

**AWARENESS OF DIAGNOSIS AMONG CANCER PATIENTS AND ITS OUTCOME***Sowmya Mathew<sup>1</sup>, Smitha Bhat<sup>2</sup>, Anoop Joseph<sup>3</sup>, Manjula Anil<sup>4</sup>*

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**ABSTRACT**

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**BACKGROUND**

Clinical experience and research evidence suggests that in India many cancer patients are not informed about their diagnosis and prognosis. Previous studies have demonstrated an increased risk for psychiatric morbidity among cancer patients. Communication with patients and relatives can be complex particularly in filial cultures where families play an important role in terminal illness management. The present study was done to assess the status of awareness of diagnosis among cancer patients with various parameters in our setup.

**MATERIALS AND METHODS**

A cross-sectional descriptive study was done on 100 patients admitted to the oncology ward for a period of 6 months from March 2016 to August 2016. Patients were evaluated by questionnaire method and assessed by Hospital Anxiety and Depression Scale (HADS).

**RESULTS**

A total of 100 patients were interviewed, out of which 58 patients (58%) were males and mean age was 51.6yrs. Out of the 100 patients, 60 patients (60%) were aware of diagnosis. The mean anxiety score was 10.05 among those aware of diagnosis and 8.05 among those not aware of diagnosis. The mean depression score was 10.45 among those aware of diagnosis and 8.275 among those not aware of diagnosis. The mean anxiety and depression score was found to be more in the age group of 20-40yrs. Out of the 100 patients, 95 patients said they had the right to know about their illness.

**CONCLUSION**

Disclosing the diagnosis is an important aspect in treating patients with cancer. Family and paternalistic relationships play a central role in disclosure of diagnosis. Although, mean anxiety and depression score was found to be more among those who knew the diagnosis of cancer, patients preferred to know the diagnosis. Hence, it is very important to educate physicians regarding issues related to diagnosis disclosure.

**KEYWORDS**

Cancer, Awareness of Diagnosis, Anxiety and Depression.

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**BACKGROUND**

Cancer is well known to be a difficult disease affecting patients and their families both physically and emotionally. Despite biomedical progress, cancer is still often considered synonymous with death, pain and suffering. Previous studies have demonstrated an increased risk for psychiatric

morbidity among cancer patients. The prevalence of psychiatric disorders in cancer patients varies greatly among studies ranging from 9% to 60%, although in large studies using standardised psychiatric interviews and applying research diagnostic criteria, the range narrows from 10% to 30%.<sup>1</sup>

Until the second half of the 20<sup>th</sup> century, the practice of concealing the diagnosis of cancer and its prognosis was prevalent in medicine. In the USA, between 1961 and 1979, the proportion of physicians indicating a preference for not telling a cancer patient his diagnosis, fell from 90% to 3%. For many years, both the law and the Medical Deontology Code have strictly required an informed consent for all medical acts and assert that information must be given to the patient rather than to the family.

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Education and training programs for oncologists as well as palliative care programs were implemented throughout the country.<sup>2</sup>

Collusion is a universal phenomenon noticed amongst both western and non-western societies. In healthcare, collusion implies any information (about the diagnosis, prognosis and medical details about the person who is ill) being withheld or not shared among individuals involved.<sup>3</sup> Many nurses and doctors discuss how managing collusion is one of the most difficult issues that they encounter in clinical practice. In India, nearly one half of the patients seeking cancer treatment are unaware of their diagnosis or treatment. When coming to the medical encounter, most patients are accompanied by a close relative, which often involves a high prevalence of various forms of collusion.<sup>4</sup>

Depression is frequent in cancerology. Despite its clear impact on patients, it continues to be underdiagnosed and inadequately treated. There are many reasons for this, ranging from the underestimation of depressive symptoms by clinicians, their widespread presence in the context of cancer, the entanglement of depressive symptoms with those associated with the cancer and its treatment or indeed the difficulty of clinicians in exploring emotional symptoms.<sup>5</sup> Untreated psychiatric disorder in the presence of co-morbid conditions may result in more frequent clinic visits, increased costs, extended hospitalisations and reduce compliance and quality of life.<sup>1</sup>

In conclusion, physicians worldwide underestimate the information needs of their patients and the negative impact of nondisclosure practice. It is essential that the process of communication between patients and professionals is monitored and assessed and that effective strategies specifically targeted at improving the quality and quantity of information given to oncological patients be implemented.<sup>2</sup>

Evidence shows that there are different attitudes toward bad news disclosure based on different cultures. In North America and Europe, most physicians express the diagnosis clearly, but in South and East Europe and China due to dominant patriarchal view, some patients are excluded to receive information about their disease.<sup>6,7,8</sup> Since patients' preferred manner of communication of bad news by physicians has recently been shown to be related to a lower level of psychological distress and a higher level of patient satisfaction.<sup>9</sup> Some recent studies have focused on preferences regarding communication style such as what information to give and how to convey it.<sup>10</sup>

Clinical experience and research evidence suggests that in India many cancer patients are not informed about their diagnosis and prognosis, although relatives are informed in detail. Communication with patients and relatives can be complex particularly in filial cultures where families play an important role in terminal illness management and treatment decision making.

The present study was undertaken to obtain a valid estimate of the number of patients aware of their diagnosis, outcome of awareness of diagnosis and

treatment expectations among the cancer patients in our setup.

## MATERIALS AND METHODS

### Study Design and Data Collection-

A cross-sectional descriptive study was done on a total of 100 patients admitted to the oncology wards in A.J. Institute of Medical Sciences and Father Muller Medical College Hospital, Mangalore for a period of 6 months from March 2016 to August 2016. Admitted patients irrespective of the oncological diagnosis were interviewed. They were evaluated by questionnaire method and assessed by HADS for anxiety and depression. Patients with cognitive problems or too sick to be interviewed were excluded.

Demographic data and clinical information (cancer site and time since diagnosis) were taken from case records. Patients and relatives were interviewed separately to assess knowledge of cancer diagnosis. Relatives were asked first whether the patient knew his or her diagnosis.

Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression.<sup>11</sup> This is a widely used questionnaire to measure psychological distress in cancer patients<sup>12</sup> with certain cut-offs suggestive of a psychiatric diagnosis.<sup>13</sup> The HADS consists of 2 categories for anxiety and depression with 14 questions. Each question is rated on a four-point scale with maximum scores of 21 for anxiety and depression. Scores of 11 or more in either categories are considered to be a significant "case" of psychological morbidity, while scores of 8-10 represents "borderline" and 0-7 "normal." The validation study of the Iranian version of the HADS proved that it is an acceptable, reliable and valid measure of psychological distress.<sup>14</sup>

### Statistical Analysis

Descriptive statistics was used to describe the data. Inferential statistics such as Chi-square test and Student's t-test was used for the analysis.

## RESULTS

A total of 100 patients were interviewed, out of which 58 patients (58%) were males and 42 patients (42%) were females. A maximum distribution of 57 patients (57%) was seen in the age group of 41-60 yrs., followed by 23 patients (23%) among 61-80yrs. and 20 patients (20%) among 20-40 yrs. The mean age was 51.6yrs. with a standard deviation of 11.89yrs. Out of the 100 patients, 41% had GI malignancies, 16% had gynaecological, 10% had haematological, 11% had lung malignancies, 8% had breast cancer and 14% had other malignancies (Figure 1). Mean Karnofsky scoring was 78.5%. Out of the 100 patients, 60 patients (60%) were aware of diagnosis with a maximum of 33 patients (55%) in the age group of 41-60yrs. and 40 patients (40%) were not aware of diagnosis with a maximum of 24 patients (60%) in the age group of 41-60yrs. (Table 1). The mean anxiety score was 10.05 among those aware of diagnosis and 8.05 among those not aware of diagnosis. The mean depression score was 10.45 among those aware of diagnosis and 8.275 among those

not aware of diagnosis (Table 2). The mean anxiety and depression score was found to be more in the age group of 20-40yrs. with a value of 12.53 and 12.86, respectively (Figure 2 and 3). Among 60 patients who were aware of diagnosis, 26 patients (43.33%) had a HADS score for anxiety >11. Among 60 patients who were aware of diagnosis, 35 patients (58.33%) had a HADS score for depression >11 (Table 3 and 4).

Among the 60 patients who were aware of diagnosis, 51 patients (85%) said they were explained about the disease condition and prognosis and 9 patients (15%) said they were not explained the disease condition and prognosis. Among the 40 patients who were not aware of the diagnosis, 12 patients (30%) said they were explained about the disease condition and prognosis and 28 patients (70%) said they were not explained the disease condition and prognosis (Table 5). Out of the 100 patient's relatives interviewed, 19 said they were not explained about disease condition and prognosis.

Out of the 60 patients who were aware of the diagnosis, 51 patients (85%) said that their disease would be cured and among 40 patients who were not aware of diagnosis 37 patients (92.5%) said that disease would be cured. No significant difference was observed (Chi-square test statistic = 1.278 with degree of freedom being 1 and P value >0.05), hence, could probably indicate that patients had a more hopeful outlook though aware of diagnosis. Out of the 60 patients who were aware of the diagnosis, 49 patients (81.66%) were compliant with treatment and among 40 patients who were not aware of diagnosis 36 patients (90%) were compliant with treatment (Table 6).

Among 60 patients who were aware of diagnosis, 52 patients (86.66%) were told of the diagnosis by the doctor. 8 patients' (13.33%) diagnosis came to know of the diagnosis through relatives. Among 100 patients, 95 patients (95%) said that they have the right to know about their illness and preferred to know about their disease condition and prognosis.

All patients said they were given emotional support by relatives. Increased anxiety, depression, inability to handle the bad news and difficulty in facing life were the reasons given by relatives for not disclosing diagnosis to patients. Patient wanting to know diagnosis, relatives unwilling to hide diagnosis, explaining all treatment options and patient's right to be aware of his/her diagnosis were the reasons given by relatives for disclosing diagnosis.

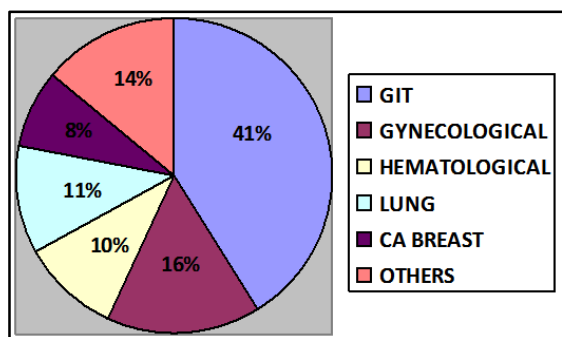


Figure 1. Distribution of Malignancies in Patients

GI malignancies were found to be the most common among the patients studied.

Age (Yrs.)	Status of Awareness of Diagnosis (Number of Patients)	
	Aware (%)	Not aware (%)
20-40	15 (75)	5 (25)
41-60	33 (57.89)	24 (42.1)
61-80	12 (52.17)	11 (47.82)
<b>Total</b>	<b>60 (60%)</b>	<b>40 (40%)</b>

Table 1. Status of Awareness of Diagnosis among Patients and Age Distribution

Difference was nonsignificant among awareness status of various age groups (Chi-square test statistic =2.566 with degrees of freedom being 2 and P value >0.05).

	Status of Awareness of Diagnosis	
	Aware (n <sub>1</sub> =60)	Not Aware (n <sub>2</sub> =40)
HADS score for anxiety (mean ± SD)	10.05±4.64	8.05±4.03
HADS score for depression (mean ± SD)	10.45±4.58	8.275±4.09

Table 2. HADS Scale for Anxiety and Depression and Status of Awareness of Diagnosis

There was a significant difference (P value <0.05) in the mean anxiety and depression score among patients who were aware of diagnosis.

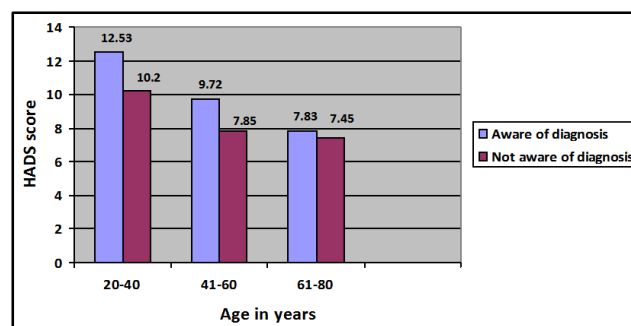


Figure 2. HADS Score for Anxiety with Status of Awareness of Diagnosis and Age Distribution

Mean anxiety score was found to be more in the age group of 20-40 yrs.

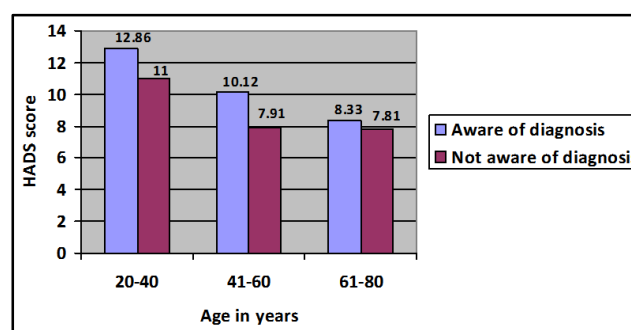


Figure 3. HADS Score for Depression with Status of Awareness of Diagnosis and Age Distribution

Mean depression score was found to be more in the age group of 20-40 yrs.

HADS Score for Anxiety	Status of Awareness of Diagnosis (Number of Patients)	
	Aware (%)	Not Aware (%)
<7	14 (43.75)	18 (56.25)
8-10	20 (64.51)	11 (35.48)
>11	26 (70.27)	11 (29.72)
<b>Total</b>	<b>60</b>	<b>40</b>

**Table 3. Status of Awareness of Diagnosis among Patients and HADS Score for Anxiety**

Among 60 patients who were aware of diagnosis, 26 patients (43.33%) had a HADS score for anxiety >11. Statistically, significant difference was observed (Chi-square test statistic = 5.302 with degrees of freedom being 2 and P value <0.05).

HADS Score for Depression	Status of Awareness of Diagnosis (Number of Patients)	
	Aware (%)	Not Aware (%)
<7	15 (50)	15 (50)
8-10	10 (45.45)	12 (54.54)
>11	35 (72.91)	13 (27.08)
<b>Total</b>	<b>60</b>	<b>40</b>

**Table 4. Status of Awareness of Diagnosis among Patients and HADS Score for Depression**

Among 60 patients who were aware of diagnosis, 35 patients (58.33%) had a HADS score for depression >11. Statistically, significant difference was observed (Chi-square test statistic = 6.524 with degrees of freedom being 2 and P value <0.05).

	Status of Awareness of Diagnosis (Number of Patients)	
	Aware (%)	Not Aware (%)
Disease condition and prognosis explained to patient	51 (80.95)	12 (19.04)
Disease condition and prognosis not explained to patient	9 (24.32)	28 (75.67)
<b>Total</b>	<b>60</b>	<b>40</b>

**Table 5. Status of Awareness of Diagnosis among Patients with Awareness of Disease Condition and Prognosis**

Statistically, very high significant difference was observed in the status of awareness among those who were explained and those who were not explained the disease condition and prognosis (Chi-square test statistic =31.143 with degree of freedom being 1. P value <0.001).

	Status of Awareness of Diagnosis (Number of Patients)	
	Aware (%)	Not Aware (%)
Patient was compliant with treatment	49 (57.64)	36 (42.35)
Patient was not compliant with treatment	11 (73.33)	4 (26.66)
<b>Total</b>	<b>60</b>	<b>40</b>

**Table 6. Status of Awareness of Diagnosis among Patients and Treatment Compliance**

No significant difference was observed, which indicates that patients were still compliant though they were aware of diagnosis (Chi-square test statistic =1.305 with degree of freedom being 1 and P value >0.05).

**DISCUSSION**

In this study, it was seen that out of the 100 patients, 60 patients (60%) were aware of the diagnosis and 40 patients (40%) were not aware of diagnosis. Among 100 patients, 95 patients said that they had the right to know about their illness and preferred to know about their disease condition and prognosis. An Italian study done by MCostantini et al in 2006 showed that in Italy the practice of withholding the truth from cancer patients is still prevalent among physicians. Evidence suggests that most elderly people wish to be informed and once informed they do not experience anymore psychological distress than the younger patients.<sup>2</sup>

In a similar study conducted in Iran in 2014 by Arbabi M et al, most patients preferred to be the first to be informed (n=151, 75.5%) by their physicians (87%). The finding of this study about most patients (n=186, 93%) preferring to be informed of their diagnosis is similar to other studies- Datson,<sup>15</sup> Kaufman, Parker and Fujimori and these studies suggests similar trends of patients' preference over the world from middle and far East to America and Europe.<sup>16</sup> A study in Nepal found that 63% of cancer patients were unaware of the nature of their disease while a survey of the general population showed that 80% of the respondents wanted to be informed if they were diagnosed with cancer. Similarly, cancer patients in Taiwan expressed a strong preference for healthcare professionals to inform them of disease-related information before disclosing information to their family members. Arguments that cancer patients from Asian cultures have different preferences regarding being informed of their cancer diagnosis and that family members have legitimate superior power in decision-making could not be supported from studies compiling data from these countries. However, evidence suggests that sensible disclosure of diagnosis and prognosis is important and is associated with a better quality of life.<sup>1</sup>

In family-centred cultures, such as in Japan, patients preferred that relatives be present at the time of diagnosis more than patients in Western cultures did. This preference

regarding discussion of prognostic information may be related to a study on a good death conducted in Japan by Miyashita et al<sup>17</sup> that unawareness of death was one of the major contributors to a good death, which was very important in Japan.<sup>10</sup>

Fear of the patient's emotional reaction was an important factor due to which physicians refused to express diagnosis.<sup>6</sup> In our study, increased anxiety, depression, inability to handle the bad news and difficulty in facing life were the reasons given by relatives for not disclosing diagnosis to patients. In a study conducted in Iran on gastrointestinal cancer patients in 2007 by T. Azadeh et al<sup>1</sup> said that one of the reasons for not informing patients is that most people in Iran as in many Middle East or Asian countries interpret the diagnosis of cancer as equivalent to death and therefore patients' families may request physicians not to tell the patient the diagnosis and the word cancer. Also, the results indicated that those who knew their diagnosis showed a significantly higher degree of psychological distress (mean (SD) anxiety score- knew diagnosis 9.1 (4.2) vs. 6.3 (4.4) did not know diagnosis,  $P < 0.001$ ; mean (SD) depression score- knew diagnosis 9.1 (4.1) vs. 7.9 (3.6) did not know diagnosis,  $P = 0.05$ ). Similarly, in Turkey and India, it has been demonstrated that psychiatric disorders occur to lesser extent in patients who are not aware of their cancer diagnosis. The authors concluded that these patients had a more hopeful outlook to the outcome of treatment.<sup>1</sup>

In our study also, it was seen that the mean anxiety and depression score was less among those who did not know the diagnosis. The mean HADS score for anxiety was 10.05 among those aware of diagnosis and 8.05 among those not aware of diagnosis. The mean HADS score for anxiety and depression was found to be more in the age group of 20-40yrs. with a value of 12.53 and 12.86, respectively. 10.45 among those aware of diagnosis and 8.275 among those not aware of diagnosis. The mean HADS score for anxiety and depression was found to be more in the age group of 20-40yrs. with a value of 12.53 and 12.86, respectively. In the study conducted in Iran on gastrointestinal cancer patients in 2007 by T. Azadeh et al<sup>1</sup>, a significant relationship ( $P=0.005$ ) was observed between anxiety and age indicating that patients aged between 30 to 39 were more anxious compared to those in other age groups. Patients are frightened about the stigma attached to cancer and there is also a higher prevalence of psychological distress among them. Treating doctors should be aware of this and should therefore involve the psychiatrist/psychologist when needed.

## CONCLUSION

Disclosing the diagnosis is an important aspect in treating patients with terminal illness. Family, community and paternalistic relationships play a central role in disclosure of diagnosis to patients. Although mean anxiety and depression score was found to be more among those who knew the diagnosis of cancer, patients preferred to know the diagnosis, treatment details and prognosis. Hence, it is

very important to educate physicians regarding issues related to diagnosis disclosure to patients and family members, also taking care of the psychological impact and morbidity while treating cancer patients. Undetected psychiatric disorder can result in frequent hospital visits, hospitalizations and reduced quality of life.

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