

NEWS FROM S·P·O·H·N·C



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Swallowing Dysfunction After Radiation Therapy For Head and Neck Cancer: Patient Considerations and Practical Suggestions

Jehee Choi, MD and Allen M. Chen, MD

The treatment of head and neck cancer often involves a lengthy course of radiation therapy, sometimes given with chemotherapy. Side effects of radiation therapy to the head and neck area are common and can significantly affect a patient's quality of life,



both during and after treatment. The most bothersome and limiting side effects include pain with swallowing, difficulty swallowing (dysphagia), dry mouth (xerostomia), loss of taste, and skin irritation. These issues often resolve gradually after completion of radiation therapy, sometimes with continued slow improvement for years. However, some of these issues do not return to pre-treatment baseline, which can pose a serious long-term problem.

Swallowing dysfunction, or dysphagia, is a well-established consequence of head and neck cancer and its treatment with radiation therapy.

Why does swallowing dysfunction develop after radiation?

Dysphagia is one adverse effect of treatment that can continue to cause problems for the patient after completion of radiation therapy. Swallowing is a complex process that involves multiple structures of the mouth and throat working in synchrony. Together,

the muscles of the oral cavity (tongue), pharynx, larynx, and esophagus work to complete each swallow movement through both voluntary and involuntary neural components. Radiation therapy, which can cause local inflammation of the esophagus, soft tissues, muscles, and blood supply, can lead to impairment of any of these structures depending on the patient's primary site of disease and disease presentation, factors that guide where the radiation beams will be targeted.

Dysphagia is caused when any part of the swallowing mechanism is impaired by treatment. If there is impairment of the oral and pharyngeal phase of the swallowing mechanism, such as limited range of motion of the oral tongue or base of tongue, movement of food to the back of the mouth can compromise the ability to eat. Laryngeal incompetence can lead to coughing or choking with swallowing, which can in turn lead to aspiration risk. Damage to the esophagus in the form of esophageal stricture, or fibrotic change of the esophagus, can prevent successful food passage into the stomach. Even after the resolution of pain with swallowing that is caused by acute inflammation of the throat, the patient can continue to find that swallowing is difficult. An inability to swallow adequately leads to a significant detriment to the patient's quality of life and overall health. The effect of dysphagia on self-esteem and ability to partake in social activities once taken for granted has also been shown to be significant.

What are symptoms of dysphagia?

In some cases, the presence of dysphagia is readily apparent, with the patient complaining of significant associated symptoms impeding normal daily activities. The most common complaint is that food seems to be "stuck" in the throat when eating. However, in others, dysphagia can take on a more indolent course. It is important to be aware of common symptoms of dysphagia in an attempt to diagnose the issue early and decrease the problems associated with chronic impaired swallowing.

Symptoms associated with dysphagia can include: difficulty controlling food in the mouth, inability to control saliva in the mouth or drooling, problems initiating swallowing, choking with eating, coughing/gagging with swallowing, pain with swallowing, wet-sounding voice, food or stomach acid backing up into the throat (reflux), regurgitation of food, unexplained weight loss, and recurrent pneumonia.

With any new or worsening pain with swallowing in the mouth or throat, the physician may need to rule out the presence of new or recurrent sites of cancer.

What can happen with prolonged swallowing dysfunction?

Long-term dysphagia can lead to many serious health issues. With impaired swallowing, the patient has limited ability to take in ample calories and liquids through the mouth, which can lead to weight

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Chris Leonardis

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 loss, malnutrition, electrolyte imbalances, renal dysfunction, and dehydration. Alternate routes of nutritional intake may need to be implemented, commonly in the form of a percutaneous endoscopic gastrostomy tube (i.e. PEG tube), through which food and liquids can be fed directly into the stomach. If swallowing function is not recovered, chronic PEG tube dependence can represent a quality of life challenge for patients, as well as a potential nidus of infection. Esophageal stricture, which causes a narrowing of the esophagus or “food pipe” due to fibrotic changes of the esophageal musculature, can limit the ability of food to pass into the stomach. This could lead to the need for esophageal dilation, in which a tube is placed down the esophagus to widen the esophageal opening and facilitate passage of food and liquids. Finally, aspiration, or the inhaling of food into the lungs, can lead to pneumonia, a serious and sometimes life-threatening infection of the lung.



Who is at risk?

Any patient receiving radiation therapy to the structures of the head and neck that contribute to swallowing is at risk for developing dysphagia. However, several studies have identified risk factors that may put the patient at higher risk of experiencing problems with swallowing after therapy. The addition of concurrent chemotherapy to radiation therapy is a well-established risk factor for increased likelihood of developing long-term dysphagia, with up to 50% of patients undergoing chemoradiotherapy experiencing this problem. This is because the chemotherapy sensitizes not only the tumor, as intended, to radiation therapy, but normal tissue as well. Other risk factors include location of the primary tumor, older age, advanced stage of disease, lymph node removal surgery of the neck after chemoradiation, weight loss, more than once daily delivery of radiation, and radiating both sides of the neck.

Studies are ongoing that are attempting to identify genomic patterns that may predispose the patient to more severe dysphagia. In addition, a large body of literature exists correlating the average radiation dose that is delivered to such structures as the pharyngeal constrictor muscles, larynx, and esophagus with dysphagia. These models have helped physicians predict who may be at greatest risk for developing swallowing dysfunction after radiation therapy.

How can swallowing function be assessed?

If there is concern for compromised swallowing function, several diagnostic studies are available to assess for the presence and severity of impaired swallowing. These include fiberoptic endoscopic evaluation of swallowing, videofluoroscopy, and modified barium swallow studies. These are outpatient procedures often performed by a speech therapist or speech pathologist, although at some centers, a specialized head and neck physician may perform these studies. These studies allow the examiner to visualize the swallowing mechanism in real-time and identify any structures that are not moving appropriately. Importantly, these studies also help determine if active aspiration is taking place due to impaired

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swallowing. Early diagnosis of dysphagia is critical so that appropriate interventions can be performed if needed.

Why is it important to see a swallow therapist before treatment?

There is increasing data that suggests that the initiation of swallowing therapy in the form of rehabilitative exercises prior to starting radiation leads to superior swallowing, nutrition, and quality of life. During this pre-treatment visit, the swallow therapist can assess for any current issues with swallowing, provide tips for diet modification as swallowing becomes difficult with treatments, and exercises that can promote the maintenance of muscles involved in swallowing. By adopting early swallow exercise habits, it has been shown that less structural damage to the muscles of the throat develops, weight is more readily maintained, and overall swallowing ability is improved. In addition, by maintaining some level of nutritional intake per mouth and performing swallow exercises throughout treatment, the likelihood of returning to a normal diet is up to 92%, versus 65% in those patients who did neither.

What is a PEG tube and when should its placement be considered?

A PEG tube is a short flexible tube that forms a connection between the inside of the stomach and outer surface of the body. These tubes are placed by a gastroenterologist or interventional radiologist. Through this tube, liquid nutritional supplements, water, and some crushed medications can be introduced into the stomach, thereby forming an alternate route for caloric intake and hydration. This device can be critically important for a patient with severe dysphagia.

PEG tubes can be placed prophylactically prior to starting treatment if the patient is already experiencing significant difficulty with swallowing, aspiration, or weight loss at baseline, in anticipation of worsening of dysphagia with the additional side effects that accompany treatment.

During treatment, if the patient begins to experience gradual worsening of pain and difficulty with swallowing and becomes severe enough to cause dehydration and inadequate nutritional intake/severe weight loss, urgent placement of PEG tube should

be considered. Intake through the PEG tube can be used to complement oral intake in this setting, with the combination of PEG and oral intake fulfilling the needed requirements during the remainder of therapy and the recovery period.

Finally, after completion of therapy, the patient can begin to experience worsening dysphagia due to subacute damage to certain structures, which can lead to laryngeal incompetence and esophageal stricture. Although less common, these scenarios should also be considered for PEG tube placement.

What procedures can be done to alleviate dysphagia?

One of the most important tactics that can help combat the development of chronic dysphagia is continued practice of the swallowing movement by the patient both during and after radiation therapy. Even with a PEG tube placed and without any current oral intake, swallowing practice is encouraged to prevent atrophy of the swallowing muscles.

Once dysphagia has developed, videofluoroscopic swallow studies, or the modified barium swallow study, can be used in an attempt to identify the specific cause of dysphagia, and can also help determine the type and consistency of food or liquid that is safe for the patient to eat. Depending on the underlying etiology of swallowing dysfunction, there may be a procedure that can help alleviate the issue. In the setting of esophageal stricture, esophageal dilatation can be performed to widen the narrowed, stenotic area of the esophagus, thus allowing more facile passage of food and liquid to the stomach. Botox injection into the esophageal sphincter musculature can help to relax the muscle, resulting in decreased interference with food transport to the stomach. In general, these procedures are performed by a gastroenterologist or thoracic surgeon.

What can the patient do to prevent and alleviate swallowing dysfunction?

- Practice swallowing frequently throughout the radiation course and thereafter.
- Limit diet to liquid and soft foods while recovering from acute radiation reaction to minimize pain.
- Avoid coarse and/or spicy foods

- Consider use of a straw to drink
- Avoid alcohol and tobacco
- Allow hot food to cool to room temperature prior to ingestion.
- Take small bites and chew thoroughly before attempting to swallow.
- Drink plenty of water, and even keep a water bottle at hand at all times, in order to combat the dry mouth that exacerbates dysphagia.
- If the patient frequently experiences coughing or choking when eating or drinking, consider referral to speech pathology for a swallow evaluation and assessment for aspiration risk.

Editors Note: Dr. Jehhee Choi is an Assistant Professor in the Department of Radiation Oncology at the University of Kansas School of Medicine. She is a graduate of Harvard College and earned her M.D. from the University of Texas Health Science Center in San Antonio. Dr. Choi just recently completed residency training at Kaiser Permanent Medical Center in Los Angeles, California and has interests in patient quality of life, survivorship, and safety initiatives in radiation oncology.

Dr. Allen Chen is Professor and Chairman in the Department of Radiation Oncology at the University of Kansas School of Medicine. He is a graduate of Cornell University, earned his M.D. from Yale University School of Medicine, and completed residency training at the University of California, San Francisco, School of Medicine. Dr. Chen is a leading expert in the management of head and neck cancers and is a frequently invited speaker for conferences across the world. He has particular interests in clinical trial development, medical education, and bioinformatics.



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Time For Sharing... "Stay Positive! Be Strong!"

My story is not about the beginning. We all know that story all too well. Sitting in an examining room nervously waiting for the doctor and the results of the tests. No matter how hard they might try, doctors can never force a smile when they greet you and get ready to tell you that you have cancer.

My news came on a sunny afternoon in July of 2007. I glanced at my husband. He was white as a sheet. At 60 years old, I had met the man of my dreams and now, 5 years later and after a week honeymoon in St. Croix, we had been married for 3 months. We had just moved from Florida to Joe's summer home in the beautiful mountains of WNC and had finalized plans for a complete renovation of the house. Time to change gears and no time for tears. "What do we do now?", I asked.

We were given an appointment at the Medical University of South Carolina, and on Sept. 11, 2007, I had my surgery. Twelve hours later and lots of stitching, a graft from my left thigh to replace the two thirds of my tongue they had removed, and, what they hopefully felt they had, clean margins. Five days later I wanted out and, much to my doctor's disapproval, they let me go. I had to promise to stay in Charleston for a couple of days to make sure everything stayed in place. It did, but a week later at home, I came unstitched. But that's another story.

I said this was not about the beginning, but folks are always curious to know what your experience was. So, in as small a nutshell as I could fit it, that's it. The surgery was followed by some ups and downs, radiation, and chemo. We all know how much fun that is. If you have not gone through this yet, don't let anyone tell you it's not so bad. What you do need to know is that you will get better. How long that takes depends on each person. Some of us are healthier to begin with when we start, some already have health issues. Other than the cancer, I was healthy as a horse. Even with that, it was a grueling experience. I'm not going to put lipstick on this pig. It will test you.

Now the story of how you get from the beginning to being a long term survivor. There are things you'll need to know to get there and a lot of it is not pretty. Your mantra needs to be, it will get better. I wish someone had told me this. It will be hard to believe a lot of the time, but you must hold onto that thought.

Don't be surprised if you get depressed. It would be surprising if you didn't. You might even feel like going into the woods, laying down under a tree, and going to sleep forever. I did. This from a very optimistic cheery person. Don't be ashamed or feel like you are a quitter. Life as you knew it is no longer the same. You are taking highly toxic drugs, and getting fried from radiation. You are sick and you feel sick. If you find that it's hard to focus, concentrate, or remember things, be sure to ask your doctor about "chemo brain". I didn't know about this and I thought I was losing my mind. It will get better.



I knew I had to do something to get myself back on track. I decided that as weak as I was, I would pick two things a day to accomplish. In the beginning it was taking a shower and walking to the end of our driveway. I barely made it with my husband's help, but after a couple of weeks we were walking around the neighborhood. Set simple goals for yourself. There will be set backs, days you can hardly hold up a newspaper, days you despair. It will get better.

Slowly over the next year, a few bumps in the road, a bout of pneumonia, and a ton of support from my husband, I slowly began making some headway. My amazing doctors were calling me their star patient and were very happy with my tests. I no longer looked out the bedroom window at the woods across the creek. Dark clouds were lifting and the sun was beginning to shine in. Things were getting better.

At my doctor's suggestion, I had a feeding tube (PEG) placed the week before my surgery. Thank goodness for that as the radiation left me with major scar tissue. I

cannot even swallow my saliva. I adjusted to this very well, but quickly got bored with canned "food". It only took a couple of months before I decided this was not going to be satisfactory. I had seen fruit smoothies in the dairy department and decided to try making some at home. Yay! Real food. This is getting better.

In the beginning you will not have much of an appetite and, in fact, food might not even taste the same. With head and neck patients, dry mouth is a huge issue. Fortunately for me I had a saliva gland surgically moved and "hidden" from radiation. If you are just starting out, check with your doctor and see if you would be a candidate for this procedure. I only found out about this after they told me I would have to have my teeth extracted. I'm a retired dental hygienist and, when I heard this, I threw the hissy fit of all time. No way was this happening. My reconstruction surgeon had just finished a study on moving the saliva gland and agreed to perform this procedure on me. This was almost 10 years ago and it might be something they do regularly now. Things are getting better every day.

I was making smoothies every day and within a very short time noticed that my energy level had really improved. I slowly started gaining some weight back, as well. I found a recipe for a beef, vegetable, barley soup that you make in the crock-pot. I was pretty sure I had a crock-pot somewhere and went to look for it. Sure enough, there it was, still in the box it came in. Made it the next day, husband loved it, and it blended up beautifully. Thinned it with some 2% milk and down the tube it went. The crock pot has a place of honor on my kitchen counter and I use it often. The vegetables don't over cook and whatever kind of meat you use is very tender. I now "eat" everything my husband does and thoroughly enjoy my food. Your sense of smell becomes more acute and makes up for your sense of taste. I love to cook and have dozens of recipes that I blend that are delicious and healthy. Life couldn't be better.

There is a learning curve to this survival business. Patience, not my strongest suit, is going to be the key to getting through this. So many obstacles to overcome. There are two good sources for information and support. SPOHNC, of course, and for folks

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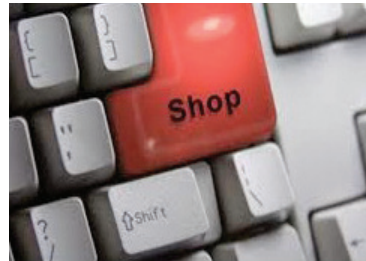
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with feeding tubes, like me, the OLEY Foundation. My nutritionist was aghast when I told her I was blending food and pouring it down my tube. She was sure I would not be getting the nutrition that I needed. That was almost nine years ago and my G.P. recently told me she wished all her patients were as healthy as I am. Always working toward making my life better.

Next year will be my 10 year anniversary. Time flies when you are having fun. We hike, bike, go to the gym, and travel with our motor home. We still live in WNC, one of the most beautiful places on earth. Ten years ago, with the level of cancer I had, it looked like I would be lucky to still be around in a couple of years. Ten years ago, prognosis for long term survivors was bleak. Ten years ago, I had an amazing team of doctors, nurses, and technicians that saved my life. Once they had done their jobs, it was up to me. The only thing I didn't have, was someone to tell me that things would get better. I'm here to tell you, things will get better.

~ Kathleen Godwin
Kateyes928@aol.com

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In Memoriam

Cynthia S. Gilliam - SPOHNC Norfolk, VA Chapter Facilitator

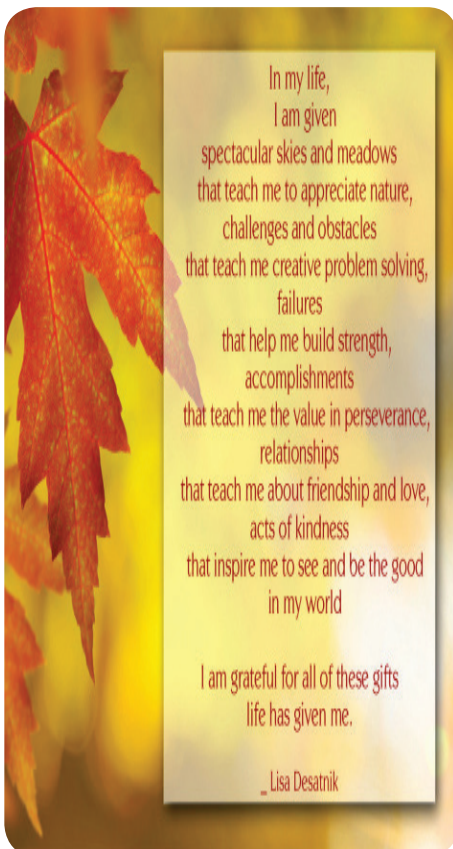
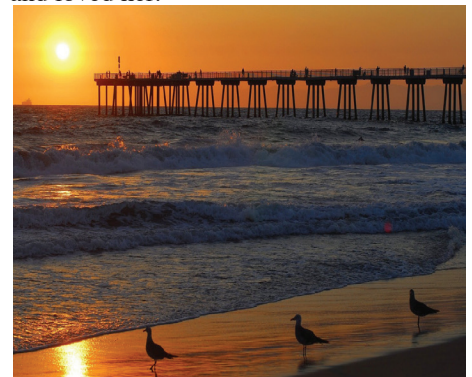
SPOHNC was deeply saddened to learn of the recent passing of SPOHNC's Norfolk, VA Chapter Facilitator, Cynthia S. Gilliam.

Cynthia was loved and cared for by her family, especially her daughter and son, grandson, her father and siblings, along with cousins, nieces and nephews. Her SPOHNC Chapter attendees were always inspired by her courage and bravery, as she continued to support those who needed hope, even while in the midst of her own cancer journey. She was a very special person.

Cynthia always put others needs before her own. She shared a special bond with those who attended her SPOHNC Chapter support group meeting each month. She was an incredible woman of such great strength and grace.



Cynthia's involvement in her community, including her church and the SPOHNC Chapter, and her love for the ocean brought many friendships to life. Her friends will miss her bright spirit, her sense of humor and all that she brought to those whom she knew. Her loss will be felt by many as they continue to remember and care for her family and legacy. SPOHNC will keep Cynthia and her family and friends in our thoughts and prayers as we extend our deepest sympathies to all who knew and loved her.



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SPOHNC, Jim Kelly and “Teammates” Partner For Your Cancer Game Plan

SPOHNC recently partnered with Football Hall of Famer Jim Kelly, Merck, the Head and Neck Cancer Alliance, and Savor Health to launch the *Your Cancer Game Plan* campaign. This program will provide people living with head and neck cancer and their caregivers with tools and resources designed to help each patient stay positive and hopeful.

In 2013, Jim Kelly was diagnosed with head and neck squamous cell cancer. Playing professional football was challenging, but fighting head and neck cancer was harder. Jim was blessed with a wonderful support system that helped him along his cancer journey, but he knows that some people aren't so fortunate.

Your Cancer Game Plan recently kicked off with Jim Kelly and SPOHNC's Executive Director, Mary Ann Caputo, participating in a nationwide media tour. More than 20 TV and radio stations interviewed Jim and Mary Ann live from across the United States! During the media

tour, they spoke about the importance of support, and reminded their audience about the FREE *Your Cancer Game Plan* webinar that was held on October 19th. It was a very exciting day for SPOHNC!

During the webinar, the partners in *Your Cancer Game Plan* talked about nutrition, emotion and communication when dealing with a cancer diagnosis. Webinar partners took questions from a live audience and lots of great information was shared, to help those who have been affected

by the diagnosis and treatment of oral head and neck cancer.

Following the webinar, 3 amazing individuals from our SPOHNC family were videotaped as they shared their heartfelt stories. Dennis Staropoli, SPOHNC's Stony Brook, NY Chapter Facilitator, and Maria and Tom Folchetti, SPOHNC Syosset Chapter attendees, travelled to New York City to join SPOHNC, Merck, Jim Kelly and partners for the day. Survivors Dennis and Maria, and caregiver, Tom, can

surely speak to the importance of support. SPOHNC is grateful to each of them for taking the time to answer questions and speak from their hearts about all that they went through during the most challenging time of their lives.



In case you missed it, the webinar is still available to view at spohnc.org. For new registrants, click on the “REGISTER NOW” button and fill in the registration information. Please select SPOHNC as the website that directed you to the page. Once you have completed and submitted your registration, you can view the webinar. If you have previously registered, click on REGISTER NOW, enter your e-mail address and log in to view the webinar.

Join SPOHNC and Football Hall of Famer Jim Kelly as we discuss motivational tips, nutritional guidance and the role of communication between caregivers, friends and family. **Look for additional information in the coming months.** We hope you gain valuable information from *Your Cancer Game Plan*. Let us know what you think!

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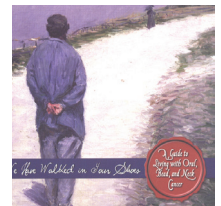


SPOHNC is seeking your selfies, for our December “Family of Faces” feature.

If you participated in our last “Family of Faces” feature, please send us a new photo. If you've never been a part of our Family of Faces, send us your photos today! In order to be included in the feature, photos must be received by no later than November 18th.

Send your selfies to c.leonardis@spohnc.org. We look forward to celebrating survivorship this holiday season through our December “Family of Faces.”

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Head and Neck Cancer News

Certain head, neck cancers associated with chronic sinusitis

October 27, 2016 - The recent approval of Chronic sinusitis appeared associated with an increased risk for head and neck cancer in elderly individuals, according to study results published in JAMA Otolaryngology–Head & Neck Surgery.

Chronic sinusitis was particularly associated with nasopharyngeal cancer and nasal cavity and paranasal sinus cancer. However, the majority of this risk appeared limited to 1 year within chronic sinusitis diagnosis.

Chronic sinusitis may be associated with head and neck cancer, due to inflammatory damage or local immunodeficiency. The risk for specific head and neck cancers in individuals with chronic sinusitis has not been widely studied.

Daniel C. Beachler, PhD, MHS, who served as a cancer prevention fellow in the division of cancer epidemiology and genetics at the NCI during the conduct of this study, and Eric A. Engels, MD, MPH, senior investigator in the division of cancer epidemiology and genetics at the NCI, conducted a case-cohort study to determine whether a diagnosis of chronic sinusitis increased the risk for nasopharyngeal cancer, HPV-associated oropharyngeal cancer, and nasal cavity and paranasal sinus cancer.

Beachler and Engels used the SEER–Medicare database to identify a random cohort of 483,546 individuals (mean age, 72.6 ± 8 years; 57.7%), 18,759 of whom developed chronic sinusitis between 2004 and 2011.

Factors associated with the development of chronic sinusitis included younger age, female sex, non-Hispanic white race and the presence of other upper airway conditions ($P < .001$ for all).

The entire source population included 826,436 cases of cancer, including 21,716 individuals with head and neck cancer.

Beachler and Engels observed a modest increase in the risk for head and neck cancer in individuals with chronic sinusitis (adjusted HR = 1.37; 95% CI, 1.27-1.48).

The risk persisted for head and neck cancer subtypes, including HPV-associated oropharyngeal cancer (adjusted HR = 1.33; 95% CI, 1.13-1.57) and laryngeal cancer (adjusted HR = 1.54; 95% CI, 1.35-1.76). The

greatest risks occurred for nasopharyngeal cancer (adjusted HR = 3.71; 95% CI, 2.75-5.02) and nasal cavity and paranasal sinus cancer (adjusted HR = 5.49; 95% CI, 4.56-6.62).

Chronic sinusitis did not increase the risk for lip cancer, tongue cancer or mouth cancer.

Researchers observed that these associations appeared largely driven by risk during the first year after chronic sinusitis diagnosis, particularly for nasopharyngeal cancer (adjusted HR = 8.88; 95% CI, 6.3-12.5) and HPV-associated oropharyngeal cancer (HR = 1.99; 95% CI, 1.56-2.53). These risks attenuated after 1 year (nasopharyngeal cancer, adjusted HR = 1.6; 95% CI, 0.96-2.65; HPV-associated oropharyngeal cancer, adjusted HR = 1.07; 95% CI, 0.86-1.32).

The risk for nasal cavity and paranasal sinus cancer also appeared most pronounced in the first year after chronic sinusitis diagnosis (< 1 year vs. 1 year: adjusted HR, 12.53 vs. 2.47).

The cumulative incidence of each head and neck cancer subtype among individuals with chronic sinusitis reduced to less than 0.07% after 8 years.

When evaluating all cancers, individuals with chronic sinusitis had an 8% increased risk for any cancer (adjusted HR = 1.08; 95% CI, 1.06-1.1).

Beachler and Engels acknowledged study limitations, including the lack of data on tobacco use, viral status of head and neck cancers, and the duration of chronic sinusitis.

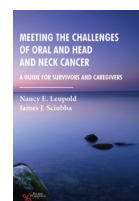
“This is one of the first studies to demonstrate associations of chronic sinusitis with HPV-associated oropharyngeal cancer, nasopharyngeal cancer, and nasal cavity and paranasal sinus cancer,” Beachler and Engels wrote. “The head and neck cancer risks within 1 year of chronic sinusitis diagnosis support that these associations can be explained in large part by artifacts such as surveillance bias, reverse causation, or diagnostic confusion.

Whereas an etiologic contribution of sinusitis-related inflammation or immunodeficiency to head and neck cancer cannot be excluded, this study suggests that they do not play a large role in promoting the early or intermediate carcinogenic stages of head and neck cancer.”

The findings of this study are limited by the older patient population, Elisabeth H. Ference, MD, MPH, rhinology and skull base fellow at UCLA Health, and Jeffrey D. Suh, MD, associate professor-in-residence in the department of head and neck surgery at UCLA’s David Geffen School of Medicine, wrote in an accompanying editorial.

“Future studies are necessary to consider whether inflammation in patients with sinusitis contributes to tumorigenesis, especially in middle-aged adults,” Ference and Suh wrote. “A future prospective cohort or retrospective case-cohort study should include younger adults at risk for inflammatory or infection-related cancers over a period of sufficient duration to capture the long-term effects of these risk factors. Sinusitis may be a weak but modifiable risk factor in the development of head and neck cancer, and the association should be further explored in order to better inform patients in regards to surveillance and treatment.”

Meeting the Challenges of Oral and Head and Neck Cancer A Guide for Survivors and Caregivers - Second Edition



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At SPOHNC, we have been reflecting upon the importance of support, especially during the holiday season. Some of our recent partnerships have reminded us of how much “support” can mean to someone who may not have family or friends to help them along the way. Each day, with every phone call, e-mail and piece of mail, we are reminded of how thankful we are to be part of something so amazing. To be able to help others is such a joy. In going through some letters, we found this, and thought it was perfect to share with our readers as we all prepare our hearts and homes for the holidays. It truly speaks to the importance of support, in a unique and very special way.

May you all enjoy a blessed Thanksgiving...

Everyone,

Lewis and I want to wish you and your families the happiest Thanksgiving ever. Even though some of us are not going to be chomping down the turkey with quite the gusto of the past, there's always the mashed potatoes and gravy to look forward to.

Since this is a time to count your blessings, we wanted you to know that this group is a blessing to us. The fact that you have made it into a family, makes it very special. Your support of others has made a big difference. We are proud to be a part of it.

~ Amy & Lewis Beilman, SPOHNC
Palm Coast, FL, Chapter Facilitators

AT THE END OF
THE DAY IT'S NOT
ABOUT WHAT YOU HAVE
OR EVEN WHAT YOU'VE
ACCOMPLISHED... IT'S
ABOUT WHO YOU'VE
LIFTED UP, WHO YOU'VE
MADE BETTER. IT'S
ABOUT WHAT YOU'VE
GIVEN BACK.

DENZEL WASHINGTON

Coming Up
Next . . .

*The December issue of
“News From SPOHNC”
will bring many exciting gifts
your way for the holiday season.*

Read about:

**Eat, Drink and Be Merry -
Nutrition for the Holidays and
New Year**

SPOHNC's Family of Faces

Your Cancer Game Plan

Head and Neck Cancer News

Genetic Variants Tied to Head and Neck Cancer Pain

October 11, 2016 - A genome-wide association study has tied common genetic variants to pre-treatment pain, a finding with potential implications for precision medicine-based therapy decisions for patients with squamous cell carcinoma of the head and neck (HNSCC).

Study findings were published in the Sept. 27 issue of Nature's Scientific Reports. The investigation was led by a multidisciplinary team including principal investigator Cielito Reyes-Gibby, Dr.PH., associate professor and research director of Emergency Medicine; co-principal investigator Sanjay Shete, Ph.D., professor of Biostatistics and Epidemiology; and co-investigator Ehab Hanna, M.D., professor of Head and Neck Surgery and medical director of the Head and Neck Center.

“We conducted this study because our previous studies have shown that pain at the time of diagnosis is an important prognostic marker for development of chronic pain, frequent visits to the emergency center, and overall survival time. Survival rates for patients with higher levels of pain are significantly

shorter than for those with less severe pain,” Reyes-Gibby said.

A review of 2,340 HNSCC patients revealed that oral cancer patients with severe pain had a 31 percent five-year survival rate versus 52 percent for those with less severe pain, Shete explained. Likewise, pharyngeal cancer patients with severe pain had a five-year survival rate of 33 percent versus 53 percent for those with less severe pain.

“In this genome-wide association study of pre-treatment pain, we identified variants influencing pain in 1,368 patients who were newly diagnosed with HNSCC and had not previously been treated for cancer,” said Reyes-Gibby. “We found three common genetic variants linked to severe pre-treatment pain, which maps to a gene known as RP11-634B7.4.”

“Pain prior to treatment varies among patients with HNSCC when they present in the clinic. Pain level variability can be due to several factors

such as site and stage of disease. The clinical implications of our findings are huge in the care of these patients, given that we can potentially intervene early by understanding their genetic makeup,” Hanna said.

“Furthermore, substantial individual variability is observed in pain sensitivity and analgesic response,” Reyes-Gibby added. “Adding to this complexity is the fact that opioids, the drug of choice for cancer pain, can be neurotoxic, with repeated dose escalation leading to increased tolerance.”

The researchers believe that the finding may be important for precision medicine, which aims to consider each patient's genetic, environmental, and lifestyle characteristics when developing and assigning treatment.

Other study team members include Jian Wang, Ph.D., assistant professor and Robert Yu, senior statistical analyst, both of Biostatistics.

The study was funded by the National Institutes of Health.

###

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Head and Neck Cancer News

As Parents Consider the HPV Vaccine, the Message Matters

An article published October 6, 2016 on blog.aacr.org, the American Association for Cancer Research's official blog

In examination rooms all around the country, a big decision turns on a single moment. A pediatrician tells a parent that his or her adolescent should be vaccinated against the human papillomavirus (HPV). Some parents have already made their choice. Others will decide on the spot.

A study published last week in *Cancer Epidemiology, Biomarkers & Prevention (CEBP)*, a journal of the American Association for Cancer Research, showed that the words the physician uses may have a strong influence on that decision.

HPV causes most cases of cervical cancer and a large proportion of vaginal, vulvar, anal, and penile cancers. It is also a risk factor for oropharyngeal cancers. The U.S. Centers for Disease Control and Prevention (CDC) recommend that boys and girls receive the three-dose HPV vaccination beginning at age 11 or 12. However, as of 2015, only 42 percent of girls and 28 percent of boys ages 13 to 17 had completed the HPV vaccine series, according to CDC statistics.

In February, the nation's 69 NCI-Designated Cancer Centers released a consensus statement that called the low HPV vaccination rates a "serious public health threat." Researchers believe there are many reasons for the low uptake, but one major factor is that physicians don't always recommend the vaccine at the right time or in the full three doses, according to a study published in *CEBP* in October 2015.

In the study published last week, Teri L. Malo, a postdoctoral research associate at the UNC Lineberger Comprehensive Cancer Center and the Department of Health Behavior, Gillings School of Global Public Health, at the University of North Carolina at Chapel Hill, set out to evaluate whether the specific language used by physicians would influence parents' decisions, and whether physicians would be more likely to use specific messages.

Malo and colleagues tested 15 messages with 1,504 parents of adolescents ages 11-17 and 776 primary care physicians. Nine

of the messages were previously approved by the CDC. Malo and her team developed six additional messages.

The most persuasive, with 65 percent of parents and 69 percent of physicians endorsing it, was: "I strongly believe in the importance of this cancer-preventing vaccine for [child's name]."

Malo was surprised to discover that even parents who told the researchers that they were considering not having their children vaccinated against HPV said they could be persuaded by some of the messages. For example, 59 percent of parents said they would be persuaded by hearing: "[Child's name] can get [anal/cervical cancer] as an adult, but you can stop that right now. The HPV vaccine prevents most [anal/cervical cancers]."

Most of the 15 messages tested in the study were effective with at least half the parents. The least effective, which only 9 percent of parents said would persuade them to have their children vaccinated: "Would you wait until [child's name] is in a car accident before you tell [him/her] to wear a seatbelt?"

Malo said the study results indicate that physicians should talk to parents extensively enough to understand their concerns, and perhaps tailor their messages to address those specific worries. "It's important to understand what drives parents' hesitation so that we can help improve provider communication to decrease hesitancy about HPV vaccine," she said.

The HPV vaccine and school-entry requirements

William A. Calo, PhD, JD

Malo's study closely followed some interesting HPV vaccine research by one of her colleagues, William A. Calo, PhD, JD, a postdoctoral research associate in the Department of Health Policy and Management at Gillings.

Calo found that parents are more likely to support laws that would make the HPV vaccine mandatory for school entry if their state offers opt-out provisions, but he was quick to caution that such provisions may weaken the effectiveness of the vaccine

requirements.

School-entry requirements have contributed to high uptake rates for vaccinations such as Hepatitis B, Tdap, and MMR, Calo said. Since 2006, half of U.S. state legislatures have introduced measures to add HPV to the list of required vaccines, however, most measures were rejected, often due to parental disapproval or ethical, political, or legal concerns, Calo said. Presently, only Virginia, Rhode Island, and the District of Columbia require the HPV vaccine for school enrollment, and all allow parents to opt out.

- Noel Brewer, PhD -

In order to evaluate parental support for making the HPV vaccine mandatory for school entry, Calo and colleagues, including Noel Brewer, PhD, the study's senior author, professor of health behavior at the University of North Carolina, and a member of the UNC Lineberger Comprehensive Cancer Center, conducted a web-based survey of 1,501 parents of adolescents between November 2014 and January 2015.

The survey stated, "Some states are trying to pass laws that would require all 11- and 12-year-olds to get HPV vaccine before they are allowed to start sixth grade." Parents were then asked whether they agreed with the statement, "I think these laws are a good idea." Overall, 21 percent of parents agreed that such laws are a good idea, and 54 percent disagreed.

Respondents who said they disagreed then received this follow-up statement: "It is okay to have these laws only if parents can opt out when they want to." When the opt-out provision was added, 57 percent of respondents agreed that the school-entry requirements are a good idea, and 21 percent disagreed.

Calo cautioned that opt-out provisions could weaken the overall effectiveness of vaccination if large numbers of families opted out. He recommended that any states considering opt-out provisions should make sure that parents receive information about the vaccine and that physicians continue to encourage parents to vaccinate their children.

["HPV vaccination saves lives," Calo](#)
[continued on page 10](#)

continued from page 9

said. “We have an unprecedented opportunity to prevent thousands of HPV-associated cancers through vaccination and unfortunately, we are missing that opportunity.”

***An AACR Distinguished Lecturer
Adds Her Voice***

Many physicians, researchers, and policymakers have raised similar calls to action. Earlier this year, Electra D. Paskett, PhD, Marion N. Rowley Professor of Cancer Research and associate director of Population Sciences at The Ohio State University Comprehensive Cancer Center, wrote a column encouraging parents to consider their role in potentially preventing HPV-related cancers.

Paskett, who received the 2015 American Association for Cancer Research (AACR) Distinguished Lecture on the Science of Cancer Health Disparities, funded by Susan G. Komen, wrote, “Every parent should ask the question: ‘If there was a vaccine I could give my child that would prevent them from developing six different cancers, would I give it to them?’ The answer would be a resounding yes, and we would have dramatic decrease in HPV-related cancers across the globe. “A cancer vaccine exists; now people have to use it,” Paskett urged.

Happy Autumn!



Photo courtesy of PJ Jordan

Lentil and Sweet Potato Stew
from Eat Well Stay Nourished Volume 2

1 Tbsp. extra virgin olive oil
1 medium onion, chopped fine
2 garlic cloves, minced
Salt to taste
3 tsp. cumin seeds, lightly toasted and ground
2 medium carrots, diced
1 ½ c. brown or green lentils, rinsed
6 c. water
2 medium sweet potatoes, peeled and diced
1–2 chipotle peppers seeded/chopped to taste (can be omitted)
Tbsp. tomato paste
1 bay leaf
¼ c. chopped fresh cilantro or parsley to taste
lime wedges for serving(optional)



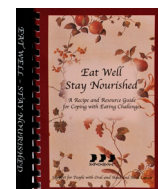
Heat olive oil over medium heat in large soup pot or dutch oven. Add onion and cook, stirring often, until it softens. Add garlic and salt to taste. Cook, stirring until the garlic is cooked. Add cumin, seeds and carrots. Stir together and then add the lentils, water, sweet potatoes, chipotle peppers (omit if desired), tomato paste, salt and the bay leaf. Bring to boil; reduce heat and cover. Simmer 20 to 45 minutes, until the lentils and sweet potatoes are tender and the broth is fragrant. Taste and adjust seasonings. Stir in cilantro or parsley. Simmer for a minute or two and serve. Lime wedges can be served so that diners can season their lentils as desired.

~ Louise E., New Jersey

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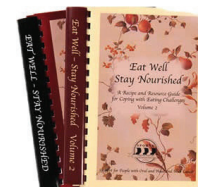
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