

An international survey of experiences and attitudes towards Transcutaneous Auricular Vagus Nerve Stimulation for people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

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Background and objectives

Myalgic Encephalomyelitis (ME) is a complex, acquired multi-systemic disease¹. Many people with ME (PwME) have symptoms associated with autonomic nervous system dysfunction (ANS) such as orthostatic intolerance, light-headedness, extreme pallor, nausea, breathlessness, temperature intolerance and bladder and bowel dysfunction². Anecdotally, some PwME have used Transcutaneous Auricular Vagus Nerve Stimulation (taVNS) to manage these symptoms. TaVNS involves stimulation of the autonomic nervous system via, in particular, the Vagus nerve using electrodes applied to part of the ear with the theory that this will stimulate the parasympathetic nervous system and improve autonomic balance². Only 2 small early stage trials^{3,4} have explored the use of VNS with PwME, both trials used alternative (more invasive and less comfortable) methods of applying VNS ie. not taVNS but do show potential benefits of VNS for PwME. There are no qualitative studies to explore the perspectives of PwME. Therefore the aim of this international survey was to collect qualitative and quantitative data about the use and experiences of taVNS in PwME.

Methods

Ethical approval was obtained from the University of Liverpool. An online survey was developed by the research team, ME researchers and PwME and 31 open and closed questions were devised. The link for the survey was sent out via facebook, twitter and websites. Participants read the information sheet before completing the online survey. The survey was open for four weeks.

Results

131 PwME completed the survey, however, 15 were excluded as they had not used taVNS. 60% of participants were from the UK, 16% from Europe, 14% Australasia and 10% N America. 85% were female, mean age group 51 – 70 years (see figure 1). 53% had ME for 10 years or more (see figure 2). 72% were currently using tVNS, 28% had stopped using it. Only 9% had used tVNS for longer than a year. Over 30 benefits in symptoms and activities were identified. Main benefits were improvement in post-exertional malaise (PEM) (39%) and brain fog (37%). Over 20 short and long term negatives were identified. Main short-term negatives were headaches (15%) and long term - irritation at the site (9%). 80% reported they would continue to use tVNS and 67% stated they would recommend it to other PwME. 56% of PwME stated that tVNS was mildly to very beneficial.

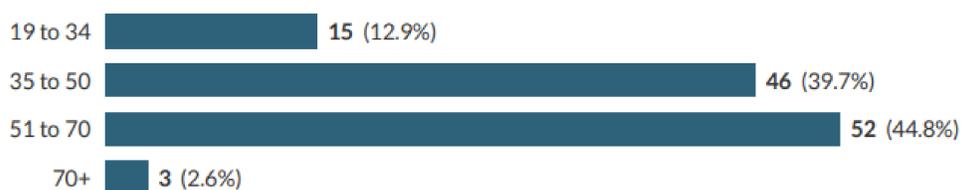


Figure 1. Distribution of age groups



Figure 2. Length of time with ME in years

Benefits

Gut motility, not constipated any longer, if I stop using tens machine constipation returns.

Big improvement in neuropathic pain, but not so much for muscles and joints.

It increased my ability to be active

Helps with sleep...helps with brainfog, concentration

My mental and physical stamina has improved a lot



Negatives

Diarrhoea...increased gut transit.

Neck pain

Flu like symptoms are worse

I had bad insomnia when I started the tVNS, that has improved now.

Worsening of fatigue levels and so had to slow things down a lot

Conclusion

TVNS may be beneficial for some PwME with benefits including reduction in brain fog and PEM although some PwME report a number of negatives with tVNS. More research is needed to identify which specific group of PwME benefit from tVNS and to determine the optimum treatment regime.

References

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