

Vasculitic neuropathy-related disability, pain, quality of life, and autonomic symptoms: a survey of 312 patients

Lay person summary, for *Vasculitis UK*

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Background. Vasculitis is a chronic autoimmune illness that causes inflammation in the blood vessels and can affect any part of the body. Peripheral nerves are like electric telephone wires which send messages up and down the arms and legs, down to the muscles and up from the skin. Vasculitis affecting the peripheral nerves is called vasculitic neuropathy. It typically causes pain, numbness, weakness and clumsiness of the feet and hands.

Most research in vasculitis has focused on its life-threatening aspects, such as when it affects the kidneys, lungs and heart. Neuropathy rarely kills people, but it can be disabling. Only very limited research has been done into vasculitic neuropathy. Therefore, we do not know if it should be treated differently from vasculitis affecting other organs. With current treatments, most people affected by vasculitis survive, but many still suffer long term disability and pain. We wanted to find out if the presence of vasculitic neuropathy was linked to any long-term symptoms.

Method. We designed an anonymous online survey to evaluate symptoms of pain, quality of life and disability. We used questionnaires previously developed by medical experts to reliably measure these problems. *Vasculitis UK* charity distributed the link to this survey to its members, who are people with vasculitis mostly living in the United Kingdom. Because this survey was anonymous, no personal data was collected, and all our information came from the people with vasculitis who participated. We could not and did not get any additional information from their doctors or hospitals.

Results. 312 people with vasculitis completed the survey. Most people were of middle or older age, and their vasculitis had not changed much for several years. People had many different types of vasculitis, most commonly ANCA-associated vasculitis (especially granulomatosis with polyangiitis, GPA).

Symptoms of numbness, pain, difficulty walking, or weakness were each reported by around half of the group (Figure 1). Symptoms differed between people, so those reporting numbness did not necessarily also report pain, difficulty walking or weakness. We concluded it was likely that someone had a vasculitic neuropathy if they answered “yes” to any of the following three questions:

1. Do you have constant numbness (loss of feeling) in hands or feet? OR
2. Do you have persistent weakness in hands or feet, such as foot drop? OR
3. Have you been told by your vasculitis team that you have damage to peripheral nerves (neuropathy)?

By this composite definition, 242 people completing the survey (78%) had neuropathy and 70 (22%) did not. We compared the survey findings in those who had neuropathy with those who did not.

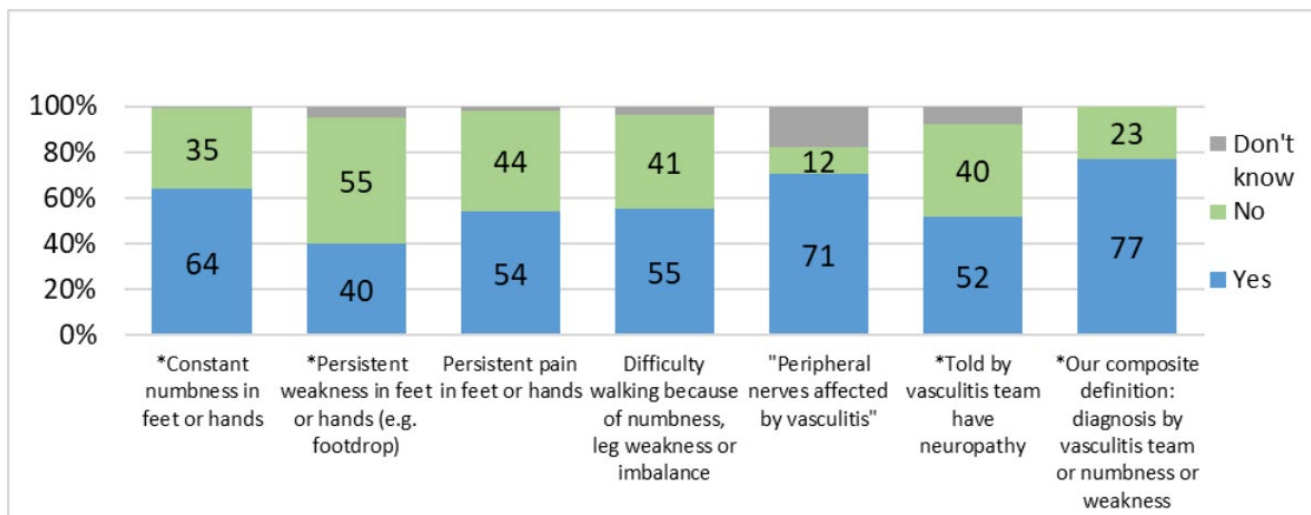


Figure 1. Patient-reported indicators of neuropathy. This graph shows two different things. The first four bars (from left to right) show percentages of people who reported four symptoms which suggest they have neuropathy. The last three bars show the source of the diagnosis of neuropathy: identified by the patient, diagnosis by the vasculitis team (patient recalls being told by their clinician), and our composite definition of neuropathy.

The most important result was that people with neuropathy had more difficulty doing everyday activities and suffered more pain than people without neuropathy (Figure 2). People with neuropathy also had worse health-related quality of life. Most individuals with neuropathy indicated that their neuropathy was frustrating, painful and tiring and that it affected everyday activities, walking, sleep and mood. Anxiety and depression were equally common in those with or without neuropathy.

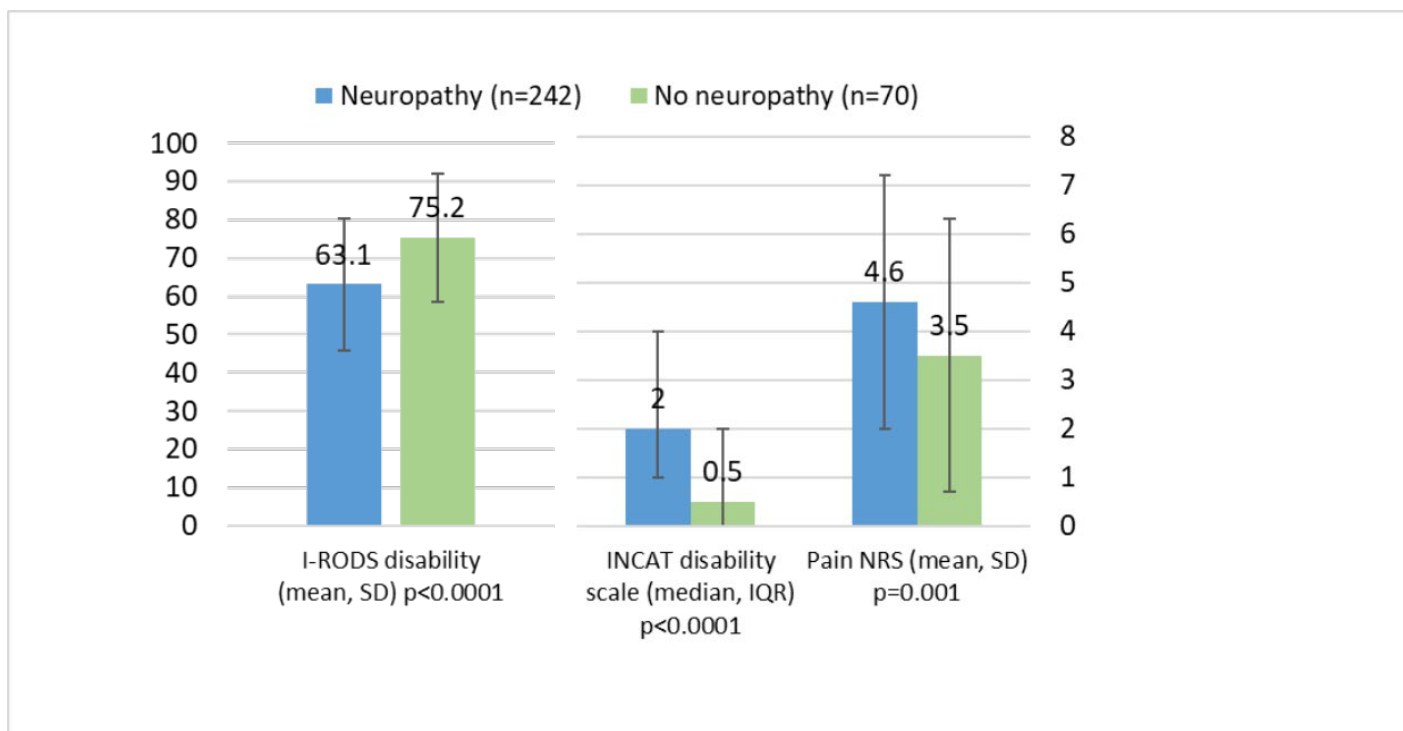


Figure 2: Vasculitis patients with neuropathy (blue) had worse pain and worse disability than those without neuropathy (green). Coloured bars show the “average”, vertical lines show the spread of results among different people. The I-RODS is a disability scale measuring activity and social limitations, developed in patients with other inflammatory neuropathies; the centile-transformed score ranges from 0 (worst) to 100 (best). The INCAT scale is a measure of arm and leg disability, developed for patients with chronic inflammatory demyelinating polyradiculoneuropathy (CIDP); scores range from 0-10 (0 best, 10 worst). Pain was measured by a 0-10 numeric rating scale (NRS).

Many said that their vasculitis also affected other parts of the body. Joints, muscles and nose/sinuses were each affected by vasculitis in over half of the people who replied to the survey.

Autonomic nerves are those controlling internal body functions. Many people with vasculitis reported experiencing faint/dizzy sensations when standing, increased sweating, dry gritty eyes, stomach bloating or constipation. However, these symptoms were equally common in people with or without neuropathy, suggesting that they were probably not caused by vasculitis affecting autonomic nerves, but rather by vasculitis affecting other body parts, by medications, poor physical fitness or other diseases. Other studies have shown that when vasculitic neuropathy causes numbness or weakness in the feet, legs or hands, it often also damages autonomic nerves to the skin in the same areas of the body, resulting in abnormal sweating or blood circulation, but our survey did not include questions about these symptoms.

In conclusion, among people with vasculitis, those with neuropathy suffered more disability and pain than those without neuropathy. Neuropathy seems to be one of the most disabling aspects of vasculitis. Some people may have vasculitic neuropathy that is unrecognized by their doctor.

The major strength of this study was that it included more people and asked more questions than any previous survey of vasculitic neuropathy. In contrast, standard rating scales for vasculitis include relatively little information about neuropathy. However, our results may have been biased towards

people with more severe neuropathy who may have been more likely to reply. Another limitation was that we received very few responses from people whose vasculitis affected only nerves and not other body parts.

We are very grateful to *Vasculitis UK* and to everyone who responded to this survey. By showing how much suffering continues despite current treatments, we hope that this survey will encourage more research into vasculitic neuropathy.

Key messages

- People with systemic vasculitis often have long-term symptoms.
- On average, those with neuropathy have worse long-term disability, pain and health-related quality of life than those without neuropathy.
- Doctors do not always recognise when someone is suffering from neuropathy.

For full details see the published scientific paper <https://academic.oup.com/rheumatology>

January 2024