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Finding My New Balance

Sophia Amalanathan, MS(ENT), DNB[1], Roy Thomas Daniel, MCH[2], and Arun Alexander, MS(ENT), DNB[3]

Abstract

All of us walk with faith, unaware of what lies ahead in our life, until we have that fall, my story is about how I lost my balance and regained it in a better form. Little did I know about this rare brain tumor that was slowly taking over my neural commands. To fight for my life was the only aim prior to surgery and getting back to living my life after neurosurgery was aiming higher than before. This narrative essay is about my trials and tribulations of a rare brain tumor that presented with audio-vestibular symptoms. It portrays vividly my experience of this brain tumor, and importantly vestibular rehabilitation that which allows the brain to achieve recovery of neural functions due to its inherent properties of neural plasticity.

Keywords

behavioral health, patient feedback, empathy, long term care

Life can throw a few "curve-balls" now and then, but sometimes it ups the ante and our very perspective toward life is irrevocably changed. Illness is the worst offender of all. As someone who "lost her balance" I can say, imbalance disables you physically, emotionally, cognitively, and socially.

I have been a faculty in the department of ear, nose, throat (ENT) at a state-run medical school in southern India for the last 10 years doing the things I love; teaching undergraduate students, performing surgeries, and treating patients. In the summer of 2018, I began experiencing intermittent brief episodes of vertigo on turning to the right and mild imbalance on walking. Initially I felt mild unsteadiness in the dark but gradually I would stagger a little even during the day. Eventually I started holding on to things or to people as I walked and realized I was even walking slower than usual. Things got worse after a fall on the pavement that left me insecure and quite embarrassed. I had frequent headaches, more so in the mornings and occasional nausea that would simply not go away. But who gives a second thought to a little "migraine?"

By the fall of 2018, my handwriting had gone from smooth and elegant to disjoined and jerky. Around the same time, I realized I was having trouble understanding speech when I used a telephone on the right ear. I however had no tinnitus.

Soon I developed problems with my vision. It started as disturbances in my depth perception and loss of sharpness of vision. I had episodes of visual-vestibular mismatch like objects jiggling or bouncing suddenly and difficulty in reading books and working on my computer. I consulted a colleague in Ophthalmology who could not find anything significant other than mild myopia for which I was prescribed spectacles. Soon people around me started to remark upon my slow speech, tremors, and the constant head tilt that was rapidly becoming a part of my personality. I was incessantly bumping into objects and people and I soon realized that whatever the reason for my illness, it was progressing.

All my training and clinical experience in ENT told me that there was some issue involving the right side of my brain, but sometimes rationality and logic take second place to abject fear. I was in the fear of losing my mind and as a result, myself. My mind was my most prized possession, it was the one thing that kept me professionally competent, academically sound, and emotionally stable. As a surgeon, I had always been passionate about my work. I was

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[1] Department of ENT, Indira Gandhi Medical College & Research Institute, Pondicherry, India
[2] Department of Neurosurgery, University Hospital, Lausanne, Switzerland
[3] Department of ENT, Jawaharlal Institute of Post Graduate Medical, Education and Research Institute (JIPMER), Pondicherry, India

Corresponding Author:
Sophia Amalanathan, Department of ENT, Indira Gandhi Medical College & Research Institute, Vazhudavur Road, Kathirkamam, Pondicherry 605009, India.
Email: drsophiaent@gmail.com

performing a routine tonsillectomy one day when I realized that my hand and my leg would not work together to use bipolar forceps. To my shock, I understood that fears were materializing and that my symptoms would leave me professionally handicapped.

It was the summer of 2019 when a colleague who had not seen me in a while realized that something was amiss. She prodded me to get scans of my brain done. A computed tomography scan of brain showed compression and displacement of fourth ventricle and a widened internal auditory meatus on the right side. Subsequently, I underwent a magnetic resonance imaging (MRI) brain with gadolinium which showed a 4.5 × 4.5 cm tumor arising from the eighth nerve in the right cerebellopontine angle with marked compression of the cerebellum and the brain stem. The fourth ventricle was compressed along with a resultant hydrocephalus. The diagnosis: A giant vestibular schwannoma with brainstem compression and hydrocephalus. Vestibular schwannoma is very rare benign tumour arising from the eighth cranial in the cerebellopontine angle that predominately causes hearing loss and imbalance.

My hearing evaluation showed a moderately severe sensorineural hearing loss in the higher frequencies and normal hearing in the lower frequencies, and my speech discrimination scores were 90%. This was probably why I did not have significant hearing symptoms.

Within a week I was fortunate to see the chief of Neurosurgery at one of the best teaching hospitals in India, where I had undergone my training in Otorhinolaryngology. My neurosurgeon explained the best course of action was to do a subtotal resection of the tumor with the aim of preservation of the facial and cochlear nerves. The surgery would then be followed on by stereotactic radiosurgery (SRS) of the residual tumor. Under a week, I underwent a Retro-sigmoid craniectomy, and subtotal excision of Vestibular Schwannoma with facial and cochlear nerve preservation.

"Is my seventh nerve alright?" was my first question after the surgery. I was beyond ecstatic to discover that I could close my eyes completely. I had an uneventful postoperative course and was soon home. My journey of recovery had begun.

I was surprised that my speech was normal almost immediately after the surgery and was able to hold a pen and write legibly the very next day, although, it took me 3 weeks before my handwriting was flowing and elegant once again. In early postoperative period I had mild to moderate gait and postural instability, but each time I walked, my vestibular memory was better and rapidly helped in gait stabilization. My vestibular reflexes were becoming sharper with my many attempts of physical movements and that felt so rewarding.

Gradually my gait and posture improved without the compensatory head tilt. Most of my photographs prior to surgery showed me with the head tilt (Vestibulo spinal signs) and I could hold my head straight on my shoulders without much stress (Vestibulo collic signs). The optokinetic responses in terms of vestibulo ocular reflex (VOR) gradually adapted to the linear and angular head and body movements, and with that my stereopsis also stabilized with time. The visual vestibular mismatch improved gradually and I could soon comfortably see moving objects while travelling, watch 3D films in movie theatres (spatial navigation), read books, walk down the steps, and step on an escalator with confidence. I persisted with my Vestibular rehabilitation exercises and ocular exercises (Cawthorne Cooksey exercises) twice a day and that aided in the Vestibulo spinal and Vestibulocollic reflexes become sharper. I was soon back to my daily routine of teaching, surgery, and doing my regular workouts within 2 months of surgery.

The vestibular adaptation continued and took almost 9 months for me to walk in a straight line and adapt to dark surroundings without the fear of falling. My cognitive functions, like mental agility, word finding, and word association, was better by the end of 6 months. Although my hearing levels did not improve significantly post-surgery, I found that I had regained the "lost balance" in my life.

Six months later, I was scheduled for a follow-up MRI that showed a 1.2 cm residual tumor along the eighth nerve up to the porous. I was scheduled for a SRS. I guess after brain surgery having a frame fixed on your skull and getting a single dose of radiotherapy is not very intimidating.

Stereotactic radiosurgery is expected to induce changes in the DNA of the tumor causing the tumor to gradually shrink in a period of probably 24 months. Stereotactic radiosurgery I must say was tough because I was fully aware of the procedure but the meticulous ways followed by the various teams involved was amazing, to treat a single patient there are atleast 30 to 40 health-care team players.

Before surgery I was manifesting signs of a chronic vestibular syndrome consisting of both static and dynamic deficits like visual vestibular mismatch, visuospatial disorientation, poor stereopsis, poor cognitive functions and posture, gait, and emotional instability. In the postoperative period, my vestibular system was rebooting itself. Scientifically it was going through the process of neural plasticity, which is an inherent property of the brain. It is known that Vestibular rehabilitation therapy plays a key role in the process of vestibular compensation that occurs through the process of neural plasticity. The Vestibular rehabilitation therapy stimulates the neuronal network remodeling and facilitates the compensation to occur through various ocular and postural exercises. The vestibular compensation aids in sharpening optokinetic responses, depth perception, posture, and gait improvement by various mechanisms like vestibular restoration, adaptation, and habituation. In short, my vestibular compensation probably occurred through the orchestration of multiple mechanisms in my brain and is continuing to adapt to newer challenges. My symptoms sure represent the collective feelings of all patients with this brain tumor and I have put in the best words to their feelings.

The way that my brain adapted to the old surroundings in a new way was fascinating. My knowledge about Vestibular rehabilitation exercises helped me to spring back to a normal life and a newly acquired balance. I have personally experienced the benefits of the ability of neural plasticity of the human brain especially of the visual and vestibular system. The ability of the human brain to adapt to neural challenges and the neural integration of vestibular system and its reorganizing capacity is truly incredible.

I will require repeat scans and audiological testing yearly, but nothing scares me anymore. As I look back, I also see the people in my life who have helped me find balance: my family, my friends, my colleagues, and the brilliant neurosurgeons who have made me whole again. By January 2020, I was even brave enough to take a much-needed holiday to Europe with my friends and would want to see more journeys ahead.

The ever-evolving advancements in neurosciences, neuroimaging, surgical technologies, and SRS have contributed dramatically in improving the outcomes for these challenging tumors thereby allowing the brain to achieve recovery of neural functions due to its inherent properties of neural plasticity. I have always been a part of health-care system as a provider for many years ironically, I found myself at the receiving end and experienced what it means to be treated with care, concern, and dignity.

Authors' Note

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ORCID iDs

Sophia Amalanathan, MS(ENT), DNB https://orcid.org/0000-0002-2241-6416

Arun Alexander, MS(ENT), DNB https://orcid.org/0000-0003-1026-4678

Author Biographies

Sophia Amalanathan is working as associate professor in the department of ENT, IGMC, India and has been teaching undergraduates and post graduate medical students for 12 years. She is a ENT surgeon and has vast experience in patient care and ENT surgeries.

Roy Thomas Daniel is a professor in Neurosurgery in Switzerland and has extensive neurosurgical skill and experience in teaching students and training neurosurgeons all over the world for more than 20 years.

Arun Alexander is working as professor in the department of ENT, JIPMER, India, and has extensive experience in teaching medical graduates for over 20 years and is a very experienced and skilled otology surgeon.