Evaluation of an Educational Tool to Enhance Outcomes for Patients With Head and Neck Cancer

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According to the American Cancer Society (ACS, 2004), an estimated 38,530 people, 70% male and 30% female, in the United States will be diagnosed with cancer of the oral cavity and pharynx in 2004. Although these cancers more commonly are seen in men, the incidence of women diagnosed with head and neck (H&N) cancer has increased in recent decades related to tobacco use. In 1977, 75% of those diagnosed with H&N cancer were male and 25% were female (ACS, 1976). These cancers frequently present in a locally advanced stage, making treatment difficult for patients and the healthcare team.

Treatment

Historically, definitive treatment for H&N cancer was surgical excision, which has been in use since the mid-1800s (glossectomy), with increasing success. The invention of mirror laryngoscopy around 1850 led to recognition of hypopharyngeal and laryngeal tumors and subsequent development of surgical techniques for the removal of disease in these areas (often laryngectomy). Shortly after the discovery of the medical usefulness of x-rays in 1896, radiation therapy was being used for H&N cancers (McCarty & Million, 1994). With improvements in surgical techniques as well as radiation advancements, modern therapy for H&N cancer often involves combined modality therapy. For locally advanced disease where surgery is too extensive, primary radiation therapy has been studied using different techniques, including accelerated and hyperfractionated schemas, with improved local control over standard daily fractionation. More recently, the addition of concurrent chemotherapy to hyperfractionated primary radiation therapy has shown improved local control and overall survival in patients with locally advanced H&N cancer (Brizel et al., 1998).

Toxicity

Oral complications from H&N primary radiation therapy result from normal tissue damage, which most commonly includes mucositis and xerostomia (dry mouth). With the introduction of more intense radiation and combined modality therapy, direct stomatotoxicity (epithelial damage) occurs, and uncontrolled mucositis often is a limiting factor to successful completion of planned therapy. Radiation therapy-induced mucositis progresses with cumulative doses. Initial symptoms include mucosal erythema with burning or soreness, followed by mucosal breakdown manifested as pseudomembranes or a fibrinous mass overlying necrotic and ulcerated tissue. Finally, full-thickness mucosal ulceration occurs and remains problematic through the end of radiation therapy and for weeks afterward (Sonis & Fey, 2002). Clinical manifestations include difficulty talking, eating, and drinking; managing thick secretions; and oral pain. Patients also cannot perform the oral care needed to reduce risk of infection.

Xerostomia resulting from radiation damage to salivary glands is an acute effect during treatment, but it also can be a chronic, lifelong problem. The degree of xerostomia relates to the volume of salivary gland tissue treated and the dose of radiation given. Generally, glandular changes are reversible when doses of less than 6,000 cGy are administered, but higher doses cause irreversible fibrous and glandular degeneration (Sonis, 1993). Chronic xerostomia significantly increases risk of dental decay, which becomes especially problematic after primary radiation therapy with the added risk of poor healing after tooth extraction. Other acute or late side effects may include...
pain, nutritional issues, skin changes, oral infections, and osteoradionecrosis. Intimacy issues often are overlooked and may directly impact quality of life when patients can no longer kiss their partners because of mucositis or pain.

**Symptom Management**

Multiple treatments have been researched and used for the management of primary radiation therapy-induced mucositis. Four main modalities used are antimicrobial agents, coating agents, anti-inflammatory agents, and cytokine-like agents (Shih, Miaskowski, Dodd, Stotts, & MacPhail, 2002). In their review, Shih et al. examined recent clinical trials using these agents. Multiple trials compared the effectiveness of antimicrobial agents, including benzylamine, chlorhexidine, hydrogen peroxide, and PTA lozenge (polymyxin E, tobramycin, and amphotericin B). Eight of 13 trials using these agents found no significant differences in the severity of mucositis between the treatment and control groups, with only three trials reporting any symptom improvement. Coating agents that may facilitate mucosal healing and cell regeneration prompted multiple studies of the effectiveness of sucralfate suspension. Seven of the eight sucralfate trials found no significant differences in the severity of

| TABLE 1. DUKE UNIVERSITY HOSPITAL DEPARTMENT OF RADIATION ONCOLOGY: MOUTH CAREa, b |
|-------------------------------|-----------------------------|-----------------------------|
| **CATEGORY**                  | **STARTING RADIATION**      | **WHEN YOUR MOUTH IS SORE** | **AFTER COMPLETING RADIATION THERAPY** |
| Brushing                      | After eating and at bedtime with a soft toothbrush; include your tongue. | Change to a toothette (spoon on a stick), and use a nonirritating toothpaste or baking soda. Change to brush after eating and at bedtime. | Continue to brush after eating and at bedtime. Include your tongue. |
| Flossing                      | Once a day with waxed floss | Stop if gums bleed. Increase rinses to five times a day. | Continue once a day with waxed floss. |
| Mouth rinse                    | Rinse three times a day using a non-alcohol solution (e.g., Biotene® rinses, Laclede, Inc., Rancho Dominguez, CA; UlcerEase®, Med Derm Division of Crown Laboratories Inc., Johnson City, TN; RadiaCare®, Oral Wound Rinse, Carrington Laboratories, Irving, TX), peroxide solution (one part peroxide, three parts water), or salt water (1 tsp salt in 1 qt of water). | | Continue as needed. Once mouth is healed, you may discontinue. |
| Fluoride                      | Use fluoride treatment with dental tray daily if ordered by doctor. | Continue as directed. | Continue as directed. If your mouth remains dry, you will need to continue to see a dentist every four to six months for cleaning and oral cavity checkups. |
| Pain medicine                 | Tell your doctor about any pain medicine you currently are taking. | Talk to your nurse or doctor. We often need to change or add new medicines until you are more comfortable. You may use numbing medicine before eating and oral care. Keep a diary of the pain medicines you are using as well as the dosage and frequency, and score the severity of your pain from 0–10. | Upon completion of radiation therapy, you may need to take pain medicine for several weeks until you are healed. Your physician will discuss with you how to stop taking the pain medicines slowly. |
| Diet                          | Increase fluids as mouth and throat may become dry. | Avoid alcohol, acidic foods and drinks (e.g., orange or grapefruit juice), spicy food, and dry foods (e.g., crackers). Eat softer foods (e.g., soups, pudding, mashed potatoes and gravy). Supplement with high-protein drinks (e.g., Boost®, Novartis Pharmaceuticals, Cambridge, MA; Ensure®, Abbott Laboratories, Abbott Park, IL; Nestlé® Carnation® Instant Breakfast®, Nestlé® USA, Glendale, CA). Increase fluids to help with dry mouth. | As your mouth continues to heal, you may begin to reintroduce foods that you could not eat before because of sensitivity. If you continue to experience dryness in your mouth, then you will want to avoid sugary and dry foods. |
| Inspect your mouth            | Look in your mouth daily. | Continue to look in your mouth daily. If you notice any white patches, bleeding, or ulcers, report them to your nurse or doctor. | Continue to inspect your mouth daily while brushing and flossing. |

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*The purpose of this form is to provide you with useful suggestions to help you through your course of treatment and to review side effects that may occur during your treatment.*

*Radiation therapy to the head and neck area may cause painful irritation to the lining of the mouth and throat; this is called mucositis. You can help decrease the symptoms by taking care of your mouth as outlined above. It is also very important to stop smoking and drinking alcohol because these behaviors can worsen symptoms.*

*Note. Adapted with permission from Duke University Medical Center.*
mucositis. Anti-inflammatory rinsing agents that have been studied include Kamilois liquidum, a mouthwash containing hydrocortisone, nystatin, tetracycline, diphenhydramine, and a prostaglandin E1 rinse. Two of four studies involving these agents showed no significant differences in severity of mucositis. Cytokine-like agents investigated for use in mucositis include granulocyte macrophage–colony-stimulating factor (GM-CSF) and immunoglobulin. Five descriptive studies with GM-CSF showed less than expected mucositis in treated patients, but a later randomized trial showed no significant difference in the severity of mucositis in patients treated with GM-CSF and sucrafate versus sucrafate alone. In these studies, GM-CSF was administered as an oral rinse or a subcutaneous injection. One study using immunoglobulin showed improvement in mucositis with patients receiving radiation and chemotherapy for H&N cancer, but no difference was found in patients treated with radiation alone. Shih et al. concluded that none of these strategies produced consistent results of decreasing intensity or prevention of oral mucositis during radiation therapy. Two other reviews regarding treatment of mucositis also determined that no consensus exists for evidence-based practice regarding the best oral care for prevention and treatment of therapy-induced oral mucositis (Köstler, Hejna, Wenzel, & Zielinski, 2001; Miller & Kearney, 2001).

Radiation Oncology Nursing Challenge

The National Cancer Institute (NCI, 2003) instructed healthcare professionals to optimally manage patient oral toxicities to best deliver cancer therapy. In H&N cancer, this must include preventive and therapeutic measures. Because of daily treatments, radiation oncology nurses are in a good position to deliver ongoing patient teaching and frequent assessment. At the authors’ institution, radiation nurses proposed a performance improvement project to standardize oral care recommendations and improve teaching for patients undergoing H&N radiation. Information was compiled from physicians, the previously mentioned literature reviews, and the nurses’ combined years of experience. A standard for oral care for the department was developed and translated into a patient educational tool (see Table 1).

The first section of the tool focuses on patient self-care behaviors to be incorporated at the beginning of treatment. The second section discusses suggested changes to these self-care behaviors that patients should make when side effects arise. This often can be a challenging time for patients and healthcare providers. Therefore, good oral care practices should be established at the beginning of treatment and reinforced throughout treatment. After treatment is completed, the healthcare team must arrange for appropriate follow-up, which also provides an opportunity to encourage patients to continue the oral care routine. Patients may not be aware that they still need to continue rigorous oral care until the acute effects of treatment subside, possibly four to six weeks after the completion of primary radiation therapy. The last section of the educational tool addresses this issue.

Foltz and Sullivan (1996) examined several education issues among patients with cancer. They compared patients’ reading levels to their stated education levels and found that more than half read below their stated education levels. As in the current study’s sample, the majority of the Foltz and Sullivan sample reported high school completion; however, they found 56% read at less than a ninth-grade level, 25% read at less than a seventh-grade level, and 6% read at less than a third-grade level. In addition, 78% of the sample preferred information that was presented in an interactive format with a healthcare worker and 13% preferred receiving reading material. Not surprisingly, 90% of the patients stated that they wanted all of the information that was available regarding their diagnosis and treatment.

In designing the tool, the authors wanted to limit it to the front and back of one printed page, have the information flow logically, and ensure easy readability. The tool was formatted in Microsoft® Word, and once completed, the software’s readability program was used to determine the tool’s reading level (Flesch-Kincaid level 5.2). The National Work Group on Cancer and Literacy recommended that when written communication with patients is essential, materials should be prepared at the fifth-grade reading level or lower (Davis, Williams, Marin, Parker, & Glass, 2002). The phrase “reading level” refers to the number of years of education required for a reader to understand a written passage (NCI, 1994). Although the reading level does not reflect comprehension, the next section of the performance improvement project addresses this.

Assessing the Effectiveness of a Teaching Tool

In developing any new educational tool, its authors must ensure that it meets patients’ needs. While the educational tool was being developed, 19 patients with H&N cancer were given a self-assessment survey (that was prepared by the authors) at the completion of radiation therapy. This survey questioned the frequency of brushing, flossing, and mouthwash use (and type) prior to radiation therapy and at the completion of therapy. It also questioned diet changes made, use of pain medications, and perception of pain control during therapy (see Figure 1). This group of patients received standard teaching material, consisting of the NCI

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
<th>Yes (skip to question 7)</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you wear dentures?</td>
<td></td>
<td>1 2 3 4 or more</td>
<td>No</td>
</tr>
<tr>
<td>2. How many times a day did you brush your teeth before starting radiation treatments?</td>
<td></td>
<td>1 2 3 4 or more</td>
<td>No</td>
</tr>
<tr>
<td>3. How often did you brush during radiation treatments?</td>
<td></td>
<td>1 2 3 4 or more</td>
<td>No</td>
</tr>
<tr>
<td>4. Did you change the type of toothbrush or toothpaste used?</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5. Did you floss your teeth regularly prior to radiation treatments?</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>6. Did you floss during radiation?</td>
<td></td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>7. Did you use mouthwash regularly before starting radiation treatments?</td>
<td></td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>8. What brand of toothpaste did you use?</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>9. Did you use mouthwash or rinses during radiation?</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>10. If yes, what brand or type of solution and how often did you use it daily?</td>
<td></td>
<td>1 2 3 4 or more</td>
<td>No</td>
</tr>
<tr>
<td>11. Did you use fluoride treatments during radiation?</td>
<td></td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>12. Did you take pain medicine during radiation?</td>
<td></td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>13. Did the pain medication help with doing mouth care and swallowing?</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>14. Did you lose weight?</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>15. How much?</td>
<td></td>
<td>How much?</td>
<td>No</td>
</tr>
</tbody>
</table>

**Figure 1. Head and Neck Educational Survey**
groups of patients had similar diagnoses and
treatment plans and were expected to have
similar treatment toxicity related to large
mucosal areas in the radiation field. Both
groups answered the self-assessment survey
during the last week of treatment or a few
days after completion.

**Patient Demographics**

Each group consisted of 19 patients. The
mean age of the control group was 60 years,
with 15 males and 4 females. The mean age of
the intervention group was 55 years, with
13 males and 6 females. Patients self-re-
ported their educational level, and they were
grouped as follows: less than a 10th-grade
reading level (control n = 4, intervention n =
1), 10th- to 12th-grade reading level (con-
trol n = 6, intervention n = 8), and greater
than a 12th-grade reading level (control n =
9, intervention n = 8). Two from the inter-
vention group did not state their educational
level. Sites of primary disease included the
oral cavity, pharynx, larynx, and one un-
known primary site (see Figure 2). The control
group consisted of 1 stage II, 4 stage III,
and 13 stage IV patients, in addition to one
patient with an unknown H&N primary site.
The intervention group consisted of 5 stage
II and 14 stage IV patients. The disease stage
was defined by the American Joint Commit-
tee on Cancer Staging (Fleming et al., 1998).

The authors reviewed the end-of-treat-
ment self-report surveys, with the aim of de-
termining whether the group that received
the educational tool differed in oral care be-
haviors from the group that received stan-
dard teaching. The survey asked about
brushing, flossing, and mouthwash use prior
to and during radiation therapy. Points were
awarded for behaviors recommended in the
educational tool such as more frequent
brushing, changing to a softer toothbrush,
more frequent use of an alcohol-free mouth-
wash, and daily flossing. Points were
deducted for behaviors such as not flossing.

For patients in the intervention group, 76.9% had positive changes in their
brushing behavior and mouthwash use, respectively (see Figure 3).

**Performance Improvement Results**

The survey assessed whether respond-
ents believed that their oral pain was con-
trolled enough to perform recommended
mouth care and assessed self-reported di-
etary modifications and weight loss. The
weight used for analysis of results was taken
from the patient record where weights were
documented on a weekly basis. Both
groups reported modifying their diet ac-
cordingly (see Figure 4).

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Conclusion
This performance improvement project surveyed a small group of patients but did demonstrate an improvement in self-care behaviors and patients’ ability to advocate for pain medication. Performance improvement projects can promote patient safety, improve patient satisfaction, and serve as a clinical foundation to promote research and evidence-based practice. Patients with H&N cancer face a variety of physiologic and psychological issues that may make treatment and symptom management challenging to healthcare providers.

In this project, the nonintervention group performed well, showing the importance of interactive communication. The authors endeavored to provide low-level written material to supplement and standardize oral care recommendations. The development and distribution of appropriate educational materials about self-care behaviors can result in patients who partner with the healthcare team and become their own best advocates.

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References

Rapid Recap
Evaluation of an Educational Tool to Enhance Outcomes for Patients With Head and Neck Cancer
- Mucositis is a common and potentially severe symptom experienced by patients receiving treatment with radiation with or without chemotherapy for head and neck cancer.
- No consensus has been reached for evidence-based practice regarding best oral care for prevention and treatment of therapy-induced oral mucositis.
- A performance improvement project was initiated to develop oral care standards and an educational tool.
- Patients who received the educational tool showed improved self-care behavior of brushing teeth and reported effective pain control.
- Developing appropriate patient education materials may positively impact patient self-care during therapy and improve patient satisfaction.

For more information on this topic, visit the following Web sites.

Medline Plus: Head and Neck Cancer

Head and Neck Cancer
www.hncancer.com

Cancer Index: Head and Neck Cancer
www.cancerindex.org/clinks2h.htm

Links can be found at www.ons.org.