

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 perspective 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

Table 1. Demographic details of the 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 than 5 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.

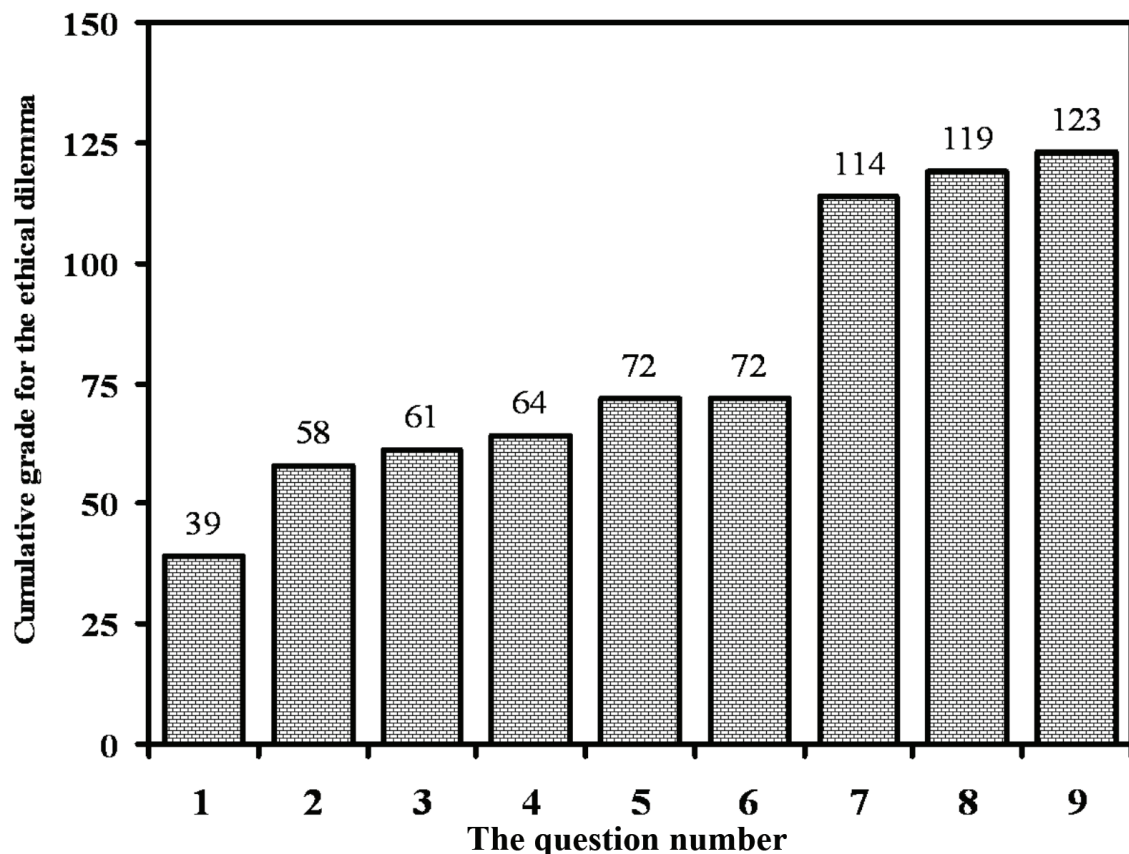


Figure 1. The cumulative score/grade for each of the questions on the ethical dilemma (1=discussing end of life issues with care caregivers; 2=conveying chemotherapy-induced loss of fertility to old patients; 3=conveying chemotherapy-induced loss of hair to old patients; 4=breast cancer screening; 5=conveying 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 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 to patient (extent of disease and progression)	Least Dilemma	0	0	72
	Minimal Dilemma	27	84.37	
	Moderate Dilemma	2	6.25	
	High Dilemma	3	9.37	
Discussing end of life issues with care caregivers	Least Dilemma	25	78.12	39
	Minimal Dilemma	7	21.87	
	Moderate Dilemma	0	0	
	High Dilemma	0	0	
Discussing end of life issues and care with patient	Least Dilemma	0	0	123
	Minimal Dilemma	0	0	
	Moderate Dilemma	5	15.62	
	High Dilemma	27	84.37	
Conveying chemotherapy-induced loss of fertility to young patients	Least Dilemma	0	0	114
	Minimal Dilemma	3	9.37	
	Moderate Dilemma	8	25	
	High Dilemma	21	65.62	
Conveying chemotherapy-induced loss of fertility to old patients	Least Dilemma	17	53.12	58
	Minimal Dilemma	9	28.12	
	Moderate Dilemma	1	3.12	
	High Dilemma	5	15.62	
Conveying chemotherapy-induced loss of hair to young patients	Least Dilemma	7	21.87	72
	Minimal Dilemma	17	53.12	
	Moderate Dilemma	1	3.12	
	High Dilemma	7	21.87	
Conveying chemotherapy-induced loss of hair to old patients	Least Dilemma	11	34.37	61
	Minimal Dilemma	15	46.88	
	Moderate Dilemma	4	12.5	
	High Dilemma	2	6.25	

Sample size selection:

The sample size was selected using the following formula: Where $\alpha=0.05$; 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, and surgery/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 dilemmas as well.¹ Regarding these 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.

References

1. Bringedal B, Isaksson Rø K, Magelssen M, Førde R, Aasland OG. Between professional values, social regulations and patient preferences: medical doctors' perceptions of ethical dilemmas. *J Med Ethics*. 2018;44(4):239-43. doi: 10.1136/medethics-2017-104408.
2. Ilemona ER. An appraisal of ethical issues in end-of-life care. *Niger J Med*. 2014;23(4):358-64.
3. Misselbrook D. Virtue ethics - an old answer to a new dilemma? Part 1. Problems with contemporary medical ethics. *J R Soc Med*. 2015;108(2):53-6. doi: 10.1177/0141076814563367.
4. Schaefer C, Weissbach L. Cancer screening: curative or harmful? An ethical dilemma facing the physician. [Article in German] *Urologe A*. 2011;50(12):1595-9. doi: 10.1007/s00120-011-2727-z.
5. Chiu TY, Hu WY, Huang HL, Yao CA, Chen CY. Prevailing ethical dilemmas in terminal care for patients with cancer in Taiwan. *J Clin Oncol*. 2009; 27(24):3964-8.
6. Daugherty CK. Examining ethical dilemmas as obstacles to hospice and palliative care for advanced cancer patients. *Cancer Invest*. 2004;22(1):123-31.
7. Tanneberger S, Malavasi I, Mariano P, Pannuti F, Strocchi E. Planning palliative or terminal care: the dilemma of doctors' prognoses in terminally ill cancer patients. *Ann Oncol*. 2002;13(8):1320-2; author reply 1322-3.
8. Tanneberger KS, Pannuti F, Malavasi I, Mariano P,

- Strocchi E. New challenges and old problems: end of life care and the dilemma of prognostic accuracy. *Adv Gerontol.* 2002;10:131-5.
9. Cotogni P, Saini A, De Luca A. In-hospital palliative care: should we need to reconsider what role hospitals should have in patients with end-stage disease or advanced cancer? *J Clin Med.* 2018;7(2). pii: E18. doi: 10.3390/jcm7020018..
 10. Partanen E, Lemetti T, Haavisto E. Participation of relatives in the care of cancer patients in hospital-A scoping review. *Eur J Cancer Care (Engl).* 2018; 27(2):e12821. doi: 10.1111/ecc.12821
 11. Krishnan M, Racska M, Jones J, Chittenden E, Schaefer KG, Spektor A, et al. Radiation oncology resident palliative education. *Pract Radiat Oncol.* 2017;7(6):e439-48. doi: 10.1016/j.ppro.2017.03.007.
 12. Zaidi D, Kesselheim JC. Assessment of orientation practices for ethics consultation at Harvard Medical School-affiliated hospitals. *J Med Ethics.* 2018;44(2):91-6. doi: 10.1136/medethics-2016-103909.
 13. Houska A, Loučka M. Patients' autonomy at the end of life: A critical review. *J Pain Symptom Manage.* 2019; 57(4):835-45.
 14. Brooks LA, Bloomer MJ, Manias E. Culturally sensitive communication at the end-of-life in the intensive care unit: A systematic review. *Aust Crit Care.* 2018. pii: S1036-7314(18)30057-2. doi: 10.1016/j.aucc.2018.07.003.
 15. Schmid W, Rosland JH, von Hofacker S, Hunskaar I, Bruvik F. Patient's and health care provider's perspectives on music therapy in palliative care – an integrative review. *BMC Palliat Care.* 2018;17(1):32. doi: 10.1186/s12904-018-0286-4.
 16. Daher M. Ethical issues in the geriatric patient with advanced cancer 'living to the end'. *Ann Oncol.* 2013;24 Suppl 7:vii55-58. doi: 10.1093/annonc/mdt262.
 17. Puts MT, Sattar S, McWatters K, Lee K, Kulik M, MacDonald ME, et al. Chemotherapy treatment decision-making experiences of older adults with cancer, their family members, oncologists and family physicians: a mixed methods study. *Support Care Cancer.* 2017; 25(3):879-86.
 18. Bousquet G, Orri M, Winterman S, Brugière C, Verneuil L, Revah-Levy A. Breaking bad news in oncology: A metasynthesis. *J Clin Oncol.* 2015;33(22):2437-43.
 19. Aitini E. Breaking bad news in onco-hematology: new hope, new words? *Leuk Lymphoma.* 2012;53(2): 328-9.
 20. Abazari P, Taleghani F, Hematti S, Malekian A, Mokarian F, Hakimian SMR, et al. Breaking bad news protocol for cancer disclosure: an Iranian version. *J Med Ethics Hist Med.* 2017;10:13. eCollection 2017. doi: 10.1093/annonc/mdt262.
 21. Constantin DA, Cioriceanu IH, ȚânȚu MM, Popa D, Bădău D, Burtea V, et al. Ethical dilemmas in communicating bad news following histopathology examination. *Rom J Morphol Embryol.* 2017;58(3): 1121-5.
 22. Ramstein JJ, Halpern J, Gadzinski AJ, Brannigan RE, Smith JF. Ethical, moral, and theological insights into advances in male pediatric and adolescent fertility preservation. *Andrology.* 2017;5(4):631-9. doi: 10.1111/andr.12371.
 23. da Luz KR, Vargas MA, Schmidt PH, Barlem EL, Tomaszewski-Barlem JG, da Rosa LM. Ethical problems experienced by oncology nurses. *Rev Lat Am Enfermagem.* 2015;23(6):1187-94. doi: 10.1590/0104-1169.0098.2665.
 24. Carvalho BR, Kliemchen J, Woodruff TK. Ethical, moral and other aspects related to fertility preservation in cancer patients. *JBRA Assist Reprod.* 2017;21(1):45-8. doi: 10.5935/1518-0557.20170011.