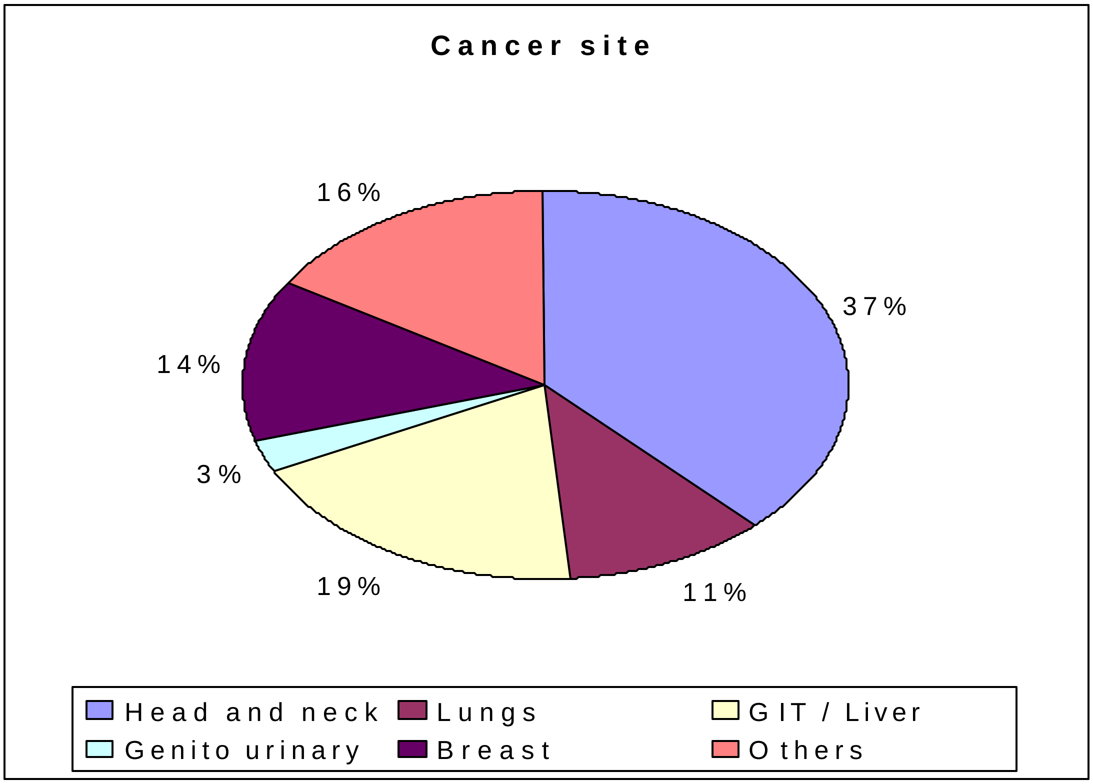


From the responded patients it is found that 59.45% belongs to poor category, 27.03% are middle class, 10.82% are well off and 2.7% are very poor (or in other words 73% are not well off)

Cancer site

The distribution of cancer site is as given below.

Cancer site	Frequency	Percentage
Head and neck	14	37.84
Lungs	4	10.81
GIT / Liver	7	18.92
Genito urinary	1	2.70
Breast	5	13.51
Hematological	-	-
Others	6	16.22



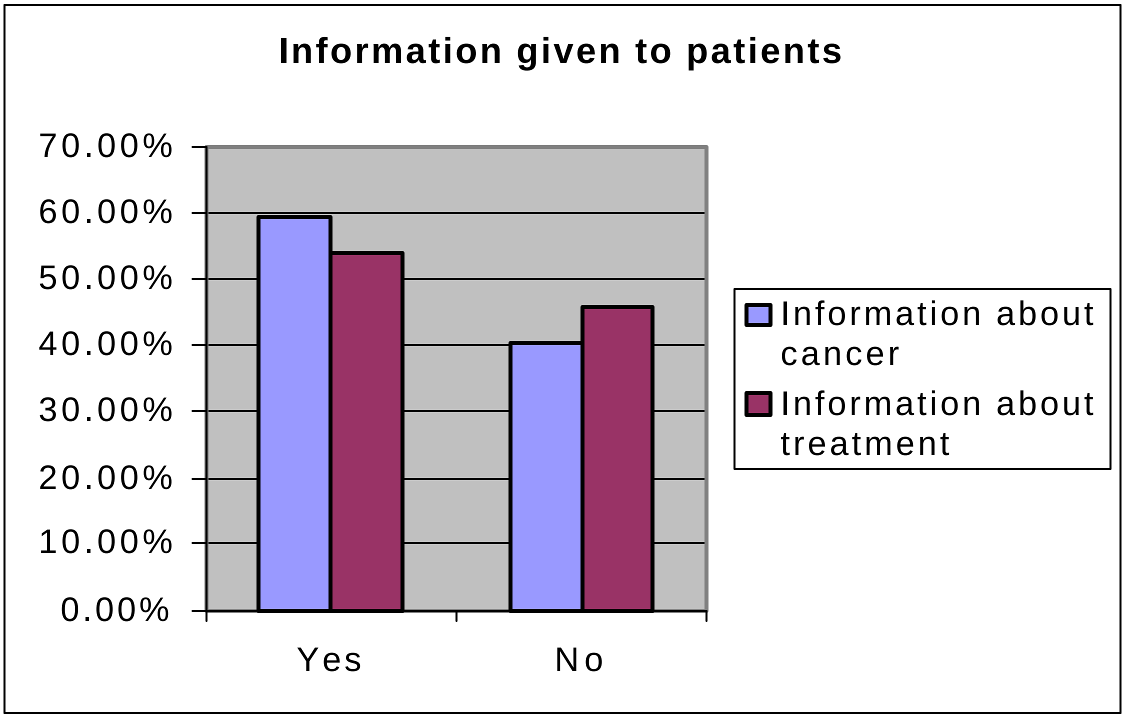
It is observed that the maximum (37.84%) patients have Cancer of Head and Neck. The second highest site is GIT/Liver with 19%.

<u>Information</u>

Information about the disease were communicated to 22 (59.46%) patients and were not communicated to 15 (40.54%) of them.

The information about the treatment were communicated to 20 (54.05%) of them where as it was not communicated to 17 (49.95%) of them. The following table shows the distribution of information given to patient:

Information : Treatment/Cancer	**Yes**	**No**
Yes	20 (54%)	3 (8%)
No	1 ((3%)	13 (35%)



It is observed that 54% of the patients were informed about their disease and the treatment. Where as 35% of them did not have both the information.

Informer

The information was communicated by local doctor in 4 patients, in 1 person it was informed by local doctor and private doctor respectively. In majority of the patients,ie 17 in number (46%) the information was communicated by government doctor. In three of them the information was handled by others who were family or friends.

Suggested Treatment

Treatment was suggested for 33 persons and in 4, they are not revealing whether treatments were suggested or not. Out of the 33 persons, 5 were suggested surgery alone, 3 were suggested surgery and chemotherapy, 3 were suggested surgery, chemotherapy and radiotherapy. 14 were suggested surgery and radiotherapy while 1 was suggested surgery, radiotherapy and Hormone therapy. 3 of the patients were suggested chemotherapy alone and 4 were suggested radiotherapy alone.

Curative treatment

Out of the 33 patients for whom curative treatment were suggested 22 (66.67%) of them done the curative treatment, 4 of them did not do the curative treatment. For 7 of them the treatment was delayed. The following table gives the details

Table (a)

Status	Frequency	Percentage
Curative treatment done	22	66.67
Not done	4	12.12
Delayed	07	21.21

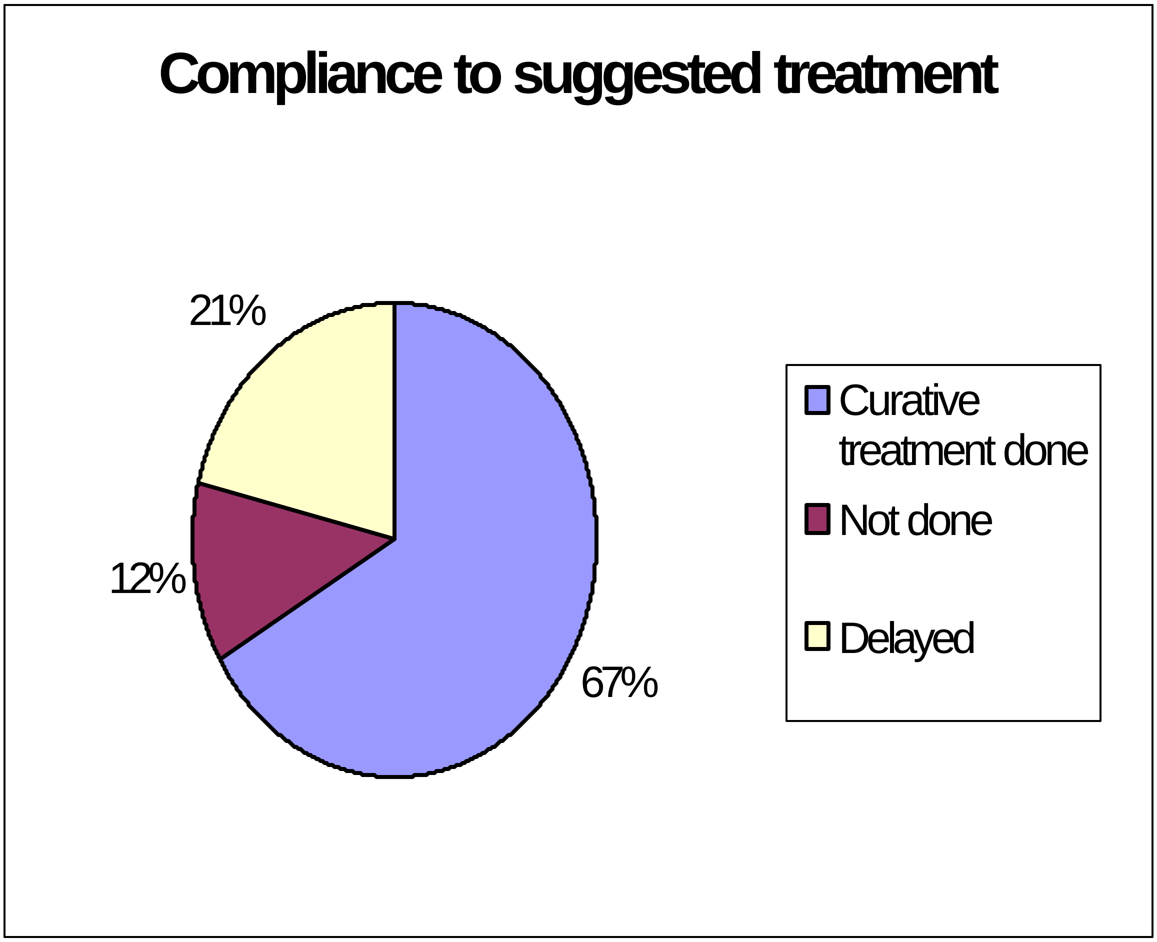
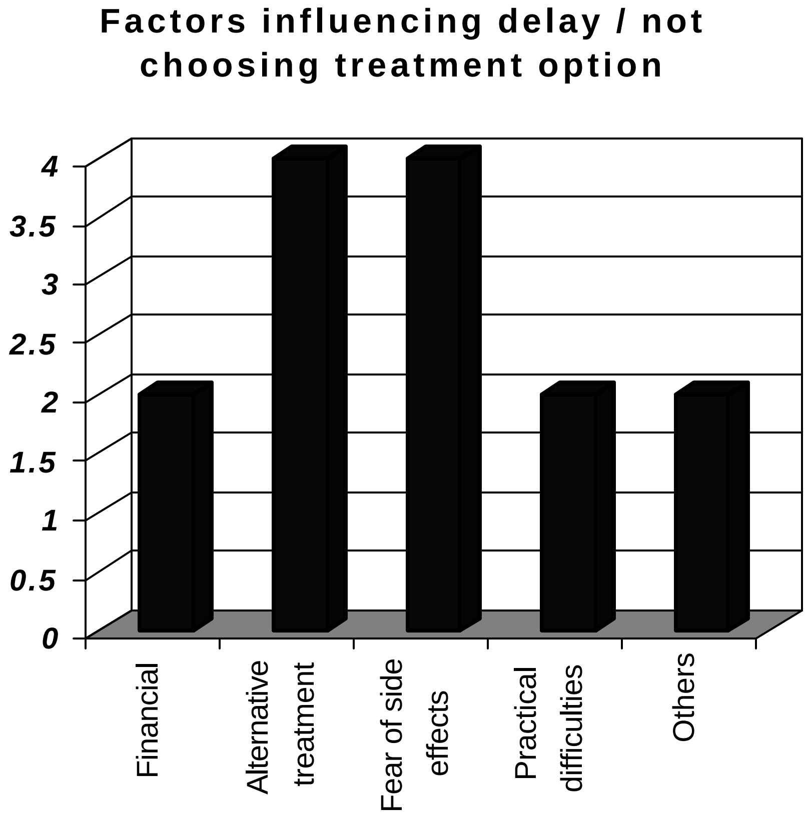


Table (b)

Factors influencing delay and not choosing curative options

Reason	Frequency
Financial	1
Alternative treatment	4
Fear of side effects	4
Practical difficulties	2
Others	2

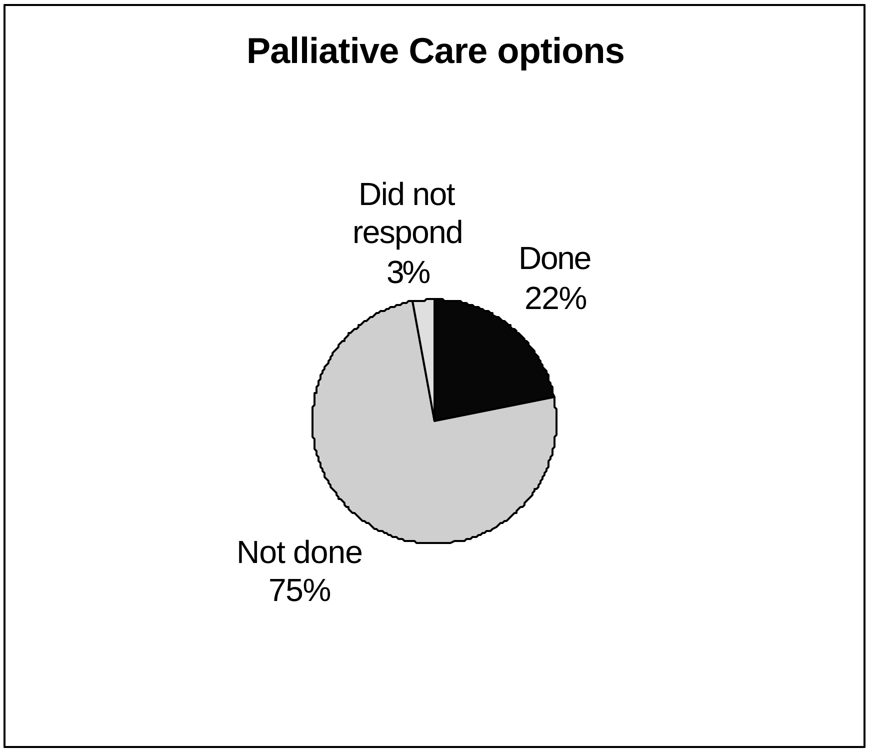


In these 11 cases the treatment was either not done or delayed. The above figure shows the different factors influencing the decisions.

11 out of 33 patients who were suggested curative options (30%) have not complied, either not done at all , (around 40%) and interrupted or delayed in 60%

Palliative Care

Status	Frequency	Percentage
Done	8	21.62
Not done	28	75.68



It is very important to note that only 21.62% had palliative care, 75.68% did not had palliative care and 2.7% was indifferent to the idea of opting for palliative care.

The following table shows the details regarding the status of patients (whether alive or dead) and they have done the curative treatment or not.

Present situation	Curative treatment		Total
	Done	Not done	
Alive	7 (29%)	7 (54%)	14
Dead	17 (71%)	6 (46%)	25
Total	24	13	

It is observed that 24 patients had taken curative treatment, only 7 of them. i.e., 29% of the patients who underwent curative treatment are alive while 17 of them, 71% of the patients who underwent the curative treatment are not alive. 13 of them did not do the curative treatment. Out of the 13, 7 (54%) of them are alive and 6 (46%) of them are not alive.

Discussion

In this pilot study, a cross-sectional survey was carried out to obtain information from 37 patients with definite diagnosis of cancer. The objective was to identify if the patients were compliant with the suggested curative options and what factors influenced their decisions.

In addition, other data like age, sex, cancer site, socioeconomic status, and medical advice were recorded.

The study planned to be conducted in pain and Palliative care clinic, Calicut included patient sample drawn from the list taken from the Department of Pathology, Medical College in the year 1998, Calicut keeping in mind the bias present in including patients attending for palliative care only.

This pilot project showed that 33.33% of patients to whom curative options were suggested did not comply. 12.12% did not choose the options at all and 21.21% had a delayed/interrupted treatment schedule.

2 patients quoted financial reasons. 4 patients each resorted to alternative treatments and had fear of side effects too. Practical difficulties (obtaining access to care because of difficulty in transportation, geographic location) were the reason in two patients. Two of them had other reasons which included other beliefs or superstitions, fear of doctors/medical system, emotional reasons etc.

Information about the disease was communicated to 59.46% and not in 40.54%. Information about the treatment was not communicated to 45.95%.

Lack of information is an important factor influencing compliance and follow up in medical treatment.

The sample size was insufficient to determine correlates of non-compliance though it would have been expected that lower socioeconomic status and lack of information regarding treatment could have been related to non-compliance.

This rate of non-compliance is similar to those rates reported in the study, where 30% to 505 was seen based on class of agents or populations studied[5].

Other interesting observations were made as part of this project. The maximum number of patients had cancer diagnosed in the head and neck region. The commonest cancers in our population are those involving head and neck[2] which generally have a high cure rate.
59.45% of patients belonged to the poor category, as the Medical colleges cater to the lower strata of the society. .

The number of patients in the sample having the disease increases from the age of 40 and is maximum for the age groups between 50 and 70 years.

It is also observed that 23 out of 27 patients are not alive at the time of study, 71% who had chosen the suggested options. The diagnosis of cancer was in 1998, and 17 of them had expired within five years.
This observation alerts to the state of cancer, when diagnosed, whether it was advanced or early stages. This can also influence the compliance and follow up rate.
A large percentage has are not alive after taking the suggested curative options, if this finding is replicated with reliable statistics with a large sample, the importance of people's understanding about curative therapy , their beliefs about its effects, death as an event after or during treatment , and how this affects their decisions to adhere to treatment schedules would be important.
It is important to note that only 21.62% had palliative care services.

Limitations of the study

Reliable conclusion can be reached only with a larger sample, based on statistical analysis. The number of patients in this study is small.
As access to a cancer registry was not possible and information about the treatment schedules and stage of cancer at time of diagnosis was unavailable, the information obtained depends only on what the primary carer reported.

Hospital records did not hold the correct postal address of many persons drawn in the first list to be studied. This affected the sample size.

Future options/ improvements

A study with a larger sample could offer reliable conclusions. To enable this, access to the cancer registry is essential. Information, documentation of the type of cancer, stage and treatment schedule should be available. The information, the details given to patient and primary carer should be also available.

A large sample would enable us to correlate between, knowledge of illness and their decisions to adhere to treatment.

The questionnaire items need to be modified to obtain more specific information such as physical condition of the patient at the time of suggestion of treatment etc.

A study in many centers would include the various strata of the society.

The observations also alert to the need to look back on maintenance of hospital records, and also vigilant early screening and detection methods to diagnose cancer at an earlier stage.

Conclusion

33.33% of patients to whom curative options were suggested did not comply.

12.12% did not choose the options at all and 21.21% had a delayed/interrupted treatment schedule.

A lot of factors- financial, fear of side effects, alternative treatments, practical difficulties, other beliefs and emotional reasons were observed to influence the decision. Also the medical advice and stage of cancer at the time of diagnosis may have played a role.

A larger study sample would contribute to reliable conclusions

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ABSTRACT

A PILOT STUDY OF FACTORS AFFECTING PATIENT-COMPLIANCE TO CURATIVE TREATMENT OF CANCER.

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A survey was conducted among patients/patient carers with definite diagnosis of cancer to identify if there was compliance to suggested curative therapy and if they did not choose to or if there was a delay or interruption in treatment, what were the factors affecting this non compliance.

37 patients in Calicut district were included. A Malayalam questionnaire was developed to obtain information from patients or primary carers of patients. Volunteers were trained to use the questionnaire and record the information.

33.33% of patients to whom curative options were suggested did not comply. 12.12% did not choose the options at all and 21.21% had a delayed/interrupted treatment schedule. A lot of factors- financial, fear of side effects, alternative treatments, practical difficulties, other beliefs, emotional reasons were observed influence the decision. Also the medical advice and stage of cancer at the time of diagnosis may have influenced

A study with a larger sample is required to establish the available findings.