Postural Orthostatic Tachycardia Syndrome: An Analysis of Cross-Cultural Research, Historical Research, and Patient Narratives of the Diagnostic Experience

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Postural Orthostatic Tachycardia Syndrome: An Analysis of Cross-Cultural Research, Historical Research, and Patient Narratives of the Diagnostic Experience

Abstract
While Postural Orthostatic Tachycardia Syndrome (POTS) is a disorder that has been studied since the mid-1800s, it is still considered to be one of the most common chronic illnesses that no one has ever heard of. The etiology of POTS is well described in modern medical literature, but the disorder continues to be misdiagnosed or overlooked entirely in patients. By reviewing historical literature, patient narratives, and cross-cultural medical literature on POTS through the context of the disease vs illness model developed by medical anthropologists, this study aims to provide a comprehensive understanding of POTS to facilitate more positive outcomes in physician-patient interactions.

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POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME: AN ANALYSIS OF CROSS-CULTURAL RESEARCH, HISTORICAL RESEARCH, AND PATIENT NARRATIVES OF THE DIAGNOSTIC EXPERIENCE

By

Megan Halstead

A Senior Thesis Submitted to the Eastern Michigan University Honors College In Partial Fulfillment of the Requirements for Graduation With Honors in Anthropology in the Department of Sociology, Anthropology & Criminology

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ABSTRACT

While Postural Orthostatic Tachycardia Syndrome (POTS) is a disorder that has been studied since the mid-1800s, it is still considered to be one of the most common chronic illnesses that no one has ever heard of. The etiology of POTS is well described in modern medical literature, but the disorder continues to be misdiagnosed or overlooked entirely in patients. By reviewing historical literature, patient narratives, and cross-cultural medical literature on POTS through the context of the disease vs illness model developed by medical anthropologists, this study aims to provide a comprehensive understanding of POTS to facilitate more positive outcomes in physician-patient interactions.
INTRODUCTION

A disorder of the autonomic nervous system characterized by an increase in heart rate of ≥ 30 bpm or an overall heart rate of ≥ 120 bpm after 10 minutes of standing upright, Postural Orthostatic Tachycardia Syndrome – known often as ‘POTS’ – was given the name by which it is currently known in 1993, but has existed by other names in society for decades (Stiles 2015a). This history of varied identifiers, coupled with the ambiguous nature of the symptomatic presentation of POTS, has led to a disorder that is challenging for patients and physicians to define which can result in diagnostic delay, erroneous attribution to ‘like’ conditions that may be better captured under the umbrella of POTS, or it may be missed entirely when a full understanding of the comprehensive nature of the disorder is lacking. This is often compounded by the differences in disease, which is diagnosed by the doctor, and illness, which is what is experienced by the patient (Eisenberg 1977). By addressing the historical interpretations of POTS alongside current cross-cultural medical literature and patient narratives in the context of the disease vs illness model developed by medical anthropologists, a more comprehensive understanding of POTS can be formed that facilitates greater insight and more positive outcomes in physician-patient interactions.
UNRAVELING THE DIAGNOSTIC AMBIGUITY OF POTS

Postural Orthostatic Tachycardia Syndrome is a complex, heterogeneous disorder with a multitude of interacting models that attempt to explain its myriad manifestations (Carew et al. 2009). A form of dysautonomia — or, failure of the autonomic nervous system — POTS is characterized by symptoms of orthostatic intolerance including fainting and light-headedness occurring as a result of blood pooling in the extremities when patients move from a prone or seated position to a standing position with the absence of orthostatic hypotension (Agarwal et al. 2007). POTS has been found to be frequently comorbid with other dysautonomic disorders such as Ehler’s Danlos and Chronic Fatigue Syndrome, as well as mitral valve prolapse and Irritable Bowel Syndrome (Carew et al. 2009).

The diagnostic criteria for POTS includes an increase in heart rate of ≥ 30 bpm after 10 minutes of standing upright, or an overall heart rate of ≥ 120 bpm after 10 minutes of standing upright (Freeman et al. 2011). Other symptoms of POTS include fatigue, sweating, tremors, feelings of anxiety, an intolerance for exercise, neurocognitive dysfunction described as ‘brain fog’, and near-syncope upon standing upright (Agarwal et al. 2007). Symptoms of POTS can be non-orthostatic in nature as well, corresponding with the fact that the autonomic nervous system regulates all unconscious bodily functions and thus a disorder of one part of that system is likely to propagate its effects across the rest of the autonomic nervous system as a whole. Non-orthostatic symptoms can include nausea and vomiting, diarrhea, constipation, abdominal pain, pupillary
dysfunction, migraines, and instances of myofascial and neuropathic pain (Carew et al. 2009).

The etiology of POTS as a dysautonomic disorder consists of multiple complex models that lead to the manifestation of the symptoms presented to physicians, however, noted frequently is the onset of orthostatic intolerance after a biological stressor. Sepsis, pregnancy, surgery, and trauma have all been cited as triggers for POTS (Agarwal et al. 2007). Recent research has also linked POTS with the development of Lyme Disease (Kanjwal et al. 2011), and while patients have been vocal in their efforts to support the notion that the HPV vaccine can trigger POTS in patients there has been no clear confirmation that Gardasil has any significant impact on a patient’s development of POTS (Arana et al. 2017). In addition to biological stressors as a frequent indicator of the development of POTS, some variants of the disorder are known to be related to genetic mutations in norepinephrine transporter proteins at the synaptic cleft (Carew et al. 2009). The development of POTS is variable in its rate of onset, with a rapid development of symptoms often being reported in the case of patients whose POTS occurs post-operatively or after a viral infection, while in other cases the progression of symptoms is slow and can take years to fully manifest (Carew et al. 2009).

Though POTS has been diagnosed in both males and females of varying ages and backgrounds, research indicates that this is a disorder that primarily affects women in a ratio of 5:1 female-to-male rates of diagnosis (Low et al. 2009). Presentation of symptoms typically occurs between ages 15-50, although onset has been noted in patients as young as 9 years old (Schub and RainesGass 2016). Some US estimates focused on
links between POTS and chronic fatigue syndrome place the number of patients affected with POTS at approximately 500 thousand (Schub and RainesGass 2016), while more comprehensive estimates of the prevalence of the disorder place this number between 500 thousand and 3 million patients – extrapolating from these numbers, this indicates that globally there are potentially 11 million patients suffering from POTS (Stiles 2015a). Currently, there is no ICD10 code available specifically for POTS. Codes such as R00.0 “Tachycardia, unspecific” or I49.8 “Other Specified Cardiac Arrhythmia” (World Health Organization 1992) are used in patient charts for billing purposes, but the lack of specificity in these coded phrases prevents effective and accurate tracking of diagnosis rates.

While the ambiguity of the ICD10 codes presents a challenge to epidemiological analysis of POTS, it is the ambiguity of the disorder itself and its presentation that presents the greatest challenge to physicians. The detective work involved with diagnosing and attempting to clarify the multi-faceted manifestations of a chronic illness can be a laborious process for both patient and provider. In many cases, POTS has been misdiagnosed as chronic fatigue syndrome or as inappropriate sinus tachycardia, sharing several similarities with these conditions in terms of physical presentation (Karas et al. 2000). More often, though, a diagnosis of anxiety or psychiatric disorder is applied to patients suffering from POTS, with over 78.5% of patients in Facebook surveys about POTS stating that their physicians had dismissed their symptoms as being psychological in origin (MyHeart.net 2015).
This is not meant to lay the blame on physicians and health care providers, rather, it is meant to address concerns that the full experience of patients suffering from POTS has not been thoroughly investigated beyond the biomedical definitions of the disorder. Most of the current literature on POTS focuses on interpretations of ‘disease’ without expanding on the disorder as an ‘illness’. The distinction between disease and illness is one made by medical anthropologists to reflect the relationship between the pathological entity that causes ill-health and the subjective response of a patient to their disease (Helman 1981). By this understanding, disease becomes “what the doctor treats” and illness becomes “what the patient suffers” (Eisenberg 1977). Therefore, the symptoms described in this section and the criteria used by physicians for diagnosing POTS are all considered to be ‘disease’ while the way in which the patient finds their life impacted by the disorder and their reaction to diagnosis becomes ‘illness’ which will be discussed later. Sir James Mackenzie, a general practitioner and pioneer in the study of cardiac arrhythmias and soldier’s heart – one of the early names by which POTS was known – alongside cardiologist Sir Thomas Lewis during the early 20th century, was one of the early physicians to make note of this distinction.
Since the late 1800s, POTS has been referred to by a variety of other names as it has been reinterpreted and more thoroughly understood by physicians. Former monikers include DaCosta's Syndrome, Irritable Heart, Soldier's Heart, Effort Syndrome, Mitral Valve Prolapse Syndrome, Neurocirculatory Asthenia, and Chronic Orthostatic Intolerance (Raj 2006). In this section, the name common to each period will be used to preserve the historical accuracy of the research being cited, but in all cases discussion is meant to reference these conditions as proto-diagnostic terms for what physicians now refer to as POTS. Dr. Charles Wooley pointed out the links between these different identifiers in his editorial ‘Where are the Diseases of Yesteryear? DaCosta's Syndrome, Soldier's Heart, the Effort Syndrome, Neurocirculatory Asthenia – And the Mitral Valve Prolapse Syndrome’ (Wooley 1976).

The symptoms of POTS were first noted with marked frequency among soldiers during periods of wartime. American physician Jacob DaCosta described occurrences of irritable heart syndrome in 1871, having noted the condition among soldiers in the American Civil War and recognizing the similarities it bore to a disorder previously noted among British troops that had colonized India and soldiers in the Crimean War (Wooley 1976). Later, Sir James Mackenzie and Sir Thomas Lewis would observe the same phenomenon among soldiers during World War I who were being sent back from the front lines (Howell 1985). Ultimately, heart conditions would become the third most common cause of discharge from the British Army during this war (Howell 1985).
In his time, DaCosta treated some 300 soldiers who manifested symptoms consistent with the etiology of POTS. Two-thirds of the cases were patients between ages 16 and 25, experiencing palpitations brought on by exertion, headaches, and 'dimness of vision' with symptoms presenting spontaneously without apparent cause or first manifesting after the afflicted had experienced episodes of digestive disturbance (Wooley 1976). Similarly, Mackenzie reported examining at least 400 cases of soldiers invalided out of active service due to heart trouble, 90% of these cases being treated by him as “heart affectations” rather than cases of mechanical failures of the heart (Mackenzie 1916). Mackenzie observed among his patients many of the symptoms described previously as characteristic of POTS, including many instances in which patients heart rates experienced a persistent increase of ≥ 120 bpm, entirely consistent with the current diagnostic criteria for POTS (Mackenzie 1916).

Biological stressors are often a trigger for the manifestation of these symptoms of syncope related to POTS in a formerly healthy patient. It is not implausible to assume that among the military populations treated by DaCosta, Lewis, and Mackenzie, a large portion of their patients did encounter such stressors as prolonged infection or digestive distress while on their tours of duty, but also that the physiological responses garnered by the psychosocial stresses of active warfare might have constituted a sufficient stressor to trigger the onset of POTS.

“Sometimes [the onset] is an attack of diarrhoea, which persists for a time; sometimes it is after a definite illness, as measles, but most give a history
which we can safely surmise as being due to an infection. In a few cases one cannot get such a definite account of the starting of the illness, but many do recognize the gradual onset of the trouble” (Mackenzie 1916: 117).

Research done by Lewis at Hampstead Hospital with sufferers of effort syndrome led to the conclusion that “The ‘effort syndrome’ is often found to have arisen as an immediate sequel of infectious or other disease, and the occurrence of these in patients who are already the subjects of cardiac trouble is apt to increase the symptoms of the latter” (“Soldier’s Heart and the Effort Syndrome” 1917). Indeed, POTS has been recognized among other military personnel today, cited as a result of infection incurred while touring (Gallagher 2010). That being said, many of the soldiers treated for these heart affectations had “never been to the front, and ... had no excessive bodily or mental strain” (Mackenzie 1916: 117). This is seen today with POTS, that while a biological stressor is often noted there is not always a readily identifiable cause for the development of the disorder. That being said, studies of the health-related quality of life (HRQOL) of servicemen versus civilians have revealed that while reserve men report better HRQOL than men with no military service record, active duty soldiers were significantly more likely to report ≥ 14 days of activity limitation, pain, and insufficient sleep related to chronic or acute disabilities and poor mental or physical health (Barrett et al 2003). This was likely due to a combination of training, occupational, or athletic injuries, shift work and rotating schedules that kept soldiers awake for long consecutive periods, and the
unique nature of a soldier’s ‘occupational stressors’ (Barrett et al 2003). In this light it is easy to see how these circumstances unite to create environments in which a soldier becomes more susceptible to both the significant and the subtle biological stressors that can trigger the development of POTS.

One thing that Mackenzie took great pains to detail is the feeling of ‘rottenness’ described to him by patients. In particular, his discussions of Soldier’s Heart attempted to specify the type of exhaustion the patients feel, describing it as a sensation similar to the fatigue and weakness induced by minor activity in someone suffering an infection, rather than the temporary weariness that is the product of strenuous exertion (Mackenzie 1916). It is this sense of exhaustion that defines a large part of the experience of patients suffering from POTS. Indeed, as described by Mackenzie, “the condition is one of general exhaustion and the circulatory symptoms are but parts of a general manifestation” (Mackenzie 1916: 118). A patient narrative offered by Mackenzie in a paper read at the opening of a discussion in the Section of Therapeutics of the Royal Society of Medicine provided an example of symptoms appearing due to exertion, leading to the collapse of an officer after he’d run a race (Mackenzie 1916). A summary of the research by Lewis published by the MRC describing primary symptoms of the disorder emphasized it as “exaggerated manifestations of healthy responses to effort” (Howell 1985: 41).

Figure 1, taken from Lewis’s paper detailing the exercise intolerance exhibited by soldiers diagnosed with Disordered Action of the Heart, illustrates an expression many physicians who will have encountered patients suffering from POTS with which they are likely to be familiar. In the photograph, taken fifteen minutes after the patient had
undertaken light exercise, Lewis notes “the tension of the sterno-mastoid, slightly opened mouth ... dilated nostrils ... the [furrowed] forehead” of the patient, noting that this expression is the result of fatigue and anxiety due to the beginnings of breathlessness felt by the patient (Lewis 1918: 364). Lewis emphasizes the significance of these facial traits as a diagnostic aid, noting that this expression is not one easily simulated (Lewis 1918). Physicians today may make note of exaggerated responses to physical exertion by patients with POTS, and certainly the rapid breathing coupled with this expression of distress due to exercise intolerance can prove to be strong indicators of POTS in diagnosis and provide a visualization of the difficulties patients face in managing even light physical exertion with their condition.

It is therefore somewhat ironic that the treatment prescribed by Mackenzie focused on engaging in moderate, enjoyable physical activity (Mackenzie 1916). While recognizing that some patients may have still been too easily exhausted by their condition, Mackenzie also suggested games and mental stimulus, but remained adamant that patients must be engaged and should take on any form of exercise they find they can tolerate as soon as they were able (Mackenzie 1916). This recommendation of exercise as
a curative seemed counterintuitive – common medical practice at the time would have advised that any condition of the heart required restricted activity. However, recognizing that a diagnosis of Soldier’s Heart was often distressing news for a patient to receive, Mackenzie assigned exercise as a twofold method of treatment (Mackenzie 1916). Approaching an understanding of the medical anthropologist’s model of disease versus illness, Mackenzie understood that the symptoms of Irritable Heart could be exacerbated by the mental state of the patient, and that patients who fell into a depression upon receiving the news of their diagnosis were at risk of deteriorating further as they turned to bedrest and avoidance of exertion (Mackenzie 1916). However, moderate and consistent physical activity was found to be one of the best ways to alleviate symptoms of Soldier’s Heart as it allowed patients to begin to rebuild their tolerance to activity and to diminish the symptoms they exhibited after suffering the exhaustion and exercise intolerance induced by the impact of their condition (Mackenzie 1916). Advocating for exercise, therefore, provided a way to treat both the symptoms of disease and illness in that it addressed both the mental health status and potential for depression in patients upon facing the impacts of their diagnosis, and provided a treatment to facilitate alleviation of physical symptoms over time.

In the 1940s research done by MacLean et al. (1944) served to provide another treatment option for patients suffering from Orthostatic Tachycardia and to elaborate on the blood pooling that frequently occurs in the extremities of patients with POTS, describing the failure of the return of adequate quantities of venous blood to the heart. The failure of venous return was found to lead to a decrease in the filling of the heart,
decreased cardiac output, and a subsequent failure of the peripheral pulse (MacLean et al. 1944). This study was able to demonstrate the therapeutic benefits of repeated use of a 'head up' tilted bed in the alleviation of symptoms of syncope and poor venous return in patients (MacLean et al. 1944). Patients who appeared with symptoms of neurocirculatory asthenia were noted to experience symptoms of significantly greater severity in the mornings, upon rising from their beds. MacLean et al. (1944) proposed that sleeping in the head-up tilted bed would help to recondition the patient's body to improve venous return and oppose gravity which leads to blood pooling in the extremities (MacLean et al. 1944).

Figure 2: The head-up tilted bed as used by MacLean et al. (MacLean et al. 1944).
Repeated trials of this tilted bed proved successful for several patients in alleviating symptoms and was noted to have maintained its effects in patients who continued the therapeutic measures six months after the trials (MacLean et al. 1944). It is of particular interest to note that MacLean et al.’s repeated use of a ‘head up’ tilted bed illustrates positive results in diminishing symptoms since POTS is primarily diagnosed today with the use of a tilt table test to induce syncope and the subsequent increases in heart rate characteristic of the condition.

Understandings of the demographics of POTS, under its various monikers, began to shift in the 1940s. It had already been understood that the disorder occurred frequently in civilian patients as well as in soldiers, but there was less awareness of the role biological sex played in diagnostic rates. According to Lewis “the syndrome is not particularly ... a soldier’s [sic] malady or an athletes [sic] malady; it is one of the commonest chronic affections of sedentary town dwellers” (Wooley 1976: 750). In the 1940s, however, it was determined for the first time that Effort Syndrome actually appeared with greater frequency among female patients than it did among male patients (Wood 1941). According to Wood, the manifestations of what was understood to be Effort Syndrome or DaCosta’s Syndrome in male soldiers were interpreted as cardiac or respiratory neurosis among female civilians, with the “change of sex, plus the lack of khaki uniform” preventing physicians from accurately interpreting the symptoms they were presented with as a female civilian would be outside the schema of someone who would suffer from Soldier’s Heart (Wood 1941: 767). Cohen and White would come to similar conclusions regarding the disparity in female versus male diagnostic rates in their
research on neurocirculatory asthenia decades later, identifying twice as many cases in female patients as compared to male patients (Cohen and White 1972). In his later research, Wood took the stance that these symptoms were cardiac disturbances associated with psychiatric states and not physiologically based – significant when one considers the fraught relationship of female illness and attributions of psychiatric disturbance or hysteria, and the modern tendency to dismiss complaints associated with POTS as psychosomatic in nature.

Many of these historical ideas about the treatment, prevalence, and origins of POTS have carried over into the present day, informing current diagnostic methods, treatment options, and etiological understanding. Most prominently, Mackenzie’s advocacy for exercise reconditioning, the acknowledgement of the significant sex disparity in diagnostic rates, and the problematic view of POTS symptoms as psychological in origin, continue to play a large role in shaping the diagnosis and treatment of POTS in patients today.
AN EXAMINATION OF CROSS-CULTURAL LITERATURE AND TREATMENT APPROACHES

While this paper has focused primarily on the history of POTS as a Western phenomenon, it must be understood that this condition has no geographical or ethnic boundaries and has been noted nearly worldwide (Stiles 2015a).

Figure 3, shown below, is a self-reported map of patients with chronic illnesses created by Dysautonomia International (Dysautonomia International 2017). When reporting, there are several diagnostic options available for patients to indicate as symptoms of their dysautonomic disorders, and often multiple are chosen as dysautonomias may be comorbid. However, there was no way to filter the results for POTS alone, so this does not constitute an exact representative model.

The self-reported nature of this map is not without flaws, many of the patient markers that appear at seemingly random points in the ocean are due to incorrectly reported latitude/longitude values, and relying on self-reporting means that there are many chances for the sample to be invalidated by false data. However, in light of an overall lack of epidemiological data on POTS, it is a start. The overall distribution serves to illustrate the widespread trends and to highlight areas of higher concentration of dysautonomic disorder from which some of the following medical literature originates.
Interpretations of the etiology of POTS, beliefs about frequency of occurrence, and recommended treatment options vary depending on the regional source of the medical literature consulted. An analysis of the language surrounding discussions of POTS in medical papers from several regions in Figure 3 where there are heavy concentrations of patient clusters illustrates some of the variations in perspective and treatment approach.

In the US and UK, where the majority of historical research on POTS occurring in military and civilian populations was focused, POTS as a disorder is understood through a strictly biomedical perspective that emphasizes the potential physiological causes and mechanisms by which POTS affects the autonomic nervous system. Medical literature from these regions tends toward an understanding of POTS as a "well-known disease
entity which is under diagnosed and also underestimated” (Agarwal et al. 2007: 480). Nonetheless, while the mechanisms of POTS are fairly well understood and the prevalence of the condition is high in the US, this disorder still persists as the “most common medical condition that no one has ever heard of” (Stiles 2015b). Because of this lack of information and the frequent non-specific presentation of symptoms, delayed diagnosis is frequent, with an average time of 5 years and 11 months spanning the period between onset of symptoms and arrival at a diagnosis (Stiles 2015a).

Western medical literature emphasizes the need for physicians to recognize the “possibility of POTS in an adolescent, as many of these patients can be misdiagnosed as having psychiatric or anxiety disorders... [and that] patients with POTS can be misdiagnosed as having chronic fatigue syndrome” (Karas et al. 2000: 349). While concerns are rightly raised about recognition of POTS and accurate diagnosis, literature from the US and UK describes the ‘good prognosis’ of the disorder, depending on the etiology of the disorder – whether it is a post-viral manifestation which can resolve with treatment or of the hyperadrenergic subset which requires lifelong symptom management (Agarwal et al. 2007). Non-pharmacological and pharmacological treatment recommendations are proposed, with an emphasis on the implementation of more holistic, non-pharmacological treatment methods before utilizing any pharmacological treatments. According to the review of POTS by Carew and colleagues, when it comes to awareness of the disorder and of treatment options, it is important for physicians to be able to recognize POTS in a clinical setting because there are treatment options available
to provide patients with relief, although the evidence base for some of these treatments is poor (Carew et al. 2009).

Pharmacological recommendations for treatment of POTS include β-adrenergic blocking agents or “beta blockers” that inhibits sympathetic responses to adrenaline, SSRIs, or α2 agonists, but it is important to note that none of these treatment regimens is licensed specifically for use in the treatment of POTS (Agarwal et al. 2007). Ultimately, it is recommended that physicians approach treatment of POTS by utilizing non-pharmacological measures first, such as the exercise regimen first advocated by Mackenzie, increased fluid intake, and a diet high in salt, implementing pharmacological intervention only in cases with more severe presentation of symptoms or those cases associated with vasovagal syncope, where fainting is due to a sudden drop in blood pressure and heart rate in response to a trigger such as emotional distress or the sight of blood (Carew et al. 2009).

In Australia, comparatively, POTS is considered to be a clinical challenge “with little data on the natural history of these chronic conditions” (Lau et al. 2015: 8). While physicians recognize that disorders such as POTS, Inappropriate Sinus Tachycardia, and Vasovagal Syncope are real, physiological disorders that have a significant impact on their patient’s quality of life, it is consistently stated in medical literature that POTS is “not well understood” and “under-recognized” in the Australian medical system (Pandian et al. 2007: 530). Recent efforts undertaken by the Heart Rhythm Society have pushed for standardization of definitions and diagnostic criteria to provide a clearer picture of POTS,
while also emphasizing the need for physicians to exercise a best judgment approach with regard to concerns about heart-rate criteria and cut off points (Lau et al. 2015).

Much like the medical literature from the US and UK, dialogue about treatment for POTS raises concerns about the lack of a solid evidence base for many of the 'recommended' treatments, discussing the use of pharmacological and non-pharmacological treatment options for patients (Lau et al. 2015). Treatments using a combined approach of pharmacological and non-pharmacological measures are advocated, supporting patients with information on avoiding ‘aggravating factors’ and increasing fluid and sodium intake, and the prescription of β-adrenergic blocking agents, SSRIs, or α2 agonists to manage symptoms (Pandian et al. 2007). However, “the current management of these patients remains suboptimal with a significant gap between knowledge and its clinical application” (Lau et al. 2015). Ultimately, Australian medical literature places the focus on a need to develop greater understanding of the clinical symptomatology, results of autonomic testing, and promote recognition of the disorder to improve treatment outcomes in patients with POTS (Pandian et al. 2007). This approach bears many similarities to the biomedical perspective of Western medicine practiced in the US and UK, but acknowledges that POTS is markedly less well-understood in Australia and New Zealand.

What little Chilean medical literature there is on the subject, suggests that diagnosis of POTS presents a ‘clinical challenge’ of a different sort in diagnosis and treatment. POTS is described as “uncommon” but disturbing to patient’s quality of life, and is considered to be “a low frequency picture within the grand universe of
dysautonomies” among Chilean patients (Jimenez-Cohl et al. 2012: 149). A retrospective review of 630 tilt table tests from the Laboratory of Autonomic Studies of the Department of Neurology of the Military Hospital of Santiago revealed that of 473 cases identified as exhibiting the criteria for a diagnosis of dysautonomia, only 15 cases – 3.1% of the sample – exhibited symptoms that fit a diagnosis of POTS (Jimenez-Cohl et al. 2012). Of note, among the particular patient population studied, 10 of the 15 patients reported a family history of orthostatic intolerance, while none of the patients gave a history of viral infection prior to the onset of their symptoms (Jimenez-Cohl et al. 2012). Whether this speaks to the rates at which different subtypes of POTS – genetically-linked versus post-viral onset – may appear in different communities cannot be determined without further information.

According to the research done by Jimenez-Cohl et al., for a patient to be diagnosed with POTS takes approximately 8-10 years in Chile (Jimenez-Cohl et al. 2012). Consistent with diagnostic trends worldwide, many patients in this study indicated that they had spent years with diagnoses of depression, anxiety, or panic disorder before attaining a POTS diagnosis, with the authors noting the presence of anxiolytics or antidepressants in several patients’ treatment histories (Jimenez-Cohl et al. 2012). Insight from the case study Taquicardia postural ortostática en 15 pacientes: disautonomía compleja indicates similar concerns as those raised in Australia about an overall lack of awareness of POTS among clinicians, stating that this misdiagnosis “occurs due to the limited dissemination of this picture in the medical community and in the general public,
where symptoms such as orthostatic intolerance or syncopes are almost always attributed to emotional stress” (Jimenez-Cohl et al. 2012: 150).

When analyzing the treatment of POTS in Chile, researchers note a tendency in the patient sample to abandon treatments and cease consultation with physicians. Of the 15 patients diagnosed with POTS, 2 patients were never medicated and did not recover from their symptoms, while the other 13 patients had received pharmacological treatments at some point in their medical care (Jimenez-Cohl et al. 2012). However, follow-up with these patients found that the average total time of drug use for symptom management was 27.3 months, and that 6 of the 13 patients receiving pharmacological treatment had ceased taking their medication, so that 53% of the sample, therefore, were not receiving treatment for their symptoms (Jimenez-Cohl et al. 2012). According to researchers, “this makes us think about the great need to educate patients and doctors about existing treatments and that it is possible to alleviate the discomfort” (Jimenez-Cohl et al. 2012; 151). The relative rarity of POTS in this region may be a contributing factor in the lack of local medical literature addressing the disorder, but nonetheless, it is significant that researchers advocate for education of patients and physicians to spread awareness of the diagnosis and potential for relief of suffering.

In China, unlike Chilean medical literature which describes POTS as an uncommon phenomenon, the disorder is recognized as a frequent clinical problem presenting in children and adolescents. POTS is seen as “not rare” and “[common] in school-aged girls” (Zhang et al. 2005: English Abstract). The literature emphasizes the importance of accurate diagnostic processes, however, due to the non-specific and often
elusive manifestations of POTS symptoms since “most of POTS cases have normal
findings in routine examinations on cardiac and central nervous system [so] they are
often unable to be correctly diagnosed and treated in time” (Zhang et al. 2005: English
Abstract).

The majority of the literature on POTS coming from China focuses on child and
adolescent patients within the spectrum of presenting symptoms of syncope. One study of
syncope in 888 child patients found that 286 patients – 32.2% of the sample – met the
diagnostic criteria for POTS and established the condition as one of “the most common
hemodynamic patterns of neurally-mediated syncope” (Li et al. 2011: 49).

Much like the Western biomedical models, Chinese medical literature places the
focus on diagnostic criteria and the parsing out of POTS from other forms of syncope and
autonomic dysfunction. However, the treatment model recommended bears some marked
differences. Beyond the Western recommendations for treatment, Chinese medical
literature advocates for a comprehensive treatment model, emphasizing health education,
support, and both physical and medical therapy for child patients (Zhang et al. 2005). The
comprehensive nature of this treatment model places more significance on emotional and
therapeutic support for patients – essentially on providing non-pharmacological treatment
options over pharmaceutical intervention. This makes some sense when considering the
high number of child and adolescent POTS cases; often, symptoms of POTS that appear
in juvenile patients will peak around age 16 and then resolve so that by young adulthood
(ages 19-24) 80% of patients are asymptomatic (Grubb et al. 2006).
A unique trend of note among Chinese medical literature is the acknowledgment of the costs that come with diagnosing POTS, with “more and more costly investigations typically yield[ing] fewer and fewer diagnoses” (Li et al. 2011: 52). A study of child patients from two different diagnostic periods, 2002-2006 and 2007-2010, compared costs for diagnostic and exclusive tests engaged in assessing patients for POTS and found significant differences in the expense both over time and in the comparison of exclusive versus diagnostic testing (Li, Deng et al. 2011). When broken down, it was found that the per-capita cost for diagnosis in 2002-2006 was (621.95 ± 21.10) Yuan – or approximately $93.74 USD – with the cost of diagnostic tests like tilt table testing accounting for 8.68% of the cost, while the exclusive tests accounted for 91.32% (Li, Deng et al. 2011). The cost for diagnosis from 2007-2010, in comparison, was (542.69 ± 23.14) Yuan – or approximately $81.80 USD – with diagnostic tests accounting for 10.50% of the cost and exclusive tests for 89.50% (Li, Deng et al. 2011). While previous diagnostic efforts in China were focused on the elimination of all other causes before arriving at a diagnosis of POTS which required a large amount of time and medical resources, there now appears to be a push to utilize newer exclusive approaches with an effort to cut down on the time and expense required to obtain a diagnosis (Li, Deng et al. 2011).

Similar to Chinese medical literature, researchers and clinicians in Japan acknowledge that POTS is “probably about 5-10 times as common as [orthostatic hypotension]” with the condition potentially affecting upwards of 200,000 Japanese patients (Mizumaki 2011: 291). Nonetheless, researchers acknowledge that “the nonspecific nature of the symptoms and the absence of orthostatic hypotension have
probably resulted in a lack of recognition of this syndrome by both clinicians and investigators” (Masuki et al. 2006: 901).

The approach taken by the Japanese medical literature toward the treatment of POTS is one that is largely consistent with Western biomedicine’s understanding of the disorder (Mizumaki 2011). However, it is important to note here the apparent contradictions in interpretations of the etiology of POTS by Japanese medical literature, which may be due different etiologies assigned to different subtypes within the diagnostic umbrella of POTS or due to a larger shift in schema.

The *Japanese clinical guidelines for juvenile orthostatic dysregulation version 1* identify the similarities between the Western model for POTS and Japanese orthostatic dysregulation, or ‘OD’, but categorizes the condition as psychosomatic due to its origins in the autonomic nervous system where the ‘fight or flight’ response originates and to links between psychosocial problems and OD noted in Japanese school-aged children (Tanaka et al. 2009). However, the comorbid presence of psychosocial problems and OD should not be taken as an indicator that the two are caused by the same mechanism – while more than half of the children presenting with OD had expressed school refusal and 30-40% of school refusals were presented by students with OD (Tanaka et al. 2009), this may be related to the student’s struggle to cope with the physical challenges of OD and not due to psychological distress or phobia as postulated.

More recent medical literature describes the symptoms of orthostatic intolerance experienced by patients with POTS as being due to brain hypoperfusion and sympathetic over-action (Mizumaki 2011). Emphasis has been placed on the insight provided by
non-orthostatic symptoms that are often overlooked as diagnostic criteria in favor of focusing on the changes in heart rate as a sole indicator of POTS (Mizumaki 2011). With POTS serving as a larger category of disease rather than as the definition of a single distinct disorder, the division of POTS into its overlapping subtypes matches the Western biomedical models (Mizumaki 2011).

Much like other treatment models, Japanese medical literature recognizes that the treatment of POTS is a challenge, in part because no single therapy has proven to be overwhelmingly effective (Mizumaki 2011). Recommendations for treatment emphasize education of the patient and family members on the nature of the disorder and the importance of avoiding aggravating factors, as well as the noted increases in fluid and sodium intake, aerobic exercise regimens, and potential pharmacological interventions (Mizumaki 2011). The *Japanese clinical guidelines for juvenile orthostatic dysregulation version 1* emphasized a treatment plan centered on psychological management of the disorder, addressing six major components of treatment: guidance and education for parents and children, non-pharmacological treatment, contact with school personnel, use of adrenoreceptor stimulants and other medications, strategies of psychosocial intervention, and psychotherapy (Tanaka et al. 2009).

There is much opportunity here for further research, with particular regard to an analysis of treatment recommendations across the current literature and how these recommendations are followed through with and implemented in clinical settings.

It is significant to note the frequency with which POTS has been linked to anxiety or other psychiatric illness across these regions. POTS acts on the autonomic nervous
system, which manages many of the physiological manifestations of anxiety, but this should not be taken to indicate that POTS itself is no more than a physiological manifestation of anxiety. The automatic dismissal of POTS as symptoms of generalized anxiety or as a psychosomatic disorder in patients delays proper treatment for patients and only serves to prolong their suffering.

This is not to say that patients with POTS do not experience comorbid mental illness or anxiety disorders. In the case of POTS, though, it is typically understood that “the heart rate response to orthostatic stress is not caused by anxiety but is instead a response to an underlying physiologic abnormality” (Sheldon et al. 2015: e43). A study performed on 10 Australian subjects found that 5 of them had been treated for anxiety and panic disorder, stating that there may be “overlap” between POTS and psychiatric illness (Pandian et al. 2007). Western medical literature acknowledges that the symptoms of POTS “may be so severe that the lives of the patients and their families may be completely disrupted. Not uncommonly, complaints such as these are dismissed as being psychiatric in nature” (Karas et al. 2000: 347).

A study designed to simulate ‘sham’ orthostatic stress and mental stress in patients with POTS and in control patients found that heart rates increased significantly for patients with POTS only during periods of significant venous pooling, and that the responses to ‘sham’ orthostatic and mental stress were similar between patients with POTS and control patients (Masuki et al. 2007). Overall, this study by Masuki et al. (2007) found that heart rate responses to orthostatic and mental stress were not related to
scores on psychological indexes, indicating that “anxiety is not the primary cause for the excessive orthostatic tachycardia seen in POTS” (Masuki et al. 2007: 901).

The study performed by Wagner et al. (2012) confirms this, using a variety of psychological questionnaires to compare how patients with POTS scored if the tests included measurement of autonomic items or not (Wagner et al. 2012). On tests such as Beck Fear Inventory (BAI) and the Trait Test of the State Traits Fear Inventory, both of which include autonomic measurements, POTS patients scored significantly higher than control patients for a range of anxiety disorders (Wagner et al. 2012). However, there was no difference noted between patients with POTS and control patients when questionnaires such as the Anxiety Sensitivity Index (ASI) and Interaction Anxiety Questionnaire (IAF) were used, which excluded autonomic items (Wagner et al. 2012). Overall, therefore, it was determined that patients with POTS were no more likely to have signs of anxiety than the control patients, but that they were diagnosed more frequently if questionnaires including autonomic items were utilized (Wagner et al. 2012).

Ultimately, an understanding of the cross cultural medical literature on POTS and how it is defined and treated in different countries allows for a greater understanding of the nuanced and differing views on POTS which is essential when considering efforts going forward to promote more widespread education of patients and physicians regarding the clinical presentation of POTS, its etiology, and the treatment options that are available and most likely to provide relief.
PATIENT INTERPRETATIONS OF POTS

Returning to the medical anthropologist's disease and illness model, it is important to recall that while presentations of the disease are relatively consistent even across cultural interpretations of etiology, the experience of a patient and their illness can be highly variable as it is a deeply personal interaction between an individual and their disorder. That being said, there are obvious resonating trends in narrative themes across chronically ill communities and among patients coping with POTS. These interpretations of illness tend to emphasize the body as not entirely one's own, to emphasize the often confusing systemic nature of a chronic illness's unclear source and non-specific symptoms, and to identify changes in or reinterpretations of lifestyle and mindset that provide coping mechanisms.

Historically, the patient's narrative was regarded as an essential diagnostic tool – almost more so than the physical examination itself. However, as scientific discoveries allowed the physical examination to advance "the study and treatment of disease became separated from the individual, and located within body systems only understood by experts, the need to attend to the patient was reduced to eliciting information about the objective signs and symptoms of the disease" (Bury 2001: 266). The recent push to reintegrate patient narratives into medical care has resulted in a wealth of insights allowing physicians to utilize these narratives to better understand the experiences of their patients and the ways in which their patients interpret illness to be able to provide the most beneficial forms of care for these patients. For example, one resonating patient
narrative of chronic illness uses the metaphor of a house fire to describe the attempts to diagnose symptoms that are non-specific and systemic.

Going to the doctor when you’re chronically ill is weird. It’s like imagine everything in your house is on fire, and you’re standing there and the fire department come in like, describe the fire to me and maybe we can find what caused it and put it out. and you can’t just say everything so you’re like... well the fire in the curtain is the biggest but the fire in the photo albums might be doing the most damage also the fire in the couch is really inconvenient occasionally the fire guy is like, well your tv is on fire so it might be electronic-fireitus but that would cause other things like fire in the dvd player and you’re like, oh yes. that’s been on fire for years. I forgot to mention it because it’s always been a relatively small fire. It’s right next to the bookshelf which has much more fire. and then the fire guy is like, oh. I wouldn’t worry about that. book shelf fire just happens sometimes (mycharliequinn 2015).

Bury divides these patient narratives into three basic schemes; contingent narratives which address patient beliefs about the origins of a disease and its immediate effects, moral narratives which account for the changing relationship between persons, illness, and social identity, and core narratives which demonstrate connections between personal experiences and cultural meanings ascribed to suffering and disease (Bury
Thus, the above narrative presents an example of a core narrative – invoking comic elements as a mechanism for coping with the pain and discomfort referenced by the metaphorical conflagration. These personal narratives of illness experience are a means by which patients can articulate the links between their bodies, sense of self, and society which allows physicians to understand how their patients interpret the biomedical aspects of disease (Bury 2001).

A moral narrative is one that seeks to account for changes in the dynamics between a personal identity, an illness, and a social identity, to re-establish the moral status of an ill individual, or help to maintain a social distance (Bury 2001). One of the most frequent moral narratives health care providers should be aware of when treating patients with POTS and other chronic illnesses is that of ‘Spoon Theory’. Developed by Christine Miserandino, the Spoon Theory has become an ingenious and well-recognized method for explaining the experiences of patients across the spectrum of chronic illness. Translated into Spanish, Hebrew, and French, Miserandino’s patient narrative describes her efforts to illustrate life with Lupus to a friend. To do this, she uses spoons as a metaphor for units of energy expended by an individual on tasks per day, an idea which has resonated strongly with other chronically ill individuals as a way to exemplify their disease to others and to shed light on the relationship between a person and their experience of illness.

In Spoon Theory, the ‘spoon’ represents a unit of energy with different daily tasks requiring a different number of spoons (Miserandino 2003). The difference between ‘healthy’ people and people with a chronic illness is that people who are healthy have an
unlimited amount of spoons – they are not required to reflect on the amount of energy a
task will take, they can simply accomplish it without detriment (Miserandino 2003). A
person with chronic illness, however, is granted
only a limited number of spoons per day and is always conscious on some level of budgeting
their energy expenditure and arranging their daily routines around symptom management
(Miserandino 2003).

As a moral narrative, the Spoon Theory serves – in part – to justify the struggles of chronically ill
individuals which are frequently invisible to healthy persons. The theory provides a context
in which chronically ill and healthy persons alike can reevaluate conceptions of illness versus wellness and persons living with a chronic disease can explore the story of their identities and experiences through an elegantly simple illustration of an otherwise complex worldview, the realities of which are often otherwise difficult to convey to the un-afflicted. This is the case for Emily Howard, an artist who has found ways to interpret her experience with POTS through narratives such as Spoon Theory and through the development of her own core narrative of illness in her body of work *Not for Medical Use* (Howard 2017).
*Not for Medical Use* is a particularly unique patient narrative. Howard uses the body of her work as a way to interpret her own illness and reevaluate the relationships between disease and self, but also as a way to make an internal and personal experience – POTS, an 'invisible' illness – visible for others to comprehend (Howard 2017). Howard's works have aspects of both core and moral narratives in this regard, as they demonstrate the sometimes turbulent relationships that exist between a person's identity and illness and provide a sense of meaning in an effort to interpret personal experiences with disease. Howard's artworks form a threefold narrative therefore; the interpersonal narrative of understanding and coping with her illness, the projected narrative of viewers interpreting her art, and the intrapersonal narrative of physician-patient relationships and questions of misdiagnosis and gender bias in healthcare.

The works of *Not for Medical Use* offer a particular insight as a patient narrative because they allow a uniquely visual perspective on the world of a patient with POTS; how patients view their own bodies and experiences with illness, how they feel others view their bodies – particularly the effect of the clinician's gaze – and the impacts of the search for answers, a diagnosis, and the right treatment. Meant to illustrate the "living truth" of chronic illness, Howard uses her artwork both as a mechanism for coping with the challenges of a life with POTS, reconciling her social identities and her experiences of illness with a sense of cultural meaning, and as a tool of enlightenment to spread awareness about invisible disabilities and chronic illness (Howard 2017).
Howard approaches her interpretation of POTS and disease, in part, through the perspective of the body as a container holding "everything that makes up a person's physical and spiritual identity" (Howard 2017; 3). It becomes difficult, then, to distance the essence of one's identity from the chronic illness which affects a part – or the entirety of – the body, because 'self' is held entirely in this physical vessel (Howard 2017). Much of Howard's artwork is meant to represent the reinterpretation of self-and-body that patients face when coping with chronic illness and the renegotiation of social identities and connections that is involved in living with disease. "Suffering from a condition can not only cause a disconnect with other people, but can also cause a disconnection with oneself. It is difficult to find that balance in life where you do not feel as though the condition is what defines you" (Howard 2017: 8).

A survey of individuals diagnosed with POTS indicated that 32.0% of the patients surveyed had consulted with 5-7 doctors before receiving a diagnosis of POTS.
(MyHeart.net 2015). The experiences described and brought to life by Howard in Not for Medical Use are largely representative of the experiences of many of these patients in their efforts to seek out a diagnosis, to find someone who will 'believe how they feel'.

"There have been times when I am going from one doctor to the next trying to be properly diagnosed or searching for a treatment that works and this has happened so often that I have begun to feel like an object on a table rather than a person looking for help. This experience has the potential to be universal to people of any race or gender who experience a struggle with invisible illness" (Howard 2017: 18).

Indeed, the experience illustrated in Howard's piece *Pile of Bones* – shown in Figure 6 – is a visual meant to encompass the experience of patients, tied down to the examination table by the weight of their disease (Howard 2017).

![Figure 6: "Pile of Bones" by Emily Howard (Howard 2017)](image-url)
Howard's artwork addresses another common theme faced by patients with POTS during the quest for a diagnosis — the dismissal of symptoms as psychosomatic or 'all in their heads' and the misdiagnosis of POTS as anxiety or panic disorder. Her piece Miss Diagnosed, Figure 7, is meant to provide a commentary on this trend, using the imagery of breathing into a paper bag to prevent hyperventilation to represent an anxiety attack (Howard 2017). Alongside this piece, All in Your Head, Figure 8, serves as a further commentary on misdiagnosis of POTS and the “diagnosing and treating [of] a symptom rather than the cause” (Howard 2017: 17). In this case, the nails being driven into the brain represent the migraines Howard suffered due to her POTS and the larger variety of symptoms all caused by a single, systemic problem that was never ‘in her head’ in the sense that medical providers had suggested (Howard 2017).
The patient narratives explored in this section can provide valuable insight to healthcare providers in their efforts to work with patients to diagnose and manage POTS. The patient narratives of individuals experiencing chronic illness are unique in that their illness becomes a permanent lens through which they view and interpret the world around them, affecting the relationships between body, self, and society in a way that physicians should be conscious of as they enter into a dialogue with patients about symptoms, management of their disorder, and treatment options. Trends in the narratives of patients with POTS highlight concerns about misdiagnosis, struggles with articulation of illness experiences to non-afflicted individuals, reconfiguring of personal and physical identities, and a desire for increased awareness from others.
EFFECTS ON THE PATIENT-PHYSICIAN RELATIONSHIP

As a form of dysautonomia, POTS can be considered within the ‘mind-body disorder’ model proposed in *The NDRF Patient Handbook for Patients with Dysautonomias*. This model challenges the traditional separation of physical and mental illnesses:

“If the disorder were physical, it would be ‘real,’ something imposed on the individual, while if it were mental, and ‘in your head,’ It would not be real, but something created in and by the individual” (Goldstein and Smith 2002: 63).

The acknowledgment of POTS as a disorder that has both mental and physical effects is essential in the physician-patient relationship. Clarity needs to be maintained in understanding that the etiology of POTS does not indicate its origins as psychological, or that the symptoms presented are psychosomatic manifestations of an anxiety disorder, but physicians should recognize that this is a common misdiagnosis and that patients may suffer psychological distress due to the challenges they face from their condition. Suggestions have been made that a biopsychosocial model be used in treatment of POTS patients with functional disability alongside a conceptualization of pain to provide a more comprehensive approach to rehabilitation (Keating et al. 2017).
A survey of patients revealed that over 78% considered the awareness and understanding of others to be “very important” in their ability to cope with POTS (MyHeart.net 2015). In this same survey, approximately 60% of respondents strongly agreed with the statement “having a strong and comprehensive understanding of POTS plays an important role in helping me combat the disease” (MyHeart.net 2015). The desire for information and awareness is essential to patients in allowing them to take control of their health experience, integrating medical knowledge into their perceptions of their illness to develop the most comprehensive understanding possible of the condition they struggle with every day. Healthcare providers, therefore, are seen as advocates and educators to their patients, not just healers (Uhrich and Hartung 2015). Thus, it becomes essential to educate physicians and allied health professionals on the peculiar presentation of POTS and its etiology to prevent the continuing narrative trend of misdiagnosis, mistrust of healthcare professionals, and feelings of frustration and helplessness encountered by patients.

“I find that as a woman it can be difficult to get a doctor to take your medical situation seriously. Out of all the doctors I have seen regarding the diagnosis and treatment of my condition, all have been male and only about four of them have listened to me and taken me seriously. Out of those four, two of them were heart specialists, one of whom openly admitted he did not know how to treat my POTS after diagnoses” (Howard 2017: 16).
This need for increased awareness is highlighted by the survey conducted by Dysautonomia International, which emphasizes the need for increased outreach to primary care physicians and pediatricians who are often the first ones to encounter these symptoms in patients, but diagnose POTS at some of the lowest rates among practitioners surveyed (Dysautonomia International 2014). This awareness is not just needed among physicians, however; “Doesn’t Anyone Believe How I Feel?” is an article on the etiology, diagnosis, and management of POTS by Uhrich and Hartung aimed at educating school nurses who may often be one of the first healthcare providers to encounter symptoms occurring in adolescent students and who play a significant role in assisting these students with managing their symptoms at school (Uhrich and Hartung 2015).

Ultimately, the physician-patient relationship is one that emphasizes the patient’s trust in the physician as a guiding figure, one with the education and insight to provide patients with the resources to manage their POTS. Often, if this need is not met by the physicians, patients will seek out information on their own – they become involved in support groups, online forums, and blogging communities aimed toward fellow POTSies, spoonies, and chronically ill individuals. This allows for a sense of community and belonging among fellow patients experiencing the same trials and tribulations, creating a body of knowledge in which methods for symptom management, physician recommendations, and all forms of patient narratives can be shared. The desire to feel heard and understood has created these communities of patients while simultaneously alienating patients from their physicians who, it is often felt, either do not take their
patient's concerns about the presentation of the non-specific symptoms of POTS seriously enough, or who potentially present their patients with misdiagnoses due to a lack of awareness leading to mistrust.
CONCLUSION

Postural Orthostatic Tachycardia Syndrome describes a cluster of disorders of the autonomic nervous system that, as of yet, has no single discernible cause, but primarily affects the heart. POTS leads to drastic increases in heart rate upon standing without significant orthostatic hypotension. These disorders range in type from genetically-linked POTS to symptoms that manifest after a biological stressor such as a viral infection, pregnancy, or surgery (Agarwal et al. 2007). While the condition is more prevalent in females, with the onset of symptoms typically occurring between ages 15-50, POTS has been noted in both males and females worldwide.

The current medical understanding of POTS was first detailed in 1993 by Schondorf and Low, but POTS has existed in medical history for centuries. Known by such names as DaCosta’s Syndrome, Irritable Heart, Soldier’s Heart, Effort Syndrome, Mitral Valve Prolapse Syndrome, Neurocirculatory Asthenia, and Chronic Orthostatic Intolerance (Raj 2006), the importance of past investigations of the condition should be reintegrated and consulted for the insight they can continue to offer even today. Consulting the research of the likes of MacLean, Lewis, and Mackenzie one can gain a valuable awareness of the depth and breadth of the symptomology of POTS and of the continuing relevance of treatments focused on a biopsychosocial model such as that advocated by Mackenzie (Mackenzie 1916).

A cross-cultural analysis of the medical literature on POTS from several areas around the world provides similarly valuable clarity with regards to how the disorder is
understood and treated worldwide. In particular, analysis of the language surrounding the etiology of POTS, rates of occurrence, symptoms and experiences of the patients, and the treatment options recommended allows a more comprehensive understanding of the disorder to be developed. While in some parts of the world, such as the US and UK, POTS is considered to be a fairly well understood disorder, in Australia and New Zealand there is a push to improve understanding and recognition of POTS. Similarly, POTS is considered to be a relatively common disorder in China and Japan, while in Chile the disorder is described as "rare" and uncommon. In these different regions, pharmacological and non-pharmacological measures are recommended as treatments at different rates. Ultimately, the cross-cultural analysis of medical literature facilitates a greater understanding of the regional differences in interpretations of POTS which allows for better initiatives moving forward to educate physicians and patients on the nature of the condition.

An analysis of patient narratives provides a third critical component in educating physicians on POTS and providing valuable insight into the experiences of their patients. The non-specific nature of the symptoms of POTS, coupled with insufficient awareness of the disorder among healthcare providers, leads to high rates of misdiagnosis for patients or dismissal of symptoms as stemming from a psychological rather than a physiological cause. Analyzing patient narratives, such as the Spoon Theory (Miserandino 2003) and works like Emily Howard's which provide a visual of the patient's view of self as well as their interpretations of the clinician's gaze, allows physicians to establish a clearer insight into the patient's experience. By reaching out to
the patient through their own interpretations of illness, the physician can therefore facilitate more positive physician-patient interactions aimed not just at providing the patient with information and instruction, but on developing a dialogue with the patient regarding perspectives on disease, illness, and treatment.

Ultimately, incorporating the historical interpretations of POTS with current cross-cultural medical literature and patient narratives in the context of the disease versus illness model developed by medical anthropologists allows a more comprehensive understanding of POTS, of the models of treatment recommended, and of the models used to interpret this disorder. Utilizing this breadth of information to understand the nature of POTS – a disorder noted for its non-specific symptoms and diagnostic challenges – facilitates greater insight and allows the promotion of further education for health care providers and patients to provide more positive outcomes in physician-patient interactions in future clinical interactions.
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“Life is a battle: may we all be enabled to fight it well” (Charlotte Bronte 2000).

It was my aim in undertaking this research project that I might shed some light onto my own experiences with POTS, and going forward, enable other patients and their health care providers in their ongoing battles for diagnosis, treatment, and understanding. I hope I have accomplished this.

Thank you to my family, for their support; especially my mother, for always being my advocate in the examination room and for making sure the doctors listened. Thank you to Dr. Moore who has been an endless source of inspiration, encouragement, and guidance for me since the start. Thank you to Kristine Wilmoth, MSCP, LLP for providing assistance and insight with translations. And thank you to the Library Services Department at St. Joseph Mercy Hospital whose archives held a wealth of information I could not have otherwise accessed.
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