Welcome to Yale Cancer Center Answers with your hosts doctors Anees Chagpar, Susan Higgins and Steven Gore. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven, Dr. Higgins is Professor of Therapeutic Radiology and of Obstetrics, Gynecology and Reproductive Sciences and Dr. Gore is Director of Hematological Malignancies at Smilow and an expert in Myelodysplastic Syndromes. Yale Cancer Center Answers features weekly conversations about the research, diagnosis and treatment of cancer and if you would like to join the conversation, you can submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. Tonight you will hear a conversation about head and neck cancer with survivor Chas Timberlake and his physician Dr. Wendell Yarbrough. Yarbrough Charles, is it okay if I call you Chas? Timberlake Absolutely. Yarbrough I know you go by Chas. Tell me a little bit about how your journey with head and neck cancer, and more specifically the neck mass that was found, started. Timberlake About a year and a half ago, I was shaving one morning and for some reasoning just pulling on the skin of my neck, and I noticed there was a lump there next to the muscle on the right side of my neck. I noted it, watched it for a couple of months and decided I should have it looked at during my annual checkup. When I went in to see my doctor, he took a look at that as well as a lot of other things and said, I think what you have there is some sort of a lipoma or probably more like a cyst and it's nothing to worry about. I went home, decided not to do anything about it for a while. Eventually, I noticed it was still there and about four months later, I decided I better have it looked at. When I went to have it checked out, I guess it was September of last year, the doctor I went to see at Stanford Hospital came back to me with results of the test and said we need to do core biopsies, at which point I realized that this was something a lot more serious than a cyst. At that point, he came back with a diagnosis of cancer, I believe he called it a carcinoma at that time, in my lymph nodes. Yarbrough That is a fairly prolonged story from the time that you first recognized it until the time it was diagnosed and I must say, we hear that story pretty frequently. Were there any symptoms that you had associated with the neck mass other than just the lump? Timberlake There were no symptoms at all; other than the lump being there, it did not cause me any pain. I did not have any other symptoms such as lethargy that would direct me to something being amiss. The only thing I noticed, and the reason I finally went to the doctor at Stanford Hospital, was that I was getting a little bit of sore throat, just enough to tickle my brain and say, hey it is not going away, this is about 2 or 3 weeks' worth, and I said, I better have it checked out. Yarbrough It sounds like that was the right decision in the long run. 3:42 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3 Timberlake It certainly was. I wish I had done it a few months early. Yarbrough So once you had the diagnosis, what was the next step? Timberlake The next step was that I decided I needed at least a second opinion and probably a third and maybe more. In the end, I ended up with two second opinions, one from a very nice gentleman at Smilow Cancer Hospital, I think his name is Dr. Yarbrough, and finally I went down to the head surgeon at Memorial Sloan Kettering. Amongst all of those, the only one who probed a little bit further as to what the mass was all about, and what was behind the cancer, was yourself. You asked several pages of a questionnaire that did not appear at any of the other ones. As a result, you decided to take extra biopsies, a couple of them, and your suspicion was that this might be related to HPV, the human papilloma virus. Yarbrough That is really an intriguing story in head and neck cancers, which as we talked about earlier, head and neck cancers are not cancers that are well recognized in the general population, even some providers do not know a lot about head and neck cancer which basically means cancers of the throat, mouth, tongue and voice box, but this human papilloma virus connection really focuses on a few areas in the throat, the tonsils and tongue base where most of these human papilloma virus tumors arise from. As you started on the path, you knew you had a neck cancer and there was a suspicion that it had risen in your mouth or throat. Can you tell me a little bit about the procedures that you went through to try to determine where this tumor may have come from? Timberlake At one point I was given a, I am not sure what you call it, the probe. Yarbrough Endoscopy. Timberlake An endoscopy, after the results of the biopsies that you performed, I believe that was the determinant of where we were going to go with it. I think after that we scheduled the surgery as I recall. Yarbrough Yeah. And back to the human papilloma virus, were you aware of human papilloma virus as a cause of these cancers, especially in men? Human papilloma virus is more or less pretty well known for uterine and cervical cancer, but had you ever heard of it causing cancer in men before? Timberlake I had not. I was aware of the HPV issue for women in cervical cancers. I had been aware of that for quite a few years, but I had never heard of it related to throat type cancers, mouth and throat cancers and especially not in men. 7:15 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3 Yarbrough And when you heard about the HPV component of your cancer, did you know anything about the treatments associated with that or the response of those tumors compared to tumors that may be caused by tobacco, which is the other major cause of head and neck cancer? Timberlake I did not, not knowing that they actually existed, I really did not have any thoughts on that and I did not have any knowledge of it. In fact, I was quite enlightened by my experience with you in terms of the prevalence of these cancers and the treatments associated with dealing with them. Yarbrough I think we have all been surprised by how rapidly this tumor has increased. It is more common in men, as we have discussed, about 3 to 1 compared to women and these tumors will be more common than uterine and cervical cancer caused by HPV by about the year 2017, that is the prediction, so it has really been a rapid increase in these tumors since about the year 2000. I do want to mention that there is a prevention strategy for human papilloma virus infections which is the vaccine. You have probably heard about that as well but these vaccines are not treatment vaccines. They only prevent infection, so it is important for boys and girls to be vaccinated and the Center for Disease Control has recommended these vaccines for both boys and girls ages 11 to 21 and for women up to 26, so we are really excited about a vaccine that can prevent cancer and can prevent head and neck cancer, so back to your story, when you initially got this diagnosis, what did you think? What was your first reaction? Timberlake My first reaction was shock. I did not go into a depression right away, but I was taken aback by it especially since I had a sort of benign diagnosis months before, it was quite a slap in the face to hear that this was a cancer. I think everybody who hears the word cancer in the modern day fears that this is the end, this is a terminal disease and that it is curtains, so my first question I think was, okay how long do I have? That really focuses your brain on what is important in life and from that standpoint, I think it was, if it can be called a good exercise, I think it was really worthwhile. It made me realize certain aspects of my life that were not wrapped up or not taken care of, especially financially. Considering what might happen to my survivors if I were going to be gone, and from that standpoint if it has to be, I think it was very worthwhile. That was my first reaction and I went through a period of a few weeks being quite scared about it, wondering what was going to ultimately be the process that I would have to go through. You had explained to me that the first procedure would be to remove the tumor from my neck; however, there were other issues as well which had to do with the tonsils, the back of the tongue, the throat in general, and those would be dealt with also by surgery at the same time that you would be removing the tumor from my neck. Furthermore, somewhere down the line, about a month later, I would be entering into a program of radiation. There would also be the possibility of having to go through chemotherapy. In my case, I only had to go through radiation, it was decided amongst us that radiation would be the recommended treatment. Yarbrough That sounds like a lot of information to come in and get thrown at you all at once. If you have cancer, the cause of it being a virus, meeting multiple doctors with multiple different treatments being discussed and not really knowing where this tumor originated and still having to chase that, 12:11 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3it seems quite overwhelming for the patients when they come in and we have these discussions and they meet the members of the team that are treating the cancer. How was your experience with navigating through that system and taking all that information in? Timberlake To take it from the beginning, it was an even bigger quest to find the right place to do it. As I said, I went to three different venues between Stanford, here at Yale and Memorial Sloan Kettering in New York, and my decision was difficult. It took me some time to come to it, especially since I did not know anything about the disease, I did not know anything about the prognosis beforehand. Without that knowledge, it is very hard to decide, okay, who amongst all of these really, really highly respected, highly recommended hospitals and doctors do I trust with my life, with my body? After the fact, I think that was the biggest problem for me. Once I had decided to go with Yale and with you, dealing with the people at Yale was really quite easy in retrospect because they are the most caring and wonderful group of people I have had to deal with in my life and dealing with something like this, they were fantastic. Yarbrough I will tell you, I hear from patients a lot that the not knowing, the uncertainty is sort of what creates a lot of the anxiety and once you understand and start learning and knowing how you are going to be treated and the team members, it creates some sense of stability. Timberlake Very much so, once I knew what I was going to go through, how it would be, my fears did not vanish, but they subsided. I was very comfortable coming here. Yarbrough We will pick back up with that when we return. We are going to take a short break for a medical minute. Please stay tuned to learn more about Chas' story and head and neck cancer. MedicalMinute Smoking can be a very strong habit that involves the potent drug nicotine and there are many obstacles to face when quitting smoking, but smoking cessation is a very important lifestyle change especially for patients undergoing cancer treatment. Quitting smoking has been shown to positively impact response to treatments and to decrease the likelihood the patients will develop second malignancies. Smoking cessation programs are currently being offered at federally designated comprehensive cancer centers such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven. The smoking cessation service at Smilow operates on the principles of the US Public Health Service Clinical Practice Guidelines. All treatment components are evidence based and therefore all patients are treated with FDA approved first-line medications and smoking cessation counseling. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven. For more information, go to yalecancercenter.org. You are listening to WNPR, Connecticut's Public Media Source for news and ideas. 15:48 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3 Yarbrough Welcome back to Yale Cancer Center Answers. This is Dr. Wendell Yarbrough and I am joined tonight by my guest, Chas Timberlake, who is a head and neck cancer survivor. As we were leaving, we were talking about the treatment process and the certainty that came with getting on a pathway and meeting your team, and I was wondering if you could just talk a little bit about your thoughts when you first heard that we may do some transoral robotic surgery to remove the back of the tongue area and the tonsillar area in search of your tumor? Timberlake I thought that was quite interesting, actually, as far as the process went, I knew I would be asleep so it really did not affect me directly, consciously anyway, but I was really pleased to hear that we were using very modern up-to-date methods and I was intrigued by it. In fact I looked into it online, the methodology and the units that you used, the robots, the actual experience of it, again I woke up and everything was gone, so that was something that really is more your domain because you get to use it and take care of what needs to be done. Yarbrough What was your recovery like after the surgery? One reason we do use the robot and other minimally invasive techniques is to try to avoid having to remove or dissect through normal structures so that we can get to the same areas without damaging those normal structures with the hope that people recover back to a better functional status. Timberlake I had had arthroscopic surgery on both of my knees and the comparison between how my knees look today, and my brother who had them done 20 years before, is quite radical. My brother has about a 10 inch scar on both of his knees. Mine, you cannot even see. The little holes that were used to introduce the arthroscope into the knees to work on them, they are invisible and I figured that that had to be a really good thing for what needed to be done in my throat. If it could be done without having to go through my neck or some other method, I thought that was great and once I knew what the procedures were going to be and I knew what the outcome might be from it, that the prognosis for this type of cancer was actually pretty good compared to a number of other ones, I was quite, if you can say, pleased, I was ready and eager to go through with it and get this on the road. Yarbrough And so after the initial surgery with the robot and the neck dissection, how long were you in the hospital and how long before you were back on your feet and swallowing? How was your communication afterwards? Timberlake I was told I would be in the hospital for probably 6 days or so, 5 to 6 days. In fact, I was out in 3. I healed pretty quickly and was quite happy to go home. It was pretty short. I have to say I have never been better taken care of in my life. I probably wish I could have stayed for 3 or 4 weeks. The staff in the hospital, the medical staff, everybody from the people who bring you trays in the morning, were the nicest they could possibly be and they really made me feel very comfortable and very taken care of. If you have to go somewhere, this is a great place to go. I was maybe 2 weeks at home experiencing a fair amount of pain, but no more than I would have had with a normal tonsillectomy. My neck where the lymph nodes were removed and the tumor from my neck was 20:23 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3removed, that really did not bother me at all. I did not even notice it except for the scar and as I was promised by Dr. Yarbrough, the scar would fade into wrinkles, which I did not really appreciate, but in fact has happened. Unless I tell people about it, nobody notices it today. Yarbrough I think one of the things you mentioned is really important, especially for head and neck cancer, the team based approach, you mentioned the nurses, the surgeons, the assistants, the coordinator who helps schedule the appointments and of course part of that team is also the people who deliver the postoperative care, and I know that we had quite a few discussions at our Tumor Board about the appropriate care for you after your surgery and after the pathology came back and I just wondered if you could tell us a little bit about your postoperative therapy and what it was like to go through that, how long it lasted and what were the side effects? Timberlake The biggest problem I think postoperatively was swallowing and eating. I actually did not have a lot of trouble swallowing, but it was painful and I am not very happy taking meds. I stopped taking the immediate meds within a day, the morphine and that sort of thing, it just does not agree with me, so I survived really on Tylenol and tramadol which I took sparingly when I needed it in order to eat my meals and eating a lot more often during the day, smaller meals, smaller bites because it was difficult to swallow. That lasted about two weeks. After that, I was basically able to eat and function quite normally. I was in the office within a week going back in to spend a few hours a day. I felt a bit tired. I rather expected that, but it did not keep me from doing my normal daily routines. Obviously, I did not go and engage in sports and that sort of thing. Yarbrough How long of a break did you have between your surgery and when you started radiation therapy? Timberlake That lasted a month. I started radiation therapy in the middle of December. Yarbrough And radiation therapy lasted roughly 6 weeks or so? Timberlake A little bit longer, it took about seven weeks mainly because there were a number of holidays, Christmas, New Years, Martin Luther King Day, so it stretched out a little bit. Yarbrough Tell me a little bit about going in for your radiation treatment, how long did it last and what is it like to get a radiation treatment? Timberlake The first time in was a bit of a shock. I spent quite some time with them having a mask built for my head which I had not expected. I did not know what that was about. That took the better part of an hour and eventually it becomes an adjunct to your therapy. In fact, when you walk into the radiation treatment room, you are faced with what looks like something out of Star Wars, it is a giant robot and an operating table, and the first time I saw it, I was a little taken aback, but everybody explained to me how it worked and what the functions were and once I got used to that, it was actually pretty simple. I would walk in at 8:30 or 9 in the morning, drive up here from New 24:36 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3 Canaan which is a bit of a hike, but when you are dealing with things like this, a little bit of discomfort and issues is not a big deal. I would walk in, they would put me on the table, put the fiberglass mask over me and lock it down onto the table so that I could not move. The idea being to pinpoint the radiation without any chance of irradiating areas that were not the target. It kept me very still. The first time or two was a little bit claustrophobic, but I got used to it. It did not take me too long to do that. Yarbrough How long would each treatment last once you were on the table? Timberlake Once on the table, the treatments lasted no more than 10 or 12 minutes and then we were done. Yarbrough At first, did you notice anything was happening or could you tell any difference at all? Timberlake It took three weeks before I really noticed any difference in my functioning or otherwise. In the end of the third week into the fourth week, I started noticing, I was tired, I was a bit lethargic and I started noticing more pain in my throat. Yarbrough Was that the main symptom that continued, throat pain, did you have any swallowing issues? Timberlake I did not, not at the time, swallowing was not an issue for me and had not been from the surgery. I had been told that might be, I guess I have a large throat opening perhaps, I am not sure, but it did not bother me. The pain was the major issue and with the tramadol and the Tylenol, I was able to manage that. Yarbrough After you finished therapy, how long was it before the pain resolved? Timberlake The therapy ended at the end of January. I took tramadol and Tylenol to eat for probably another 4 or 5 weeks after that, at which point I stopped taking the tramadol and I took some Tylenol for another month or so and that was it. After that, I still had discomfort, but I prefer not to medicate if I can. Yarbrough Now are you totally back to normal without discomfort, or do you notice a change? Timberlake There is certainly a change. There is a residual hangover from it, if you will. I have noticed that there is some tissue where the tonsil was removed which I can feel, it is a little bit swollen and perhaps there is some edema there as well on that side of the neck. Also the sinus area, the back of the throat, actually, into the sinus still has a little bit of pain that I notice primarily when I am exercising when it dries out. Those are the major issues that I have other than the problem that I have with taste which is something that developed during the radiation process. After about two weeks, I noticed that my mouth tasted like it was full of aluminum foil and by the fourth and fifth week, that translated into tasting more like it was a bit of foil and a bag of salt, some sea salt. 28:18 into mp3 file https://az777946.vo.msecnd.net/cancer/2015%200816%20YCC%20Answers%20-%20Chas%20Timberlake_229691_5.mp3 Yarbrough Has your taste returned or started to return? Timberlake It has gotten better. It has taken some time. It took longer for the effects of the radiation to start to wear off than I expected. It took about two months after the radiation stopped. It seemed as if the radiation were continuing somehow for those two months, but at that point, I noticed when the pain started subsiding to the point where I did not need any medication at all, that got better. The taste is still not 100%. It has come back a bit and I noticed it coming gradually. Yarbrough I know you are a very active person and I just wanted to talk a little bit about your activity level and your life and how this has affected you, have you gotten totally back to where you wanted to be, how has it changed you? Timberlake In terms of activity, I went back to what I normally do within a couple of weeks after the radiation stopped. In fact, I was up in Vail with my family two weeks after the radiation was over for a week skiing. I thought I would be having a lot of trouble. I did not. My stamina was down a little bit but that built up even within that week. Two weeks after that, I went up to Aspen with a group of 16 guys and skied as if nothing had ever happened. I play tennis. I like to golf. I bike regularly. In fact, last week, I did about 85 kilometers on my bike in the New Canaan area. From that standpoint, I am back I would say 99 to 101%. Chas Timberlake is a Head and Neck Cancer Survivor. We invite you to share your questions and comments, you can send them to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC and as an additional resource, archived programs are available in both audio and written format at yalecancercenter.org. I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR, Connecticut's Public Media Source for news and ideas.