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# Social, Ethical and Treatment Related Problems Faced by Healthcare Workers in the Care of Head and Neck Cancer Patients: A Narrative Review from the Bioethics Consortium from India

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#### Abstract

Head and neck cancer (HNC) presents a variety of ethical difficulties for an oncologist involved in screening, diagnosis, treatment, and rehabilitation that are challenging to address, especially for those professionals/people who are not trained in medical ethics. The bioethics department has spent the last ten years compiling information and rating the seriousness of numerous niche ethical concerns and their effects on healthcare professionals practising in India. Based on these findings, the current analysis makes an effort to outline the different challenges faced by oncologists when screening, diagnosing, treating, and rehabilitating people affected with HNC, particularly in a traditional nation like India. According to the authors, this is the first overview to address these issues from an Indian viewpoint, and it represents a small effort to document a crucial but unaddressed component of cancer treatment. It is hoped that these endeavours would aid in educating upcoming healthcare professionals on how to effectively handle the difficulties.

**Keywords** Bioethics  $\cdot$  Dilemma  $\cdot$  Head and neck cancer  $\cdot$  Breaking bad news  $\cdot$  End-of-life issues  $\cdot$  Body disfigurement  $\cdot$  Geriatric oncology  $\cdot$  Cancer follow up  $\cdot$  Rehabilitation

#### Introduction

Head and neck cancers (HNC) rank as the seventh most common type of malignancy globally. According to the Global Cancer Observatory, the occurrence of these malignancies

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<sup>3</sup> Member, International Chair in Bioethics, University of Porto Portugal (Formerly UNESCO Chair in Bioethics, University of Haifa) Directorate of The Asia Pacific Division and Education Department, Cleeland Street, Melbourne, Australia is continually increasing and is predicted to reach 30% by 2030 [1, 2]. Data suggest, at a global level HNC present with 50% mortality risk and that two-thirds of cancer cases and three-quarters of the deaths related to them happen in Asia [2, 3]. Anatomically, HNC includes a variety of cancers

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that develop in various locations in the head and throat. It can affect the larynx, the pharynx and its three divisions, the nasopharynx, oropharynx, and hypopharynx, as well as the air sinuses, oral cavity structures such as the tongue, gums, and salivary glands, and the roof of the mouth regions [2–4]. Although many other histological variations of these tumours have been identified, squamous cell carcinomas are the most common across the HNC sub regions and also in the world. Aetiologically, abuse of alcohol and tobacco in various forms, as well as exposure to oncogenic viruses including the Epstein–Barr virus (EBV) and the Human Papilloma virus (HPV) are all cited as risk factors [2, 5, 6].

Historically, due to the use of oral tobacco with or without areca nut that contain over 60 documented carcinogens, people who are especially the habitual, from Southeast Asia and Australia are more likely to get these cancers than rest of the world population [3, 5, 6]. Also, when compared to women, men are more likely to develop this [3, 5, 6]. When compared to globally, the demographics, dietary preferences, personal histories, and risk factors that HNC in India follows to are special and distinctive. In India, about 80,000 cases of oral cancer and over 200,000 cases of HNC are detected annually [3, 5, 6]. In India, where betel quid is frequently chewed in this part of the mouth for extended periods of time, bucco-gingival cancers are fairly common and referred to as Indian oral malignancies due to their aetiology and location [2, 3, 5, 6].

In developed and wealthy nations, oropharyngeal squamous-cell carcinomas have now surpassed cervical cancer as the most common malignancy linked to HPV particularly HPV-16, and HPV 18 [2]. Oropharyngeal HPV infection in both men and women are fostered by the bidirectional transfer of HPV between the genital and oral regions [2, 7-9]. Additionally scientific studies have now proved that the molecular mechanisms underlying the oncogenic processes of HPV-related and HPV-unrelated (tobacco or alcohol) HNC are different and that the prognosis of HPV-related cancers is better. In lieu of these observations, it has become increasingly important to distinguish between HNC that are HPV-related and those that are not and molecular techniques like P16 immunohistochemistry, FISH, and genetic studies of the HPV gene from histopathological and liquid biopsy specimens, have been regularly used and appropriate therapy with EGFR TKI and low-dose radiation therapy used depending on the findings of the differential diagnosis [2, 7-9].

Clinically, the treatment of HNC is multimodality and surgery to remove the tumour, radiation utilising highenergy rays like X-rays, and chemotherapy—either alone or in combination—are some of the treatment options [4, 10–12]. The organ-preserving approach preferably with definitive concomitant chemoradiation (CRT) is attempted for locoregionally restricted tumour and involves using surgery as a last resort [12–14]. Surgery followed by adjuvant radiation therapy is the other treatment option options [4, 12, 15]. The management of HNC is complex, including a number of disciplines, including medicine, pathology, surgery, radiation oncology, radiology, and supportive services, such as physical and occupational therapy, speech and swallowing therapy, and nutrition [11, 16].

HNC is a very difficult condition for medical professionals to handle because of the many social and ethical issues that the illness and its effects on affected patient can bring both during treatment and after it is completed [16, 17]. According to published reports, the ethical dilemma differs from place to place and, to make matters worse becomes more convoluted when social, cultural, religious, and societal factors are linked. During diagnosis, treatment, and rehabilitation care, healthcare professionals must take into account all of these factors. In these situations, training on how to handle moral and ethical dilemmas while taking into account social, religious, and local societal values and practises can be very beneficial for the healthcare professionals and treating oncologists, who are the most important professionals in patient care [11].

"Ethics is not always about what is right or wrong, acceptable or unacceptable, ideal or less than ideal," and it also encompasses abiding by the Hippocratic Oath and the law of the state [18]. It could also be described as making the best choice possible in a given situation and occasionally "opting for the lesser of the two evils" [18]. Unbelievably, there are occasions when an ethical problem lacks a perfect answer, and the least unpleasant course of action must be taken. In these situations adhering to the four fundamental bioethical principles-respect for "autonomy, non-maleficence, beneficence, and justice"-proposed by Beauchamp and Childress (2008)-help decision-makers reach morally sound conclusions in the face of tremendous difficulty [19]. Technically, to put it briefly, "beneficence" and "non-maleficence" prioritise the rights and welfare of the patient, while "autonomy" refers to the individual's right to choose and pursue whatever they like [18, 20]. Additionally, in recent years, emphasis has been focused on professionalism, justice, dignity, empathy, truthfulness and honesty, which are crucial in cancer and are an essential aspect of medical care [18, 20, 21]. According to studies, there are a variety of ethical concerns related to HNC, including those related to screening, treatment, rehabilitation and death, which are discussed here.

## **Ethical Issues for Cancer Screening**

Most HNC cancers are diagnosable by screening. Terminologically "To screen" means "to search for disease in the absence of symptoms or, in other words, to attempt to find disease in someone not thought to have a disease" [22, 23].

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But, screening for the disease is accompanied by numerous ethical dilemmas that physicians need to confront with utmost caution. Screening is ethical only when the screening is recommended and validated by scientific methods, to avoid reasons for suspension, or negatively that can cause anxiety during screening and most importantly to not doing harm (non maleficence) [22–24]. The need for screening, the reporting of the observed findings, and the interpretation of results should be efficient and communicated to the patient or his family members in a comprehensible simple language [22–24]. The physician and the concerned hospital should abide by the ethical principles and guidelines and maintain strict privacy and confidentiality of the patient details and any volunteers [22–24].

## **Ethical Issues for Cancer Education**

HNC are most prevalent among men and women in India's urban and rural populations, and they can also be greatly reduced with sustained cancer awareness programs. From the perspective of community education, it is essential to inform people of the dangers of smoking, chewing tobacco, alcohol and exposure to HPV due to oral sex with multiple partners. Reports do suggest that the prevalence of oral-genital contact is frequently used by teenagers and also that most teenagers often do not view this as a dangerous behaviour, while about 90% of oral malignancies that are HPV-related are found to be HPV 16 positive [25]. Despite suggestions in the media that oral sexual practises are prevalent but present extreme difficulty to identify and understand the trends in these behaviours across time especially in a conservative society like India [26]. In Indian context cancer education on the role of tobacco and alcohol is comparatively easy, while it can be more difficult than it appears to discuss orogenital transmission of the HPV with general public. However, failing to discuss it would mean missing a chance to stop oropharyngeal cancer and these conflicting aspects present severe ethical ramifications in health care professionals involved in community education.

#### **Breaking Bad News**

When compared to other medical sub branches, an oncologist often has to convey unwelcome news in the course of medical care [21]. He must go through the arduous process of telling the patient, a close relative, or the patient's primary carer that they have cancer [21, 27]. It is inevitable that the people concerned will experience trauma after hearing the tragic news [21]. Giving the patient knowledge that significantly changes their world entails breaking unpleasant news and this is a routine in cancer care [21, 27]. The diagnosis is now typically disclosed by clinicians and would frequently see the patient express a wide range of emotions, such as shock, fury, denial, and dismay [21].

Numerous studies have shown that patients want their doctors to inform them about their conditions and provide them with information on all available treatments so they may make more logical and practical decisions about how to handle their circumstances [21]. This presents a difficult decision for the treating doctor, who must determine how much of the diagnosis should be shared with cancer patients who are towards the end of their lives and how to do it in the most effective way [21]. Some patients or their family members use this opportunity to exercise their autonomy rights. The doctor is frequently asked to keep the diagnosis a secret, which puts him in a difficult position where he must choose between being moral and upholding the patient's right to confidentiality and disclosing all the information [21].

According to reports, patients from Western societies should be as informed as possible about their diagnosis and outlook [21, 28-30]. If carried out poorly and with insensitivity, it could seriously harm the patient's psychological health and their ability to advance. Although there is structured training available to handle such circumstances, doctors lack appropriate preparation in this soft skill [28, 29]. The earlier paternalistic models have given way to a more patient-centred, autonomous, and shared decision-making situation [28, 29]. Many cancer sufferers are not informed of news affecting their health [21]. Eastern countries experience this more frequently than Western ones [21]. In Eastern traditions, family members help the sufferer by acknowledging their rights and obligations [21]. This could develop into a condescending attitude that might violate the patient's fundamental right to information and shared decision-making [21]. Instead than conveying a bleak diagnosis and prognosis, patients expect doctors to communicate their condition to them in a way that makes them aware of the potential treatment options and a workable strategy to deal with the disease [21, 31]. Patients need to be aware of the different ways their disease could develop, that it might get better or grow worse, and to be emotionally ready for it [21, 31].

#### **HPV-Related Cancer**

While alcohol and tobacco use has been associated with HNC, the role of HPV was established recently, principally due to the sensitivity of molecular techniques like Polymerase chain reaction (PCR) and In situ hybridization (ISH) in affirming viral clonality in numerous oral and oropharyngeal cancers, and the International Agency for Research on Cancer (IARC) classifying it as risk factor in 2007 [2, 9]. In fact, the prevalence of these tumours is growing in developed nations and will soon exceed the other risk factors for oral cancer especially in people having several oral sex partners [2, 9].

Aetiologically, although both men and women are both at greater risk when they have more relationships, reports suggest women are less likely to acquire throat cancer linked to HPV because of possible development of immunity, while the men lack the same level of immunity [2, 9]. Also, smoking increases the incidence of throat cancer and reduces the effectiveness of treatment in those with HPV-related oropharyngeal cancer, thereby complicating the clinical scenario [2, 9]. The development of effective HPV immunisation is reported to be useful in preventing HPV-related oropharyngeal and cervical cancer in women [2, 9]. However the vaccine especially among boys, who are at a higher risk of developing HPV-related oropharyngeal cancer, is a matter of concern [2, 9]. For the treating doctors advocating HPV immunisation to boys is a difficult aspect. Even worse, in traditional nations like India, it to tell the patient that their oropharyngeal cancer is caused by oral sex with several partners and is HPV positive presents severe ethical dilemma to the treating doctor [32].

# **Treatment Costs**

Cancer requires an accurate diagnosis so that a definite plan of treatment can be decided upon [33, 34]. The basic treatment of HNC involves surgery and cycles of radiation and chemotherapy. The cost can range from Rs 27,702-Rs 4065,409.2 for treatment with cetuximab [35]. Additionally, advancements in the treatment of cancer have led to the development of targeted therapies and this has led to the drugs becoming very expensive. Cetuximab, an IgG1 monoclonal antibody targeting EGFR over expressing tumor is clinically useful [36]. However, in the Indian market, the cost of cetuximab amounts to 94,544.4 INR which is onerous even for financially stable families to bear, while for the poor and uninsured patients, this is unimaginable. From financial perspective, when compared to other medical specialties, cancer care is becoming more expensive and professionals should try to keep healthcare costs down while upholding their ethical duty to offer the best care possible for every patient [34–37]. However, the global increase in the national cancer expenditures compels oncologists to look at practise patterns and attempt at reducing the health care cost burden especially for the uninsured patients [34-37]. This presents severe treatment related ethical dilemma for the treating physicians.

#### **Dilemmas in Treatment Decision**

The usual treatment protocol for HNC is surgery, radiotherapy, chemotherapy, hormonal therapy, and immunotherapy [4, 11]. The choice of the above modalities is based exclusively on the tumour characteristics, location, stage and general health. If the tumor is localized with accessibility, and the general health of the patient is good, surgery is opted for with or without the use of radiation [4, 11]. Following surgery, radiotherapy, or chemotherapy [adjuvant chemotherapy] may be used to attain an optimal elimination of the residual neoplastic cells to eradicate the disease and attain a complete cure [10]. On the contrary, if the tumor is quite large, or a molecular analysis suggests that it is an aggressive tumor, then chemotherapy with or without immunotherapy is the preferred treatment[neoadjuvant chemotherapy] [10, 38, 39]. This is primarily done to curtail the chances for metastasis, shrink the tumor and decrease the need for lymph node dissection [10, 38, 39]. An oncologist faces the intense dilemma of choosing between neoadjuvant chemotherapy and follow-up with head and neck conservation surgery.

# Ethical Issues in Patient Education and Informed Consent

Obtaining informed consent is one of the most crucial tenets in the provision of healthcare and bioethics [40]. It is mandatory that the physician must provide patients with the information they need to make an informed decision about a suggested course of medical or surgical intervention through the process of informed consent [41]. In clinics majority of patients prefer that doctors inform them in advance of any dangers associated with diagnostic or therapeutic treatments [31, 42–44]. Although verbal communication is the most convenient means of information transfer, patients frequently misunderstand and/or forget the communications the doctor had with time [45]. In lieu of this, the written consent drafted in the patient's native language that is in lay person's terminology and with simple common words lucidly explaining the treatment process and any potential consequences is always preferred for both patient and the physician's well being [40]. However for the treating doctor obtaining informed consent at times poses severe dilemma as on how much needs to be told to the patient without making them scared and/or depressed and abstain from undergoing the planned treatment [31, 42–44]. Another perplexing situation is when elderly patients with mental illness, dementia, and Parkinson's disease are involved because the issues regarding informed consent and the quality of home care offered are important ethical yet distressing dilemmas the treating physicians must consider [46].

#### **Disfigurement of Face**

HNC and its treatment induce a lot of bodily changes in the persons affected by it. Body image is defined by thoughts, feelings, and perceptions about the body and its functions [47–49]. Visible changes begin to appear in the areas of the head and neck which can negatively impact the patient's body perception [48]. Vital functions such as breathing, speaking, and swallowing can be affected. Surgical treatment of the affected part leading to tracheostomy, or an amputated facial area (eyes or nose) can affect the contour and expression of the face. Radiotherapy may induce swelling, and fibrosis, and alter skin pigmentation [48, 50]. Patients undergo distressing emotional transitions from being the constant eye of unwanted attention of others who look at them because of their disfigurement, and painful, or itching sensations that they may have [47-50]. Even though the patient becomes resilient to such situations more insight into such experiences of the patient is needed. Body image distress profoundly affects the health-related quality of life of the patient [47-50]. This is so because it affects the identity of the person and may weigh on social relationships and sexual problems because these individuals no longer feel sexually desirable or attractive [49].

HNC treatment modality is primarily based on a definitive diagnosis, accurate staging of the tumor, and then, depending on the size and location either a partial or whole debulking of the tumor to prevent the spread of cancer and improve patient survival [47-49, 51]. Surgical excision however alters the cosmesis and the image of the individual in society [49]. It may cause functional changes that may affect the psychological well-being and quality of life of the patient [47-49]. This almost inadvertently leads to discrimination, stigmatization, and rejection from the family and society [47–49]. Scars on the head and neck may affect the sexual life of the individual because it may make the person lose their self-esteem [47–49]. Unmarried individuals' face a dearth of future marriage prospects and yet still in the case of some patients who are married, may get disowned by their spouse and their family. Addressing a specific body disfigurement is a perplexing issue for the treating oncologist or surgeon especially if the patient is young, the chances of a complete cure are high and chances of marital discord or breakdown are a high possibility [47–49]. This is further aggravated when interplay of issues that are less discussed in a traditional society like marriage, sexuality, fertility, and procreation poses an ethical dilemma to the treating oncologist on how to efficiently handle and address it [21].

# **Treatment-Induced Side Effects**

It has often been reported that cancer debilitates the affected person and that at times the treatment associated side effects can compromise the therapeutic benefit the curative modalities have bestowed [52-54]. Curative therapy is accompanied by a multitude of side effects that materialize over a period of months or years and maybe after the planned treatment has been completed [52-54]. Following cancer surgery, the common adverse effects people frequently experience include speech impairment, temporary or permanent loss of one's regular voice, trouble chewing or swallowing, which may necessitate having a feeding tube placed in the stomach.

Patients who get radiation therapy endure considerable short- and long-term side effects and this is dependent on the total radiation dose given, how long it was given over, and which areas were exposed to radiation [54]. Some of the important side effects observed include xerostomia, osteoradionecrosis, pharyngoesophageal stenosis, dental caries, trismus, soft tissue necrosis, oral cavity necrosis, fibrosis, impaired wound healing, skin changes, skin cancer, lymphedema, hypothyroidism, hyperparathyroidism, light headedness, chronic sinusitis, headaches, secondary cancer, and damage to the eye, ear, neurological, and neck structures [54–56].

The development of chemotherapy-induced side effects like cardiac complications like hypertension, pulmonary, and renal damage, immunosuppression, osteoporosis, secondary diabetes, and metabolic syndrome often nullify the therapeutic benefits of curative anticancer regimens completed [52, 53, 57, 58]. Cancer survivors are riddled with these long-term side effects and this compromises their quality of life [52, 53, 57–59]. Cardiac complications may often need lifelong monitoring by an onco-cardiologist to check the progression or aggravation of these side effects [52, 53, 55–58]. These are ethically difficult situations to handle especially when disease-free cancer survivors develop treatmentinduced side effects and the oncologist has to address this.

## Follow-Up Care Dilemma

In cancer care the follow-up visits, where clinical and radiological investigations are performed are essential for addressing treatment side effects, detecting locoregional recurrence and secondary primary tumours [60–62]. This is especially very important in HNC because depending on the primary site and stage, the incidence of local recurrence can vary from < 10% to about 50% and preferentially requires critical observation by more than one professionals and with sensitive, state of the art radiological diagnostics like computed tomography (CT) scan, magnetic resonance imaging (MR), and 18-F-fluorodeoxyglucose positron emission tomography (18-FFDG-PET) [60, 61]. The only aspect

that needs to be considered is that the treating doctor must decide which modality to use and that the baseline imaging examination used for the post-treatment assessment should be the same in the follow up care [60, 61].

Clinically, in HNC patients on follow up the care of adverse symptoms or post-treatment consequences and recurrence/metastasis are always the main focus. To assist the doctors, several guidelines are available at the moment, but those from the National Comprehensive Cancer Network (NCCN), European Society for Medical Oncology (ESMO), Associazione Italiana Radioterapia Oncologica (AIRO), and British Association of Head and Neck Oncologists (BAHNO) are the most commonly used [61]. However, there is not enough data to endorse a single recommendation, and the lack of agreement on the best post-treatment follow-up for patients with H&N cancer is confusing and a management Dilemma [61]. In addition to this, a HNC patient who has been treated also has a risk of acquiring a second primary cancer in the lung or upper aerodigestive tract due to the same risk factors, such as prolonged alcohol and nicotine use, and the extent of follow up care, considered the possibility of exposing patients to needless risks and expenses is again a follow-up care dilemma [61]. In a developing country like India where most patients cannot afford the sequential radiological imaging and treatment responses the treating doctor faces severe ethical dilemma.

## Ethical Issues in Post Treatment Rehabilitation

In HNC, the post-treatment period following the aggressive curative therapy is often typified by a slow process of recovery and improvement, and as a result, the subsequent year/s of survivability are marked by enduring treatmentrelated side effects and declining functional status [52, 53, 57]. Some of the cardinal aspects of importance are radiation induced mucositis, dermatitis, salivary dysfunction, fatigue, dysgeusia and psychological distress [16, 52, 53]. However the biggest aspect that interferes in the post treatment rehabilitation is facial disfigurement caused by surgery and many people experience psychological problems due to altered appearance [16, 52, 53]. The other side effect which affects the rehabilitation is the development dysphagia, which is characterised by difficulty swallowing and passing food through the pharynx and the most frequent long-term side effect of radiotherapy [16, 52, 53, 57, 63-65]. Dysphagia is linked, among other things, to prolonged tube feeding (through nasogastric or jejunostomy), significant alterations in eating habits and social interactions [16, 54, 58, 63–65].

The other important side effect commonly seen is speech being affected when the tumors affected vital sub parts of HN region having a role in speech (like the thyroid, salivary glands, nose, lips, tongue, jaw, maxilla, hard and soft palates, nasopharynx, oropharynx, hypopharynx, larynx, and oral cavity) and cause temporary or permanent speech impairments develops in the patient post surgery, chemoradiotherapy, or a combination of these treatments [16, 54, 58, 63–65]. All these side effects ultimately contribute to a lower quality of life and in worse situation lead to suicide. In India, for the number of HNC patients being treated, the specialists in allied health care who can tackle these post treatment problems are in dearth and patient management for the side effect is challenging. These are morally challenging circumstances for oncologists, particularly when the disease-free cancer survivor experiences treatment-related side effects and needs to be on therapy.

# Handing Over Patients to Other Health Care Professionals

Depending on the curative treatment method used, people who have undergone curative modalities for HNC may experience a variety of systemic, physical and psychological health problems and require long-term care from a nononcologic specialistlike physician, gynocologist, endocrinologist, cardiologist, speech therapist, dietician, physiotherapist or occupational therapist and psychologist [59, 66, 67]. The treating oncologist is morally obligated to take the initiative and participate in their care of patient for their non-oncological illnesses [67]. In this sense, the treating oncologist will be exclusively responsible for directing the patient to a qualified, compassionate, and ethical specialist. Finding the option to refer the cancer patient to a non-oncology specialist presents a significant challenge for treating cancer doctors, particularly when the patient comes from a rural area where general healthcare, the most basic requirement itself, is lacking and the patient is in urgent need of adjunct non-oncological care from specialists in other disciplines. In India, where there is a severe scarcity of allied health care experts, particularly in rural areas where the prevalence of HNC is high, these are highly difficult circumstances that raise serious moral and ethical questions for the treating oncologists.

# **End-of-Life Issues**

Patients with HNC typically have a dismal prognosis and depending on the general health, the tumor's stage and location, between 30 and 70% of patients survive five years, while those with incurable illness have a short median survival time [68, 69]. The end-of-life issues in HNC patients are chiefly dependent on the site of recurrence and or extent of metastasis to the various vital organs like brain, liver,

or lungs [68, 70]. EOL symptoms like pain, dyspnoea, laboured, loud and rapid breathing, and delirium, and drowsiness, sounds of moaning and groaning are all extremely stressful for the patient's family or primary healthcare provider [70]. It is the duty and responsibility of the treating doctor and healthcare professionals like nurses and counsellors to prime and prepares the family members to comprehend the progression of the disease and make them realize that it is inevitable [71, 72]. The challenge however is to decide whether to withhold or withdraw life-sustaining treatments and to determine passive euthanasia. This could severely aggravate the ethical dilemma and moral distress.

In EOL situation, medical interventions like artificial nourishment and respiratory support can lengthen people's lives by providing secondary assistance [73]. However, the choices involving resuscitation, mechanical breathing, artificial nourishment and hydration, terminal sedation, withholding and withdrawing therapies, euthanasia, and physician-assisted suicide are the key situations that cause ethical challenges for healthcare workers [71-73]. From and bioethical perspective, it is crucial to communicate about endof-life care and decision-making throughout the final few months of a person's life [74]. This is principally because multiple reports do affirm that, people with advanced cancer are less stressed and are better able to handle their condition if they talk to their treating doctor early about their treatment options [74]. Also patients are happier when they and their doctor have an honest discussion about options for end-oflife care early in the course of their illness [74]. However, the patients' desires conflict with family carers' choices of not to inform the patient of the condition. In these situations the health care staffs are subjected to severe ethical dilemma especially on how much patient involvement is to be allowed in clinical decision-making.

#### **Care of the Elderly**

The aggressiveness of HNC advances with age and with it increases the ethical challenges for an oncologist while treating patients. The choice of appropriate treatment and further discussions with the patient is exhausting to the physician [20, 75]. This holds, especially for elderly people with co-morbidities. The human body dynamics and organ functioning are altered in the geriatric population [20, 75]. The functional efficiency of the various vital organs of the body like the heart, kidney, liver, gastrointestinal system, and brain is in the phase of decline [76]. The pharmacokinetics and pharmacodynamics of any drug, particularly antineoplastic agents that are intended for administration may vary drastically in the elderly [76]. The treatment and monitoring become more arduous when the patient is afflicted with comorbidities like hypertension, diabetes, cardiac, renal, or hepatic issues that could compromise the anticancer drug's bioavailability, metabolism, and excretion thus potentially endangering the functioning capacity of the organ [76]. In addition to this, special care is to be maintained to prevent drug-drug, drug-food, and any adverse drug events because they can be life-threatening to the already ailing geriatric patients further compromising their general health [76]. Hence, the drug regimen, dosage calculation, and sequencing for the proposed antineoplastic drugs need to be curated accordingly by the treating oncologist.

Coordinating with other physicians who handle nononcological ailments needs to be prioritized to prevent the over dosage of any drug and its resulting toxicities [76]. Elderly patients with mental illness, dementia, and Parkinson's disease present another puzzling scenario because the issues of informed consent and the calibre of the provided home care present important ethical yet upsetting dilemmas that the treating physicians must take into account [46]. At times the treating doctors will have to treat an elderly without any family caregivers. Planning oncology treatment for these orphans is challenging. The issue is further complicated when the caregiver is the spouse and has multiple co-morbidities that affect self-care and carrying out routine household activities [77, 78]. Under these situations, the doctor hasto use both his moral and medico-social judgment for the benefit of both patient and the caregiver. These are ethically demanding and although the patient comes first the treating doctor will have to deal with the complicated environment of the patient as well as the elderly spouse with geriatric syndromes.

#### **Confidentiality and Privacy**

Medical ethics is fiercely guided by ethical principles. It is of utmost importance to respect and uphold the patient's rights, dignity, and confidentiality [79–81]. This is assured keeping in view the patient's religious sentiments and cultural beliefs. The treating doctor and the hospital have the responsibility of safeguarding the patient's privacy and confidentiality and this forms the basis of any doctor-patient relationship [79–81]. The right to privacy and confidentiality are of paramount importance as it helps vulnerable individuals to avail sustained and stress-free treatment. Breach of confidentiality is a grave violation of an individual's human rights. It encroaches on his privacy and can cause psychological distress leading to emotional agony [79–81]. It could threaten social aspects like his job which could culminate in financial loss to the patient.

Ensuring confidentiality on the patient's ailment and treatment details including the possible outcome which is collectively termed "Protected Health Information" is mandatory and should not be disclosed to any unrelated person without the consent of the patient or next of kin. They should be informed and assured of all the precautions that the doctor and the healthcare institution adopt to keep their details entirely confidential. The hospital should ensure that the identifiable data in hard copy files or the electronic medium are well protected and have stringent policies in place to prevent any risks of information being leaked [79–81]. Failure to prevent this can subject the doctor or the institution to face legal consequences that can go severely punishable by law. Disclosure of personal information would subject the patient and their family to unfathomable mental trauma.

# **Covid and HNC**

The outbreak of coronavirus pandemic [COVID-19] was an unanticipated issue and presented severe dilemmas for healthcare specialities across the streams but with more severity to otolaryngology and oncologists [82–85]. The COVID-19 virus was a major problem for the medical professionals caring for patients with HNC principally because of the need for extra safety measures and to limit the possibility of aerosol-forming procedures like while doing biopsies, endoscopic examination and surgery involving the upper aerodigestive tract safeguarding the patient, the medical team, and the community from COVID-19 [84, 85]. In these situations striking a delicate balance to be able to give patients the right care and safeguarding the employees who deliver it and their family members back home was inexplicably a very severe dilemma for most intervening physicians and otolaryngologists. In the early days of Covid, all surgical interventions were put on hold and alternative modalities like radiation and chemotherapy was preferred [84, 85]. The delays in diagnosis, surveillance or treatment all had serious implications thereby affecting prognosis and survival [82–85].

During Covid pandemics "Public Health Ethics" superseded the "Clinical Ethics" and emphasis was predominately on safety of the population than individuals [86]. For professionals who cared for HNC, to observe and accept this paradigm change was challenging and dilemmatic [82–85]. Also unlike in the past, lack of accessibility (due to lock down), healthcare or financial resources had a major role in preventing the patients choose the course of care and physicians at providing them and this discrepancy was severe in the developing countries [82–85].

The Covid pandemic presented an extra layer of difficulty for both people affected with cancer and for cancer healthcare professionals. The total block on transportation and shutdown impacted patients from reaching for hospital services [82–85]. During peak pandemics, to accommodate COVID-19-related situations, oncological treatments had to be requisitioned at numerous general and medical college hospitals, and complex medical operations had to be scaled back [82, 83]. All these events impacted cancer patients the most, and the interruption of care combined with delaying the start of treatment and its continuance led to rapid progression and accelerated death from cancer. Also, people with cancer and those receiving treatment were more likely to develop severe forms of COVID-19, and this feature

ETHICAL ISSUES IN HEAD & NECK CANCER Multidisciplinary Cancer health facets education Screening Distributive justice Adverse drug reaction Prohibitory Head & Neck costs cancer Confidentiality Innovations Privacy Economic issues End of life issues Covid and Sedation Analgesia Head & Neck Breaking cancer bad news Fertility Disfigurement Care issues

**Fig. 1** Schematic representation of the various ethical issues plaguing health care professionals in the treatment and care of head and neck cancer patients presented a serious ethical dilemma and moral harm to the medical staff [84, 85]. Another significant ethical problem was the frequency with which healthcare personnel and their families suffered consequences while performing their duties [82–85].

During the early stages of the pandemic, surgical procedures were postponed as so many surgeons and personnel contracted the infection and some of them succumbed from it [82, 85]. This caused dread and confusion over whether or not to "treat or not to treat." Also in the absence of guidelines and restrictions against performing elective surgery numerous operating rooms and ventilators were reorganised to accommodate the COVID-19 patients [82, 85]. All these events impacted patients, particularly those with earlystage cancer, for which surgical excision is the best course of action for a full recovery. From a clinical standpoint, the difficulty of performing elective surgery and delaying it raised serious ethical problems [82, 85]. While surgery was postponed, moving to neoadjuvant chemotherapy or radiotherapy raised the chance of disease progression and unwarranted adverse effects from the treatment, which in some cases proved fatal. Additionally, it was important to take into account that chemotherapy was immunotoxic and raised the risk of COVID infection [82, 85]. Additionally, during the lockdown, there was a forced restriction of antineoplastic pharmacological therapies due to the decrease in pharmaceutical drug manufacture and transportation [82-85]. Additionally, a lot of clinical trials that were in progress were stopped; depriving the subjects of any potential health advantages [82-85]. Worse, when patients needed to be put on a ventilator, choosing a Covid patient who was cancerfree over a cancer patient or a healthy cancer survivor was likely the most difficult and morally challenging decision for many medical professionals and resulted in severe moral injury [82-85].

# Conclusion

Medical science has advanced through leaps and bounds and with it has come the intense pressure to uphold ethical principles in clinical decision-making. The article has made attempts to tackle the ethical issues in patients afflicted with HNC and has been represent in a schematic way through Fig. 1. Decisions guided by bioethical principles allow the incorporation and application of the various principles in ethical decision-making that can benefit the patient greatly and give them a chance to live with improved quality and standard of life.

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