

PROJECT HEALING

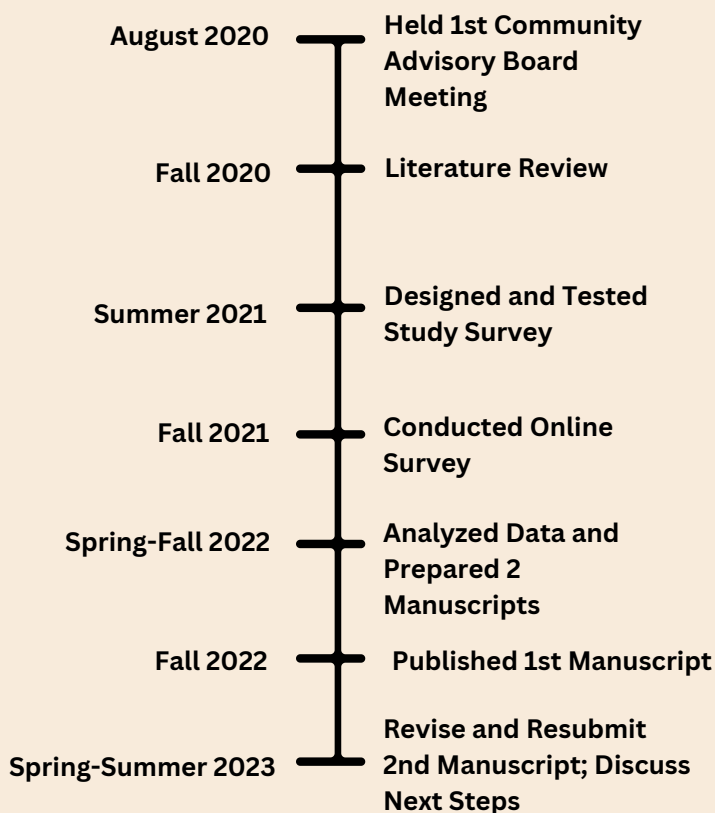
PERIPHERAL NEUROPATHY

The University of Texas at Austin School of Nursing, with generous funding from Neuropathy Alliance of Texas, conducted an online survey in 2021 to learn more about the experiences of people with peripheral neuropathy (PN). With help from PN support group leaders, a nationwide sample of 608 eligible people from 49 US states completed the electronic survey.

Purpose:

- Better understand the experiences of people with PN.
- Raise awareness of how PN symptoms are affecting people's lives.
- Long-term goal: develop a novel program to improve quality of life for people with PN.

Project Timeline



In this survey you told us about the physical symptoms you have, which are described in our first publication (Fall of 2022). The results are summarized in this newsletter.

Survey Results

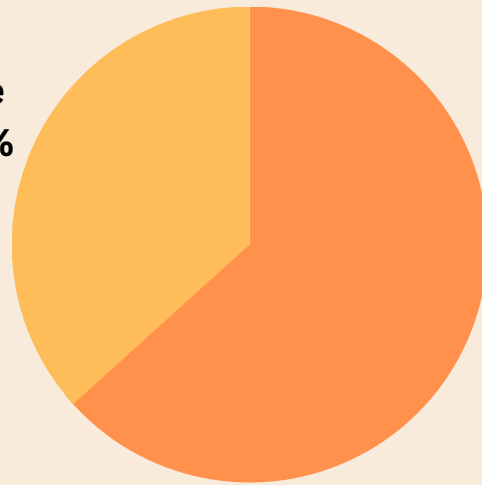
Survey Participants

Average age = 63 yrs.

Male = 36.7%; Female = 63.3%

Average length of symptoms or
PN diagnosis = almost 10 yrs.

Male
36.7%



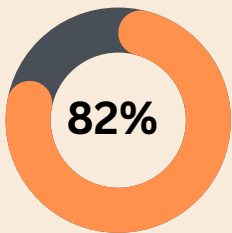
Female
63.3%



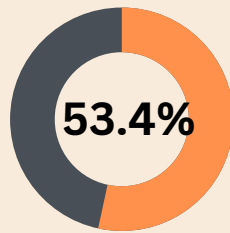
1 out of 3 participants are still working



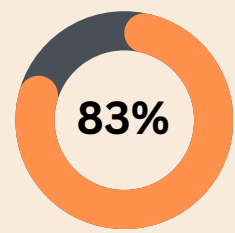
2 out of 3 participants received a college education or more



82% of participants identified as White



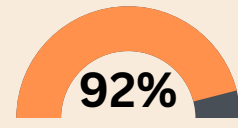
53.4 % of participants had **no known cause** for their PN



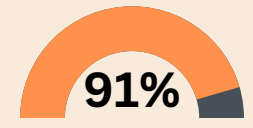
83 % of participants had PN symptoms more than once daily.



Most Common PN Symptoms



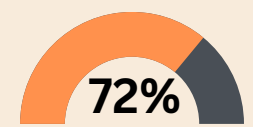
Tingling



Numbness



Pain

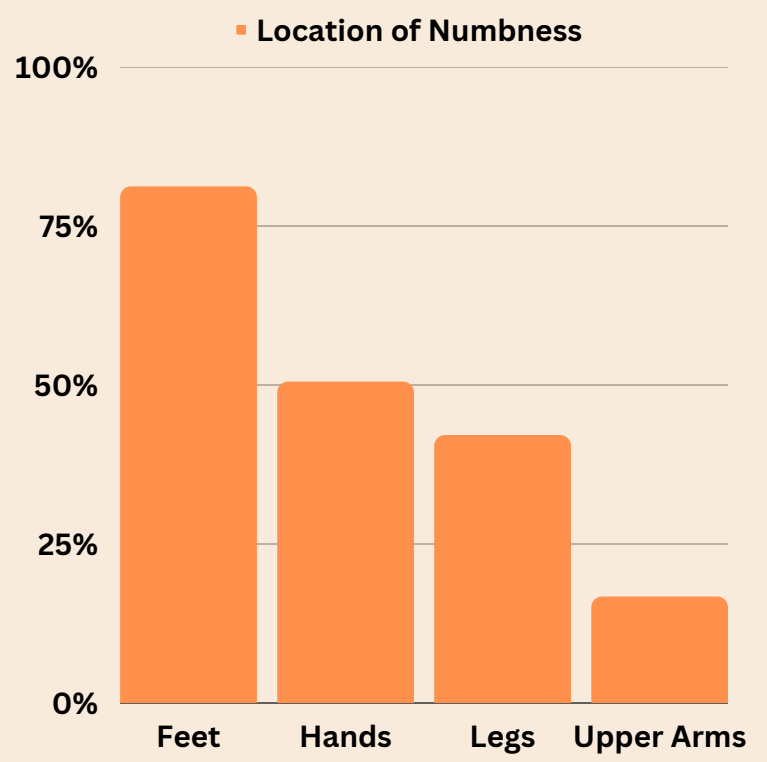


Muscle Weakness

Tingling was felt in a similar way as **numbness**, suggesting that they may occur together.

Known vs. Unknown PN Cause:
Those with a **known PN cause** had:

- more symptoms
- more severe pain
- greater pain intensity



Those without a known PN cause had symptoms more often.

Comments from participants

Lack of Information:

- *“There is an appalling lack of information or research to find a cure.”*
- *“The worst thing is the lack of control and uncertainty.”*

Emotional Suffering:

- *“It’s miserable.”*
- *“It’s a daily struggle. I’ll never be the same.”*
- *“It’s isolating and you fear ending up all alone.”*

Pain:

- *“The pain is relentless. It never goes away.”*
- *“It’s very hard to get and stay motivated when in constant pain.”*

Helpful Strategies:

- *“Focusing on balance is critical.”*
- *“Being proactive in my own health and researching helps me feel in control of my health.”*
- *“...it is critical that we advocate for ourselves.”*



First Manuscript: Kim, MT, Murry, N, Hecht, J, Hutson, T, Nnaka, T, Ewere, T, Heitkemper, E, Hebert, E, Radhakrishnan, K, and Stuijbergen, A. (2022). Patterns and correlates of physical symptoms among people with peripheral neuropathy. *Journal of Neurological Disorders*, 10(11). DOI: 10.4172/2329-6895.10.11.523. <https://www.hilarispublisher.com/open-access/physical-and-psychological-symptoms-among-people-with-peripheral-neuropathy.pdf>

UNCERTAINTY ILLNESS

The survey was guided by Uncertainty in Illness theory, which explains how people find meaning in their illness. People with PN often face significant uncertainty, particularly when the cause is unknown. **This theory views uncertainty as neither positive nor negative.** Rather, uncertainty creates a chance to reevaluate and determine the best response. Our second manuscript aims to explore how individuals with PN manage uncertainty and how it affects their health. As of Spring 2023, the second manuscript is being revised and resubmitted for publication.

What is Illness Uncertainty? Illness uncertainty refers to the difficulty in understanding illness-related events, often due to unclear explanations for symptoms and an unpredictable disease course.

Two main ways of coping with illness-related uncertainty:

- **Active coping** involves actively participating and engaging in efforts to enhance personal well-being. People who use active coping are more likely to:
 - work with healthcare providers,
 - follow their recommendations,
 - find ways of managing symptoms that works best for them.
- **Avoidant coping** involves denying, downplaying, or avoiding direct measures to address uncomfortable or painful symptoms.



Study Findings:

1. **You are not alone** - Many people with PN have painful, debilitating symptoms. Your approach to coping can play an important role in your overall quality of life.
2. **Those with less illness uncertainty** - Report higher physical and mental well-being and better quality of life.
3. **Active coping** is linked with more helpful self-management behaviors and improved mental and physical health.
4. **Avoidant coping** is linked with less participation in symptom-improving behaviors, resulting in poorer mental and physical health.

Summary:

- Coping style plays an important role in health outcomes for people with PN.
- People with PN may benefit from developing more active coping styles to improve well-being.
- More education and support are needed to help people with PN adapt their lifestyle and routines to include helpful behaviors that improve overall mental and physical well-being.



For more information and resources please visit our website,
<https://nursing.utexas.edu/research/project-healing>

Thank you for helping to participate in this survey and for sharing your experiences!