



Truth Disclosure –Its Influence on the Quality of Life in Cancer Patients at A Tertiary Care Teaching Hospital

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Abstract

Background: *The dilemma of whether and how to disclose a diagnosis of cancer or any other terminal illness continues to be a subject of worldwide interest. In many countries around the world, cancer patients are often not told the truth about their illnesses.*

Aims: *The present study provides an insight about the influence which Truth Disclosure on quality of life in cancer patients at a tertiary care hospital.*

Materials and Methods: *A cross-sectional study was carried out at the OPDs of Oncology and Radiotherapy Departments of Kasturba Medical College Hospital, Attavar, Mangalore. A sample of 82 cancer patients were chosen of which 47 were grouped under Truth Concealed (TC) cancer patients and 35 under Truth Disclosed (TD) cancer patients. The Functional Living Index Cancer (FLIC) Questionnaire was used in the study.*

Results: *The responses to the FLIC Questionnaire were grouped under Emotional Factors, Physical wellbeing and Ability Factors, Sociability Factors and Miscellaneous Factors and most of them were statistically significant for TD cancer patients compared to TC cancer patients.*

Conclusions: *TC cancer patients were found to have better quality of life than TD cancer patients. Psychological counseling to patients before truth disclosure to patients and counseling to family members for extension of their supportive and caring attitude is a major determinant of quality of life, even so when life cannot be prolonged its quality has to be preserved.*

Key words: *Cancer patients, Truth Disclosure, FLIC questionnaire.*

Introduction

Truth disclosure to cancer patients has been an ethical and controversial issue in the medical profession, as some physicians are of the opinion that disclosure of truth to the patients having cancer may harm the psychological state of the patient, while others say that one must subject the patient to psychological counseling prior to truth disclosure. Cancer is the leading cause of death in economically developed countries and the second leading cause of death in developing countries.¹ Cancer is the second biggest killer after heart disease in India, accounts for 15% of all deaths in 2013.² Information dissemination to the patients about cancer is a controversial issue. Its practice in country like India, where truth disclosure is not mandatory, calls for a deep study to reach a point of view. The issue has provided a deep impact on physician patient relationship. Medical practice is associated with ethical dilemmas and these may vary between countries. Ethical principles formulating physician's obligations in one country may not be necessarily be regarded as appropriate in another.³ Thus the issue is a bioethical problem. The term 'Bioethics' came to us only in 1970 but its origin is as old as human origin.⁴ India is a vast country where the society is highly segmented on the basis of economic and professional status of individuals. The Indian society is in state of socio-economic transition. Here diseases like cancer are regarded as giant monsters and patients relinquish all hopes of survival. India is culturally a diverse country. Each culture possesses its own canonical and

content full understanding regarding how to provide appropriate information to the right person in the right place at the right time in a right way.⁵ Currently, Indian society leads the physician to tell a terminal diagnosis or prognosis to a representative of patient's family rather than to the patient directly. The physicians seem to be particularly concerned about emotion in truth disclosure. Although one Japanese study showed that truth disclosure had no harmful effect on cancer patients⁶, virtually there is no further information regarding the influence of truth disclosure on quality of life in cancer patients. Therefore the present investigation was undertaken to establish a point of view where dilemmas and contradictions nullify and yield an acceptable conclusion.

The cross-sectional study was carried out in the patients of Oncology and Radiotherapy Departments of Attavar Hospital of Kasturba Medical College, Mangalore which is tertiary care teaching and referral hospital taking into account the socio-demographic variables, morbidity profile and the disclosure of the diagnosis on emotional, physical well being and ability, sociability and miscellaneous factors of the study population.

Materials and Methods

A cross-sectional study was carried out for a period of 3 months at the Out Patient Departments (OPD) of Oncology and Radiotherapy of Kasturba Medical College Hospital, Attavar, Mangalore. A convenient sample of 82 cancer patients were

chosen, of which 47 were grouped under Truth Concealed (TC) and 35 under Truth Disclosed (TD). Patients who were given appropriate information by their attending physicians were included under the TD category. Patients who were aware of their disease, who were in suspicion or in state of ambiguity, were considered in TC category. The Functional Living Index Cancer (FLIC) Questionnaire was used for carrying out this study. The FLIC was originally developed for cancer patients during a clinical trial.⁷ Part of the questionnaire was adapted for this study purpose. The questionnaire has 20 questions that were concerned with four factors like emotional, physical well being and ability, sociability and others. A copy of the questionnaire was handed to the patient and they were asked to answer at the place of study. The patient was assured that the study was entirely voluntary and there would be no inconvenience if they refused to participate. Items in the questionnaire were translated to Malayalam and Kannada from the original questions in English if they did not understand English. The word 'disease' replaced the word 'cancer' as the same questionnaire was meant for both TD and TC groups. The questionnaire had "good" and "bad" ends and it was on a Likert type scale with all items scored on a scale of 1 to 5. The ends of the scale was reversed in items 3,4,15,16,17,18 and 19 of the questionnaire.

Data was analyzed using SPSS (Statistical Package for Social Sciences) version 12 for windows. Proportions and Chi-square test was

done to find out the association between various factors and the cancer patients.

Results

In this study, the sample constituted 82 (100%) cancer patients of which 48(58.5%) were males and 34(41.5%) were females. 47(57.3%) of the cancer patients were categorized into Truth concealed (TC) group and the remaining 35(42.7%) were categorized into Truth disclosed (TD) group. **(Table-I)**

Of the 82 (100%) cancer patients, patients having Cancers of the Oral and GIT constituted 28(34.2%) followed by Cancer Cervix patients 19 (23.2%), Cancer Lung patients 16 (19.5%), Cancer Breast 12 (14.6%) and the least were Lymphoma patients who constituted 7 (8.5%).

The responses to the questions of the FLIC Questionnaire were grouped under various headings like Emotional Factors, Physical wellbeing and Ability Factors, Sociability Factors and Miscellaneous Factors.

Emotional Factors:

It was observed from our study that majority of the TD cancer patients were very often depressed compared to the TC cancer patients. The association between frequency of depression and TD cancer patients was found to be statistically very highly significant. ($p < 0.0001$). Majority of the TD cancer patients were unable to cope up with daily stress when compared to TC cancer patients. The association between coping with daily stress and TD cancer patients was found to

be statistically very highly significant. ($p < 0.0001$). The study revealed that most of the TD cancer patients spend most of the time thinking about the disease than TC cancer patients. The association between time spent thinking about the disease and TD cancer patients was found to be statistically very highly significant. ($p < 0.0001$). It was observed that the feeling of discouragement was felt very often in TD cancer patients compared to TC cancer patients. A statistically very highly significant association was found between the feeling of discouragement and TD cancer patients. ($p < 0.0001$). It was noted in the study that degree of anxiety about future was more in TD cancer patients than TC cancer patients. The association between degree of anxiety about future in life and TD cancer patients was found to be statistically very highly significant. ($p < 0.0001$). (Table –II)

Physical Well Being and Ability Factors:

In the present study it was observed that ability to maintain normal leisure activities was worse in TD cancer patients than in TC cancer patients. A very highly significant association was found between ability to maintain normal leisure activities and TD cancer patients. ($p < 0.0001$). It was noted that there was increased frequency of effect of nausea on daily routine in TD cancer patients than in TC cancer patients. The association between increased frequency of effect of nausea on daily routine and TD cancer patients was found to be statistically very highly significant. ($p < 0.0001$). An interesting observation

was that the effect of pain on daily routine was felt more in TD cancer patients than in TC cancer patients. However, the association between increased frequency of effect of pain on daily routine and TD cancer patients was not found to be statistically significant. ($p > 0.05$). Overall feeling of well being today was found to be worst in TD cancer patients than in TC cancer patients. The association between overall feeling of well being today and TD cancer patients was found to be statistically very highly significant. ($p < 0.0001$). It was seen in the study that effect of disease on the cancer patients over last 2 weeks was worst in TD cancer patients than in TC cancer patients. However, the association between effect of disease on the cancer patients over last 2 weeks TD cancer patients was not found to be statistically significant. ($p > 0.05$). Job satisfaction over last 1 month in TD cancer patients was least satisfactory compared to TC cancer patients. The association between unsatisfactory job satisfaction over last 1 month and TD cancer patients was found to be very highly significant. ($p < 0.001$). As far as satisfaction of household duties over last 1 month in cancer patients was concerned it was seen that TD cancer patients were not satisfied compared to TC cancer patients. The association between no satisfaction of household duties over last 1 month and TD cancer patients was found to be statistically very significant. ($p < 0.01$). (Table-II).

Sociability Factors:

An interesting observation in the study was family support was slightly more in TD cancer patients

compared to TC cancer patients as reflected in the proportions. However, the association between family support and TD cancer patients was not found to be statistically significant proving that family support was there in both groups of cancer patients .($p>0.05$). Similarly as far as effect of disease on relatives over last 2 weeks was concerned it was observed in the study that it was slightly more in TD cancer patients compared to TC cancer patients. However, the association between effect of disease on relatives over last 2 weeks and TD cancer patients was not found to be statistically significant proving that the effect of disease in fact was telling over last 2 weeks on the relatives of both the groups of cancer patients there in both groups of cancer patients .($p>0.05$). The TD cancer patients were seen to be unwilling to interact with friends as compared to TC cancer patients and their association between them and

their unwillingness was found to have a highly significant statistical association.($p<0.001$).

Miscellaneous Factors:

Satisfaction with the doctor's cooperation in TD and TC cancer patients was almost equal and the association was statistically insignificant. ($p>0.05$). It was observed that the satisfaction with the doctor's work in TD cancer patients was slightly more than TC cancer patients as reflected by the percentages. However, the association between satisfaction with the doctor's work and TD cancer patients was not found to be significant. ($p>0.05$). Similarly though the confidence in doctor's present treatment in TD cancer patients was slightly more than TC cancer patients the association between them and the present treatment was not statistically significant. ($p>0.05$).

Table – I Distribution of study population

Sex	TC(%)	TD(%)	Total (%)
Male	35(74.5)	13(37.1)	48(58.5)
Female	12(25.5)	22(62.9)	34(41.5)
Total	47(100)	35(100)	82(100)

Table –II Distribution of various factors among the study population

Depression	Frequently	Very Often	Often	Rare	Never	Total (%)	χ^2	p
TC(%)	4(8.5)	2(4.3)	13(27.7)	26(55.3)	2(4.2)	47(100)	11.515	< 0.001
TD(%)	1(2.9)	24(68.5)	9(25.7)	1(2.9)	0(0)	35(100)		
Total (%)	5(6.1)	26(31.7)	22(26.8)	27(33.0)	2(2.4)	82(100)		
Coping with Daily stress	Worst	Bad	Neutral	Good	Much better	Total (%)	χ^2	p
TC(%)	4(8.5)	11(23.4)	24(51.1)	7(14.9)	1(2.1)	47(100)	27.307	< 0.0001
TD(%)	5(14.3)	26(74.3)	4(11.4)	0(0)	0(0)	35(100)		
Total (%)	9(11.0)	37(45.1)	28(34.1)	7(8.5)	1(1.2)	82(100)		

Thinking about the disease	Frequently	Very Often	Often	Rare	Never	Total (%)	χ^2	p
TC(%)	5(10.6)	6(12.5)	18(38.3)	17(36.2)	1(1.2)	47(100)	32.291	< 0.0001
TD(%)	3(8.6)	25(71.4)	6(17.1)	1(2.9)	0(0)	35(100)		
Total (%)	8(9.8)	31(37.8)	24(29.2)	18(22.0)	1(1.2)	82(100)		
Discouragement in life	Frequently	Very Often	Often	Rare	Never	Total (%)	χ^2	p
TC(%)	3(6.4)	2(4.3)	12(25.5)	25(53.2)	5(10.6)	47(100)	43.296	< 0.0001
TD(%)	5(14.3)	21(60)	8(22.8)	1(2.9)	0(0)	35(100)		
Total (%)	8(9.8)	23(28)	20(24.4)	26(31.7)	5(6.1)	82(100)		
Degree of anxiety	Highly anxious	Anxious	Same as before	Not anxious	Absolutely not anxious	Total (%)	χ^2	p
TC(%)	4(8.5)	12(25.5)	18(38.3)	11(23.4)	2(4.3)	47(100)	37.758	< 0.0001
TD(%)	13(37.1)	22(62.9)	0(0)	0(0)	0(0)	35(100)		
Total (%)	17(20.7)	34(41.5)	18(22)	11(13.4)	2(2.4)	82(100)		
Ability to maintain normal leisure activities	Worst ever	Worse	Same as before	Better	Best ever	Total (%)	χ^2	p
TC(%)	7(14.9)	14(29.8)	24(51.1)	1(2.1)	1(2.1)	47(100)	27.56	< 0.0001
TD(%)	5(14.3)	29(82.9)	1(2.8)	0(0)	0(0)	35(100)		
Total (%)	12(14.6)	43(52.4)	25(30.5)	1(1.2)	1(1.2)	82(100)		
Effect of nausea on their daily routine	Frequently	Very Often	Often	Rare	Never	Total (%)	χ^2	p
TC(%)	0(0)	3(6.4)	11(23.4)	24(51.1)	9(19.1)	47(100)	31.116	< 0.0001
TD(%)	2(5.7)	16(45.7)	12(34.3)	5(14.3)	0(0)	35(100)		
Total (%)	2(4.4)	19(23.2)	23(28)	29(35.4)	9(11)	82(100)		
Effect of pain on daily routine	Frequently	Very Often	Often	Rare	Never	Total (%)	χ^2	p
TC(%)	6(12.8)	9(19.1)	21(44.7)	9(19.1)	2(4.3)	47(100)	7.044	> 0.05
TD(%)	3(8.6)	16(45.7)	9(25.7)	7(20)	0(0)	35(100)		
Total (%)	9(11)	25(30.5)	30(36.6)	16(19.5)	2(2.4)	82(100)		
Overall feeling of well being today	Worst ever	Worse	Same as before	Better	Best ever	Total (%)	χ^2	p

TC(%)	0(0)	13(27.7)	25(53.2)	9(19.1)	0(0)	47(100)	20.147	< 0.001
TD(%)	4(11.4)	22(62.9)	8(22.9)	1(2.8)	0(0)	35(100)		
Total (%)	4(4.9)	35(42.7)	33(40.2)	10(12.2)	0(0)	82(100)		
Effect of disease on self over last 2 weeks	Worst ever	Worse	Same as before	Better	Best ever	Total (%)	χ^2	p
TC(%)	2(4.2)	10(21.3)	24(51.1)	10(21.3)	1(2.1)	47(100)	5.551	>0.05
TD(%)	1(2.9)	16(45.7)	12(34.3)	6(17.1)	0(0)	35(100)		
Total (%)	3(3.7)	26(31.7)	36(43.9)	16(19.5)	1(1.2)	82(100)		
Job satisfaction over last one month	Highly satisfied	Satisfied	Same as before	Less satisfied	Least satisfied	Total (%)	χ^2	p
TC(%)	1(2.1)	0(0)	19(40.4)	19(40.4)	8(17.0)	47(100)	18.939	< 0.001
TD(%)	0(0)	1(2.9)	0(0)	21(60)	13(37.1)	35(100)		
Total (%)	1(1.2)	1(1.2)	19(23.2)	40(48.8)	21(25.6)	82(100)		
Satisfaction of household duties over last 1 month	Highly satisfied	Satisfied	Same as before	Less satisfied	Least satisfied	Total (%)	χ^2	p
TC(%)	0(0)	3(6.4)	13(27.7)	23(48.9)	8(17)	47(100)	15.859	< 0.01
TD(%)	0(0)	1(2.9)	0(0)	18(51.4)	16(45.7)	35(100)		
Total (%)	0(0)	4(4.)	13(15.9)	41(50)	24(29.2)	82(100)		
Extent of family support	Fully supportive	Above average	Average	Neutral	Not at all	Total (%)	χ^2	p
TC(%)	29(61.7)	11(23.4)	2(4.3)	4(8.5)	1(2.1)	47(100)	2.527	> 0.05
TD(%)	17(48.6)	11(31.4)	4(11.4)	3(8.6)	0(0)	35(100)		
Total (%)	46(56)	22(27)	6(7.3)	7(8.5)	1(1.2)	82(100)		
Effect of disease on relatives over last 2 weeks	Worst ever	Worse	Same as before	Better	Best ever	Total (%)	χ^2	p
TC(%)	1(2.1)	1(2.1)	37(78.7)	8(17)	0(0)	47(100)	1.723	> 0.05
TD(%)	0(0)	3(8.6)	29(82.8)	3(8.6)	0(0)	35(100)		
Total (%)	1(1.2)	4(4.9)	66(80.5)	11(13.4)	0(0)	82(100)		
Willingness to interact with relatives	Completely willing	Partially willing	Same as before	Hesitant	Completely unwilling	Total (%)	χ^2	p
TC(%)	5(10.6)	3(6.4)	38(80.9)	1(2.1)	0(0)	47(100)	14.751	< 0.01

TD(%)	1(2.9)	0(0)	24(68.6)	10(28.5)	0(0)	35(100)		
Total (%)	6(7.3)	3(3.7)	62(75.6)	11(13.4)	0(0)	82(100)		
Willingness to interact with friends	Completely willing	Partially willing	Same as before	Hesitant	Completely unwilling	Total (%)	χ^2	p
TC(%)	5(10.6)	3(6.4)	39(83)	0(0)	0(0)	47(100)	17.865	< 0.001
TD(%)	1(2.8)	0(0)	24(68.6)	10(28.6)	0(0)	35(100)		
Total (%)	6(7.3)	3(3.7)	63(76.8)	10(12.2)	0(0)	82(100)		
Satisfaction with doctor's co-operation	Fully satisfied	Above average	Average	Neutral	Not at all	Total (%)	χ^2	p
TC(%)	41(87.2)	4(8.5)	2(4.3)	0(0)	0(0)	47(100)	2.104	> 0.05
TD(%)	30(85.7)	5(14.3)	0(0)	0(0)	0(0)	35(100)		
Total (%)	71(86.6)	9(11)	2(2.4)	0(0)	0(0)	82(100)		
Satisfaction with doctor's work	Fully satisfied	Above average	Average	Neutral	Not at all	Total (%)	χ^2	p
TC(%)	40(85.1)	3(6.4)	3(6.4)	0(0)	1(2.1)	47(100)	3.201	> 0.05
TD(%)	32(91.4)	3(8.6)	0(0)	0(0)	0(0)	35(100)		
Total (%)	72(87.8)	6(7.3)	3(3.7)	0(0)	1(1.2)	82(100)		
Confidence in present treatment	Very much	Hopeful	Neutral	Don't know	Hopeless	Total (%)	χ^2	p
TC(%)	23(49)	22(46.8)	1(2.1)	1(2.1)	0(0)	47(100)	1.578	> 0.05
TD(%)	17(48.6)	18(51.4)	0(0)	0(0)	0(0)	35(100)		
Total (%)	40(48.8)	40(48.8)	1(1.2)	1(1.2)	0(0)	82(100)		

Discussion

The present dilemma with respect to truth disclosure among the physicians in India and the analysis of FLIC questionnaire between the two groups reveals that there is a lacuna in physician patient relationship.

In this study it was found that truth disclosure in cancer patients caused depression, stress, made them think always about the disease and were discouraged and anxious about future. These

emotional factors had a statistical significant association with TD cancer patients. The overall FLIC score for TC cancer patients was more than TD cancer patients. In a similar study conducted by Ranjan R and Dua KK⁸ in cancer patients it was observed that these emotional factors had insignificant statistical association with TD cancer patients. However, the overall FLIC score for TC cancer patients was more than TD cancer patients

for emotional factors which is similar to our observations.

It was noted in the present study that subsequent to truth disclosure in cancer patients, these patients were unable to maintain normal leisure activities, had increased frequency of effect of nausea on daily routine, had increased effect of pain on daily routine, worst overall feeling of well being today, worst effect of disease over last 2 weeks, decreased job satisfaction and decreased satisfaction of household duties. Except pain and effect of disease over last 2 weeks all other physical well being and ability factors had a significant association with TD cancer patients. Pain of cancer in any case is unavoidable and similar effect of disease over last 2 weeks in both groups can be explained by unstable mind. Overall FLIC score for TC cancer patients was more than TD cancer patients. Similar observations were made by Ranjan R and Dua KK⁸ where it was found all physical well being and ability factors had a significant association with TD cancer patients. Pain and effect of disease over last 2 weeks had a significant association with TD cancer patients which differs from these observations in our study. The overall FLIC score for TC cancer patients was more than TD cancer patients for physical well being and ability factors which is similar to our observations.

It was noted that good family support, bad effect of disease on relatives over last 2 weeks, unwillingness to interact with relatives and friends was seen in TD cancer patients. A significant statistical association was however seen between

TD cancer patients and unwillingness to interact with friends and relatives. Overall FLIC score for TC cancer patients was more than TD cancer patients except support of family members. Ranjan R and Dua KK⁸ found in their study that only unwillingness to interact with friends had a significant statistical association with TD patients which confirms to our observation. The overall FLIC score for TC cancer patients was more than TD cancer patients for sociability factors which is similar to our observations.

It was distinctly seen in the study that satisfaction with doctor's cooperation, satisfaction with doctor's work and confidence in doctor's present treatment was more in TD cancer patients though there is no significant statistical association between them. The overall FLIC score for TC patients was more than TD cancer patients except in confidence in doctor's present treatment. This is contrast to Ranjan R and Dua KK⁸ observations in their study where there was a significant statistical association between them. The overall FLIC score for TC patients was more than TD cancer patients which is in contrast to our study. The confidence in treatment in Japan was better in a similar study conducted there by Tanida et al.⁶ among truth disclosed patients. This comparative study confirms apathetic attitude of physicians in India towards patients having knowledge of their disease. These results indicated that TD cancer patients demanded more support and care from their physicians. Deeper understanding on the issue of truth disclosure and care of cancer patients is necessary for physicians to respond to

the needs of the patients. Cancer patients in the late terminal stage may not want to be informed of their condition.⁹ So respect must be shown for patients who have expressed a wish not to be informed of Truth.¹⁰ The study in Japan showed that TD patients had an initial shock followed by stress reactions such as denial, anger, bargaining and depression⁶, as described in western countries.^{11,12} However these patients recovered from initial shock within a week due to supportive care of health workers and physicians.⁶ This supportive and caring attitude was not found to be the same in Indian context. The physicians favouring truth disclosure never tried to study the psychological makeup of their patients.

Conclusion

Pre-disclosure psychoanalysis to ascertain whether the patient can bear the shock or not and post disclosure counseling to facilitate coping with stress as part of stress management may be practiced by the physicians in our hospitals.

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