Patient’s experience: Patient, 50 yrs of age, having a leiomyosarcoma tumour of size 3x2x1 cm, in the front 1/3 portion of the tongue. The patient had a condition of chronic submucous fibrosis

Initial symptoms

There was an acute pain in inner right ear, which would not subside with pain killers. Patient consulted an ENT specialist who examined his ear and found nothing in there. He said it has something to do with the oral cavity of the patient. He examined patient’s oral cavity also but did not find anything. The other symptom was redness of the right edge of patient’s tongue. Blood red. After a month Patient saw a boil on the right front one third of his tongue. It was a painful boil. After taking some medication from a homeopathy doctor the boil which was basically a tumour shrank in size substantially with a month of medication but after that it started growing again. At that point a decision to go for a biopsy was taken. Many physicians’ patient met before biopsy felt that since it was painful it was most likely a benign tumour.

**Biopsy and diagnosis**

Biopsy report was positive, but the diagnostic lab was not very clear about the exact type of cancer though they had guessed it to be a “sarcoma”. Though the biopsy report was not clear to pin point the type of sarcoma, but had mentioned that the cancer was very aggressive. Therefore, the surgeons thought that if they try to shrink the tumour by chemotherapy it will take a few months and there was a risk of cancer spreading to the other parts of the body as it was very aggressive. Aggressive here meant malignant cells multiply and spread very fast. Surgeon suggested that they would do detailed biopsy after surgery and scheduled immediate surgery and scheduled it 3 days after patient met him. Earlier the first line of treatment was chemotherapy to shrink the tumour so that a smaller portion of the tongue would be removed to minimize speech and eating related complications however the aggressive nature of cancer dictated immediate surgery according to the doctors.

Post Surgery

Initial experience was good till surgery. After surgery final autopsy was done to determine the exact type of Sarcoma (Leiomyoma sarcoma). It became clear that cancer had not spread anywhere in the body and was confined to the tumour in the tongue. Even though it was Leiomyosarcoma, but in this case it did not follow established behaviour of Leiomyosarcoma such as spreading to the other parts of the body rapidly. Therefore, established characteristic of these cancers is a pattern which might differ from patient to patient. Junior surgeon assured my wife saying man is mortal and this patient will also die, but not from cancer. That was the level of confidence. He could make this statement on the basis of successful surgery and removal of the tumour with sufficient margins and the fact that cancer was restricted to the tumour area and had not spread to other part of the body. However, I felt I was not given a very good understanding of that the fact that my speech and eating abilities would be affected even after successful surgery.

However, when it came to further course of action the doctor was not only confused, but clearly has no knowledge of what to do next. A thorough gentleman and a good acquittance my wife and me had full faith in him in the sense that he will not exploit us, and he never did, but his limited knowledge was a problem. On the day of release post-surgery he said we are trying to find out the next steps in the treatment. Chemo is ruled out only immunotherapy and radiation or the options. After speaking to a radiation therapist in a Pune hospital he called us to meet him and go for radiation therapy. Jehangir does not have this facility. The therapist was very firm on radiation therapy. He showed us familiarity for the entire duration of therapy, but looking back we are sure he exploited us. I told him about my precondition (Oral Submucous Fibrosis) and whether it will impact my oral cavity. He said it will make it worse. But we can handle it. He sold me a very expensive medicine to alleviate the effect through a vendor and not through the hospital. It did not work at all. I am sure he just took a commission from the vendor.

After a month of surgery, twenty-eight sessions of therapy were scheduled. Within 3 days of radiation, I realized that my condition has worsened. I met my surgeon that I cannot sustain radiation and some alternate treatment should be explored. He got upset saying do you want your cancer to return? This was the same surgeon who had told that they have removed the tumour with sufficient margin and since it has not spread to other parts of the body there was no need for any therapy and no chance of recurrence. Lack of knowledge evidently. My radiation therapist got a bit upset when I asked him to suggest alternate therapy in place of radiation as I was not able to cope with it. I myself suggested immunotherapy. But he dismissed it as useless. Lack of knowledge again as immunotherapy is the most promising therapy today. Was it as popular and effective five years ago I don’t know. My overall well being regarding quality of life after radiation treatment was affected negatively but I feel I was not given a clear understanding/picture of how radiation would affect my overall quality of life

I was supposed to come for radiation from home and after the session go back home. But my condition became so pathetic that I stayed in the hospital for the entire duration of radiation. Things became a little better after sometime until bleeding event tool place after a year and eight months after conclusion of radiation therapy.

I was put in ICU to stop bleeding and nerves supplying blood to oral cavity were blocked. Doctors were not sure if this was because of side effects of radiation, inflammation or recurrence of cancer. What if bleeding returns was the worry of my surgeon as it perhaps happens sometimes in case of recurrence. He told my wife to be ready for any eventuality as anything can happen. My subsequent CT scan revealed a scar on my right jaw bone. Tumour was also in the same side of the tongue/mouth. Both surgeons visited me in the hospital after CT scan report and told me the scar could be due to three possible reasons. (1) Effect of radiation (2) Due to inflammation and subsequent bleeding and (3) My disease has come back. They asked to go for whole body Pet Scan and consult Dr Mistry in Kokilaben, Mumbai. They connected me to him and my next phase of journey started with Kokilaben.

Dr Mistry saw my Pet scan report and said there is always a chance of recurrence in any cancer. However, all the patches you see in the scan is not cancer. He connected me to sonography department to find out if there any soft tissues in the right side of the cheek and jaw. Extract the soft tissues is any and send it for biopsy. The head of sonography department checked, but did not see any soft tissue and dismissively said there is nothing. The statement of Dr Mistry that every patch in the scan is not cancer and sonography examination which did not find any soft tissues gave me the first glimpse of hope for survival. Though I had the gut feeling that its nothing but the inflammation, because little bleeding started happening since August 2020 only. I would feel irritation in the throat and when I would to the washroom to spit out few drops of blood would ooze out. But on 15 Nov 2020 it was a massive bleeding.

Dr Mistry asked me to come after 3 months with full body scan which I did. But the second pet scan was as bad as the first one. He again asked me to come after 3 months with scan. This time it was a little better and showing only some activities inn the right Jaw on the mandible. He said need to rule our cancer in the Jaw (mandible) and asked me to come after 6 months. This time also there was a reduction in the activity, but it was there nonetheless. He did mention that it was not cancer for sure. He asked me to come after one year and it was in April 2024 I was declared free of any symptom.

Summary of my experience

1. Doctors in India from old school of thought mistake experience for knowledge. Experience you accumulate with every patient you treat. But knowledge you gain by knowing how other doctors in the same area in India or abroad are treating their patients.
2. They choose safest and beaten tracks. They are in love with what they know and do not do research. Saving life is priority and everyone from surgeon to radiation therapist took the credit for saving patients life, but patient’s life became miserable afterwards is not on the records
3. They do not experiment even if the condition is safe enough. Radiation therapy must be done after surgery even though if you ask them (in my case) if there is any biological basis or proof that it works, they don’t explain except saying that it destroys malignant cells and some healthy cells are also destroyed. And then healthy cells grow again. But there is not reason to believe malignant cell will not grow back as mutation happens at genetic level and cancer is nothing but mutation gone mad.
4. If the disease is rare data and knowledge associated with the disease and treatment is also scarce. In that case every new patient is a case study. Doctors did not capture my experience and knowledge. In fact, they were not eager to record my experiences giving the impression that they already know. But the truth is both of my surgeons and the radiation therapist they had never treated Leiomyosarcoma in the head and neck area leave alone the tongue.
5. It would have been better if I had consulted other doctors in major hospitals to get other opinions before committing to one doctor for the treatment.
6. Radiation therapy doses are typically 30to 40 Gy. In my case as patient, it was a dose of 60Gy. Oral cavity is different from other parts of the body such as legs, stomach, bladder or uterus where sarcoma generally occurs. Was this dose very high for the patient resulting in high adverse side-effects?
7. Lack of knowledge and business interest do cloud the advice doctors give to patients and seeking second opinion is something patients must utilize to safeguard their interests.