



Breaking the Bad News in Cancer: An In-Depth Analysis of Varying Shades of Ethical Issues

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Abstract

Oncology has a range of ethical issues that are difficult to address and breaking the bad news is probably the most important and common across the world. Conventionally, breaking the bad news has been exclusively used in the situation where definitive diagnosis of cancer is to be conveyed to the patient. On a practical note, for the treating doctor, breaking the bad news is not restricted only to the confirmation of cancer and its prognosis at the initial diagnosis but also includes conveying futility of curative treatment, changing from curative to palliative treatment, recurrence/metastasis posttreatment, end of life care, and finally informing death of the patient to the family members. In addition to this, informing pregnant women that she has been diagnosed with cancer, about surgery-induced body disfigurement, loss of fertility due to chemotherapy/ radiotherapy, and of treatment-induced irreversible health complications are also challenging for the treating oncologist. On the basis of an in-depth analysis, the current review presents the various situations, complexities, and the related ethical issues in breaking the bad news in various situations from the perspective of an oncologist in detail in Indian context.

Keywords

- ▶ ethical issues
- ▶ breaking the bad news
- ▶ end-of-life issues
- ▶ oncofertility

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Introduction

Ethics is an integral part of medicine and healthcare professionals are obligated to make sound clinical decisions, reduce harm, by considering the patient's religious beliefs, cultural values and societal norms.¹⁻⁴ In this regard, the four main principles of bioethics "autonomy, beneficence, non-maleficence, and justice" form the base for all ethical dealings and behavior in healthcare sciences.² Importantly, all healthcare workers have to remember this and take the most suitable decision and choose standard medical interventions by keeping the best interest of the patient and their family members as priority.² On the part of the treating doctor, honoring these principles during medical practice and in personal life is considered ethical to ensure that he is doing full justice to his patient and their family members.¹⁻⁴ Treating doctor has to also ensure that the patient's rights are protected in accordance with the recommended guidelines on moral principles and will also have to help the patients and their family members navigate through the trajectory of the treatment, recovery, and rehabilitation.²

In addition to this, the healthcare professionals will also have to follow the principle of sincerity and accountability for the decisions they take while attending to the patients and their family members while making complex choices⁵ considering the moral norms of the right conduct that transcends the barriers of cultures, geographical regions, and religions.^{1,6} Principally, moral norms which by definition means "*rules of morality that people ought to follow*" are classified in to two groups as common morality and particular morality.^{1,7} Terminologically, common morality indicates aspects like not causing any harm or suffering to others but instead relieving them of it, while particular morality refers to norms that tether people to their culture, religious beliefs, and professional standards.⁷ It is also important that the healthcare workers and the treating doctor endure value in cancer care by focusing on patient's physical and psychological welfare with empathy and professionalism.²⁻⁴ In spite of all these guidelines, healthcare workers face a multitude of ethical dilemmas at regular intervals, and at most times they are distressing and difficult to handle.^{8,9}

When compared with other specialties in medical sciences, the ethical issues in cancer care are divergent and complicated. Some of the most important ethical issues reported are in the areas of cancer screening, genetics, diagnosis, breaking the bad news, the extent of patient information to be provided, and topics in planning the optimal treatment, follow-up, cost-benefit aspects, psychological and physical rehabilitation, sexuality and reproductive aspects, supporting the caregivers, transitioning from curative to palliative treatment, care of vulnerable groups, and the various end-of-life issues.¹⁰⁻¹³ On a practical note, arriving at an ethical decision for some of the above said aspects is straightforward and with a solution, while few end as unresolved and inflict conflicting moral injury, feelings of frustration, and powerlessness in the oncology staff.^{8,9} On a comparative note, when compared with the developed countries, the situation of helplessness and moral injury in

healthcare workers working in cancer care in resource limited developing countries may be more, but is under reported.

Previous studies aimed at understanding the most difficult situation for medical doctors in treatment and care of cancer patients in Indian context had indicated that breaking the bad news was the most difficult.^{8,9} Although myriad factors are documented to be associated with the complexity and difficulty in breaking the bad news, in the Indian context one of the important factor that contributes to the difficulty is the role of the family member in the process and requesting to withhold information from patients.^{14,15} The principal reason for this is that the family members feel that revealing the bad news can cause fear and depression in the patient and can lead to self-harm and suicide.^{14,15} For a treating doctor, the conflicting requests of the patient versus that placed by their family members present a dilemma because withholding information from patients is against the tenets of medical ethics.¹

On the contrary, most patients are desirous to know the prognostic details, treatment choice and the sequence, side effects, chances of recurrences, complications of treatment, quality of life, and the life expectancy posttreatment.¹⁶ Nonmaleficence is the principle of refraining from causing unnecessary harm and not informing the patient about their diagnosis and prognosis can cause anxiety and affects adversely.^{1,17} The principle of justice mandates that the patient is informed of the diagnosis and made fully aware of the nature of his disease to allow them to be prepared for the disease trajectory and course of the disease treatment, and to face the adversities effectively.^{1,17} The act of withholding information is maleficent and affects the patient autonomy and beneficence.^{17,18} On the contrary, it is accepted to be beneficent to discuss the treatment options and allow the patient to choose.¹⁹

In principle, a doctor should ideally follow the principle of autonomy in accordance with good clinical practice with the recommended evidence-based treatment.^{1,17} Some doctors often adopt a paternalistic attitude toward the diagnosis and treatment of patients and feel that the person who is ill does not have much role in treatment decision.²⁰ It was only in the recent past that physicians have begun to accept the importance of patient's autonomy.²⁰⁻²² Even today, physicians from the India are hesitant to break the bad news²³ and have reluctance to allow individual autonomy. This is common in several Asian societies that believe autonomy is more collective rather than being individualistic.²⁴⁻²⁶

Technically, accepting autonomy would mean that the physician and the patient would become partners in arriving at choices and decisions in the planned treatment and the schedule.²¹ In this, the physician dons the role of teaching their layman patient to make logical decisions and must encourage and motivate them to make the right choices.²⁷ The "Autonomy" provides patient with their individual prerogative to the knowledge of their disease, its prognosis, the treatment choices, their benefit, ill effects, and costs.²² This is especially important when a critical decision needs to be arrived at with regard to choosing complex treatment.^{28,29}

At times, when the doctor upholds patient's right to autonomy, he may also have to face the distressing challenge of watching the patient make erroneous decisions like choosing anecdotal alternative treatment or refusing treatment.³⁰ The important aspect here with is that the treating doctor will have to devote sufficient time to help and guide the patient and their family member with provision of care that is standard, cost-effective, and individual specific.^{31,32}

Clinically, the right of the patient to make decisional control preferences is a major predictor of patient satisfaction and the doctor must actively assess a patient's decisional control preferences to ensure optimal communication and patient satisfaction.^{16,17} For the treating doctor, this is an important aspect as this paves the way for a fruitful conversation and for arriving treatment decisions through discussion.^{16,17} Reports also suggest that the educated patients desire more information than patients with less formal education^{15,33} and that they value doctor's ability to provide sufficient details with emotional, structural, and informational support.³⁴ Also, patients who prefer to be active in decision-making during illness want more information about their illness and sequelae during and after the treatment.^{19,27} On the contrary, studies by Ghoshal et al¹⁶ have also shown that patients affected with advanced cancer prefer passive decisional control, where the family members make decisions on their behalf.¹⁶ In the subsequent sections, the ethical dilemmas faced by oncologists in breaking the various bad news in oncology are addressed:

Initial Diagnosis

The disease cancer is associated with severe apprehensions, and reports suggest 50 to 90% of the patients expect a full disclosure,³⁵ and under these circumstances, the way the bad news is broken assumes importance. Historically, breaking the bad news was seldom done and the accepted practice was to withhold information from the patient as it was believed to be in their best interests.^{36,37} However, in the recent past, most doctors and professionals share information with the patient along with their family caregivers. In most instances, the physicians break the bad news either directly to the patient or to the family member or the patient's caregiver with utmost sincerity and empathy.³⁸ Precisely at this stage, the doctor becomes a witness to shock, denial, rage, dismay, fright, acceptance, and sadness, intertwined with confusion and distress that culminate in heartbreaking emotions of the patient and their family members.³⁹ The situation is more complicated when breaking the bad news is about a child or when the individual is the sole bread earner with children and family to support.⁸

In India, at most times some family members exercise their right to autonomy and request the doctors to keep the diagnosis a secret from the patient citing psychological breakdown of the patient or fear of inflicting self-harm and suicide.^{15,16} At this stage, most doctors and healthcare professionals find themselves at crossroads unable to decide whether they should follow and honor the patient's right to confidentiality, or if they should not disclose the information

to the patient in accordance with the family's wish.⁸ Under these situations, the treating doctor will have to assess the mental condition of the patient, ascertain the situation, and carefully divulge the details and the extent of information on cancer to the patient without breaking hope in an empathetic manner. Also, at times in certain cases, the doctor may have to answer questions like "Why me" or "Why did this happen to my family" presenting a difficult situation.⁸

The Transition from Curative to Palliative Treatment

In cancer, the therapeutic objective is principally to eradicate the ailment. However, at times, during the ongoing treatment, the clinical signs and diagnostic results can indicate that the patient has an aggressive refractory cancer and the planned treatment is not as effective as previously observed in other patients and expected to be. At this point, and more so when there are no alternative effective modality/regimen available, the treatment objective shifts from curative to palliative care. For the treating physician and the associated healthcare staff taking care of the patient, this is an extremely difficult situation and emotionally demanding.⁴⁰ This is principally because, during the course of the treatment, a bond would have developed between the patient, their family, and the healthcare workers, and the realization that the patient's health condition is plummeting is difficult to express for the treating doctor.⁸

When Cancer Has Recurred or Metastasized after Curative Treatment

The third and one of the most difficult situations for any doctor is to tell a cancer survivor treated long back that cancer has recurred or has spread to distant organs.⁸ From the patient's and their family's perspective, the curative treatments are associated with severe immediate and long-term side effects and the patient endures it with the hope of living for self and their loved ones. With time, the intrinsic resilience and coping skills help the individual recuperate. Also, a strong support system and love from the family and the community help in reducing the ill thoughts and reintegrate the survivor back into society. Breaking the bad news that cancer has resurfaced triggers flashback memories of painful events endured by the patient and their family members during the initial curative treatment and informing the bad prognosis to the patients and their family members is distressing.⁸

End of Life Situation

The end-of-life situation, which by definition "is the last few days or hours in a patient's life," is very tumultuous and draining to the family.⁴¹⁻⁴⁴ In most cases, the common symptoms seen include fatigue, pain, dyspnea, lack of hunger and thirst, delirium, drowsiness, short attention span, respiratory secretions, confusion and delirium, sudden movement or jerking of the body, labored rapid or hard noisy breathing,

sounds of groaning or moaning indicating progressive decline in patient's health.^{41,44,45} A patient whose death is imminent will require medication to mitigate the ill effects and provide comfort and have a less suffering death.^{42,43} Morally, at this point of time the healthcare workers will have to also focus on supporting the family members, help them understand the progressive trajectory of the disease, and to expect death of their loved one anytime soon.⁴²⁻⁴⁵ The healthcare team has to also support and honor the patient's treatment preference and worse at times make decisions on withholding or withdrawing life-sustaining treatments.^{41,45} For the healthcare workers, these are very distressing and breaking the bad news of imminent death is a difficult task.

Breaking News of Death to Bereaved Relatives

Death, although an indispensable fact of life, is very difficult for the loved ones of the deceased to accept.⁴⁶ For the treating doctors, it is very difficult to convey to the family members that their loved one has succumbed to the ailment.⁴⁶ The problem is severe especially when the death is sudden than when expected. On a relative grade, in oncology breaking the news of death is not that stressful as relatives are aware of the serious nature of the illness and death is anticipated in advance.⁴⁷ However, there are instances in oncological setups where breaking news of death can be extremely difficult especially when the patient is a child, or when the family bonding is strong with the deceased individual. In these situations, the relatives of the deceased patient are sensitive and the atmosphere is emotionally charged and use of any unsympathetic callous words and neglect on the part of the treating doctor or by the healthcare staff can cause severe grief response.^{46,48} Worse such instances can trigger angry action, maladjustment, violence, and vandalism against the staff and the hospital.^{46,48} From a treating doctor's perspective such situations are extremely difficult. In these situations, the professionalism, empathetic communication, and the rapport the treating doctor has developed with the patient's family play a vital role.⁴⁹ In addition to this, facilitating the bereaved family to carry out the cultural and religious procedures always has a beneficial and long-lasting opinion of gratitude and appreciation toward the treating doctor and the hospital.^{50,51}

Cancer during Pregnancy

Pregnancy brings joy, happiness, and satisfaction not only to the couple but also to the extended family. Reports suggest that malignancies during pregnancy are extremely rare and accounts to 0.07 to 0.1% of all cancer.⁵² Of all cancers, the most common malignancies reported in pregnant women are cancers of breast, cervix, ovary, melanoma, lymphomas, and leukemia.⁵²⁻⁵⁴ The ethical issues that arise in the process of care of the pregnant woman with cancer are extremely challenging because both chemotherapy and radiation, the two important modalities, are cytotoxic and can irreversibly affect the fetus.^{55,56} Clinically, emphasis is to provide the best

possible cancer treatment by minimizing harm to the fetus and planning safe maternal and neonatal outcomes. In this regard, factors like the gestational age of pregnancy, site and stage of the cancer, the planned treatment and its impact on the pregnancy need to be critically analyzed before initiation of the treatment.⁵⁷ The oncologists will have to coordinate with obstetrician and pediatrician, and have detailed discussion on proposed treatment considering the mothers and child's well-being.^{57,58}

Clinically, if the fetus is above 36 weeks in age, delivery of the child is facilitated through normal process or through cesarean section, while if it is below 24 weeks, abortion may be required. These decisions that are based on tumor board discussion will be decided on the basis of the site and tumor prognosis and on the necessity for treatment intervention. Attempts are will always be toward saving mother and the child, while when faced with the inevitable choice of only one, the woman's life is the priority. Chemotherapeutic agents are mutagenic and teratogenic and can affect the fetus. Hence, there is a conflict of interest for use of chemotherapy in a pregnant patient. Although very rare, for the oncologists, breaking the bad news to a couple expecting their baby and in worse case scenarios that the baby may need to be aborted is an extremely difficult choice to make.

Body Disfigurement

Cancer surgery causes body disfigurement and this is observed in people affected with head and neck, breast, cervix, and penile cancer.⁵⁹ Performing partial or extensive excision of the organs to eliminate the cancer causes limited or severe functional and cosmetic changes and adversely affects the quality of life.⁵⁹ On a comparative note of all organs, the disfigurement of the head and neck has been extensively investigated and severely affects the functional efficacy of the oral cavity and also alters the facial appearance.⁵⁹ To support this, studies have shown that body image concerns should be ascertained before surgical intervention in oral cancer patients as disfigurement induces psychological stress and depression, and the patient and their family members should be aware of it in the initial stages and take part in discussion process⁶⁰

With regard to breast, cervix, and penis, the surgical excision can help achieve complete cure when the cancer is localized and in early stage.⁶¹⁻⁶⁴ When compared with oral/head and neck cancer, the disfigurement is not visible. However, disfigurement in these organs can affect sexuality and this can severely hamper the psychological well-being, the sexual, and marital life, especially in the young cancer patients in the reproductive age group. This is ethically a very sensitive issue for the treating surgeon and factors like the age of the patient and socioeconomic factors during the breaking of the bad news can further complicate/aggravate the dilemma.

Fertility and Sexuality Issues

Cancer modalities like chemotherapy and radiation affect the rapidly proliferating normal tissues like the germinal

epithelium and cause premature ovarian failure and azoospermia in females and males respectively.^{65,66} In the past, main focus had always been on saving the life of the patient, and issues like loss of fertility were never considered.⁶⁷ The recent advances in oncological diagnosis and effective treatment have increased the disease-free condition for many cancers especially when detected early and the tumor is localized and in early stage.⁶⁷ Also, in recent years due to increased awareness and screening, the incidence of cancer being detected in people in the reproductive age group is high.⁶⁸ The early diagnosis and effective treatments have increased the patient survival and procreation and children of their own are desired by many cancer survivors with disease-free and good health condition and in the reproductive age group.⁶⁷⁻⁶⁹

In the recent past in the developed countries, "Oncofertility" has been gaining importance and fertility preservation like oocyte vitrification and sperm banking for female and male cancer patients is undertaken before start of cancer treatment.⁶⁹⁻⁷² However, the concept of fertility preservation is yet to gain acceptability and implemented throughout India. Worse there is no insurance coverage for oocyte or sperm preservation and this affects the patients and their family members. Under these situations, chemotherapy is initiated without preserving the gametes. For the treating doctor, it is very demanding situation to express the oncofertility issues to the parents of children and to young adults of reproductive age planning family.

Cancer Treatment-Induced Health Complications

In the recent past, cancer treatment-induced long-term side effects are being documented principally because the advancement of oncological treatment has increased the disease-free condition and survival in many patients.⁷³ Most of the side effects observed are understood to be specific to the treatment modality and the drug used for the curative regimen.⁷³ In cancer survivors, these side effects appear months or years after the completion of the treatment and present an additional health risk to the survivor. Some of the important long-term side effects include chemotherapy (- Herceptin/doxorubicin/ daunorubicin/ epirubicin/ cyclophosphamide), radiotherapy-induced heart problems, drug (bevacizumab/sorafenib/sunitinib)-induced hypertension, chemotherapy (bleomycin/carmustine/methotrexate)/radiotherapy-induced lung damage, drug (cisplatin)-induced kidney damage, and drug (chemotherapy, steroid medications, hormonal therapy)-induced osteoporosis.⁷³

In addition to this, cancer treatment can induce metabolic syndromes like central obesity, dyslipidemia, hypertension, and insulin resistance in higher incidence in childhood cancer survivors and people with improved survival and disease-free conditions.⁷⁴ Also when compared with the general population, cancer survivors are at higher risks of cardiovascular events.^{74,75} In cancer survivors who are disease-free, the development of these health issues adversely affects their quality of life and also causes severe financial

toxicity. For oncologists, breaking the bad news of the development of long-term cancer treatment-induced side effects and addressing cancer survivor's apprehensions is difficult. This is principal because the oncologist is aware of the ordeal the patient has gone through and the statement "why me" and "why this now" has a colossal impact during breaking the bad news.

Conclusions

The current review attempted at presenting the difficulty healthcare workers and oncologists working in cancer care face in India especially with breaking the bad news. The review is based on an in-depth study performed with various groups of healthcare workers in both oncological and non-oncological settings for the past 5 years. The most important problem was with regard to handling emotions of not only the patient but also of the doctors and other healthcare workers. Gauging the reaction of the patient amid response would compromise the veracity principle, by taking the easy way out. Handling familial pressures and vagaries of treatment can lead to complications further, inciting problems. Such important issues were left to the hidden curriculum, forcing the medical fraternity to grapple with their imitable manners, which have antecedent risks. We emphasize that a structured training program that focuses on breaking the bad news through dyadic and triadic communication skills is necessary. Also, it is recommended that efforts should be directed toward improving the communication skills of healthcare workers and residents. Also, it is strongly recommended that structured training programs should be included mandated in the healthcare curriculum as this training will help in the effective handling of ethical issues.

Conflict of Interest

None declared.

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