Occupational Adaptation as a Model for Intervention in Postural Orthostatic Tachycardia Syndrome (POTS)

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Postural Orthostatic Tachycardia Syndrome (POTS) often presents with chronic symptoms and impacts a wide variety of areas of occupation, including activities of daily living, sleep, work, school, leisure, play, and social participation. The Occupational Adaptation theory supports practitioners in offering clients opportunities to develop internal adaptive processes to achieve relative mastery in desired occupations. The present manuscript provides a foundation for Occupational Adaptation theory as an appropriate model for intervention in POTS with specific assessments and interventions to guide occupational therapy practitioners in implementing this approach. A case study describes the use of Occupational Adaptation in the clinical intervention of a college student with POTS.

Keywords: postural orthostatic tachycardia syndrome; POTS; occupational therapy; practice model; occupational adaptation

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Postural Orthostatic Tachycardia Syndrome (POTS) is a condition of autonomic nervous system dysfunction, characterized by tachycardia with positional changes, without meeting criteria for orthostatic hypotension. Approximately 31-37% may experience full resolution of their symptoms (Bhatia et al., 2016; Sousa et al., 2012), but the remainder will experience ongoing symptoms for months or years, thus classifying POTS in this segment of individuals as chronic. Some individuals maintain full-time employment with little-to-no functional limitations, while others are on disability, unable to work, and might require a wheelchair for mobility (Benrud-Larson et al., 2002; Rich et al., 2021). As a result of the persistent nature of symptoms in most clients, adaptive strategies are critical for functioning that is efficient, effective, and satisfying.

Self-management is essential for individuals living with POTS, but many cannot meet the challenge independent of external guidance. Co-morbid conditions commonly accompany POTS and often contribute to complexity in treatment (Garland et al., 2015). At present, intervention models or practice guidelines related explicitly to POTS do not exist in occupational therapy. Due to the limited intervention options, an average diagnostic delay of more than four years (Shaw et al., 2019), and long waitlists for specialty providers, clients often experience a scarcity of interventions. Occupational therapy practitioners have a role in facilitating an increase in participation and self-management to decrease the burden on medical providers while guiding adaptability.

Occupational Adaptation as a guiding theory

The Occupational Adaptation (OA) theory is well suited to guide therapeutic intervention for persons with POTS. Central to the assumptions of Occupational Adaptation is a process by which humans adapt to changing needs and conditions through occupation, where occupations are defined as everyday activities that "occupy" one's time. Further, the desire to participate in occupation is the intrinsic motivational force leading to adaptation. Occupational adaptation is a normative process that is most pronounced during periods of transition, such as Molly's transition from home to college in the case that follows. The greater the adaptive transitional needs, the greater the importance of the occupational adaptation process, and the greater the likelihood that the process will be disrupted. When a person is stuck in a dysadaptive state, a primary aim is to produce an adaptive response to occupational challenges (Schkade & Schultz, 1992; Schultz & Schkade, 1992). You will see that Molly was stuck in a downward spiral of increasing symptoms and declining function and needed assistance to enhance adaptive responses to her various occupational challenges.

Mastery is more than the ability to perform a discrete task; it reflects the client's experience as an occupational being. Because of the desire for mastery, the person intends to produce a response for the occupational challenge that will be adaptive and, therefore, will lead to mastery. Relative mastery is the extent to which the person experiences the occupational response as efficient (use of time and energy), effective (production of the desired result), and satisfying to self and society; that is, it is pleasing not only to the self but also to relevant others as agents of the *occupational environment* (Schkade & Schultz, 1992; Schultz & Schkade, 1992).

The following case study describes how an occupational therapist, guided by OA theory, helped "Molly" reengage in her occupational roles.

Case Study

Background. Molly, a twenty-year-old female with a POTS diagnosis, was forced to take a one-year leave of absence from college after finishing her freshman year. Being away from home, she failed multiple courses while experiencing declining health and participation. Upon starting college, Molly entered a rigorous course load, living on the third floor of a building with no elevator with new roommates, and away from her support system at home with needing to do all the laundry, shopping, cooking, and cleaning on her own. Despite pharmacologic intervention and a previously adequate baseline level of function, the stress, physical demands, and time constraints of this life changing transition led to declining health and poor academic performance. Molly's neurologist referred her to occupational therapy in an outpatient setting due to her occupational challenges in school and instrumental activities of daily living (IADLs).

Molly came to occupational therapy with the goals of returning to her roles as a student and an independent living adult, which meant improving physical and psychological health, increasing participation, and maintaining adequate health while performing well in college courses. Upon presentation, Molly had past experiences of failure affecting her motivation. However, she still experienced a *desire for mastery* including schooling; endurance for self-care, cleaning tasks, and meal preparation; and socializing as a college student. Additionally, Molly faced overwhelming environmental *demands for mastery.* The college environment demanded new strategies for learning and managing multiple responsibilities, her living environment had built in challenges requiring creative modifications, and a lack of social support demanded time to locate and invest in new resources. The desire for mastery combined with the demands of the environment created a *press for mastery.* Because her adaptive capacity was overwhelmed by the demands for mastery, assistance in producing adaptive responses to

the occupational challenges provided a press for mastery and demanded increasing adaptive capacity.

Evaluation. At the initial evaluation, the occupational therapist used the semi-structured interview of the *Canadian Occupational Performance Measure* (COPM) (Law et al., 1990) to identify the client's prioritized occupational challenges and current level of performance and satisfaction in these challenges. The assessment outcome demonstrated the following top five areas of importance to Molly: health management, completing household tasks and grocery shopping, climbing stairs, academic performance, and social participation with persistent health challenges. Molly's self-reported performance and satisfaction were low (four or less) in all identified areas. To successfully adapt, Molly needed to teach the therapist about her meaningful occupational roles and the environmental context surrounding those roles. Together Molly (as the expert on her life roles and aspirations) and the occupational therapist (as an expert on resources, adaptive strategies, and symptom management) developed an intervention plan.

Intervention. *Occupational readiness* activities included cognitive-behavioral techniques, motivational interviewing, an interest checklist, energy conservation techniques, and sleep hygiene. Additionally, targeting the specific nature of her condition, activities included breathing strategies, heart-rate variability training, education and planning for proper salt and fluid balance, and learning about the pathophysiology of her condition for a comprehensive understanding of symptom triggers. These activities can be seen as skill-building strategies for a foundation to begin developing adaptive capacity.

Occupational activities describe real-world tasks in-context. These included a trial of various scripts for social interactions to articulate her health needs, use of a

calendar for daily routine, recognition of symptom aggravation and implementation of skills (e.g., tachycardia management through breathing and mindfulness, positioning, counterpressure maneuvers). Sessions also included activities of daily living (ADL) and IADL participation with modifications (e.g., positioning, planning, increasing efficiency), regulation of exertion using the rate of perceived exertion scale, and implementing cognitive tools for academic performance.

Through adjustments to the occupational environment, Molly successfully performed laundry, cooking, and grocery shopping using appropriate positioning, assistive devices, and delivery services. Molly received a modified dorm placement on the first floor of the building and used a modified laundry bag which facilitated energy conservation. She purchased a robot vacuum and used long-handled cleaning and self-care items, which minimized the exertion demands of holding her arms overhead and bending over. Accommodations through the college disability center provided options for a note-taker, extended time on tests, closer parking on campus, and ample time to complete projects in the case of a flare of symptoms. These accommodations fostered an environment of success and increased Molly's self-efficacy in academics despite her limitations.

Molly found occupational engagement through new leisure activities she could perform with peers, alternative routines and strategies for self-care, and an appropriate physical exercise routine. At the start of therapy, the occupational therapist led the sessions by providing information and strategies that she felt could support Molly. Over time, however, Molly relied less on the practitioner and began to customize strategies to her own life, making the concepts her own. As sessions progressed, Molly and the practitioner worked as a team to individualize strategies to her specific needs. Eventually, Molly was able to produce solutions independently using the practitioner as

a sounding board. By modifying the frequency, duration, complexity, and demands of various occupations, Molly successfully performed a variety of activities.
Self-management of her condition was enhanced through self-evaluation of *relative mastery* by reflecting on perceived efficiency, effectiveness, and satisfaction to self and others.

The occupational therapist observed an increase in internal adaptation through observation of generalizing adaptive strategies to new activities. For example, Molly utilized a method she had practiced in the kitchen - using counterpressure maneuvers to increase static standing endurance - by spontaneously implementing this skill while waiting in line to board an airplane. Additionally, Molly initiated a new approach in a novel situation when she used a visualization memory strategy in the shower, where she could not write a reminder. At this stage of intervention, Molly showed sufficient adaptive capacity through independent problem-solving in various activities. Follow-up assessment on the COPM showed clinically meaningful improvement in satisfaction and performance in all domains and overall averages, as demonstrated by an increase of more than two points on each scale.

After 12 visits over four months, she was discharged from occupational therapy with plans to return to school the following semester. Molly described a sense of satisfaction in her ability to perform the identified areas of importance, including managing her health, using modified techniques for IADLs, accommodations for stairs and college coursework, as well as navigating peer relationships. Her mother also expressed increased confidence in Molly's ability to return to college and manage challenges that previously exceeded her capacity. Since the described roles and activities were meaningful to Molly, she experienced more efficient outcomes with increased generalizability. Rather than focusing on learning discrete skills, Molly was

motivated by her desire to return to meaningful roles, most notably as a student and friend. Molly successfully returned to school at the start of the following academic year with improved self-management skills, participation, and overall health.

Effects of Occupational Dysadaptation

Due to symptom provocation with positional changes, POTS symptoms often lead a person to a hyperstable adaptive response (or rigid adherence to previous behaviors), including disengagement in activities. As individuals seek stability, this state of hyperstability is not necessarily a negative response. Hyperstability may present as increased time spent lying in bed or less physical movement and sensory stimulation. However, overreliance on withdrawal as a primary adaptive behavior becomes dysadaptive, contributing to increased debility and worsening symptoms associated with *person system* deficits: decreases in muscle tone, lower tolerance of upright postures or positional changes, and less social engagement. Additionally, clients may experience increases in sensitivity to sensory input, pain, and overall medical costs as a result. In our case example, Molly's hyperstable adaptive responses led to withdrawal from everyday activities and a need for rehabilitation (occupational therapy intervention) to return to her occupational roles.

Individuals have different participation outcomes due to their occupational environments, including the physical, cultural, and social aspects. Disengagement in work or school tasks may contribute to financial hardship and a decreased sense of productivity. Limitations in leisure, play, or social participation may have a psychosocial impact on the person. Increased dependence on others for self-care tasks or decreased participation in daily activities can negatively impact psychosocial, cognitive, and sensorimotor person systems, with subsequent decreases in *adaptive*

capacity. Molly's difficulties due to a new living environment and role as a college student impacted her ability to participate as a student, friend, and family member.

As the internal occupational adaptation process improves, the following outcomes result: (a) the person begins to initiate changes in approaching occupational activities; (b) the person starts to generalize knowledge and competencies to other occupational activities spontaneously, and (c) the person begins to experience greater relative mastery (Schkade & McClung, 2001). Although the client may be improving in functional skills, a change in occupational adaptation may not be occurring. Molly was presented with information for occupational readiness, but the information alone did not make her functional in her occupational roles. Spontaneous generation of adaptive responses in novel situations signals that a person's positive adaptive capacity is functioning well, so Molly was prompted to engage in occupational activities that presented a just-right challenge to produce an adaptive response. An increase in relative mastery (as measured by formal assessment measure, client perception, and therapist observation) is the best indicator that change in the occupational adaptation process is taking place. Therefore, intervention provides a person with opportunities to produce adaptive responses to meaningful occupational challenges (Schkade & McClung, 2001; Schkade & Schultz, 1992; Schultz & Schkade, 1992).

[Insert Table 1 about here]

View of POTS from an Occupational Adaptation perspective

Like Molly, individuals with POTS may experience a disruption in occupational performance due to primary or secondary effects of the condition symptomatology. POTS symptoms commonly impact the occupational environments of self-care, work, and leisure or play. Each occupational role is influenced by the environment's physical, social, and cultural factors, which provide information about external role expectations.

Molly felt the external expectations of her parents, roommates, instructors, and medical professionals, each of these influencing her internal expectations for mastery of her occupational roles.

How expectations impact adaptive response generation can be illustrated with an example of a young mother with POTS. The ability to complete childcare is affected by the layout of the home, the presence of stairs, the height of the crib or playpen, and the weight and height of the child (physical environment). Access to or a lack of resources such as a nanny, family and friends nearby, daycare, and father or co-parent involvement all play roles in the demands of childcare placed on this mother (social environment). Lastly, expectations of family and community members, the decision to work outside the home or stay home with the child, paternal leave, and involvement of the health care system influence the occupation of parenting a child (cultural environment).

Internal or person system deficits (psychosocial, cognitive, and sensorimotor) are all commonly impacted, in various degrees, in individuals with POTS and may adversely contribute to diminished adaptive capacity. However, individuals with POTS have the potential to adapt, despite person system deficits, when provided with a just-right challenge to which they can generate an adaptive response. The resulting experience of relative mastery will increase the desire to meet the demands of additional occupational challenges with an improved adaptive repertoire. Intervention recommendations include both occupational readiness activities and occupational activities. It is important to understand that the manifestation of barriers to functioning in POTS are unique and varied and require an individualized approach to each client.

The OA theory is client-centered and encompasses all parts of the person (e.g., physical, emotional, intellectual, social, spiritual, environmental, occupational),

essential when working with individuals with chronic conditions. Rather than a collection of techniques, OA guides the practitioner's thought process in facilitating the client's internal adaptation process (Schkade & McClung, 2001). Outcomes for persons with POTS do not often result in complete resolution of symptoms; therefore, success must be defined in other ways. The OA theory provides both client and practitioner an opportunity to recognize progress and define a successful outcome. Increased adaptive capacity and relative mastery facilitate more opportunities for self-management in future challenges.

Description of Intervention Approach

The OA approach in this population is unique as compared to other approaches. Rather than instructing a client or directing them to the "correct" solution, the practitioner should expose the individual to ideas and allow them to choose the most appropriate solution for their life. This allows the person the opportunity to generate an adaptive response. In this way, the practitioner presents an artist's palette, giving a sample of many different approaches, and the client is the artist, designing their process to achieve the desired outcome.

As the individual evaluates their occupational response, the elements of relative mastery are considered. Finally, during *adaptive response integration,* information and experiences are internalized, resulting in homeostasis, occupational dysadaptation, or occupational adaptation. Rather than depending upon the practitioner, the client makes self-initiated changes through exposure to novel challenges, intending to develop an adaptive response. The accumulation of responses to occupational challenges leads to an expanded adaptive repertoire that in turn contributes to the generalization of adaptive behaviors and enhanced adaptive capacity.

Since the client is the active agent of change, the practitioner's role is to act as an agent of the environment, specifically modifying the environment, grading tasks, and providing feedback. The following are specific functions of the practitioner when working with clients with POTS (see Table 2 for activities in a plan of care):

1. Support psychosocial processing and learn about the client's unique experience.
2. Provide information and opportunities for modifications in client-centered ways.
3. Facilitate occupational adaptation by providing appropriate, meaningful novel challenges.
4. When the client begins to generalize skills to novel challenges and consistently demonstrates adaptive capacity, this indicates readiness for discharge.
5. Prepare client for discharge, including empowerment to tackle future challenges using an adaptive repertoire of successful strategies. Encourage self-management and forward momentum with an internal drive to limit dependence on external sources.

[insert Table 2 about here]

Phases of intervention

Time frames will vary, depending upon the client's unique circumstances, but the following phases for weekly intervention are recommended for their potential therapeutic value:

- Phase I: establish a therapeutic relationship, occupational readiness, provision of resources/sources of reliable information (2-4 weeks)
- Phase II: psychosocial support, opportunities to engage in meaningful just-right challenges, modifications as needed, ongoing reassessment (4-10 weeks)
- Phase III: provision of novel challenges to assess generalization of adaptive behaviors, formal re-evaluation (4-8 weeks)

- Phase IV: preparation for discharge, discharge (2-4 weeks)

Outcome measures

At re-evaluation or discharge, the practitioner documents evidence of a change in function and participation. Practitioners may measure change through several common assessment procedures. Symptom-specific questionnaires, such as decreased pain, dizziness, or fatigue, are useful indicators of general well-being. Improvement of self-report measures addressing function, quality of life, or self-efficacy may prove valuable. Assessment of self-perceived performance or satisfaction of performance on a measure such as the COPM is recommended. Objective improvement on the performance of tasks may include measures of cognitive function, physical abilities, or demonstration of performance on a functional activity. Improvement on any relevant measures would suggest better functioning but do not necessarily equate to satisfying role performance. Although these outcome measures may demonstrate objective or subjective external changes, they do not always reveal internal adaptive responses needed for ongoing progress and self-management after discharge.

Measurement of OA-specific outcomes can be attained through several means. Researchers have reported various methods to help clients self-assess relative mastery, some using a tool crafted for a particular population (Beddenberg & Schkade, 1998; Stelter & Whisner, 2007). The *Relative Mastery Measurement Scale* (RMMS; George et al., 2004) and the *Occupational Adaptation Practice Guide* (OAPG; Boone & George-Paschal, 2017) are recommended for their established and developing reliability and validity. *Goal Attainment Scales* (GAS) have been used successfully to measure the change in functional status (Stelter & Evetts, 2020) within specific occupational roles. Skilled observation of self-initiated engagement in occupational activity and

generalization of adaptive responses to novel challenges also contribute to a comprehensive assessment.

Conclusion

The overall goal of intervention using occupational adaptation is to increase adaptive capacity so that individuals can better self-manage their condition and address future challenges. As adaptive capacity increases, one's ability to participate in a variety of desired occupations increases. Although this approach will not result in a "cure" of POTS, the goal is to increase participation. The practitioner's role is to promote adaptive capacity rather than to provide directives for discrete skill-building. Ultimately, through intervention, clients will grow closer to achieving relative mastery in meaningful occupations with increased adaptive capacity for future challenges.

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Table 1. Occupational Adaptation: Terminology and definitions.

Definitions
● Adaptive Capacity: reflects ability to generate adaptive responses to occupational challenges ● Adaptation Gestalt: sensorimotor, psychosocial, cognitive ● Adaptive Response Mechanism: three constructs – adaptation energy, adaptive response behaviors, and adaptive response modes ● Adaptation Energy: energy that drives the process of occupational adaptation. Two types: primary (focused attention, structured, high energy usage) and secondary (more creative and sophisticated, lower energy usage). ● Adaptive Response Behaviors: particular behavior types used in attempt to adapt. Three types: primitive (hyperstable), transitional (hypermobile), and mature (blended mobility and stability). ● Adaptive Response Modes: patterns of responding to challenges that develop through time and experience. Three types: existing, modified, new. ● Occupational Activities: engagement in meaningful occupational roles through active participation with an outcome. ● Occupational Environment: the context in which a particular occupational role is carried out. ● Occupational Readiness Activities: activities that address person-system deficits and preparation for occupational participation. ● Occupational Adaptation: both a state and a process. A change in functional state of a person as a result of movement toward relative mastery over occupational challenges (Schkade & McClung, 2001; Schkade & Schultz, 1992). ● Occupational Role Expectations: person-generated, environment-generated ● Person System: sensorimotor, cognitive, psychosocial ● Relative Mastery: reflects idiosyncratic feelings of efficiency, effectiveness, and satisfaction to self and others

Table 2. Occupational Adaptation Plan of Care for persons living with POTS.

Initial Assessment
● intake paperwork (prior medical history, current symptoms, impact on occupation) ● evaluation (occupational profile, detailed medical history, physical exam, outcome measures, occupational impact) ● goal setting
Intervention
Occupational readiness: ● Strategies: energy conservation, nutrition management and electrolyte balance, sleep hygiene, pain management, exercise tolerance, positioning, heart-rate variability biofeedback, mindfulness, home modifications, assistive device(s), cognitive training concepts, social skills ● Information (e.g.: pathophysiology of condition, energy conservation, pain management, lifestyle modifications, sensory systems) ● Psychosocial supports (e.g.: skill building, processing, coaching, cognitive-behavioral interventions, problem-solving, self-compassion, relaxation strategies, motivational interviewing, stress-management) **Occupational activities** (application in-context): ● ADL, activity endurance in-context, self-regulating exertion, implementation of breath regulation during tasks, psychological strategies, anxiety-management, cognitive strategies in-context
Intervention Methods
● Collaborative relationship o Goal setting (S.M.A.R.T. short-term and long-term goals) o Reflection by practitioner and client to assess impact of intervention ● Guided practice in activities of daily living o Relevant occupational challenges o Agent of the occupational environment o Environmental or task modifications