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Abstract

The level of functional impairment that people with Postural Orthostatic Tachycardia Syndrome (POTS) experience is life changing. Reduced engagement in purposeful and meaning activities because of functional impairments increases the emotional impact of POTS and decreases quality of life. By including occupational therapy early on in treatment, people with POTS can learn ways to adapt, cope, and incorporate changes into their lifestyles. Increasing participation in purposeful and meaningful occupations that are of value to the individual leads to increased quality of life, increased participation in desired roles, increased sense of well-being, and increased perception of health.

Comments

The authors report they have no conflicts of interest to disclose.

Keywords

POTS, dysautonomia, orthostatic intolerance, functional limitations, increasing quality of life, adaptations for POTS

Occupational therapy skills are being recognized for their benefit in treating a variety of conditions and for the ways they engage in areas of practice that have not been considered previously. Examples include pain management, obesity, oncology, prevention, and chronic illness management (Yamkovenko, n.d.). Pain management is one area in which the distinct and valuable role of occupational therapy in treating people with pain disorders is slowly being recognized. When occupational therapy is an integral part of the treatment team in its early stages, other facets of pain, such as sensory, cognitive, emotional, psychosocial, and cultural issues, can be addressed (Opp-Hofmann, n.d.). The result is a comprehensive approach to intervention and better outcomes. Occupational therapy can have a significant impact on a person's perception of his or her ability to cope, sense of suffering associated with a condition, and quality of life (American Occupational Therapy Association [AOTA], 2017). Postural Orthostatic Tachycardia Syndrome (POTS) is one such condition for which occupational therapy should be considered early in the treatment process. This article introduces ways to address POTS through occupational therapy treatment.

Symptoms, Types, and Prevalence

POTS is characterized by an increase in heart rate of > 30 beats per min (> 40 beats per min in children and adolescents) or greater than 120 beats per min within 10 min of assuming an upright position in the absence of orthostatic hypotension (Stewart, 2013). Symptoms must persist for more than 3 months and not be caused by prolonged bed rest (Raj, 2006). When an individual with POTS stands, he or she may experience tachycardia, dizziness, lightheadedness, pre-syncope, syncope, extreme fatigue, shortness of breath, exercise intolerance, tremors, headache, and brain fog (Grubb, Kanjwal, & Kosinski, 2006). Regardless of their position, individuals with POTS can also experience attention deficits, gastrointestinal disturbances, thermoregulation disturbances, and sleep disturbances (Grubb et al., 2006; Raj, 2006; Stewart, 2013). Therefore, POTS can be associated with significant disability (Stewart, 2013).

While the pathophysiology of POTS is not fully understood, a main mechanism of dysfunction in the autonomic nervous system leads to excessive blood pooling in the lower extremities. The body compensates by increasing the heart rate in an attempt to redistribute the blood (Grubb, 2008; Raj, 2013). There are several forms of POTS that are classified as primary or secondary (Raj, 2006). Even though the types of POTS often overlap, knowing the nuances of the condition's variations assists in designing proper interventions.

Primary forms of POTS include partial dysautonomic POTS and hyper adrenergic POTS. Partial dysautonomic POTS, which presents as an inability of peripheral vasculature to constrict, resulting in excessive vein pooling in the legs, includes neuropathic POTS and developmental POTS (Grubb et al., 2006). In neuropathic POTS, sympathetic denervation of the lower extremities results in excessive blood pooling and reflex tachycardia (Grubb, 2008). Hypovolemia is likely present, possibly because of similar effects of partial sympathetic denervation on the kidneys (Raj, 2006). In developmental POTS, symptoms often begin after growth spurts, progress until age 16, and then taper off in young adulthood (Grubb et al., 2006; Stewart, 2013).

Hyper adrenergic POTS is the most complicated and least encountered form (Raj, 2013). In the hyper adrenergic form of POTS sympathetic nervous system over activity impacts the brain, heart, and kidneys, triggering unique signs of increased blood pressure; increased plasma catecholamines, like norepinephrine and epinephrine; increased urinary output; increased sweating; hyperthermia; and reflex tachycardia upon standing (Grubb, 2008; Raj, 2006). Migraines also frequently accompany hyper

adrenergic POTS (Grubb, 2008). Secondary forms may be associated with joint hypermobility syndrome, amyloidosis, sarcoidosis, alcoholism, Sjögren's syndrome, lupus, and diabetes (Grubb et al., 2006).

POTS can also be triggered by pregnancy, viral infections, and trauma (Raj, 2006). POTS occurs most often in females, with a 4:1 ratio to males. The age of onset most often occurs in the 20's and 30's (Raj, 2006). However, children as young as 7 years of age have developed the symptoms (Grubb, 2008). It is estimated that POTS affects approximately 500,000 to 3 million people in the US (Garland, Celedino, & Raj, 2015). Because POTS' symptoms overlap with other conditions, such as anxiety (V. Raj et al., 2009), accurate diagnosis is often delayed. As physicians have become more aware of this syndrome, POTS is being more readily diagnosed (Garland et al., 2015).

Occupational Therapy Interventions

Occupational therapists recognize the importance of the whole person (mind-body-spirit) as the client participates in meaningful and purposeful activities in daily life (AOTA, 2017). The occupational therapy models that can be used to provide a theoretical framework for clinical reasoning and guide development of interventions for individuals with POTS are the Person Environment Occupation Model (Law et al., 1996) and the Model of Human Occupation (Kielhofner, 2008). By adapting or modifying the environment or occupation, individuals with POTS can increase their participation and occupational performance.

Targeted outcomes of occupational therapy for people with POTS may include improvement in occupational performance, increased independence in activities of daily living, increased participation in purposeful and meaningful occupations, and increased quality of life (Benrud-Larson et al., 2002). Because of the substantial impact of POTS on functioning, the ability to pursue normal employment and typical schooling is limited (Grubb et al., 2006). Once occupational performance is increased and adaptive engagement in activities of daily living is achieved, then it may be possible to address areas related to participation in modified schedules of school and work.

Theoretical Background

The Person Environment Occupation Model addresses the interdependent interaction of the three components. The person is seen as a unique being inhabiting various roles over a period of time that cannot be separated from the context in which occupations are performed. This model accounts for the physical environment, but also for the cultural, social, psychological, socioeconomic, and institutional context. Self-care, productivity, and leisure occupations are addressed in this model. Occupations are activities and tasks that a person engages in to satisfy intrinsic needs for self-maintenance, self-expression, and life satisfaction. Dysfunction is seen when there is not a good fit between the three components. Occupational therapists can then address any of the three areas to increase occupational performance, which, in turn, increases satisfaction and quality of life (Law et al., 1996).

Kielhofner's Model of Human Occupation is holistic, evidence-based, and client-centered. This model considers both mind and body as the client's thinking, feeling, volition, and motivation for participating in occupations are central to therapy (2008). Roles and habits are addressed in this model. This area is particularly pertinent to individuals with POTS, as symptoms often disrupt their normal social identities, roles, and habits. The environmental context (physical, social, economic, and political) impacts how occupations are performed, motivated, and organized (Kielhofner, 2008). By adapting the environment to meet the client's needs, occupational performance and participation are likely to increase. Helping individuals with POTS learn to become occupationally adaptive through reshaping

and redefining their occupational identities and occupational competencies aids in the ability to cope with changing symptoms and limitations.

The level of functional impairment that individuals with POTS experience is similar to that of chronic obstructive pulmonary disorder and congestive heart failure (Grubb, 2008). As a consequence, their quality of life is often significantly impacted (Benrud-Larson et al., 2002). Upright activities, such as cooking, cleaning, and showering, can exacerbate symptoms, often forcing individuals with POTS to reduce their engagement in activities (Grubb et al., 2006; Raj, 2006). This decreased participation in normal activities can lead to dysfunction in multiple areas that need to be assessed and addressed.

Occupational therapy is an essential component in the treatment of an individual with POTS. While traditional medicine and physical therapy are also important, it is occupational therapy's unique domain and process that offers a treatment plan based on knowledge about a client's environment, values, goals, and desires, and that uses that information to develop interventions that are occupation-based, client-centered, contextual, and evidenced-based (AOTA, 2017). The profession of occupational therapy holds the core belief that there is a positive correlation between participation in occupations and health (AOTA, 2017), recognizing the importance of the whole person (body-mind-spirit) as the client participates in meaningful and purposeful activities in daily life. Active engagement in occupations promotes, facilitates, supports, and maintains health and participation.

Approaches and Interventions

Occupational therapists interview and evaluate an individual with POTS for occupational performance issues, functional deficits, and quality of life. A treatment plan is then developed that considers the client's environment, goals, values, and desires (AOTA, 2017). The treatment plan may include learning compensatory techniques to perform activities, such as using energy conservation strategies; adaptive ways to engage in occupations, such as using an office chair in the kitchen to stay seated while cooking; and using adaptive equipment, such as a bath chair to make showering easier.

Because significant fatigue is a daily factor for individuals with POTS (S. R. Raj et al., 2009), learning energy conservation strategies can help these individuals become more willing and able to participate in exercise training. Exercise training, such as increasing lower extremity skeletal muscle pumps to assist venous return (Grubb, 2008), can reduce the symptoms of POTS when initiated in a seated or recumbent position (Fu et al., 2011). Pacing strategies can be used to help people with POTS to incorporate time for exercise in their schedules. Beyond activities of daily living, occupational therapists can also address engagement in occupations related to recreation, socialization, and school or work (AOTA, 2017).

Other client factors that have not been discussed elsewhere in the literature are the psychosocial and cultural impacts of having POTS. The occupational performance limitations that result from POTS can have psychosocial and sociocultural repercussions as well. Examples include the limited ability to connect with peers in typically age appropriate activities. Activities, such as shopping or walking with friends, waiting in line at a movie theater or concert, going skiing or to an amusement park, or going to a bar or dancing, involve standing or walking, all of which increase symptoms in a person with POTS.

Sociocultural factors may include religious activities, such as standing to sing in church and walking or bowing to participate in interactive parts of the service. Familial roles, such as washing dishes or mowing the lawn; gender roles, such as carrying an infant or carrying in groceries, also include walking or standing, which can exacerbate symptoms. Occupational therapists understand the impact of a disability and how it affects role performance. Because roles are important to our identities, the

inability to perform in desired roles can lead to dissatisfaction and decreased participation (Law, 2002). Decreased ability to participate in desired roles can be isolating (Kielhofner, 2008) for a person with POTS.

Occupational therapists can adapt occupations related to different environmental constraints to increase participation (AOTA, 2017). By working with clients in their natural environments, occupational therapists can address specific individual needs. Making adaptations to contextual factors and the environment can significantly increase the ability of individuals with POTS to participate in meaningful and purposeful occupations (Law, 2002) and desired roles (See Appendix A for case example).

Conclusion

Occupational therapy's distinct domain and process can be of significant benefit to an individual diagnosed with POTS. Giving clients the tools to adapt and increase functional abilities can lessen the emotional impact of living with a serious condition. Increasing participation in purposeful and meaningful occupations that are of value to the individual leads to an increase in quality of life, participation in desired roles, a sense of well-being, and perception of health. Given these benefits, including occupational therapy as a part of the treatment plan early on may offer individuals with POTS a more comprehensive approach to treatment with the possibility of better treatment outcomes. There is great potential for the profession of occupational therapy to engage this population in intervention. The full needs of an individual with POTS are not being addressed, and it is possible that occupational therapy is the missing component to comprehensive care and better treatment outcomes. Future research could address the role of occupational therapy in increasing quality of life for this population.

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Appendix

Case Example

Gemma, a 34-year-old female with onset of POTS symptoms 14 months ago following a car accident, was an active mother and sales clerk at a grocery store. Gemma is currently unable to work and is overwhelmed with debilitating symptoms of dizziness and tachycardia on standing, along with significant fatigue and frequent nausea. She has tried several medications, including propranolol, verapamil, and clonidine, without much benefit, and began Bystolic about 2 months ago. Through the occupational interview, it was found that she was becoming depressed because of “not being able to things [she] used to do.”

Gemma noted she was often exhausted by the time she showered and dressed. Because of the fatigue, she had been spending most of the day on the couch. She has difficulty standing at the stove preparing a meal for her family and feels guilty that she is no longer providing good meals. Her hobbies included cooking, jewelry making, and bowling. At the time of the interview, she had not been doing any of these activities since the accident.

The results of the occupational evaluations noted decreased functional abilities, significantly reduced levels of participation in purposeful and meaningful activities, and decreased quality of life (see Table 1). From these results, the therapist assisted the client in prioritizing goals and objectives (see Table 2). The first area the client identified as wanting to address was cooking. Gemma learned energy conservation skills, such as gathering all the things needed for a recipe before beginning, staying seated during food prep, and using a wheeled office chair at the stove.

Pacing was also taught. Gemma learned to budget her energy by scheduling an easier meal on a day she had a doctor’s appointment, or breaking down a more strenuous activity into parts and resting in between. Energy conservation skills were learned for the bathroom and the bedroom, such as using a shower chair and keeping all things needed in the shower in a plastic basket nearby. As her second goal was to get showered and dressed without expending as much energy or aggravating symptoms, she learned to dry off by putting on a thick terry cloth robe. Gemma noted that by learning how to do things easier and conserve energy, that she might now be able to find time for the physical therapy recommended by her physician.

Gemma’s third goal was to do something fun with her 9-year-old daughter. They used to go bowling together, and she has missed that. The therapist introduced Gemma to Wii bowling. It was something she could do with her daughter from a seated position on an exercise ball. It also helped strengthen her core muscles without aggravating symptoms. As therapy progressed, Gemma was happy to share that there were many active Wii games she could play with her daughter while seated on the exercise ball. She also noted that her endurance was increasing.

Throughout the 12 weeks of twice weekly occupational therapy, coping and relaxation skills were taught as well. Gemma learned that deep breathing and living in the present moment were essential tools for coping with a chronic illness. She also learned the importance of carving out some time for herself to relax while jewelry making. The client learned that when all supplies and tools were in a tackle box conveniently located, she could easily get it out to work after her daughter went to bed. Gemma reported that she liked the feeling of doing something she enjoyed and being productive again.

Table 1*Evaluations: Standardized and Non-Standardized Assessments*

Evaluation					
Non-Standardized Assessments	Occupational interview	Home evaluation	Observation of daily activities performance		
Standardized Assessments	Canadian Occupational Performance Measure	Modified Fatigue Impact Score	Roles Checklist	Quality of Life Scale	Functional Independence Measure

Table 2*Intervention Plan: Symptoms, Goals, Interventions, and Outcomes*

Symptom	Goal	Interventions	Outcome
Dizziness and tachycardia upon standing	Client prepares healthy meals 5x/wk	Energy conservation training, planning, and preparing ahead	Achieved completed meal prep while seated 5x/wk
Fatigue with ADLs	Client participates in PT for 1 hour 2x/wk	Energy conservation and pacing training to enable PT participation	Successful incorporation of PT into schedule 2x/wk
Trouble carrying out role as parent	Client plays Wii bowling with daughter for 45 min 2x/wk	Using exercise ball to Wii bowl while seated for 2x/wk	Increased activity participation with daughter in Wii bowling
Stress	Client uses leisure activity 3x/wk to reduce stress	Mindfulness training, learning importance of hobbies in OT 2x/wk	Verbal report of successful coping to reduce stress