

HEADWAY

SINCE 2007

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Deep learning to enhance care

By Carrie Fogel

More than half a million head and neck cancers are diagnosed each year globally, with an increased amount of cases being found in a much younger population. Younger men and women without the traditional risk factors, like tobacco and alcohol use, are part of a growing population of patients who develop the disease from the human papillomavirus. The majority of patients with head and neck cancer (HNC) present with an advanced stage of the disease and require treatment with multimodal therapy, which includes a combination of surgery, radiation, and chemotherapy. Although these aggressive treatment regimens have resulted in increased survival, especially for those with human papillomavirus (HPV) associated HNC, this improved survival comes at a cost to the survivors, compromising their functional capacity and physical health, and impacting the family or support network of the survivor.

As the intensity of the standard treatment protocol has amplified, survivors experience a substantial increase in acute and late treatment-related toxicities, resulting in the need for emergency room and inpatient visits. A retrospective analysis showed that of 147 head and neck cancer patients undergoing a combination of radiation and chemotherapy at our institution, 37% are hospitalized during or shortly after treatment. The main reasons for Emergency Room visits and hospitalization were dehydration, difficulty swallowing, pain, nausea/vomiting, fever, and sudden drop in blood pressure.

In 2016, Jonas T. Johnson, MD, Chairman of the Department of Otolaryngology at the University of Pittsburgh, and Marci Nilsen, PhD, RN, Assistant Professor in the Department of Acute and Tertiary Care in the University of Pittsburgh School of Nursing joined together to establish the UPMC Survivorship Clinic for Head and Neck Cancer. In addition to improving the care that survivors receive by coordinating care and providing patients with

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Dr. Jonas Johnson and Dr. Marci Nilsen during a patient visit in the Survivorship Clinic.

Cancer through covid

By Marla Pettit
Cancer survivor



At 60, as my husband and I early anticipated finally completing the process and subsequent relief of putting our four children through college, an unforeseen,

life-altering event struck. It was March 2020, with whispers of Covid-19 growing to shouts of concern. I finally took notice of a lingering pain, like heartburn, that I had felt for some period of time. A routine night that would have included a trip to gather food, ended up in an urgent care, then our local hospital. As Covid-19 literally exploded around us, my initial blood work raised eyebrows and eventually resulted in my admission to the hospital for further testing.

My husband and I have run a Montessori school for 30 years which was, in hindsight, fortuitously closed due to Covid-19, just days after my initial admission to the hospital. As we struggled briefly with the obvious challenges to our lifeline, our school being closed indefinitely, our attention quickly and wholeheartedly shifted to the medical emergency that rapidly unfolded before our eyes.

My liver was functioning very poorly, and the doctors' attention quickly focused on my bile duct. After many tests, procedures, and extended hospital stays, it was determined that a tumor on my pancreas was putting pressure on my bile duct, and therefore, adversely affecting the functioning of my liver. How fortunate it was that my bile duct reacted as it did. Though early tests and procedures found no evidence of cancer yet, the tumor on my pancreas was eventually determined to be malignant. I was immediately scheduled for the Whipple Procedure which was completed in April 2020. The good news was that the cancer had not spread to my lymphs and that it was, unusually, detected very early. Stage 1 pancreatic cancer was my diagnosis.

Six months of chemotherapy followed, of which anyone who has gone through it knows is a daunting challenge in

itself. All four children came home from Philadelphia, Providence, and Los Angeles, with one already in the Pittsburgh area, to be with me throughout my chemotherapy. Our school being closed for Spring 2020 was providential. While Covid-19 brought the world so much suffering, it oddly enabled us to hunker down as a family and be together as no other time or circumstance would have allowed. Many of my friends, school parents and the organization Mrs. Claus Club of North Hills (MrsClausClub.org), showed up to help our family. Our school reopened in September 2020. I was able to teach throughout my chemotherapy because of my family and school staff, terms that surely became interchangeable. I am firmly convinced that the love, kindness, and generosity from so many kind people got me to where I am today through this challenge.

With the help of my family and many kind friends, I am getting through this, and I have been cancer free for one full year. We take it one screening at a time, savor every minute we have together, and live in endless thankfulness for the kindness, medical expertise, and the many rich blessings that have been bestowed upon us, and look forward, always forward, to happy memories yet to be made.

Physical Therapy's role in survivorship following head and neck cancer

By Karen Losego, PT, DPT, CLT-LANA
Senior Physical Therapist, Certified Lymphedema Therapist; UPMC Centers for Rehab Services Women's Rehab and Men's Health Program; Physical Therapy Liaison to the UPMC Head & Neck Survivorship Clinic



A physical therapist (PT) specializes in restoring, enhancing, or preserving physical function that has been impaired by disease, injury, or medical treatment. Cancer and treatment for

the disease can cause side effects that affect the patient's ability to move and function. Physical therapy addresses the side effects of cancer treatment to help patients return to daily activities and baseline function.

Common side effects of surgery, radiation and chemotherapy that can be addressed by physical therapy include:

- Neck pain or stiffness that make it hard to look over your shoulder
- Neck spasms that may occur with movement, eating or at random
- Shoulder or shoulder blade pain, weakness or decreased motion that limits your ability to reach overhead into cabinets, shower or style your hair
- Radiation fibrosis or scar restrictions that cause tightness or pain
- Postural changes that make it harder to hold your head up
- Difficulty opening your mouth (trismus)
- Pain and stiffness in your jaw or tongue
- Difficulty moving your tongue affecting both speaking and eating
- Swelling in your face and neck (lymphedema)
- A decline in balance or a fear of falling
- Weakness, poor endurance or fatigue that affects your arms, legs or entire body
- Numbness in your hands or feet and difficulty walking
- Pain, stiffness or swelling around your donor site

Many of these symptoms can affect your ability to swallow. For example, if you cannot open your mouth or move your tongue, it will be more challenging to eat. Because of this, PTs work closely with UPMC speech and swallowing therapists (SLP) to do our part to help swallowing improve.

Due to the unique side effects of cancer and cancer treatment, we encourage patients to see therapists who are specially trained in treating patients who have had cancer. In the UPMC system, we have approximately 30 therapists at 20 outpatient clinics across Western Pennsylvania. Our group of specially trained therapists (the Women's Health/Men's Rehab therapists) participate in the weekly UPMC Head & Neck Cancer Survivorship Clinic led by Dr. Jonas Johnson and Dr. Marci Nilsen. At the clinic, we screen all patients who may have physical therapy needs. If a patient is in need of PT, we find them a clinic close to their home to allow for easy access to care.

A patient may benefit from PT at any time through the cancer journey – it is never too early or too late to start PT. Most patients benefit from PT following surgery or radiation since these treatments can cause muscle stiffness, decreased motion and pain. Often, we will suggest therapy before radiation so a patient can learn a home exercise program to improve or maintain their neck, jaw and shoulder motion. Once you are referred to therapy, your local specialized therapist will evaluate you and tailor a PT program to your needs. Depending on the severity of your symptoms, a patient may attend therapy once a week for a few weeks or may attend for a more prolonged period of time. PT will focus on teaching you how to independently manage your symptoms. During therapy, your PT will use a number of manual “hands on” techniques to address scars, lymphedema, radiation fibrosis or muscle spasm. Your PT will also give you exercises to improve your posture, strength and motion. By the end of your PT treatments, our goal is to empower you to maintain your gains long term via a personal home exercise program.

As the physical therapy liaison to the UPMC Head & Neck Survivorship Clinic, I am always happy to answer any questions you may have. Feel free to contact me at peltzkj@upmc.edu or via phone at 412-854-5077.

Flourishing for Headway

By Alex Harris



Head and neck cancer survivors understand that diagnosis and treatment of disease have a large, often long-term effect on their health. When it comes to overall

health, many areas are frequently overlooked. Physical, mental, and social well-being contribute to how a patient is affected by treatment and in their post-treatment course. While it is important to focus on treatment results, it is increasingly important to include health aspects beyond the hospital setting. The clinical team at the UPMC

Head & Neck Cancer Survivorship Clinic has been looking into how satisfied patients feel about their overall well-being following treatment.

Many questionnaires have been developed to understand well-being, but these miss the patient's perception on their own virtue and health. Flourishing is a way to view how well a survivor is doing in their lives beyond the hospital. Flourishing is measured by asking questions on happiness, well-being, relationships, community, and your perceived meaning, purpose, and virtue. These areas of life have been shown to promote positive health outcomes. The Flourishing Index, established by researchers at Harvard, includes questions about how the patient feels about their health and character strengths when looking at patient feedback.

Particular areas of focus of the flourishing index include family, work, education, and community, along with personal happiness and satisfaction, physical and mental health, meaning and purpose, character and virtue, and close relationships. This survey allows for a more complete evaluation of well-being, avoiding pitfalls of focusing purely on physical and mental health. It also includes questions focusing on relationships with others, or social health. This promotes the goals of survivors and clinicians to understand the full effects of treatment and find ways to address these for future patients.

Together with other measurement scores, clinicians have been working to understand the relationships between the effects of treatment and flourishing. Survivors have generously donated their time to complete questions about how their lives have been impacted by treatment and their overall flourishing. This is the first examination into how head and neck cancers and their treatment affect survivors' life satisfaction. This

For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit www.hillmanresearch.upmc.edu/about/news/publications for archived issues of Headway.



type of research aims to adjust how and what questions are asked during follow-up and how clinicians can better support survivors in their long post-treatment journey. Thanks to survivors' participation in the Head & Neck Survivorship Clinic, we can share this impact with other organizations and promote a holistic and multidisciplinary approach for survivors.

Literacy as language: navigating healthcare as a caregiver

By Jymirah Morris
ENT Research Associate



I have heard that the best way to learn a new language is to travel to a country where that language is spoken and immerse yourself. This advice dictates that you leave your

English at home and delve into a circumstance where you understand nothing. For anyone who has ventured to try an experiment like this, it is known that things are fine until you are in an acute situation where it is imperative that your needs are understood, and that you understand the language of those around you. Without that understanding, it becomes very difficult to function. For many patients, this analogy is tantamount to their experience when walking into a physician's office: the patient doesn't have the tools necessary to function in that setting. In health care, this “tool” is health literacy (HL).

Health literacy is defined as personal characteristics and social resources that enable a person to be able to access, understand, appraise, and use information and services to participate in decisions related to their health. Low HL among adults in the general population has been associated with worse health outcomes, difficulty managing chronic illnesses, and higher utilization of the healthcare system. Almost 40% of Americans have low health literacy, a reality that costs our economy approximately \$236 billion annually. In the general public, low health literacy is more prevalent among the elderly, men, members of ethnic minority groups, those with less formal education, and those with low

Head and 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 rbogus@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.

socioeconomic status. The patients who are coming into the physician's office – this foreign environment – often struggle with high anxiety, depression, worse sleep, and an overall lower perceived quality of life.

In the United States, approximately 40.4 million people serve as caregivers for adult care recipients. Of these, 46% perform medical, nursing, or other management tasks for adults with complex chronic health needs. 66% report having decision-making power regarding the care recipient's condition and adjustment of care, and 63% engage in communication with healthcare providers on behalf of the care recipient. For patients with complex care needs, it is important that they be able to adequately understand the details of their care so that they can be active participants in that care. In the case of caregivers, it is similarly important that they have the tools to participate on behalf of or alongside their recipients. For cancer survivors, patient care is often a team effort which includes tremendous support from that patient's caregiver.

It follows that for patients with caregivers who shoulder much of the burden of managing those care needs, the caregivers' health literacy – or lack thereof – could have similar impacts on outcomes as the patient's own HL. We don't know much about the impact of caregiver HL on adult care recipient outcomes. As such, at the UPMC Head & Neck Cancer Survivorship Clinic, we are conducting a study of caregivers of adult survivors of HNC. The subjects, the caregivers, and their care-recipients, the patients, will be those who are seen in this clinic. We believe that there will be an association between the health literacy of caregivers and a variety of quality of life outcomes for both.

Based on the results of this study, we as a medical community can work to improve caregiver HL. As we seek to improve outcomes in HNC survivors, we must also consider the outcomes of those closest to them. We want to ensure that no one – not the patient or the caregiver – feels like they are in a foreign land when they come to receive care.

Why health literacy?

By Randall Harley
Third-year Medical student



Treatment of head and neck cancer is very much a team sport. We of course expect health professionals to be knowledgeable regarding the most effective cancer treatment options,

however, we sometimes fail to consider how helpful and important it is for patients to understand the illnesses they are facing and how these illnesses are treated. This is because every person is unique and will have their own set of challenges and goals as they move through the treatment and recovery process.

Therefore, to optimize patient care, it is important for health professionals to use their expertise to lay out the most effective treatment plan, but it is also essential for healthcare providers to understand where a patient might have gaps in health knowledge and fill them. This all sounds simple, but in practice identifying what a patient does and doesn't know can be very challenging.

As a medical student who is encountering new clinical scenarios every single day,

I certainly understand this. Sometimes things are so new and even overwhelming that I am unaware of what I don't know until I am tasked with doing something myself. Patients are given an incredible amount of ownership and responsibility which is important for tailoring one's care to their specific needs. The downside is that if there are elements of the treatment and recovery process that a patient doesn't fully understand, then they are at risk for adverse outcomes.

This brings us to the topic of health literacy. Health literacy is defined as one's ability to process and understand health information needed to make informed decisions and participate in the implementation and execution of treatment plans. Previous studies have shown that low health literacy levels can contribute to more hospitalizations, greater use of emergency care, poorer overall health status, and higher death rates. Additionally, a study from UPMC showed that low health literacy is tied to lower social-emotional quality of life.

One strategy to help prevent these adverse outcomes is to use tools that measure the health literacy of patients, to better identify at-risk populations. Considering the limited health literacy outcomes data for head and neck cancer patients, our first goal is to determine which adverse outcomes those with low health literacy within this population are at risk for. We recently received funding from the Eye and Ear Foundation to do exactly this. We will meet with people recently diagnosed with head and neck cancer, have them complete a health literacy assessment, and then follow them throughout treatment and recovery. Our primary outcome will be to determine whether those with low health literacy are more likely to be readmitted to the hospital within 30 days of surgical treatment. We then would like to interview survivors with low health literacy to explore which aspects of the treatment and recovery process are most difficult to manage. This information will allow us to identify specific aspects of treatment and recovery that are difficult to manage and adverse events that this population is at greatest risk for. We hope that this new insight will provide health care providers with a greater ability to anticipate future issues and intervene before anything outside of the plan of recovery occurs.

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Feeding tubes: The dietitian and speech pathologist's role in management of enteral feeds

By Alyssa Mrozek Weinfurther, MS, RD, CSO, LDN; Tami Wasserman-Wincko, MS CCC-SLP; and Sarah Pomfret MS CCC-SLP



Pictured left to right: Tamara Wasserman-Wincko, Sarah Pomfret, and Alyssa Mrozek Weinfurther

A feeding tube is a medical device that can be used to help patients receive nutrition and hydration when they are unable to take enough calories by mouth or if it is not safe to consume food orally. There are several reasons why patients with head and neck cancer may require a feeding tube. Post-operatively, feeding tubes may be necessary until swallowing is safe and efficient. This often depends on the extent and type of surgery. During the course of chemoradiation therapy, side effects from the treatment can cause difficulty swallowing. This can lead to weight loss and/or dehydration if not monitored closely. A feeding tube is often used to help provide nutritional support while encouraging the patient to eat/drink what is safe by mouth.

Types of feeding tubes

- **Nasal feeding tubes** – Nasal feeding tubes go into the nose, down the esophagus, and end in the stomach or intestines. These tubes are used for short term support – usually 6 weeks at most.
- **Surgical tubes** – Surgical tubes enter the body at the abdomen. They can end in the stomach, gastric tube (G-tube) or percutaneous endoscopic gastrostomy (PEG), or the jejunum (J-tube). These tubes bypass the esophagus. Surgical tubes are generally used for longer-term needs. These tubes are a safer, more comfortable choice for those patients in need of enteral feeds for at least 6-8 weeks.

Feeding plans

Dietitians provide recommendations for the most appropriate feeding schedule based on

the patient's lifestyle, tube feed tolerance, and nutritional requirements. Patients who are at home with a feeding tube are either on a cycle feeding (administered through a pump for a specific number of hours per day) or on a bolus/gravity feeding (follows traditional mealtimes through a syringe or gravity bag usually 2-4 times per day). Bolus feedings are only used in a gastric placed feeding tube.

Discontinuing tube feeds

A feeding tube may be beneficial for patients as they continue to work towards improving their swallowing function. Short-term feeding tubes can help to optimize the patient's nutrition during swallowing therapy. Patients who participate in swallowing therapy with a speech-language pathologist and receive nutrition counseling with a Dietitian can work towards feeding tube removal.

A Speech-Language Pathologist (SLP) will instrumentally evaluate swallowing and collaborate with the dietitian and physician to determine if and when a short-term or long-term feeding tube can be discontinued.

How can I determine if my tube is ready to come out and I can return to an oral diet?

- Discuss your goals with your physician. Each patient is different and there are many things to consider before having a tube removed:
 1. Is your swallowing safe? Are you adequately protecting your airway and preventing food/liquid from entering your lungs when swallowing?
 2. Will you be able to obtain enough oral nutrition without use of a tube and do this without losing weight?

3. Will you be able to take all medications orally?
4. Will eating everything by mouth be too much work? Sometimes patients benefit by having a tube and eating small amounts by mouth.

- If your physician thinks you are ready to explore different feeding options, you will be referred to a speech-language pathologist who will instrumentally evaluate your swallowing. Swallowing strategies may be used during a swallowing exam to prevent food/liquid from going down the wrong pipe, or the SLP may suggest certain food textures that are safer and more efficient to swallow.
- A dietitian will help with the transition to oral nutrition and will provide recommendations for increasing calorie and protein intake. The goal is to increase oral intake, decrease use of tube feedings (generally by one can of feeds at a time), and maintain weight. Once you are able to consume all nutrition by mouth and maintain your weight, the feeding tube may no longer be needed.
- If an oral diet is recommended, the SLP and dietitian will work together to help identify the best food options and to establish an eating routine that works best for you.

Summary

Feeding tubes may be used for short-term or long-term nutritional support. Management of feeding tubes and oral intake is a collaborative effort between physicians, dietitians, and speech-language pathologists. With the help of these medical professionals, tube feeds may be discontinued when safe and adequate oral intake is achieved.

Why health literacy?

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As the medical field shifts away from the paternalistic model of health care, it makes sense that the entire team, which includes the patient, will need a certain level of health knowledge for optimal outcomes.

We hope that with better insight into patient health literacy we can expand yet another domain of personalized medicine, giving patients the autonomy they deserve without sacrificing their safety.



Deep Learning to enhance care

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comprehensive plans for their recovery, Drs. Nilsen and Johnson are beginning important research trials that offer new models of care and study their efficacy.

With nearly three years of data collected from patient-reported outcome surveys, which assess patients’ most common symptoms and problems they face during and after treatment, we are now uniquely positioned to implement a pilot project to enhance care coordination and reduce hospitalization for HNC patients. To do this, support is needed to secure the time of two health-care providers, a registered nurse, and a speech-language pathologist, to implement the project two days per week.

The Enhanced Care trial places two healthcare providers embedded at Shadyside Hospital, two days per week, to enhance symptom monitoring and better coordinate care during and immediately after completion of therapy when patients are suffering from acute effects. The intent is to reduce hospital utilization (i.e., hospital admissions, emergency room visits, inpatient observation) by 15%. Dr. Johnson and Dr. Nilsen believe that this can make a difference in the experience that patients have during treatment by deploying interventions early and making patients aware that there exists a first point of contact who they can reach out to as soon as symptoms of their treatment arise.

This project represents a transition toward improved value of healthcare. The UPMC Hillman Cancer Center has recognized the need to improve and expand the type of Survivorship Care that is offered. With the support of Dr. Robert Ferris, Director of UPMC Hillman Cancer Center, Associate Vice Chancellor for Cancer Research, and Professor of Otolaryngology, of Immunology, and Radiation Oncology, the Head & Neck Survivorship Clinic is implementing this pilot project at the Hillman Cancer Center in Shadyside.

Additionally, the UPMC Health Plan is introducing the use of coordinated care through the Oncology Care Model of reimbursement for head and neck cancer patients. Our pilot project will collect and present data to the Health Plan, which is essential to establish the value of this approach. Coordination of care and enhanced navigation can lead to reduced hospital visits and cost savings. If successful, it will form a basis for reimbursement of coordinated care.

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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.

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