



August 2021

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Recommended Citation

Mike, E. (2021). The Impact of Postural Orthostatic Tachycardia Syndrome (POTS) on Function & Quality of Life: A Descriptive Case Study. *Journal of Interprofessional Practice and Collaboration*, 3(2). Retrieved from <https://repository.ulm.edu/ojihp/vol3/iss2/1>

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Abstract

This study aimed to identify and describe how an individual with postural orthostatic tachycardia syndrome (POTS) is impacted by the symptoms of the disorder. A descriptive case study was used to gain understanding of the lived experience of an individual with POTS. A semi-structured interview was conducted, and data analyzed to develop a theme. Following data analysis, one overarching theme emerged, the participant did not realize the impact that POTS has on her daily function and quality of life. The descriptions and summary provide evidence for the unique role that occupational therapists play in providing care for individuals with POTS.

The Impact of Postural Orthostatic Tachycardia Syndrome (POTS) on Function & Quality of Life: A Descriptive Case Study

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Abstract

This study aimed to identify and describe how an individual with postural orthostatic tachycardia syndrome (POTS) is impacted by the symptoms of the disorder. A descriptive case study was used to gain understanding of the lived experience of an individual with POTS. A semi-structured interview and follow-up phone call were conducted, and data analyzed to develop a theme. Following data analysis, one overarching theme emerged: the participant did not realize the impact that POTS has on her daily function and quality of life. The descriptions and summary provide support for the unique role that occupational therapists play in providing care for individuals with POTS.

Keywords: Postural orthostatic tachycardia syndrome, POTS, occupational therapy, quality of life, function, health management

The Impact of Postural Orthostatic Tachycardia Syndrome (POTS) on Function & Quality of Life: A Descriptive Case Study

Postural Orthostatic Tachycardia Syndrome (POTS) is an autonomic disorder that affects over half a million people in the United States alone (Stewart, 2013). It is defined as chronic orthostatic intolerance characterized by an increase in heart rate of greater than 30 beats per minute (greater than 40 in children and adolescents) or greater than 120 beats per minute within 10 min of assuming an upright position (Stewart, 2013). Individuals with POTS experience symptoms such as postural tachycardia, lightheadedness, dizziness, or presyncope with any changes in posture as well as with prolonged standing (Stewart, 2013). The physiological mechanisms of POTS are variable and may include neuropathies, hypovolemia, impaired vasoconstriction, exaggerated hyperadrenergic response, and autoimmune dysfunction (Del Pozzi et al., 2019). In addition to the physiological response that individuals experience secondary to positioning, environmental stressors such as heat can exacerbate symptoms (Bryarly et al., 2019). Other symptoms such as anxiety, excessive fatigue, exercise intolerance, frequent headaches, cognitive symptoms, gastrointestinal dysfunction, and sleep disturbances may also persistently accompany POTS and disrupt daily function (Bryarly et al., 2019; Del Pozzi et al., 2019).

Health management is a vital area of occupation that occupational therapists are skilled in supporting (American Occupational Therapy Association [AOTA], 2020). Developing, managing, and maintaining health and wellness routines are important daily activities for many people; therefore, it is important to consider how this impacts individuals with chronic disorders (AOTA, 2020). Occupational therapy is currently recognized as having a significant

impact on the function and quality of life of individuals with chronic disorders (i.e., pain, cancer, autoimmune disease, etc.) especially when considered in the initial treatment process (Dochod & Grapczynski, 2019). Thus, for the common but not well-known chronic autonomic disorder POTS, occupational therapy assessment of everyday tasks, rest/sleep, health management, work/school, leisure, and social activities after diagnosis may facilitate an easier transition into the symptom and condition management of this debilitating disorder (AOTA, 2020).

Symptoms of POTS can range in severity and can significantly impair activities of daily living (ADLs) (Bruce et al., 2016; Del Pozzi et al., 2019). Fatigue, a huge determining factor in an individual's ability to participate in all daily activities, is overwhelmingly prevalent in those with POTS (Strassheim et al., 2018). Conditions such as gastrointestinal dysmotility, chronic pelvic pain, and overactive bladder, present in some individuals with POTS, can have an enormous impact on the ADLs of eating, toileting, and sex in addition to instrumental activities of daily living (IADLs) such as meal planning and preparation (Bryarly et al., 2019). Exercise intolerance is another symptom that not only impairs the individual's health management and leisure occupations but can also lead to cardiac deconditioning (Fu & Levine, 2018). In addition, POTS symptoms such as anxiety and "brain fog" interfere with cognitive functioning required for work, school, and social participation (Bryarly et al., 2019). Benrud-Larson et al. (2003) reported that at least 25% of patients with POTS are unable to work or attend school. This not only affects the function and quality of life of the individual with the disorder, but also impacts society (Strassheim et al., 2018).

Medical research shows that one of the first, nonpharmacological treatment for POTS is regular, structured, progressive exercise, enhanced by increased salt and fluid intake (Bryarly et

al., 2019; Fu & Levine, 2018). A number of lifestyle changes are also effective in the management of POTS symptoms, such as decreasing alcohol intake, adjusting bed positioning, and structuring mealtimes (Bryarly et al., 2019; Strassheim et al., 2018; DiBaise et al., 2018). Occupational therapists have the knowledge and skills to adapt and structure daily occupations and develop effective health management programs to meet the comprehensive needs of clients with POTS. This case study aims to show how POTS impacts the daily function and quality of life of one individual and how occupational therapy intervention can improve outcomes for individuals with POTS.

Participant

The participant is a 27-year-old female with a diagnosis of POTS and no other diagnosed underlying conditions. At the time of this study, she has lived with this diagnosis for almost 10 years. The participant was 18-years-old when she first began experiencing symptoms that led to the diagnosis. She was diagnosed through the use of a tilt table test by a cardiologist shortly after experiencing her first couple of episodes. She experiences a mild form of the disorder and has symptoms such as tachycardia, dizziness, and blurry vision each time she stands or crouches down. She also experiences extreme fatigue and shortness of breath. The participant works as a mail carrier on a city route, which includes driving, entering and exiting the vehicle, lifting, and walking all day in all types of weather. In addition to her work and regular self-care activities, she participates in a myriad of IADLs, including cooking and pet care, and she enjoys quiet leisure activities including art and reading.

Ethics approval to conduct the study was obtained from an institutional review board. The participant provided informed, written consent prior to participating in the interview.

Data Collection

A descriptive case study approach was used to gain understanding of the actual lived experience of the participant and to summarize outcomes that were achieved. The participant initially completed semi-structured interview questions in electronic mail format. The pre-formatted questions were emailed to the participant, and she was given one week to reflect on her experiences and record her responses thoroughly. Upon receiving and reviewing the participant's completed self-report, the researcher scheduled a follow up call at the participant's convenience. The researcher reviewed the semi-structured, open-ended interview questions and answers with the participant and asked additional guiding questions to complete the information collected through the self-report. The participant's responses were boldfaced typed into the original self-report document and emailed to her to verify the accuracy of the facts recorded. After receiving the verified information from the participant, the researcher then reviewed the completed interview to identify themes. Responses provided by the participant were manually coded using inductive, descriptive coding and key concepts and statements were identified. Recurrent accounts and perceptions were inductively categorized into themes and subthemes and validated through critical discussions and member-checking with the participant.

Results

Using content analysis, one overarching theme developed, the participant had not fully examined the impact that POTS has on her daily life. As a result of this revelation, the participant (a) identified occupations that are inhibited and (b) discovered new strategies for managing her disorder.

Overarching Theme

During data collection a pattern began to emerge, the participant found that she adjusts the position and speed to which she performs nearly all of her daily activities to avoid exacerbating her symptoms (Table 1). During the phone interview, when asked how she performs each of her daily tasks, the participant explained her performance and then stated repeatedly, “I did not realize that I did that.” She reported that there are activities that she chooses not to or cannot participate in because of her symptoms including many outdoor activities, like bike riding, playing with her pets, and landscaping. The participant also identified gastrointestinal issues, hot/cold disturbances, and sleep disturbances that impact her daily function, and she was not aware these could be associated with her POTS diagnosis. These discoveries indicate that the diagnosis has made an incredible impact on her life especially on the leisure and social activities that she engages in.

Revelation A

The participant discovered through the interview process that she alters her daily tasks, her schedule, and her chosen leisure activities to manage her POTS symptoms (See Table 1). Daily self-care tasks require extra time so that she can slowly and carefully perform each positioning change. Work tasks and most IADLs require slow movements, rest breaks, and caution with changes in position. She also realized that she no longer participates in many desired outdoor activities secondary to heat and activity tolerance precautions.

Table 1

Daily Tasks	Modifications
Getting out of bed	"I take it slowly."
Dressing	"I have to take it slowly reaching down to put on my pants and shoes."
Grooming	None
Toileting	"I have to be careful getting up, and I will get lightheaded sometimes with a bowel movement."
Shower	"I don't close my eyes and tilt my head back to wash my hair anymore." "I bring my legs up so that I don't have to bend over to wash them and I don't look down."
Cooking	"I will get symptoms if I bend over to get things out of a low cabinet or to get something out of the oven."
Cleaning	"All up and down motions cause symptoms, vacuuming is the only thing that doesn't bother me, even reaching up/standing on tip toes will aggravate my symptoms."
Driving	"Getting out of the car, I have to take it slowly."
Work	"I have to be careful getting out of vehicle, bending down to pick up mail, and bending over my buggy." "The weight of what I am lifting doesn't seem to bother me."
Community Mobility	"I do have to be careful in the grocery store, lifting things from low shelves or reaching up high."
Pet Care	"I bathe my dogs in the sink so that I don't have to bend over the tub."
Leisure	"I like to read and draw so nothing bothers me doing that." "I would like to be able to ride a bike, but the doctor told me not to."

Revelation B

The phone interview merged into health management education as the participant began to learn more about her diagnosis and how it is impacting her occupational performance. She asked questions related to the physiological symptoms of POTS to gain a greater understanding of the diagnosis. She also questioned the OT researcher regarding her current performance of various tasks leading to a discussion of strategies to manage POTS symptoms during daily activities (Table 2).

Table 2

Daily Tasks	OT Strategies
Getting out of bed	Rolling to side before sitting to get out of bed, while keeping head in midline, rather than sitting straight up
Dressing	Sitting, bringing foot to lap, to don pants/shoes to decrease bending forward
Toileting	No straining for bowel movements
Shower	Lifting legs to wash when standing in the shower to decrease bending over
Cooking	Moving frequently used items to counter level. Using a stool and sitting frequently between cooking tasks.
Cleaning	Utilizing a golfer's lift, while keeping the head level, rather than squatting to pick up things from the floor

The causes of POTS symptoms in relation to positioning was the main focus of the discussion. She was aware that bending over and tilting her head back exacerbated her symptoms, but she was unaware that the position of her head exacerbates the dizziness symptoms and the position of her legs exacerbates the tachycardia. She was also instructed on positioning techniques such as counter maneuvers to neutralize symptoms when they do occur and that elevation of the head of the bed for sleeping is more effective than sleeping on multiple pillows (Fu & Levine, 2018).

In regard to daily nutrition, she received instruction from her physician to increase her salt intake and drink water, but she was unaware of the extent to which she must do this in order to make an impact. Therefore, the participant and OT researcher discussed nutrition management and how to incorporate salt (5 to 10mg) and water (3L) into her meals throughout the day and not overwhelm her system with an exorbitant amount of salt and water in one period of the day (Bryarly et al., 2019).

The interview also increased the participant's awareness of activity choices that impact her condition. She was unaware that work tasks, though strenuous, did not qualify as the type of exercise that she required, which lead to education on appropriate exercise activities that would improve cardiac function yet not exacerbate her symptoms (Fu & Levine, 2018). The participant was aware that extreme fatigue was a symptom of POTS; however, she did not realize that it is not necessarily a result of lack of sleep or rest and that an excessive amount of rest could cause cardiac deconditioning and contribute to more problems (Strassheim et al., 2018). Strategies were developed to avoid extreme levels of fatigue such as managing energy and activity appropriately to fit the participant's daily schedule. Lastly, she was educated on physical activities that will not exacerbate symptoms but serve to preserve muscle strength and increase energy levels (Strassheim et al., 2018).

Discussion

This case study was designed to identify and describe how an individual with POTS is impacted by the symptoms of the disorder in daily life. It subsequently aided the participant in identifying impaired occupations and developing new strategies to manage symptoms. In this case, the individual was not aware of the impact of POTS on her life. Throughout the interview, the participant asked questions such as, "Is this related to my POTS?" and made statements such as, "I didn't know that." Therefore, the OT researcher was able to provide health management education and functional strategies to improve the participant's quality of life.

There were significant limitations to this case study. It focuses on the lived of experience of only one individual which may impart bias, thus limiting transferability. Research conducted

by a single investigator limits the ability to triangulate the data or validate themes through interrater reliability and peer-consensus.

Conclusions

This case study describes the impact of POTS on the daily functioning and quality of life of one individual living with the disorder. It also provides evidence for the unique role that occupational therapists can play in providing care for individuals with POTS through health management education. Because of the limited research regarding the role of OT in the care of this disorder, this study is instrumental in providing the perspective of one individual, the impact on daily tasks, and OTs role in providing care. The interview and discussion alone aided in the improvement of the quality of the individual's life just simply through reflection and education. Indicating that further study into functional interventions is necessary and that occupational therapy may be an essential discipline contributing to the treatment of individuals with POTS.

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Disclosure Statement

The author reports no conflict of interest.

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