

HEADWAY

SINCE 2007

NEWS ON ADVANCES IN THE PREVENTION, DETECTION, AND TREATMENT OF HEAD AND NECK CANCERS

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Enhancing patient-centered care

By Carrie Fogel, *Director of Development, Eye & Ear Foundation*

When Marci Nilsen, PhD, RN, Assistant Professor in the Department of Acute and Tertiary Care in the University of Pittsburgh School of Nursing, and Jonas T. Johnson, MD, Chairman of the Department of Otolaryngology at the University of Pittsburgh, began their work to establish the Head and Neck Cancer Survivorship Clinic in 2016, they knew that the list of side effects and symptoms related to their treatment was long. Now, having operated the clinic for more than three years, Drs. Johnson and Nilsen are beginning to understand the most common symptoms that patients deal with, and are beginning to turn the data they have collected from their patients into bench to bedside research initiatives.

Dr. Nilsen knew that an important element of the Survivorship clinic was the collection of data using 'Patient-reported outcomes' (PROs). According to Dr. Nilsen, "The utilization of PROs encourages the patient to be engaged in their health care and allows their voice to be heard. For providers, this is essential in order to provide high-quality care." These measures allow for systematic and standardized collection of symptoms and treatment-related effects. The utilization and real-time evaluation of PROs in clinical practice can enhance patient-centered care and help healthcare providers to identify interventions to optimize the results a patient sees in his or her health. The 'patient-reported outcomes'



Dr. Johnson and Dr. Nilsen with a patient.

process of the clinic visits has provided tremendous insight into the struggles that head and neck cancer (HNC) patients have as they move through life post-treatment.

Drs. Johnson and Nilsen have identified three areas where research studies could provide important knowledge to the rapidly growing field of survivorship medicine: intensive symptoms management, cognitive decline in head and neck cancer patients, and the impact of caregiver burden.

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Becoming a survivor

By Jack Ganster

My story begins in Seattle. A native of Gibsonia, Pa., I have lived in Port Angeles, Washington since 1991, maintaining my friendships from the Pittsburgh area.

In the fall of 2003, I received a call – a few of the old gang were coming to the Steelers vs Seahawks game and would I like a ticket? Of course!

While we were enjoying the Steeler Nation crowd, my life changed forever. I was trying to repeat a sentence that I had just used...my ability to speak abruptly stopped. It was frustrating and frightening at the same time. I didn't have time to decide which emotion would win as I blacked out.

I woke up in a hospital bed with a bad headache, not knowing why I had passed out, but I vaguely remembered something with my speech and not being able to talk.

I was introduced to my new reality when a doctor escorted me down the hall, explaining I had just had a seizure. We came to a room full of images, an MRI of a brain – my brain. The fact was apparent. I had a brain tumor.

The feelings associated with this news are difficult to explain...shock and disbelief are a good place to start. I needed to absorb this information before I could act.

Hosting my friends offered a week of distraction and a form of therapy. It also helped with a time of transition – a process from former life to a future of uncertainty.

The doctors in Seattle told me that this was a serious matter, that the best course of action was to have it removed. They also told me that I had enough time to weigh my options.

At the time, I was married to my business, Olympic Mountaineering, but my partners could get by without me. Owning a business is like having your own family, but my real family was in Pittsburgh. It was time to go home. Plus, my mother said she would send someone out to get me if I didn't come back on my own – a classic "mom" statement.

I flew home on Christmas day and had a brief and purposeful time of denial as I enjoyed time with my family. Making the most difficult



Jack Ganster

decisions of my life could wait for the festive season to end.

My sister Kathleen signed up for being my second-in-command and we forged ahead. I was ready to make these decisions and prepare for battle.

I made appointments with two different brain surgeons in the same building on the same day. After meeting with each doctor, I chose who I wanted to do the surgery. In some regards you feel out of control, but I felt like I was interviewing the person who was going to save my life.

I had surgery as soon as possible. At the follow-up appointment, we were told "It's worse than we thought." The doctor soon followed up, saying the best course of action was to operate again to "clean up" the remaining questionable tissue. I had a glioma with some astrocytoma characteristics, and it was a grade two with grade three characteristics.

Somehow, I had thought that I would be alright. Now my world was collapsing.

This was the day that I became a **survivor**. I decided that being a survivor is a state of mind, not a state of body. That manifesting success could only help.

Being with family was so comforting and healing, but as much as this meant to me, my 'real life' was waiting for me and I was able to fly back to Washington in March.

This was a huge step for me – I needed to get back to a normal life. For me, this meant living a healthy and active lifestyle. Our store and guide service were born based on us wanting to share our love for the outdoor recreation that was so important to who we were.

I continued my fight by having radiation and continued to hold hope in my heart. That proved to be the end of my treatment. After many MRIs and 16 years, I have no evidence of disease.

As life went on, we sold the store, and each moved on with our lives. It was during this period of my life that I searched for a way to help other folks that had been diagnosed with cancer.

It soon came to me – if I could encourage and guide folks to have an outdoor experience before a cancer diagnosis – why couldn't I guide folks that have had a cancer experience?

Survivor's Outdoor Experience was born. SOE speaks to the healing power of nature and our ability to overcome. SOE began hosting "Healing Adventure Retreats" in 2010 in Port Angeles. The retreats bring a small group of survivors, of all stages in their cancer journeys, together for a weekend of informative presentations, activities, good food and sharing. Last year, the first SOE East Retreat was held at Chatham University Eden Hall Farm Campus in Pittsburgh.

Unfortunately, due to the Coronavirus pandemic, the 2020 Healing Adventure Retreat has been postponed.



Cancer survivors gather at a Healing Adventure Retreat in 2019.

Head and neck cancer patients continue treatment during COVID-19 with teletherapy

By Tami Wasserman-Wincko, MS, CCC-SLP, Director of Speech-Language Pathology, Department of Otolaryngology; Kelly Young, MA, CCC-SLP, Department of Otolaryngology



L-r: Tami Wasserman-Wincko and Kelly Young

Cancer care has continued despite the pandemic of COVID-19. Beyond the surgeries and chemotherapy, cancer care includes supportive and rehabilitative services to manage the life-changing effects of cancer and its treatment.

Head and neck cancer and its treatment can have profound negative effects, one of which is difficulty swallowing. Speech language pathologists provide evaluation, therapy and counseling to manage swallowing difficulty both during and after treatment. Swallowing therapy throughout radiation treatment helps patients to maintain strength of swallowing muscles, optimize eating and drinking, and reduce risk of developing pneumonia. Swallowing therapy after treatment aims to improve quality of life by helping patients return to eating foods they enjoy. We have learned that without swallowing therapy, many patients are hospitalized, require feeding tubes for longer than necessary or have debilitating swallowing impairments that are very challenging to come back from.

The pandemic of COVID-19 has caused us to pause and re-evaluate new ways to continue providing treatment to our patients. One method of doing this is through telepractice.

What is Telepractice?

Telepractice is a method of doing therapy through real-time video conferencing. Initially, telepractice was intended to reach patients in remote areas where speech services were not available. Now it is being used to reduce environmental exposure to COVID -19 by refraining from face to face visits. During teletherapy, speech language pathologists can

continue to assess and monitor swallowing function, teach strategies for safe and efficient swallowing, and introduce and review swallowing exercises.

How do I get started?

Before any treatment program is initiated, a swallowing evaluation is required. The UPMC Head & Neck Cancer Survivorship Clinic continues to offer services. For more information about this clinic, contact UPMC.com/ENT or 412-647-2100.

If teletherapy is offered, the next step is to download the MyUPMC app and create an account. If you have a smart phone, tablet, or computer with camera/microphone, you are ready to go! When it's time for your appointment, open the app and click on the video icon to start your session.

Is teletherapy here to stay?

Teletherapy has been a method for staying connected to our patients during the pandemic, but as restrictions are starting to lift, face to face visits will return. Some patients have expressed that video conferencing has helped them to be more accountable with their treatment plans and is a convenient option. Others, who may not have the technology, prefer to continue with face to face visits.

Teletherapy has allowed us to continue to help head and neck cancer patients to the best of our ability during such an unprecedented time. This most likely will change the way we treat patients in the future and may be a solution to challenges we have faced when treating patients in the past. Perhaps there is a silver lining in all of this and a combination of face-to-face visits and teletherapy will be the solution for treating patients through this pandemic and beyond.

Kelly Young, MA, CCC-SLP and Tami Wasserman-Wincko, MS, CCC-SLP are swallowing therapists in the Department of Otolaryngology at UPMC and work extensively with head and neck cancer patients in the UPMC Head & Neck Cancer Survivorship Program.

The relationship between reported quality of life symptoms and sleep quality in head and neck cancer patients



By Harish Dharmarajan, MD
UPMC ENT Resident

Problems with sleep are extremely common in cancer patients, including those with head and neck cancer. In the

past, our research showed that head and neck cancer survivors who experience trouble sleeping were more likely to report psychological distress. However, we did not know whether physical symptoms (either after surgery or other therapies such as radiation/chemotherapy) impacted the sleep quality in head and neck cancer survivors. So, we studied whether there was any link between sleep and these reported symptoms.

In our study, we included patients who originally had cancer of the mouth, throat, or voice box and finished treatment (surgery, radiation, chemotherapy, or a combination of these). These patients were seen at the UPMC Head and Neck Survivorship Clinic and filled out surveys about their symptoms. These surveys have been standardized and the survey scores have a specific clinical meaning. The Insomnia Severity Index (ISI) and Pittsburgh Sleep Quality Index (PSQI) are two surveys that focus on sleep quality. We used the ISI survey score to determine how severe one's sleep problems were. Troublesome symptoms like difficulty swallowing, altered taste, and dry mouth were recorded using the University of Washington Quality of Life survey. Finally, we looked in detail at severity of swallow-



For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit http://www.upmc.cancercenters.com/portal_headneck/publications.cfm

for archived issues of Headway.

Head & neck cancer support groups*

- A cancer support group, primarily for head and neck cancer patients, family members, and caregivers, meets the first Wednesday of each month at UPMC Cancer Center, Upper St. Clair, 200 Oxford Drive, Suite 500, Bethel Park, Pa. To register, call 412-622-1212.
- **Let's Talk Laryngectomy Support Group** - Meetings are held the first Tuesday of each month at 7:00 pm, Forbes Regional Hospital, 2570 Haymaker Road, Monroeville, Pa. Contact: Rich Boguszewski at rbogos@gmail.com or Dan Evans at djevans222d@gmail.com. <https://LetsTalkGroupPgh.wixsite.com/LaryngectomyHelp>.

*Please check availability of these meetings during the ongoing Covid-19 pandemic.

ing difficulty with the 2 following surveys: Functional Oral Intake Scale (FOIS) and the Eating Assessment Tool (EAT-10).

We found some interesting associations through studying the collected data. 278 people took part in the study. About one in five patients had mild sleep symptoms ("subthreshold insomnia") whereas about one in ten had moderate or severe trouble sleeping ("clinical insomnia"). Those with difficulty sleeping (clinical insomnia group) were more likely to be dependent on a feeding tube as compared to those without sleep problems. In addition, those with difficulty sleeping reported worse pain control, trouble swallowing and chewing, speech changes, altered taste, and dry mouth compared to those who had mild or no sleeping difficulties. Even though we have shown that these symptoms are related to sleep disturbances, it is hard to pinpoint exactly how this happens. We will continue to investigate how sleep quality is affected in head and neck cancer survivors. Our hope is to design specific solutions to reduce or even eliminate the sleeping difficulties that our patients experience.

Reiki in the treatment of cancer

Imagine a stressful day...well, most of us don't need to imagine - it's our norm. Add the challenges of coping with major illness, and stress levels really rise. Reiki can help.

What is Reiki?

"Reiki" is a Japanese word that refers to vital energy or universal life force. Like Prana in yoga and Chi in eastern medicine, Reiki works with our bioelectrical fields to support our innate ability to heal and revitalize physically, emotionally, mentally, and spiritually.

Developed in Japan in the 1920s by Mikao Usui, Reiki is now practiced throughout

the world in a variety of settings including homes, private practices, hospitals and hospices.

Reiki treatments provide safe, natural, and relaxing hands-on healing that is compatible with medications, chemotherapy, and other cancer treatment therapies.

How can Reiki help?

Increasingly, complementary therapies like Reiki are being integrated into cancer care to reduce stress and anxiety, manage symptoms, and support wellness for cancer patients and their support communities. Over 800 hospitals in the U.S. offer Reiki treatments as part of their integrative medicine services.

Many studies have shown that stress and anxiety decrease our emotional and physical well-being, and negatively affect the body's ability to heal. Stress and anxiety are linked to increased insomnia, fatigue, and even increased pain levels. Reiki has been shown to bring about both physical and psychological relaxation, effectively manage cancer-related symptoms, and improve quality of life for cancer patients.

Research regarding Reiki's effects on health is in its early stages, but studies so far indicate that, among other effects, Reiki activates the Parasympathetic Nervous System, that part of the Autonomic Nervous System that restores the body's balance during times of stress, much as the brakes in a vehicle slow it following a period of acceleration. The effect of this action is to restore digestion and elimination cycles, improve concentration, reduce the intensity of pain, decrease fatigue and nausea and improve sleep. Additionally, because of this action, Reiki can boost the body's immune system, reducing vulnerability to disease and enabling the body to work with prescribed treatments to fight cancer growth.

Reiki recipients almost universally report stress reduction and deep relaxation from

their Reiki session. Reiki recipients also report pain relief, relief of nausea and fatigue associated with chemotherapy and radiation therapy, reduced agitation and emotional upset, support for emotional processing and insights, and increased sense of well-being and peace. Cancer patients indicate that they often feel more relaxed, less anxious, more comfortable, and are better able to sleep after receiving Reiki treatments.

What happens during a Reiki treatment?

Reiki treatments are designed to provide a relaxing experience. You remain fully clothed, and sit or lie down comfortably. Your privacy and comfort are respected and maintained at all times.

The trained practitioner conveys Reiki energy (not his or her personal energy) by gently holding his or her hands on or just above your body starting at the head, moving down the torso, and including your legs and feet. You can also ask the Reiki therapist to focus on particular physical, mental and/or emotional needs. Treatments typically last about 45 minutes to one hour, and you can simply relax - no effort or concentration is required.

The treatments are very adaptable, and can easily accommodate special needs and circumstances. Moreover, anyone can learn to provide Reiki energy to self and others - no special skills or abilities are required.

Locally, free Reiki services are offered to cancer patients and members of their support circles by a variety of organizations including (but not limited to) the Cancer Caring Center, and Our Club House. Numerous Reiki therapists also practice privately throughout the Pittsburgh area. Consider Reiki for a safe, effective support for your healing and well-being.



Philip Buttenfield and Lella Lombardi are Reiki Shihans (masters/teachers) with over 30 years of combined experience in Reiki and energy healing.

They have served cancer patients and their support communities through the Cancer Caring Center's Reiki program since its inception in 2007. They are happy to answer questions about Reiki in general or Reiki and cancer care. Learn more at www.ReikiHandsOpenHearts.com, or email: info@ReikiHandsOpenHearts.com.

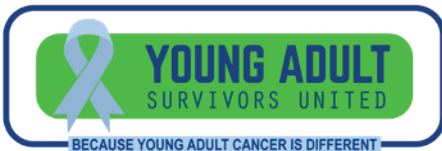
Closing the gap for young adult cancer survivors



By Stephanie Scoletti

Life as a 20-year-old, bald, Leukemia patient is never something we ever imagine in our wildest dreams growing up. Not knowing anyone else similar in age who can share how they coped with such fear and uncertainty was only the beginning of Stephanie Scoletti's concerns. Little did she know that this disease would blossom into a mission that Pittsburgh, Pa. has never seen. Spending eight years building a young adult cancer community as a program of the Cancer Caring Center, Stephanie built a model for meeting the emotional, social, and financial needs of young adult cancer survivors. As 2019 came to an end, she realized that it was time to make her dream a reality.

Young Adult Survivors United was established as a 501(c)(3) nonprofit and was launched on March 1, 2020. It is the largest community in Western Pa. for



young adult cancer survivors and co-survivors, providing them the ability to cope and thrive from emotional, social, and financial support. We offer them a better quality of life and safe space to connect with others their age who understand and can relate. They're then empowered to thrive from the hand they're dealt after being diagnosed with

cancer. We support their entire journey; from newly diagnosed and post-treatment to those with advanced, metastatic disease.

Why only focus on young adults? What is so different? What age range qualifies one as a young adult? These valid questions are often asked and important for everyone to know. The cancer population primarily in this program are those in their 20s and 30s but we extend it to those who are diagnosed between ages 18 and 40.

Cancer puts a hard, fierce, unprecedented pause on their life and at a time when they're earning a degree or have recently graduated and just landed their first full-time job. Imagine a 27-year-old male who is diagnosed with a terminal brain

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Young adult cancer survivors meet regularly to enjoy social outings.

Enhancing patient-centered care *continued from page 1*

• Intensive symptoms management

As the intensity of standard therapy (chemotherapy and radiation) for head and neck cancer has amplified, survivors experience a substantial increase in acute and late treatment-related toxicities. Studies have shown that some patients are hospitalized following treatment once or multiple times. From the data the Survivorship team has collected, they hypothesize that systematic symptom assessment and intensive symptom management will decrease hospital utilization of their patients (i.e., hospital admissions, emergency room visits, inpatient observation).

• Cognitive impairment after head and neck cancer treatment

One of the most concerning, yet poorly understood, treatment-related effects is reduced cognitive function. Deterioration in cognitive function among cancer survivors is a strong predictor of high symptom-burden, disease recurrence, and morbidity. However, it is unclear whether

these deficits in neurocognitive function in HNC survivors are due to population variation, the disease, or the treatment modality superimposed upon a pre-existing cognitive impairment. We intend to study these connections to gain a clearer sense of why this decrease in cognitive ability occurs.

• Caregiver burden

Patients with head and neck cancer face a diversity of symptoms and functional impairments due to treatment-dependent toxicity. Patient caregivers (CGs) play a vital role in the treatment and recovery process, providing routine care and psychological support. Emotional distress is a problem commonly faced by CGs and can impact not only CGs themselves but their ability to provide care to patients. The survivorship team seeks to determine if there exists a difference in illness perception between patients and CGs and if this difference is associated with increased levels of distress in caregivers.

Because the field of Survivorship is relatively new, it has proven somewhat difficult to find sources for support for research projects aiming to collect pilot data and pose new hypotheses. In the fall

of 2019, the Eye & Ear Foundation received a grant from the Jack Buncher Foundation to launch these research projects to better understand the correlation of these trends relative to head and neck cancer treatment. "The Jack Buncher Foundation has long supported important work in the Pittsburgh community, especially in cases where their support can offer assistance to those who are economically disadvantaged or vulnerable to poor health outcomes. I have been told many times that support for unmet needs for individuals who cannot afford care has been a long standing priority for the Jack Buncher Foundation," states Lawton Snyder, CEO of the Eye & Ear Foundation.

The support from the Jack Buncher Foundation will allow the Survivorship team to hire a research coordinator to formulate the PRO data into research questions for each of the three areas of focus and will hopefully contribute to the growing body of knowledge that exists about head and neck cancer survivorship, with the ultimate goal of offering patients a more comprehensive plan to continue to optimize their life after cancer.

Closing the gap

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tumor and immediately forced to quit his job and apply for Social Security Disability Insurance, trying to accept this new source of income. Young adult parents (and some who are single parents) try working during cancer treatment and caring for their young children because they have no other option and need to be the provider for their family. These survivors suffer from trauma, anxiety, and depression. Trying to find their identity, figure out how to start dating, or be intimate with their significant other is challenging; especially after having major surgeries which cause scars, amputations, and the obvious...insecurity and lack of self-esteem.

We welcome these survivors to a community unlike any other; a space where there is no judgment, only love and endless support. They instantly share a common bond which has only gotten so much stronger as more survivors join. Aside from monthly support groups, we host monthly uplifting social outings that provide an opportunity for young adult cancer survivors and their co-survivors to take a break and enjoy themselves with others in the program. Examples of social outings include Pirate games, summer picnics, game nights, bowling, axe throwing, cooking classes, kayaking, and so much more. During these outings, the survivors don't carry feelings of isolation and inability. Instead, they're given opportunities to have fun, serve a purpose, and not have to think about the expense of the activity since it is always free for them.

Last but not least, and one that is most likely the obvious, we continue providing young adult cancer survivors with financial assistance. Those in need can apply annually and use the stipend for medical and non-medical related expenses. This is a population that already has debt from school loans, mortgage and rent payments, and childcare, in addition to medical bills, copays, deductibles and more.

If you or someone you know is a young adult cancer survivor or co-survivor caring for one, please contact us. We're here for you and can be contacted via our website, www.yasurvivors.org, email stephanie@yasurvivors.org, phone 412-715-9700, or search for us on social media (Young Adult Survivors United). We remain a volunteer organization to ensure all donations directly support the population we're assisting. Please visit our website for different ways of giving. We thank and appreciate you.

Contact information

American Cancer Society.....	1-800-227-2345
Assistance with Coping.....	412-623-5888
Cancer Caring Center.....	412-622-1212
Cancer Information and Referral Services.....	412-647-2811
Clinical Trials.....	412-864-1728 or 412-864-3759
Eye & Ear Foundation.....	412-383-8756
Face2Face Healing.....	1-844-323-4325
Family Care Giver Education and Support.....	412-623-2867
Gumberg Family Library.....	412-623-4733
Head and Neck Cancer Support Group.....	412-622-1212
Heart and Hands Ministry.....	724-935-3636
Hopwood Library at UPMC Shadyside.....	412-623-2620
Hyperbaric Oxygen Treatment.....	412-647-7480
Our Clubhouse.....	412-338-1919
Pain and Supportive Care.....	412-692-4724
Prostate Cancer Support Group.....	412-647-1062
Satchels of Caring Foundation.....	412-841-1289
Swallowing Disorders Center	
UPMC Eye & Ear Institute (Oakland).....	412-647-6461
UPMC Shadyside.....	412-621-0123
UPMC Division of Sleep Surgery	
Mercy.....	412-232-3687
Monroeville.....	412-374-1260
American Cancer Society website.....	www.cancer.org
Head and Neck Cancer	
Program website.....	UPMCHillman.com/headandneck

Head and Neck Cancer Program website

Looking for more information about patient services, current research, clinical trials, news and events, and other valuable information pertaining to head and neck cancers? Check out the website for the Head and Neck Program of UPMC Hillman Cancer Center at UPMCHillman.com/headandneck.

Clinical trials

For more information about head and neck clinical trials, contact Amy at 412-864-1728 or Denise at 412-864-3759.

Head and Neck Oncology

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203 Lothrop St., Ste. 300
Pittsburgh, PA 15213
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