



## Commentary

# Diagnosing and Caring for Patients with Postural Orthostatic Tachycardia Syndrome in Primary Care

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## Abstract

Primary care is critical in the diagnosis and treatment of postural orthostatic tachycardia syndrome (POTS), a common disorder of the autonomic nervous system found primarily in women ages 12-50. Symptoms can vary widely between individual patients, making diagnosis difficult. Taking orthostatic vitals in patients with a variety of chronic nonspecific symptoms like fatigue, nausea, pain, and dizziness/light-headedness is warranted. Treatment of POTS symptoms is challenging, as there is not a standard pharmacological or non-pharmacological approach that works well for the majority of patients. Difficulty in diagnosis and treatment of POTS can lead to mistrust of healthcare practitioners and maladjustment to their new reality as a chronically ill person. We recommend a team-based approach to treatment of both physical and behavioral aspects of this multifaceted disorder in primary care.

**Keywords:** Postural Orthostatic Tachycardia Syndrome (POTS); Diagnosis; Quality of life; Primary care; Behavioral health

## Introduction

Postural orthostatic tachycardia syndrome (POTS) is a broad, multisystem disorder of a dysfunctional autonomic nervous system. POTS is indicated by a supine-to-standing heart rate increase of  $\geq 30$  beats per minute (bpm) in adults and  $\geq 40$  bpm in adolescents in the absence of postural hypotension [1]. POTS typically manifests in young Caucasian women of childbearing age, with approximately half developing symptoms as teenagers [2]. Nearly all POTS patients present with lightheadedness, tachycardia, pre-syncope, headache and difficulty concentrating [2]. Approximately 90% of POTS patients report severe fatigue and sensitivity to temperature, while 69% experience neuropathic or other significant pain [3]. Other common POTS symptoms include orthostatic intolerance, gastrointestinal complaints, venous pooling in the extremities, facial flushing and livedo reticularis [4]. Nearly all POTS patients report activity limitations, and 30% required assistance for activities of daily living [5].

The quality of life for those with POTS is comparable to those with rheumatoid arthritis, end-stage renal disease [6], congestive heart failure, and chronic obstructive pulmonary disease [7]. Approximately 25% of POTS patients are too disabled to work or attend school [7]. Because of their healthy outward appearance, patients are often blamed for their symptoms and accused of being lazy, anxious, or physically deconditioned [8].

### Diagnosing POTS in a primary care setting

In primary care, POTS is the most common cause of syncope or near-syncope related to autonomic dysfunction [9]. Despite this, POTS patients visit an average of seven physicians before proper diagnosis [10]. Many are told that symptoms are “all in your head” before they find a practitioner who takes them seriously [8].

Orthostatic vitals are indicated when a patient presents with longstanding ( $>6$  months), nonspecific symptoms like light-headedness, fatigue, near or recurrent syncope, nausea, headaches and chest discomfort. A poor man’s tilt test is a quick, inexpensive assessment for orthostatic intolerance. While conducting the medical history, the patient should lie supine  $>5$  minutes. Record the baseline heart rate and blood pressure before easing the patient to the standing position. Document the heart rate and blood pressure at 1, 3, 5, and 10 minutes of standing still without physical support [9]. POTS is indicated when the heart rate increases  $\geq 30$  bpm in an adult or  $\geq 40$  bpm in an adolescent  $<19$ , and the overall heart rate  $>120$  bpm in the absence of sustained orthostatic hypotension (20/10 mm Hg drop in blood pressure) [1]. The poor man’s tilt table is likely to underestimate heart rate increases compared with the head up tilt table [11], but may be sufficient to diagnose patients [9]. Orthostatic vitals are best taken in the morning, due to significant diurnal variability in POTS symptoms [12].

In addition to orthostatic testing, a detailed medical history, physical examination, and resting electrocardiogram are important for proper diagnosis [1]. The medical history should consider possible causes of symptom onset. Approximately 25-50% of patients developed POTS after infection, while others occurred after concussion, surgery, pregnancy, or trauma [13, 14]. Primary care providers (PCPs) should ask about current medications, diet, and exercise, as well as a personal and family history of heart disease, joint hypermobility, and autoimmune or neurological disorders. PCPs should also explore possible triggers for worsening symptoms such as upright position, time of day, exercise, and menstruation in females [9]. During the physical examination, assess facial flushing, rashes, livedo reticularis, blood pooling in the lower extremities, and Raynaud’s phenomenon [15]. PCPs can also evaluate joint hypermobility, because 25% with POTS also present with Ehlers-Danlos syndrome [2]. A resting electrocardiogram and blood tests are required to

exclude anemia, cancer, chronic infection, diabetes, and dysfunction of the kidney, thyroid and adrenal glands [16] as potential causes of orthostatic intolerance.

### The difficulties in treating POTS

There are significant barriers in effective treatment of POTS once diagnosed. First, most treatments are currently symptom-based because the etiology of POTS is not well understood. Second, there are no U.S. Food & Drug Administration approved medications for POTS [17], requiring PCPs to prescribe off-label. Third, most current treatment approaches increase blood pressure or decrease heart rate, peripheral vasoconstriction or sympathetic tone [18], but fail to address the fatigue, cognitive dysfunction, headache, gastrointestinal symptoms, or insomnia common in POTS patients [19]. To further complicate matters, many medications used to treat comorbid conditions may exacerbate POTS symptoms [20]. As a result, many POTS patients get little relief from current treatment regimens.

Many with POTS have been diagnosed with co-morbid disorders [9]. The majority of POTS patients meet the criteria for chronic fatigue syndrome [21]. Mast cell activation, chemical sensitivities, and Ehlers-Danlos syndrome are also common [22], as is fibromyalgia [23]. Other common comorbidities include median arcuate ligament syndrome, irritable bowel syndrome, Sjogren's syndrome, celiac disease, and a variety of other autoimmune conditions [19]. Sometimes POTS patients are labelled as "diagnosis shopping" as they struggle to identify the underlying cause of their illness, when in fact they are seeking explanations for their recalcitrant symptoms.

### Quality of life for people with POTS

Many POTS patients continue to be symptomatic years after diagnosis, despite ongoing treatment. POTS that begins in adolescence often extends into adulthood [19]. While many improve with treatment, a significant number of POTS patients only manage to stabilize symptoms and some continue to deteriorate. A study at Mayo Clinic showed that 70% of patients improved one year after diagnosis, but 30% were actually worse [24]. A similar study showed that after five years, 19% of POTS patients were asymptomatic, 51% had improved, and 12% had either unchanged or worsening symptoms [25]. In a phone questionnaire conducted 10 years after diagnosis, only 31% of POTS patients reported being symptom free [26].

Often, POTS can limit mobility and stamina so that even young adults require assistive devices (e.g., wheelchair, shower chair, and handicap placard). Requiring help with personal care can be humiliating and may cause patients to perceive that they are a burden to family and friends [27]. Perceived burdensomeness, in particular, has been linked to increased suicidal ideation in POTS patients [28]. Even within their support system, misunderstandings about the severity of POTS symptoms can increase social isolation and thwarted belongingness, the feeling that one does not fit into a social group [27].

Suicide is a major cause of death in many chronic illness communities. Physical illness and functional disability are known risk factors for suicide [29], and suicide risk increases when multiple physical illnesses are present [30], as is seen in many POTS patients. Approximately half of POTS patients were found to be in the high-risk group for suicide [5, 28].

### Psychosocial treatment for people with POTS

Because of the impact of POTS on quality of life and suicidal ideation, psychosocial care is an important aspect of treatment. Chronic illness represents more than the physical manifestations of the disorder – patients may be grieving the loss of a healthy body and adjusting to new physical limitations. POTS patients may benefit from working with a behavioral health provider in order to make the necessary cognitive shifts to improve functional status and treatment adherence. Teens and adults may have difficulty accepting their need for assistive devices like wheelchairs or shower chairs before reaching middle age [31-33]. Additionally, behavioral health providers can use cognitive behavioral therapy (CBT) and solution-focused interventions (e.g., Problem Solving Treatment) to facilitate functional improvements and increase treatment adherence for non-pharmacological treatments like increased fluid intake, compression stockings/abdominal binders, and exercise. Motivational Interviewing is another approach to resolve ambivalence towards treatment adherence [34].

Due to the complexity of POTS and the length of time between initial symptom presentation and a formal diagnosis, patients with POTS may experience increased frustration with the healthcare system due to prolonged misdiagnosis [8]. Because of distrust in the healthcare system and the profound life changes associated with a chronic health condition, it is imperative that a patient-centered approach be used as part of routine treatment planning. Patient-centered care fosters collaboration and shared decision making between patients and their healthcare team to customize both physical and behavioral health care in primary care. Primary care practiced in this manner can contribute to the development of trust through the patient-PCP relationship [35].

At the present time, there are no established guidelines for the treatment of psychological factors impacting this medical condition or treatment adherence [36]. Instead, behavioral health providers can formulate intervention plans to match the needs of the particular patient with an evidence-informed approach. These interventions include elements of CBT such as psycho-education, cognitive restructuring, stress management, relaxation training, *in vivo* exposure, and symptom discrimination [36,37]. A CBT-based treatment approach can address problems such as situational anxiety and allow patients to differentiate between physical symptoms and anxiety while also decreasing POTS-related functional impairment [36]. Interdisciplinary approaches to care have been linked to improved functional status [38, 39], and a team-based approach to care due to the multidimensionality of POTS is warranted [36].

## Conclusions

Primary care is critical for the quick diagnosis and long-term treatment of POTS patients. This multifaceted disorder can be difficult to treat, and requires an individualized approach to find the right combination of treatment options for each patient. A patient-centered, team-based approach in primary care, one that includes aspects of both physical and behavioral health, can assist patients in navigating the multidimensional nature of the disorder and can dramatically increase the patient's quality of life.

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**Received date:** August 14, 2019; **Accepted date:** September 22, 2019; **Published date:** September 23, 2019

**Citation:** Pederson CL, Ogbeide SA (2019) Diagnosing and Caring for Patients with Postural Orthostatic Tachycardia Syndrome in Primary Care. *J Health Sci Educ* 3(4): 167.

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