

**MARCI NILSEN:** So what my talk is today is I'm going to talk to you a little bit about the changing epidemiology and, therefore, the changing demographic of head neck cancer survivors. To identify some of the late and long term effects of treatment, which have already kind of been highlighted by Dr. Klump. And then, to discuss the models of care for survivorship in head and neck cancer. Primarily, I'll talk about what the initiative that we're doing at UPMC's Eye and Ear Institute. So, I have no conflicts of interest and I have nothing to disclose.

So head and neck cancer represents about 3 to 5% of all cancers in the United States. So it's a small percentage. It's also a collective term to describe a number of different malignant tumors that develop in and around the throat, mouth, and nose. So larynx, hypopharynx, oral cavity, and oral pharynx, that's where we see the majority of head and neck tumors are in those sites, nasal cavity and perinasal sinuses, nasal pharynx and salivary gland.

So epidemiology, most of what we see are squamous cell carcinomas. When you think of a head and neck cancer patient, you may think of something like this. So primary risk factors have been smoking and alcohol use. In combination, that's the most significant risk factor. It's more common in men. And the age of diagnosis, for the most part, has been between the ages of 55 to 74. So in the 1980s, about-- over 50% of patients were diagnosed in this time frame. And so this has changed over the years. It's actually the age of diagnosis now is younger. And again, that has a lot to do with HPV, which we'll talk about.

And survival is really site specific, as Dr. Klump said. If you have oral pharynx HPV cancer, your cure rate is about 90%. But otherwise, the overall cure rate is about 60%. So over the last 20 years, or 10 to 20 years, patients have also started to present differently, which Dr. Klump talked about. But patients were coming in with these smaller asymmetric primary tumors, and really large cystic nodes. They were poorly differentiated. And they had unpredictable metastases.

In 2000-- most people would say in 2000, there was an article that came out by Maura Gillison. And she pointed to a retrospective analysis that she did, where she identified HPV. And so which strain of HPV is related to head and neck cancer? 16. Yes. So there are two low risk types, six and 11. And then 16 and 18 are the high risk types. And these are covered in the HPV vaccine.

But it happens most often in the oral pharynx. And that's in the area of the tonsil and the base of the tongue. And then, the incidents are still-- they're higher in men. It's about eight to one. And the age of diagnosis is younger. So as I mentioned earlier, about 50% were diagnosed between the ages of 55 and 74. And now about 50% of our patients are diagnosed between the ages of 45 and 65. And so one of the big contributors to that is the fact that HPV head and neck occur in younger males and has a favorable prognosis.

And so in 2000-- in the late 2000s, the World Health Organization actually recognized an additional risk factor for head and neck cancer and that is sexual behavior. So, in particular, oral sex is now a risk factor for head and neck cancer. So here you can just see a little bit more information of what I have in terms of cervical cancer.

So you can see how oral pharynx, HPV oral pharynx, cancer has passed in 2010. And by 2025, we expect oral pharynx to surpass cervical cancer. And as you can see here, cervical cancer has been going down. And so a lot of that is due to the detection, and now they've shown the rates of vaccinations have helped decrease it. We do not have a way to screen for dysplasia or anything of that sort for HPV, oral pharyngeal cancers.

So treatment options, so we still do surgeries. So there are the surgeries that you may think, like laryngectomies. Those still occur, mandibulectomies, glossectomies. We also do transoral robotic surgery. And I'll have a picture later. And then the non-surgical treatments, so chemotherapy, radiation, and combination chemoradiation. We also are having more use with immunotherapies, so monoclonal antibodies, like Cetuximab and also PD-1, which are-- OPDIVO, which you see commercials for for lung cancer but also KEYTRUDA which was mentioned earlier.

And so RTOG 91-11 was one of the landmark-- is the landmark study that really kind of shifted this focus of going from major surgeries to organ preservation. So this study looked at three non-surgical methods, it looked at radiation versus concurrent chemotherapy, and then induction chemotherapy followed by radiation.

And what they saw was that the radiation plus chemotherapy had a survival benefit at five years. But then when they went back and they looked at the long term-- this is the 10 year follow-up study-- they saw that there was really-- the survival benefit was lost at about 10 years. So you can see that the yellow line is what we're-- what I'm talking about. And they tried to do an additional analysis to look at what this cause of death was and they didn't have enough power to make any conclusions.

But most of the speculation is that these patients, some of them developed very severe dysphasia, which can lead to aspiration and pneumonia and death. So in this study, this is just another highlight. It analyzed three RTOG studies. And it saw that with concurrent chemo and radiation, that severe toxicities, dysphasia, were common in about 43% of the patients. And so they said severe toxicities were toxicities that affected or caused laryngeal, pharyngeal dysfunction, leading to dysphasia, leading to tube-- feeding tube dependency and aspiration.

So the risk factors were old age, advanced T-stage, so advanced tumor stage. So you imagine if you have a really big tumor, it's got to-- there could be a lot of damage based on how big your field is from the radiation. And then the larynx and hypopharynx primaries, so again that's your functioning organs for swallowing and speech.

So there is treatment de-escalation. So this was in the paper. So this is Dr. Uma Duvvuri. He's doing a transoral robotic surgery. So if for these oral pharynx patients, if they can go in and do a robotic resection, then the hope is that they can get less radiation. So there's also been a move to use Cetuximab, which we mentioned earlier. But so far the data show that the dysphasia rates are fairly similar. And most of it is we feel that is related to just the radiation that causes most of the laryngeal dysfunction.

So in 2005, there was a Institute of Medicine HARP article published-- or book on it's called *Lost in Translation*. And what it really recognized was that there's this period when patients transition to survivorship. And during that time, there's really a fragmentation of care. And so a lot of these late toxicities and continuing issues are not identified. It recommends that there should be comprehensive care, and summary, and follow-up plans. But you should also use evidence based practice guidelines to assess tools and to screen patients for issues, both physical and psychosocial issues.

So the components of survivorship care, there should be prevention and detection of new cancers and recurrent cancers. So when we talk about head and neck cancer, a lot of these patients are smokers. So I'm trying not to move away. I walk a lot. I'm sorry. So, I'm trying not to move away from the microphone. But, to try to give them education and screen for additional cancers, surveillance for recurrences in new primaries, and then interventions for long term and late effects of treatment.

But also coordination of care. So there have been a couple of studies that have asked patients what they need, long term survivors. And many of them talk about just the really lack of coordination of care, but also the lack of identification of their psychosocial needs. So the American Society of Clinical Oncology has given more guidelines on what they qualify as high quality survivorship care. So providing screening recommendations for second cancers, providing education regarding diagnosis, treatment exposure, and potential latent long term effects, providing referrals to specialists, guidance about diet, exercise, and health promotion activities, providing resources to assist with financial and insurance issues, and empowering survivors to advocate for their own health care needs.

In 2016, the American-- so the American Cancer Society came out for guidelines, again highlighting the need for survivorship care in head and neck cancer patients. And they focused-- they provided an outline for some of the late and long-term effects that should be screened for and monitored for. And you can see them here. So things like trismus, the inability to open your mouth very wide, this can cause trouble for chewing and swallowing for dental care.

We talk about sleep apnea. So one of the residents in the Department of Otorhinolaryngology did a pilot study, and he enrolled 16 patients, which he did sleep studies on. And half of those patients had sleep apnea. And as you know, sleep apnea can cause a lot of adverse outcomes, heart disease and other problems as associations. Speech changes, swallowing, dental caries, and dental issues, we see those a lot.

And so actually conveniently, just this week, ASCO sent out an email, and it endorsed the ACS guidelines for head and neck cancer survivorship. And so this came out in the *Journal of Clinical Oncology* at the end of February. And so what it says is that head and neck cancer survivors require a team-based approach that includes primary care providers, oncologists, otolaryngologists, dentists, and other allied health professionals. So I'd like to say this is perfect, because this is what we're doing and we started to do.

So I guess let me talk a little bit about how we got to what we're doing now. So somebody earlier had said they had not heard that we were doing this. And that's probably because we just started doing this in December.

And so I worked with Dr. Johnson, who is the chairman of the Department of Otorhinolaryngology as a post-doc. And I was interested in patients and how they communicated after head and neck surgery. And so I had done some work in the ICU with patients. And this kind of transitioned to head and neck cancer.

And during this time, I was embedded in the clinic. And so I saw these patients who had survived their treatment. They were out. They were five, they were 10 years out. And they had some significant issues. And so we talk about fibrosis. We talk about dysphasia.

And it became clear to me that a lot of patients didn't even realize some of their issues that they were suffering with were related to their treatment. We had one woman that came in, and she said, oh, she had pneumonia three times last year. And so she was having what was not recognized at the time was that she was having trouble swallowing. And this was contributing to her kind of continual dealings with pneumonia.

And so in August, we talked about what we could do for these patients. How can we better provide them with survivorship care? So systematic approaches to evaluating their needs, both physical and psychosocial. So in September, we said we're going to open a survivorship clinic in December.

So that was fun. And so there were a lot of components that had to go into that. We wanted to develop a team to help evaluate these patients.

And so the E&T department has had a swallowing clinic. They have one at Shadyside, and they have one in Oakland for years. And so they see patients, but that that's just one component.

You saw the list. So cervical dystonia and shoulder dysfunction, so those kind of fall into the realm of physical therapy. Dental issues, osteoradionecrosis, those fall into dentistry. Psychosocial issues, behavioral health.

So in the beginnings, on December 1, we started seeing patients. We did two days in December. And we did a half days. So we saw about 10 patients initially. And so we started out with a small group.

So you can see here Dr. Johnson. Tammy Wasserman is in the back. She's a speech language pathologist. There I am. Next to me is a dentist. Her name is Dr. Susan Calderbank. And she practices at Greenville, but she also practices at Montefiore's Dental Center.

And then [INAUDIBLE] is our MA with the providers. We have several providers now. It's very important to kind of keep everything moving very systematically. And she helps us with that.

So that was December. Now this is March. And so we've already changed drastically since then. And we also got a better camera if you can't tell. We went from an iPhone to a real camera.

So what you can see here is that we have additional providers. So we have two dentists now. And we have two physical therapists, one that's pictured here. And they're from the Centers of Rehabilitation Services UPMC, Men's and Women's Health. And so they come and they evaluate patients.

Tammy is still our speech language pathologist. Deborah is one of the nurses that helps me out.

During this time we also actually had a psychiatrist in the clinic. But she got promoted to medical director. So she had a couple other responsibilities to do and couldn't be with us. But we have been meeting with UPMC's psychiatric liaison and consultation service and trying to figure out a way to have somebody in clinic with us.

So when you think about a typical visit for these patients, we try to warn them that it can be long. And it's really dependent on what they're having trouble with. And so I know that the program says post-treatment patients. That's what the title of your conference today is. And we actually see patients pretreatment.

And so we take the stance that a survivor is someone who's been diagnosed. And from diagnosis on, you're a survivor. And so that presents some unique challenges. And so the visits may be different based on someone who's pretreatment versus a survivor.

But everyone when they come in, they get patient report reported outcome questionnaires. This comes on an iPad. And it's given to them. And so once they come in, these are actually something that I review immediately. So before I go in to see the patient I have an idea of what they're already struggling with.

So the first person the patient actually sees beyond our medical assistant is Lori Zitelli. She is an audiologist. So we know and we've seen about 80% of our patients have some degree of hearing loss. And so she screens them at three different hertz at 30 decibels. And if they fail at three levels, they'll actually get a little amplifier so that they can hear, because if you can't hear what's being said to you, it really makes effective communication and the visit a little bit more difficult. She also has the ability to do a comprehensive audiogram there for patients who would like it. And then it helps facilitate getting patients in to get hearing aids.

Assessment of treatment effects, which is what I do, that starts with what the patient reported outcomes. And then I go through a checklist very similar to the ACS recommendations for screening for late and long-term effects.

Then they have the opportunity to-- well, they have to. So they have to see Dr. Johnson. He does cancer surveillance.

And then the next step for these patients is to really see the rest of our providers if they need to. And so if patients are pretreatment, we try to have everybody be seen. So patients, some are already having or can have trouble swallowing. And so Tammy Wasserman can come in. She does her fees with Dr. Johnson. She can make diet recommendations there for the patient. She can give them strategies for the patients to start.

And also, if the patient is going to go through treatment, she can start and get them into swallowing therapy. She does have an eight-week kind of intensive swallowing therapy that can be done after treatment. So we really try to get patients into that if possible.

Dentists, so when I talk about dentists I know you think about teeth, but the dentist does just more than look at teeth. She also does just oral health. She talks about xerostomia, trismus.

And just a lot of it's education, what can and can't be done after you have radiation therapy. And for pretreatment patients, we've actually worked out a connection with the dental center, so patients can get a panorex done. They can get evaluated to see if they do need teeth extracted prior to treatment.

If they do, we've taken two approaches. One, extractions have happened that day. So that may not seem like a big task, but the inability to get these teeth extracted in a timely fashion can cause patients to have a delay in their treatment being started. And so we've really tried to break down these barriers and get patients in quickly.

Patients can be also be seen by an oral maxillofacial surgeon. We've had that happen usually within the day that they come to the survivorship clinic.

And last is physical therapy, especially post-treatment. With the fibrosis and the scarring and in addition to if you've had surgery with the neck dissection, we have the ability to kind of evaluate patients. And with working with CRS, they have lots of sites in the community. So we've been able to get patients into places closer to home so they don't have to come here, trying to make it as convenient as possible. And so of the patients that have been evaluated, about 75% of them have actually gone in and started physical therapy.

Then in coordination of care and education, so obviously there are other things that may come up during the visit that patients may need and we don't have providers there for them. And so we've worked with Hillman's Cancer Support and Counseling Center. We have a social worker through the department that we contact.

And we also develop a survivorship care plan. And so this is one of the initiatives that we wanted to have in place before we started December 1. So it sounds like it would be easy. Maybe it sounds like it was easy. But let me tell you it's not.

So what I did first to get an idea of what people were doing-- so survivorship care plans are done at Magee. So I went down to Magee, and I talked to some of their mid-level providers to see what they were doing and how they had implemented in Epic.

And so after that, I went back to our Epic liaison. And I said, we would like to do this. And they said, fill out a ticket. And I said, we want to do it by December 1.

And so it took a little bit of time to get them on board, but they are on board. And they are working hard with us. And so it's come together. And actually by December 1, we were able to have this in the medical record.

And so if you've heard, the American College of Surgeons' commission on cancer recommends and for accreditation standards for facilities by 2018 providing survivorship care plan should be done for 75% of the patients. So all of the patients who come through the survivorship clinic get a plan.

So this is kind of what the plan looks like. So this is a fictitious patient. It's a mixture of people, Eye, Nose names. Except for-- you can see Dr. Klump is on here-- I didn't get too creative with the providers.

But it pulls in from the medical records. So the patient's information pulls in. Then typically, the days before the clinic I do the rest. So I enter in the providers. I enter in the head and neck cancer characteristics. So you can see here date of diagnosis, date of treatment, and then just some of the information. Typically, the day before clinic, Dr. Johnson and I review these to make sure that it's accurate.

And so you can see here the example patient is a stage 4A oral pharynx in the tonsil. It's HPV positive. And so if patients have second primaries or recurrences, those columns get added to the side. So far today I think I've had to add five columns and reduce the font, because it's very difficult to get it all into one page.

And then biopsies, chemotherapies, radiation. So we try to be not very detailed with this, because if somebody is going to get additional treatment, they should go back to their records from the radiation oncologist or whoever to get that information. This just gives providers an idea of what they've had and when they completed it.

And sometimes I'm able to change these forms kind of on the fly. And so sometimes reasons for just continued, if there's a comment, I usually change that and put comments in there instead.

We've listed the late and long-term effects that the ACS has advised that we screen for. And so here if patients report these or we identify them in clinic, they're identified on this sheet.

And so this is the part that's a little bit different than what's done at Magee. So when we wanted to initiate this, we wanted it to be very individualized. We wanted it to be very patient specific and patient centered.

And so you have recommendations based on the provider. So surveillance, so for example, this patient was treated in 2015. So they should be still going through fairly frequent follow-ups or cancer surveillance. This happened to be a Dr. Johnson patient. So it was recommended that they come back in four months.

So this plan is given to them before they check out. But we encourage them on checkout to make sure that they have a follow-up appointment. If we're seeing a patient from a different surgeon and in the review of the chart, I identify that they had don't have a follow-up for whatever reason-- they ran out-- we try to also get that scheduled before they leave to just make sure that no one kind of falls through the gaps.

When possible, if patients are being seen by Dr. Klump and Dr. Orr, I reach out to Carrie, Dr. Klump's nurse, and try to figure out when either their next test is going to be scheduled for, who's scheduling it, or when their next appointment is, and we just kind of put it in there so they have it.

The audiology results are here. This just gives an idea if what they passed at. So we've gotten a little bit more patient friendly with some of our language. And then the speech language pathology recommendations continue, a regular diet, for example, or if interventions are recommended.

So dental care. So our dentist actually recommends if you've had radiation that you see your dentist every three months and then no later than every six months. Use soft tooth brush. Floss daily.

One of the big questions we get frequently is, can I have an implant? Can I have an implant? Can I have an implant? No.

So if you have a radiated bone, we recommend to patients that they do not. And if you're post-radiation, they ask if they can get a tooth extracted again, it has to go back to the radiation oncologist where the field was. They may have to get hyperbaric oxygen before they can get anything done. Because if you pull teeth without taking precautions, you have the risk of osteoradionecrosis, which can cause fracturing of the jaw, in addition to severe infections.

And then physical therapy. So with CRS, what we do is we do provide the phone number. But the CRS physical therapist that we have in clinic contact a therapist from that center, and they call and they schedule. And so at the end of every month, I bug everyone to tell me so I have the records of who's been referred. But we try to keep track of who's been referred, if they followed up. And so physical therapy in our monthly report, we get if they followed up and how many sessions they've had and if they've been discharged.

And so we're trying to get better at finding ways to kind of measure pre and kind of post for these patients. We recommend that we see patients once a year just because it gives us the opportunity to hopefully identify any issues before they progress too far.

So then this is a section that targets the primary care provider. We will probably tailor this-- it's a work in progress-- to highlight a little bit more about monitoring for your thyroid, especially for patients who've been radiated to the neck.

So the survivorship care plan, really the goal is to facilitate communication. It's to facilitate communication for the patient. So the patient has a better idea.

And some patients are very on top of it. I've given them their plan. And they say, mm, there was actually something else in between here, or this is the exact person, or this is the exact date. And so patients have really appreciated it.

We also send it to the care team. So it goes to their primary care doctor. It goes to their oncology team. It goes to any outside E&T they've seen or any person that they've seen for swallowing. I try to get all the people that I can, figure out.

And then they get this beautiful bag. So they get this bag. And in this bag, it has information. It has a binder, which focuses on patient education, things they should look for, things that should watch for, phone numbers of people they can call for help.

And we also have a very detailed section about support groups. And the support groups are actually broken down by county in southwestern Pennsylvania, because we know that over 60% of our patients come from outside the county. So making sure that we kind of identify resources closer to home.

So patient feedback. So I said, we started December 1. And this is March 9. So we don't have-- we've been giving patients a survey. It's a separate survey. It's a client satisfaction survey. It's anonymous. They don't have to fill it out. But we really are interested in getting their feedback, so that we can help develop this clinic further.

And so you can just see some patient feedback here. This was a patient that came in, and she said the idea of the survivorship clinic is wonderful. I felt abandoned after my surgery. And there were side effects that I didn't know who to go to deal with. I came away from this appointment with a lot of information and a better sense that I can care for myself better. Thank you.

The second is coming here I had several questions. All were answered or addressed. Moreover, Dr. Jonas Johnson and everyone else did not rush me through. They spent quality time with me, answering concerns, explaining things, and offering encouragement. I was impressed and thankful.

And so while this person appreciated we did not rush her, the one comment that we have gotten, received, is that the visit is long. And so when patients are scheduled, we try to tell them it is about an hour. It's about an hour. And if you have needed dental work, it could be longer if we're able to and you're willing to stay to have it done that day.

So obstacles-- coordination and time. So we've mentioned that there are five providers in clinic. Making sure that people come through quickly, one of the issues that we were running to was that I was entering all the provider information to the survivorship care plan. And so I resorted to a lot of copying and pasting from notes. But again, worked with our e-record ambulatory system analyst. And she's developed a new toolbar on the side, which lets the providers put their recommendations in, and it pulls right into that care plan.

And then time. As I mentioned, the visits can take about an hour.

Sustainability. So we have five providers. And most of these providers have been gifted to us. The center's rehabilitation service has provided us PT because they view that the kind of downstream referrals will make up for the time for the physical therapist being there. And similar with the dentist and the collaboration, most of the departments we've worked with recognize that this is a very significant area that needs work and these patients need a lot of help. And so they've been very accommodating.



But we are looking for ways to make it more sustainable, possibly bundling care for UPMC Health Plan providers. We've received some small grants from the Beckwith Institute. And we also just recently put in a proposal for additional funding. And hopefully if we get it, we'll know in June.

So one of the other issues that we've come across is that these patients can benefit from therapies, sometimes therapies that occur on a weekly basis. But if patients travel from Erie to come down or travel from somewhere, it really makes coming for these regular visits almost impossible. And so we realize that there's a real need to train community providers, especially allied health providers, about the survivorship needs of head and neck cancer patients. And we're working to develop proposals to address those issues.

So there is this burgeoning population of head and neck survivors who are at risk for unmet physical and psychosocial needs. And that multidisciplinary survivorship care allows us to provide individuals care to head and neck cancer patients in order to help meet their complex needs.