

Psychological And Psychosocial Implications Of Head And Neck Cancer

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Abstract

Cancer can have a devastating effect on individuals and their families. Head and neck cancer can be particularly difficult because of the possibility of disfigurement and functional impairment. Psychosocial issues facing the head and neck cancer patient are numerous and include: coping with the initial cancer diagnosis, adjustment to living with cancer and the treatments involved (including difficulties with speech, eating and drinking, and sexual adjustment), depression and anxiety. The patient must also often confront issues with a spouse and family, facial disfigurement, rehabilitation, and for the terminal cancer patient, accepting death. It is recommended that additional psychosocial research and patient education efforts continue in order to assist head and neck cancer patients and their families.

INTRODUCTION

The diagnosis of cancer can have a shattering impact upon individuals and their families. Head and neck cancer is especially traumatic emotionally because of disfigurement and functional impairment resulting from both the cancer and its treatment. Unfortunately, there is scant research on the psychological and psychosocial implications of head and neck cancer. Although some studies have considered the psychosocial issues of the head and neck cancer patient, comprehensive research in this area has not been conducted. Numerous concerns exist from a psychological perspective for the head and neck cancer patient, including the reaction to the cancer itself, the threat to one's mortality, body image issues, fears of treatment (surgery, radiation, and chemotherapy) and potential disfigurement, family, social and vocational issues, and normal psychological responses such as anxiety and depression.

THE HEAD AND NECK CANCER DIAGNOSIS

The psychosocial effect of cancer on the patient is both profound and varied, depending upon the individual's basic personality, coping strategies, support system, and numerous other factors. The diagnosis of cancer often evokes a sense of overwhelming discouragement, depression, fear, anxiety, and numerous other human emotions. Frequently patients seek an explanation for the cancer. They are often plagued by fears of death, loneliness, separation, body image changes, loss of control, loss of identity, disfigurement, and

the unknown (Pattison, 1967). Anxiety is a disturbing experience, and therefore a series of defense mechanisms may evolve to provide protection from that overwhelming sense of fear (Schnaper & Kellner, 1986).

Various defense mechanisms may be used. A frequently employed and often effective initial means of coping with the diagnosis of cancer is denial. Denial represents an unconscious defense that actually prevents an individual from seeing an unpleasant or difficult situation, particularly with regard to self. Numerous techniques are used by patients in an effort to provide this type of defense mechanism: Some patients intellectualize regarding their illness. Some may withdraw, while others employ humor as a means of coping. Still others may vent anger at people and things other than the disease.

A well-known study by Greer et al. (1979) researched the relationship between psychological factors and disease outcome. Their research led to the identification of four coping styles among patients with a diagnosis of cancer: the denier, the fighter, the stoic, and the helpless/hopeless patient. Of the four coping styles identified, fighters and deniers were significantly more likely to have a favorable outcome of their illness. Greer and associates hypothesized that the psychological coping mechanisms used by patients affected their disease outcome.

Deniers were described as exhibiting little emotional

expression after diagnosis and as tending to minimize the illness, often to the extent of believing that perhaps their test results belong to someone else. Such patients are often able to maintain a denial of the illness and submit to medical treatment merely to please family and physician. It is theorized that as long as the denying patient is receiving adequate medical attention, urgent acceptance of the reality of the disease is not important and, in fact, may be harmful to that patient.

The other type of patient who experienced a favorable outcome was the fighter. The fighter is characterized by emotional expressiveness, which seems to assist him or her in the ability to cope. Such patients may present as sad, discouraged, anxious, or even combative toward the medical staff following the diagnosis. Initially they may be pessimistic about the outcome. If told there is a chance of beating the disease, however, they may adopt the attitude that they can fight and defeat it. These patients often want to become involved and active participants in their treatment. While they may be difficult to deal with because of their aggressive or combative tendencies, their ability to express emotions is important to their prognosis.

Stoic acceptance was identified as another coping strategy employed by cancer patients studied by Greer and associates. Stoics display characteristics somewhat similar to deniers, often showing little emotion; the difference is that stoics internally experience a great deal of anxiety regarding the illness, yet their personalities prevent them from expressing these feelings. The stoic facade protects friends and family and perhaps even the physician from knowing the amount of emotional pain which the patient is experiencing. These patients often live in isolation, feeling internally depressed and receiving little support and nurturing. Sleep difficulties and depressed mood in contrast to a more comfortable or positive exterior may be clues to the possibility of a stoic coping style. These individuals function best when provided with encouragement to express their physical and emotional needs, and referral to a mental health professional may be extremely helpful.

The fourth coping style recognized by Greer and associates is that of the helpless or hopeless patient. This coping mechanism is correlated with poor disease outcome; however, these patients may appear overly compliant during the early stages. They often adopt the attitude that things are over for them, and it is only a matter of time. These patients present an attitude lacking in hope. They are often difficult to motivate and may have difficulty following treatment

recommendations because they are pessimistic and feel that they are going to die regardless of treatment response. It was recommended that these patients be given permission to communicate their pessimism and therefore perhaps lessen their despair. The patient who is hopeless, overwhelmed, lethargic, and carries a flat affect should be considered for referral for psychotherapy. These patients may also benefit from anti-depressant medication (Telfer & Shepherd, 1993).

The impact of the diagnosis of cancer is far-reaching. For some people, it can be an opportunity for great personal growth. Simonton and colleagues (1989) conclude that it is important to address the spiritual dimension in understanding and caring for patients with cancer. Some people feel that their diagnosis is a punishment from God. Others may question why God allowed it to happen. They may also wonder what they have done to deserve this devastating diagnosis. When a cure is not possible, providing the opportunity for spiritual reconciliation on the patient's part is often important. Recognition of spiritual and psychosocial relationships and interdependence will result in a more holistic approach to dealing with the head and neck cancer patient. Patients with head and neck tumors often face a difficult rehabilitative process because of the importance that society places on physical appearance, physical ability, and overall ability to function. Tumors in the head and neck region often result in numerous obstacles to adjustment. Medically, there may be more physical symptoms, the cancers may be more advanced at the time of diagnosis, and the treatments (surgery, chemotherapy, or radiation) may pose a risk to the integrity of the face. Additionally, loss of the ability to enjoy intrinsic pleasures, such as eating and speaking, can require an extremely difficult adjustment.

ADJUSTMENT TO HEAD AND NECK CANCER

A number of factors are very important in the adjustment to head and neck cancer. Some primary factors that must be considered include the threat to one's life, decisions regarding treatment, the effects on body image, vocation, and sexuality, as well as difficulties associated with feeding and speech. Other psychosocial issues of importance to the head and neck surgery patient include self-concept, pain, physical limitations, speech, sensory deficits, nutrition, odor, financial concerns, and the effects of radiation. Additional issues involve the resistance to resume self-care activities, psychological stressors which may impede functional rehabilitation, fatigue and loss of appetite, and assessment of the patient's spiritual needs. Difficulties with speech, eating, and sexual adjustment face the head and neck cancer patient

and should be considered in assisting the patient in his/her adjustment.

DIFFICULTIES WITH SPEECH

Verbal communication plays a major role in one's life style, and when it is distorted by surgical treatment of head and neck cancer, the patient often feels a very real sense of loss. Following surgery, artificial speech can be attained in the laryngectomy patient, and important predictors of successful speech rehabilitation relate to problem-solving behavior, age, and marital status/support system. When speech impairments result from reconstructive procedures, this deficit or loss of a primary means of expression can be devastating. Quality of speech is often compromised and vocal expression related to routine, special and emotional situations may be sacrificed. Understanding and patience are needed to assist the patient in overcoming this difficulty.

DIFFICULTIES WITH EATING AND DRINKING

Changes in the ability to eat and drink in a socially acceptable fashion are often difficult issues for the patient. Many patients require an altered diet, which is often blended and relatively tasteless. Some patients will separate themselves entirely from the ritual family meal. Aside from the physical difficulties and embarrassment encountered in eating with radically altered and sometime insensate mouth structures, patients often experience altered taste sensation, which reduces the enjoyment formerly associated with eating and drinking. This is frequently a difficult loss for the patient physically, emotionally, and socially. Encouragement from friends and family can prove helpful to the patient facing these difficulties.

SEXUAL ADJUSTMENT

Due to body image concerns as well as concerns about odor and disfigurement, sexuality becomes a major issue with which the head and neck cancer patient and his or her spouse or significant other must deal. Couples often report ceasing a physical relationship following treatment for head and neck cancer. It is possible that such cooling of physical desire may be coincidental, since other factors may also be at work. Some additional factors associated with human sexuality as they relate to head and neck cancer include alcohol, aging, depression, and facial appearance. Broaching the topic of sexual function early by allowing the patient to know that it is appropriate to focus on this concern and also that the health care team is willing to address this issue helps to assure that this problem will be adequately addressed.

DEPRESSION AND ANXIETY IN HEAD AND NECK CANCER PATIENTS

Depression may present as an early symptom of cancer, even developing prior to the diagnosis (Brown & Paraskevas, 1982). Davies, Davies, and Delo (1986) attempted to ascertain levels of anxiety and depression in patients undergoing diagnostic investigations for head and neck cancers. Patients who attended a regional head and neck oncology unit were evaluated for depression and anxiety before a diagnostic biopsy. Patients whose biopsies subsequently proved positive for tumor had significantly higher depression scores than those with a negative biopsy. Anxiety was also evaluated in this study, but there was no difference between groups with respect to anxiety. Following the diagnosis of head and neck cancer, depression is a common manifestation which should be treated aggressively and appropriately (Telfer & Shepherd, 1993).

Psychological difficulties, in addition to adversely affecting quality of life, may interfere with treatment and rehabilitation in patients suffering from head and neck cancer. Higher levels of fatigue are often reported, and the fact that depression and somatization may be issues for the head and neck cancer patient dictate that the psychological needs of the patient be carefully evaluated (Jones, Lund, Howard, Greenberg, McCarthy, 1992).

THE PATIENT'S SPOUSE AND FAMILY

Families of head and neck cancer patients often express concerns. According to Mah and Johnston (1993), the most frequently cited concerns of families include cancer and its meaning, social relations, the hospital experience, treatment, and future placement. Findings indicated that the caregiver's age and state of health may have an impact upon the concerns expressed. In addition, caregivers may have chronic illnesses themselves. Results of this study also indicated that the caregivers' concerns about their role may have an impact on their own health. A need for support for caregivers during rehabilitation was evident.

In another study, Gotay (1984) investigated the experience of cancer on patients and their mates. Some of the fears described included the fear of the cancer diagnosis, future ability to perform family functions, general emotional disturbances, the effect of illness on employment, the possibility of a terminal illness, restrictions on activities, side effects of treatment, and concerns about the family's future. Various coping strategies were employed, and among the primary strategies reported in this study, taking firm

action was most frequently reported by both patients and their mates in early as well as advanced stages. Patients and their mates also attempted to cope by seeking more information, talking with others, and attempting to find something favorable about the situation. They reported praying, making use of faith and hope, and trying to forget the situation. In another study evaluating the effects of laryngectomy on female spouses, Kommers and Sullivan (1979) reported that a need for improved family counseling existed both before and after surgery. Within the family system, the diagnosis of cancer of the head and neck or other sites affects not only the patient but other family members as well. The impact of this diagnosis on the family system is a challenge which should be adequately addressed during all phases of treatment and rehabilitation.

FACIAL DISFIGUREMENT AFTER CANCER TREATMENT

Van Doorne, Van Waas, and Bergsma (1994) made several observations regarding the coping of cancer patients who suffered facial disfigurement. They observed that the patient's fear of dying of cancer was intense, often overshadowing the fear of facial disfigurement. As the fear of possible death diminished, the process of accepting the mutilation was able to begin. It also seemed important for the patient to establish a revised self-image. In essence, this refers to the fact that the best time to assist patients in returning to their careers or social activities is probably after they have accepted the facial disfigurement. Encountering relatives and friends poses special concerns for some patients. The immediate family frequently provides an important support system, usually reacting with compassion. The reaction of others may be varied, and conflicting reactions from others may confound the patient's coping process. Additionally, patients who experience facial disfigurement can find a medical setting frustrating, especially if they encounter delays, scheduling difficulties, or lack of empathy from the medical staff. Continuity and continuous exchange of information among team members may assist the patient in his recovery.

Van Doorne et al. (1994) concluded that the process of adjustment to facial disfigurement is extremely difficult from a psychological perspective. The patient must cope first with the possibility of imminent and premature death and then must accept the fact that his or her face may be disfigured and people will respond differently. Facial disfigurement is a particularly difficult challenge to adjustment because the face is in a visually prominent area

of the anatomy, it reflects animation, intellect, and emotion, and it serves as a means of communicating with others. Unfortunately, society's emphasis on physical attractiveness may impose additional burdens upon the individual who suffers facial disfigurement or dysfunction following surgery. Part of a complete recovery involves a complex process described as body image reintegration, which occurs gradually over time as the patient learns to accept and compensate for anatomic alterations (Dropkin & Scott, 1983).

Many factors should be considered in looking at reintegration with respect to body image following head and neck cancer:

1. age,
2. sex,
3. marital status,
4. previous body image acceptance,
5. the extent of structural and functional loss,
6. extent of disfigurement,
7. state anxiety (indicative of anxiety at a particular time),
8. trait anxiety (an overall measure of one's general level of anxiety),
9. previous emotional stability,
10. ability of the individual to engage in self-care activities, and
11. the patient's self-acceptance in a social situation.

THE TERMINAL HEAD AND NECK CANCER PATIENT

It is often difficult for the medical community to cope with the problems of the terminal cancer patient. Many terminal cancer patients will spend their last weeks of life in a hospital or hospice. Some questions the patient and family must consider involve the preferred place of death, which may depend upon the absence or presence of family members or support persons and the ability of the patient to care for himself or herself. Many emergency hospital admissions are occasioned by intractable pain, change in mental status, airway distress, or poor nutritional status. In

general, the terminal cancer patient will experience significant pain; however, various indicators suggest that good pain control is possible for most patients (Shedd & Shedd, 1980). The head and neck cancer patient facing the final days will need appropriate management of terminal cancer pain, and the family would benefit from the support of the medical team.

According to Elizabeth Kubler-Ross (1969), preparation for death involves several stages, among them denial, rage, bargaining, depression, and acceptance. While these stages are only a guide to understanding and may not occur always in the same order, most individuals experience each stage as they go through the process leading up to acceptance. The physician/medical team can assist both patient and caregivers to better understand this process. Sometimes referral to a mental health professional is beneficial in assisting patient and family as they cope with the emotional stages of grief and the relevant issues at each stage.

PSYCHOSOCIAL REHABILITATION OF THE HEAD AND NECK CANCER PATIENT

Special areas of importance when thinking about the head and neck cancer patient have been identified by Lou Coté at the Department of Medical Social Service, University of Texas System Cancer Center at M.D. Anderson Hospital (1978). Coté recommends that the following factors associated with psychosocial rehabilitation be considered:

1. Patients have the right and responsibility to ask questions and receive honest answers, so that they can make the best possible decisions regarding quality of life and treatment;
2. It is necessary to consider the characteristics common in this population of patients, and it is observed that difficulties such as alcoholism, family conflict, difficult work histories and lack of satisfying personal relationships tend to recur among this population. When these difficulties are combined with illness, adaptation may be difficult for the patient.
3. It must be recognized that not every patient can be successfully rehabilitated. It is necessary to establish unique and individual goals for each patient.
4. It should not be assumed that the more radical the procedure the greater the psychosocial adjustment. Patients who hold a good self-image and have

good strategies for managing and coping with stress are likely to make a successful adjustment to radical surgery. Unfortunately, the dependent and insecure patient who bases self-worth primarily on physical appearance may have an extremely difficult time adjusting to disfigurement associated with surgery, even if it is relatively minor.

5. The attitude of those individuals involved with the patient is of great importance. Avoidant reactions or expressions of sympathy that could be interpreted as pity can increase a patient's fears concerning rejection.
6. The reactions of family members will have an influence on a patient's adaptation. When patients are encouraged to regain a sense of independence, the support of family is essential. As with the patient, family members must make their own psychological and social adjustments.
7. When working with head and neck patients on a daily basis, it is easy for caregivers to take some things for granted. Therefore caregivers should remember that the patient is dealing with issues associated with disfigurement, speech impairment, social isolation, employment considerations, loss of sexuality, pain, and discomfort. (Coté, 1978).

EDUCATION AND SUPPORT OF THE HEAD AND NECK CANCER PATIENT

Several dilemmas confront the head and neck cancer patient. The threats recognized by Cohen and Lazarus (1979) include threats to life, the unmarred body, self-concept, emotional balance, fulfillment of customary social roles and activities, and the threat from the medical setting. Maintaining emotional balance and pursuing social roles and activities are essential tasks for the head and neck cancer patient. In fact, consenting to undergo a mutilating operation carries an implicit request for survival at the cost of disfigurement.

It is the opinion of numerous experts that coping should be regarded as a process (Cohen & Lazarus, 1979; Koster & Bergsma, 1990). The rehabilitation process for head and neck cancer is often lengthy and involved. Many patients are faced with long hospitalizations and unpredictable treatment results. Individuals often require speech therapy, vocational therapy, occupational and physical therapy, and dietary management as well as surgery, chemotherapy, and radiation. They also may need psychotherapy, family

therapy, or some other type of supportive therapy to assist them in coping. The demands of all these rehabilitation efforts frequently lead patients to feel that rehabilitation has become their primary responsibility in life.

SUMMARY

Issues associated with the head and neck cancer patient are far-reaching, and the ramifications of treatment often extreme. Therefore it is important for patients, caregivers, and medical staff to understand the many facets of adjustment to cancer and the impact of treatment on the patient's quality of life as well as its medical impact. Psychological support is often necessary in assisting these patients to make a successful adjustment to all the difficulties they will encounter as a result of the illness. Even long-term survivors report difficulties in coping, and therefore caregivers must remember that patients make a lifetime adaptation when undergoing treatment for head and neck cancer. Because their lives are changed, they must make appropriate personal changes in order to assist them in ensuring the highest possible quality of life following treatment.

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