

## *Review*

# **End-stage head and neck cancer coping mechanisms**

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### **Abstract**

Coping mechanisms are patients' means of adapting to stressful situations and involve psychological and physical changes in behavior. Patients adapt to head and neck cancer in a variety of ways. Head and neck cancers are extremely debilitating, especially in advanced stages of the disease or in end-of-life situations. While an oncology team needs to address the needs of all oncology patients, the advanced terminal patients require special attention. Most of these patients do not cope well with their situation and have a tendency to cease social interactions. Pain is the most frequently experienced medical disability in patients having an end-stage illness experience, and thus an important medical endeavor is to afford dignity to the dying patient facing an incurable disease. In such cases, the medical community should never refuse therapy or to assist a dying patient. In some instances, the patient and family may derive benefit from their religious beliefs.

**Keywords:** palliative care, advanced terminal stage, death, psychological status



## Introduction

Coping mechanisms are patients' means of adapting to stressful situations and typically require psychological and physical changes in behavior. "Bad news" typically leads to stress, anxiety, and depression and may instigate significant life changes for patients, relatives, and friends. Head and neck cancers are extremely debilitating, especially in advanced stages of the disease and in end-of-life situations.

While the oncology team must address the needs of all oncology patients, advanced terminal patients require special attention. Most head and neck cancers are squamous cell carcinoma having various levels of differentiation. Supportive and palliative oncology therapy is intended to relieve patient suffering. A poor or often fatal prognosis is frequently anticipated by head and neck cancer patients and their families, with presentation of the diagnosis typically relegated to the specialist. Patients experience a variety of emotions before and after receiving the diagnosis, and even when considered well adjusted individuals, they may experience emotions ranging from shock, denial, anger, negotiation, and acceptance to depression, anxiety, and even suicidal tendency. A multi-stage psychological model for grief iterates some of the coping strategies patients use when given life changing or threatening news (1).

The presence of a tumor relapse or skin and soft tissue lack of substance, the association with necrosis and bad smell, purulent secretions, the presence of a tracheostomy or a naso-gastric feeding tube, along with the aesthetic scarring, all result in decreased self-esteem and severe impediments to social reintegration. Thus, head and neck cancer patients suffer poor coping ability and a lack of social interaction, often leading to social isolation.

## Discussion

### *Coping with pain*

Pain is common among end-stage head and neck cancer patients. It is also the most frequent medical disability patients in end-stage illness experience and is one of the most important concerns for the care-givers. Most patients with this condition anticipate death (2, 3). An important medical goal is to afford dignity to a dying patient facing an incurable disease. Some patients view themselves as useless and a burden to family, friends, and even society. Thus, in an attempt to end psychological and physical suffering, they often have extremely low adherence to the therapy plan.

Pain management is the primary goal of palliation for end-stage head and neck cancer patients, and it should be continued until the patient's death in order to minimize suffering. Thus, a physician should never refuse therapy or assistance for a dying patient. Pain caused by malignant neoplasia is debilitating and is a major cause of stress, anxiety, and depression which by themselves may augment physical manifestations of pain. Clinical manifestations of pain are translated into altered psychological status even before the start of the oncology therapy (4). Pain distorts the patient's personality, behavior, mood, reasoning, and coping. This vicious cycle may be managed by drug use and psychological counseling (5-7). Medication is administered by the oncologist after revision by the tumor board.

The etiology of pain in cancer patients depends on the site of the primary tumor and the local or distant site metastasis. Pain is a complex process that starts in peripheral nerve terminals and has a central nervous system projection and integration. Although understanding the underlying complexity of pain mechanisms is not the concern of the physician, pain

therapy approaches can be determined by establishing gross models, such as idiopathic, nociceptive, neuropathic, psychogenic, or mixed disorders (8). Tumor growth generates somatic pain due to tissue injury of the bones, cartilages, and soft tissue of the head and neck, and is the most common type of pain related to head and neck cancers. Neuropathic pain due to abnormal peripheral or central nervous system stimulation is considered responsible for as much as 40% of pain syndromes related to cancer (9). While psychogenic pain is difficult to differentiate from idiopathic pain, the therapy plan is the same for both. Psychological factors may contribute to pain syndromes when the patient exhibits excessive negative thought patterns (10), although psychogenic pain seldom appears in head and neck cancer patients. Furthermore, patients tend to experience pain differently depending on the site of palliative care (11). Some studies indicate that patients with end-stage cancer prefer to suffer and die in a comfortable environment, usually their own homes (12, 13).

#### *Nutrition status impairment*

End-stage head and neck cancer patients often experience a critical decrease in their oral intake of fluids and solid food, and this impoverished nutritional status may further induce anxiety and depression. Furthermore, the development of late-stage head and neck cancers makes oral feeding impossible due to the localization of the primary tumor in the upper aerodigestive tract. The imbalance of fluid and solid food intake needs to be corrected by administering nutrients through a naso-gastric feeding tube, a classical or a percutaneous gastrostomy tube, or by parenteral feeding. Mixed nutrition, enteral and parenteral, should be used if the gut is functional but the necessary amount of nutrients cannot be achieved through enteral feeding alone.

Lack of appetite is another major concern for the oncology team, a result of the overall biological status of the patient, sedation, metabolic imbalance, or altered mental status. As a well-fed patient copes better with the disease, nutrition status should be addressed as soon as possible. Not only is the quality of life better for patients who are able to feed themselves and appreciate the taste of food and beverages, but physicians and family are less anxious when a patient is able to feed himself, as most associate lack of food intake with advanced terminal illness. However, according to several authors there are no significant scientific data to support the idea that better nutrient intake increases functional and metabolic status or prolongs survival. Other studies even suggest that neither enteral nor parenteral nutrition should be used in terminally ill patients (12-14).

The physician usually informs the family about the ongoing process of end-stage disease and reviews any decline in food and fluid intake. In most cases family and friends experience significant distress when the patient reaches this stage. Dehydration may be a decisive factor that augments suffering and hastens death in end-stage head and neck cancer patients. If oral or enteral administration of fluids or rehydration solutions is impossible, parenteral fluid administration is required. Whether parenteral rehydration in end-stage illness has benefits on quality of life, survival, and improving dehydration symptoms is still being debated. In a series of studies, various authors have noted no differences between treatment and control groups regarding parenteral rehydration (14).

One of the most important problems caused by oral intake impairment is that drugs must be administered through feeding tubes or parenteral catheter. Such is the case for pharyngoesophageal junction malignant neoplasia in which the digestive tract is entirely occupied by tumor mass. Care-givers need to ensure

timely administration of drugs for end-stage head and neck cancer patients by non-oral routes (15).

#### *Physician-patient relationship*

During disease diagnosis and evolution, patients may find themselves progressing through a variety of psychological stages. Coping mechanisms are used by patients to overcome difficult hurdles, with both coping strategies and emotions changing over time. The interval between receiving the initial diagnosis and the end-stage condition is characterized by emotion shifting and depends on the patient's character and support from care-givers, family, and friends. Head and neck cancer patients need to adapt their decision making processes and mental/psychological status as they face a curable or an incurable disease. A positive attitude towards overcoming the disease is sometimes replaced with disbelief and abandon, leading to a relatively high number of patients that eventually neglect their illness and search for a spiritual resolution.

Patients adapt to head and neck cancer in different ways. Although the cancer has multiple forms and stages, the attitude and psychological profile of the patients may not differ all that much. A number of studies have assessed the psychological processes and physical manifestations of cancer patients, thus enabling physicians to better understand the mental strategies patients use to cope with the life threatening disease (16). Some studies have investigated cancer patients' need for information, concluding that each individual has a different approach to the problem. Most patients, however, are interested in medical data about their diagnosis, the therapy plan, second choice therapy, time interval for complete therapy, prognosis, and therapy consequences. Despite positive attitude towards dealing with their disease, patients often search for medical opinions that afford more hope for sustaining their

functional status, thus electing less invasive therapies despite being recommended for intense, optimal oncology therapy. Such instances reiterate the importance of the physician-patient relationship and the need for the medical team to earn the patient's trust to ensure adherence to the therapy regimen. The medical team must balance the pros and cons of withholding facts from the patient concerning the disease and the point at which the specialist fully informs the patient of the details. The appropriate time to give the patient the necessary information should not overlap with the time line for receiving the therapy. The patient's projection of the disease should be shaped by the physician in terms of optimal therapy without interfering with the patient's self-determination. The perception of the disease tends to modify over time, although it may show stability during a particular phase of disease (17).

#### *Relatives and social support*

Several studies have noted the importance of social support in developing good coping mechanisms for cancer patients. This support may prevent or decrease stress, anxiety, and depression and helps patients adhere to multimodal cancer therapy. Head and neck cancer patients represent a special category regarding family and social support, due to the fact that their suffering is highly visible.

As the disease progresses, some patients refuse treatment, denying the inevitable. Patients that have refused primary oncological therapy typically show a poorer psychological profile and impaired coping mechanisms. Social support for end stage head and neck cancer patients should involve the presence of an integrated medical system that offers the patients both hospital and home assistance. In some cases, however, family and friends are sometimes either incapable of dealing with the situation or may overreact in their

support of the patient. There are situations in which patients avoid any encouragements and support from their family, which can lead to lack of control over their own medical condition. This might be extremely distressful for the patients and can lead to depression and isolation in cancer patients (18, 19). At the same time, facing an end-stage disease can destabilize entire families due to intense emotions of grief, disbelief, and emotional burn-out. The functionality of relationships within the family coping with an end-stage head and neck cancer member is based on love, emotional attachment, respect, and the capability of dealing with end-stage illness decision making.

### *Spirituality*

Religious belief and seeking spiritual guidance are common among head and neck end stage cancer patients (20). Because religiosity in some societies is more prevalent among those of lower social/socioeconomic status (21), religious belief may play an important role particularly for these patients. Spirituality, even though less prevalent nowadays, helps some people cope with their disease and may afford them additional hope (20, 22). In recent years, however, patients appear to rely increasingly on the scientific advances of modern medicine than on prayer and faith: among younger patients with end-stage head and neck cancer, "God's will be done" has often been replaced with "Is there any medication that can help?" In fact, patients often hope for a "magic" pill that can bring relief from their pain and suffering. The absence of religious faith may, for some, lead to greater suffering along with feelings of despair and hopelessness, which negatively affects coping mechanisms (23). Several studies have attempted to integrate a spiritual approach with medical services, with results suggesting a decrease in the need for highly invasive surgical interventions during palliative care

(24). As various religions worldwide offer different perspectives regarding the end of life, patients may be affected quite differently by their religious tenets.

## **Conclusions**

Psychological impairment is common in end-stage head and neck cancer patients. Cancer affects the whole body, resulting in the patient's loss of a sense of integrity. Patients react idiosyncratically to threats regarding their way of life and eventual death, with reactions ranging from positive coping actions to unreasonable, desperate reactions. Physicians may need to evaluate the psychological values and needs of their patients to better understand the processes that drive the decision making regarding cancer.

The physician-patient relationship influences the patient's ability to cope with the disease. Physicians need to respect the rights of the patient and the principle of self-determination, and dignity in the face of suffering and death should be ensured for the life-ending patient. Furthermore, the physician should show respect for the family and their social, cultural or religious beliefs, especially in situations of where low health literacy, lack of education, or deprived socio-economic status may be factors.

Palliative care can be received by head and neck cancer patients in E.N.T. departments, intensive care units, or in the intimacy of their home. Although end-stage head and neck cancer patients receive health care services throughout their life-threatening disease, they often benefit from spending their last days in a comfortable environment such as their home.

Surgical intervention for end-stage head and neck cancer patients may be necessary to open airway passages, stop hemorrhage and abscess formation, and ensure adequate feeding/nutrition. Essential drugs to

control pain, nausea, anxiety, and upper respiratory tract mucolysis should be prescribed as soon as needed, while non-essential drugs and enteral and parenteral supplements should be discontinued.

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