

## Poorly understood postural syndrome blights lives of young well educated women

*Symptoms can be severe and disabling, but frequently misdiagnosed and inconsistently treated*

**[Postural tachycardia syndrome is associated with significant symptoms and functional impairment predominantly affecting young women: a UK perspective doi 10.1136/bmjopen-2013-004127]**

A debilitating syndrome that causes an excessively rapid heartbeat on standing up, predominantly affects young well educated women, and blights their lives, because it is so poorly understood and inconsistently treated, reveals a small study published in the online journal BMJ Open.

Postural tachycardia syndrome, or PoTS for short, is a by-product of orthostatic intolerance - a disorder of the autonomic nervous system in which the circulatory and nervous system responses needed to compensate for the stress put on the body on standing upright, don't work properly.

PoTS is associated with an excessively rapid heartbeat, or tachycardia. Symptoms include dizziness, fainting, nausea, poor concentration, excessive fatigue and trembling, and can be so severe as to make routine activities, such as eating and bathing, very difficult to do.

The impact of the syndrome has been likened to the level of disability associated with serious and debilitating long term conditions, such as chronic obstructive pulmonary disease (COPD) and congestive heart failure.

In the US, PoTS is thought to affect around 170 per 100,000 of the population, one in four of whom is disabled and unable to work.

But the symptoms, and their impact, are frequently not recognised in the UK, or attributed to anxiety, panic disorder, or chronic fatigue syndrome (CFS), say the researchers, who wanted to find out if PoTS affects particular groups, and how.

They therefore assessed 84 members of the national charity and support group, PoTS UK, and 52 patients diagnosed with the syndrome at the NHS falls and syncope clinic in Newcastle, north east England, between 2009 and 2012.

All participants completed a validated set of questionnaires specifically aimed at gauging levels of fatigue; sleepiness; orthostatic intolerance; anxiety and depression; ability to carry out routine tasks; and brain power.

The profile of the two groups was broadly similar, and indicated that people with PoTS are predominantly young - average age of diagnosis 30-33 - well educated to degree or postgraduate degree level, and female.

Poor health had prompted a significant number to change their jobs or give up working altogether, and both groups experienced high levels of fatigue, daytime sleepiness, orthostatic symptoms, anxiety and depression, memory and concentration problems, and considerable difficulty carrying out routine tasks.

Around one in five people had been diagnosed with CFS and a similar proportion had Ehlers-Danlos syndrome (inherited connective tissue disorders), suggesting that there may be an underlying overlapping cause, say the researchers.

Beta blocker drugs, which regulate heart rate, were the most common treatment for PoTS. But altogether, patients reported taking 21 different combinations of drugs. And a significant number were taking nothing at all or just salt.

“Patients with PoTS ... have significant and debilitating symptoms that impact significantly on their quality of life,” write the researchers. “Despite this, there is no consistent treatment, high levels of disability, and associated comorbidity.”

They go on to emphasise that their findings indicate that patients with PoTS experience a similar level of disability to people with CFS, but yet don't receive the same protection in law. “Our experience suggests that some patients never recover, and that a subset will worsen over time,” they conclude.