

**SPEAKER 1:** So I'm going to talk to you about the lessons we've learned over the last year of having a multidisciplinary head and neck cancer survivorship clinic. So I have nothing to disclose. In 2005, the Institute of Medicine wrote a report called Lost in Transition. And what it really raised awareness of were the needs of head and neck cancer patients, or cancer patients in general, as they transition from regular surveillance into more permanent survivorship. It also highlighted the need for comprehensive care summaries and follow-up care plans, really to help connect oncology teams with primary care providers and the patients. It also focused on the use of evidence based clinical practice guidelines for assessment tools and screening instruments to help identify and manage late and long term effects of cancer and its treatment. Many of these treatment effects don't really become prevalent until after patients are out of that really frequent follow up window.

So the American Society of Clinical Oncology piggybacked on this and mentioned four components of what they view as high quality survivorship care. The first is prevention and detection of new cancers and recurrent cancers. And so the prevention aspect goes into health promotion, so if you have a patient who comes in with a head and neck cancer and has a history of smoking, really talking to them about smoking cessation and looking for second primaries in the lung, or any other cancer, and then looking at recurrences. And surveillance of recurrence is a new primaries, interventions for late and long term effects of cancer and its treatment, and the fourth is coordination, so coordination between the specialists, primary care providers, other health care providers that are taking care of this patient, to really ensure that survivor's needs are met and they're not lost.

In 2016, the American Cancer Society highlighted what they viewed as evidence based guidelines for long term survivors. And it took almost a year, but in 2017, ASCO endorsed these guidelines and said, moreover that there needs to be a comprehensive team based approach to head and neck cancer survivorship care. So this includes primary care, clinicians, oncology specialists, otolaryngologists, dentists, and other allied health professionals like physical therapists, nurses, speech language pathologists, and that we really need to focus and coordinate our care.

So I'd like to say that in 2016, so before ASCO endorsed these guidelines, we actually started to put these guidelines into practice. And as you can see here, this is our UPMC head and neck cancer survivorship clinic. We have a nurse, an audiologist, head and neck surgeon, physical therapists, speech language pathologists, and dentist in clinic. And so what does a clinic visit look like for a patient? Patients come into the clinic and they complete the patient reported outcomes questionnaire. So these questionnaires are on a tablet based system and they focus on areas that we know are prevailing and prevalent issues for patients, so quality of life, symptoms of depression and anxiety, swallowing difficulties.

And as we progressed through our clinic over the last year, we added additional instruments-- neck disability, health literacy, and oral health. So once the patient's roomed by the medical assistant, we actually do an audiology screening. So this is a brief audiologic exam, and then a hearing screening. The hearing screening only takes about one to two minutes, and it's done at 30 decibels with three different frequencies. The selection of this was purposeful, and so if a patient fails at those three frequencies, at that decibel, the World Health Organization recognizes that as a disabling hearing loss. And so we will offer patient amplification during this visit. We'll offer them a more comprehensive audiogram at the end. And for patients that want to start talking about hearing aids, we can do that there also.

After that, myself or one of the other nurses goes in. And we, at that time, have already looked at the treatment summary. And so we make sure we have accurate information. Many patients come from outside of UPMC or Hillman, so just review those with the patients see if there's anything additional. And then, we've already looked at the patient reported outcomes that the patients have finished. And we discuss them with the patient. That's usually how we start the conversation. And then we identify and ask about other symptoms in latent long term effects that are covered under the American Cancer Society's guidelines. Once that happens, the nurses give an update and help identify the patient's main concerns for that visit. And then we do cancer surveillance. Our head and neck surgeon does cancer surveillance, and we'll talk about those latent long term effects that the patient's experiencing, and develop a plan of care.

So at that point, the visit can really be tailored for the patient based on the patient's patient reported outcomes, and the assessment done during the time with a nurse and head and neck surgeon. Patients can see a speech language pathologist. They would assess swallowing with the fees, recommend exercises and diet, and then coordinate therapy for patients. We do see patients who are either beginning treatment or in the middle of treatment. So we connect them to a therapist closer to where they're getting treatment. And if patients are from outside facilities, our speech language pathologist will follow up and call to see how they're doing.

We have a dentist, so she does an assessment of dentition, mucosa, trismus. She recommends strategies to maintain their oral health and manage their estomia. She also will communicate with patients' dentists, and will help if patients need referral for oral maxillofacial surgeon or any other dental work. And we have a physical therapist. The physical therapist we work with is connected to the centers of Rehab Services, and she will assess range of motion, myofascial restriction, pain, trismus-- so it really kind of overlaps some with what our speech language pathologist does-- strength, postural abnormalities, which we're seeing more of in our survivors, and then she'll recommend and coordinate therapy.

The benefit of working with the centers of Rehab Services are that they have multiple sites up western Pennsylvania. So patients can get the physical therapy they need by a trained PT closer to home. And at the end, we do compile all these recommendations, and I'll show you the plan in a second. And the goal of these survivorship care plans are really to facilitate communication, to give the patient something in-hand to take home, something tangible, so they can remember what we've discussed, but also coordinate with the care team. This also is just kind of a record going forward that we can modify and change. And so at this point, this is delivered by the nurses and then we also, after the visit, we'll help coordinate any care that the patient needs, or getting into appointments, arranging visits.

So when we're looking at the head and neck cancer treatment summary, this is in EPIC. It's under the problem list, and this is sent to the providers through EPIC. So what it generally has, and this is just an example, is general information about the patient, the care team, and we can add additional providers if the patient requests, or send the treatment summary to them, and then a really brief head and neck cancer characteristics, so this goes into the diagnosis, when the treatments ended, stage, recurrence, sight, tumor type, HPV status. And if the patient were to have a recurrence or a second primary, we expand on this.

The treatment is broken down into primary treatment, treatment for recurrence or treatment for second primaries. And this is done in kind of chronological order just make it easier to follow. But this would be an example of a primary treatment-- so a biopsy and then the chemotherapeutic agents or immunotherapeutic agents and radiation. The late and long term effects are what the patient has reported during this visit. I think this is what sets our treatments summary apart from other treatments summaries, is that we've worked with EPIC to really identify a way that each provider can leave a personalized message and recommendations for the patient.

So surveillance would come from the head and neck surgeon. Audiologist, they mention your results of your screening and they identify the place it's closer to you, if you wanted an audiogram or needed more follow up. Speech language pathologist will write a note. Most of the providers also provide their phone number at the bottom or mention when their appointment is set up for. Dental, we do two separate. It's pre or undergoing treatment, and then what to do afterwards, and physical therapy. And the way we coordinate our care with CRS, the Centers of Rehab Services, is that the site closest to them will call the patient and set up the appointment. So they should know where they're going and even potentially who the PT will be to see them. The next step is really just identifying those issues, that if patients have between visits, they need to call us for. And again, if there's anything severe, they should go to the ER.

We mentioned health promotion and surveillance as one of the main components of high quality care. And so you can see here that all patients who've got radiation to the neck should have a TSH. So this reminds other providers, but also the primary care physician. And then based on their smoking history, a chest ET. And again, since we coordinate with the primary care doctors, these are just reminders for them of things that they should be doing and looking for this patient in terms of health promotion, for a cancer survivor. And the primary care providers also get a little bit extra when we send this. So they get a letter that precedes this in EPIC that just identifies who we are, the purpose of this, and has our phone number in case they notice any issues during a visit, and also links them to the American Cancer Society's guidelines. So if they wanted to just read through that, they could. And it would be easy to identify and locate.

So we've been doing this for a year now, actually, a year. So since December 1, 2016 to November 30, 2017, we've had 479 visits and we've seen 438 unique patients. So our mean age of patients is 63, predominantly male. Most are white, and the histology we see most often is squamous cell carcinoma. The most common sites are oral cavity, oral pharynx, and larynx. And 65% of our patients were diagnosed with advanced stage. Now just looking at our post treatment survivors, we have seen 389. The majority of his patients, as you can imagine, since they're present with advanced stage, get multi-modality treatment. That could be surgery and radiation, surgery chemoradiation, or chemoradiation.

Our survivors' mean-- this is skewed because we do have survivors who are in the 30 to 40 years post treatment-- but our median is about three years, our mean 5 years. And we do see patients who have local recurrence, [INAUDIBLE] metastasis and second primaries. Many of these patients are coming to us before they start their treatment for these additional diagnoses. So I mentioned the patient reported outcome. So I'm just going to give you a brief overview of what we've seen in the last year. And these are for our post-treatment patients specifically, so 89% of our post-treatment patients report at least one latent long term effect. And half report three. So these are latent long term effects such as swallowing, chewing, pain, that have affected them in the last seven days. So these are things that affect their daily activities. The most common reported cancer and cancer treatment effects are swallowing, saliva, pain, chewing, and speech. And so these are what patients report is important to them. So that's just something to know.

And then 30% of our patients, which I was slightly surprised at-- I thought it might be higher-- report that the quality of life is somewhat to much worse than it was prior to developing their cancer. So what we've seen in other studies, looking at a large seer data set, they actually noted that, over time, quality of life for head and neck cancer patients continues to go down. So there may be some component here of patients reflecting on the fact that they have been cured of cancer, and so everything's better than the other reality that could have happened. And so it could be accommodation.

So additional patient reported outcomes-- 11% of our patients report symptoms of major depression and 10% of our patients report symptoms of generalized anxiety. So these are really just cut offs based on our patient reported outcomes. And what these indicate are that these patients really need a more comprehensive behavioral health evaluation to see if they can get diagnosed and treated. Not surprising, I'm sure, to most providers who've seen these patients, 73% of our patients report symptoms that indicate that they're not swallowing efficiently or effectively. So this is a little higher than what you've noted on the slide before. And this is really a more comprehensive questionnaire related to swallowing. The University of Washington focuses on four items, and this is 10 items looking very independently at trouble swallowing liquids, trouble swallowing solids, and even the distress that swallowing can have.

54% of our patients, half of our patients, report some degree of disability, with 20% reporting moderate to complete neck disability. So this incorporates difficulty in doing activities, chronic pain, trouble sleeping, driving. All of those things are incorporated into this. And then 20% of our patients report inadequate health literacy. And this is really important, because health literacy has been tied to patients' ability to make decisions, or can influence their ability to make decisions, and also compliance with treatment and plans of care.

So I wanted to focus, really quickly, a little bit more on neck disability, because we are seeing more patients that are having non operative treatment. So this was a secondary analysis, and so it was actually done a month or so ago. So the patients are a subset of what I just presented. 173 patients were looked at in this analysis. 55% of patients reported some degree of neck disability, and 20% had moderate to complete impairment. So while these numbers are different, you can see that the percentage really hasn't changed as we've accrued more patients. At the time, the most common tumor site was oral pharynx, oral cavity, and larynx. And you can see here what they had for their treatment.

So in terms of treatment and neck disability, patients who received surgery and adjuvant therapy were most likely to have neck disability, and so that's something that I think everyone would expect. However, when we looked at the non-operative group, the chemo and radiation group, the RT alone group, half of those patients had neck disability. So it's really important. I think we think of surgery as one of the main contributors, but radiation can also play a role. And it's important to identify this early, so that patients can get appropriate therapy.

What do patients say? So we employ a client satisfaction survey. This is an option for the patient. We give it to them at the end. We ask them to complete it and return it, so we have about a 30% to 40% return rate. And overall, our satisfaction is very high. Some of the actual comments that patients have made are all areas necessary for continued recovery and survival. We're addressing the same appointment in one setting. So instead of seeing five providers at five different times, they're able to work through the clinic and see these patients in one setting, and then complete therapy closer to home. The idea of a survivors' clinic is wonderful. This person mentioned that they felt abandoned after their surgery, and they had side effects that they didn't know who to go to or how to deal with. And they came away with, really, a better sense that they could care for themselves.

So I think that one of the main parts of developing high quality care is really empowering patients, and educating patients, and helping patients to do what they need to do to maintain their quality of life. And then coming here, I had several questions. All were addressed and answered. Moreover, Dr. Johnson and everyone else didn't rush me, so we don't rush patients. That being said, visits can take an hour to two hours depending on how complex patients' needs are. And if they need something emergent, we do try to get them into the dental center when possible. But they spend quality time with me answering concerns, explaining things, and offering encouragement. They were impressed and thankful.

And so what I hope you've seen during this presentation is that head and neck cancer survivors do have complex effects related to their treatment, and that these effects can last longer than their typical surveillance, especially when patients are at that five year mark. What do you do? Do you follow them up? But we see patients who have issues that need addressing after that point. So just remembering that it's multi-disciplinary needs that these patients experience and there are providers that can help you. We see patients once a week on a Thursday here in Oakland, and this is the information for scheduling appointments.