FEATURE ARTICLE

Laryngectomy: Beyond Loss of Voice—Caring for the Patient as a Whole

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A diagnosis of laryngeal cancer is devastating, both for patients and their families. They must face decisions about complex treatment choices, the potential for disfiguring surgery, and possible mortality. The American Cancer Society (ACS) estimates 8,900 new diagnoses of laryngeal cancer in 2002, representing approximately 1% of cancer diagnoses in men and 0.3% of cancer diagnoses in women (ACS, 2002). Although not the most prevalent cancer diagnosis, the unique physical and emotional treatment sequelae for patients with laryngeal cancer make this disease particularly significant. For patients who require laryngectomy, anxiety about preservation of function and quality of life (QOL) may be especially distressing—and may be even more so for their families.

Although a laryngectomy is a relatively routine procedure, the patient population that often presents requiring it is anything but routine. Significant alcohol and tobacco use commonly are associated with a diagnosis of laryngeal cancer, which can predispose to a “stormy postoperative period and lengthy rehabilitation” (Byrne, Walsh, Farrelly, & O’Driscoll, 1993, p. 174). To some degree this defines the stereotypic characteristics of patients with laryngeal cancer: significant alcohol use, coping skills, marginal economic resources, and poor familial or social support all may be relevant issues. However, not all patients with laryngeal cancer fit this profile, and, as a result, considerable variability can be found in their coping mechanisms. The stress induced by such invasive treatment as laryngectomy is likely to exaggerate deficiencies in coping skills, rather than improve them. Poor compliance in this population also may contribute to difficulty postoperatively (Kunkel et al., 1995).

For patients with laryngeal cancer, rehabilitation following laryngectomy may be difficult. However, significant variability in coping skills and adaptation of this patient population exists. Healthcare providers commonly perceive disfigurement, alteration in function (i.e., loss of natural voice), and disease control as the most relevant issues in the postoperative period, yet patients and their families may not share these same priorities. Management of physical symptoms, social reintegration, participation in enjoyed activities, and vocational issues following laryngectomy may present significant barriers to achieving optimal quality of life. Comprehensive preoperative counseling that includes patients and their caregivers is an important aspect of preparation for surgery. This review examines dimensions of adaptation, rehabilitation, and quality of life following laryngectomy.

As an oncology nurse, postoperative care and follow-up of laryngeal cancer postlaryngectomy appeared to be a defined course, with the usual multidisciplinary interventions (e.g., speech therapy, occupational therapy, nutrition, social services), but as the daughter of a man who underwent laryngectomy, apprehension and uncertainty predominated. As a result, determining what is known about adaptation to alaryngeal life and what can be done to promote successful transition in such a challenging patient population became paramount importance. What follows is a literature review encompassing many aspects of perioperative care and long-term outcomes. No amount of preoperative counseling fully prepares patients or their families for the aftermath of such a devastating surgery. Despite the obvious impact on self-image and self-expression (laryngectomy leaves patients without the ability to shout, whisper, cry, or be heard), distress also may be experienced at unanticipated moments (e.g., holding a spoonful of soup to the mouth and finding no breath to cool it). Cons cientious assessment of patients’ coping mechanisms, social situations, risk factors, and systematic rehabilitation efforts with ongoing counseling and support may improve outcomes for many patients who are experiencing great difficulty following laryngectomy.

The Aftermath of Surgery

A number of studies have been conducted to evaluate QOL and functional outcomes of patients who have undergone laryngectomies. However, success in achieving esophageal speech is often the primary outcome measure. Few studies have evaluated other dimensions of functional outcomes, such as returning to work, resuming previous activities of interest, interacting successfully in social situations, and functioning in a family dynamic.

Olsen, Rohe, Perry, and Keith (1995) evaluated 148 patients being treated for laryngeal cancer (i.e., by total, near-total, or partial laryngectomy) in the preceding 3–48 months. Although many patients reported good adjustment to their cancer surgery (i.e., 71% in the total laryngectomy group and 84% in the near-total laryngectomy group), negative impact on work, spousal and familial interactions, sexual interest and performance, and financial concerns were reported; this indicates that even though patients may be able to meet clinical rehabilitation goals (e.g., being able to talk and eat), for some, their day-to-day lives still may be affected profoundly.

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Some indication exists that a gradual improvement in QOL occurs that may stabilize about two years post-treatment. Deleyiannis, Weymuller, Coltrera, and Futran (1999) reported that many patients continued to experience a variety of functional disabilities two years following laryngectomy, but a significant correlation was not found between the importance of these disabilities and QOL, with many patients reporting the same or better function and general health than one year prior to the diagnosis. Deleyiannis et al.’s findings may not be generalizable because of the small sample size (N = 10) and because survey respondents and disease-free survivors may be physically better off, which may bias them toward a more favorable picture than the entire laryngectomy population. Differences do exist in characteristics between patients who do not survive two years post-laryngectomy because of recurrent disease, surgical complications, or other reasons and those who are able to do well long term.

Perceived stigma and illness intrusiveness have been identified as contributors to compromised QOL following laryngectomy and have been associated significantly with decreased life happiness and increased emotional distress (Devins, Stam, & Koopmans, 1994). Illness-induced lifestyle changes related to social stigma perception may contribute to avoidance of social exchange; in Devins et al.’s study, these lifestyle changes were an important determinant of depressive symptoms, particularly with regard to family relations. Additionally, illness intrusiveness attributable to laryngectomy appeared to have the greatest impact in the domains of work, self-expression and self-improvement, active recreation, and financial situation, all of which contribute to the sense of self-identity, security, and QOL.

Many studies have identified discrepancies between healthcare provider and patient assessments of QOL, indicating that providers may not be aware of the most important concerns for patients (Mohide, Archibald, Tew, Young, & Haines, 1992; Otto, Dobie, Lawrence, & Sakai, 1997). Mohide et al. found that providers ranked communication impairment, self-image and self-esteem, and worry about cancer control as the three most important dimensions of QOL in laryngectomised (in order), whereas patients reported physical consequences and interference with social activities as most important, followed by communication impairment. Similarly, Herranz and Gavilan (1999) reported no significant differences in QOL assessments between patients undergoing laryngectomy with permanent tracheostoma compared to patients who underwent partial supraglottic laryngectomy or cordectomy (with ultimate stoma closure and preservation of voice). This suggests that loss of natural voice and permanent stoma may not be the primary factors affecting long-term QOL following laryngectomy. Olsen et al. (1995) and Schuler, Trudeau, Bistline, and LaFacee (1990) documented similar findings.

**Physical Problems**

Following laryngectomy, patients are left with a variety of physical symptoms, which often are chronic. The impact of these symptoms can be more important to patients than the adjustment to the loss of their natural voices, and when these physical symptoms are ameliorated, some indicate that psychological stress, social functioning, and QOL also improve (McQuillon & Hurt, 1997). This underscores the importance of educating patients about what to expect postoperatively and providing strategies to assist them in self-care upon discharge from the hospital.

Dysphagia (sometimes requiring esophageal dilatation), altered sense of taste, and xerostomia (particularly if patients have had prior radiation therapy) commonly are encountered postoperatively and may present significant nutritional challenges to patients. Patients with xerostomia should pay particular attention to their dental care. A diminished sense of smell may contribute to compromised nutritional status, as well as personal hygiene. Although loss of olfaction may not seem to be an extremely important issue, it can create significant safety problems because anything from irritating fumes to toxic gases may be inhaled directly into the lungs without patients’ awareness. Because this is a critical safety issue, healthcare providers should stress the importance of properly working smoke detectors (Renner, 1995).

Mucus collection around the stoma is a common complaint, as well as increased cough, frequent colds, and difficulty with nose blowing. Patients may be more sensitive to perfumes, dust, and other irritants. An altered ability to protect the lower airway may lead to a sense of vulnerability and fear of water or of covering the stoma.

Significant pain or limitations related to pain have been reported in patients following laryngectomy, and chronic pain in this population is not uncommon (Terrell, Fisher, & Wolf, 1998). Whether this is related directly to the surgery or other comorbid conditions is uncertain.

**Vocational Issues**

Many patients find returning to work difficult following laryngectomy; however, this receives little attention in the literature. Many QOL studies include vocational outcomes in their assessments, yet findings vary as to the number and reasons laryngectomised do not return to work. Some studies have indicated that as few as 11%–30% of patients successfully return to work following surgery (Herranz & Gavilan, 1999; Olsen et al., 1995). Although patients may not return to work because of symptoms, fatigue, or fear of rejection by colleagues and clients, employers may terminate employment or demote patients following surgery. In one study of the impact of head and neck cancer treatment, a greater number of treatment modalities was associated with a greater risk of subsequent work disability (Terrell, Nanavati, Esclamado, Bradford, & Wolf, 1999). Further investigation into outcomes specific to the unique needs of patients post-laryngectomy is needed.

Consultation with social services personnel may provide some support in the workplace by advocating continued or modified employment for patients or by providing referrals to an appropriate vocational counseling or job-retraining agency (Dhooper, 1985). Given the risk for underemployment this surgery imparts and the significant impact this may have on patients’ financial situations and the resulting stress for patients and their spouses, healthcare providers should discuss factors associated with the risk of not returning to work and intervention strategies to help patients meet their full postoperative potential. Preoperative counseling also must address this important issue for patients and families to be adequately prepared.

**Psychosocial Implications**

A number of studies have investigated the immediate and long-term psychosocial implications of treatment for head and neck cancer patients with laryngectomy. Although many report adequate or acceptable psychosocial adjustment following surgery, many others indicate significant continued distress beyond the acute transition period, illustrating large variation in the adaptation of this population. Poor coping or emotional distress may contribute to many ongoing problems, such as difficulty returning to work with resulting financial problems and reduced participation in previously enjoyed activities or social interactions, contributing to depression. Healthcare providers must vigorously support patients in maintaining involvement in important relationships, activities, and interests; promote development of coping strategies; and provide psychotherapeutic assistance in the immediate recovery period following treatment (Devins et al., 1994).
Many psychological symptoms have been reported by patients following laryngectomy, including anxiety, uncertainty, depression, loss of self-esteem, suicidal thoughts, uselessness, shame, irritability, fear of recurrence, and a sense of inferiority (Pruy et al., 1986). Often, the primary concern in the immediate postoperative period is focused on disease eradication and management of physical symptoms, rather than preventing psychiatric morbidity. Although laryngeal cancer has been associated with increased risk of psychosocial stressors, depression, and suicide (Byrne et al., 1993; Shapiro & Kornfeld, 1987), psychological intervention for every patient is prohibitive. However, under-diagnosis of depression and psychological distress may contribute to reduced patient QOL, increased hospital stays, and complications with therapy and may affect patients’ capacity for self-care and even survival (DeBoer et al., 1998; de Leeuw et al., 2001). This highlights the importance of identifying those patients at risk for psychosocial morbidity following surgery to target appropriate interventions.

With successful rehabilitation, depressive symptoms may improve two to three years following surgery; however, rates of depression appear to remain higher in this group compared to the general population (de Leeuw et al., 2001). For many, depression is self-limiting. Clinicians should be careful to monitor for symptoms of major depression, including medical and treatment non-compliance, diminished decision-making ability, behavioral changes, and suicide ideation (Renner, 1995).

One of the most important risk factors identified as a predictor of significant depression following surgery is the presence of depressive symptoms prior to treatment (de Leeuw et al., 2001). Presence of emotional-oriented support, a larger social network, and more openness to discuss cancer within families before treatment are associated with a decreased risk of post-treatment depression. In general, three specific areas should be considered when assessing a patient’s risk for significant psychological disturbance following treatment for laryngeal cancer: patient variables (e.g., history of depression, substance abuse, coexistent medical problems, poor social and family support, limited financial resources, poorly differentiated coping skills, male gender), disease- and treatment-related variables (e.g., extensive or advanced disease, combined modality or aggressive treatment), and communication between patients and the treatment team (McQuellon & Hurt, 1997) (see Figure 1). Hypothyroidism also is a concern as it occurs in more than 30% of patients following laryngectomy—often within the first 14 months (Gal, Gal, Klotch, & Cantor, 2000). Clinically significant hypothyroidism must be identified and treated in patients with a risk for depression.

In the immediate postoperative period, self-care (i.e., performance of basic hygiene and grooming and tasks related to postoperative surgical care taught by the nursing staff) and resocialization (i.e., interaction with staff and visitors, voluntary ambulation out of the room) have been identified as primary behavioral manifestations of effective coping (Dropkin, 1983). Performance of self-care activity also has been shown to precede a reduction in postoperative anxiety levels (Dropkin, 2001). Dropkin (1983) identified postoperative days four and five as being pivotal in patients’ demonstration of acceptance of and participation in self-care postoperatively. Current lengths of hospital stays have shortened since this study was conducted, resulting in increased pressure for patients to adjust and participate in performance of postoperative self-care earlier. This, in turn, reduces the amount of time patients are able to “test out” their new appearance and communication skills (and reactions of others to them) in a relatively safe environment, which reinforces the importance of structured and supportive follow-up interventions in the early postdischarge period. Knowledge of these indicators of effective coping and the expected time frame in which they optimally should occur can be used by the nursing staff to identify patients who are coping poorly and provide more intensive intervention prior to discharge (Dropkin, 1989).

**Figure 1. Predictors of Psychological Disturbance for Patients With Laryngeal Cancer**

Note. Based on information from McQuellon & Hurt, 1997.

Substance Use

Alcohol abuse commonly is associated with a diagnosis of laryngeal cancer, and the stress of diagnosis and treatment or postoperative depression may exacerbate this behavior. Alcohol use following treatment for laryngeal cancer has been reported to be as high as 83%, with a significant number of patients reporting enough use to be considered at risk for additional alcohol-related illnesses (Terrell et al., 1998). Excessive use following surgery may affect well-being and physical rehabilitation. Evidence also suggests that alcohol consumption as an independent variable is a significant predictor of five-year survival (Prader et al., 1993). Although assessment of alcohol as a risk factor during diagnosis and staging may take place, constructive discussion of the impact of ongoing use and evaluation for the need for alcohol rehabilitation prior to laryngectomy in those patients at risk appears to be less common. Successful rehabilitation following laryngectomy requires mastering many novel and complicated tasks (e.g., using an electroarynx, learning esophageal speech) and attentive self-care (e.g., tracheostoma care, attention to nutritional needs) that will be unachievable if patients drink to excess (Renner, 1995). This meticulous attention to self-care required for successful rehabilitation may be challenging, particularly in a population that does not understand the concept of self-care. A paucity of information in the literature exists assessing the impact of alcohol-related comorbidity following surgery or addressing evaluation and intervention for this complicated issue, despite the significant prevalence in this population. Treatment of the primary problem (i.e., substance abuse) is essential to the successful rehabilitation of patients and prevention of comorbidity.

Ongoing tobacco use is another important issue. Although evidence is contradictory regarding the impact of smoking on overall survival in patients with laryngeal cancer (Crosignani, Russo, Tagliabue, & Berrino, 1996; Prader et al., 1993), clearly assessing tobacco habits and encouraging reduction or cessation appear to be of benefit. The potential benefits of smoking cessation, such as improvement in pulmonary symptoms and possible prevention of second primary tumors or other comorbidities, should be explored with patients. A significant body of literature describes the impact of tobacco on the development of laryngeal cancer, but investigation of the impact of tobacco use and benefits of cessation following laryngectomy have not been explored as thoroughly.
Spousal and Familial Impact

The impact of laryngectomy on patients is yet to be fully described; however, the effect of this event on patients’ spouses and families is understood even less. Significant role changes within families may occur as a result of surgery and may strain the integrity of the unit; this can lead to a breakdown in communication requiring counseling intervention (Renner, 1995). High levels of stress and perceived burden have been reported by spouses of patients following laryngectomy and appear to be greatest in the first six months following surgery; a plateau usually is found following the 12-month benchmark (Blood, Simpson, Dineen, Kaufman, & Raimondi, 1994). In one study of patients and their spouses, depression and anxiety commonly were reported in patients three years following laryngectomy; however, spouses reported even higher depression and anxiety scores and demonstrated worse adaptation than patients in several domains (Herranz & Gavilan, 1999). Stressors indicated by spouses of patients with laryngeal cancer included altered communication patterns, financial concerns, and lack of social support (McQuellon & Hurt, 1997). Spousal reports of inadequate preoperative education and counseling and lack of postoperative support as contributors to perceived stress are pervasive in the literature (Blood et al.; Pruyn et al., 1986; Zeine & Larson, 1999).

Spouses or family members may experience guilt or express feelings of responsibility for patients’ illness, particularly if the families believe they “should have done more” to encourage patients to discontinue smoking or alcohol use prior to diagnosis. In families in which a member has a history of alcohol abuse, codependency is a common phenomenon, and family members often assume responsibility for that individual’s problematic behavior (Renner, 1995). Care should be taken to support family members, promote boundary limitations, and focus on dealing with the current problems, rather than assigning blame.

Patient Education

Many studies have evaluated the efficiency of critical pathway implementation to coordinate care of patients after laryngectomy; however, few studies have examined learning needs pre- and postlaryngectomy of patients or their family members or studied patient evaluation of preoperative expectations. Implementation of clinical pathways may shorten hospital stays and reduce readmission rates following laryngectomy (Sherman, Matthews, Lampe, & LeBlanc, 2001). Healthcare providers must ensure systematic and comprehensive teaching and counseling that include both patients and their families. Although reviews of topics to teach patients undergoing laryngectomy often discuss specific tasks (e.g., nutritional strategies, stoma care, suctioning, speech strategies), common symptoms and issues patients may encounter postlaryngectomy and strategies to avoid them are equally important to discuss.

Zeine and Larson (1999) investigated patient and spouse satisfaction with pre- and postoperative laryngectomy counseling. Preoperative counseling was important in facilitating postoperative coping for 84% of patients and 93% of spouses. Provision of additional information about physical changes following laryngectomy (e.g., loss of taste, changes in feeding, mucus in trachea, stoma care) was requested by both patients and their spouses. Spouses also expressed the desire for more information about a number of social changes, such as possible rejection of friends, distancing of children, guidance with insurance, and other financial matters. Of particular interest was the finding that 21% of the patients questioned were unaware that laryngectomy would leave them without a natural voice, clearly indicating the need for more preoperative discussion (Zeine & Larson). Other studies have confirmed general dissatisfaction among a significant number of patients about the effectiveness of preoperative education and counseling in preparing them for the changes experienced postlaryngectomy (Olsen et al., 1995).

Several aspects of care should be addressed with patients and their identified caregivers throughout the perioperative period, including strategies for effective symptom management, assessment of symptom monitoring and report, safety issues, nutritional and speech therapy support, and support with effective coping strategies (see Figure 2). Meeting with a successfully rehabilitated laryngectomee preoperatively (e.g., a Lost Cord Club volunteer) may be a valuable opportunity for many patients and may prove a useful addition to preoperative teaching plans. Ongoing support may be available through a laryngectomy support group. However, offering patients a list of phone numbers or Web sites is not enough; close follow-up and clinical support is essential. The stress of a new diagnosis may limit the retention of some important information; therefore, providing written supplementation of educational materials, such as “patient pathways” (i.e., written patient-education materials designed to chart the expected course of treatment/patient treatment through recovery), for later reference will enhance the learning process and reduce anxiety for many patients (Clarke, 2002).

Physical care
- Tracheostoma or inner cannula care
- Postoperative stoma humidification
- Feeding tube care and alternative nutritional strategies
- Dental care

Symptom management
- Mucus production, increased cough
- Dysphagia
- Xerostomia

Speech therapy
- Electrolarynx
- Esophageal speech
- Transesophageal prosthesis

Safety
- Working smoke detectors
- Advise local emergency medical services that a patient with a laryngectomy is present in their location (address, phone number).
- Keep a hemostat immediately available for removal of mucus or foreign bodies.

Psychosocial and functional considerations
- Assess need for alcohol intervention and advise as appropriate.
- Assess risk factors for inability to return to work and discuss implications with patient and family.
- Evaluate patients’ support resources and learning and coping needs of identified caregiver(s).

Implications for Practice

Healthcare providers must examine their attitudes and biases to offer better patient care. Straightforward counseling and guidance about the difficulties likely to be encountered postoperatively with meaningful strategies to address them may be a good first step in improving QOL for many patients postlaryngectomy. The literature must be expanded and particularly address effective rehabilitation strategies beyond speech therapy. Coping strategies for patients and their caregivers, identifying those at risk for major depression and possibly suicide, addressing alcohol and tobacco use in this population, and promoting vocational rehabilitation all are important dimensions of recovery that deserve more comprehensive research. Additional studies are needed to identify the unique supportive needs of those patients who are single or without familial support and women with laryngectomies. Nurses are the primary source of information and support for these patients; understanding, anticipating, and addressing
their needs is an essential component of promoting successful rehabilitation.

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References


Rapid Recap

Laryngectomy: Beyond Loss of Voice—Caring for the Patient as a Whole

- Implications of laryngectomy for treatment of laryngeal cancer extend beyond loss of voice and alteration of appearance.
- Patients’ partners and family members frequently experience high levels of stress the first year following laryngectomy and commonly report deficient preparation to care for patients (preoperative education and counseling) and lack of support.
- A significant number of patients do not return to work postlaryngectomy; reasons include risk factors and intervention. Counseling strategies are important in assisting patients to achieve their optimal postoperative potential.
- Assessment of continued harmful behaviors (e.g., tobacco and alcohol use), with particular attention to risk for alcohol comorbidity, is important in promoting successful rehabilitation.
- Depression is prevalent postoperatively in this population; although successful adaptation may contribute to improvement one to two years postoperatively, significant psychological symptoms may persist at higher levels than found in the general population.
- Preoperative education and counseling ideally should address both patients and their caregivers and provide guidance as to common symptoms with intervention strategies and acknowledgment of larger issues.