Head and Neck Cancer: Historical Evolution of Treatment and Patient Self-Care Requirements

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The purpose of this literature review is to explore the historical progression of treatment and its impact on care requisites in patients with head and neck cancer. Head and neck cancers are some of the most visible types of cancer. Patients often experience difficulties in self-care because of problems adapting to and coping with the diagnosis and disease management. Evaluation of the literature from the 1960s to present indicated a shift from coping with disfigurement to focusing on dysfunction and rehabilitative self-care. The process of assisting patients with self-care activities occurs from the time of diagnosis through post-treatment and beyond. Adapting to and coping with changes in physical appearance and function begins with the cognitive decision to initiate treatment modalities specific to the cancer site. Current knowledge of the manifestations of head and neck cancer provides the healthcare team with a better understanding of the disease trajectory and how best to assist patients in adapting to and coping with changes affecting their quality of life.

Head and neck cancer is a disease process that occurs in a visible way. Cancers in this region are defined as malignant tumors involving structures located above the clavicle and within the aerodigestive tract of the face and neck (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009). Bony structures, glands, organs, and soft tissues can be involved. Treatments often alter the structure, function, and appearance of the head, face, and neck area.

Treatments for patients with head and neck cancer include surgery, radiation, chemotherapy, or some combination. Each treatment option can potentially cause disfigurement and dysfunction, leading to difficulty adapting to changes (related to appearance or inability to perform activities of daily living), coping problems, and diminished quality of life.

Surgery entails physical insult by instruments; manipulation; and removal of bony, glandular, and soft tissue structures; and is contingent on the location and stage of the tumor (Harish, 2005; Hudgins, Kingdom, Weissler, & Mukherji, 2005). Tumor and cancer dissection are labeled radical, modified, or selective. Levels of dissection are not only dependent on the location of the tumor, but also depth, size, differentiation, vascular or perineural invasion, and metastasis (Saikawa, 2010). Any surgical procedure invades the tissue and can cause disfigurement and dysfunction because of scarring, organ and structure manipulation, and disturbance of the senses.

Radiation entails treating the cancer area with external radiation therapy. Radiation therapy has an acceptable morbidity rate and virtually no systemic ramifications with good control of most early lesions (Harish, 2005). Adverse side effects include skin reactions, redness or rash, and skin dryness that are visible to observers, as well as functional disturbances leading to mucositis, dysphagia, dental and salivary gland changes, speech disturbances, radionecrosis, and humoral- and cell-mediated immunity suppression.

Chemotherapy is the systemic treatment of cancer cells with various pharmaceuticals. IV chemotherapy may cause disfigurement because of port location, as well as nail, skin, or tooth discoloration and hair loss. Chemotherapy-related dysfunction includes multiple symptoms related to the inability to swallow or speak (List et al., 1999).

The head and neck area is a focal point of all individuals and is the outward presentation of any individual, whether asleep or awake, animated or inanimate (Callahan, 2004). Expression of self includes communication (verbal and non-verbal), emotions (visible and non-visible), feelings (expressed and suppressed),...
and senses (active and inactive). The communicating face is a complex myriad of muscles, structures, and nerves. Changes in the face because of treatment transform the individual whole being, owing to adjustments to accommodate routine activities of daily living. The stressors created by these changes affect the person’s sense of self, ability to cope, and quality of life (Callahan, 2004).

Past literature had focused on disfigurement in the care of patients with head and neck cancer as a source of maladjustment and discord with the coping process, thereby decreasing the individual's quality of life. Early studies (1970–1997) emphasized patient concerns of facial disfigurement associated with head and neck cancer surgery (Bowers, 2008; Callahan, 2004; Dropkin, 2001; Koster & Bergsma, 1990). Surgical procedures before 1990 created highly visible changes in facial appearance. Studies conducted prior to 1997 upheld pretreatment concerns around disfigurement, distress, anxiety, and coping difficulties in patients during and after therapies (Fingeret et al., 2012). Initial care of these patients focused on the nurse role in assisting in grooming and basic hygiene in the early postoperative period. Studies found that individuals experienced a reduction in anxiety and stress, facilitating the ability to perform increasingly arduous tasks (Dropkin, 1997, 1999, 2001).

Since the late 1990s and early 2000s, treatment has shifted away from radical surgical procedures to less invasive chemotherapeutics and radiation treatments, resulting in less insult to facial structure and appearance. The emphasis on functionality means incorporating rehabilitation activities at time of diagnosis and after treatment, with the intent of mitigating alterations in function and activities of daily living. Rehabilitation programs use therapeutic swallowing maneuvers and speech modalities to improve function and health outcomes of individuals while reducing feelings of anxiety and stress associated with head and neck cancer treatments.

The purpose of this literature review is to explore the historical progression of treatment and its impact on care requisites in patients with head and neck cancer. This compilation of the literature is designed to help nurses and other healthcare providers better understand the impact of the disease process, treatment effects, and coping strategies used by patients developing effective self-care behaviors toward their head and neck cancers.

**Literature Review**

A literature search of PubMed, CINAHL®, and PsycINFO was conducted using the following key words: *head and neck cancer*, *surgery, radiation, chemotherapy, disfigurement, dysfunction, adaptation, quality of life, self-care, coping, rehabilitation, and health behaviors*, which resulted in a total of 80 articles. A critical review of the reference lists provided an additional 24 articles for consideration. A total of 24 articles were included because they contained one or more keywords searched and spanned from 1960–2012. Studies that met inclusion criteria focused on adaptation patterns, coping behaviors, quality of life, and self-care behaviors of patients pre- and post-treatment (single or multimodal therapies) for head and neck cancer. Articles were excluded if they were not published in peer-reviewed journals, conducted outside of the United States, or written in a foreign language. Articles that focused on psychosocial and psychological care, cancer programs and services, cancers other than those in the head and neck, families and caregivers, and pediatric patients also were excluded from the review.

Of the 24 articles in this review, 12 focused on patient outcomes associated with disfigurement and self-care practices after radical procedures and less-invasive treatment strategies. Many of these articles are classic studies in medicine and nursing from when research in this area was very limited. The other 12 articles from 2006–2012 demonstrated the shift in focus from coping and adaptation from disfigurement to functional and rehabilitative care following treatment.

**Historical Perspectives**

Dissection of head and neck cancers was described first by Crile (1906), who initially performed neck dissections for tumor removal. The challenging procedure involved extensive surgical removal of the cancer beyond tumor borders, significantly invading adjacent structures such as neurologic, musculature, or glandular tissues. Radical dissections created severe disfigurement and dysfunction, and were the primary treatment modality of the head and neck cancer population. In the 1960s, changes in surgical procedures, prompted by these invasive dissections, yielded a “variety of new methods” (Saikawa, 2010, p. 2) identified as functional and selective neck dissections aimed at decreasing disfigurement and improving function.

Additional improvement in preservation of function and decrease in disfigurement occurred with the inclusion of radiotherapy and chemotherapy in this population. These therapeutic options are currently the initial standard of care for organ preservation (Patel & Shah, 2005). Although these treatment options preserve organ and tissue sites, they still may cause disfigurement and dysfunction. Defined disfigurement related to radiation and chemotherapy is seen in fibrosis of the skin and soft tissues, edema, appearance of port site, and discoloration of teeth and nail beds; symptoms such as mucositis, xerostomia, and pain may contribute to dysfunction identified as dysphagia and impaired speech.

These dramatic alterations in physical appearance and function can significantly impact the individual’s quality of life. Quality of life is described as “a person’s perception of his/her ability to function in meaningful areas of living after illness as compared to before illness” (Onakoya, Nwaorgu, Adenipekun, Aluko, & Ibekwew, 2006, p. 765). Quality of life is a dynamic process that frequently changes. Individual perception of one’s image of self is related to the person’s cognitive understanding of who they are, how they physically appear to others, what they are able to physically do, their behavioral and emotional patterns, and their social inclinations and habits (Callahan, 2004).

**Disfigurement in Head and Neck Cancer**

The groundbreaking work of Dropkin (1997, 1999, 2001) focused on the impact of disfigurement of patients with head...
and neck cancer as a source of stress and inability to cope, thus affecting quality of life. Coping is defined as the ability to handle and control environmental and internal needs and the conflicts between them which exhaust an individual’s mental reserves (Koster & Bergsma, 1990). These threats are (a) life, (b) the unmarred body, (c) self-concept, (d) emotional balance, (e) fulfillment of customary social roles and activities, and (f) the medical setting (Koster & Bergsma, 1990). According to Callahan (2004), emotion-focused and problem-focused coping combine to create adaptation (maladaptation) or adjustment (maladjustment) in the patient. The ability to cope with these physical changes influences one’s quality of life. Dropkin’s (1997, 1999, 2001) research played a key role in understanding the challenges experienced by patients with head and neck cancer.

Body image is defined as “the dynamic perception of one’s own bodily appearance, function, and sensations, as well as feelings associated with this perception” (Dropkin, 1999, pp. 309–310). Those perceptions are mostly subconscious thoughts, which are regulated by changes in the body (Dropkin, 1999). Superimposed on the concept of disfigurement is the inability to perform normal routine activities of daily living visible to the outside world. The face is the most visible representation of an individual, incorporating two-way audio and visual communication with others. The coping process is influenced by the patient’s level of anxiety, cognitive abilities, and self-care behaviors. Dropkin’s (1999) study found that individuals experienced a reduction in anxiety with the inclusion of self-care practices during the early postoperative period. Elevated preoperative anxiety levels have been shown to decrease a person’s ability to effectively cope after surgery (Dropkin, 2001). Self-care activities concentrated on participating in basic hygiene and grooming for the person with disfigurement from head and neck cancer (Dropkin, 2001). Early implementation of self-care practices postoperatively helped diminish anxiety and stress so that more laborious tasks that demanded increased psychomotor skills were more readily achieved by patients.

Functionality in Head and Neck Cancer

Although significant correlations between quality of life and level of disfigurement were identified in these early studies, the physical dysfunction experienced by patients became a critical component in their ability to effectively cope with the treatments for head and neck cancer (Krouse, Krouse, & Fabian, 1989). People diagnosed with head and neck cancers are altered by the disease, its treatment, and its impact on daily activities. Physically, these individuals are threatened by the inability to swallow, taste, and speak, as well as their psychosocial well-being (Onakoya et al., 2006). The primary focus on disfigurement left a persistent gap in understanding the ramifications of these treatments, and attention shifted from coping and adaptation related to surgical disfigurement toward symptom management and functional impairment in the patient with head and neck cancer (Ahlberg et al., 2011).

The impact of the disease and its treatment on the quality of life of patients is seen in problems such as an inability to effectively communicate (Rogers, 2009), altered physical and psychosocial outlook (Fingeret et al., 2012), depression or anxiety about presenting health conditions, loss of self-esteem, loss of social interaction, and uncertainty about the future (Arunchalam, Thirumooorthy, Devi, & Thennarasu, 2011). Altered functionality has been identified in essential activities such as mastication, deglutition, phonation, speaking, tasting,olfaction, and vision. The late 1990s through early 2000s saw an increase in studies on quality of life and functional abilities of patients with head and neck cancer. Important social issues for this patient population included the ability to speak and be understood in public (De Boer, McCormick, Pruyn, Ryckman, & van den Borne, 1999). Bowers (2008) referred to the value of identifying patient needs prior to treatment and providing additional information to help the person and family prepare for these outcomes. Identifying functional challenges prior to and after treatment allows the individual the opportunity to plan, procure, and commence an individualized rehabilitation program.

Current literature identified dysphagia and impaired speech as two areas of dysfunction during pretreatment, treatment, and post-therapeutic rehabilitation. The evidence supporting speech dysfunction was identified in a study conducted by Borggreven et al. (2007), where patients with a diagnosis of advanced oral or oropharyngeal cancer scored worse on speech and oral function tests related to quality of life prior to treatment. The specific speech and oral function abnormalities seen in patients were intelligibility (17%) and articulation (37%).

Dysphagia has a profound impact on the quality of life of these patients. The reality of increased patient survival post-treatment warrants additional investigation of this functional impairment (Ahlberg et al., 2011). Swallow impairment identified through clinical assessment and instrumental evaluation confirm that inadequate swallowing ability prior to treatment leads to greater risk of chronic swallowing dysfunction after treatment. Disability related to reduction in functional capacity is common in patients with head and neck cancer after treatment (Ahlberg et al., 2011; Raber-Durlacher et al., 2012). Health-related quality of life can be improved during the early rehabilitation period by reducing functional impairment (Raber-Durlacher et al., 2012). The education of patients shortly after diagnosis of head and neck cancer and prior to treatment also can have a positive effect on quality of life (Ahlberg et al., 2011; Kulbersh et al., 2006). Carroll et al. (2008) conducted a study that demonstrated improved function after treatment when pretreatment swallowing exercises were used. Pretreatment swallowing therapeutic modalities such as Mendelson’s maneuvers, Shaker exercises, tongue hold, tongue resistance, and Falsetto phonation significantly improved post-treatment swallowing function in the areas of posterior tongue

Implications for Practice

- Use less-disfiguring techniques for the treatment of head and neck cancers.
- Plan teachable moments for patients and families that occur around the time of diagnosis and initiation of treatments.
- Educate patients on maintaining functional status through specific self-care skills to help them effectively cope with cancer and improve their quality of life.
base position (p = 0.03) and epiglottis inversion (p = 0.02) in this patient population (Carroll et al., 2008). The willingness of the patient to engage in self-care tasks helps reduce functional impairment, improves quality of life, and extends survival (Ahlberg et al., 2011). Creating individualized programs, such as those described in these studies, can improve future functionality, health outcomes, and quality of life of patients with head and neck cancer.

Conclusions and Implications for Nursing Practice

Head and neck cancer is unique in terms of the visible disfigurement and significant functional disturbances affecting speech and swallowing compared to other cancers. Quality of life and individual well-being are disrupted by the damaging effects of these types of cancer and their treatments on the person’s speech and ability to eat and swallow (Handschel, Naujoks, Hofer, & Krüskemper, 2013). Changes in treatment options starting in the 1970s have evolved from radical dissections to organ and site preservation. Head and neck preservation is an appealing concept to patients who have been diagnosed with the visible disease process that exposes their illness and vulnerabilities in a transparent and deliberate way, but functional disabilities still occur. Historically, the treatment process of this population was recognized as disfiguring and led to multiple levels of dysfunction. The negative impact of these changes prompted healthcare professionals to proactively provide reassurance and guidance throughout the adjustment process, educate on self-care practices, and assist with resocialization into the family and community. Initially, studies of patients with head and neck cancer were limited in number and size. However, those early studies provided valuable information about adaptation during the postsurgical period and the benefits of initiating self-care tasks designed to facilitate coping strategies that might improve one’s quality of life.

With the advent of new treatment techniques, the life span of patients with head and neck cancer has been extended and the extent of disfigurement has decreased. Studies of symptom management and dysfunction have led researchers to investigate the functional status of these patients following treatment. Recognizing functional changes that occur at the time of diagnosis and after treatment provides an important opportunity for nurses to focus teaching strategies on the most critical areas to these patients and their families. Nurses play a pivotal role in instructing and supporting patients during the pre- and post-treatment periods and throughout recovery. As studies found, patients benefit from information about their cancer diagnosis, functional status, and expected health outcomes prior to treatments. The value of informing patients based on their ability to understand and integrate materials within a realistic period of time encourages hope and planning for the future (Rogers, 2009). Adapting to the stressors of diagnosis, treatment, and treatment outcomes is a self-regulatory task that, when studied, will provide increased understanding of the experiences of patients with head and neck cancer in relation to quality of life. Evaluation and assessment by speech and language pathologists, as well as physiotherapists, are necessary for effective rehabilitation to occur.

Patient perspective around the diagnosis and management of head and neck cancer is essential to the treatment-planning process. Patient acceptance of self-care management and rehabilitation plans can improve survival rate, reduce morbidity, and improve quality of life (Rogers, 2009). Educating patients on how to maintain their functional status through specifically designed self-care skills enables them to most effectively cope with their cancer, adjust to these changes, and improve their overall quality of life. Based on this literature review, additional investigations on the rehabilitation process for patients with head and neck cancer are needed. By better understanding functional problems that are most troublesome to patients, clinicians and researchers can work on developing and testing rehabilitation therapies that are most beneficial in optimizing treatment outcomes and enhancing quality of life.

References


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References


Crlis, G. (1906). Excision of cancer of the head and neck with specially reference to the plan of dissection based on 132 operations. JAMA, 47, 1780–1786.


