



The hidden impact of an invisible illness: postural tachycardia syndrome

Katie Bourne

Cardiovascular and Respiratory Science program, University of Calgary

Introduction

Postural Tachycardia Syndrome (POTS) is an under-recognized [1], debilitating disorder of the autonomic nervous system that primarily affects women of child-bearing age [2]. POTS is characterized by an inappropriately high heart rate upon standing, in association with chronic orthostatic symptoms (3). POTS is estimated to affect 0.1-1% of the North American population [2]. The causes of POTS are not well understood, and are likely multiple pathologies arriving at a similar end presentation [3]. POTS is frequently misdiagnosed, and many patients suffer an extended diagnostic delay [1]. As well, there are no medications approved specifically for POTS treatment [4].

Quality of Life

POTS patients experience significant impacts to their quality of life (QOL) [5], including activity limitation [4], impaired sleep [5] and increased suicide risk [6]. QOL in POTS is comparable to patients with Chronic Obstructive Pulmonary Disease [7], Congestive Heart Failure [7] and Chronic Fatigue Syndrome [1]. Patients often experience exercise intolerance as well as extreme fatigue, limiting everyday activities including tasks as simple as bathing and household chores [4]. In a study of 624 POTS patients, 97.1% reported activity limitations, versus only 31.7% of the health controls [6]. Sleep concerns including lack of refreshing sleep and daytime sleepiness are also reported and contribute to reduced QOL [5]. Interestingly, POTS patients also have a higher suicide risk when compared to healthy controls, however, the exact etiology of this is unknown [6].

Economic, Educational and Social Impact

POTS patients are significantly impacted in multiple aspects of their lives. Patients who are disabled and unable to work have greater impairment in multiple QOL domains including physical functioning and social functioning, compared to those who are able to work [7]. In a recent survey of 3,210 POTS patients age 18 and older, only 46% were currently employed [8] and 70% reported

income loss due to their POTS symptoms [8]. This same survey found that 89% of patients missed school days as a result of their symptoms (9). Social impacts are also prevalent in this patient population with 60% of patients reporting they have lost a close friend, and 23% reported the loss of their spouse or partner because of POTS [9].

Diagnosis and Treatment

Diagnostic delay is common for a number of potential reasons including a clinical presentation of non-specific symptoms, no orthostatic measurements in clinic, and a lack of physician knowledge. [10]. Current treatment includes symptom mitigation with medications to lower heart rate, increase fluid volume and increase vasoconstriction [4]. Increasing salt and fluid intake may also aid in symptom management [4]. However, as the etiology of POTS is unclear, the specific underlying mechanisms cannot be directly targeted.

Conclusion

POTS is an invisible illness that has significant impacts on quality of life. However, despite evidence supporting the severity of this illness, POTS remains largely unknown, with many patients waiting years for diagnosis and specialized care. With increased awareness of POTS, patients could benefit from earlier diagnosis and specialized treatment, improved quality of life.

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Kate is a first year Masters student in the Cardiovascular and Respiratory Science program at the University of Calgary. Her research focuses on autonomic disorders, specifically Postural Tachycardia Syndrome. Previously, she has completed a B.Sc. in Microbiology at the University of Victoria.