# NO SToPS: Reducing Treatment Breaks During Chemoradiation for Head and Neck Cancer

Colleen K. Lambertz, MSN, MBA, FNP, Jacque Gruell, RN, OCN®, Valerie Robenstein, RD, CSO, LD, Vicki Mueller-Funaiole, RN, MSN, CWOCN®, Karrie Cummings, MS, CCC-SLP, and Vaughn Knapp, MSW, LCSW

The addition of chemotherapy to radiation aids in the survival of patients with head and neck cancer but also increases acute toxicity, primarily painful oral mucositis and dermatitis exacerbated by xerostomia. The consequences of these side effects often result in hospitalization and breaks in treatment, which lead to lower locoregional control and survival rates. No strategies reliably prevent radiation-induced mucositis; therefore, emphasis is placed on management to prevent treatment breaks. The NO SToPS approach describes specific multidisciplinary strategies for management of nutrition; oral care; skin care; therapy for swallowing, range of motion, and lymphedema; pain; and social support to assist patients through this difficult therapy.

oncurrent chemoradiation therapy can result in an absolute survival benefit of 7% at five years when compared with radiation alone in locally advanced head and neck carcinoma (Pignon, Maitre, & Bourhis, 2007). The addition of chemotherapy as a radiosensitizer also adds to acute toxicity, primarily painful oral mucositis (OM) and dermatitis often complicated by xerostomia. The consequences of these side effects include pain, dysphagia, odynophagia (painful swallowing), dysgeusia (distortion or decreased sense of taste), excessive secretions with gagging, nausea, vomiting, loss of appetite, weight loss, dehydration, infection, fatigue, aspiration, and economic strain, often resulting in hospitalization and breaks in treatment (Bensinger et al., 2008; Patel, Abboud-Finch, Petersen, Marron, & Mehta, 2008; Rosenthal & Trotti, 2009).

Unplanned breaks in radiation treatment from toxicity result in lower locoregional control and survival rates in patients with head and neck cancer (Russo, Haddad, Posner, & Machtay, 2008). Unplanned interruptions or modifications of radiation from ulcerative OM occur in 8%–27% of patients and may reduce the tumor control rate at least 1% for every day that radiation is interrupted (Russo et al., 2008). The rate of hospitalization for severe OM increases by 16% with radiation alone and by 50% with the addition of chemotherapy. Higher OM severity increases costs—as much as \$1,700–\$6,000 depending on grade (Sonis, 2004).

To date, no approved agents or strategies reliably prevent radiation-induced mucositis, so emphasis must be placed on management strategies (Rosenthal & Trotti, 2009). To better manage the side effects and minimize the risk of toxicity-related

## At a Glance

- Daily nursing assessment of weight, vital signs, mucosal and skin integrity, signs of infection, secretion management, hydration, nausea, bowel function, and pain management can lead to early detection of complications for patients with head and neck cancer.
- → The goal of early nutrition, swallowing, and psychosocial interventions is to avoid unnecessary delays or breaks in treatment caused by dietary or resource limitations.
- Mucositis and dermatitis management strategies are provided in a progressive, stepwise approach according to standardized rating scales.

Colleen K. Lambertz, MSN, MBA, FNP, is a family nurse practitioner, Jacque Gruell, RN, OCN®, is a staff nurse, Valerie Robenstein, RD, CSO, LD, is an oncology dietitian, Vicki Mueller-Funaiole, RN, MSN, CWOCN®, is an RN, Karrie Cummings, MS, CCC-SLP, is a speech language pathologist, and Vaughn Knapp, MSW, LCSW, is an oncology social worker, all at St. Luke's Mountain States Tumor Institute in Boise, ID. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the *Clinical Journal of Oncology Nursing* or the Oncology Nursing Society. (First submission January 2010. Revision submitted March 2010. Accepted for publication April 4, 2010.)

Digital Object Identifier: 10.1188/10.CJON.585-593

treatment breaks, a multidisciplinary team from St. Luke's Mountain States Tumor Institute in Boise, ID, with five community treatment facilities reaching across 120 miles, collaborated to develop a proactive and unified approach to the care of this challenging patient population. Representatives from radiation and medical oncology nursing; nutrition services; speech and language pathology; wound, ostomy, and continence nursing; and social work developed a comprehensive approach to supportive care based on published guidelines and clinical experience.

Diagnosis:

Implementation of the NO SToPS multidisciplinary approach began in June, 2008, and included all patients receiving chemoradiation for head and neck cancer. The approach focuses on nutrition; oral care; skin care; therapy for swallowing, range of motion, and lymphedema; pain; and social support. The primary goals are reduction in treatment breaks and hospitalizations for treatment-related side effects. Secondary goals include reduction in weight loss and improvement in comfort, all measured by chart review subsequent to full implementation.

# **Team Captains: Radiation Oncology**

Thorough initial assessment, education, and the introduction of available resources to the patients prior to treatment are essential to the NO SToPS approach to successful side-effect management. The radiation oncologist initiates the approach with review of the treatment plan, potential side effects, and, when indicated, the importance of smoking and alcohol cessation with the patient. The radiation oncologist then completes the preprinted head and neck chemoradiation treatment management orders (see Figure 1). Guided by the preprinted physician orders, the radiation oncology nurse coordinates the NO SToPS plan of care from pretreatment evaluation through post-treatment follow-up.

Pretreatment preparation starts with a dental referral for repair or extraction of damaged teeth (Pignon et al., 2007; Rosenthal & Trotti, 2009). Preprinted prescription pads provide dentists with instructions for the evaluation and fitting of patients with fluoride gel trays to wear during radiation treatments. Along with bite blocks, athletic mouth guards, or guaze pads, the empty gel trays may be worn during treatments to help prevent radiation scatter to the tongue and cheek from metal work in the mouth that may increase mucositis (Bensinger et al., 2008). Nightly fluoride gel treatments are recommended during and after treatment to prevent further dental deterioration caused by treatment-related xerostomia (Bensinger et al., 2008; Rosenthal & Trotti, 2009). Alternatively, fluoride varnishes may be applied every three months (Patel et al., 2008).

For more detailed education, each patient is scheduled for radiation oncology and medical oncology treatment learning classes. During these classes, members of the treatment team provide specific information on the treatment process and logistics, side effects, and symptom management in an interactive environment. Patients unable to attend the classes are provided a DVD with the information and questions are answered at a later appointment or by telephone.

Immediate referrals to the dietitian and social worker are ordered for all patients with head and neck cancer. Referral to speech and language pathology occurs immediately if the

Allergies:		
PRETREATMENT		
Dental evaluation  ☐ Fluoride trays for daily use ☐ Fluoride varnishes every 3 months		
Feeding tube insertion  ☐ Radiologist ☐ Gastroenterologist ☐ Surgeon		
Tube feeding instruction ☐ Wound, ostomy, and continence nurse ☐ Home health		
Feeding tube site care  ☐ Wound, ostomy, and continence nurse ☐ Home health		
Dietitian consultation and weekly follow-up		
Social work consultation		
<ul> <li>Neck and jaw range of motion</li> <li>Swallowing</li> <li>Video fluoroscopic swallowing study prn</li> <li>Physical therapy evaluation for neck and shoulder range of motion and strengthening prn</li> <li>Lymphedema management prn</li> </ul>		
Call referral to: Phone: Fax:		
Other:		
<u>ON TREATMENT</u>		
Oral cleansing: Daily spray and weigh per RN		
Skin care: Wound, ostomy, and continence nurse prn		
Amifostine: See preprinted orders		
Other:		
POST-TREATMENT		
Follow-up with nurse practitioner or physician every week x 4		
Spray and weigh per RN every week x 4 prn		
Follow-up with dietitian every week x 4		
Other:		
Figure 1. Head and Neck Cancer Chemoradiation Treatment Management		
Note. Courtesy of St. Luke's Mountain States Tumor Institute. Used wit		

*Note.* Courtesy of St. Luke's Mountain States Tumor Institute. Used with permission.

patient exhibits pretreatment dysphagia or may be deferred until later in treatment or after according to patient need. If xerostomia prophylaxis with amifostine is ordered, preprinted orders guide the radiation oncology nurse in coordination with pharmacy and education of the patient. Finally, daily oral assessment, weight, and saline spray cleansing—called the "spray and weigh"—is scheduled.

#### **Nutrition**

As many as 50% of patients with head and neck cancers exhibit some malnutrition before treatment begins (van Bokhorst-de van der Schuer et al., 1999). Patients with head and neck cancers receiving concurrent chemoradiation therapy have an increased incidence of malnutrition related to side effects that make eating more difficult. Severe weight loss of more than 10% of body weight has been observed in up to 58% of patients with head and neck cancer receiving radiation in the absence of intensive nutrition support (Beaver, Matheny, Roberts, & Myers, 2001; Lees, 1999; Newman et al., 1998). Pain from oral mucositis, nausea, and swallowing difficulties can result in a patient being unable to meet their nutrition needs orally (Murphy & Gilbert, 2009). As a result, inadequate nutrition may impede the healing process and result in weight loss.

Nutrition issues must be addressed early in the course of care and throughout, as patients experiencing weight loss greater than 20% of their total body weight are at an increased risk of toxicity and mortality (Colasanto, Prasad, Nash, Decker, & Wilson, 2005). Research shows that patients who received individualized nutrition care during cancer treatment lost significantly less weight, had a significantly smaller deterioration in nutrition status as measured by the Patient-Generated Subjective Global Assessment score, and had a significantly smaller decrease and faster recovery in global quality of life and physical functioning (Isenring, Capra, & Bauer, 2004).

A thorough initial nutrition assessment is made by a registered dietitian prior to initiation of treatment, including, but not limited to age, sex, weight history, height, diet history, and biochemical profile (e.g., serum albumin, prealbumin, glucose, creatinine). Patients are at high risk of OM if they present with weight loss and dysphagia, are receiving platinum-based chemotherapy, or are receiving radiation to a large-volume tumor. Patients at high risk for significant OM have a gastrostomy tube (G-tube) placed prior to treatment by interventional radiology, gastroenterology, or a surgeon depending on physician or patient preference. Prophylactic placement of the G-tube avoids the need for placement later when the patient has severe treatment-related OM, esophagitis, or immunocompromise, which may require a break in treatment to accomplish (Bensinger et al., 2008; Wiggenraad et al., 2007). The G-tube serves as a means for delivery of nutrition and hydration as the treatment regimen impacts oral intake.

The dietitian follows the patients at least weekly during treatment. Interventions include oral diet modification for comfort, increasing calorie and protein intake, and initiation of enteral nutrition via the G-tube. Ongoing monitoring of tolerance to oral intake, tube feeding, laboratory values, weight, and quality of life related to nutrition is included in the weekly visits. The weekly nutrition visits continue for at least one month after

treatment is completed for continued management of enteral nutrition and to facilitate the patient through the transition to an oral diet. Dietitian follow up continues at increasing time intervals until the patient is able to maintain nutrition status with oral intake. The feeding tube is removed when the patient can safely take oral nutrition and maintains weight for approximately one month without using a G-tube to supplement.

## Oral Care

## The Daily Spray and Weigh

Oral care of patients undergoing chemoradiation for head and neck cancer starts on day one of radiation with the daily spray and weigh. The patient's weight is measured on the same scale every day and recorded. Then oral, skin, and pain assessments are performed by radiation oncology nurses based on the National Cancer Institute's [NCI] Common Toxicity Criteria grading scale for mucositis (Trotti et al., 2000), the Radiation Therapy Oncology Group (RTOG) acute toxicity scale for radiation dermatitis (Dow, Bucholtz, Iwamoto, Fieler, & Hilderley, 1997), and a 0-10 verbal report scale for pain (Cork, Isaac, Elsharydah, Saleemi, Zavisca, & Alexander, 2004). These standardized assessment tools guide documentation in the medical record (Bolderston, Lloyd, Wong, Holden, & Robb-Blenderman, 2005; Bruner, Haas, & Gosselin-Acomb, 2005; Quinn et al., 2008).

The RN then performs a gentle spray oral cleansing with warmed saline every day, either before or after radiation treatment (see Figure 2). The spray cleansing assists with secretion removal, hygiene, and comfort for the patients, and provides the opportunity for reinforcement of patient self-care instructions (Elise Carper, personal communication, January 15, 2008).

Importantly, spray and weigh allows for daily nursing assessment of weight, vital signs, mucosal and skin integrity, signs of infection, secretion management, hydration, nausea, bowel function, and pain for early detection of treatment-related side effects and complications that may result in treatment breaks.



Note. Warmed saline spray cleansing is performed with nursing assessment

## **Figure 2. Spray and Weigh Procedure**

*Note.* Image courtesy of St. Luke's Mountain States Tumor Institute. Used with permission.

Verbal feedback from patients during spray and weigh indicates that the spray is soothing and helps with secretion removal. The daily assessment, early identification of problems, and proactive management also provide a sense of reassurance and safety for this complicated patient population.

Along with the spray and weigh, patients are instructed on oral care basics, including regular use of a soft toothbrush, flossing, and bland rinses such as salt and baking soda four to six times daily (Keefe et al., 2007; Vendrell-Rankin, Jones, & Redding, 2008). Avoidance of trauma from rough, acidic, or spicy foods, ill-fitting oral prostheses, or caustic oral products is encouraged (Bensinger et al., 2008).

Tolerance to therapy and immunocompetence are monitored through serum chemistry evaluation and complete blood counts in conjunction with the medical oncologist. If oral infections occur, systemic antimicrobials are recommended over topical ones. Although benzydamine is recommended to prevent mucositis in patients with head and neck cancer receiving moderate-dose radiation, it is currently unavailable in the United States. Chlorhexidine, antimicrobial lozenges, and acyclovir are not recommended to prevent mucositis because of a lack of benefit in this setting. Similarly, chlorhexidine and sucralfate are not recommended to treat mucositis (Keefe et al., 2007).

## Xerostomia Management

If ordered to reduce xerostomia, subcutaneous amifostine is initiated via preprinted physician orders. Sialogogues (medications to stimulate saliva flow) such as pilocarpine, cevimeline, or bethanechol also may be initiated on the first day of treatment (Bensinger et al., 2008). Side effects of these medications, such as nausea, hypotension, allergic reactions associated with amifostine and gastrointestinal upset, sweating, tachycardia, and blurred vision from sialogues, often are significant, making completion or continuation of these therapies difficult (Vendrell-Rankin et al., 2008).

As secretions thicken with onset of mucositis and xerostomia, mucous thinning agents such as over-the-counter guaifenesin two to three times daily and/or a mucous solvent with menthol, eucalyptol, and a blend of natural extracts and oils often provide a measure of symptomatic relief (Treister & Woo, 2008). Lorazepam may help reduce the gag reflex and gagging on pooled secretions (Bensinger et al., 2008).

Following completion of chemoradiation therapy, xerostomia management focuses on patient comfort and protection from dental caries. Although no ideal saliva substitute exists, many mucosal lubricants are available for the patient's comfort (e.g., Biotene® [GlaxoSmithKline], moisturizing mouth spray or gel, Mouth Kote® [Parnell Pharmaceuticals]). Patients are encouraged to consult with their dentists regarding sugar-free products with the proper pH and remineralizing properties.

Avoiding products and foods with high sugar content and frequent water intake may help decrease the risk of dental caries (Bensinger et al., 2008). Tooth brushing with daily flossing and dental examinations every three months are recommended. Regular application of topical high concentration fluoride treatments on the teeth for life is important. Acupuncture has been found to improve xerostomia inventory scores and physical well-being and is available as part of some integrative therapy programs (Cho, Chung, Kang, Choi, & Son, 2008; Garcia et al., 2009).

## **Skin Care**

The wound, ostomy, and continence nurse is involved in skin management of patients undergoing chemoradiation for head and neck cancer prior to treatment. Skin care is introduced in the radiation treatment learning class, where strategies related to minimizing radiation skin reactions are discussed. Symptom management of skin reactions may be needed by the third week of treatment for erythema and dry or moist desquamation anticipated with this population. In more severe cases, ulceration can occur (McQuestion, 2010). A topical gel containing aloe vera, hyaluronic acid, and a moisturizer is used three times daily to reduce the intensity of skin reactions (McQuestion, 2006).

A skin care protocol (see Table 1) based on the RTOG acute toxicity scale (Dow et al., 1997) guides the nursing staff in early interventions based on daily skin assessments performed during spray and weigh. Dry desquamation may be improved by the use of concentrated moisturizing or emollient agents. Patients may begin treatment of skin discomfort by using a medical grade aloe vera gel or a cream containing 2% lidocaine to soothe burning and itching skin. Treatment of moist desquamation may involve domeboro solution soaks or rinses, protective nonadherent and/or absorbent, or gel-based dressings. Prescription topical antimicrobial products may be required. By following the four-stage grading system, care can be individualized according to symptoms and appearance of the skin during and after radiation therapy.

Patient education on care and use of the G-tube for enteral feeding is provided by the wound, ostomy, and continence nurse; home health nurses; or clinic nurses depending on the patient's situation and the timing of tube placement. To standardize tube education, a feeding tube tool kit is present in each of the outpatient clinics. Education and evaluation occurs during each clinic visit in an effort to minimize feeding tube complications such as cellulitis, leakage, irritant dermatitis of the skin, and tube migration.

# **Therapy**

The speech and language pathologist's role in the care of patients with head and neck cancer who undergo chemoradiation treatment includes assessment and treatment of dysphagia, jaw and neck mobility, and lymphedema. Swallowing problems are a common occurrence among this population and may include dysgeusia, dry sore mouth, trismus (inability to open the mouth), and pharyngeal weakness (Dingman et al., 2008; Nguyen et al., 2006, 2008).

A swallow screen is recommended for every patient early in radiation treatment to identify baseline swallowing difficulties and to implement strategies or perform treatment to reduce or overcome treatment-induced dysphagia or exacerbation of dysphagia. The NO SToPS approach includes assessment of dysphagia that occurs either as a clinical evaluation and/or a video fluoroscopic swallow study. In either case, oral and pharyngeal functioning is observed in detail. Treatment of dysphagia for this subset of patients may include diet modification, strengthening of the oropharyngeal swallow, and/or compensatory strategies that decrease aspiration risk or make swallowing more functional.

Table 1. No SToPS Head and Neck Chemoradiation Dermatitis Skin Care

GRADE	SYMPTOMS	CARE
0 <b>–</b> I	Faint erythema or dry desquamation	Medical-grade aloe gel or hyaluronic acid and no-sting barrier film
II	Moderate to brisk erythema or patchy moist desquamation, mostly confined to creases or skin folds, or moderate edema	Medical-grade aloe gel or hyaluronic acid; moisturizing cream, lotion, or ointment; wound, ostomy, and continence nursing referral; over-the-counter cortisone 1% cream as needed for itching; and aluminum acetate astringent for patchy moist desquamation (rinse off prior to XRT)  Hygiene: handheld shower head  Topical anesthetics: medical aloe gel with lidocaine 2% and medical moisturizer with lidocaine 2%  Dressings: solid hydrogel sheets, hydrocolloid, abdominal pad dressings, telfa, roll gauze, nonadherent dressings, and net holders (tubular roll)
III	Confluent moist desquamation greater than 1.5 cm; not confined to skin folds	Wound, ostomy, and continence nursing referral  Topical: antimicrobial creams, gels (prescription may be required; remove prior to XRT); and aluminum acetate astringent soaks or rinses three times daily (rinse prior to XRT)  Cleansing: antimicrobial wound cleanser  Hygiene: handheld shower head  Topical anesthetics: medical aloe gel with lidocaine 2% and medical moisturizer with lidocaine 2%  Dressings: solid hydrogel pads (remove prior to XRT), hydrocolloid, ABDs, roll gauze, telfa pads, vaseline-coated nonadherent dressings, silicone-based adherent dressings, no-sting barrier film, nonadhesive foams, moisture barrier ointments, and net holders (tubular roll)
IV	Skin necrosis or ulceration of full thickness dermis; bleeding not in- duced by minor trauma or abrasion	Wound, ostomy, and continence nursing referral  Topical: antimicrobial creams, gels (prescription may be required; remove prior to XRT); and aluminum acetate astringent soaks or rinses three times daily (rinse prior to XRT)  Cleansing: antimicrobial wound cleanser  Hygiene: handheld shower head  Topical anesthetics: medical aloe gel with lidocaine 2% and medical moisturizer with lidocaine 2%  Dressings: solid hydrogel pads (remove prior to XRT), hydrocolloid, ABDs, roll gauze, telfa pads, vaseline-coated nonadherent dressings, silicone-based adherent dressings, no-sting barrier film, nonadhesive foams, moisture barrier ointments, and net holders (tubular roll)

ABD—abdominal pad dressing; XRT—radiation treatment *Note*. Based on information from Dow et al., 1997.

Trismus in this population may be caused by surgery, involvement of the fifth cranial nerve, or radiation-induced contraction of the masticatory muscles and the tempormandibular joint capsule (Vendrell-Rankin et al., 2008). Radiation-induced trismus usually occurs three to six months after radiation, but may begin during treatment or be exacerbated by surgical resection, patients' reluctance to open the mouth fully because of painful mucositis, and lack of use of these muscles while unable to eat. Trismus can affect patients' ability to chew or eat, clear secretions, or swallow.

Evaluation of trismus involves measuring the distance between the upper and lower teeth when the patient is opening his mouth as wide as possible. This initial measurement becomes a baseline for treatment. Treatment for trismus may involve the use of a commercially available device that gently stretches the jaw opening incrementally. Patients unable to afford the device may seek assistance for resources from the social worker in their interdisciplinary team. Alternatively, patients may use stacked tongue depressors under the guidance of the speech language pathologist to gently stretch the jaw (Vendrell-Rankin et al., 2008).

The amount of improvement gained with trismus therapy increases when exercises are performed multiple times per day. When maximum range of motion for the jaw is obtained, patients are encouraged to continue to exercises daily to sustain what they have gained and prevent recurrence.

Scar tissue from radiation fibrosis tethers muscle movement in the neck, limiting the up and forward movement of the larynx required for functional swallowing (Chen, 2003). Patients are given illustrated neck range of motion exercises and encouraged to perform the exercises daily to sustain mobility of the neck. If these exercises are not sufficient to maintain mobility, referral is made to physical therapy for more intensive treatment.

Therapy for treatment-related facial and neck lymphedema also can be helpful in decreasing swelling in a radiated neck area and aid in mobility and comfort (Ewald, 1996). Lymphedema therapy is provided by physical therapists specially trained in lymphedema management.

Prior to implementation of routine early swallowing and mobility evaluation, some patients went more than a year with difficulty swallowing. In screening every patient, the goal is to decrease the severity and duration of dysphagia and mobility complications.

## **Pain and Comfort Management**

## **Pain**

Pain is assessed daily during the spray and weigh and is managed with a step-wise approach that begins with topical therapies. Bland rinses such as salt and baking soda are introduced at

the onset of radiation as previously described. Mucosal surface protectants containing calcium phosphate, xylitol, and/or hyaluronic acid may be added. Topical anesthetics containing hyaluronic acid and benzocaine or compounded products with viscous lidocaine, antacid, and diphenhydramine often are used. If these are not sufficient, topical morphine rinses may be offered (Cerchietti et al., 2002). Patients are instructed on potential side effects of the numbing agents, which include potential numbness of the gag reflex and systemic absorption (Bensinger et al., 2008). When possible, the patient's medications are converted to liquid form for ease of swallowing or administration through the feeding tube.

Systemic analgesia begins with over-the-counter pain relievers such as nonsteroidal anti-inflammatory drugs (NSAIDs) or acetaminophen, advancing to oral opioids if swallowing. NSAIDS may be contraindicated in the setting of thrombocytopenia or anticoagulation. Liquid opioid pain relievers containing alcohol are administered via the G-tube to avoid mucosal irritation. Transition to transdermal fentanyl for continuous pain control with liquid morphine or oxycodone per G-tube for breakthrough pain generally is recommended earlier in the treatment course with the NO SToPS approach than prior to implementation.

#### **Nausea and Bowel Care**

Symptom management protocols guide RNs in the management of constipation, diarrhea, and nausea and vomiting, along with maintenance of adequate hydration to avoiding opioid-induced constipation. The protocols also guide initial treatment of diarrhea that may occur as a side effect of chemotherapy, treatment-induced lactose intolerance, bacterial pathogens (Peterson, Bensadoun, & Roila, 2009), or enteral feedings. If symptoms persist beyond the scope of the protocols, consultation with the nurse practitioner or physician occurs.

Nausea prophylaxis for amifostine therapy is addressed in the preprinted physician orders and coordinated with chemotherapy-induced nausea management through the medical oncologist. Pain, bowel, and nausea management are addressed daily through information garnered during the spray and weigh.

#### **Treatment Follow-Up**

As a minimum, weekly follow up with the physician or nurse practitioner is recommended for the first four weeks following therapy, more frequently if needed. The RN continues the assessments and spray and weigh procedure daily to weekly as needed.

## **Social Work**

## **Psychosocial Distress**

Mucositis and, for some, disfigurement from head and neck cancer treatment intimately affects the clinical, economic, psychological, and social aspects of a patient's life, including personal relationships and sexuality. Rapoport, Kreitler, Chaitchik, Algor, and Weissler (1993) identified that these patients' psychosocial coping deteriorates over time. In addition, 20% of cancer suicides occur in this group despite comprising only 5%

of the total cancer population (Semple, Sullivan, Dunwoody, & Kernohan, 2004). Katz, Irish, Devins, Rodin, and Gullane (2003) showed that women patients with head and neck cancer with less social support were at higher risk for post-treatment psychosocial issues than men or women with more support, even six months or more after treatment. Functional difficulties following treatment and obvious visible changes with disfigurement led Koster and Bergsma (1990) to characterize head and neck cancer as more emotionally traumatic than any other type of cancer. Treatment and surgical techniques have improved since that time, but many patients still deal with those issues as part of survivorship.

Studies from Sweden, Norway, and other countries where head and neck cancer is prevalent have confirmed depression, anxiety, and mood disorder rates of 30%-40% on the Hospital Anxiety and Depression Scale and other standardized tests (Hammerlid, Persson, Sullivan, & Westin, 1999). Even in palliative care, the challenges patients with head and neck cancer face in terms of physiological function and body image differ significantly from those faced by most other patients with cancer. These challenges include airway obstruction, fungating open wounds, communication disorders, and pain from extensive node dissections extending into the shoulder and arm. The same issues play an even larger role when the disease is progressing and patients are receiving palliative care (Chen, 2003).

Specific statistics regarding the effect of psychosocial intervention on risk factors for patients with head and neck cancer are limited (Semple et al., 2004). Frampton (2001) and Semple et al. (2004) reviewed the literature and found very little consistency by healthcare providers in screening these patients for psychosocial needs or postsurgical cosmetic outcomes that would affect social functioning. They recognized the need for screening and recommended that a standardized testing instruments specific to quality-of-life issues in patients with head and neck cancer be used initially to assist them in coping with predictable stressors related to their treatment and outcomes.

Semple (2004) showed that short-term cognitive behavioral interventions substantially increased patients' quality of life, and that education alone failed to achieve desired results. A combination of psychosocial and physiological interventions was needed to predict impact on patient quality of life, which showed effect even five years after treatment (Holloway et al., 2005). Verdonck-de Leeuw et al. (2007) found clinical levels of distress in 27% of these patients and 20% of their spouses; intervention for both groups was beneficial.

Social work support for this subset of patients is important in gaining access to health care and coping with global situational stressors that steadily drain patient coping resources as treatment progresses. In the authors' program, new patients complete a health history on which they may indicate areas of concern. Social workers then meet with patients on their initial visit to conduct a more specific verbal assessment for stressors related to their diagnosis, relationship issues, and financial issues that may impede access to or completion of care. One of the authors' goals for the program is to administer the National Comprehensive Cancer Network/Holland Distress scale to all new patients to better standardize this initial assessment across the facilities.

#### **Financial Concerns**

In the authors' experience, many patients are nearly as worried about the financial debt they may leave on their families as their cancer diagnosis. In the United States, only 33% of patients were given the opportunity by their physician to discuss financial concerns prior to treatment (Mathews & Park, 2009). To alleviate this concern, the authors instituted financial assistance procedures for patients that include preauthorization for treatment, discussion about out-of-pocket costs with a financial advocate, and proactive help navigating access to financial assistance programs in the authors' state.

A social worker then continues to follow patients through the labyrinthine process of garnering resources if they are uninsured or underinsured. Social workers often help procure assistance with transportation and housing necessary to access daily radiation treatment. A social worker also helps patients apply to pharmaceutical or manufacturer assistance programs with widely varying criteria to help procure medications or tube feeding supplies. If surgery or treatment renders a patient disabled, a social worker assists in applying for disability or with subsequent appeals if denied benefits.

The authors' geographical area is home to significant refugee resettlement populations that present unique challenges with each new group of families that arrive in the area. Refugees with head and neck cancer may present with unique cultural challenges, such as a history of torture leading to post-traumatic stress disorder (National Partnership for Community Training seminar, 2007). In addition, cultural history can lead to distrust of medical providers or phobic responses to medical procedures. A social worker will follow these families to assist them in surmounting those barriers. Many of these patients also face only a single year of medical care benefits as part of their resettlement package, and social work advocacy can sometimes extend these benefits so that patients are not left with insurmountable medical debt.

## **Psychological Concerns**

Almost all patients face anxiety after diagnosis. For patients with preexisting psychological distress, anxiety can be exacerbated beyond their ability to cope, even if coping previously. Social workers provide counseling or group support to assist with anxiety and comorbid psychological conditions which can prevent patients from accessing or complying with care, often meeting with them daily to de-escalate their anxiety and ensure that they are able to complete treatment. Referral to community-based mental health resources is provided if counseling from the social work staff is not effective in resolving the patient issue or at least allowing access to treatment.

Alcohol and smoking are contributing factors to developing head and neck cancer in 85% of this patient population, with use of both substances increasing risk substantially (NCI, 2005). The initial health history completed by patients on their first visit to the clinic assesses for alcohol and tobacco use. The issue is first addressed by the radiation oncologist and is revisited frequently by physicians, nurses, and social workers during the course of treatment and follow-up as long as tobacco and alcohol abuse occurs. Patients often require assistance with cessation programs and support related to those substances during and after treatment.

Although sexual health is a recognized need once the initial goals for treatment are met, this aspect of patient quality of life has not been consistently addressed. Issues affecting sexuality include changes in self-esteem, family roles, body image, xerostomia, and fatigue, as well as questioning of existential schema that can undermine self confidence and exacerbate erectile or orgasmic dysfunction and other relationship difficulties (Kotronoulas, Papadopoulou, & Patiraki, 2009). The social workers at the authors' institution help by using cognitive behavioral trust-building techniques adapted from trauma therapy and strengths-based therapeutic techniques. Outside referrals to specialists in marriage and family therapy can assist couples with preexisting relationship issues that are brought to the forefront by treatment-related stressors.

To better facilitate discussions regarding sexual health, staff education regarding the effect of treatment on sexuality has been provided in seminars and conferences and was the keynote issue in the nursing education oncology seminar offered this year at the authors' institution. Social workers also are trained through Association of Oncology Social Work conference presentations on techniques that can help patients with anxiety and body image issues.

Fatigue is an issue caused by dietary insufficiency as well as radiation and chemotherapy treatment for most patients with head and neck cancer (Jereczek-Fossa et al., 2007). Nursing assessment of fatigue and social work assistance with cognitive reframing intervention helps patients change their cognitive schema and expectations of themselves. Education in Cella's (1998) I Can Cope model helps patients cope as fatigue becomes a more pervasive issue. Patients also are offered referrals to the LiveSTRONG® program at the local YMCA, where services modeled on the Stanford Supportive Care Program are provided free of charge.

## **Conclusion**

Implementation of the NO SToPS team approach to side-effect management of patients undergoing chemoradiation for head and neck cancer is in progress to ensure a consistent standard of care across the authors' institution. Preliminary feedback from patients and providers has been very positive and indicates improvement in patient adherence to oral care and nutrition regimens; early identification of oral infections, volume depletion, and nutritional deficits; and improved pain control. Evaluation of treatment breaks and hospitalizations for side effect-related complications, weight loss, and improvement in comfort is underway.

The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the authors, planners, independent peer reviewers, or editorial staff.

**Author Contact:** Colleen K. Lambertz, MSN, MBA, FNP, can be reached at lambertc@slhs.org, with copy to editor at CJONEditor@ons.org.

#### References

- Beaver, M., Matheny, K., Roberts, D., & Myers, J. (2001). Predictors of weight loss during radiation therapy. *Otolaryngology-Head and Neck Surgery*, *125*, 645–648. doi: 10.1067/mhn.2001.120428
- Bensinger, W., Schubert, M., Ang, K., Brizel, D., Brown, E., Eilers, J., . . . Trotti, A. (2008). NCCN task force report: Prevention and management of mucositis in cancer care. *Journal of the National Comprehensive Cancer Network*, 6(Suppl. 1), S1-S21.
- Bolderston, A., Lloyd, N.S., Wong, R.K., Holden, L., & Robb-Blenderman, L. (2005). The prevention and management of acute skin reactions related to radiation therapy [full report]. Retrieved from http://www.guideline.gov/content.aspx?id=6828
- Bruner, D.W., Haas, M.L., & Gosselin-Acomb, T.K. (Eds.). (2005). *Manual for radiation oncology nursing practice and education* (3rd ed.). Pittsburgh, PA: Oncology Nursing Society.
- Cella, D. (1998). Factors influencing quality of life in cancer patients: Anemia and fatigue. Seminars in Oncology, 25(3, Suppl. 7), 43-46.
- Cerchietti, L., Navigante, A., Bonomi, M., Zaderajko, J., Menendez, P., Pogany, C., & Roth, B. (2002). Effect of topical morphine for mucositis-associated pain following concomitant chemoradiotherapy for head and neck carcinoma. *Cancer*, 95, 2230–2236. doi: 10.1002/cncr.10938
- Chen, T. (2003). Palliative care in advanced head and neck cancer (Part I)—Palliative medicine grand round. *Hong Kong Society of Palliative Care Medicine Newsletter*, 1, 1–3.
- Cho, J., Chung, W., Kang, W., Choi, C., & Son, C. (2008). Manual acupuncture improved quality of life in cancer patients with radiation-induced xersotomia. *Journal of Alternative and Complementary Medicine*, 14, 523–526. doi: 10.1089/acm.2007.0793
- Colasanto, J.M., Prasad, P., Nash, M.A., Decker, R.D., & Wilson, L.D. (2005). Nutritional support of patients undergoing radiation therapy for head and neck cancer. *Oncology*, *19*, 371–379.
- Cork, R., Isaac, I., Elsharydah, A., Saleemi, S., Zavisca, F., & Alexander, L. (2004). A comparison of the verbal rating scale and the visual analog scale for pain assessment. Retrieved from http://www.ispub .com/ostia/index.php?xmlFilePath=journals/ija/vol8n1/vrs.xml
- Dingman, C., Hegedus, P., Likes, C., McDowell, P., McCarthy, E., & Zwilling, C. (2008). A coordinated, multidisciplinary approach to caring for the patient with head and neck cancer. *Journal of Supportive Oncology*, *6*, 125-131.
- Dow, K., Bucholtz, J., Iwamoto, R., Fieler, V., & Hilderley, L. (Eds.). (1997). *Nursing care in radiation oncology* (2nd ed.). Philadelphia, PA: Saunders.
- Ewald, H. (1996). Radiotherapy of ENT tumors and risk of lymphedema. *Journal of Lymphology*, 20, 21-26.
- Frampton, M. (2001). Psychological distress in patients with head and neck cancer: Review. *British Journal of Oral and Maxillo-facial Surgeons*, *39*, 1-4. doi: 10.1054/bjom.2000.0547
- Garcia, M.K., Chiang, J.S., Cohen, L., Liu, M., Palmer, J.L., Rosenthal, D.I., . . . Chambers, M.S. (2009). Acupuncture for radiation-induced xerostomia in patients with cancer: A pilot study. Retrieved from www.ncbi.nlm.nih.gov/sites/entrez?orig\_db=%20 PubMed&db=pubmed
- Hammerlid, E., Persson, L., Sullivan, M., & Westin, T. (1999).
  Quality-of-life effects of psychosocial intervention in patients with head and neck cancer. *Otolaryngology and Head and Neck Surgery*, 120, 507-516. doi: 10.1053/hn.1999.v120.a90352
- Holloway, R., Hellewell, J., Marbella, A., Layde, P., Myers, K., & Campbell, B. (2005). Psychosocial effects in long-term head

- and neck cancer survivors. *Head and Neck*, *27*, 281-288. doi: 10.1002/hed.20147
- Isenring, E.A., Capra, S., & Bauer, J.D. (2004). Nutrition intervention is beneficial in oncology patients receiving radiotherapy to the gastrointestinal or head and neck area. *British Journal of Cancer*, *91*, 447–452. doi: 10.1038/sj.bjc.6601962
- Jereczek-Fossa, B.A., Santoro, L., Alterio, D., Franchi, B., Fiore, M.R., Fossati, P., . . . Orecchia, R. (2007). Fatigue during head-and-neck radiotherapy: Prospective study on 117 consecutive patients. *International Journal of Radiation Oncology, Biology, and Physics*, 68, 403–415. doi: 10.1016/j.ijrobp.2007.01.024
- Katz, M., Irish, J., Devins, G., Rodin, G., & Gullane, P. (2003). Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender and social support. *Head and Neck*, 25, 103–112. doi: 10.1002/hed.10174
- Keefe, D.M., Schubert, M.M., Elting, L.S., Sonis, S.T., Epstein, J.B., Raber-Durlacher, J.E., . . . Peterson, D.E. (2007). Mucositis study section of the multinational association of supportive care in cancer and the international society for oral oncology. *Cancer*, 109, 820–831. doi: 10.1002/cncr.22484
- Koster, M., & Bergsma, J. (1990). Problems and coping behaviour of facial cancer patients. *Social Science Medical*, 30, 569–578. doi: 10.1016/0277-9536(90)90155-L
- Kotronoulas, G., Papadopoulou, C., & Patiraki, E. (2009). Nurses knowledge, attitudes and practices regarding the provision of sexual health care in patients with cancer: Critical review of the evidence. *Supportive Care in Cancer*, *17*, 479–501. doi: 10.1007/s00520-008-0563-5
- Lees, J. (1999). Incidence of weight loss in head and neck cancer patients on commencing radiotherapy treatment at a regional oncology center. *European Journal of Cancer Care*, *8*, 133–136. doi: 10.1046/j.1365-2354.1999.00156.x
- Mathews, M., & Park, A. (2009). Identifying patients in financial need: Cancer care providers' perceptions of barriers. *Clinical Journal of Oncology Nursing*, *13*, 501–505. doi: 10.1188/09. CJON.501-505
- McQuestion, M. (2006). Evidence-based skin care management in radiation therapy. *Seminars in Oncology Nursing*, *22*, 163–173. doi: 10.1016/j.soncn.2006.04.004
- McQuestion, M. (2010). Radiation-induced skin reactions. In M. Haas & G. Moore-Higgs (Eds.), *Principles of skin care and the oncology patient* (pp. 115–126). Pittsburgh, PA: Oncology Nursing Society.
- Murphy, B.A., & Gilbert, J. (2009). Dysphagia in head and neck cancer patients treated with radiation: Assessment, sequelae, and rehabilitation. *Seminars in Radiation Oncology, 1*, 35–42. doi: 10.1016/j.semradonc.2008.09.007
- National Cancer Institute. (2005). Factsheet. Retrieved from http:// www.cancer.gov/cancertopics/factsheet/Sites-Types/head-and -neck
- National Partnership for Community Training Seminar. (2007). *Medical considerations for serving survivors of torture: A technical assistance training.* Boise, ID: Author.
- Newman, L., Vieira, F., Schwiezer, V., Samant, S. Murry, T., Woodson, G., . . . Robbins, K. (1998). Eating and weight changes following chemoradiation therapy for advanced head and neck cancer. *Archives of Otolaryngology-Head and Neck Surgery*, 124, 589–592.
- Nguyen, N.P., Moltz, C.C., Frank, C. Karlsson, U., Nguyen, P.D., Vos, P., . . . Sallah, S. (2006). Dysphagia severity following chemoradiation and postoperative radiation for head and neck cancer.

- *European Journal of Radiology, 59,* 453–459. doi: 10.1016/j.ejrad.2006.03.019
- Nguyen, N.P., Vos, P., Moltz, C.C., Frank, C., Millar, C., Smith, H.J., . . . Sallah, S. (2008). Analysis of the factors influencing dysphagia severity upon diagnosis of head and neck cancer. *British Journal of Radiology*, *8*, 706–710. doi: 10.1259/bjr/98862877
- Patel, S., Abboud-Finch, M., Petersen, J.A., Marron, J.T., & Mehta, V.K. (2008). Treatment breaks due to mucositis in patients with head and neck (H&N) cancer [Abstract 17024]. Retrieved from http://meeting.ascopubs.org/cgi/content/abstract/26/15\_suppl/ 17024
- Peterson, D., Bensadoun, R.J., & Roila, F. (2009). Management of oral and gastrointestinal mucositis: ESMO clinical recommendations. *Annals of Oncology*, 20(Suppl. 4), iv174-iv177. doi: 10.1093/announc/mdp 165
- Pignon, J.P., Maitre, A.L., & Bourhis, J. (2007). Meta-analyses of chemotherapy in head and neck cancer (MACH-NC): An update. *International Journal of Radiation Oncology, Biology, and Physics, 69*(2, Suppl.), S112–S114. doi: 10.1016/j.ijrobp.2007.04.088
- Quinn, B., Pottin, C., Stone, R., Blijlevens, N., Fliedner, M., Maruiles, A., & Sharp, L. (2008). Guidelines for the assessment of oral mucositis in adult chemotherapy, radiotherapy and haematopoietic stem cell transplant patients. *European Journal of Cancer*, 44, 61–72. doi: 10.1016/j.ejca.2007.09.014
- Rapoport, Y., Kreitler, S., Chaitchik, S., Algor, R., & Weissler, K. (1993). Psychosocial problems in head and neck patients and their change with time since diagnosis. *Annals of Oncology*, *4*, 69-73.
- Rosenthal, D., & Trotti, A. (2009). Strategies for managing radiation-induced mucositis in head and neck cancer. *Seminars in Radiation Oncology*, *19*, 29-34. doi: 10.1016/j.semrad onc.2008.09.006
- Russo, G., Haddad, R., Posner, M., & Machtay, M. (2008). Radiation treatment breaks and ulcerative mucositis in head and neck cancer. *Oncologist*, *13*, 886–898. doi: 10.1634/theoncologist .2008-0024
- Semple, C., Sullivan, K., Dunwoody, L., & Kernohan, W. (2004).
  Psychosocial interventions for patients with head and neck cancer. *Cancer Nursing*, 27, 434–441. doi: 10.1097/00002820-2004 11000-00002

- Sonis, S.T. (2004). Oral mucositis in cancer therapy. *Supportive Oncology*, 2(Suppl. 3), 3–8.
- Treister, N., & Woo, S. (2008). Chemotherapy-induced oral mucositis. Retrieved from http://emedicine.medscape.com/ article/1079570
- Trotti, A., Byhardt, R., Stetz, J., Gwede, C., Corn, B., Fu, K., . . . Curran, W. (2000). Common toxicity criteria: Version 2.0. An improved reference for grading the acute effects of cancer treatment: Impact on radiotherapy. *International Journal of Radiation Oncology Biology, and Physics*, 47, 13–47. doi: 10.1016/S0360-3016(99)00559-3
- van Bokhorst-de van der Schuer, M.A., van Leeuwen, P.A., Kuik, D., Klop, W., Sauerwein, H., Snow, G., & Quak, J. (1999). The impact of nutritional status on the prognoses of patients with advanced head and neck cancer. *Cancer*, *86*, 519–527. doi: 10.1002/(SICI)1097-0142(19990801)86:3<519::AID-CNCR22>3.0.CO;2-S
- Vendrell-Rankin, K., Jones, D., & Redding S. (Eds.). (2008). *Oral health in cancer therapy: A guide for health care professionals* (3rd ed.). Retrieved from http://www.doep.org/images/OHCT\_III\_FINAL.pdf
- Verdonck-de Leeuw, I.M., Eerenstein, S.E., Van der Linden, M.H., Kuik, D.J., de Bree, R., & Leemans, C.R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngo-scope*, 117, 238–241. doi: 10.1097/01.mlg.0000250169.10241.58
- Wiggenraad, R.G., Flierman, L., Goossens, A., Brand, R., Verschuur, H.P., Croll, G.A., . . . Vriesendorp, R. (2007). Prophylactic gastrostomy placement and early tube feeding may limit loss of weight during chemotherapy for advanced head and neck cancer, a preliminary study. *Clinical Otolaryngology*, 32, 384–390.

Receive free continuing nursing education credit for reading this article and taking a brief quiz online. To access the test for this and other articles, visit http://evaluationcenter.ons.org/Login.aspx. After entering your Oncology Nursing Society profile username and password, select CNE Tests and Evals from the left-hand menu. Scroll down to Clinical Journal of Oncology Nursing and choose the test(s) you would like to take.