NEUROPATHY TESTIMONIAL

In autumn of 2021, while still recovering from my second surgery within 10 weeks, blood clots in both lungs, a post-op infection, and blood transfusions, I sat for the first time in the Infusion Center at the state-of-the-art Lemmen-Holton Cancer Pavilion in Grand Rapids, Michigan. Having just received a diagnosis for both stage 3 endometrial (womb) cancer and an aggressive form of ovarian cancer, I watched the first drip of life-saving fluid enter my body.

Before I even began the several-week moulting process, I spent many moments leading up to the first infusion, sobbing, as I slowly and painfully lost every single strand of my curly, waist-long brown hair. And remembering my grandmother on chemo for multiple myeloma in the 1980's, I was very concerned that I would be stuck toting a bucket with me everywhere I went like she was forced. Thankfully, however, new anti-emetics now exist; and my oncology nurse fully prepped me on a whole multi-drug regimen and arsenal of tips to lessen nausea and vomiting, bone pain, and risk for infection from immune suppression.

What I was not at all prepared for, however, was CIPN: chemotherapy-induced peripheral neuropathy. Though I had been placed on 2 of the top culprits for this affliction: Paclitaxel (Taxol) and Carboplatin, I received no pre-treatment CIPN prevention education on cryotherapy–despite its efficacy having been proven for over a decade in patients receiving taxane and platinum-based therapies or other neuro-toxic agents.

Through palliative care providers, I was prescribed meds that would minimally lessen the severe pain while causing adverse side effects. They sent me to PT to help with my loss of balance which subsequently caused general weakness and deconditioning of my entire body.

In fact, only prior to my final infusion of my second round of chemo did I learn of cryotherapy for CIPN prevention through my new physical therapist who informed me that she successfully avoided CIPN during her breast cancer treatment several years prior! After learning about this, I informed my sweet nurse who kindly did her best by providing a mixture of quickly melting bags of ice packs placed on towels. They were uncomfortable with their inconsistent temperature and wetness and kept me immobilized throughout my 6-hour visit, since they could only merely be laid on top of my stationary extremities, keeping me from engaging in my usual distractive activities.

Over 3 years have passed since my treatment completion. I am not in remission yet–I must wait 2 more years for that proclamation. After an initial prognosis of a 30-percent chance of a 3-year survival, I sometimes feel guilty complaining to care providers about my CIPN, especially my oncology team, but it has significantly impacted my quality of life and general health. I can no longer work full shifts or get adequate nights' sleep due to intense burning from my toes to my knee. The numbness and tingling cause me to easily lose my balance–especially on stairs or uneven ground, causing me to take a bad tumble about every 3 months and prevents me from engaging in recreational activities like badminton or square-dancing.

CIPN has led to additional pain from fall injuries, and the subsequent avoidance of activities has led to weak ankles with additional deconditioning. During treatment and in the months to follow, my hands were also afflicted, making it difficult to write, play the piano, or simply open packages. My CIPN has been so intense that developing rheumatoid arthritis went completely hidden, delaying treatment that would have prevented permanent joint damage.

Though I have significantly improved compared to during treatment, I am forced to take 3-hour roundtrips bi-weekly to receive acupuncture as it is too costly in my area. Although my insurance covers this proven treatment for CIPN, many practitioners decline to join the HMO network due to perceived lack of adequate reimbursement. I nightly apply expensive compounded topical applications, but my insurance does cover any compounded creams. I have trialed oral meds Neurontin, Cymbalta, or Lyrica that are covered by insurance, but they were very cognitively impairing, preventing me from driving or working.

So, I ask several poignant questions:

Why do insurance companies not reimburse for minimal up-front cryotherapy for CIPN yet are willing to pay for potentially decades-worth of expensive rehabilitation services, acupuncture, or medications for the same condition?

Why are insurance companies beginning to cover cryotherapy for prevention of temporary hair loss yet not for potentially permanently disabling CIPN (increasing the likelihood of patients having to remain on SSDI)? And are they not aware that cryotherapy in extremities for chemo patients can also prevent fingernail/toenail loss?

It has been my mission since a year ago to spread the word about CIPN prevention, but my biggest hurdle has been the lack of reimbursement for cryotherapy. Even with me offering to donate start-up funds that I raised through a charity event, infusion centers have been reluctant to initiate/invest in cooling sleeves or chemo wraps, even acknowledging their known benefit.

In the middle of a national opioid crisis, why are insurance companies so reluctant to reimburse for proven complementary modalities for prevention of long-term pain?

"Spa grade" chemo mitt/sock options on the internet require excessive changing to keep the ideal temperature for therapeutic effect and are difficult/heavy to transport by sick patients. Very busy nurses may not have available time for the frequent gel pack exchanges that these "spa grade" mitts/socks require. However, cooling sleeves and medical-grade gel pack wraps are the answer for efficacy and efficiency for patients and hospital staff in the effort of CIPN prevention.

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