Evidence-Based Oral Mucositis Prevention and Treatment

Michele Farrington, BSN RN CPphon®, Clinical Healthcare Research Associate and Staff Nurse, University of Iowa Hospitals and Clinics

Providing evidence-based supportive care and symptom management to pediatric oncology patients after chemotherapy or radiation treatments is important. Pediatric oncology nurses confront this challenge on a daily basis.

Oral mucositis, one of the most challenging, costly, and distressing symptoms, occurs in at least 40% of oncology patients (Brown & Wingard, 2004; Dodd, 2004; Fulton, Middleton, & McPhail, 2002; Peterson, Bensadoun, & Roila, 2008) and may occur in up to 90% of patients undergoing high-dose chemotherapy with hematopoietic stem cell transplantation (Cawley & Benson, 2005). Is evidence-based prevention or treatment possible for oral mucositis? If so, what research has been done and what practice gaps remain for research to address?

Oral mucositis is an old problem and has been documented extensively over the years (Sonis, 2009). The majority of the literature focuses on the desire of healthcare professionals (physicians and nurses) to locate a medication—common with traditional practice—as an easy solution to this problem.

Significant developments related to its management date back to the 1960s with mouthwashes and analgesics being introduced in 1965 and Chlorhexidine and Sucralfate in 1975 (Keefe et al., 2007). Some of these early medications were even tested through research and synthesized in a Cochrane Systematic Review, which focused on prevention of oral mucositis through administration of prophylactic oral agents (e.g., fluconazole, chlorhexidine mouthrinse). Unfortunately, no benefits were found (Worthington & Clarkson, 2002). Practice recommendations have also emerged from the following groups: the Multinational Association of Supportive Care in Cancer and International Society for Oral Oncology, National Comprehensive Cancer Network, American Society of Clinical Oncology, Oncology Nursing Society, and European Society for Medical Oncology.

The common theme found in these practice recommendations is the need to shift attention from prescribing medication to prevent or treat oral mucositis back to taking preventative measures. Healthcare professionals must start by promoting good oral health through evidence-based interventions.

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Pediatric Hematology/Oncology Nurses Confront the Challenge of Assessing and Managing Disease-Related Patient Symptoms

Sharon Bergeron, BSN RN CPON®, Research Educator, CHOC Children’s Hospital, Editor

It is critical that pediatric hematology/oncology nurses recognize treatment-related symptoms experienced by their patients. As nurses, we are constantly challenged to advance the care of our patients through new ideas and technology so that we can ensure their comfort and enable them to be symptom-free as much as possible, thus achieving the highest healthcare standards of care. We strive daily to care for our patients with sensitivity and respect, listen to their important concerns, and address their countless disease-related symptoms, but there is always room for improvement!

Our spring issue provides an extensive review of evidence-based symptom management techniques that can directly affect patient outcomes. Additionally, the importance of promoting preventive-care approaches through the use of patient and family education material is highlighted in this issue and authors stress that these methods can often reduce the stressful treatment side effects and improve the quality of life for the hematology/oncology patient.

CALL FOR AUTHORS

Become a Guest Author for APHON Counts

The column editors of APHON Counts are inviting all interested nurses to write an article for their columns. Writing for APHON Counts is a great opportunity to share your expertise and resources with our membership. Please contact APHON Counts Editor, Sharon Bergeron, at sbergeron@choc.org if you are interested in collaborating with our enthusiastic editorial team!
Recognizing the Amazing Projects Accomplished by the APHON Membership

Melody Ann Watral, MSN RN CPNP CPON®, Pediatric Nurse Practitioner, Duke University Health System, APHON President

I’m sitting here at my desk, reviewing my first year as president of this incredible organization, and I’m truly amazed at everything that has transpired during 2012. I am so pleased with our membership, and I just wanted to let everyone know what a pleasure this year has been for me as APHON president.

Our conference in October was very well received by the membership, based on the feedback from the conference evaluations. The Annual Conference Program Planning Committee did an incredible job. I know that the 2013 committee members are already putting together a program that will prove to be filled with interesting and useful presentations. I’m looking forward to our next “group hug” in Louisville in fall 2013.

As an organization, APHON is dependent upon the efforts of an incredible army of volunteers who help make things happen. As an example of a recent accomplishment, we were recently notified that the APHON/PBMTC Foundations of Pediatric Hematopoietic Progenitor Cell Transplantation: A Core Curriculum, 2nd Edition flash drive received a Bronze award for Best Educational Product in the Association TRENDS All-Media Contest. Kudos to Vicki Fisher, Ellen Olson, and their team of contributors for all their hard work!

This is the third year in a row that an APHON product has been recognized.

The newly formed Evidence-Based Practice (EBP) Committee got off to a quick start, seeking feedback and ideas from the membership regarding projects of interest in our day-to-day workplace settings. Our collaboration with the COG Nursing Discipline’s EBP Committee is proving to be beneficial to both groups. By the next issue of APHON Counts, we hope to have at least two projects in the queue.

Our organization continues to thrive, and it is all because of you. I’m honored to be able to serve as your president for another year and hope that APHON is meeting your needs. This year has gotten off to a good start, and there is much more to come. I’m just an e-mail away if you have any questions, ideas, or would just like to chat!

NEWS ON CERTIFICATION

Pamela Asfahani, BS, Communications & Marketing Manager, Oncology Nursing Certification Corporation, Column Editor

New details are available for the Blood and Marrow Transplantation Certified Nurse (BMTCN) examination, including the eligibility criteria, test blueprint (content outline), and samples of test items.

The BMTCN examination will address autologous and allogeneic transplants, as well as other forms of cellular therapies in both adult and pediatric populations.

The first BMTCN examination will be offered in February 2014. Candidates who apply to take the examination in the first administration will receive a $50 discount. Candidates in this group will not receive immediate pass/fail results at the testing center because extensive statistical analysis will first be performed on all of the items. Poorly performing items will not count toward the candidate’s score. The first group of candidates will receive pass/fail results when this analysis is complete (within 3 months). Candidates who test in later administrations will receive immediate results at the test center but will not qualify for the discounted fee. Registration for the BMTCN examination will open in the fall of 2013.

Visit the Oncology Nursing Certification Corporation (ONCC) website at www.oncc.org/TakeTest/Certifications/BMTCN to review the eligibility criteria, test blueprint, and sample test items.

Keep Your Record Up to Date with ONCC

Communicating electronically is a cost-effective option for many organizations. ONCC has found that using a combination of regular mail, e-mail, and telephone calls to communicate with certified nurses is effective. However, those efforts can be successful only if an individual’s contact information is up to date.

Does ONCC have current information for you? If you’ve changed your name, moved, taken a new job, or changed your e-mail address, there’s a good chance your information is not up to date. What’s the risk? You may not be receiving important information about your certification.

Most ONCC communications are sent via e-mail. Please be sure the e-mail address listed in your record is accurate and one that you check regularly. If it’s a work e-mail address, check to be sure messages are being delivered. Many institutions filter messages and deliver those from selected senders only. You may wish to check with your information technology department or use a personal e-mail address. If you’ve moved since you last applied for certification, you may not be receiving mailed communications either.

Take a few moments to log in and update your ONCC profile at https://profile.ons.org so you won’t miss out on any information related to your certification.
Managing symptoms, especially the symptoms of patients in the pediatric oncology population, is quite challenging. One of the most difficult issues that nurses face is determining what their pediatric patients are telling them. It is often tough for a young patient to explain how something feels. Yet, when assessing a patient, pediatric oncology nurses often ask only a couple of basic questions, such as “Do you have pain?” or “Are you having any nausea or vomiting?” The nurses are asking about two of the most common complaints that plague this population, but what about all of the other symptoms? Cancer-related treatment causes countless symptoms, so why are only a couple of symptoms regularly addressed?

When caregivers at St. Jude Children’s Research Hospital noticed this gap in the thorough identification, assessment, and management of patients’ symptoms, a study was piloted. It was surmised that pediatric oncology patients might have complaints of additional symptoms but are unsure of how or unable to report those symptoms. The purpose of the study was to find a tool that would be effective in identifying and assessing a wide range of symptoms so that appropriate management could be implemented. Patients who had a hematopoietic stem cell transplant (HSCT) were chosen as the study group.

The project began by sending the nursing staff a quality improvement survey, which identified how satisfied they were with their assessment skills regarding symptom management. The survey showed that most nurses felt there was room for improvement.

Next, a chart review was performed on approximately 65 former HSCT patients in order to further understand how many symptoms were routinely documented. For consistency purposes, three specific posttransplant days were chosen to be reviewed. The chart analysis showed that an average of three symptoms were documented on an HSCT patient on any one of the three specific posttransplant dates.

With this information, a symptom assessment tool, which could be used with many age groups, was created. The tool focused on patients’ symptoms, and it allowed patients to rate how distressing each individual symptom was. Offering a tool that lets patients rate the severity of a symptom was important because many patients are aware of a symptom but do not feel it needs treatment.

The tool addressed 11 symptoms, including sleep disturbances, diarrhea, and loss of appetite. Additionally, the tool used a five-point Likert scale because a pediatric population could easily understand it. At the bottom, there was a section where the patient or caregiver could write down any additional symptoms. Pain was excluded from the symptom assessment tool because many effective pain scales are already used in the pediatric population.

An important aspect of the study was to have the patient answer the questions on the symptom assessment tool in order to gather the most accurate information. If the patient was unable to answer the questions, then the parent or guardian was asked to give his or her opinion of how the patient had felt during the last 24 hours. If neither the patient nor the parent or guardian were willing or able to fill out the assessment tool, then the patient’s nurse would complete the tool with his or her assessment of the symptoms.

Prior to implementing the tool, the nurses at St. Jude Children’s Research Hospital felt that it would be useful. However, when the tool went live, it was challenging for nurses to use regularly and, therefore, was used inconsistently. Ultimately, nurses stopped using the tool, it was reevaluated, and it was taken off the HSCT unit.

Although the study was not completed, it still found that the patients and families reported more symptoms when the tool was used appropriately. Additionally, when the tool was used correctly (on a daily basis), most of the patients and families found it to be useful for symptom management. Families also felt that the tool was a good way to get information to the medical team. This information points to the importance of nurses keeping a vast array of symptoms in mind when completing assessments. Even if there is not a specific tool to use, it is still critical that nurses ask patients about multiple possible symptoms and give patients and families the opportunity to discuss additional symptoms that patients may be experiencing.

Pediatric oncology nurses recognize that symptoms, often debilitating ones, are part of patients’ daily lives. Nurses strive to keep patients as comfortable and symptom-free as possible, but there is always room for improvement.
Symptom Management for Local Chapters

Janice Nuuhiwa, MSN RN APN/CNS CPHON®, Staff Development Specialist, Ann & Robert H. Lurie Children’s Hospital of Chicago, Column Editor

Fatigue is a significant side effect of cancer therapy and a major consequence for many of our patients with blood disorders. Fatigue greatly impacts one’s quality of life. Did you know that APHON local chapters can suffer from fatigue? Many chapters struggle, at some point, with this symptom. It manifests itself in a chapter’s ability to succession plan, as well as in the membership and educational events that are offered. There are many ways to infuse energy into the local chapter in to combat fatigue.

For those newly formed chapters, it’s all about fatigue prevention through pacing and planning. Transform those brainstorming sessions into a 2–3 year strategic plan for expanding the chapter and implementing all of the fresh ideas that bubble out of a new chapter. Start looking for the next set of leaders, and engage them early. Ask our colleagues from other disciplines to assist in educational offerings or as project leads. Keep in touch with your local chapter liaison, who can be a great encouragement and help you solve problems.

Established chapters may need an infusion of new ideas, new members, or new projects in order to be refreshed and energetic. Consider expanding the membership to include local home care agencies, hospice providers, and other community professionals who support our patient population. Reach out to local nursing schools. Students often need to participate in a professional organization’s meeting to meet curriculum requirements, but you just might recruit a future hematology/oncology nurse in the process!

Are you out of new ideas? Send out an SOS call through the chapter president’s Listserv, touch base with your local chapter liaison, or peruse the local chapter desk on the APHON website at www.aphon.org/members/chapter_committee.cfm, which houses the previous year’s chapter activities gleaned from the local chapter reports. Don’t forget that your best ideas come from the membership. Query your chapter members to find out what they want to learn about and which fundraising or community service projects interest them.

Are you eager to take on a new project, but have some trepidation? Make an inquiry to a neighboring chapter to see if a collaborative effort might benefit the target audience from both areas. For example, the Long Island, New Jersey, and Metro New York chapters band together to hold an annual conference. In the past, the Chicago and Wisconsin chapters collaborated on a CPON® review course. Other chapters can be wonderful resources for those chapters looking for guidance with a particular activity or initiative.

Need to recruit new leaders? Succession planning can be a challenge, but we know that a chapter cannot exist without the elected officers. As you acquire new members, consider getting them involved in small projects early on in their membership. This allows you to assess their leadership style and interest in developing this aspect of their career. Provide opportunities for everyone to lead, whether it’s a portion of a meeting, an educational session, a fundraising project, or a community service event. Cultivate those individuals who have an interest in leadership, but don’t forget about those who are hesitant—sometimes a professional challenge is what is needed to propel an individual forward. Have a conversation with those nurses who can provide leadership to your chapter. Support new officers to maximize their experience and impact their ability to provide support to their successors.

Purposeful attention to preventing and combating local chapter fatigue will keep the chapter healthy, vibrant, and professionally satisfying!

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Educational Opportunities

**APRIL 24, 2013**

**APRIL 25–28, 2013**

**MAY 9–10, 2013**

**SEPTEMBER 19–21, 2013**
APHON 37th Annual Conference and Exhibit, Kentucky International Convention Center, Louisville, KY.

**OCTOBER 17–19, 2013**
Preparing Professional Nurses for Cancer Survivorship Care, Disneyland’s Paradise Pier, Anaheim, CA. For registration information, visit www.cityofhope.org/survivorship-training.
Nurses Focus on Prevention of Oral Mucositis in a Children’s Oncology Group Study

Ellen Olson, MS RN CPNP, Nurse Practitioner, Children’s Healthcare of Atlanta-Egleston, Aflac Cancer Center and Blood Disorder Service

Although oral mucositis (OM) remains a major complication and an important nursing issue in the care of pediatric patients undergoing hematopoietic stem cell transplantation (HSCT), there is not a widely accepted standard of care for preventing or minimizing OM. For that reason, the Children’s Oncology Group (COG) is conducting a study on whether an oral rinse with Caphosol can effectively decrease the duration of OM in children undergoing HSCT.

Two nurses, Christina Baggott, PhD RN PNP-BC CPON®, and Ellen Olson, MS RN CPNP, represent the COG Nursing Discipline as members of the study committee for the supportive care protocol ACCL1031, “A Randomized Double Blinded Trial of Topical Caphosol to Prevent Oral Mucositis in Children Undergoing Hematopoietic Stem Cell Transplantation.”

Caphosol® (Jazz Pharmaceutical) has U. S. Food and Drug Administration (FDA) approval for managing OM pain. It is a supersaturated calcium phosphate solution, which means it has a higher concentration of the dissolved material than is possible under normal circumstances. Although its mechanism of action is not well understood, it is thought that Caphosol can decrease tissue damage and promote healing through direct delivery to the mucosa. Its safety has been established, and there are no known drug interactions. In a single-center Phase 3 trial in adult HSCT, patients who were assigned randomly to Caphosol had significantly reduced days of mucositis, duration of pain, and days of morphine use compared to those receiving the standard regimen.

The primary objective of the COG ACCL1031 study is to compare Caphosol oral rinses with placebo saline rinses to see whether the duration of severe OM is decreased; severe OM is defined as World Health Organization (WHO) grade 3 or 4. There are three additional (secondary) objectives. The first is to determine whether Caphosol reduces OM incidence and severity, narcotic pain medication use, and total parenteral nutrition (TPN) incidence and duration. The second is to learn whether Caphosol reduces the incidence of febrile neutropenia and invasive bacterial infections. The third is to validate a new pediatric OM measure: the Children’s International Mucositis Evaluation Scale (ChIMES). ChIMES assesses the study participants’ daily experiences with mucositis including pain, function, use of pain medication, and appearance of the oral mucosa.

The study includes patients age 4–21 years who are undergoing myeloablative HSCT. In order to participate, patients must be able to do oral rinses correctly as instructed. Oral rinses are administered four times daily while the patient is awake, beginning on the first day of the stem cell conditioning regimen. Assessments begin prior to transplant (Day -1) and are continued until 20 days posttransplant (Day +20) or discharge from the hospital, whichever comes first. Study participants are randomly assigned to Caphosol or to placebo saline rinses. The oral rinse, either Caphosol or placebo saline, is supplied in two syringes (see diagram), which are mixed together immediately prior to administration, and must be directly observed by the nurse to ensure proper administration. Four scales are used for OM assessments in the following order: (1) the OMDQ (oral mucositis daily questionnaire), (2) the mouth pain categorical rating scale, (3) the WHO Oral Mucositis Scale, (4) and the ChIMES.

Nurses have an especially important role in this study because we
• educate the patient and family to perform the oral rinses correctly
• are responsible for mixing the rinse solution, which must be done immediately prior to use
• directly observe oral rinse administration
• perform the mucositis assessments.

With strong nursing representation on the COG ACCL1031 study team and well-informed involvement of nurses in participating institutions, this study can help develop the evidence in symptom management for children by addressing one of the most distressing symptoms associated with treatment.

Guidelines for Administration of Caphosol or Placebo

continued on page 15
Learn more about clinical trials for children with moderate to severe chronic pain

If you are a healthcare professional aware of a pediatric patient requiring analgesia who might be appropriate for and interested in participating in clinical studies, please contact Purdue Pharma L.P.’s Medical Services Department at:

Email: purduepediatrics@pharma.com

Phone: (Toll-Free) 1-888-726-7535; Option #1

Business Hours: Monday-Friday, 8 am – 5 pm EST (USA)
STEERING COUNCIL NEWS

New Telephone Triage Resource Helps Nurses Manage Patient Symptoms

Kristin Stegenga, PhD RN CPON®, Nurse Researcher, The Children’s Mercy Hospital, Column Editor

Soon you will have a new resource at your fingertips to use when you receive a call from parents with concerns about a symptom their child is experiencing. APHON’s new Telephone Triage Guidelines are coming soon! A team of volunteers led by Susie Burke and Meghan Belongia have been working for more than a year to pull together the best recommendations from the literature to guide your practice in this important area. You may have seen their poster at the 2012 conference.

The Steering Council is excited to provide this important resource to the APHON membership with information about legal obligations when providing information to parents and patients via the telephone as well as symptom management guidelines on a wide array of symptoms, including mucositis, pain, dysphagia, urinary retention, difficulty swallowing, fatigue, and many other symptoms that you encounter in your everyday practice as hematology/oncology nurses. These guidelines are in an easy-to-use, succinct format and will also include educational guidelines on sun safety, school issues, and alopecia, just to name a few.

The resource will be in a spiral bound book. There will also be a template included (via a media that will allow editing), which will provide nurses with a structure for documenting interactions with patients and families on the telephone. Nurses will be able to stop by the APHON booth at the 2013 APHON Annual Conference in Louisville, KY, to view this exciting resource publication. We are quite certain that this will provide useful information to your practice!
TREATMENT INNOVATIONS

From Killer to Savior: The Use of Inactivated Human Immunodeficiency Virus to Treat Oncologic Malignancies

Elizabeth Randall, BSN RN BC, Professional Development Educator II, St. Jude Children’s Research Hospital

Recently, the medical community was elated to learn of the complete remission of a 7-year-old female with acute lymphoblastic leukemia. She was originally diagnosed in 2010 and subsequently relapsed twice. The decision was made to use what could be considered a controversial and experimental therapy—a treatment that had only been administered to seven adults with a different form of leukemia than the type afflicting this young girl. Three of the seven adults achieved total remission, while the rest experienced partial or no remission.

The treatment involves encoding the patient’s own immune system to patrol for, identify, and attack the CD-19 protein located on the surface of both healthy and malignant B-cells. This is accomplished by harvesting the patient’s T-cells and genetically altering them by introducing what we have previously known as a killer, the human immunodeficiency virus (HIV). With this therapy, the virus has been rendered harmless and is used as a transport agent.

Under normal circumstances, HIV invades the T-cell, which then becomes a replicating HIV cell. This continues until the normal T-cells, approximately 1 million cells per milliliter of blood, are replaced and the individual develops active disease.

With this treatment, millions to billions of the patient’s T-cells are harvested and genetically altered to attack B-cells, and the disabled HIV virus is used to transport the altered genetic material into the T-cell. The cells are then referred to as chimeric antigen receptor cells and are returned to the patient intravenously to target the B-cells.

There is a familiar phrase that essentially says, if it doesn’t kill you, then it may just cure you. Such is the case with this treatment innovation. The patient experiences a cytokine storm often referred to as “shake and bake,” which involves extremely high fevers and bed shaking chills or rigors. Cytokines are released from cells, resulting in violent reactions such as high fevers, rigors, and potentially severe hypotension. Lung tissue can also be affected, and even death may occur.

Oddly enough, this violent reaction is actually an indication that the genetically altered cells are doing the job that they were designed to do. When the malignant cells are attacked and killed by the genetically altered T-cells, cytokines are released and the resulting reactions occur.

When this storm occurred in the young girl, she became comatose and had to be placed on a ventilator. Physicians and family members believed that she was dying. Fortunately, lab work indicated the patient showed a 1,000% increase in the cytokine, IL-6. Tocilizumab, a biologic modifier, was administered to lower the level of IL-6 with astounding results. She began to quickly improve and within 1 week was no longer comatose. At this time, she has achieved a 7-month remission. This drug has since been used in a variety of other patients.

This treatment innovation holds great promise, but it is not without equally great risk. It is hoped that the small contingent of the engineered T-cells remaining in the body after long-term remission is reached will repopulate in significant numbers, if needed, to wage another fight. However, as the T-cells attack both healthy and malignant B-cells, the patients must receive periodic infusions of immune globulin to protect from infections. Pediatric hematology/oncology nurses will be tasked to do what we do best—teach the patients and families about what to expect and the necessary treatments used to protect our patient population from these side effects.

There are questions that still remain regarding this type of therapy. Are there other malignancies, such as solid tumors, for which this treatment might also prove beneficial? Why did some patients not receive a full or lasting remission? Will it someday replace bone marrow transplantation as we know it? More work will be necessary, but one thing is certain—top-quality nursing care will be essential to our patients’ quality of life both during and after treatment.

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At the start of the New Jersey winter, on one of those cold days that always seems to come as a surprise for my patients with sickle cell disease, I saw a 7-year-old boy with pain crisis in our outpatient clinic. His mom, a “sickle cell pro,” knew exactly what she needed to do at home to keep her son well. What she needed on that day was morphine in liquid form, so I sent her home with a prescription. The next morning he was listed as an inpatient on our census. The pharmacy did not have the liquid morphine I prescribed, and ibuprofen alone was not enough to relieve his pain.

It seems that medication shortages have become the standard, not the exception, in pediatric hematology/oncology. Although our practice has struggled mostly with shortages of chemotherapy, pain medication scarcities have had their impact as well. Between September 2006 and August 2011, pain medications made up 9% of all reported shortages. Eighty percent of drug shortages involve generic medications. Almost our entire arsenal of pain fighters consists of generic drugs. Additionally, our most rapid and noninvasive way of relieving a child’s pain is intravenously. Injectable medications account for 80% of all drug shortages (IMS Institute for Healthcare Informatics, 2011).

Many reasons have been cited for drug shortages. There is very little profit in the production of generic medications. As a result, there are only a limited number of manufacturers for each generic drug. Should one of these manufacturers face a production crisis (e.g., a shortage of raw materials, aging production plants, or a failed safety inspection), the availability of the drug is drastically cut (Link, Hagerty, & Kantarjian, 2012).

The shortage of pain medications has many impacts on our pediatric hematology/oncology nursing practice. We may be asked to ration certain pain medications. Pharmacists may have to dispense medications past their expiration date. Prescribers may need to rely on less effective alternatives with which nurses may be unfamiliar. If we are not cautious, this could result in medication errors.

Brand-name drugs may be used, but these can be quite costly. In fact, a recent study estimated the cost of all drug shortages to the United States healthcare system to be $216 million annually (Kaakeh et al., 2011). We need to be cognizant of the fact that, unlike many generic medications, these alternatives could incur a prescription plan copayment, which the family may find challenging to meet.

What is the role of the pediatric hematology/oncology nurse with regard to pain medication shortages? We must:

• be aware of national pain medication shortages as well as our individual institutions’ supplies
• keep up to date on substitutions and their safety profiles
• work with the healthcare team to identify adjuvant medications and nonpharmacological pain management techniques that can limit the amount of a scarce drug that a child requires
• explore other delivery routes such as tablets or dermal patches
• strongly dissuade families from sharing medications prescribed to others as a way of dealing with a shortage
• caution families to make substitutions, such as crushed pills in place of liquid pain medications, only after reviewing them with the healthcare team
• verify with the family’s pharmacy prior to discharge from the clinic or hospital that the medications prescribed are available and covered by the prescription plan.

For more information, a complete and up-to-date list of medications in short supply, and frequently asked questions for families, visit www.fda.gov and click on the “Drugs” tab. For another great resource with more information and suggestions for dealing with drug shortages, visit the American Society of Health-Systems Pharmacists’ website, www.ashp.org.

The reference list for this article is available at www.aphon.org.
Antidepressant Doxepin Relieves Pain of Oral Mucositis

Head and neck cancer patients undergoing radiation therapy may be able to significantly reduce the pain associated with oral mucositis with an oral rinse containing the antidepressant doxepin, according to the results of a new study. The phase 3 study was led by the Mayo Clinic and presented in Boston at the American Society for Radiation Oncology’s annual meeting in October 2012. The researchers enrolled 155 head and neck cancer patients receiving radiation therapy who reported a pain score of 4 or more for mucositis on a 10-point scale. During the 2-day study, participants received either a single dose of doxepin (25 mg in 5 ml water) or a placebo on the first day, and then switched over to the opposite group on the second day. All participants completed a pain questionnaire that asked them to describe their pain associated with oral mucositis on a scale of 0 to 10 at 5, 15, 30, 60, 120, and 240 minutes after the doxepin rinse. Overall, patients who received doxepin reported a larger reduction in pain than those who received the placebo (-9.1 versus -4.7). The pain reduction peaked at the 30-minute mark for doxepin. After the study was completed, 64% of patients elected to continue doxepin. Although the doxepin was well tolerated, patients reported three adverse effects that were more common in those who received the doxepin compared with those in the placebo group: increased stinging/burning (mean pain score, 3.7 versus 1.1), unpleasant taste (mean unpleasant taste at 5 minutes, 2.9 versus 1.6), and greater drowsiness (mean drowsiness score, 3.9 versus 2.8). Although further research is needed to confirm the results, the researchers expect doxepin to become the new standard of care for cancer patients with oral mucositis in the future.


Cancer Symptoms Eased by Foot Massage

A new study reports evidence that reflexology performed on the feet can help cancer patients manage their symptoms and perform daily tasks. Reflexology is based on the idea that stimulating specific points on the hands and feet can improve the functioning of other parts of the body. This study is the first large-scale, randomized study of reflexology as a complement to standard cancer treatment. The study involved 385 women undergoing chemotherapy or hormonal therapy for advanced-stage breast cancer. The women were divided into three groups: some received treatment by a certified reflexologist, others got a foot massage meant to act like a placebo, and the rest had only standard medical treatment and no foot manipulation. The participants were surveyed about their symptoms at intake and then again after 5 and 11 weeks. The reflexology group reported less shortness of breath, and the participants were also better able to perform daily tasks such as climbing a flight of stairs, getting dressed, or going grocery shopping. According to the researchers, the effects of the reflexology appeared to be primarily physical, not psychological. An unexpected result was that the placebo foot massage group reported reduced fatigue, a result not reported by the reflexology group. The reflexology did not reduce pain or nausea. Health researchers are only beginning to study reflexology, and further research is required to confirm the results of this study.

Sleep-Wake Disturbances in Children and Adolescents Undergoing Cancer Treatment

Amy J. Walker, PhD RN, Assistant Professor, University of Washington, Department of Family and Child Nursing

Sleep is a complex, integrative process essential for survival. Children and adolescents who are undergoing cancer treatment are at risk for developing sleep-wake disturbances. These disturbances result from normal developmental changes in sleep, disease and treatment factors, and sleep hygiene behaviors (often in combination). Developmental changes in sleep patterns and duration occur during childhood. Daily sleep duration declines from 16–20 hours in newborns to 11–12 hours for young children and then to 9 hours for adolescents. Sleep patterns become more consolidated over childhood, and daytime naps usually end by early school age (Division of Sleep Medicine at Harvard Medical School, 2008).

During adolescence, the timing of sleep is delayed and adolescents go to bed later despite earlier school start times, which results in short sleep durations (and sleep deprivation) on school days and weekend oversleep. This pattern leads to unstable sleep patterns with large discrepancies between bedtimes and waketimes on school days and weekends (Carskadon, Acebo, & Jenni, 2004).

Cancer diagnosis and treatment introduces a myriad of additional factors associated with sleep-wake disturbances, including changes in routines, hospitalizations, physical and psychological symptoms, chemotherapeutic agents, supportive and symptom management medications, daytime sleep, and inactivity. My doctoral dissertation study explored sleep-wake patterns and sleep-hygiene behaviors in adolescents age 10–19 years at home the week following intravenous chemotherapy administration, using wrist actigraphy and standardized questionnaires (Walker, Johnson, Miaskowski, & Gedaly-Duff, 2012; Walker, Johnson, Miaskowski, Lee, & Gedaly-Duff, 2010). Despite meeting or exceeding the recommended sleep duration for their age group (i.e., 9–10 hours; Mindell & Owens, 2003), these adolescents averaged 1.25 hours of wake time during the night, suggesting disrupted sleep. Increased nocturnal wake time is the most consistent research finding for sleep in children and adolescents with cancer in the hospital and at home (Hinds, Hockenberry, Rai, et al., 2007; Hinds, Hockenberry, Gattuso, et al., 2007; Walker et al., 2012). Although sleep experts suggest that healthy adolescents need about 9 hours of sleep per night (Carskadon et al., 2004), the sleep need of adolescents with cancer is unknown but likely higher. Unlike healthy adolescents who exhibit large discrepancies between bedtimes and waketimes on schooldays and weekends, the adolescents in my study did not exhibit the dramatic differences between weekday and weekend sleep patterns. Although they went to bed later, they woke up later because they were not attending school, much like healthy adolescent sleep patterns on weekends. Unfortunately, when they return to school, they will have to adjust to early school start times in addition to their long school absence.

Healthcare providers should assess for sleep-wake disturbances in all children and adolescents undergoing cancer treatment. They often go unreported simply because patients and families expect sleep-wake disturbances as an inevitable part of cancer treatment. Good sleep quality is defined as a period of restorative sleep that meets an individual’s sleep-related needs and allows for optimal daily functioning. A child or adolescent with good sleep quality goes to bed easily at bedtime, transitions effortlessly from wakefulness to sleep, maintains sleep without disruptions, reinitiates sleep if aroused, and transitions easily in the morning from sleep to wakefulness (Berger et al., 2005). Sleep-wake disturbances can occur at any of these transitions: going to sleep, staying asleep, and waking in the morning. A thorough assessment should include questions about each of these transitions. These questions may include: Do you have trouble going to sleep at night? Staying asleep at night? Waking up in the morning? Do you take naps during the day? How often and how long? If yes (to any of the questions), what do you think is causing your sleep problem? How do you manage it? How is this working for you? Answers to these questions may reveal important information about symptoms, worries and concerns, and self-management strategies, which often include using medications ordered for other purposes, exploiting the side effect of sleepiness (e.g., diphenhydramine, opioids, antiemetics). This information can be used to identify appropriate pharmacological or behavioral interventions.

Currently, evidence-based interventions to improve sleep in children and adolescents with cancer are not available, likely due to the complexity of childhood cancer treatment and relatively small numbers of patients. A thorough assessment can reveal targets for improvement such as the timing of corticosteroids (i.e., take doses earlier in the day if protocol allows), napping for shorter periods or earlier in the day, and increasing physical activity even by a small amount. Medications specifically made for sleep (e.g., zolpidem, eszopiclone) may be indicated to facilitate sleep without the hangover effects of other drugs. Promoting positive sleep hygiene behaviors (i.e., sleep facilitating behaviors) at home and in the hospital will likely have the greatest yield. Positive sleep hygiene behaviors include quiet time with dim light and avoiding stimulation from televisions, computer screens, and cell phones in the hour before bedtime. Journaling, meditation, and listening to music may also help facilitate sleep by calming the mind.
Sleep-Wake Disturbances in Children and Adolescents Undergoing Cancer Treatment

Promoting sleep can be especially difficult in the hospital. I would like to see a culture change in which sleep is prioritized in hospitalized children and adolescents. Interventions should include making and following a bedtime plan in the hospital, limiting the number of room entrances and exits, and turning the television off prior to bedtime. Hospitalized adolescents should also be encouraged to adhere to an appropriate bedtime, rather than staying up all night talking with staff. These practices will improve sleep not only while they are in the hospital, but also when they go home. Also keep in mind that sleep patterns and behaviors that are developed during treatment can be very difficult to break and can make returning to normal school routines more difficult.

The reference list for this article is available at www.aфон.org.
mucositis (Clinical Affairs Committee, 2008; Djuric, Hillier-Kolarov, Belic, & Jankovic, 2006; McGuire, Correa, Johnson, & Wienandts, 2006).

Oral care is a low-cost and often underutilized approach for prevention of this distressing side effect of cancer treatment. Even though routine oral care is recommended (Bensinger et al., 2008; Farrington & Cullen, 2010; Harris, Eilers, Harriman, Cashavelly, & Maxwell, 2008; Keefe et al., 2007; Worthington, Clarkson, & Eden, 2007), evidence suggests that clinicians’ knowledge of oral care is limited (Barker, Epstein, Williams, Gorsky, & Raber-Durlacher, 2005; Binkley, Furr, Carrico, & McCurren, 2004; Potting, Mank, Blijlevens, Donnelly, & van Achterberg, 2008) and nurses’ skills with oral care need improvement (Potting et al., 2008).

Implementation of multidisciplinary oral care regimens must address patient and family education, patient screening and treatment by dental professionals, oral assessment, brushing, flossing, rinsing, lip care, and dietary considerations. A brief description of practice recommendations follows.

**Patient and Family Education**

Educational brochures (English and Spanish versions) that are available for free highlight the impact of cancer treatment and prevention strategies (U.S. Department of Health and Human Services, 2009a, 2009b). However, healthcare professionals often overlook the first critical step, which is evaluation of current oral care practices of the patient and family. Children and families may have barriers to good oral health. The variability among patients’ baseline oral care practices emphasizes the need for nurses to individualize patient education while highlighting all of the multifaceted components.

**Patient Screening and Treatment by Dental Professionals**

If possible, dentistry consults or visits should occur before chemotherapy or radiation treatments begin so the mouth is as healthy as possible going into treatment (U.S. Department of Health and Human Services, 2009a, 2009b), and regular dental visits should continue during treatment.

**Oral Assessment**

For hospitalized patients, assessment of the oral cavity must occur at least daily using a validated tool (Jaroneski, 2006; Keefe et al., 2007; Peterson, Keefe, Hutchins, & Schubert, 2006) such as the Oral Assessment Guide (OAG) developed specifically for nurses (Eilers, 2004; Eilers, Berger, & Petersen, 1988; Farrington, Cullen, & Dawson, 2010; Knoos & Ostman, 2010; Luke, 2006). At home, oral cavity assessments must be completed daily with changes communicated to the healthcare team (U.S. Department of Health and Human Services, 2009a, 2009b).

**Brushing**

Patients need to brush their teeth (or have them brushed) at least twice a day for 2 minutes using an ultrasoft toothbrush (Antunes et al., 2010; Harris et al., 2008; McGuire et al., 2006) as well as Biotene® toothpaste (Epstein, Emerton, Le, & Stevenson-Moore, 1999; Jyoti, Shashikiran, & Reddy, 2009; Nagy, Urban, Fazekas, Thurzo, & Nagy, 2007; Warde et al., 2000).

**Flossing**

Flossing should continue daily with waxed floss, avoiding areas that are sore or bleeding (U.S. Department of Health and Human Services, 2009a, 2009b), if white blood cell and platelet counts are at acceptable levels (Farrington & Cullen, 2010).

**Rinsing**

Bland rinses, such as salt and soda, should be started and done at least four times daily as soon as redness or breakdown of the oral mucosa is noted (Harris et al., 2008; McGuire et al., 2006; Scarpace, Brodzik, Mehdi, & Belgam, 2009; Vokurka et al., 2005).

**Lip Care**

Assessment of a patient’s lips should occur at least twice daily, and lanolin-based products should be applied (Schubert, Peterson, & Lloid, 1999; Semba, Mealey, & Hallmon, 1994; Stone, 2000). Common petrolatum-based lip care products fail to moisturize and may promote bacterial growth (Barker, Barker, & Gier, 2000).

**Dietary Considerations**

Patients should be encouraged to choose soft, easy-to-chew foods and to avoid hot foods, foods with sharp edges, tobacco products, and alcoholic drinks (U.S. Department of Health and Human Services, 2009a, 2009b).

Future research efforts must focus more on these specific components, methods, and frequencies of oral care and which evidence-based products should be used, as these practice recommendations are yet to be standardized. Additional research is also needed to guide management of pain related to oral mucositis.

This shift in focus to preventative health care supports current literature about getting back to the basics of foundational nursing care, which is often forgotten and neglected in our current fast-paced, technology-driven settings (Kitson, Conroy, Wengstrom, Profetto-McGrath, & Robertson-Malt, 2010; Pipe et al., 2012). The hope is that the promotion of good oral health during cancer treatment will promote lifelong habits related to the importance of oral hygiene for both pediatric patients and family members.
Accurate and trustworthy study results depend on these critical nursing functions. For this reason, all staff members involved in assessments for COG ACCL1031 are required to complete COG protocol-specific live webinar training before the study can be activated at the institution. The training includes instruction about accurate mucositis assessment, oral rinse preparation and administration, documentation, and completion of case report forms. Training is essential to reduce the risk of variability in mucositis grading that can occur in assessments performed by different individuals. Providing this training helps to maintain rater consistency and obtain valuable data to answer the study question about Caphosol’s effect on OM.

Almost a decade ago, Hockenberry (2004) reviewed the literature on symptom management in children with cancer and noted that, “Limited knowledge exists regarding pain and suffering caused by mucositis during treatment for childhood cancer. Even less is known regarding interventions that are most appropriate and most effective for use in children. Frequently, adult intervention strategies are implemented that are not tolerated by children. Research is needed to examine more effective methods to prevent and manage mucositis in the future” (p. 134). With strong nursing representation on the COG ACCL1031 study team and well-informed involvement of nurses in participating institutions, this study can help develop the evidence in symptom management for children by addressing one of the most distressing symptoms associated with treatment. This is an area in which nurses can directly affect patient outcomes, such as reducing suffering and improving quality of life.
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