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Ethical Dilemmas Expressed by Non-oncology Specialists Involved in Diagnosis and Care of Cancer Patients: A Preliminary Study

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Abstract

Background: Ethical problems routinely arise in the healthcare profession and more so in hospitals providing cancer diagnosis and care. Literature study indicates that almost all studies addressing ethical issues in cancer have been qualitative and reported from the developed countries, while there has been no study reported from developing countries. For the first time, we performed a questionnaire study to quantify the ethical issues plaguing the healthcare fraternity in the diagnosis and care of people with cancer.

Method: This prospective study was conducted under the aegis of UNESCO Bioethics Education and Research Unit of the UNESCO Chair in Bioethics, Haifa at Mangalore Institute of Oncology Mangalore, India. The investigators approached the healthcare professionals involved in diagnosis, treating, and caring for patients with cancer and ascertained various ethical issues they faced. Data were tabulated and subjected to frequency and percentage.

Result: The results indicated that discussing end-of-life issues with the patient and breaking bad news were the two most difficult ones while discussing end of life issues with family caregivers was the least.

Conclusion: According to this study, oncology treatment involves a series of dilemmatic issues and breaking bad news. Based on the detailed studies and emphasis on handling these issues, it is possible to develop a teaching module for training the health care professionals and workers for managing the ethical issues effectively.

Keywords: Ethical dilemma, End of life issues, Breaking bad news, Medical doctors, Physicians

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Introduction

Since antiquity, the field of medical sciences consisting of many subspecialties has been one of the most respected professions. In fact, the famous Sanskrit adage "Vaidyo Hari Narayana" – which means Doctors are Lord Vishnu – mentioned in the Vedas justifies the respect attributed to the doctors. Like with all streams of profession, healthcare sciences are loaded with a myriad of conflicting dilemmas. As the care of patients and their lives are involved, it is necessary that the treating doctors follow the righteous path, adhere to practice prescribed in the tenets of medical ethics, and adopt ethically sound decisions that will guarantee the scrutiny of the fraternity, public, and rule of the land.¹

Recent reports from around the world indicate that cancer is a major cause of suffering and death and that its number will increase in the coming decades. From the perceptive of medical and ethical viewpoint, caring for people afflicted with cancer is recognized to be a subject full of ethical dilemmas. 1-3 The major reason for this complexity may be the fact that the ailment cancer is associated with death and has a high level of fear and misconceptions in the minds of the general public and also in the healthcare fraternity.² This is in spite of the advances in diagnosis and treatment that has resulted in increased survival and cure of most cancers. Reports indicate that the anxiety and fear associated with cancer diagnosis disrupts the orderliness in the life of the individual and their family. 1-6

From a clinical perspective, people affected with cancer have been the paradigm for advance care and ethics plays a pivotal role in this regard.^{2,7,8} This is primarily because oncology deals with care of patients who may be terminally ill and decisions on life/death, extension of life without concern for its quality, breaking bad news, judicious use of precious resources (like ventilator), pressure from family caregivers, extent of patient information, inclusion in clinical trials for novel therapies, disclosing information about the risk of inherited disease, oncofertility for adolescents, facilitating end-of-life care

discussions, and religious/spiritual concerns in caring of the patient.⁴⁻⁶

In addition to providing care, it is imperative that clinicians also understand and manage the ethical aspects involved in the cancer diagnosis, care, and meeting the requirements of the patient and their family caregivers.²⁻⁵ The doctor has to plan the ideal modality considering the general health, financial condition, treatment resource, and also help the patient. At the same time, their caregivers should be adjusted emotionally and psychologically to their diagnoses and treatment.^{5, 6, 9} For a treating doctor, cancer care interweaves with a myriad of ethical issues and factors like breaking the bad news, mediating family disagreements about treatment goals, perception of risk, allocation of scarce resources, challenges regarding therapeutic roles and end-of-life decision-making, instilling hope while respecting patient autonomy is the most common and challenging issue.^{2,4-6}

In clinical practice, the care of people with cancer always presents serious ethical dilemmas and studying/documenting these has been a neglected aspect. Little is known about the viewpoints regarding the ethical problems faced by the healthcare professionals and especially by the doctors. Studies in the existing literature indicate that there have been no documents on the ethical dilemmas Indian doctors face when caring for people afflicted with cancer. The present questionnaire-based study conducted with general practitioners, surgeons, obstetrician, and gynecologists is an attempt toward understanding the dilemma.

Materials and Methods

This is a single-center study conducted under the aegis of the UNESCO Bioethics South India Unit after obtaining the permission of the Institutional Ethics Committee. The questionnaire was designed by the investigators and was developed by a local panel of experts in oncology, bioethics, obstetric care, and a researcher after a focus group discussion. Special attention was given for clarity and the inclusion of the full

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Table 1.	Demographic	details of the	he volunteers.

		Frequency (32)	Percent	
Gender	Female	20	62.5	
	Male	12	37.5	
Age	Less than 35	3	9.37	
	35-40	13	40.63	
	More than 40	16	50	
Years in profession	Less than5 years	9	28.12	
	6 to 15	11	34.37	
	More than 15	12	37.5	
Speciality	Medicine	8	25	
	OBG	13	40.62	
	Surgery/ENT	11	34.37	

range of response options. The questionnaire was pilot-tested for the comprehension and understanding of the meaning of each question. The final instrument consisted of 4 demographic and 9 subject specific questions. As it was planned

to conduct this study by personally meeting the doctors during CMEs, the questionnaire was kept short and answering them took approximately 10 minutes.

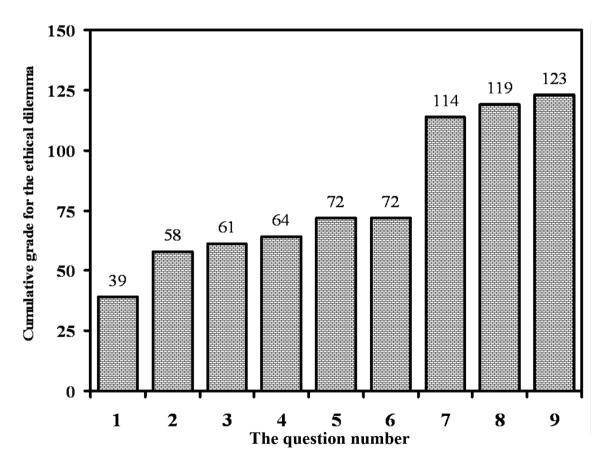


Figure 1. The cumulative score/grade for each of the questions on the ethical dilemma (1=discussing end of life issues with care caregivers; 2=conveying chemotherapy-induced loss of fertility to old patients; 3=conveying chemotherapy-induced loss of hair to old patients; 4=breast cancer screening; 5=conveying chemotherapy-induced loss of hair to young patients; 6=providing information to patient (extent of disease and progression); 7=conveying chemotherapy-induced loss of fertility to young patients; 8=breaking bad news; 9=discussing end of life issues and care with patient)

Table 2.	Rating of	the ethical	dilemmas by	v the volunteers.

		Frequency (32)	Percent (%)	Cumulative Score
Breaking bad news	Least Dilemma	0	0	119
	Minimal Dilemma	3	9.37	
	Moderate Dilemma	3	9.37	
	High Dilemma	26	81.25	
Breast cancer screening	Least Dilemma	6	18.75	64
	Minimal Dilemma	22	68.75	
	Moderate Dilemma	2	6.25	
	High Dilemma	2	6.25	
Providing information	Least Dilemma	0	0	72
o patient (extent of	Minimal Dilemma	27	84.37	
lisease and progression)	Moderate Dilemma	2	6.25	
1 0 /	High Dilemma	3	9.37	
Discussing end of life	Least Dilemma	25	78.12	39
ssues with care	Minimal Dilemma	7	21.87	
aregivers	Moderate Dilemma	0	0	
0	High Dilemma	0	0	
Discussing end of	Least Dilemma	0	0	123
ife issues and care	Minimal Dilemma	0	0	
vith patient	Moderate Dilemma	5	15.62	
	High Dilemma	27	84.37	
Conveying	Least Dilemma	0	0	114
chemotherapy-induced		3	9.37	
oss of fertility	Moderate Dilemma	8	25	
o young patients	High Dilemma	21	65.62	
Conveying	Least Dilemma	17	53.12	58
hemotherapy-induced		9	28.12	
oss of fertility	Moderate Dilemma	1	3.12	
o old patients	High Dilemma	5	15.62	
Conveying	Least Dilemma	7	21.87	72
chemotherapy-induced	Minimal Dilemma	17	53.12	
oss of hair	Moderate Dilemma	1	3.12	
o young patients	High Dilemma	7	21.87	
Conveying	Least Dilemma	11	34.37	61
chemotherapy-induced	Minimal Dilemma	15	46.88	
oss of hair	Moderate Dilemma	4	12.5	
o old patients	High Dilemma	2	6.25	

Sample size selection:

The sample size was selected using the following formula: Where a=0.05; estimated proportion (p)=0.5 and estimated error (d)=0.18 to give a sample size of 30.

Methodology

The study population consisted of medical doctors who had attended the continuous medical education programs conducted by Mangalore Institute of Oncology. The investigators approached the attending participants and briefed them about the study purpose. They were also informed that their participation was voluntary. Written consent was obtained on a separate sheet from the willing volunteers before the administration of the questionnaire. As some questions were dilemmatic, the volunteers were also requested not to write their names or leave any identification mark on the study questionnaire and were requested to return the filled sheets back. The choice for the complexity in the ethical dilemma was categorized as least, minimal, moderate, and high dilemma. In addition, total quantitative numerical for each of the question cumulative sum was ensured by multiplying the number of people with a grade assigned (1=least, 2=minimal, 3=moderate, and 4=high dilemma) and arriving at a cumulative sum by adding up the individual scores. The data were imported to Microsoft Excel and answers on the questions were subjected to a quantitative analysis using frequency, percentage, and cumulative score/grade for each of the subject-specific questions.

Results

The questionnaire was filled by 32 medical doctors, of which 20 were female (62.5%) and 12 (37.5%) were male (Table 1). Most of the volunteers were in the age group above 51 years with more than 15 years of experience (37.5%). The volunteers were from the fields of medicine, obstetrics, gynecology, surgery/ and otolaryngology. The study showed the high ethical dilemma as follows: discussing end of life issues with patient > breaking the bad news > conveying chemotherapy-induced loss of fertility to young patients > conveying chemotherapy-induced loss of hair to young patients > conveying chemotherapy-induced loss of fertility to old patients > providing information to patient (extent of disease and progression) > screening for breast cancer=conveying chemotherapy-induced loss of hair to old patients > discussing end-of-life issues with caregivers (Table 2). The cumulative grade severity in the ethical dilemma is represented in table 2 and figure 1.

Discussion

Cancer specialists deal with a group of people who need great medical care and this may inadvertently cause ethical dilemmas, at times.^{2,4,5,7-10} To substantiate this, global studies have unequivocally shown that oncology is full of ethical issues and in some countries and hospitals, the treating healthcare professionals are trained to handle them. 11,12 In India, there has never been a study to document the ethical issues bothering health care professionals involved in the diagnosis and care of cancer patients. Generalizing the dilemma documented in other countries will not be prudent as every civilization and country has its own set of culture, a way of living, spiritual beliefs, and a set of juxtaposing and engrossing well.1 dilemmas as Regarding considerations, the present study was conducted to ascertain the dilemmas faced by medical doctors in the diagnosis and care of people afflicted with cancer.

In this study, discussing end-of-life issues and care was the most difficult issue. Previous studies have emphatically shown that a large majority of patients are interested in knowing about their life span, quality, and end-of-life care from doctors. 13, 14 It is the doctor's responsibility to initiate a dialogue on the issue and to mitigate the plethora of issues bothering the dying patient and his/her family.¹³ In the developed countries, the doctors are known to include the family members and to initiate a dialogue with the patients who are terminally ill.¹³ This is shown to mitigate the fear of pain, indignity, and abandonment and to pave way for an open and direct discussion between the patient and others. 13-¹⁵ Reports also suggest that involving family members in these discussions strengthens the relationships within the family, reduces the fear, and improves the feeling of being cared in the terminally ill person. 13-17

The second most important dilemma was with regard to breaking bad news of cancer diagnosis. The first principal reason for this dilemma is because Indian healthcare professionals are never taught breaking bad news during their training and the other is the pressure from the family not to

reveal the diagnosis as cancer. 18-20 Compared to India, studies from developing countries have shown that although people do not wish to hear that they are diagnosed with cancer, the majority of them will inquire about the treatment and chances of cure from their doctors. 18-20 Breaking bad news requires training and empathy and the physician doing so will have to respect patient autonomy and rights to information and also choose the words responsibly with professional honesty, clarity, and instill hope when needed. 19,20 These issues are important because most of the informed patients will cooperate better with the treating doctors and complete the planned treatment. 1-3, 21

Another important dilemma in this regard was conveying the chemotherapy-induced loss of fertility and hair to young people diagnosed with cancer and requiring chemotherapy. Recent reports have indicated that in India, the incidence of cancer is on a rise in the younger population. To have a child of their own is an important wish of most people and the information that chemotherapy can cause loss of fertility is devastating to most people. 22 Also, hair/mane has an important beauty quotient and hair loss is not considered favorably especially by the women.²³ The realization of the loss of the idea of family and hair loss is an important issue in the counseling²⁴ and a very difficult dilemma for the physicians breaking the bad news. The other important dilemma is on how much information is provided to the patient/caregiver, without causing depression or despair in the patient. This dilemma was reported for the question pertaining to discussing end-of-life issues with the patient caregiver.

Conclusion

The study indicates that initiating/discussing end-of-life issues with the patient, breaking bad news, and conveying the loss of fertility and hair to young patients were the most dilemmatic to medical doctors. The biggest drawback of this study was that this was a single-center study conducted with a small sample size. Further

studies are warranted with a bigger sample size and with doctors from different fraternities, years of experience, and parts of India. Reports also suggest that the majority of doctors and nurses involved in the care of people with cancer experience psychological distress that may affect their emotional well-being and work satisfaction. Studies are also required in this direction as the outcome of all these studies will be useful in formulating a structured teaching program for the healthcare professionals involved in catering to the medical needs of people with cancer and their family. This will also be of help in working on modalities that will assist in mitigating the psychological distress that the healthcare professionals undergo while caring for a person with cancer and their family.

Conflict of Interest

None declared.

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