A Perspective into POTS Management: A Manual for Occupational Therapists

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy

By

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Certification of Approval

I certify that I have read *A Perspective into POTS Management: A Manual for Occupational Therapists* by Jason Cao, Madi Chaffee, Kevin Columna, and Russell Deguia, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

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Dedication

We dedicate our thesis project to all the occupational therapists that have dedicated their work for service of others and who motivate us to pursue our passions to be the catalyst of change for the people we met.

Acknowledgments

We would like to thank our thesis advisor Dr. Kaitlin O'Hara for her continued support, encouragement, and guidance throughout this study. We are also grateful for the organization, Standing Up To POTS, for allowing us to use their platform to reach a population that has been constantly misunderstood and overlooked. We commend the POTS community for their participation and honesty. With your insight into this invisible and indescribable condition, we were able to create a thesis and manual. We hope that with this manual you feel seen and heard and give a chance to allow more occupational therapists to be a part of your care team and in the forefront to help you with the management of POTS.

Abstract

Postural orthostatic tachycardia syndrome (POTS) is a chronic condition within the umbrella of dysautonomia. It is characterized by sustained sinus tachycardia during orthostasis or when standing up with the absence of orthostatic hypotension during changes in position. Current literature reveals that POTS is not well understood; however, symptom management is sought. The purpose and aim of this study were to compile a concise manual of best practice interventions in which occupational therapists can refer to when working with this population. A review of the literature was conducted to identify common themes in the treatment of POTS. Then a survey comprised of 12 questions and 1 narrative response was posted to Standing Up To POTS. The survey received 431 responses and only 417 people met the inclusion criteria. From the literature review and the survey eight modules were created to support the management of POTS. We hypothesize that individuals with POTS have difficulty engaging in meaningful occupations and health management due to the severity of their symptoms. The results from the survey and the literature review support our hypothesis that individuals have difficulty engaging in meaningful occupations and health management due to their symptoms. The modules provide evidence-based interventions and assessments within the scope of occupational therapy that support the management of the symptoms that most commonly impact occupations.

Keywords: postural orthostatic tachycardia syndrome, postural orthostatic tachycardia syndrome and occupational therapy, POTS, occupational therapy for postural orthostatic tachycardia syndrome, OT treatments for POTS

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Postural orthostatic tachycardia syndrome (POTS) is one of the most common presentations of syncope and presyncope secondary to autonomic dysfunction and is characterized by sustained sinus tachycardia during orthostasis or when standing up (Arnold et al., 2018). Syncope is defined as fainting or a temporary loss of consciousness whereas presyncope is the sensation of feeling faint with symptoms including lightheadedness, nausea, and confusion in the absence of fainting. Autonomic dysfunction, also known as dysautonomia, is a term used to describe conditions that are caused by improper regulation of the autonomic nervous system. Sinus tachycardia refers to a faster than normal heartbeat which results in an increase in cardiac output. Another distinguishing trait of POTS is excessive tachycardia with the absence of orthostatic hypotension is a distinguishing trait in POTS. Although the precise etiology of POTS is not well understood in the literature and even the true prevalence is also unknown, it is estimated to affect between 0.1 to 1% of the United States population (Arnold et al., 2018). POTS is also known to primarily affects females of child-bearing age. The common symptoms of POTS include lightheadedness, fatigue, dizziness, sweating, tremor, palpitation, exercise intolerance, and near syncope on upright posture (Karas et al., 2000). However, individuals with POTS can also experience attention deficits, headaches, anxiety, depression, sleep disturbances, gastrointestinal disturbances, and vision changes.

Patients with POTS have trouble engaging in occupations and normal activity levels because of the symptoms induced when in the upright posture which subsequently impair their quality of life. In accordance with the aims of the American Occupational Therapy Association and American Occupational Therapy Foundation, we hope to better

outline the occupational therapist's role in the treatment of the POTS population with current and evidence-based practices. There are currently no approved pharmacological treatments for POTS; therefore, occupational therapists can play a vital role in improving outcomes by identifying impaired occupations, educating their clients on new strategies and lifestyle changes, and implementing various evidence-based interventions that can help alleviate their symptoms. These can include dietary changes, incorporating an exercise routine, wearing compression stockings, maintaining a healthy sleep hygiene, psychophysiological training for management of pain/anxiety, and caregiver education. However, there is no single manual that occupational therapists can use to reference these treatment plans. In an effort to streamline occupational therapy services, a compilation of these interventions is needed to better serve the population and contribute to the American Occupational Therapy Association's 2025 Centennial Vision to maximize occupational engagement and quality of life.

Statement of Purpose

The purpose of this study is to compile a concise manual of best practice interventions in which occupational therapists can refer to when working with individuals with POTS. Utilizing a survey targeting the POTS population, we can focus on the most prevalent symptoms along with any additional concerns that people with POTS may have. We hypothesize that individuals with POTS have difficulty engaging in meaningful occupations and health management due to the severity of their symptoms. The question we aim to answer with this study is: what are the best practices occupational therapists can provide to promote health management and optimal engagement in meaningful occupations for individuals with POTS?

Literature Review

Impact on Occupations and Occupational Roles

The loss of identity is a shared theme amongst different studies as many people with POTS feel as though there are restrictions placed on their livelihood due to their condition. Studies have shown there is a disconnect between an individual's sense of personal identity prior to their diagnosis and how they feel today due to the limitations on their quality of life imposed by POTS (Waterman et al., 2021). Individuals with POTS have expressed an impact on their occupations of activities of daily living (ADLs), instrumental activities of daily living (IADLs), leisure, sleep, work, education, and social participation.

Waterman et al. (2021) found similarities in lived experiences of the POTS community due to the fluctuating and unpredictable nature of the condition. The frequent fainting spells and extreme fatigue associated with a variety of unknown triggers increased the isolation of these individuals and prevented them from doing the activities they wanted. Waterman et al. also found links to increased loneliness, emotional stress, and comorbidities including depression and anxiety due to POTS. Similarly, Raj et al. (2018) found that individuals with POTS are more at risk for mental distress as a result of anxiety symptoms overlapping with orthostatic symptoms. As a result, individuals with POTS may become more reluctant to participate in social settings in fear of experiencing an episode.

Pain may also be a significant contributor in causing individuals with POTS to decrease or disengage from valued occupations and their occupational roles. Chronic pain is prevalent among the POTS community with the most common types being headaches, migraines, abdominal pain, muscle cramping, joint pain, leg pain, and musculoskeletal pain (Junghans-Rutelonis et al., 2019). Individuals with POTS may also experience

hypersensitivity, making normal tactile stimuli much more painful than it should be, preventing individuals from performing meaningful occupations and maintaining an active lifestyle. The lack of physical activity can lead to deconditioning, which can further exacerbate the symptoms of POTS (Cleveland Clinic, 2022). In addition, Pederson and Brook (2017b) suggest that pain causes disrupted sleep, decreased sleep quality, and poor subjective sleep efficiency in individuals with POTS.

Pederson and Brook (2017a) also found that many individuals with POTS have difficulties with rest and sleep. A survey administered to 705 individuals revealed that 98.4% of POTS patients had poor sleep quality and worse mean overall sleep compared to a non-POTS group. Persons with POTS also have higher subjective daytime sleepiness, fatigue, and worse sleep and health related quality of life (Bagai et al., 2011). Poor sleep is associated with reduced physical performance, greater functional limitation, and increased risk for cardiovascular diseases. Inadequate sleep has also been linked to chronic diseases like diabetes, hypertension, depression, obesity, cancer, early mortality, and reduced quality of life and productivity (Centers for Disease Control and Prevention, 2015).

Fatigue is one of the most common and ubiquitous symptoms described by individuals with POTS (Kavi et al., 2016; Raj, 2006). Fatigue can involve difficulties with energy, motivation, concentration, memory, and attention (Cleveland Clinic, 2020). Conditions, medications, and lifestyle factors also contribute to the severity of fatigue (Healthline, 2020). Outcomes observed are decreases in the engagement of daily activities and in occupations including education, play, leisure, and social participation. Fatigue can also negatively affect the ability to perform work related tasks resulting in taking on fewer responsibilities, reducing work hours, and taking extra days off (Burkin,

n.d). Similarly, Strassheim et al. (2018) found that individuals with fatigue are often less able to work, and if they do work, they may feel that they are less productive.

Decreased work ability also plays a factor in their loss of self-identity. Studies have shown increased unemployment and wage losses due to the symptoms of POTS. Bourne, Chew, et al. (2021) explains a median of 2.5 workdays per month are missed due to poor health and physical symptoms and 20.9% of employed POTS patients lost their jobs due to their decreased work ability. In addition, the work environment may also expose the population to factors that will exacerbate the symptoms like excessive heat exposure, stressful conditions, and intensive physical exertion (Barbic et al., 2020). Thus, working activity may become unsustainable for this population which increases the likelihood for these individuals to leave their job even when they do not want to.

Lack of Understanding

POTS is still not well understood in terms of pathophysiology which contributes to increased difficulty in seeking effective treatment. Due to the nature of symptoms, individuals are often misdiagnosed or dismissed which further impedes their access to health care. Shaw et al. (2019) reports that 75% of individuals in a sample of 3,421 were misdiagnosed and did not receive a proper diagnosis until 12 to 24 months after initial symptoms appeared. Waterman et al. (2021) further explains that this lack of awareness and the emotional impact of being dismissed heightens the distrust between the POTS community and healthcare system. The lack of physician awareness may also raise concerns on how to effectively be a caregiver since this condition is not widely known. Furthermore, the lack of awareness from the general population can impact all other areas of a person’s life.

This general lack of awareness can carry over to employment ordeals. Denials in government assistance was a common experience in the targeted population. Although wage and job loss were directly influenced by the physical symptoms, only a success rate of 64% were seen in applicants. This suggests there may be barriers due to the lack of understanding of POTS from disability evaluators (Bourne, Chew, et al., 2021). Financial worries then plays a significant factor when dealing with this condition and add on further stress to the individual.

There is also a lack of understanding for the condition and the people who experience it. POTS is an invisible, indescribable, and immeasurable disorder which makes it difficult for others to grasp as a client can have an outward appearance that seems relatively healthy. This disconnect contributes to feelings of loneliness which in turn affect health outcomes and may lead to suicidal ideation (Pederson & Brook, 2017a). Individuals often feel like a burden when unforeseeable symptoms appear. Although the lack of knowledge applies to their personal lives, it can also affect them in other areas.

Condition Management

Although POTS has only recently begun to garner attention, a common theme that has emerged from literature is lifestyle modifications for symptom management as opposed to drug therapy. Fu et al. (2011) found that increasing physical activity can help manage symptoms and combat cardiovascular deconditioning as opposed to prescribed medication. Exercise training also showed greater results than propranolol (β-blocker) treatment at restoring upright hemodynamics, normalizing renal-adrenal responsiveness, and improving quality of life.

Both Fu et al. (2011) and Shibata et al. (2012) found that a three-month exercising training program increased stroke volume in people with POTS which lowered their heart

rate at any level of oxygen uptake. Thus, a normal cardiac output response to exercise with a normal relationship to blood volume and peak oxygen uptake can be achievable to those with POTS. Functional recovery and the restoration of blood flow may be attained with consistent exercise (Fu et al., 2011; Shibata et al., 2012).

Dietary changes can also be an alternative way to minimize symptoms in POTS. Garland et al. (2021) explains that a high dietary sodium diet can decrease heart rate changes that can occur from transitioning to an upright position. It was also determined that increasing salt intake (300 mEq) a day decreased heart rate, corrected plasma volume deficits, and reduced plasma norepinephrine. Zha et al. (2022) also demonstrated that implementing a gluten-free diet which is defined as a diet that is at least 95% free of any gluten products may be an effective strategy for reducing the symptom burden in individuals with POTS. Zha et al. found that pre and post COMPASS-31 scores, which are designed to evaluate autonomic symptom burden, had a mean reduction of 33.9%. This implies there were improvements of orthostatic intolerance, vasomotor symptoms, and gastrointestinal symptoms. Wearing compression garments is another strategy that could be used to manage POTS symptoms. Bourne, Sheldon, et al. (2021) found that abdominal and thigh compression or full lower-body compression garments that were non-inflatable can reduce orthostatic tachycardia as well as other orthostatic symptoms.

By understanding alternative methods to better manage POTS symptoms, occupational therapists can assist their clients in the development of new strategies and improve engagement in occupations without the adverse side effects from standard drug treatment.

Role of Occupational Therapy for Chronic Conditions and Self-Management

At its core, occupational therapy focuses on enabling people of all ages to live life to its fullest by promoting their overall well-being and participation in meaningful activities through prevention or rehabilitation of injuries, illnesses, or disabilities. Occupational therapists have the appropriate skill set and expertise to address a variety of chronic conditions to help individuals adapt, cope, and incorporate changes to their lifestyles to manage their condition (Dochod & Grapczynski, 2019). Occupational therapists should be considered an integral part of the treatment team because they have the ability to address an individual's sensory, cognitive, physiological, emotional, psychosocial, and cultural issues. Thus, occupational therapists can provide a comprehensive approach to treatment by managing symptoms of POTS and other related problems that limit participation in occupations. Occupations that are within the *Occupational Therapy Practice Framework: Domain and Process- Fourth Edition* (OTPF-4) include social participation, leisure, health management, sleep and rest, and work (American Occupational Therapy Association, 2020).

Approaches that occupational therapists can use to enhance functional abilities for this client population include the utilization of compression garments, dietary modifications, lifestyle modifications, improving sleep hygiene, and lastly fatigue, stress, and pain management. Self-management, which the American Occupational Therapy Association (2015) defines as, “being in charge of one’s life and managing one’s condition”, is also an effective approach to managing chronic health conditions. Through this approach, occupational therapists can educate and empower their clients to take responsibility for managing their condition and overall health. Understanding the role of occupational therapy and the ideology behind the Occupational Adaptation model can improve a client’s quality of life and health outcomes.

Assessments

Assessments can be utilized by occupational therapists to gain a better understanding of their clients for the development of their occupational profile which includes the Occupational Questionnaire and Activity Record. These assessments summarize an individual's participation in occupations throughout the day and their general experiences, patterns of daily living, interests, values, needs, and relevant contexts. Symptom-related assessments include the Fatigue Assessment Scale which evaluates symptoms of chronic fatigue, the Pittsburgh Sleep Quality Index which assesses sleep patterns, the Dizziness Inventory which quantifies the impact of dizziness on daily life, pain scales, and executive function assessments. The Canadian Occupational Performance Measure is another assessment tool that measures an individual's perceived occupational performance and satisfaction over time. The Brief Pain Inventory is an assessment that highlights the highest and lowest times of pain over 24 hours, and its impact on occupations. The Pain Self-Efficacy Questionnaire is used to rate how confident people feel in performing different activities, despite their pain. Lastly, the 36-Item Short-Form Survey is an assessment that measures physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, general mental health, social functioning, energy/fatigue, and general health perceptions.

Remaining Gaps in Evidence

Gender and age differences in response to treatments are important considerations that warrant further research. Future studies could address whether a longer duration of training or the level of physical activity can help achieve and maintain normal cardiac function or functional capacity. Furthermore, evaluating the time spent when using

compression garments in different settings can help us better understand the practicality of using the garments during daily activities. The long-term effects of implementing a high sodium diet for its efficacy and safety should also be further analyzed. Future studies can also focus on education for healthcare professionals to minimize the disparity between the POTS community and healthcare as well as implement support systems and networks to evaluate mental health stemming from isolation and loneliness. Filling the knowledge gap on effective treatments, the psychosocial effects and tolerance of symptom reduction strategies can help occupational therapists implement unique interventions that promote clients' occupational wellness.

Clinical Significance of the Evidence

Studies by Waterman et al. (2021) and Mike (2021) highlighted the importance of occupational therapists in providing health management education and functional strategies to their clients with POTS. Both studies found many impaired occupations due to symptoms, however, it is also crucial to understand that some individuals may not be fully aware of the impact of POTS on their life. Employment is also a major area in life that is significantly affected by POTS (Bourne, Chew, et al. 2021). The loss of occupational roles elicits negative emotions and the lack of understanding of the condition contribute to increased misdiagnoses which lead to poor outcomes (Pederson & Brook, 2017a; Waterman, 2021). Therefore, it is vital to develop and disseminate more research findings on POTS to remove barriers. Occupational therapists can cooperate with individuals with POTS to reflect and educate them on new strategies that can manage their symptoms and return to participation in occupations.

Furthermore, with the results found by Fu et al. (2011) and Shibata et al. (2012), occupational therapists can help their clients establish an appropriate exercise routine to

prevent cardiovascular deconditioning and better manage their symptoms. Helping clients with POTS develop a lifetime adherence to an active lifestyle or greater participation in meaningful activities can help maintain normal functional capacity and improve occupational well-being.

In addition, the results found by Bourne, Chew, et al. (2021), Fu et al. (2011), and Garland et al. (2021) can help occupational therapists develop an intervention that better align with personal needs and values of their clients. For example, occupational therapists can provide insight on what combination of treatments works for them to better manage their symptoms. By using a holistic approach, occupational therapists and their clients can collaborate to develop strategies which utilize effective treatment options including exercise, high sodium dietary changes, and compression garments.

Lastly, occupational therapists should gain a better understanding of the impact of POTS on everyday activities as well as the psychosocial impact of the condition. Providing evidence-based intervention can help promote adherence to treatments and subsequently improve their client's quality of life and overall well-being.

Theoretical Framework

The Occupational Adaptation (OA) model is used as a theoretical base along with the reference to Lifestyle Redesign® to guide the development of this manual. The OA consists of three basic elements: the person, the occupational environment, and the interaction between these two elements. The person includes the sensorimotor, cognitive, and psychosocial systems while the occupational environment includes work, play and leisure, and self-maintenance.

As described in Cole and Tufano (2019), Schkade and Schultz first published their occupational adaptation model in 1992 which encourages healthy participation and

engagement in occupations through the person's natural ability to adapt. This holistic approach focuses on the interaction between a person, their environment, and the person's ability to adapt when engaging in activities. Through this model, occupational therapy can promote the use of occupations to improve functionality and performance to master environmental and internal demands. Occupational roles naturally have expectations, examples being values or social standards, that need to be met for successful participation. Thus, the individual's capacity to adapt and master their environment is important. The combination between the demands of the environment and the person's desire for mastery creates occupational press, or the required behaviors needed to meet expectations for an individual. The most common interventions include adapting the environmental demands to help a person gain relative mastery, promoting a client's ability to self-regulate and self-evaluate, and fostering a client's strengths. As an occupational therapist using this theoretical framework, it is crucial that the therapist has a high level of understanding of the condition and the occupations in order to therapeutically grade the tasks and assist in adaptations that are appropriate to the client. Implementing this framework to the POTS population can help clients identify their own internal and external barriers and develop adaptations to facilitate successful participation and performance in occupations

POTS can create barriers in an individual's livelihood. This in turn can affect the person's sensorimotor, cognitive, and psychosocial capabilities. The occupational challenges presented in the environment due to POTS are ADLs, IADLs, health management, rest and sleep, education, work, play, and social participation (Rich et al., 2022). OA can be implemented to overcome barriers to actively engage in meaningful

activities. This framework aims to facilitate clients' ability to make the needed modifications to reintegrate in their previous lifestyle successfully.

The OA theoretical framework highlights the person, the environment, and the interaction between the two in POTS whereas the Lifestyle Redesign ® aspect utilizes lifestyle-based interventions to create health-promoting habits and routines to better manage their lives.

Methodology

A literature review was conducted and was completed using the databases CINAHL Complete, Academic Search Complete, MEDLINE Complete, PsycINFO and Education Resource Information Center. Keywords used included “postural orthostatic tachycardia syndrome,” “postural orthostatic tachycardia syndrome and occupational therapy,” “POTS,” “occupational therapy for postural orthostatic tachycardia syndrome,” “treatments for POTS,” “quantitative articles and POTS,” “qualitative articles and POTS,” “chronic conditions management for POTS,” “chronic conditions management,” “Lifestyle Redesign®,” “lifestyle-based interventions for POTS,” and “Occupational Adaptation.” Upon completion of the literature review, a compilation of treatment methods and strategies along with occupational therapy interventions were developed to help the POTS population. After an evaluation of the evidence, it was organized into a manual for occupational therapists to reference in order to assist their clients to manage their POTS symptoms. Overall, the manual contains information on the impact of POTS, standard assessments, and handouts as well as resources that occupational therapists can utilize. This study was approved by the Institutional Review Board.

After referencing a questionnaire made by Scaffa et al. (2011), we created an online survey with 13 questions that is based on a mixed model study design and

identifies areas of concern, general knowledge, and information that individuals with POTS may have. The survey included closed-ended questions as well as one narrative response and was estimated to take 10-15 minutes to complete. The online survey using Google Forms was implemented for the manual with the purpose to highlight concerns and gain a better understanding of individuals with POTS. Participants that completed the online survey must be at least 18 years old, have basic English reading comprehension, and be formally diagnosed with POTS and excluded from other causes of sinus tachycardia. The survey did not require the individual's email to be collected and to ensure anonymity and improve the participant's experience, participants did not need to provide their name and were able to skip questions that they did not feel comfortable answering or withdraw from the study at any time. Consent to participate in the survey was placed at the beginning of the questionnaire which stated, "By checking this box, I agree to give consent to have my information used in the research study and have read the information above." Two screening questions have been placed within the survey and will ask if the participant has been formally diagnosed with POTS and what age range they fall into. The participants that did not answer "yes" to the question of being formally diagnosed with POTS were excluded from the study. A list of POTS resources was also provided in conjunction with the survey from websites Standing Up to POTS, Dysautonomia Project, and Dysautonomia International.

To recruit participants for the survey, we reached out to an organization, Standing Up To POTS, to request promotion of our survey uploaded on their Facebook and Instagram pages. A flyer was also created to introduce the researchers, provide information on the study, state the inclusion and exclusion criteria, contact information, and a QR code. Prior to administering the survey, we received permission from the

organization head to get confirmation that our survey and flyer do not violate the sites or platforms' terms of use agreement. We also asked participants that have completed the survey to share the link or the QR code of the survey to others that are formally diagnosed with POTS. There was no reimbursement or compensation for participants that completed the survey. The advantage of implementing the survey through an online format allows participants to easily access and complete the survey. We then analyzed the surveys and identified common themes between participants and linked strategies that occupational therapists could use for their client's intervention which have been addressed within our manual.

Data obtained was stored within the thesis team's password-protected google account. Since the survey was a mixed model study design, the quantitative data obtained was analyzed manually and aimed to use descriptive statistics to summarize the data gathered and understand which symptoms or issues are most prevalent and will likely hinder a person's wellbeing. The qualitative data obtained was analyzed using manual coding and aimed to find common themes between each participant's lived experience with POTS and its impact. We used the data collected from our study to focus our manual on the areas that could be addressed within the scope of occupational therapy based on the OTPF-4.

Ethical and Legal Considerations

There are several ethical and legal considerations that were involved with our research. Informed consent from each participant confirm they have been informed on all parts of the research and that they are willing to participate. Any sensitive participant information should remain confidential to protect the identity of the individual. Preserved ethical principles throughout the study include respect for persons, beneficence, and

justice. In order to maximize efficacy and positive results, evidence-based interventions should be selected through evaluations of their strength and relevancy. These evidence-based practices should also be curated or selected with the occupational therapy scope in mind and display an appropriate occupational therapy application to symptom management of POTS. The interventions selected have been thoroughly vetted to ensure there is no harm placed on the participants. Ethical considerations include how we gather data and apply our own contextual positioning as it may influence how we analyze and perceive the evidence collected. Content analysis, statistical techniques, and narratives can help minimize these biases.

Results

Participant Demographics

The survey collected 431 responses. Out of the 431 participants, n = 417 met the inclusion criteria of being formally diagnosed with POTS, 18 years or older, and having basic comprehension of English. As Figure E1 shows, a greater proportion of individuals were found to fall within two age groups, ‘20 to 25’ and ‘35 and older’. This equated to a total of 60.2% of total participants. Results also supported current literature in that POTS predominately affects females. Of the 417 individuals, 97.8% or n = 408 were women as seen in Figure E2. It is also evident that the most common types of residence are a multi-level home (45.1%), followed by a single level home (24.9%), and then an apartment complex (22.5 %).

Quantitative Item Results

The survey administered 12 questions to identify common areas of concerns, prevalence of symptoms and comorbidities, current care team, and interests in learning

new strategies. The responses to the questions were then quantified to scale the exact percentages of each occurrence for a participant.

As seen in Figure E4, common comorbidities that individuals with POTS experience are chronic fatigue, chronic headache, insomnia, mental health issues, and gastrointestinal disorders. Within these co-existing conditions, most participants experience chronic fatigue alongside POTS (n = 272; 65.2%). Similarly, the most prevalent symptom experienced in this population is fatigue (n = 409; 98.1%, see Figure E7 in Appendix E) followed by pain, difficulty with memory, headache, and dizziness or balance problems. Individuals with POTS can also experience difficulties in activities due to prevalent symptoms. As Figure E8 shows, most participants report experiencing difficulties with exercise (n = 384; 92.1%) followed by problems in social participation (n=302; 72.4%), bathing/showering (n=298; 71.5%), care of home (n=287; 68.8%), sleeping (n=285; 68.3%), and symptom/condition management (n=301; 72.2%).

A trend observed is how individuals with POTS receive their care. It was found that the most common health providers sought were primary care doctors (n=357; 85.6%), cardiologists (n=306; 73.4%), neurologists (n=190; 45.7%), physical therapists (n=122; 29.3%), and other specialized health professions (n=148; 35.5%). Occupational therapy (n=28; 6.7%) was not a popular mode for health care as seen in Figure E5 in Appendix E. Further data analysis revealed that many individuals living with the chronic disease reported they have had it for 1-5 years (n=124; 29.8%). As seen in Figure E9, many participants also reported that they need assistance from friends and family for 1-2 activities per day (n=177; 42.7%).

Question 11 and 12 of the survey were added to provide input for any areas of concerns a participant may have. As Figure E10 shows, many participants identified that

they feel “pretty knowledgeable” about self-managing POTS (n=161; 38.6%). Individuals, however, were open to learn more strategies to aid with mental clarity (n=311; 74.6%), “energy conservation/fatigue management” (n=346; 83%), and “communicating with healthcare professionals and caregivers” (n=254; 60.1%).

Qualitative Item Results

Along with the 12 administered questions pertaining to quantitative information, the final part of the survey was a free response question that asked, “How has POTS impacted your life?” Out of the 431 survey responses we received, 51 people decided not to provide a free response, and 14 people did not meet the inclusion criteria for our study. The resulting total number of responses that we included for our qualitative data was 366 responses. The responses were collected, analyzed, and manually coded according to common themes that we identified. Among these responses we developed four parent codes which include, “Impact on Occupations and Roles”, “Successful Engagement”, “Comorbidities”, and “A Call for Compassion”.

“Impact on Occupations and Roles” is comprised of child codes that indicate how POTS has negatively impacted an individual’s occupations, occupational roles, and routines. The frequency of each child code out of 366 total responses is as follows; “Impact on Occupations and Occupational Roles (171:366), “Loss of Occupations” (93:366), “Impact on Social Participation” (70:366), “Everything” (70:366), “Financial Stress” (3:366), “Medication Management” (23:366), and “Symptoms” (90:366).

“Successful Engagement” contains codes that display the strategies and solutions used for self-management and promotion of engagement in meaningful occupations. The

frequency of each child code out of 366 total responses is as follows: “Positive Self-Management” (28:366), “Using Assistive Devices to Engage in Occupations” (16:366), “Learning how to Manage, Plan, Regulate, and Cope” (34:366), and “Needing Social Support” (32:366).

“Comorbidities” exhibits responses that explain the conditions individuals have experienced along with POTS. The frequency of each child code out of 366 total responses is as follows: “Comorbidities” (18:366), “Adverse Side Effects” (25:366), and “Mental Health” (60:366).

“A Call for Compassion” describes experiences where individuals with POTS have felt a lack of understanding about their condition when communicating with people in their community, healthcare professionals, and even with themselves. The frequency of each child code out of 366 total responses is as follows: “Lack of Knowledge of Themselves” (15:366), “Communicating with Healthcare” (26:366), and “Lack of Awareness from Community” (29:366).

Discussion

In congruence with the ideas of the American Occupational Therapy Association and American Occupational Therapy Foundation, this research study aimed to identify the occupational therapist's role in aiding in a client’s self-management of POTS. This study gave insight into which occupations were most impacted as well as the most prevalent symptoms. The data from the survey and literature review guided the recommendations for interventions. Results from this study allows us to get client-driven data to target the areas of need. This study highlighted the demographic most impacted, comorbidities, healthcare team, most prevalent symptoms, most impacted occupations, knowledge of POTS, which interventions they would be interested in learning more

about, and a narrative about how POTS has impacted their life. Data from people formally diagnosed with POTS is critical for understanding the impact of the condition and areas that occupational therapy can address. We believed that this was crucial to our thesis because we were able to identify client factors that impacted occupational participation and performance that were not previously outlined in the literature review. It was also necessary that we had an authentic perspective as to what interventions would be feasible for someone with POTS to implement rather than strictly looking at the physiological benefits. In doing so we were able to derive interventions that were not only evidence-based but client-driven as well.

Based on the survey results from 431 participants we were able to identify the most impacted occupations, symptoms, and qualitative experience with POTS which we used to create our modules. Figure E8 shows that the most impacted occupation was exercise, basic ADLs, social participation, and sleep. Figure E4 identified significant co-morbidities, including chronic fatigue, chronic headache, insomnia, mental health issues, and gastrointestinal disorders. Figure E5 showed that only twenty-eight of the participants have occupational therapy on their care team. In seeing this, the occupations and co-morbidities impacted we felt that occupational therapists would be the best candidate to serve this population as each area of concern falls within our scope.

After reviewing the literature and evaluating the data from the survey, we were able to create a manual with eight modules that supported our findings. Within each module, we defined an occupational therapy approach as well as its relevance for the POTS population. We also specified the role of occupational therapy along with suggested interventions, handouts for clients, and appropriate assessments that could be used when evaluating clients.

The first module titled “Lifestyle Modifications” serves as a resource to improve an individual’s daily routine, improve occupational performance, and reduce the symptoms syncope, presyncope, and dizziness. Evidence supports that maintaining a healthy routine of exercise and nutrition may aid in the prevention of orthostatic intolerance which can improve engagement in exercise, ADLs, and social participation. Results from the survey further support the need of these interventions as these three activities were heavily impacted. Occupational therapists can work with these individuals in health management to develop, manage, and maintain new routines.

The second module “Personal Care Device Management” aids in mitigating syncope, presyncope, and dizziness through compression garments. The literature supports that lower-body and lower-body-abdominal compression garments facilitate normal orthostatic reactions and reduce orthostatic tachycardia from changes in position. The reduction of these symptoms can improve engagement in exercise, social participation, and IADLs. Similar to the lifestyle modifications, an occupational therapist’s role in this intervention is helping to implement personal care devices into the individual’s routine. The occupational therapist can also assess the client’s environment in order to make appropriate recommendations to improve adherence.

The third module relates to “Fatigue Management” as chronic fatigue was the most prevalent co-morbidities found in our survey. Fatigue can negatively impact participation in several occupations including ADLs, IADLs, social participation, work, and school. Suggested interventions are energy conservation management and activity tolerance. An occupational therapist’s role is multifaceted. The occupational therapist can work by implementing compensatory techniques. They can complete an activity analysis in order to determine specific periods, triggers, or activities that exacerbate symptoms of

fatigue. They can also work to educate clients and caregivers on strategies to incorporate into their routines to promote energy conservation.

The fourth module is “Stress Management.” This module was determined to be needed because Figure E14 showed that 241 participants would like information regarding stress and relaxation strategies. The literature also highlighted anxiety and stress due to the unpredictability and difficulty of managing a chronic condition. Poor stress management can result in impairments in social participation and level of functioning. The intervention in the manual is mindful meditation which has been shown to reduce stress and improve quality of life. The occupational therapist’s role in stress management is providing adaptations and modifications as well as instructing the stress relief interventions.

The fifth module is “Pain Management” which addresses the prevalence of chronic migraines which was highlighted in Figure E4. The literature also showed that persons with POTS experience both neuropathic pain and chronic pain. These symptoms and conditions can impact ADLs, IADLs, work, exercise, sleep, and other occupations. In fact, sleep quality is disturbed due to the increased pain that occurs during rest resulting in sleep deprivation. Interventions provided in this manual are self-management education and training which include establishing non-pharmacological and pharmacological approaches into the daily routine.

The sixth module is “Sleep Hygiene” because persons with POTS have higher subjective daytime sleepiness, fatigue, and worse sleep and health related quality of life. Sleep is an occupation that when negatively affected can cause problems to other occupations. Poor sleep also exacerbates symptoms due to the activation of the sympathetic nervous system. In order to promote sleep and good sleep hygiene, three

interventions are provided. The first being cognitive behavioral therapy, in which the occupational therapist can recommend strategies including cognitive restructuring, sleep hygiene education, relaxation training, stimulus control therapy, and sleep restriction therapy. The second intervention is environmental modifications, where the occupational therapist will make recommendations to the home environment that have been shown to promote sleep and help in establishing these habits and routines. The third intervention is sleep aid/assistive devices, within this intervention the occupational therapist can work with the client to determine if weighted blankets, noise machines or other sleep aids would be beneficial.

Figure E4 showed that 214 participants experience mental health issues which was used to develop our seventh module "Mental Health". The open response of the survey also identified mental health as an area to address. The loss of participation in activities has shown to significantly impact persons with POTS as there is a disconnect with their past selves. The unpredictable nature of the symptoms leads to isolation increasing the risk of depression and anxiety. As a result, persons with POTS engagement in all occupations is impacted. The suggested interventions within this module are self-efficacy, self-esteem, and role development. The occupational therapist's role in this intervention is to help the individual feel confident about managing their condition in a variety of different situations as well as providing support to diminish the burden of the psychosocial issues within this condition.

The eighth module "Communication with Healthcare System" was guided by the data shown in Figure E13 where 254 participants stated they would like more information about communication with healthcare. The qualitative portion of the survey also gave light on the need for understanding within the medical field. The suggested intervention

provided for this module is assertive communication. Assertive communication will teach an individual with POTS how to effectively express their point view to their care team in a clear and direct manner to ensure proper treatment. An occupational therapist's role in treatment would be health management specifically communication with the healthcare team as well as aiding in health literacy. The therapists can also work with other healthcare professionals to educate them on the condition as well as provide skilled listening and motivational interviewing strategies.

Each module and intervention were selected to address a specific area of need that was outlined by the survey and the literature review. We tried to be mindful of the comments from the qualitative response in order to make suggestions that were not only helpful in the management of POTS but were feasible and practical for individuals. There were areas of need that were shown in the survey and literature that were not put into this manual as they were not within the scope of practice of occupational therapy. Each module was designed to fall within an occupation outlined within the OTPF-4. The modules can be used together to target multiple areas that are impacted by POTS. We are using a top-down, holistic approach to the management of POTS with interventions and assessment recommendations to do so.

Limitations

Due to the nature of the study, several limitations were identified. The first being that data collection on the basis of an online survey may affect verifiability and increase sampling bias. Consequently, the mode of online delivery in which the active participation of study participants is required to distribute the survey to one another may create limitations by not reaching the targeted population. A small sample size is expected in our study as POTS only affects 0.1 to 1% of the general population (Arnold

et al., 2018). Thus, the data collected may not accurately depict the symptoms of the general POTS population to create a manual for occupational therapists. Currently, there is no extensive research done on POTS, so there may be significant findings found in the survey that have not yet been addressed in current literature. For instance, symptoms highlighted in our survey were show to impact participation in occupations but could not be addressed due to the lack of information in literature or simply because they were outside our scope of practice. The inconsistencies between what is currently known and the challenges individuals with POTS encounter will need to be further investigated.

Implications

The literature review revealed there were many occupations, roles, and routines that were impacted by POTS and demonstrated how symptoms decreased an individual's overall well-being. The results of this research study allowed us to gain a better understanding of the role of occupational therapy in the treatment and management of POTS for the adult population. The study also emphasized the need for occupational therapists to address specific client factors and performance patterns in order to increase engagement in occupations, maintain valued roles, and improve quality of life. In addition, we were able to determine which intervention strategies have the highest efficacy for addressing common symptoms or concerns for individuals with POTS including lifestyle modifications for diet and exercise, personal device management, fatigue, stress, pain, sleep, mental health, and communication with the healthcare system.

After reviewing the data, we found that most individuals with POTS also experience chronic fatigue, gastrointestinal disorders, mental health problems, and chronic headaches. In addition, individuals with POTS may also experience dizziness, difficulties with memory, pain, and difficulties with sleep. Occupational therapists are

uniquely skilled at understanding and addressing these problems. By using the OA model which considers the person, the occupational environment, and the interaction between these two elements, an occupational therapist can effectively implement a holistic and client-centered approach for the client with POTS' treatment. Focusing on the client's ability to adapt and master environmental and internal demands is crucial for promoting engagement in occupations and improving functionality. However, results also found that individuals with POTS expressed having difficulties with many healthcare professionals being unaware or having limited understanding of POTS. Research into the condition and management of POTS would significantly improve rapport between the providers and clients which would lead to better outcomes. It would be beneficial for occupational therapists to have greater access to resources that focus on the management of POTS for their intervention. Therefore, the data and manual from this study can help occupational therapists in different settings who are treating a variety of clients learn and identify effective interventions and further emphasizes the importance of the role of occupational therapy in addressing POTS related issues.

Conclusion

Postural orthostatic tachycardia syndrome is a disorder within the umbrella of dysautonomia. It is most prevalent in females of child-bearing age with various symptoms displayed in each individual. There are, however, common symptoms associated with the condition including lightheadedness, fatigue, dizziness, sweating, tremor, palpitation, exercise, and near syncope in an upright position (Karas et al., 2000). Current literature has shown these symptoms severely impact a client's participation and performance in their daily activities and overall well-being. The goal of this study was to create a manual with evidence-based interventions that occupational therapists can

reference in treatment. A literature review was conducted to find best practice interventions that will support participation in ADLs, IADLs, social participation, leisure, health management, sleep and rest, and work while managing symptoms that the participants identified.

Four themes were identified from the current literature: impact on occupations and occupational roles, lack of understanding, condition management as well as the role of occupational therapy with chronic conditions. These themes help support and provide evidence for the interventions named in this manual. It should be noted that there is limited research in the field regarding POTS as well as symptom management, more research should be done to gain a better understanding. We hope that this manual provides clinicians a guide to treatment of POTS that is within the scope of occupational therapy and is also evidence-based. This manual will help address concerns and provide interventions to clients with POTS and contribute to the American Occupational Therapy Association's 2025 Centennial Vision to increase participation in meaningful occupations and improve their quality of life.

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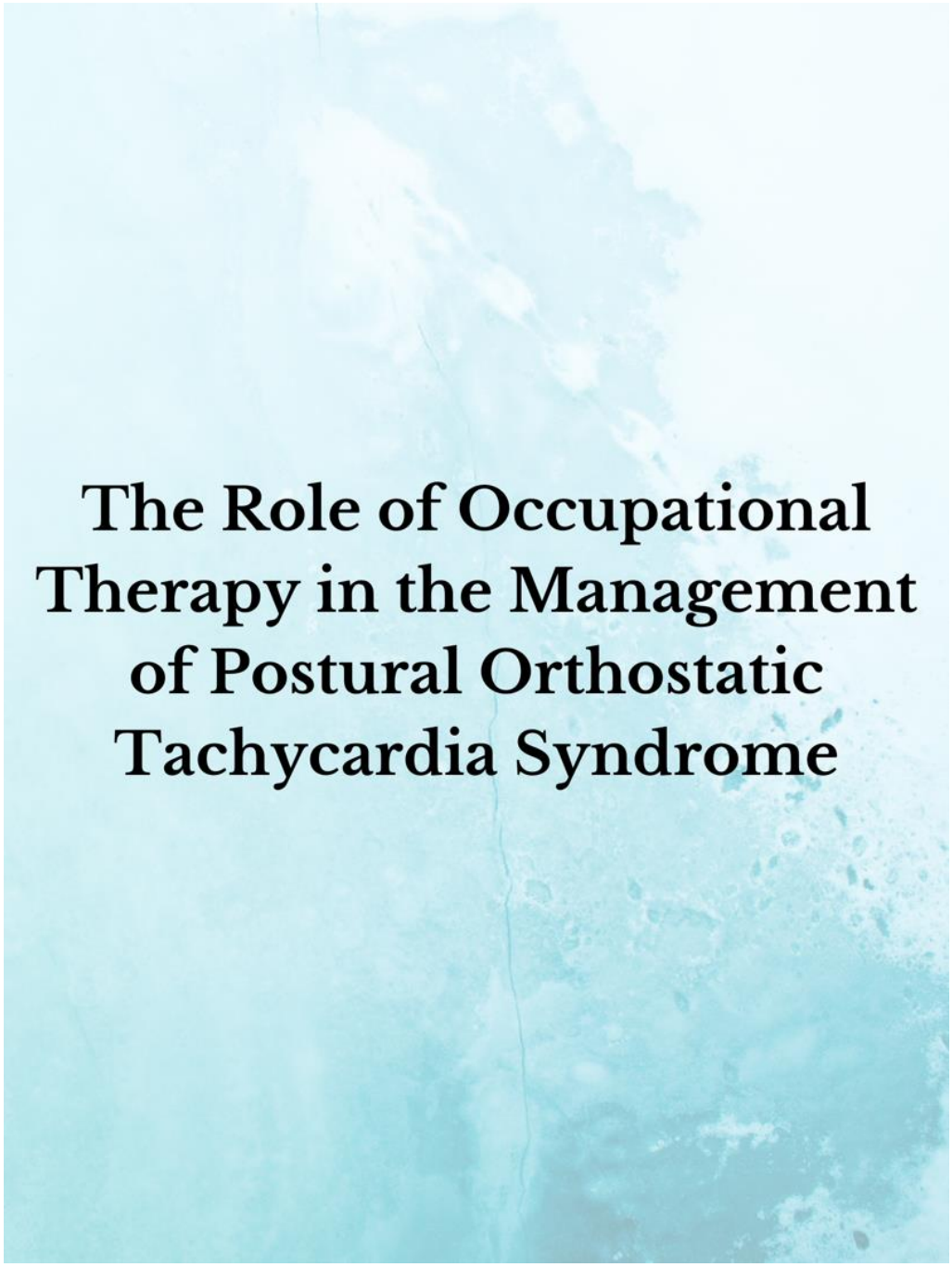
Appendix A

The Role of Occupational Therapy in the Management of POTS



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Lifestyle Modifications: Diet & Exercise

What are Lifestyle Modifications?

Lifestyle modifications are defined as altering long-term habits in different areas such as physical activity or diet (Nature Portfolio, n.d.). The goal of making lifestyle modifications is to do smaller aspects of one's life differently in order to positively impact another aspect, typically quality of life or health. It is often common for lifestyle modifications to be used as an alternative to pharmaceutical interventions.

Lifestyle Modifications in the POTS Population

According to the literature, lifestyle modifications can have a significant impact on symptom reduction for persons with postural orthostatic tachycardia syndrome (POTS; Fu et al., 2011; Shibata et al., 2012). One of the most prevalent and dangerous symptoms that a person with POTS deals with is syncope or pre-syncope. Modifications to one's lifestyle, specifically diet and exercise, have been shown to reduce the incidence of syncope as well as mitigate pre-syncope experiences. The research states that physical activity can help manage symptoms and combat cardiovascular deconditioning. In addition, improvements seen with exercise training showed restoration in upright hemodynamics, normalization in renal-adrenal responsiveness, and improvement in quality of life when compared to typically prescribed medications. Studies suggest that consistent exercise can establish a normal cardiac output response. (Fu et al., 2011; Shibata et al., 2012). The goal of the interventions done by Fu et al. (2011) and Shibata et al. (2012) was to reduce the impact that changes in orthostatic position have on the body by strengthening the cardiovascular system.

Another lifestyle modification is changing the individual's diet. Dietary modifications have been shown to be effective in symptom reduction. Research shows a

high sodium diet can decrease heart rate changes that can occur from transitioning to an upright position. This is due to increasing the volume of the blood (Garland et al., 2021). Increasing the volume of the blood allows the body to continue normal cardiovascular input and outputs and reduces the risk of decreased blood flow to the brain.

Relevance of Occupational Therapy

Occupational therapists are skilled and trained in helping individuals of any age or condition establish routines, provide time management strategies, adapt environments for success, and promote community accessibility. An occupational therapist can work with a client with POTS to implement recommendations from a registered dietitian, physical therapist, and physician in such a way that will improve adherence and feasibility for the client. Lifestyle modification interventions fall under the health management section of the fourth edition of the *Occupational Therapy Practice Framework: Domain and Process* (OTPF-4) which defines the scope of practice for occupational therapists. Health management is defined as, “activities related to developing, managing and maintaining health and wellness routines, including self-management with the goal of improving or maintaining health to support participation in other occupations.” (American Occupational Therapy Association, 2020) Within the occupation of health management, the sub-categories of physical activity and nutritional management are outlined. The subcomponent of physical activity highlights the occupational therapist's role in helping a client implement an active lifestyle as part of their daily routine as well as providing adaptive equipment to aid in the participation of physical activity. Occupational therapists could also help with grading the exercises based on the client's current level of function. For nutritional management, occupational therapists can work with a client in preparing meals in order to achieve dietary goals. Occupational therapists can also help the client in

the grocery store and help the client identify foods that fit their dietary plan. An occupational therapist will work with the client to help implement these lifestyle modifications into their everyday routines.

Suggested Interventions

Diet

Specific diet recommendations have been shown to reduce POTS symptoms specifically syncope and pre-syncope. Research shows a high sodium diet (salt intake of (300 mEq)) a day can decrease heart rate changes that can occur from transitioning to an upright position (Garland et al., 2021). Which can contribute to the faint or feeling faint.

OT Role & Relevance to POTS

POTS is a difficult chronic condition to manage that can impact participation in activities and social outings due to the fear of experiencing a flare up of symptoms. The symptoms become more manageable by implementing lifestyle modifications like a high sodium diet the symptoms become more manageable. An occupational therapist can work with the client to establish routines and help in meal preparation as well as meal planning for eating out with friends. By working with an OT, the client is more likely to maintain adherence to their recommendations.

Assessments

- Compass-31 questionnaire is a self-rating questionnaire evaluating six domains of autonomic function: orthostatic intolerance, vasomotor, secretomotor, gastrointestinal, bladder, and pupillomotor domains
    - Cost: Free
    - Administration: online self-assessment questionnaire that can be completed by the client
    - Assessing six domains of autonomic function: orthostatic intolerance, vasomotor, secretomotor, gastrointestinal, bladder, and pupillomotor.

https://www.mvpctr.com/compass-31-online-questionnaire/

- Katz Index of Independence in ADLs assesses functional status as a measurement of the client's ability to perform ADLs independently
    - Cost: Free
    - Administration: 6-question interview, paper and pencil
    - Assessing independence level of 6 ADLs (bathing, dressing, toileting, transferring, continence and feeding)

https://www.alz.org/careplanning/downloads/katz-adl.pdf

HIGH SODIUM DIET

WHY SALT?

Research has shown that a high sodium diet reduces symptoms associated with POTS. In theory, a high sodium diet in junction with a high water intake will increase blood volume. In a study assessing the recommended high sodium diet patients had increased plasma volume, lower standing plasma norepinephrine, and decreased change in heart rate. (Garland et. al, 2011)

THINGS TO KNOW

Sodium vs. Salt: experts recommend 8-10g of salt per day, 1g of salt is approximately equivalent to 387.6mg of sodium. Take the recommended salt amount from your doctor and multiply it by 387.6 to calculate your recommended sodium intake.

Most table salt is iodized, try to couple this with non-iodized salt such as sea salt to not end up with more iodine than you need.

Tips and Tricks

- Try different types of salt to keep it interesting ie. rosemary salt, chile lime
- Add soy sauce to foods
- Keep a can of tomato juice on you
- Keep the little salt packets from fast food restaurants, also be sure to ask for extra when you're out.
- Opt for larger grains of salt to increase sodium intake but not overpower food.
- Use pickle juice as a chaser when out
- High salt diets cause the body to excrete more calcium so make sure to keep an eye on your calcium and potassium intake to keep your bones strong

HIGH SODIUM FOODS

- PICKLED FOODS
- CANNED FISH
- JUICES: V-8, TOMATO, CLAMATO
- CHEESES: PARM, FETA, ROMANO
- SOUPS: BROTHS, CHOWDERS
- SAUCES: SOY, TAMARI, LIQUID AMINOS
- SNACKS: SALTED NUTS, BEEF JERKY

HTTPS://WWW.DYSAUTONOMIAINTERNATIONAL.ORG/PDF/SALT.PDF

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Suggested Interventions

Exercise

Regular and moderate cardiovascular exercise can improve orthostatic tolerance, normal cardiovascular output, and combat cardiovascular deconditioning.

OT Role & Relevance to POTS

Occupational therapist can work with their clients to establish routines to incorporate exercise into their daily lives. Occupational therapists can also provide activity pacing and grading recommendations in order to promote participation without exacerbating symptoms. Occupational therapists are able to assess the environment and client factors that may pose barriers to participation and make recommendations. Should adaptive equipment be needed the occupational therapists would be able to assist with this as well.

Assessments

- PASS (Performance Assessment of Self-Care Skills) measures the occupational performance of functional mobility skills, ADLs, IADLs, and safety.
    - Cost: Free
    - Administration: observation-based assessment, paper and pencil
    - Assessing: 5 functional mobility tasks, 3 basic activities of daily living tasks, 4 instrumental activities of daily living tasks with a physical emphasis and 14 IADL tasks with a cognitive emphasis

https://pitt.co1.qualtrics.com/jfe/form/SV_8k2Ya1AiRsYCt9Q

Note: users are required to complete a brief survey before going to the assessment link.

PHYSICAL ACTIVITY

POTS EXERCISE PROGRAM

- Months 1-4 recommend horizontal positioning. (recumbent bike, rowing, swimming)
- Month 4 begin integrating upright positioning as tolerated (cycling)
- Month 5 start to incorporate more upright cardio (treadmill, elliptical)
- Month 6-8 start to add arm movements and incline to upright cardio (treadmill, elliptical)

https://www.dysautonomiainternational.org/pdf/CHOP_Modified_Dallas_POTS_Exercise_Program.pdf

BENEFITS

Research states that physical activity can help manage and mitigate fainting or feeling faint. The research has also found exercise can help manage symptoms associated with POTS including cardiovascular deconditioning. Regular moderate exercise training has also been shown to restore upright hemodynamics and normalize the renal-adrenal responsiveness. Consistent exercise is shown to establish a normal cardiac output response.

RECOMMENDED EXERCISES

Perform 3 sets of 8-10 repetitions

- Seated leg press
- Leg curl
- Leg extension
- Calf raise
- Chest press
- Seated row
- Abdominal crunches
- Back extensions
- Bridges
- Straight leg raises
- Side lying leg raise
- Clamshells
- Plank holds

MONITORING HEART RATE

- Monitoring your heart rate while exercising is beneficial to help you stay in the proper range.
- Ask your healthcare provider what an appropriate range would be for you.
- A general recomendadtion is 165-175 beats per minute which falls withing the Maximal Steady State zone.

HOW OT CAN HELP

- Establishing routines
- Modifying exercises
- Adaptive equipment

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Personal Care Device Management

What are Compression Garments?

Compression garments are a form of tightly fitting clothing applied to a specific area of the body via the application of mechanical pressure. This pressure stabilizes and supports tissues (MacRae, 2011). Compression garments are recommended for many people, both with and without specific medical diagnoses. For example, individuals in professions with prolonged standing may wear compression garments but it can also be recommended for individuals with hypotension. There are different types of compression garments: lower leg compression, abdominal thigh compression, and full abdominal leg compression. Lower leg compression garments are used to prevent the pooling of blood in the lower extremities and the mechanical pressure helps to facilitate blood return (Bourne et al., 2021).

Compression Garments and the POTS Population

Common symptoms of POTS that impact participation in daily occupations are syncope, pre-syncope, and lightheadedness (Karas et al., 2000). A common solution that could aid with these symptoms is the use of compression garments. These personal care devices can help maintain the pressure within the vasculature to facilitate a normal orthostatic reaction. The results from Bourne et al. (2021) support the use of abdominal and thigh compression or full lower-body compression garments that were non-inflatable as they were found to reduce orthostatic tachycardia and other orthostatic symptoms. Although compression garments that cover the lower extremities, as well as the abdominals, were found to have the most significant impact on reducing symptoms of POTS, all forms of the garment had some impact as well.

Relevance of Occupational Therapy

Personal care device management is defined in the OTPF-4 as procuring, using, cleaning, and maintaining personal care devices, including adaptive equipment (AOTA, 2020). Compression garments can be argued to fall into the category of personal care devices. Occupational therapists can also play a direct role in helping clients with POTS implement these recommendations into their routines. There are many factors that occupational therapists should consider in order to be client centered when addressing this concern with their clients with POTS.

First and foremost, compression garments will only help if the client actually wears them; therefore, it is important to consider the practical and environmental factors at play. For instance, it is common for a client with POTS to experience increased symptoms in heat. In wearing full-length compression garments under clothing, this may actually pose a negative outcome. Thus, it may be suggested that the client only wear compression garments in certain circumstances (e.g., when indoors with air conditioning). Alternatively, routine changes can be suggested (e.g., attempting to limit time outdoors). Additionally, occupational therapists can work with their client to problem solve barriers to compression garment implementation. For example, if the client feels it is too hot for full body garments, a strategy may be to only wear lower leg garments to prevent overheating.

Another factor that should be addressed with these clients is the impact they may feel socially. Through our study, the data showed that younger individuals with POTS express more hesitancy to wear compression garments because of the way they look or how others perceive them. In addressing such concerns, occupational therapists should validate their client's feelings and work to solve perceived barriers. Recommendations to overcome this could be to opt for workout compression clothing. These clothing items

may be compressive while maintaining the look of more typical fashion. It can also be recommended that the client opt for clothing one size down, as it may offer more compressive support.

Lastly, occupational therapists are skilled in implementing a routine according to the OTPF-4. A skilled occupational therapist can work closely with their client to set up strategies to have success in adhering to wearing compression garments. For instance, an occupational therapist can work with their client to fit the garments into their everyday morning routine.

Suggested Interventions

Compression Garments

Compression garments are a form of tightly fitting clothing applied to a specific area of the body via the application of mechanical pressure. This pressure stabilizes and supports tissues (MacRae, 2011).

OT Role & Relevance to POTS

Occupational therapists can work with a client to integrate personal devices that help manage their symptoms. The implementation of compression garments or compression alternatives that fit the needs and wants of a client can reduce their symptoms and improve overall outcomes. This may also mean caregiver or support training as to how to put on compression garments. An occupational therapist can also work closely with their client to assess what barriers may impact the client's ability to wear the garments and work towards solutions to overcome these. Other personal device equipment could also be approached with this same mindset and tailored to the client's individual needs. Overall compression garments have been a successful tool to manage POTS symptoms and in turn help a client reengage in their meaningful occupations.

Assessments

- Canadian Occupational Performance Measure (5th edition) is a semi-structured interview with a five-step process to measure client-identified problem areas in daily function.
    - Cost: $49 for American Occupational Therapy Association members and $69.50 for non-members
    - Administration: open dialogue & pen and paper
    - Assessing client outcomes in the areas of self-care, productivity, and leisure

https://www.thecopm.ca/

- General Self-Efficacy Scale is a self-report questionnaire that measures self-perception.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing life participation, quality of life, self-efficacy, and stress & coping.

http://userpage.fu-berlin.de/~health/selfscal.htm

- Occupational Profile is a summary of a client's (person's, group's, or population's) occupational history and experiences, patterns of daily living, interests, values, needs, and relevant contexts" (AOTA, 2020)
    - Cost: Free
    - Administration: formal/ informal interview and conversation
    - Summary of a client's occupational history and systematically describe patterns of daily living, interests, values, and needs.

https://www.aota.org/~/media/Corporate/Files/Practice/Manage/Documentation/AOTA-Occupational-Profile-Template.pdf

COMPRESSION GARMENTS

BENEFITS OF COMPRESSION GARMENTS

Compression garments are used to reduce symptoms associated with POTS such as orthostatic tachycardia, syncope, and lightheadedness. The compression garments maintain pressure within the vasculature to reduce blood pooling and facilitate normal orthostatic reactions. Compression graded 40-60 mmHG and legs-abdominal stockings have been seen to have the most significant results

WHERE TO BUY THEM

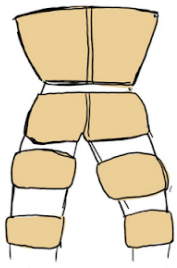
- Amazon.com
- Dick's Sporting Goods
- Compressionsale.com
- Jobst-usa.com
- Brightlife Direct
- VIm and Vigr

DIFFERENT KINDS

LOWER LEG

ABDOMINAL THIGH

FULL ABDOMINAL LEG



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Fatigue/Endurance Management: Energy Conservation & Activity Pacing

How Does Fatigue Affect an Individual?

Everyone feels fatigue to a degree; however, fatigue is more than being tired or sleepy. Rather, it can involve difficulties with energy, motivation, concentration, memory, and attention (Cleveland Clinic, 2020). Many conditions, disorders, medications, and lifestyle factors can cause fatigue and the level of severity can range from mild to serious (Cleveland Clinic, 2020; Healthline, 2019). With that being said, fatigue can have an extensive impact on an individual's life and can cause an individual to decrease their engagement in daily activities and affect engagement in occupations including education, play, leisure, and social participation.

However, fatigue does not just affect the ability to perform activities of daily living but also the ability to perform work related tasks, like accepting fewer responsibilities at work, reducing work hours, and taking extra days off (Burkin, n.d). Similarly, Strassheim et al. (2018) also found that individuals with fatigue are often less able to work, and if they do work, they may feel that they are less productive. Fatigue can also lead to problems with decision-making, poor performance, and even adversely affect social and personal relationships. In addition, fatigue may even cause feelings of depression, anxiety, frustration, and irritation due to disengagement in meaningful occupations, loss of occupational roles, and general lack of understanding of POTS from others (Burkin, n.d). Overall, fatigue can not only affect an individual's level of functioning but also reduce their quality of life.

Fatigue in the POTS Population

Fatigue is one of the three most common symptoms described by individuals with POTS and almost all persons with POTS have associated fatigue (Kavi et al., 2016; Raj, 2006). Similarly, Hoad et al. (2008) found that POTS is frequently diagnosed alongside individuals with chronic fatigue syndrome/myalgic encephalomyelitis. Some individuals may have a period of exhaustion that may last hours to days after a bout of symptoms. In others, overwhelming fatigue may be chronic and persistent for months (Thieben, 2007). Potential factors that could be the cause of fatigue in individuals with POTS include POTS itself, other associated comorbidity chronic fatigue syndrome, Ehlers Danlos Syndrome, and fibromyalgia, medications, sleep problems, and managing symptoms (Strassheim, 2018). Other physiological factors related to POTS that may also contribute to fatigue include "inadequate hydration, heat intolerance, low blood volume, decreased cerebral blood flow, increased noradrenaline levels, increased sympathetic tone, or activation of reflex pathways" (Strassheim, 2018). Hot weather can also exacerbate symptoms of fatigue in individuals with POTS.

Relevance of Occupational Therapy

Occupational therapists have a unique role and skill set for addressing multiple areas, including fatigue, that impact function. According to OTPF-4, occupational therapists are skilled in evaluating all aspects of the domain of occupations which includes and is not limited to the occupation of health management which addresses symptom and condition management (AOTA, 2020). When working with clients with POTS, managing fatigue from multiple perspectives will have the best result (Strassheim, 2018). Occupational therapists can assess their client's level and impact of fatigue through questionnaire-based assessments including the Fatigue Impact Scale or the

Fatigue Severity Scale. Defining specific periods, triggers, or activities that exacerbate symptoms of fatigue is an essential starting point from which an occupational therapist can work with their clients to manage and improve and therefore enable their clients to feel more control of their symptoms.

One of the ways occupational therapists can help clients with POTS that are experiencing fatigue is by implementing compensatory techniques that help conserve energy into a client's treatment plan. Energy conservation is an important strategy that could be applied to any aspect of a client's life such as at home, work, leisure, play, and rest/sleep. Energy conservation techniques provide a client the means of adapting their day-to-day life, redistributing their efforts, utilizing correct positioning, and modifying the environment in order to re-engage in occupations that are most important to them (Strassheim, 2018). Occupational therapists can promote energy conservation strategies by educating their clients and caregivers on treatment options that best fit in their daily routines, such as planning and organizing one's time, delegating tasks, utilizing adaptive equipment, and simplifying tasks (Vatwani & Margonis, 2019).

Suggested Interventions

Energy Conservation Management

Energy conservation management involves modifications in an individual's daily life to reduce the impact of fatigue for better participation in necessary tasks (Blikman et al., 2019).

OT Role & Relevance to POTS

One method occupational therapists could use with their clients to understand their energy levels is through analogies. Visualizing that way energy is used through analogies such as having an energy bank account or through Spoon Theory can be a good start to understand what activities require more or less energy or effort (Miserandino et al., 2003). Spoon Theory can allow a client to determine how much energy they spend throughout their day through spoons and how many spoons they would have to use for each activity (Mayv, n.d.). The greater the effort for an activity, the more spoons that are required, and if a client utilizes the majority of their spoons, then there will be fewer to spend for other activities later in the day or even the next day. Finding patterns of energy levels is the first step for planning which activities clients should prioritize. Identifying important activities is also a key component to prioritizing which tasks needed to be completed first as individuals often experience greater levels of fatigue later on in the day. Overall, recommending clients to visualize and detail how they spend energy could assist in identifying the amount of effort they spend on each activity throughout the day, how to plan a routine that is consistent and predictable, and how to effectively utilize their time and energy (Strassheim, 2018). Energy conservation management techniques can help allow individuals with POTS to engage in meaningful occupations by prioritizing and pace activities appropriately.

Assessments

- Fatigue Severity Scale is a 9-item questionnaire that assesses the severity and effect of fatigue.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing the severity of fatigue and its effect on a person's activities and lifestyle.

https://www.sralab.org/rehabilitation-measures/fatigue-severity-scale

- Fatigue Assessment Scale is a 10 item self-report scale that assesses the symptoms of fatigue.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing symptoms of chronic fatigue as represented by both physical and mental symptoms.

https://www.med.upenn.edu/cbti/assets/user-content/documents/Fatigue%20Assessment%20Scale%20(FAS).pdf

Suggested Interventions

Activity Tolerance

Activity tolerance is the endurance required to complete any activity. It relates to all aspects of a task including the initiation, engagement, and termination phase (Stromsdorfer, 2017).

OT Role & Relevance to POTS

It is important to ensure that each intervention and strategy is monitored closely to ensure that it does not exacerbate a client's symptoms (Strassheim, 2018). Understanding that certain movements may cause physiological stress while also considering an individual's responses to management strategies, occupational therapists may need to modify or implement adaptations to ensure improved compliance and better outcomes. If a client has identified certain movements or activities as difficult or challenging, occupational therapists can gradually increase the intensity or the task through grading and the "just right challenge," or it could be modified with simplification, adaptive equipment, or behavioral changes in order to improve function.

Another strategy that could be used to manage fatigue is activity pacing. Activity pacing can be defined as a strategy in which an individual plans and segments their daily activities in multiple shorter time blocks with rest breaks in order to not exacerbate their symptoms (Murphy et al., 2010). It is important to encourage time to rest in order to allow the body to recover, and this is especially true when there is an exacerbation of symptoms. It is also important to work with a client's caregivers and other family members in order to alleviate some of the stress that is placed on the client, whether it is through education or finding methods to allow members to assist in the client's daily activities. Overall, individuals with POTS can engage in meaningful occupations by modifying and simplifying difficult activities, using adaptive equipment, or delegating tasks to others.

Assessments

- Modified Fatigue Impact Scale is a 21 item self-report scale that assesses the effect of fatigue.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing the effects of fatigue on three domains of daily life: cognitive functioning, physical functioning, and psychosocial functioning.

https://nms2cdn.azureedge.net/cmssite/nationalmssociety/media/msnationalfiles/brochures/msqli_-a-user-s-manual.pdf

- Modified Fatigue Impact Scale - 5 Item Version is a 5 item self-report scale that assesses the effect of fatigue.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing the effects of fatigue on three domains of daily life: cognitive functioning, physical functioning, and psychosocial functioning.

https://nms2cdn.azureedge.net/cmssite/nationalmssociety/media/msnationalfiles/brochures/msqli_-a-user-s-manual.pdf

FATIGUE MANAGEMENT

What is Fatigue

Fatigue is more than being tired or sleepy but rather it can involve difficulties with energy, motivation, concentration, memory, and attention (Cleveland Clinic, 2020). Fatigue has an extensive impact on an individual's life and causes a decrease in engagement in daily activities and quality of life. Fatigue can also lead to problems with decision-making, poor performance, and even adversely affect social and personal relationships.

How to Manage Fatigue

Fatigue isn't always relived after sleeping or napping which is why it is also important to look into other methods to minimize the impact of your symptoms and get back to doing your everyday activities.

Energy Conservation

- Rest frequently. Several small breaks are better than one large break.
- Use a timer to enforce breaks especially with engrossing tasks.

The Five P's for Energy Management

1. Prioritize
2. Plan
3. Positioning
4. Pace Yourself
5. Positive Attitude

Work Simplification:

- Cut unnecessary steps.
- Cut unnecessary tasks.
- Delegate.
- Avoid unnecessary lifting, carrying, and manipulation.
- Reduce standards.

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Stress Management

How Does Stress Affect an Individual?

Stress responses have a range of effects that can negatively impact the different systems of the body and act as a trigger for symptoms or diseases. According to Yaribeygi et al. (2017), stress can cause structural changes to the brain, resulting in a reduction of memory and cognition, changes to mood, memory disorders, and negatively impact reaction time. Stress responses may activate the release of hormones, which can collectively inhibit the function of the immune system, creating an association between stress and being more likely to become ill. Stress responses can exhibit themselves in the gastrointestinal system by affecting appetite, movement of food through the gastrointestinal tract, absorption and digestion of food, and inflammation of the gastrointestinal system (Yaribeygi et al., 2017). Stress can have an effect on the sympathetic and parasympathetic nervous systems, having both inhibitory and stimulatory effects on the cardiovascular system. Stress can increase or decrease heart rate and strength of contractions of the heart while also affecting vasodilation of arteries or veins, blood pressure, and activity of the heart, kidneys, and spleen (Yaribeygi et al., 2017).

Stress in the POTS Population

Studies have shown that individuals with POTS are more at risk for mental distress as a result of anxiety. According to Raj et al. (2018), “to summarize, while individuals with POTS are commonly perceived to be anxious, studies suggest this is largely driven by orthostatic symptoms that overlap with common anxiety symptoms.” Although individuals with POTS commonly experience orthostatic intolerance symptoms, some of these symptoms are also common somatic and psychological

symptoms that are normally experienced with anxiety (Raj et al., 2018). Unhealthy responses or anxiety that is unaddressed can exacerbate symptoms of POTS as well as take a toll on an individual's daily functioning. Individuals with POTS may become more reluctant in participating in certain activities or social settings in fear of experiencing the symptoms of POTS and may feel as if their condition is unpredictable. A lack of coping strategies can result in decreased quality of life, mental health, social engagement, and level of functioning.

Relevance of Occupational Therapy

Individuals with POTS may have functional impairments that have an effect on most aspects of a daily lifestyle. According to Dochod and Grapczynski (2019), occupational therapists focus on keeping their clients engaged with meaningful activities to increase motivation, quality of life, levels of functioning, and overall health. In order to reduce stress and anxiety while also keeping clients with POTS engaged with meaningful activities, occupational therapists offer compensatory strategies, adaptations, and modifications to help increase participation and decrease the likelihood of exacerbation of symptoms. Strategies for stress management specific for individuals with POTS can include balancing the response to somatic symptoms without getting distressed, calming the fight/flight response, preventing anxious thinking, addressing physiological cues instead of ignoring them, addressing unhealthy dissociated tendencies and replacing them with healthy coping strategies, and challenging the idea that their body and the condition is scary and unpredictable (Raj et al., 2018). Relaxation techniques can be implemented into a client's set of responses to stress in order to reduce the chances of exacerbating symptoms. According to Freedenberg et al. (2017), some examples of relaxation techniques include deep breathing, progressive muscle relaxation, autogenic relaxation,

and visualization all of which can decrease stress and improve coping skills as well as aid in the reduction of stress, anxiety, and depression. Through adaptations and modifications to lifestyle routines as facilitated by an occupational therapist, a client with POTS can better prepare themselves through mindfulness strategies if conditions arise that may impact their functional performance. Through engagement with stressful but meaningful activities, clients with POTS can gain the experience to know when to implement the strategies they have arranged or have been taught. Studies have shown that individuals can better adjust to stress responses through direct engagement with their source of stress and that secondary control engagement coping skills can help reduce anxiety symptoms, depressive symptoms, somatic complaints, and withdrawal effects (Freedenberg et al., 2017).

Suggested Interventions

Mindful Meditation

Mindful meditation involves being fully aware of your cognitive thoughts and bodily feelings while fully engaging the mind in mental focus exercises. A study has shown that young adults who participate in mindful meditation felt much more relaxed, at peace, and focused. Young adults who often felt stressed felt like mindful meditation helped them to develop daily routines, have more control in their life, and reduce the stress brought on by factors that they could not control. (Jones et al., 2020)

OT Role & Relevance to POTS

Many persons with POTS feel as if their condition has gone out of control and they no longer understand the limitations of their bodies which can have a negative impact on the client's emotional state as well as quality of life (Dochod & Grapczynski, 2019). They can feel defeated or even betrayed by the unreliability that has become a normal part of their day-to-day lives. Mindful meditation can help bring awareness and understanding for the client in order to gradually take control of their lives. In addition, the relaxation and focus gained through mindful meditation can help serve as a healthy coping mechanism when facing high-stress situations or as a daily routine activity to unwind at home. Through mindful meditation individuals with POTS can become more confident in the activities used to take part in, re-engaging them with meaningful occupations that they had lost the capacity to do.

Assessments

- Perceived Stress Scale: A 10-item scale used to help measure one's perception of stress in their life.
    - Cost: Free
    - Administration: A form with 10 questions will be given to the client for them to answer on a scale from 0-4 (0 being never and 4 being very often) about how often they felt a certain way.
    - Assessing: Assesses feelings and thoughts of stress within the last month

https://www.das.nh.gov/wellness/docs/percieved%20stress%20scale.pdf

- Coping Resources Inventory: Measures how people handle stress in 5 different categories: Cognitive, Social, Emotional, Spiritual/Philosophical, and Physical.
    - Cost: Individual report $15.00 (Manual $50.00)
    - Administration: For each item of the different categories, clients are asked to rate on a scale from 0-4 (0 being never and 4 being very often) how often they behaved the way that is described in the statement.
    - Assessing: Cognitive and Behavioral responses to certain stressful situations

https://www.mindgarden.com/88-coping-resources-inventory

- Depression Anxiety Stress Scales (DASS): A 42-item self-report tool used to measure the negative states of depression, anxiety, and stress.
    - Cost: Free (DASS manual contains more detailed information for $55.00)

- Administration: Clients are asked to rate on a scale from 0-4 (0 being never and 4 very often and severe) how often they have experienced each state over the past week.
- Assessing: Symptoms of depression, anxiety, and stress as well as how often they occur and find the focus of the negative emotional state.

http://www2.psy.unsw.edu.au/dass/

STRESS MANAGEMENT

WHAT CAN STRESS DO?

Individuals with POTS may experience a **worsening of their symptoms or constant anxiety** when participating in activities. It's best to stay mindful and know your limitations when participating in activities to better undertstand your body to avoid the effects of stress

HOW DOES STRESS EFFECT POTS?

- Extreme worsening of symptoms
- Anxiety when engaging in activites
- Fear of symptoms arising in public
- Dissociative Tendencies
- Unhealthy Coping Strategies
- Changes in appetite and energy
- Problems with sleep

WHAT CAN YOU TRY?

• Connect with your loved ones and community • Staying mindful • Find time for exercise and relaxation
• Get organized with a schedule or routine • Setting healthy boundaries • Communicate with loved ones
• Address symptoms without becoming distressed • Find strategies to calm the fight/flight response
• Reinforce beneficial coping skills • Positive Thinking • Acceptance of the situation • Healthy Distractions
• Changing your mindset or way of thinking • Remembering to be patient with yourself

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Pain Management

What is Pain?

"Pain is a subjective experience unique to the person, one that is influenced by biological, psychological, and social factors" (Breeden & Rowe 2021). Pain is often described as an uncomfortable or unpleasant sensation as a result of noxious stimuli. The noxious stimuli are then picked up by pain receptors located in the tissue of the body and are transferred through the nerves and spinal cord to the brain. This signal then motivates the person to back away from whatever caused the noxious stimuli and to avoid it in the future.

Pain in the POTS Population

Although POTS and its symptoms may vary from person to person, chronic pain is common among the POTS community. Individuals with POTS will experience pain that persists for much longer, often known as chronic pain. The most common types of chronic pain that individuals with POTS report include headaches, migraines, abdominal pain, muscle cramping, joint pain, leg pain, and musculoskeletal pain (Junghans-Rutelonis et al. 2019). The interrupted blood flow to the upper parts of the body may often cause headaches and neck pain, however, individuals with POTS can have more severe causes of chronic pain due to certain conditions. According to Cleveland Clinic (2022), an individual may experience neuropathic pain which can manifest as a burning, tingling, or stabbing sensation in the affected area. These symptoms generally start in the feet or hands and work their way up and can increase in intensity during sleep. Individuals with POTS may also experience central sensitization, affecting the nerves and making them more sensitive to touch. Normal sensations that normally do not cause pain are suddenly painful to the individual making it difficult for them to complete tasks or

activities. A combination of venous pooling and dysautonomia greatly impacts one's ability to exercise or move around in general. This can lead to severe deconditioning, which can further exacerbate POTS symptoms and make the pain even worse for an individual (Cleveland Clinic, 2022). It's important for individuals with POTS to focus on solutions that can help to alleviate pain while building strength. Cognitive behavioral therapy and lifestyle modifications such as compression stockings, sodium intake changes, and routine exercises can help to ease painful sensations while increasing an individual's functional exercise capacity.

Relevance of Occupational Therapy

People with POTs experience pain experiences throughout their daily routine and pain is enough to inhibit their motivation to perform meaningful activities. The pain is enough to convince individual that they should give up on working or going to school because any amount of activity can exacerbate their symptoms and cause a flare-up in symptoms and pain. Occupational therapy seeks to find adaptive solutions to help participate in activities that the client finds meaningful in order to increase occupational engagement, overall health, and quality of life. According to the American Occupational Therapy Association, "Through the occupational therapy process, specific performance problems in daily living are assessed, valued activities are identified, and evidence-based therapeutic approaches are used to address the client's goals" (Rochman. 2014). Occupational therapists focus on educating and training their clients to engage in activities without eliciting pain or being proactive in controlling and managing that pain. Intervention approaches that occupational therapists normally use with chronic pain are functional goal setting, safe body mechanics, ergonomics, neuromuscular re-education, muscle tension reduction, pacing, and proactive problem-solving. Again, these

approaches focus on non-pharmacological approaches to help improve engagement in meaningful activities and routines without adverse side effects that may prove to be contradictory to the overall purpose of pain management.

Suggested Interventions

Self-Management Education and Training

Self-management training and education of pain can include pharmacological and non-pharmacological approaches and can help ease or block signals of painful stimuli from the brain. Through educating and training, a client with POTS can be more prepared to re-engage with physical activities and rehabilitation in a safe and efficient manner. Clients should seek approaches such as heat or cold applications, physical agent modalities, safe body mechanic education, cognitive behavioral therapy, physical therapy exercises, or relaxation techniques to efficiently manage pain while also reducing the amount of medication needed to suppress pain (Rochman, 2014).

OT Role & Relevance to POTS

Pain associated with POTS can lead to disengagement from meaningful occupations and affect other aspects of daily living such as sleep, exercise, and socializing (Rochman, 2014). People with POTS who experience chronic pain may need constant dependency on others and can cause a loss of self-identity and quality of life. Occupational therapy seeks to re-engage clients with their meaningful occupations by examining the client's goals and using evidence-based approaches and strategies in order to provide adaptive methods for engagement. This client-centered care aims to improve the satisfaction of daily living for clients who have lost a significant amount of their functional capacity due to POTS and the pain associated with POTS (Rochman, 2014).

Assessments

- Numerical Pain Rating Scale (NPRS): A pain screening tool used to subjectively measure pain severity on a 0-10 numerical scale.
    - Cost: Free
    - Administration: The client is asked to make three pain ratings (current, best, worst) from the past 24 hours on a scale of 0-10 (0 being no pain and 10 being the worst pain imaginable. The average of the 3 ratings represents the patient’s pain level over the past 24 hours.
    - Assessing: The NPRS is used to screen pain severity.

https://www.sralab.org/rehabilitation-measures/numeric-pain-rating-scale

- West Haven-Yale Multidimensional Pain Inventory (WHYMPI): A 52-item, 12-scale inventory made up of three parts: The experience of the pain, how significant others respond to pain behaviors, and how clients participate in different common activities
    - Cost: Free
    - Administration: The client is first asked 2 pre-evaluation questions about identifying a significant other who they feel closest to and identify if they live with them or not. Each section is then completed by providing a statement and the client will respond with a numerical scale of 0-6 (0 being the lowest value and 6 being the highest value).
    - Assessing: Assesses chronic pain/related disability in clients and its impact on the person's life, the responses of others to their communication

of pain, and the extent or limitations of participation in the person's daily activities.

https://www.sralab.org/rehabilitation-measures/west-haven-yale-multidimensional-pain-inventory

- Brief Pain Inventory (BPI): A self-report or interview measure that comes in two forms (Short [9] and Long [32]) in order to quickly measure pain severity and how it negatively impacts daily functioning.
    - Cost: Free
    - Administration: The BPI form asks clients to complete questions asking about identifying their pain type as well as location, severity scales with several time frames, current medications as well as relief from medication, and how severely pain impacts aspects of daily functioning.
    - Assessing: Pain severity and its impact on functional activity

https://www.sralab.org/rehabilitation-measures/brief-pain-inventory

PAIN MANAGEMENT

PAIN AND POTS

Pain with POTS may vary from person to person however any pain can keep individuals from participating in meaningful activities. Occupational therapy focuses on education and training to help people with POTS engage in activities **without eliciting pain or being proactive** in managing pain.

OT INTERVENTIONS

- Cognitive Behavioral Therapy
- Functional Goal Setting
- Relaxation Technique
- Safe Body Mechanics
- Neuromuscular Re-education
- Body Ergonomics
- Muscle Tension Reduction
- Pacing and Proactive Problem Solving

TYPES OF PAIN

- Headaches and Neck Pain
- Neuropathic Pain
- Central Sensitization
- Venous Pooling and Dysautonomia

WHAT CAN I TRY?

- Compression Stockings
- Changes to Sodium Intake
- Routine exercises
- Hot/Cold Applicaitons

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Sleep Hygiene

How Does Inadequate Sleep Affect an Individual?

Sleep is defined as a recurring, reversible state of relative perceptual disengagement from, and unresponsiveness to, the environment (Sheth & Thomas, 2019). Sleep is an essential daily occupation, and although the recommended hours of sleep changes through the lifespan, people spend at least one third of their lives asleep. Sleep provides the foundation for optimal performance, participation, and engagement in daily life and is also vital for human growth and development (AOTA, 2017; Solet, 2014). Sleep is also important for improving concentration, attention, and memory and allows the body to repair and replenish bodily functions (Smith et al., 2018).

However, a disrupted sleep schedule can cause sleep insufficiency and sleep deprivation. Sleep insufficiency is defined as the lack of restorative sleep and sleep deprivation is defined as not obtaining adequate total sleep (CDC, 2015; American Sleep Association, 2018). Anything that disrupts the sleep-wake cycle, sleep stages, total time asleep, or the quality of sleep may be classified as a sleep disturbance. Sleep can be disturbed by a number of difficulties or deficits in several domains in the OTPF-4, including client factors, performance patterns, contexts, and environments. Examples of this can include the influence of health conditions (e.g., depression, anxiety, or stress), lack of adequate sleep hygiene or sleep schedule adherence, consumption or usage of stimulants, alcohol, drugs, or certain medications, or the experience of pain or frequent urination in the night. The lack of proper sleep can not only negatively impact an individual's physical, cognitive, emotional, social wellbeing but also affect occupational performance and quality of life. People who are sleep-deprived will often experience reduced physical performance, greater functional limitation, excessive daytime

sleepiness, fatigue, clumsiness, and abnormal weight gain or weight loss (Sheth & Thomas, 2019). In addition, sleep insufficiency has been linked to chronic diseases such as hypertension, diabetes, depression, obesity, cancer, early mortality, along with social isolation, increased risk of falling, motor vehicle crashes, increased health care utilization, industrial accidents, and decreased work productivity (CDC, 2015; Leland et al., 2014).

Sleep in the POTS Population

Persons with POTS have higher subjective daytime sleepiness, fatigue, and worse sleep and health related quality of life (Bagai et al., 2011). Furthermore, Bagai et al. (2011) also suggests that "a high proportion of diminished quality of life is due to sleep problems." Many persons with POTS have also described poor sleeping at night, waking up repeatedly at night, sweating at night, and experiencing significantly more sleep problems such as excessive daytime somnolence, sleep related dyspnea, and headaches. Studies suggest that the activation of the sympathetic nervous system, hyperarousal, and chronic pain may explain poor sleep efficiency and higher rates of sleep fragmentation and sleep disruption (Pederson & Brook, 2017). Individuals with POTS also have a reduction in the percentage of rapid eye movement sleep which is one of the stages of sleep that is important for learning and memory (Pederson & Brook, 2017; WebMD, 2020). According to Pederson and Brook (2017), sleep disruption in individuals with POTS should be a significant concern because insomnia is a known risk factor for suicide and has also been linked with increased rates of depression. Pederson and Brook results suggest that individuals with POTS have a significantly higher risk for suicidal ideation while also finding that persons with POTS also have pain that disrupted sleep, poor subjective sleep efficiency, difficultly staying awake during the day, and worse self-

ratings of sleep quality. Treatment to improve sleep efficiency and sleep quality is therefore an important step towards improving the quality of life and overall well-being for individuals with POTS.

Relevance of Occupational Therapy

"Occupational therapists use knowledge of sleep physiology, sleep disorders, and evidence-based sleep promotion practices to evaluate and address the ramifications of sleep insufficiency or sleep disorders on occupational performance and participation," (AOTA, 2017). In addition, according to the OTPF-4, occupational therapists are skilled in evaluating all aspects of the domain of occupations which includes and is not limited to the occupation of rest and sleep which addresses rest, sleep preparation, and sleep participation (AOTA, 2020). Occupational therapists are skilled at understanding how illnesses, environments, habits, routines, and psychosocial factors can affect sleep preparation and participation and utilize effective and client centered interventions to improve an individual's sleep hygiene. Sleep hygiene is defined as lifestyle modification to promote sleep (Green et al., 2015). Sleep hygiene includes having a relatively steady sleep schedule, with a standard bedtime and waking time every day, including the weekends. Occupational therapists may want to focus on sleep education which is the best intervention for understanding of the benefits of sleep hygiene (Sheth & Thomas, 2019). Occupational therapists can also work with their clients with POTS to modify behavioral or environmental factors in order to help promote healthy sleeping routines for increased engagement, improvement of health, and overall better quality of life.

Occupational therapists can begin by understanding and analyzing which areas of rest and sleep are affected and the input and priorities of clients. This can be done with a series of needs interviews and assessments including the Pittsburgh Sleep Quality Index.

Following the evaluation, interventions that incorporate sleep management strategies can be implemented. According to the OTPF-4 sleep management strategies encompasses activities related to obtaining restorative sleep and rest to engage in meaningful occupations and improving health (AOTA, 2020). For example, environmental modifications that aid in sleep include setting a low and comfortable temperature, limiting bright lighting and sound. Sleep aids such as using weighted blankets, comfortable blankets, pillows, and mattress may also be a topic that should be addressed. Recommendations for daytime routines that an occupational therapist can suggest to their client include limiting daytime naps, exercising during the day, establishing consistent routines, and avoiding stimulants like caffeine, nicotine, and alcohol close to bedtime (AOTA, 2017). Other occupational therapy interventions that promote optimal sleep performance include educating clients on sleep misconceptions and expectations, addressing performance deficits, addressing secondary conditions, addressing sensory disorders, and time management (AOTA, 2017). By implementing sleep management strategies, making environmental adaptations, using assistive equipment, and making lifestyle changes occupational therapists can help address the sleep problems of clients with POTS (Ho & Siu, 2018).

Suggested Interventions

Cognitive Behavioral Therapy

Cognitive behavioral therapy targets negative thoughts and beliefs an individual may have to elicit better outcomes and behaviors, such as affecting an individual's ability to fall or stay asleep (Morin, 2006).

OT Role & Relevance to POTS

Cognitive behavioral therapy aims to restore sleep by addressing and replacing negative behaviors, feelings, and psychological factors with healthy sleep habits. Depending on the individual's needs, an occupational therapist may recommend some cognitive behavioral therapy interventions such as, cognitive restructuring, sleep hygiene education, relaxation training, stimulus control therapy, and sleep restriction therapy (Pigeon, 2010).

To elaborate, relaxation training can consist of progressive muscle relaxation, deep breathing exercises, and biofeedback. Stimulus control therapy aims to limits the amount of time an individual spends awake in bed or in the bedroom in addition to developing a more consistent sleep schedule, regular circadian sleep–wake cycle, and decreasing a client's bed as a cue for arousal while increasing its cue for sleep (Pigeon, 2010). Stimulus control therapy can include using an alarm to wake up at a fixed time, not or reducing naps during the day, only use the bed for sleep or sexual activity, going to sleep only when you are sleepy, and leaving the bedroom when you are unable to sleep. Sleep restriction therapy aims to limit the amount of time that individuals spend in bed awake by first calculating the amount of time the individual actually sleeps and adjusting their schedule to reflect that amount of time plus 30 minutes. Following this technique allows individuals to spend most of their time in bed sleeping. By identifying and reframing any sleep misconceptions and challenges, this would help guide individuals with POTS into creating a healthy sleep routine by strengthening the relationship between the bed and rest and sleep.

Suggested Interventions

Environmental Modifications

Environmental modification is the process of adjusting the physical environment to promote better sleep quality (Westover & Miller, 2017).

OT Role & Relevance to POTS

Environmental factors like noise, light, temperature, external distractions, bedding, and technology use are vital to address as external stimuli are still processed by the sensory functions, despite having a non-conscious perception (Muzet, 2007). To effectively address an individual's sleep needs, it is essential for an occupational therapist to examine the interaction between the environment and the engagement in sleep. An occupational therapist can educate their client on environmental modifications that include making the bedroom quiet, setting the room's temperature neutrally cold, and having the room completely dark or with limited lighting. A client should also avoid excessive use of cellphones, tablets and laptops before sleeping. If the environment still causes difficulties with sleep, sleep aids, fans, or ear plugs can also be used.

Suggested Interventions

Sleep Aids/Assistive Devices/Equipment

Personal device equipment can be essential to improve an individual's rest and sleep. Equipment includes consumer technology such as sleep aids or white noise machines which was found to be items to promote sleep (Peake et al., 2018). Other equipment can include position pillows and weighted blankets.

OT Role & Relevance to POTS

Occupational therapists could also introduce and educate their client with POTS on assistive aids which can also be used to facilitate sleep. There is much evidence supporting the effectiveness of sleep aids and sleep tools including the Dreampad Pillow®, weighted blankets, eye masks, earplugs, and white noise machines to promote sleep and reduce sleep disturbance during hospital stays or reducing symptoms like pain and fatigue (Ho & Siu, 2018). The Dreampad Pillow® conducts soothing music in order to improve sleep duration and shorten latency, improve sleep quality, and reduce nighttime awakenings. Similarly, the weighted blanket could also increase sleep duration and shorten latency.

Assessments

- Pittsburgh Sleep Quality Index (PSQI) is a 19-item self-rated questionnaire that assesses sleep quality and disturbances over a 1-month time interval.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing quality of sleep using several domains, which include subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction.

https://www.sleep.pitt.edu/instruments/

SLEEP HYGIENE

Is Sleep important?

Sleep is an essential daily activity and sleep provides the foundation for optimal performance, participation, and engagement in daily life and is also vital for growth and development (AOTA, 2007; Solet, 2014). Sleep is also important for improving concentration, attention, and memory and allows the body to repair and replenish bodily functions (Smith et al., 2018).

How to Improve Your Sleep

It is important for the body to recognize that the bed is for sleeping, and in order for the body to establish a consistent sleep schedule try to limit activities in the bedroom and bed to just sleep and sex (Pigeon, 2010). Only go to bed when you are sleepy. Leave the bedroom if you are unable to sleep. Noise, light, temperature, external distractions, bedding, and technology use may also be affecting your ability to sleep. Also keep in mind that, what you do during the day can also impact the quality of sleep you get at night.

Tips and Tricks

- Establish consistent routines during the day and night
- Avoid stimulants (caffeine, nicotine, alcohol) close to bedtime
- Make the bedroom as quiet as possible
- Temperature should be neutrally cold
- The room should be completely dark or have limited lighting
- Avoid using devices such as cell phones or tablets.
- Wake up at a fixed time
- Limit daytime naps
- Exercise

Sleep Aids

Weighted blankets, eye masks, earplugs, and white noise machines can also promote sleep and reduce sleep disturbance (Ho & Siu, 2018)

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Mental Health

How Does Mental Health Issues Affect an Individual?

Psychosocial aspects can be defined as the relationship between social factors and an individual's thoughts and behaviors. These aspects are integral in the area of occupations, which include meaning, purpose, motivation, symbolic expression, relationships, roles, and the unconscious dynamics that may influence occupational behavior (Ramsey, 2004). The driving force to perform meaningful activities may be related to personality, temperament, energy, and drive. Understanding the dynamic interaction between the different contexts (personal and environmental factors) of an individual and the nature of the occupation, an everyday activity that occupies time and is meaningful, can demonstrate the influence each one has on the other. The disruption in an individual's ability to perform in necessary and important occupations can elicit emotional and psychological responses including denial, anger, fear, hopelessness, resistance to treatment, loneliness, sadness, grief, and anxiety, among other things. These psychosocial issues can impede occupational engagement in all areas of a person's life

Mental Health Issues in the POTS Population

POTS is a chronic condition that affects an individual's day to day life. Common symptoms of POTS include lightheadedness, fatigue, dizziness, sweating, tremor, palpitation, exercise intolerance, and near syncope in upright posture (Karas et al., 2000). Individuals with POTS can also experience attention deficits, headaches, anxiety, depression, sleep disturbances, gastrointestinal disturbances, and vision changes. Due to the nature of the symptoms, persons with POTS feel a disconnect with their past selves, especially with the inability to participate in valued occupations. The fluctuating and unpredictable nature of the condition also increases loneliness, emotional stress, and

mental health conditions like anxiety and panic disorder (Waterman et al., 2021). Stigma is a relative occurrence as POTS is invisible, indescribable, and immeasurable. Thus, the lack of understanding from the community can also contribute to individuals with POTS sense of loss.

Relevance of Occupational Therapy

Occupational therapy has the foundation to understand an individual's psychological, physical, emotional, and social needs that may hinder their performance in daily life (AOTA, 2022). This holistic approach allows occupational therapists to understand how a condition can affect the body and mind to give insight on how to help their clients with POTS regain independence through meaningful activities. This can be associated with what a person wants, needs, or is expected to do but cannot, does not, or is not satisfied with the way they do it (Canadian Occupational Performance Measure, 2022). The OTPF-4 also indicates that health management is an important occupation to address. Within this category, there is social and emotional health promotion and maintenance, which encompasses identifying strengths, managing emotions, developing self-identity, and improving quality of life (AOTA, 2020). Areas of specialties an occupational therapist can implement to aid with this are self-care, stress reduction techniques, coping strategies, emotional regulation, symptom management, community mobility, social skills, communication training, and education to help alleviate mental health issues for re-engagement in occupations. Occupational therapists can specifically target self-efficacy, self-esteem, role development, and provide resources for the POTS community to avert the loss of identity and negate the feelings that stem from the lack of community awareness.

Suggested Interventions

Self-Efficacy

Self-efficacy is the capability to effectively create and execute a plan to act in a variety of different situations. It encompasses what an individual can do with the skills they possess (Chan, 2021).

OT Role & Relevance to POTS

The fluctuating and unpredictable nature of POTS can discourage symptom management as there is an underlying fear associated with it. Improving self-efficacy in coping for clients with POTS can reflect a perceived ability to manage challenges related to the condition and give a sense of control over their lives (Chan, 2021). Thus, providing training can relieve some psychosocial issues.

Assessments

- Canadian Occupational Performance Measure (5th edition) is a semi-structured interview with a five-step process to measure client-identified problem areas in daily function.
    - Cost: $49 for American Occupational Therapy Association members and $69.50 for non-members
    - Administration: open dialogue & pen and paper
    - Assessing client outcomes in the areas of self-care, productivity, and leisure

https://www.thecopm.ca/

- General Self-Efficacy Scale is a self-report questionnaire that measures self-perception.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing life participation, quality of life, self-efficacy, and stress & coping.

http://userpage.fu-berlin.de/~health/selfscal.htm

- 6-item Chronic Diseases Self-Efficacy is a 6-item visual analog scale, ranging from 1 to 10, determining how confident an individual is in managing their chronic condition.
    - Cost: Free
    - Administration: paper and pencil
    - Assessing fatigue, physical discomfort/pain, emotional distress, other symptoms/health problems, tasks/activities needed to manage health conditions, and things other than just taking medication.

https://selfmanagementresource.com/resources/evaluation-tools/english-evaluation-tools/

SELF-EFFICACY

WHAT IS SELF-EFFICACY?

Self-efficacy is the capability to effectively create and execute a plan to act in a variety of different situations. It encompasses what an individual can do with the skills they possess (Chan, 2021).

HOW IT HELPS

- Link between knowledge and action
- Empowerment factor
- Greater confidence in doing activities
- Improved autonomy and self-determination

How to Improve Self-Efficacy

- Performance experiences : focus on your strengths & make attempts at new tasks
- Verbal persuasion: encouragement to see one's capability
- Increased social support
- Healthy coping style
- Self-regulation

BENEFITS:

1. Reduces psychosocial problems
2. Comes to terms with a change in roles and lifestyles
3. Fulfills needs

Chan S. W. (2021). Chronic Disease Management, Self-Efficacy and Quality of Life. The journal of nursing research : JNR, 29(1), e129
Ebrahimi Belil, F., Alhani, F., Ebadi, A., & Kazemnejad, A. (2018). Self-efficacy of people with chronic conditions: A qualitative directed content analysis. Journal of Clinical Medicine, 7(11), 411.

Suggested Interventions

Self-Esteem

Self-esteem is how an individual perceives and values themselves based on their own opinion and beliefs. Studies have found a correlation between self-esteem and protective factors for well-being and health. Thus, self-esteem is associated with anxiety and depression, which significantly affects an individual's quality of life and shows links to suicidal ideation (Nguyen et al., 2019).

OT Role & Relevance to POTS

POTS is an invisible, indescribable, and immeasurable condition. This may cause stigma due to a lack of understanding from the community, which can negatively affect a person's self-esteem by being constantly judged. It was also found that many people in the POTS community feel like a burden (Pederson & Brook, 2017). This, along with the disconnection to their past selves, can cause issues in their sense of self and identity. Thus, providing training can relieve some psychosocial issues.

Assessments

- Rosenberg Self-Esteem Scale: A 10-item scale that measures global self-worth by measuring both positive and negative feelings about the self.
    - Cost: Free
    - Administration: paper & pencil or online
    - Assessing positive and negative feelings about the self

https://wwnorton.com/college/psych/psychsci/media/rosenberg.htm

- Tennessee Self Concept Scale (TSCS) is a 120-item true-false questionnaire designed to assess self-esteem in adults
    - Cost: $259 for kit & $624 for software
    - Administration: paper & pencil or online
    - Age Range: 7-90 years old
    - Assessing self-concept

https://www.parinc.com/Products/Pkey/462

What is Self-Esteem

Self-esteem is how an individual perceives and values themselves based on their own opinion and beliefs. The relationship between protective factors and self-esteem contributes to health and well-being (Nguyen et al., 2019).

How to improve self -confidence

Notice Negative Thinking → Positive Affirmations & Self-Talk

Emphasize

Your Strengths
Your Successes
Your Positive Attributes

Focus on Healthy Habits

- Understand what is in your control & keep up with the routine!

How to form healthy habits

1. Set an attainable goal
2. Disrupt old patterns
3. Build on existing habits
4. Commit to a timeline
5. Hold yourself accountable
6. Progress

Nguyen, D. T., Wright, E. P., Dedding, C., Pham, T. T., & Bunders, J. (2019). Low self-esteem and its association with anxiety, depression, and suicidal ideation in vietnamese secondary school students: A cross-sectional study. Frontiers in psychiatry, 10, 698.

Suggested Interventions

Role Development

Role development is the development of social roles that an individual may have lost, never had but wishes to gain, or wants to further expand. Interpersonal skills or role analysis are important factors when assessing this.

OT Role & Relevance to POTS

An individual with POTS may feel as though their life conflicts with that of their "past-life" when they find out they can no longer participate in activities they once loved. Members of the POTS community may feel they can no longer partake in roles they previously had leading to social withdrawal due to their condition and symptoms (Waterman et al., 2021).

Assessments

- Role Checklist v3: A 10-item screening tool that measures a patient's participation levels, satisfaction with participation, and reasons for non-participation.
    - Cost: $44
    - Administration: paper & pencil
    - Assessing life participation, motivation, and occupational performance.

https://www.sralab.org/rehabilitation-measures/role-checklist-version-3

- Participation Assessment and Recombined Tools (PART-O): objective measure of participation, representing functioning at the societal level
    - Cost: Free
    - Administration: paper & pencil
    - Assessing social and societal functioning

https://www.tbims.org/parto/index.html

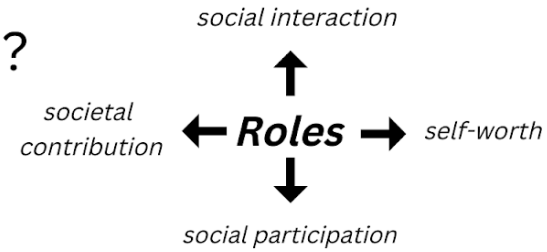
- Occupational Performance History (OPHI-II): semi-structured interview that explores a client's life history in the areas of work, play and self-care performance
    - Cost: $40
    - Administration: pen & pencil, fillable pdf
    - Assessing life narrative

https://moho-irm.uic.edu/productDetails.aspx?aid=31

ROLE DEVELOPMENT

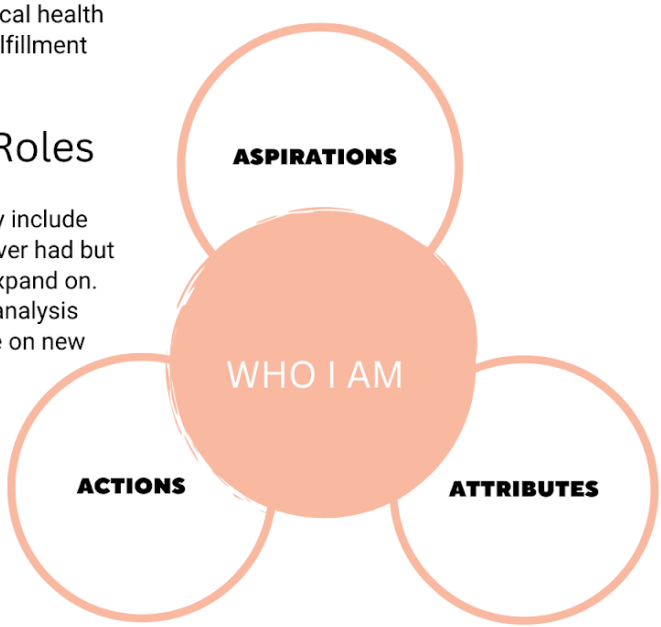
What are Social Roles?

Social roles are identities that people adopt which in turn becomes who they are. For each role a person takes on, their behaviors may change to fit the expectations of one's own thoughts and beliefs or to satisfy those around them. Competence in these roles improve autonomy and psychological health which lead to a greater sense of fulfillment (Talley et al., 2012).



Development of Roles

The development of social roles may include roles an individual may have lost, never had but wishes to gain, or wants to further expand on. Interpersonal skills and task or role analysis are important factors needed to take on new roles.



Talley, A. E., Kocum, L., Schlegel, R. J., Molix, L., & Bettencourt, B. A. (2012). Social roles, basic need satisfaction, and psychological health: The central role of competence. Personality & Social Psychology Bulletin, 38(2), 155–173.

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COPM in use. (n.d). Canadian Occupational Performance Measure. https://www.thecopm.ca/use/

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Vietnamese secondary school students: A cross-sectional study. *Frontiers in Psychiatry, 10*, 698. https://doi.org/10.3389/fpsyt.2019.00698

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Communication with Healthcare System

What is Communication with the Healthcare System?

Effective physician-patient communication is necessary for improved health outcomes. Tiwary et al. (2019) explains how communication problems can lead to decreased adherence to treatment, clients' dissatisfaction, and inefficient use of resources. Understanding that the first mode of communication when an individual's health declines is a visit to a healthcare practitioner, it is easy to see how a person may become deterred from finding help all together when they feel undermined or rejected. It is important that healthcare practitioners have strong communication skills when working with their clients. It is also in the best interest of people with underlying conditions to be health literate in order to advocate for themselves. Health literacy is defined as how a person understands or is able to use gathered information to make well-informed decisions regarding their health (Centers for Disease Control and Prevention, 2022). In doing this, health equity is improved.

Communication Issues within Healthcare and POTS

POTS is a chronic condition that is invisible, indescribable, and immeasurable. Thus, the lack of understanding from the community and healthcare providers can contribute to a sense of mistrust, which can lead to negative outcomes. In a study describing the diagnostic journey and impact of POTS, it was found that three quarters (75%) of individuals sampled report that their symptoms were misdiagnosed and did not receive a proper diagnosis until 12 to 24 months after initial symptoms appeared (Shaw et al., 2019). Feelings of anger, discredit, and the need to fight for a diagnosis surfaced in many individuals but also created doubt of their own condition in others (Knoop &

Dunwoody, 2021). Due to the complex nature of POTS, it is often misdiagnosed with anxiety, panic disorders and other mental health conditions.

Relevance of Occupational Therapy

According to the OTPF-4, the occupation of health management is a domain within the scope of occupational therapy. This category encompasses communication with the health care system through advocacy, expression of needs, and health literacy (AOTA, 2020). It is found that the lack of awareness and the emotional impact of being dismissed further increases distrust between the POTS community and the healthcare system (Waterman et al., 2021). The lack of physician awareness may also raise concerns on how to effectively be a caregiver since this condition is not widely known. Many individuals with POTS feel a disconnect between them and their provider; however, occupational therapists can bridge the gap in communication between them through assertiveness training, motivational interviewing, listening skills, and providing resources for the POTS community to avert mistrust and negate the feelings that stem from the lack of understanding.

Suggested Interventions

Assertive Communication

Assertive communication is the ability to express your point of view in a clear and direct manner, while respecting others. This allows you to communicate your wants and needs (Cancer Care, 2022).

OT Role & Relevance to POTS

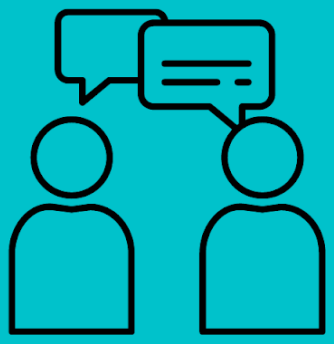
Currently, there is a disparity between healthcare providers' knowledge of POTS and how to empathetically express their lack of understanding. This leads to issues with persons with POTS often feeling dismissed and uncertain of how to move forward (Waterman et al., 2021). It was found that assertiveness can help improve the quality of care one receives, while poor communication can impact how a client regulates their emotions, discourages understanding of crucial medical information, and creates a barrier in identifying a patients' needs, perceptions, and expectations (Ha & Longnecker, 2010).

Assessments

- The Assessment of Communication and Interaction Skills (ACIS) is an assessment that gathers information on an individual's communication and interaction skills through observation.
    - Cost: $40
    - Administration:pen and paper
    - Assessing a client's physicality, information exchange skills, and relations to gain a better understanding of their communication style and interaction skills

https://moho-irm.uic.edu/productDetails.aspx?aid=1

ASSERTIVE COMMUNICATION



WHAT IS ASSERTIVENESS?

The ability to express your point of view in a clear and direct manner, while respecting others. This allows you to communicate your wants and needs (Cancer Care, 2022).

HOW IT HELPS

- Clear understanding of you wants, needs, and expectations
- Improve quality of care
- Exude confidence
- improve communication

How to Improve Assertiveness

- **Use "I" statements**
- **Avoid attacking or blaming a person by beginning a statement with the word "you."**
- **Honest and detailed with what you want or need**
- **Ask speaker to explain clearly if confused**
- **Speak up**

BENEFITS:

Helps regulate emotions and translates a person's needs, perceptions, and expectations to any situation

Ha, J. F., & Longnecker, N. (2010). Doctor-patient communication: a review. *The Ochsner Journal, 10(1)*, 38–43.
https://www.cancercare.org/publications/317-the_value_of_assertiveness_when_talking_to_your_doctor#:~:text=Let%20the%20doctor%20know%20if%20you%20need%20them%20to%20speak,Be%20honest%20and%20detailed.

Suggested Interventions

Health Coaching

Health coaching is a role in which a person, whether a professional or peer, supports a patient to be an active participant in the self-management of their condition or life circumstance. The scope of coaching can range from symptom management or education, behavior change strategies, and emotional support (Lindner et al., 2003). This can also be used to improve health literacy and advocacy.

OT Role & Relevance to POTS

A supportive relationship between healthcare practitioners and clients is vital as it can foster trust and increase adherence to treatment. Individuals with POTS face misdiagnosis due to the invisible, indescribable, and immeasurable nature of the condition and more often than not have their concerns dismissed (Shaw et al., 2019). The complex nature of POTS and the lack of empathy from healthcare practitioners can produce increased feelings of anger, discredit, and doubt individuals (Knoop & Dunwoody, 2021). Occupational therapists can offer health coaching to help advocate for patients who may be undiagnosed or misdiagnosed. Coaching can be used to educate clients, provide emotional support, and provide strategies for behaviors and management. Occupational therapists can teach individuals to use assertive communication skills to communicate efficiently with healthcare professionals. This can foster health literacy and efficacy to encourage advocacy when patients feel dismissed.

What is Health Coaching

Health coaching is a role in which a person, whether a professional or peer, supports a patient to be an active participant in the self-management of their condition or life circumstance. The scope of coaching can range from symptom management or education, behavior change strategies, and emotional support (Linder, 2003)

Key Points

- Educate
- Offer strategies to change behaviors
- Emotional support

→

- Foster advocacy
- Increase efficacy
- Improve health literacy

Encourage

Assertive Communication
Skilled Listening Skills
Adherence to treatment

Lindner H., Menzies D., Kelly J., Taylor M. (2003) Coaching for behaviour change in chronic disease: A review of the literature and the implications for coaching as a self-management intervention. Australian Journal of Primary Health 9, 177-185. https://doi.org/10.1071/PY03044

Suggested Skills for Healthcare Provider

Motivational Interviewing

Motivational interviewing is a collaborative and goal-oriented style of communication. It is characterized with a change as its focus. It builds on empathy, understanding, and emotional attitudes when conversing with an individual. Through this, motivational interviewing promotes a conversation that is non-judgmental to build trust and improve a person's motivation and commitment (Szczekala et al., 2018).

OT Role & Relevance to POTS

Waterman et al. (2021) found that one of the biggest issues individuals with POTS face is communication with the healthcare system. They often feel dismissed or not taken seriously, as their condition is not widely known. Additionally, individuals with POTS may initially receive an inaccurate diagnosis because their symptoms may overlap with those of a condition. Healthcare professionals can help gain trust and improve empathy with this population by incorporating motivational interviewing.

OT Handout

Motivational Interviewing

ENGAGE, FOCUS, EVOKE, & PLAN

Engage:

Focus:

Evoke:

Plan:

OARS

O: open-ended questions

A: affirmations

R: reflections

S: Summarizing

Important Takeaways:

https://motivationalinterviewing.org/understanding-motivational-interviewing

Suggested Skills for Healthcare Provider

Listening Skills

Skilled listening, especially when active and empathetic, has demonstrated improvements in professional and personal relationships, strengthened compliance, and facilitated understanding between individuals. It also fosters trust and mutual respect in many situations (Doas, 2015). Incorporating these skills into practice also promotes effective communication which in turn facilitate good doctor-patient communication to help regulate clients' emotions and allow for better identification of clients' needs, perceptions, and expectations (Ha & Longnecker, 2010).

OT Role & Relevance to POTS

Due to the unpredictable nature of symptoms, individuals with POTS are often misdiagnosed or dismissed which further impedes their access to health care. Shaw et al. (2019) reports that 75% of individuals in a sample of 3,421 were misdiagnosed and did not receive a proper diagnosis until 12 to 24 months after initial symptoms. Oftentimes, individuals feel brushed off before receiving the proper diagnosis to the point where they are not taken seriously. Mastering empathetic and active listening techniques can help a healthcare practitioner fully understand a client's concerns for the promotion of health.

OT Handout

Listening Skills

Hurier Listening Model

H: ***Hearing***
U: ***Understanding***
R: ***Remembering***
I: ***Interpret***
E: ***Evaluate***
R: ***Respond***

Effective Listening

- **Improves interpersonal trust/relations**
- **Encourages direct and frequent communication**
- **Improves individual's self-perceptions**

Active Listening Techniques

- Observing
- Reflecting
- Emotion Labeling
- Restating
- Encouraging
- Giving Feedback
- Probing
- Silence/Effective Pause
- "I" messages
- Redirecting
- Validating
- Summarizing

Listening skills promote effective communication

Brownell, J. (1994). Creating strong listening environments: A key hospitality management task. International Journal of Contemporary Hospitality Management, 6, 3-10. https://doi.org/10.1108/09596119410059182
https://www.bumc.bu.edu/facdev-medicine/files/2016/10/Active-Listening-Handout.pdf

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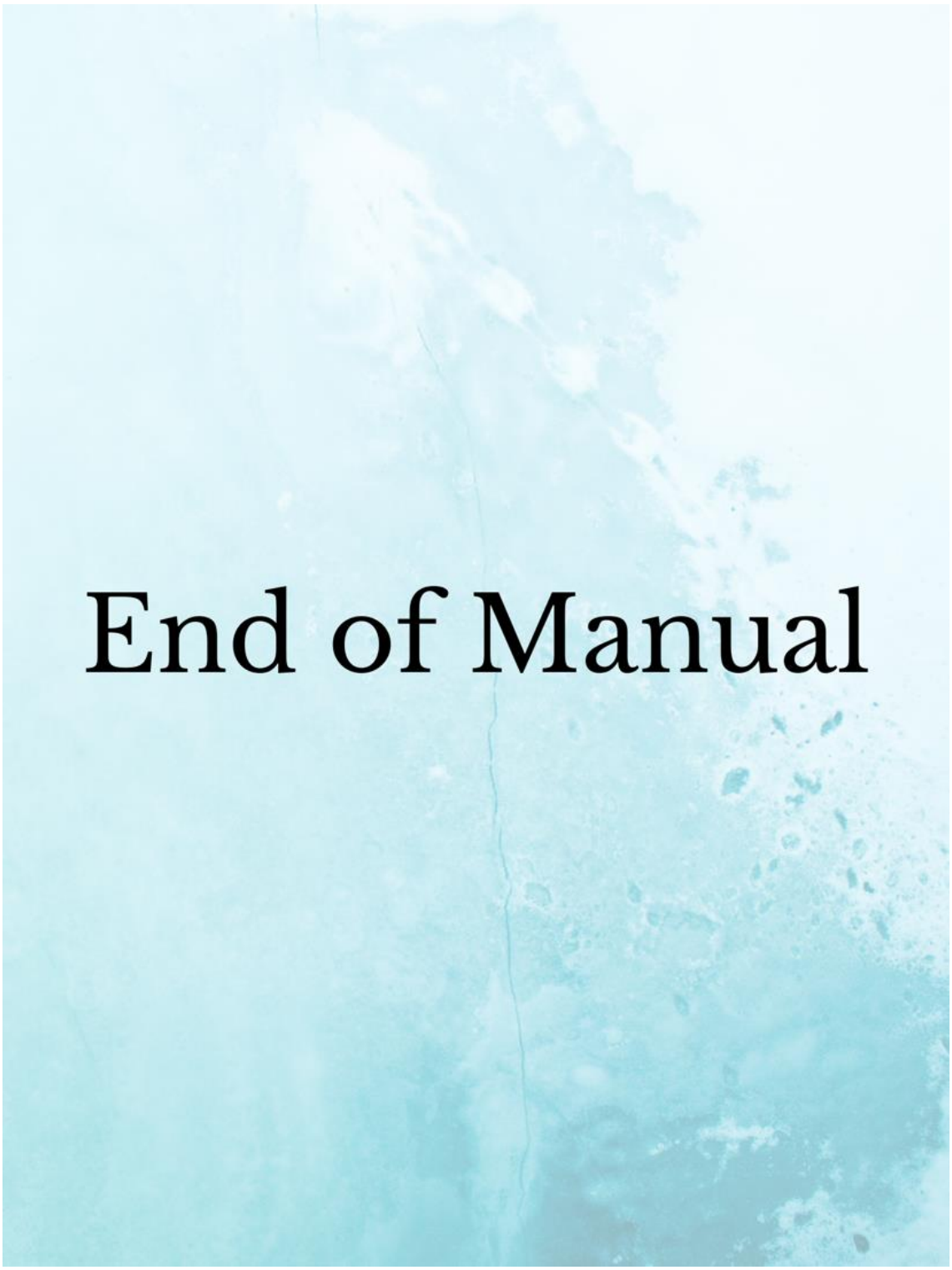
Waterman, S., Opie, M., Waterman, D., & Langdon, D. (2021). Experiences of living with postural tachycardia syndrome. *Chronic Illness*, Advance online publication. https://doi.org/10.1177/17423953211054032

Resource Page

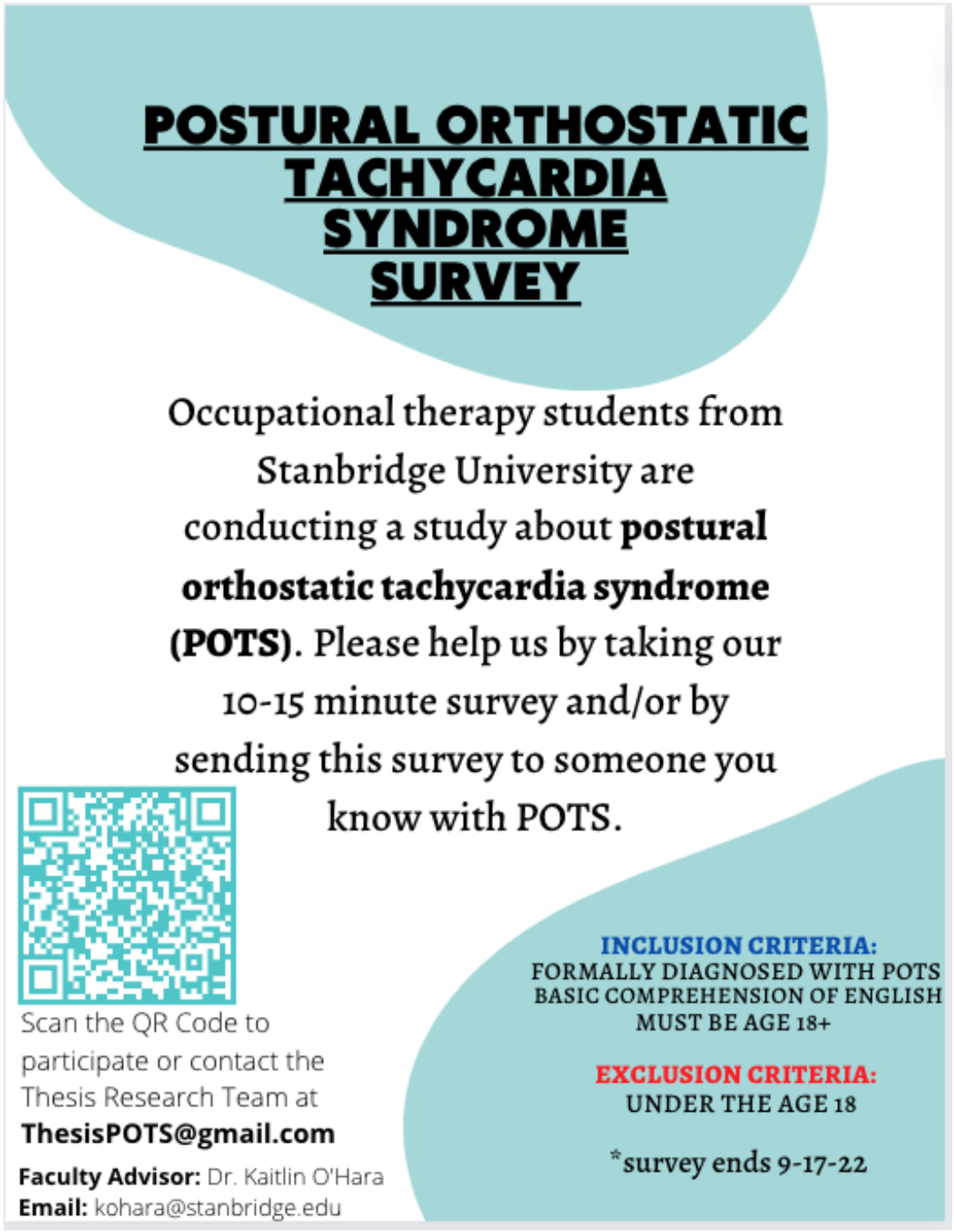
Online

- **Dysautonomia groups**
  - https://thedysautonomiaproject.org/resources/
  - http://www.dysautonomiainternational.org/page.php?ID=24
- **NAMI- National Alliance on Mental Health**
  - https://nami.org/Home
- **Standing up to POTS**
  - https://www.standinguptopots.org/livingwithpots/pots-tricks
- **Suicide & Crisis Lifeline**
  - https://988lifeline.org/


End of Manual

Appendix B

Recruitment Flyer



Appendix C

Postural Orthostatic Tachycardia Syndrome Survey

The purpose of this survey is to gather insight into the lived experience of individuals with Postural Orthostatic Tachycardia Syndrome (POTS). Your participation in this survey is greatly appreciated and will contribute to the advancement of lifestyle-based treatment interventions for POTS. We look forward to sharing the results of our survey and subsequent manual we will compile off of participant results and evidence-based literature reviews. We have provided the following resources in the interim to assist those individuals who may be currently experiencing POTS symptoms:

Dysautonomia groups:
https://thedysautonomiaproject.org/resources/
http://www.dysautonomiainternational.org/page.php?ID=24

Stand up to POTS website:
https://www.standinguptopots.org/livingwithpots/pots-tricks

By completing this survey, you are agreeing that you are 18 years or older, and you have provided consent to be a participant in this study and for us to use the information submitted in our manual development.

- ❑ By checking this box, I agree to give consent to have my information used in the research study and have read the information above.

1. **What age range do you fall within?**
   - ❑ Under 20
   - ❑ 20-25
   - ❑ 26-30
   - ❑ 31-35
   - ❑ 35+

2. **Which sex are you? (Referring to biological characteristic)**
   - ❑ Male
   - ❑ Female
   - ❑ Other
   - ❑ I prefer not to say

3. **What type of residence do you live in?**
   - ❑ Apartment Complex
   - ❑ Unit housing
   - ❑ Single Level Home
   - ❑ Multiple Level Home
   - ❑ Other: _____

The following questions are asked to provide insight on whether you were formally diagnosed with postural orthostatic tachycardia syndrome (POTS) or any other comorbidities. We would also like to know your current care team when dealing with this condition.

4. **Have you been formally diagnosed with POTS?**
   - ❑ Yes
   - ❑ No
   - ❑ Other: _____

5. **Other than Postural Orthostatic Tachycardia Syndrome (POTS), do you experience any other comorbidities? (Check all that apply.)**
   - ❑ Chronic fatigue
   - ❑ Chronic headache
   - ❑ Insomnia
   - ❑ Fibromyalgia
   - ❑ Ehlers-Danlos Syndrome (EDS)
   - ❑ Mental health issues
   - ❑ Joint hypermobility syndrome
   - ❑ Gastrointestinal Disorders
   - ❑ Other: _____

6. **What does your current care team look like?**
   - ❑ Primary care doctor
   - ❑ Neurologist
   - ❑ Physical Therapist
   - ❑ Occupational Therapist
   - ❑ Cardiologist
   - ❑ Other: _____

7. **How long have you been living with chronic disease? (Check the one that applies.)**
   - ❑ less than 1 year
   - ❑ 1-5 years
   - ❑ 5-10 years
   - ❑ 10-15 years
   - ❑ 15 years+

The next set of questions will help us determine how symptoms affect your day-to-day life and whether you require assistance to complete tasks.

8. **Have you experienced any of the following? (Check all that applies.)**
   - ❑ Pain
   - ❑ Difficulty with memory
   - ❑ Fatigue

- ❑ Weight changes
- ❑ Depression or mood changes
- ❑ Muscle weakness
- ❑ Headache
- ❑ Dizziness or balance problems
- ❑ Difficulty sleeping
- ❑ Syncope (fainting)
- ❑ Appetite changes

9. What activities are you experiencing difficulties with? (Check all that apply.)

- ❑ Bathing/Showering
- ❑ Care of home
- ❑ Dressing
- ❑ Exercise
- ❑ Education
- ❑ Grocery Shopping
- ❑ Hobbies/Leisure
- ❑ Moving in the home/community
- ❑ Social Participation
- ❑ Transportation
- ❑ Work Activities
- ❑ Sleeping
- ❑ Sexual Activity
- ❑ Nutrition
- ❑ Emotional well-being
- ❑ Symptom and condition management
- ❑ Medication management
- ❑ Other: _____

10. Do you require assistance from friends or family?

- ❑ No time at all, completely independent
- ❑ Assistance in 1-2 activities per day
- ❑ Assistance in 3-5 activities per day
- ❑ All the time, dependent on friends or family

The following questions will determine what areas you may need help with.

11. Which of these statements do you identify with most?

- ❑ I don't know anything about self-managing POTS
- ❑ I know a little bit about self-managing POTS
- ❑ I feel like I know a decent amount but could use more information about self-managing POTS
- ❑ I feel pretty knowledgeable about self-managing POTS
- ❑ I feel very knowledgeable and confident about self-managing POTS

12. What information would you like to learn more about related to POTS? (Check all that apply.)

(Cognitive) *The mental action or process of thinking, reasoning, or remembering*

- ❑ Strategies to aid with memory problems
- ❑ Strategies to help with concentration
- ❑ Strategies to aid with mental clarity
- ❑ Other: _____

(Psychosocial) *The relation between social factors and individual thought and behavior.*

- ❑ Coping with stress or relaxation strategies
- ❑ Feeling confident in yourself
- ❑ Staying positive throughout your day
- ❑ Community Resources
- ❑ Communicating with healthcare professionals and caregivers
- ❑ Other: _____

(Sensorimotor) *Relating to sensory and body movement functions.*

- ❑ Energy conservation/fatigue management
- ❑ Making your home more accessible
- ❑ Moving about in your home or community
- ❑ Pain management
- ❑ Other: _____

13. How has POTS impacted your life?

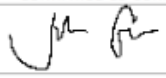
Thank you for participating in our study and completing this survey. We also would like to ask if you could share this survey to other people diagnosed with POTS. We will greatly appreciate your assistance to further our efforts and once again, thank you for your time and effort!

Appendix D

Institutional Review Board Approval

Dear Dr. Kaitlin O'Hara and Students,

The Stanbridge University Institutional Review Board has completed the review of your application entitled "An Occupational Perspective into POTS Management: A Manual for Occupational Therapists." Your application (MSOT011-514) is approved and categorized as Expedited.

IRB Application Number	MSOT011-514
Date	08/27/2022
Level of Review	**Expedited**
Application Approved	X
Conditional Approval	
Disapproved	
Comments	The requested Minor changes have been reviewed and confirmed as completed by the IRB. (08/27/2022)
Signature of IRB Chair	

Please note that any anticipated changes to this approved protocol requires submission of an IRB Modification application with IRB approval confirmed prior to their implementation.

Sincerely,
Julie Grace, M.S., M.A.
IRB Chair

Appendix E

Figures

Figure E1

What age range do you fall within?

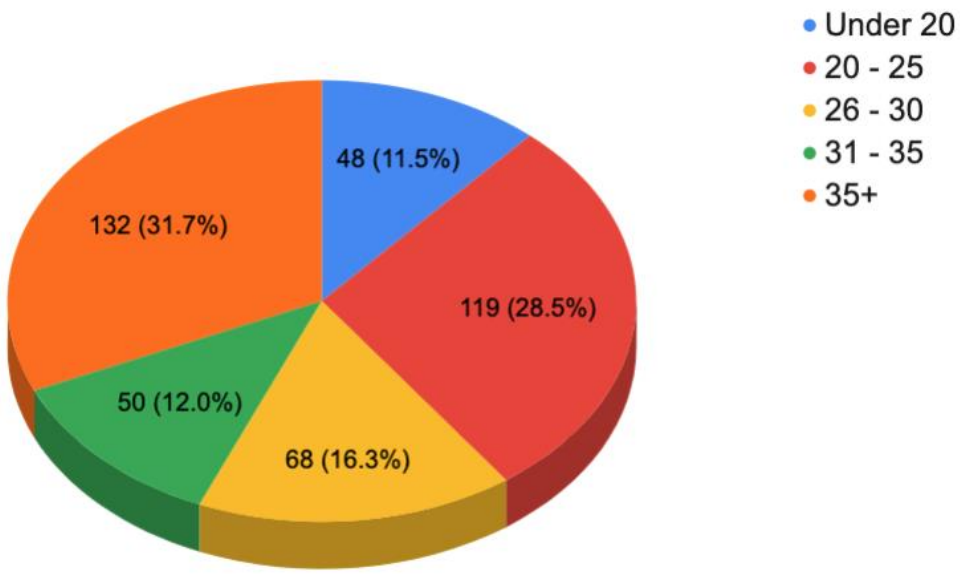


Figure E2

Which sex are you? (referring to biological characteristic)

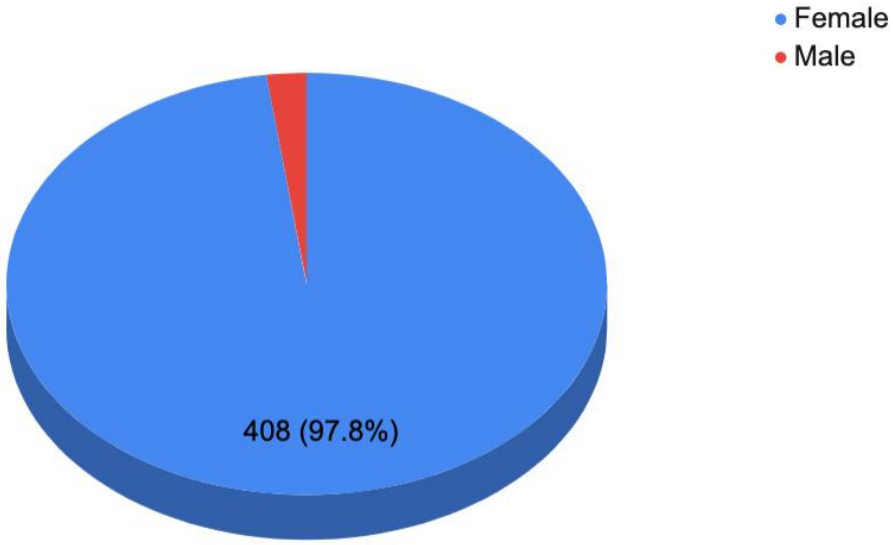


Figure E3

What type of residence do you live in?

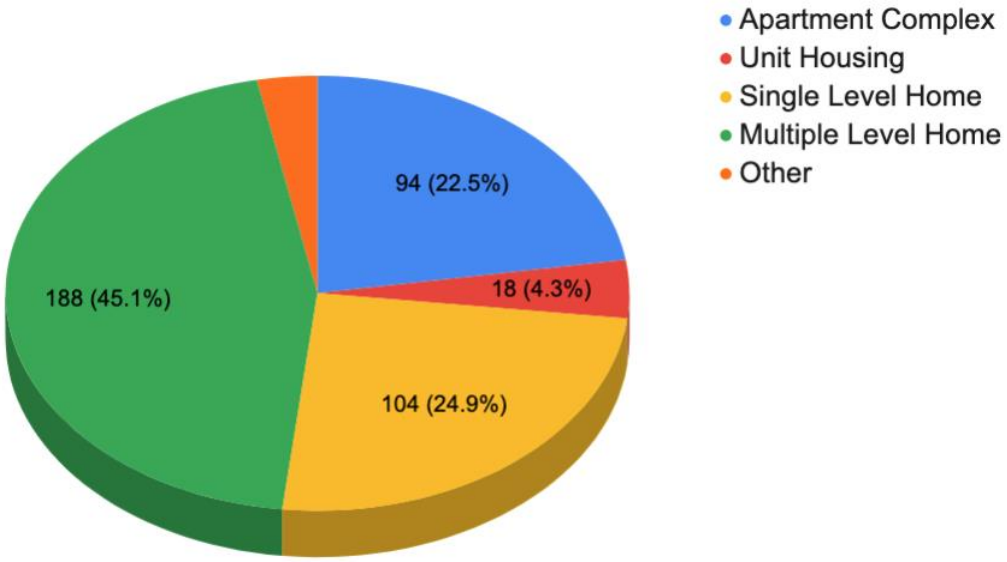


Figure E4

Other than postural orthostatic tachycardia syndrome (POTS), do you experience any other comorbidities? (Check all that apply.)?

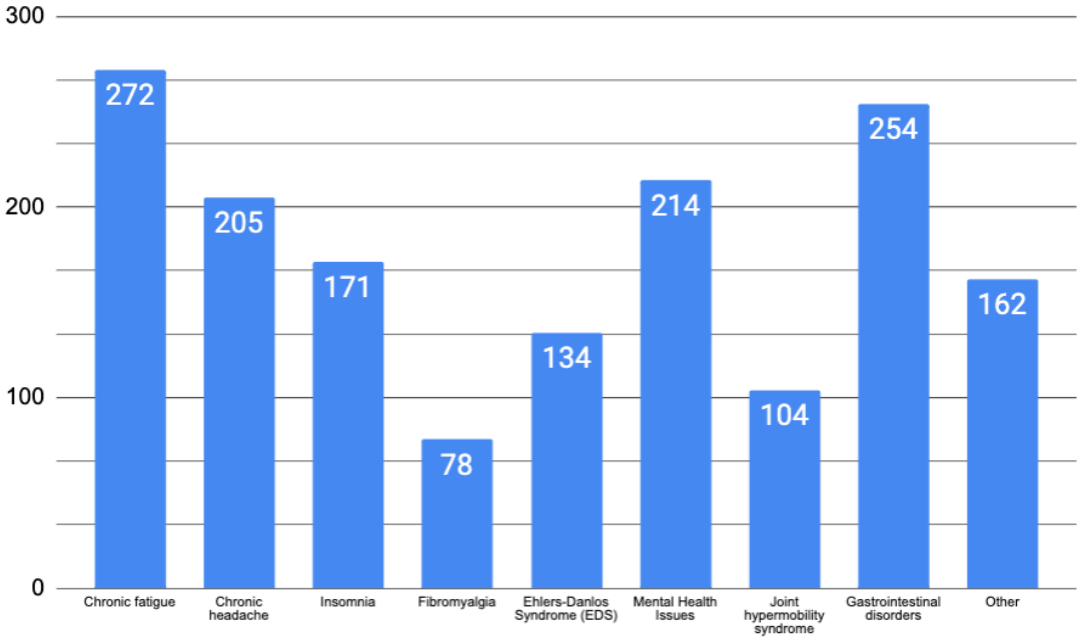


Figure E5

What does your current care team look like?

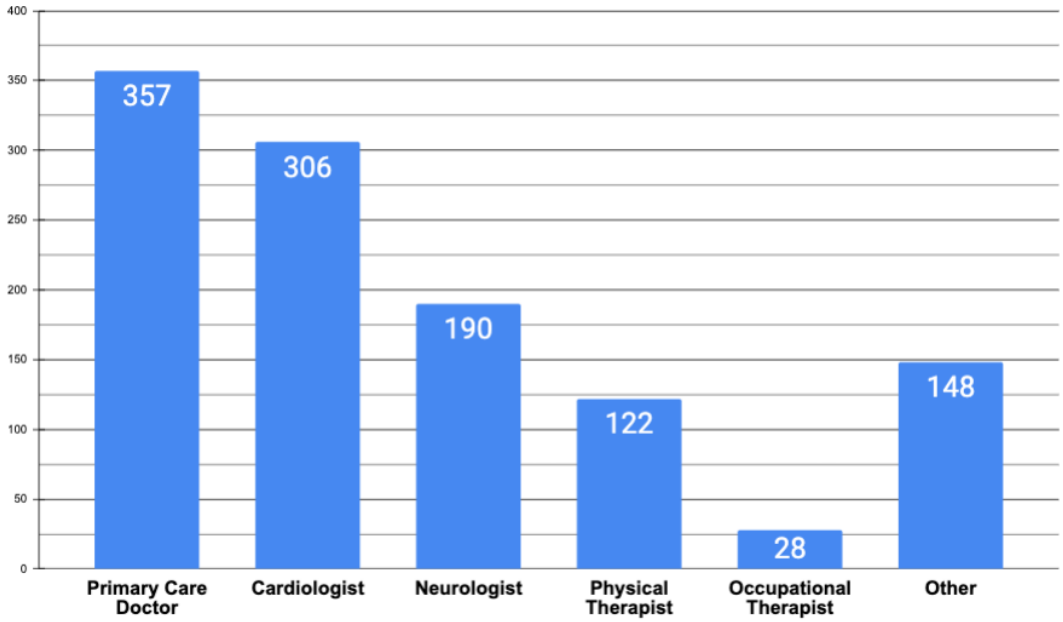


Figure E6

How long have you been living with a chronic disease?

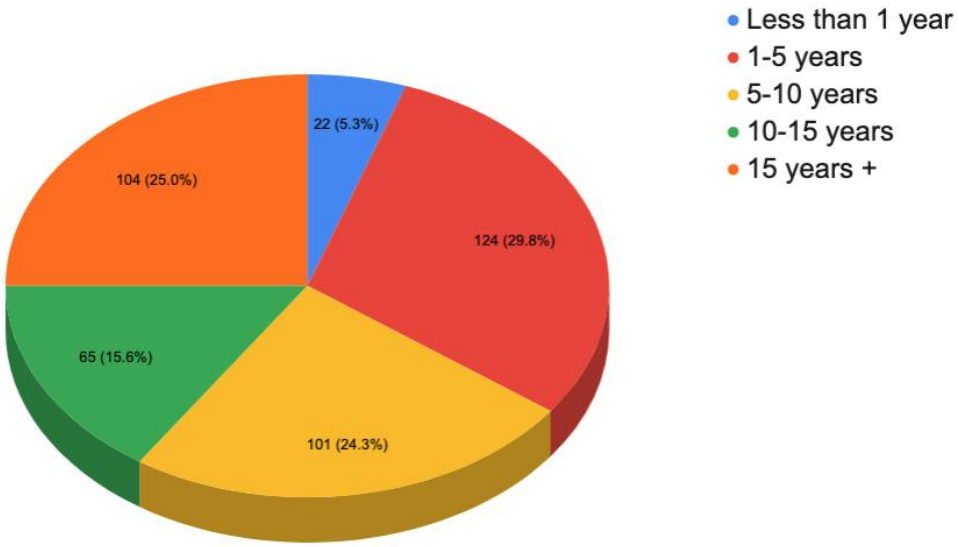


Figure E7

Have you experienced any of the following (Check all that applies.)

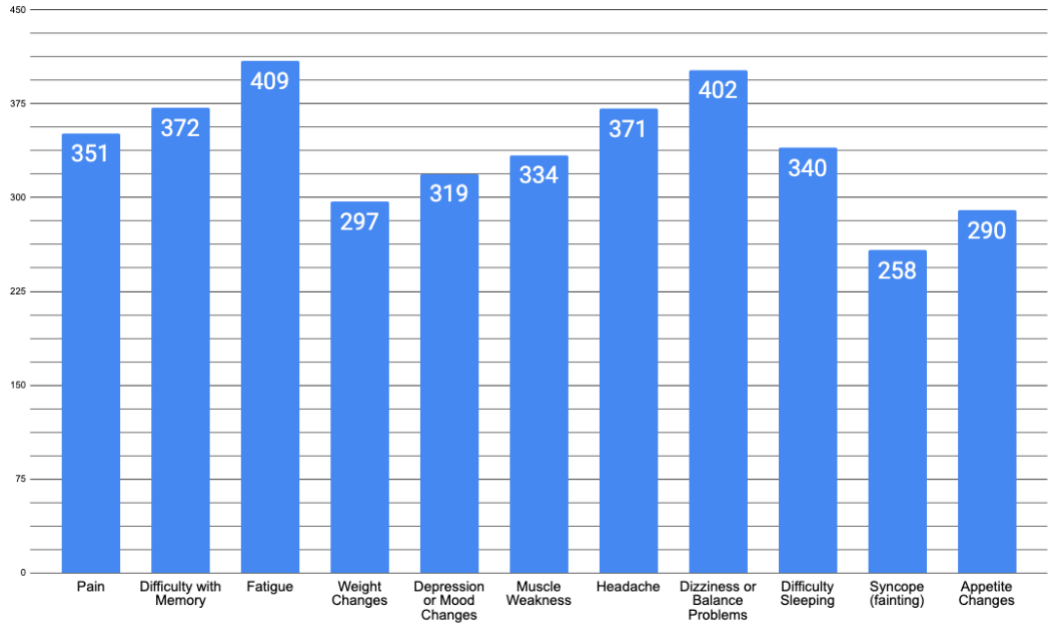


Figure E8

What activities are you experiencing difficulties with? (Check all that apply.)

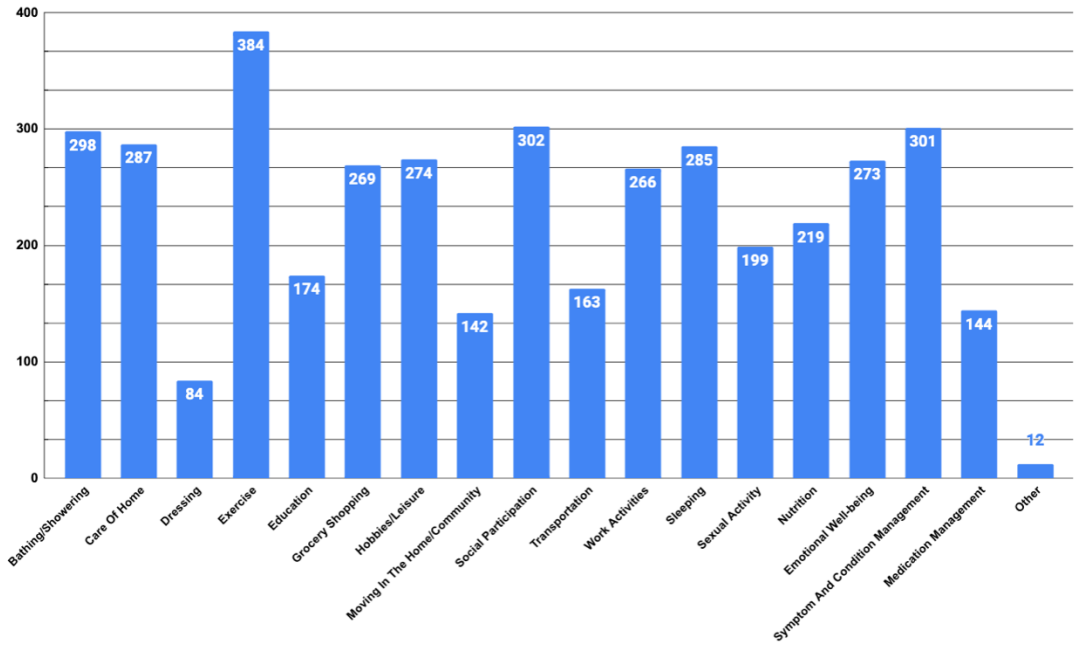


Figure E9

Do you require assistance from friends or family?

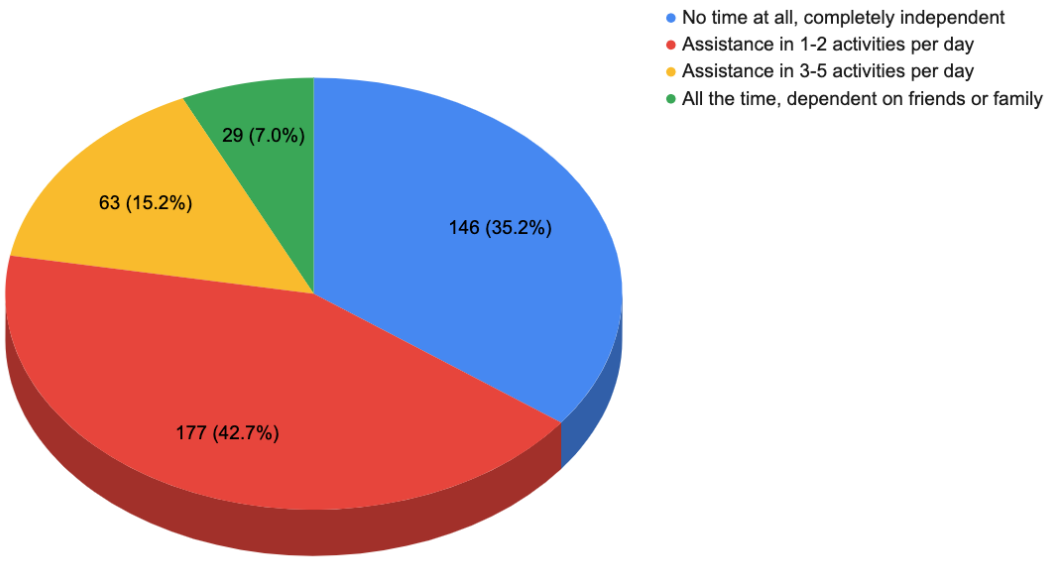


Figure E10

Which of these statements do you identify with most?

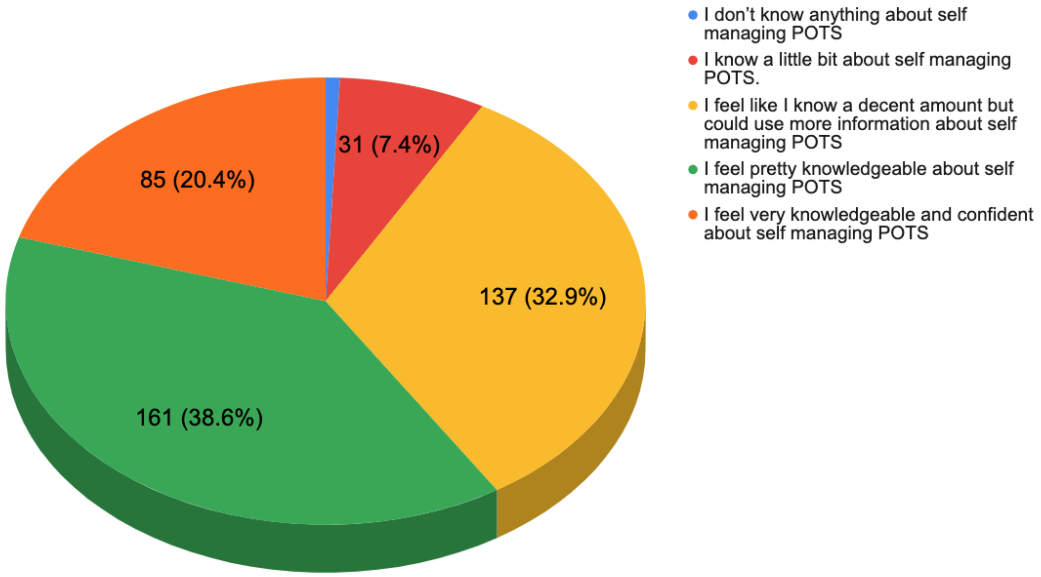


Figure E11

What information would you like to learn more about related to POTS? (Check all that apply.)

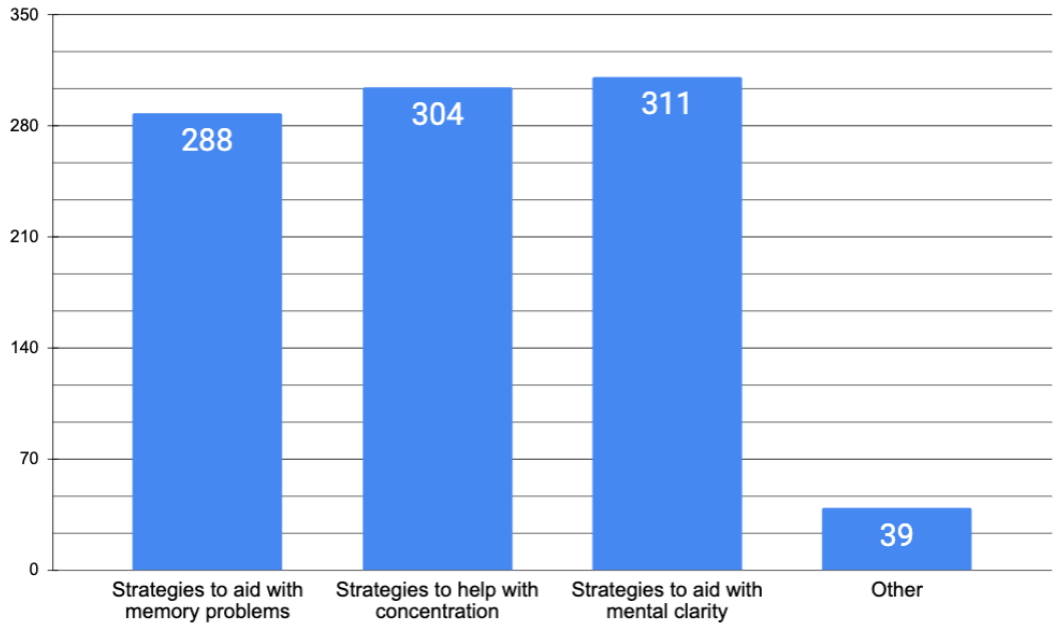


Figure E12

What information would you like to learn more about related to POTS? (Check all that apply.)

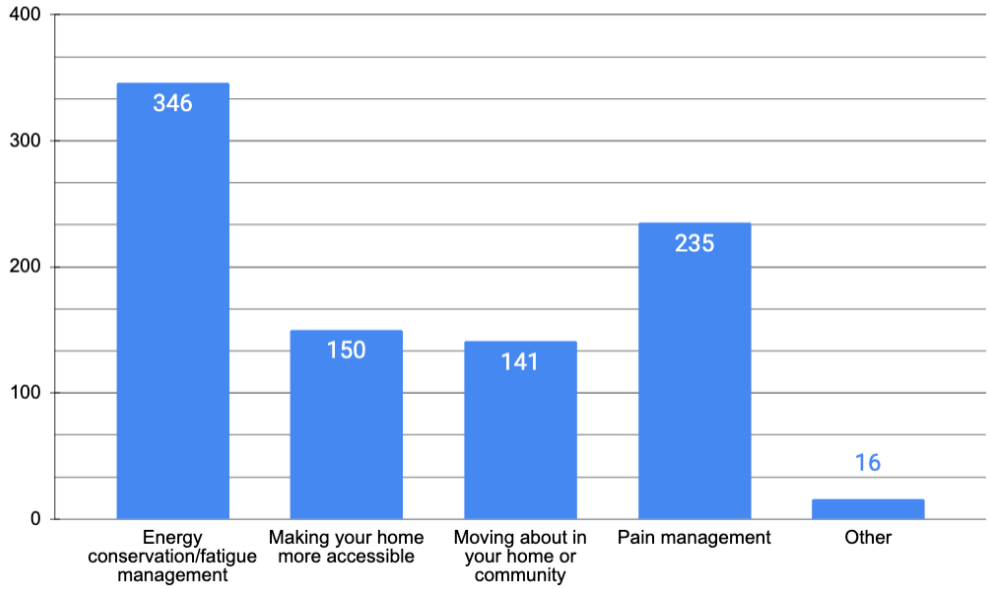


Figure E13

What information would you like to learn more about related to POTS? (Check all that apply.)