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Commentary: Finding Relief from Chemo-Induced Peripheral Neuropathy

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ABSTRACT

This commentary by a patient describes a syndrome that often develops residual to chemotherapy and yet escapes timely detection and effective treatment: chemo-induced peripheral neuropathy (CIPN). Physicians and their patients who suffer from CIPN, particularly those with unremitting small fiber neuropathy (SFN), may benefit from the evidence-based guidance provided. The author also calls for deeper listening by the medical community, interdisciplinary collaboration and patient self-advocacy.

Introduction

As a nonsmoker, my diagnosis of lung adenocarcinoma 13 years ago was shocking. From that point forward, I joined the unfortunate ranks of those facing a disease that kills more people[1] than any other form of cancer. However, I am one of the rare long-term survivors, at least to date. My survival is due to proactive self-advocacy, access to quality healthcare, and the privilege of education and insurance. These are advantages that many patients do not have. Far too often, a lack of resources, time, and medical literacy leaves them vulnerable to uninformed, outdated, or even harmful treatments.

During my battle with cancer, I encountered a devastating secondary challenge: advanced small fiber neuropathy[2] (SFN), an excruciating and poorly recognized condition caused by the platinum-based chemotherapy used to treat my cancer. My experience navigating the medical system to identify and manage this debilitating condition has exposed systemic failures that put patients at risk. These failures include a lack of physician knowledge[3], inconsistent care, and insufficient research into long-term treatment side effects.

The Unseen Pain of Small Fiber Neuropathy

SFN affects the small nerve fibers responsible for pain, temperature, and autonomic functions. For some chemotherapy patients, nerve damage is temporary and resolves once treatment ends. But for others, like me, the damage becomes permanent, progressive, and unresponsive to most conventional therapies[4].

My symptoms began nine months after completing a round of platinum-based chemotherapy. The soles of my feet turned blackish-blue, accompanied by an unimaginable burning pain (level 8-9 on a scale of 0-10). Sitting worsened the symptoms, as did walking, and standing made the discoloration shift to an angry, fiery red. (Figure 1 & 2)

Even placing my feet on a pillow was agony. Although the level of pain fluctuated, there were no pain-free moments from that point on. Panicked, I sought help from my primary care physician, who admitted she had never seen anything like it.

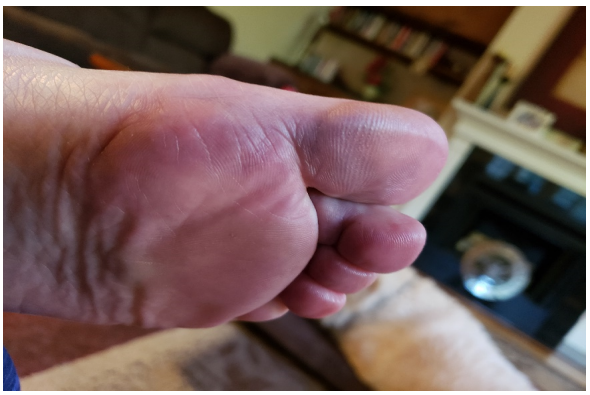

Figure 1: Bluing while seated

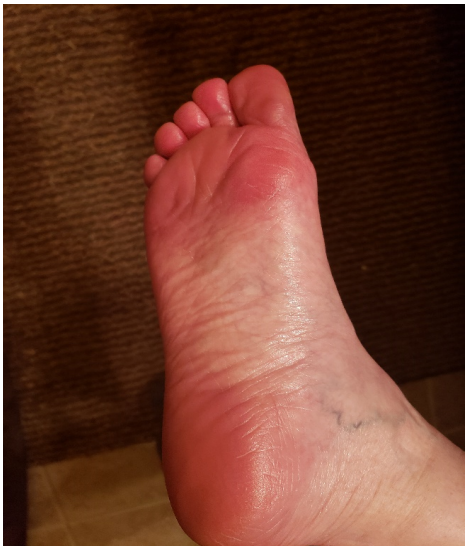

Figure 2: Flushed when standing

From there, I embarked on a long and frustrating search for answers. I consulted 16 different specialists—dermatologists, neurologists, oncologists, pain specialists, and podiatrists—none of whom could identify the cause or offer relief. Their collective bewilderment left me feeling helpless, as though my condition was so rare it was beyond understanding.

Finally, after months of suffering, a neurologist performed biopsies of my thigh and ankle and diagnosed me with advanced SFN, an insidious form of chemotherapy-induced peripheral neuropathy (CIPN). Although CIPN is a known side effect of platinum-based chemotherapy and is quite common with 30-60% of patients[2,5] developing chemotherapy-induced peripheral neuropathy (CIPN), its most severe forms—like SFN—are rarely discussed or effectively treated. My case highlighted a troubling gap between physician awareness and the medical literature that directly impacts patient outcomes.

Lessons Learned: Navigating the Unknown

After initial diagnosis, I tried everything, from medications, salves, and neurogenerative therapies, to a lumbar block, with no significant improvement. But now, over these past 4 years, I have discovered ways to reduce my pain and regain some semblance of control over my life. These strategies came only after extensive self-advocacy, independent research, and a willingness to try unconventional approaches. Here are some of the key lessons I've learned that may help others living with this condition:

Medications Have Limits

Anticonvulsants[6] like gabapentin or Lyrica are commonly prescribed to reduce neuropathic pain by inhibiting the release of excitatory neurotransmitters. Although they provided some relief, the side effects—such as fluid retention and cognitive fog—limited my ability to tolerate higher doses. I continue to take gabapentin at a lower dose (300mg 3x a day) and when I miss a dose, I know it's helping because the pain spikes up. Opioids don't tend to have a desired effect as they primarily target pain from tissue damage and do not effectively address the abnormal nerve signaling that characterizes neuropathic pain. NSAIDs are well known to be entirely ineffective because they reduce inflammation but don't address the nerve damage associated with neuropathic pain. And antidepressants with pain-suppressing properties caused side effects I couldn't manage, but patients may want to explore their potential benefit, even if partial[7].

Supplements Matter

Through research, I discovered a regimen of supplements to support nerve health[8], including turmeric, omega-3 fatty acids, vitamin B complex, alpha-lipoic acid, co-enzyme Q10, and l-carnitine. Though these are not cure-alls, they have reduced the severity of pain and have potential to slow disease progression.

Movement Is Essential

One of the most surprising insights I gained is that staying active—even minimally—can improve circulation and reduce pain intensity[9]. I use pedals under my desk during the day and in front of my armchair in the evenings. Sitting hurts as much as standing and walking due to the constriction in blood flow, so keeping my legs moving—albeit slowly—have been an essential part of my self-directed treatment regimen. I also stretch daily, and incorporate low-impact exercises like recumbent biking, light weightlifting, and balancing exercises. Movement is challenging, but it makes a difference.

Explore Alternative Therapies

Acupuncture proved to be a game-changer[10]. Though initially skeptical, I found a practitioner well-versed in

anatomy and nerve function who tailored treatments to my specific needs. This therapy has significantly reduced my pain and improved my quality of life over time.

Topical Remedies Can Help

I rely on menthol-based creams and a compounded solution containing gabapentin, amitriptyline, and lidocaine for short-term relief. These options are not cures but provide valuable respite during particularly painful moments.

Addressing Systemic Gaps

My journey has revealed a troubling reality: the medical community is often unprepared to address rare or severe conditions like SFN. Physicians face immense challenges keeping up with the pace of medical advancements[3], and many lack the time or resources to explore beyond standard protocols.

This knowledge gap has real consequences. Delayed diagnoses, ineffective treatments, and insufficient communication between specialties leave patients to fend for themselves. As a result, many patients give up or suffer in silence, unable to access the life-changing interventions they need.

The medical system must do better. This includes:

- Encouraging multidisciplinary collaboration and integrative, multi-modal strategies to address complex cases.
- Increasing funding for research into chemotherapy-induced neuropathy and its long-term effects.
- Prioritizing patient education and empowering individuals to advocate for their care[11].

Finding Hope

Living with SFN is a daily challenge, but it has taught me the importance of persistence, community, and self-care. Staying connected to loved ones, finding purpose, and maintaining a healthy lifestyle have all been integral to my journey. While pain is an ever-present reality, I am living proof that relief—however partial—is possible.

To patients navigating SFN or any other complex condition: advocate for yourself relentlessly. Question your care, seek second opinions, and explore alternative treatments. Relief may not come easily, but it's worth fighting for.

And to the medical community: remember that the patients you treat are more than their symptoms. By staying informed, listening deeply, and collaborating across disciplines, you have the power to transform lives.

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