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Utilizing Dance/Movement Therapy to Help Alleviate the Physical and Emotional Effects of

Thoracic Outlet Syndrome: A Literature Review

Capstone Thesis

Lesley University

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Dance/Movement Therapy

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Abstract

This capstone thesis literature review investigates dance/movement therapy as a complementary intervention to address the physical, mental and emotional effects of thoracic outlet syndrome. No research currently exists linking DMT and TOS in any capacity, so the author analyzes her own experience of utilizing various DMT techniques throughout her TOS recovery and reviews literature regarding DMT and conditions with similar symptoms to TOS, such as chronic pain, chronic illness, chronic fatigue syndrome, fibromyalgia, depression, stress and anxiety. The author hypothesizes that dance/movement therapy would be an effective complementary treatment to combat the physical, mental and emotional effects of TOS. The work presented in this literature review indicates that the author's hypothesis has merit, because the research demonstrates a positive correlation between DMT and all conditions and symptoms that were investigated. The author states that further research is needed to explore and test this hypothesis, and she proposes a research method that could do so. This method utilizes a control group with TOS that does not receive any mental health services, a control group with TOS that is provided traditional talk therapy in a group setting, and a test group with TOS that is provided DMT group therapy interventions.

Keywords: dance/movement therapy, thoracic outlet syndrome, chronic illness, DMT, TOS, TOS treatment, thoracic outlet syndrome treatment.

Utilizing Dance/Movement Therapy to Help Alleviate the Physical and Emotional Effects of
Thoracic Outlet Syndrome: A Literature Review

Capstone Thesis

Dance/movement therapy has been researched and studied in many ways, demonstrating its efficacy in the treatment of numerous mental and physical challenges individuals or communities may face. It has been tested regarding work with populations who have experienced trauma, depression, anxiety, chronic pain and other ailments. However, little is known about the benefits of dance/movement therapy as a primary or complementary intervention for more rare disorders. Thoracic outlet syndrome is one example of a diagnosis of which the potential benefits of dance/movement therapy are entirely unexplored.

My capstone literature review will look at dance/movement therapy as a possible intervention to help combat the physical, emotional and mental health toll for individuals suffering from thoracic outlet syndrome (TOS). TOS is a rare, debilitating and often misunderstood “group of etiologically and clinically distinct disorders with one feature in common: compression of one or more neurovascular elements as they traverse the thoracic outlet” (Ferrante, 2017). Depending on whether the TOS is classified as neurogenic, venous, arterial or traumatic neurovascular, it can cause neck, arm and back pain, blood clots, swelling, numbness, headaches and other chronic pain. Thoracic outlet syndrome is commonly treated through three approaches: physical therapy, surgery and long-term pain medication (Caputo, et. al., p. 149). I can find no research to date that investigates the dance/movement therapy modality as a supplementary or complementary intervention for individuals diagnosed with TOS.

This capstone thesis is a personal journey for me. I was diagnosed with TOS in November 2016 while a graduate student at Lesley University studying dance/movement therapy. I was sidelined with a blood clot in my subclavian artery and was struck by the physical and emotional toll this diagnosis had on me. I was 32 years old, in peak physical health, and had never had any ailment worse than strep throat or bronchitis. Out of the blue, my arm was swollen, purple and immobilized and the doctors at the emergency room had no idea how I could have developed a blood clot. As the days went on, I found myself caught in a whirlwind of unexpected and frightening experiences. I was diagnosed by a vascular surgeon with this rare condition, thrust into emergency surgery, and told I would need to have my first rib removed in order to fully recover.

Through all of this uncertainty, I tried to attend as many of my classes at Lesley that I could and found that the dance/movement therapy techniques we were learning greatly helped my physical and my emotional state. I also learned that not all sufferers of TOS are as lucky as I am to have the mind-body connection, the training and awareness, and a supportive community. I was introduced to a community of people through online support groups who also suffer from TOS. Many had not been as privileged as I am to live near some of the best hospitals in the world. I found I wasn't alone in tackling the mental and emotional components of this disorder, and I learned that many individuals with TOS faced numerous obstacles that I was fortunate not to face. I learned anecdotally as well as through informal research that many individuals go years without a proper diagnosis. They are misdiagnosed with fibromyalgia, chronic pain, clotting disorders or hypochondria. They are told that their pain is psychosomatic. They are told they are weak, or whiny, or crazy. They are fired from their jobs having struggled to perform due to pain. Some learn that they will need to find a new career that doesn't exacerbate their symptoms.

According to their stories, their surgeries are event botched by doctors who are uneducated about their condition. I also learned that through all of these struggles, many individuals longed to move or dance again, and that music was used by many to cope. Yet no one I interacted with through this online community even knew dance/movement therapy existed.

There is currently no research that I can find that speaks specifically to connections between TOS and DMT. In order to frame the hypothesis, I will look at all of the ways in which TOS is treated currently and how effective they are in treating the mental health component of this chronic condition. Then, I will look at how DMT has been utilized in addressing the physical and emotional toll that chronic pain and illnesses, depression and anxiety can have on a patient. I will then investigate, hypothesize and demonstrate how DMT interventions could be woven into a treatment plan for TOS patients and the potential benefits this alternative approach might promote for this population.

There is much research available that suggests utilization of DMT interventions in the treatment of chronic pain “may help people living with chronic pain to foster resilience through the corporeal experience of the moving body” (Shim, 2016). While none of the research speaks specifically to TOS as the culprit for this chronic pain, I believe a strong connection can still be made.

Because this diagnosis and the treatment of this condition is very personal to me, I will incorporate artistic experiences of my own to monitor my mental, emotional, physical and spiritual progress through this journey. I think it is important to keep close track of myself so I do not get lost within the weight and depth of my recovery and of this project.

While this capstone thesis will demonstrate the viability, importance and potential for dance/movement therapy within the existing treatment system for thoracic outlet syndrome, I do

not advocate that DMT be used in place of physical therapy or surgery. I personally have found those two interventions were integral to my recovery. I hope that DMT can help address the mental and physical component as people with this condition struggle to find some sense of normalcy again within a body that has betrayed them, within a medical model that doesn't always diagnose them correctly or quickly, and within their families, cultures or communities who don't believe that their pain is as real or as debilitating as it truly is. Through this literature review process, I have hypothesized that DMT could serve as a viable replacement for long-term pain medication in the current treatment model offered to TOS sufferers.

Since my TOS diagnosis, I have conversed with many individuals who have struggled for so long, faced so much uncertainty and lived in sadness, depression and fear. It is my hope that this literature review and DMT reflection will offer another potential path to holistic wellness for these patients. I hope that this research will help people in this community find the strength, confidence, and support to continue on, while raising awareness about both TOS and DMT in the greater clinical field.

What is Thoracic Outlet Syndrome?

Thoracic outlet syndrome, commonly referred to as TOS, is a rare condition affecting fewer than 200,000 people in the United States per year (Mayo Clinic, n.d.). There are three major classifications of TOS (neurogenic, venous, arterial) and one classification some doctors use, known as traumatic neurovascular, which typically denotes TOS caused from a car accident or other abrupt injury. For clarity in this capstone thesis, TOS will only be denoted by the three main classifications and not traumatic neurovascular, because this presentation of TOS shares all of the symptomology of the other three classifications and only differs in the how the syndrome is acquired. The other types of TOS are more often caused gradually by overuse and/or structural

abnormalities in the thoracic outlet, an area of the body found behind the clavicle that includes the first rib, the subclavian vein, the subclavian artery, the scalene muscles, the pectoral minor muscle, and in some cases a cervical rib. Most people diagnosed with TOS have the issue on only one side of their body, but some experience symptoms on both sides, which is referred to as bilateral TOS.

TOS has gained some notoriety in recent years due to its diagnosis in notable professional athletes, including baseball pitchers, basketball players, swimmers and hockey players. This is because the syndrome is a potential risk for overhead athletes -- those who often put significant and repeated strain on their neck, chest, shoulders and thoracic outlet by forcefully lifting their arms over their heads. The structural abnormalities common in the thoracic outlets of TOS sufferers may not have caused issue otherwise without the physical strain and muscle development common in these athletes. In fact, venous thoracic outlet syndrome is sometimes referred to as effort thrombosis because the main symptom is a blood clot. However, elite athletes are not the only ones who suffer from TOS. Recreational athletes, fitness enthusiasts, individuals who work many hours at a desk job and individuals with poor posture, tight pectoral minor muscles and weak trapezius muscles have also been diagnosed with TOS.

Many thoracic outlet syndrome sufferers, regardless of the type they have been diagnosed with, experience similar symptoms including neck, arm and back pain, swelling, numbness, headaches and other chronic pain (Ferrante, 2017).

Diagnosis and treatment of thoracic outlet syndrome have proven to be challenging for the medical community and have caused derision amongst medical professionals, as some classifications of TOS are easier to diagnose and treat than others.

Venous TOS (vTOS) and arterial TOS (aTOS) are easier to diagnose than neurogenic TOS (nTOS) because there is usually a clotting event that precedes significant symptoms and diagnosis. However, even with a clot present, medical professionals not well-versed in TOS may misdiagnose the cause for the clot.

Neurogenic TOS, despite representing 95% of all TOS cases (Chang, et. al., p. 630), is the most difficult to diagnose and treat. It has also been the cause for the most confusion, division and discussion amongst those treating and experiencing the disorder. There are few accurate measures for testing for neurogenic TOS, meaning that it is a diagnosis of elimination. As a result, many people who actually suffer from nTOS go misdiagnosed for years, especially if they encounter a doctor or physical therapist who is not well-versed in the symptoms and warning signs. Misdiagnoses are detrimental for two significant reasons. First, patients won't get the appropriate treatment that matches and addresses the underlying causes of their symptom set, meaning relief and recovery may not be sustainable or may not come at all and they may also feel confusion and blame over not being able to feel better. Second, patients will feel frustration, anger, stress, depression, anxiety and other mental health components due to the stigma related to their symptoms not being fully understood or taken seriously. In fact, "this lack of misunderstanding and uncertainties in diagnostic testing for this condition led some to question whether this was a valid medical condition" (Beteck, et. al., p. 270).

Personally, this diagnosis meant that I was swept into chaos, confusion, uncertainty and pain, which took a hefty toll physically, mentally and emotionally. I learned later on, however, that I was quite lucky. The other TOS sufferers that I have spoken to tell me that their accurate diagnoses often took months or even years to finally obtain.

The Physical, Mental and Emotional Toll of My TOS Diagnosis and Treatment

My diagnosis journey with TOS was swift, and I will forever be grateful to the medical community in Boston, and my doctors at Beth Israel Deaconess Medical Center in particular. I was diagnosed just one day after the blood clot in my subclavian vein was confirmed at the emergency room through an ultrasound. While the doctors at the ER were perplexed at to what may have caused it, they were certain it was a blood clot, advised me to stop taking my prescription for birth control, and sent me on my way with a prescription for an anticoagulant, or blood thinner. However, the next morning, my primary care physician followed up and informed me that she believed the actual cause to be TOS and I was seen that day by the head of vascular surgery at Beth Israel, who officially gave me my diagnosis.

A week later, I was heavily medicated on an operating table, watching via monitor as the vascular surgery team at Beth Israel performed a venous thrombolysis, sending a balloon catheter through my right elbow, my arm and into my chest. While the local anesthesia and sedatives were quite strong, I will never forget how that procedure felt. It is impossible to fully describe, but the closest I can come is that it felt like someone was tickling my clavicle from the inside. After this initial procedure, I spent a 24 hours with a catheter through elbow and arm into my subclavian vein where the clot first presented. Heparin, a popular anticoagulant medication that my surgical team referred to as “blood clot Drano” was pumped through the catheter to flush the thrombus. Because the full day is so painful, my right arm was strapped to a board to remove any chance that I’d jostle anything loose. I couldn’t get up to use the restroom, so I was catheterized for that purpose as well. Every hour, a phlebotomist had to come and take blood samples from my other arm, and some of those professionals were far less gentle or skilled than others, which caused me increased distress.

I was used to constantly moving, dancing, and expressing myself physically, so this 24 hour period was a dark one for me. I felt like a prisoner in my own body. I felt trapped. I felt completely helpless. No amount of chocolate pudding (my very favorite snack) spoon-fed to me could allay my anxieties. I can't even remember the names or frequency of the pain and anxiety medications that were given to me. I only know they were doled out in plentiful doses.

After this procedure was complete, I was back two more times over the following months for ultrasounds, venograms and venoplasties, to see if the clot had been fully dissolved and if the vein was healthy enough to handle regular blood flow again. What my doctors found was quite interesting. While blood flow had been restricted in my arm only recently, there was evidence in my body that suggested the clot was likely there for a long time, although it would be impossible to know the exact timeframe. The doctors hypothesized this because so much of the clot was still adhered to my vein wall, even after a 24-hour heavy duty anticoagulant assault. My body had also grown a large system of collateral veins, which are blood vessels that branched off and circumvented the obstruction. Upon hearing this information, I was in awe that my body was able to evolve and survive in that way. However, the next thought that struck me was a feeling of fragility, weakness, fear and doubt. I had lived with what now felt like a tiny ticking time bomb in my body for so long and never noticed. I pride myself in my body knowledge and awareness, and I had no idea there was a small part of me that was threatening my life.

Due to the stubborn nature of my condition, the vascular surgery team decided I was a strong candidate for a first rib resection (FRR), meaning that they would remove most of my right first rib, which had been the main culprit behind the vein compression and subsequent clot. During this procedure, they would also remove scar tissue in that area of my chest, repair the vein and fully remove any remnants of the clotting. My surgeon used an infraclavicular

approach, meaning he accessed my first rib by entering through the indentation just below the clavicle. As discussed the procedure further with the surgical team, I learned that other approaches used by TOS surgeons include supraclavicular, meaning above the clavicle, and transaxillary, meaning through the underarm (see Figure 1 and Figure 2 for photographs of my incision site). While there is debate in the TOS community about which approach is best practice, in my experience the entry point is determined simply by the technique that the surgeon prefers and there are risks and benefits to each incision.

Before the clot, I had never had a medical procedure more serious than a wisdom tooth extraction, and all of my previous surgeries for my TOS had been performed while I was sedated and locally anesthetized. The FRR would require me to be under full anesthesia, a fact that terrified me. Other risks included the potential for them to accidentally injure or puncture my lung, internal bleeding, and many others I have blocked from my memory in order to cope.

Just three months after my clot presented, I found myself recovering from my FRR at Beth Israel. I became a minor medical celebrity on the vascular ward during my five days in recovery. No one on the nursing staff that I encountered had ever seen a patient so young with such a massive clot, and most had never experienced a TOS surgical recovery first-hand. One nurse told me that Beth Israel only treats one or two TOS patients per year. This fact would have been more exciting to me had I been able to breathe, lift my arm or move my head without significant difficulty, and these actions became my main focus. I also had an unsightly drain tube protruding from my chest, which expelled blood and other fluids from the surgical area yet severely impeding my comfort and range of motion.

Those five days were painful and challenging physically, but my mental and emotional state was far more manageable in comparison. I was encouraged to get up and move as much as

possible by the medical staff to avoid stiffening joints and muscles, unlike my previous procedure when my movement was restricted as much as possible. A physical therapist was at my bedside regularly, guiding me to slowly expand my range of motion in my surgically repaired arm, neck and chest. My first exercise was to simply crawl my fingers up a wall like a spider, which was no easy task. It took me several attempts to even remember how to use my fingers in the first place, and even when I figured out the motion, I could only manage an inch or two of crawling at a time. My second exercise was to walk around the vascular ward, which was approximately a 10-yard loop but felt to me like 20 miles. My first try, I barely made it out of my hospital room door before I was too tired to go on, but after three days I could shuffle the entire distance.

Through all these challenges, my body awareness and dance/movement therapy lens helped me perceive each of my miniscule movement expansions as monumental pride-worthy milestones, which improved my mental and emotional state and inspired me to persevere. There were moments that I felt defeated, but I didn't have the trapped or anxious feelings experienced during my previous TOS hospitalization a few months prior. Instead, I felt hopeful and resilient. My body may not have been moving the way I was accustomed to prior to the surgery, but the small victories in my recovery efforts were just enough to inspire me through my hospital stay and subsequent two-week period of home care.

Coping with My New Normal

I returned to my job teaching dance and my DMT classwork two weeks after my FRR surgery, and initially felt comfortable. I was so happy to find some semblance of what I viewed as normal. I had made incredible strides in my recovery over the previous half month, and I was confident that I would continue to my forward momentum toward fully functioning. I was

unfortunately not prepared for the proverbial roller coaster ride of recovery, and the physical, mental and emotional blocks I would continue to face.

It seemed as though every time I hit a positive milestone in my recovery, such as brushing my own teeth, pouring myself a glass of water, or writing a handwritten note with my favorite pen, that joy was short lived. The strain of each of those actions caused my body to regress into more pain and helplessness. After a while, no gain seemed worthy of celebration, because each upward progression toward recovery was seemingly always met with a crashing downward regression. In the hospital and shortly after returning home, the growth in recovery was noticeable from minute to minute, hour to hour and day to day. However, as the weeks, months and years pressed on, the gains seemed harder and harder to see and feel, while every backslide was so apparent, with pain flares lasting for days or weeks at a time.

My main coping mechanism at the beginning of my TOS journey also began to crumble. The true mental toll this experience had on me became very apparent. During my time in the hospital, every time I was afraid or feeling sorry for myself, I kept repeating mantras such as “it could be so much worse” and “so many others struggle with real, life-threatening illnesses and face death daily, and my situation isn’t that bad.” In my mind, this was all true and my health concerns in these moments were miniscule compared to what others faced. By minimizing my own experience and emotions, I was able to maintain a mostly positive disposition and put on a brave, smiling and often humorous persona in front of the medical staff. However, I couldn’t hide from my true feelings for long and my worry and sadness evolved into anxiety and depression during my recovery, thanks in part to my self-minimizing mantras. I was feeling weak and afraid as I faced the reality of my own mortality, but my duplicitous self-talk seemed to tell me that these very real feelings were silly and frivolous. My brain seemed to be splitting in two.

However, once I realized this was happening, I was able to access my DMT training to explore how I was truly feeling, first on a body level.

I began to move and dance whenever possible, and I developed a system similar to Mary Whitehouse's authentic movement approach, adapting it so I could dance alone. In its truest form, Whitehouse's practice of authentic movement was done without music, theme, structure or directive of any kind, and her clients were asked to simply move, often with their eyes closed. The mover improvises movement and the witness (the person watching the mover's experience) watches without judgement, without diagnosing and without prescribing a solution, allowing the movers to experience their body and their feelings on their own terms.

I wasn't ready to explore this expression in front of another person, because it felt too raw and uncharted. Instead, I practiced authentic movement while I videotaped myself, then went back and watched the tape, essentially becoming my own witness. I gathered strength and inspiration from the authenticity and safe containment that Whitehouse provided to people in her care. I decided to treat myself on the videotape with the kindness, patience and lack of judgment that I would give to my own client. I decided to essentially meet myself where I was at, the way DMTs are trained to meet their patients. "Starting where the client is can only mean willingness to be anonymous oneself in favor of observing, quickly and without barriers, what is available to that individual" (Levy, p. 57). Whitehouse also felt that the dance therapist must "put aside preconceptions of what the client should do and instead, take the role of not knowing what is correct for a particular individual, letting the individual find his or her own solution" (Levy, p. 57).

This experience made me more forgiving of myself, of my feelings and of my body. I realized that my anatomy was going to move the way it needed to move within the constraints of

recovery. My mind and body could heal together, simultaneously, as long as I was able to forgive them both. I began to forgive my body for betraying me and I began to forgive my mind for experiencing the emotions it felt and continued to feel. I reconciled what had happened in the past and accepted a new normal within my life, my mind and my body.

I also found great comfort, wisdom and insight, during my recovery, in transferring my movement experiences into intermodal art creations. I particularly enjoyed working with Photoshop, manipulating pictures of myself from different aspects of my medical process to better reflect the feelings that the memories and the experiences hidden within those photos evoked. I struggled with many aspects of art during my recovery because I felt frustrated and defeated when I couldn't manipulate the materials without pain, but Photoshop brought me great reward with very little physical fallout. Photoshop helped me feel capable and expressive again through a method other than movement (see Figure 3 to view one of my creations), and it reminded me that there is more to me and my self-image than my ability to dance.

I know now that I was, and continue to be, blessed throughout my TOS journey. I have a heightened sense of my body in space, an arsenal of body-oriented and expressive arts mental health approaches that I have recently learned studying DMT. I also have a community of kind, insightful and caring people around me. Even though I still struggle with pain flare-ups from time to time, my experience with dance/movement therapy has helped me maintain mental and physical wellness. I wondered if it was possible to analyze current research and data from both communities, to solidify the connection to DMT techniques and TOS recovery that I knew so intimately in my own body, and to demonstrate to others suffering from TOS that DMT interventions can offer opportunities for healing that have not always been accessible to them.

Why Dance/Movement Therapy?

I was inspired to investigate dance/movement therapy as a possible intervention for TOS symptoms because of my own first-hand experience with it. While I have felt body level benefits, there is a breadth of research supporting what I felt during my recovery. I will delve into deeper later in this literature review. Humans have been dancing and moving recreationally, culturally, communally, individually and therapeutically for thousands of years, yet dance/movement therapy as an organized and researched form of psychotherapy in the United States began with DMT innovator Marian Chace, who was born in 1896. “Dance has been used as a healing ritual for thousands of years and has its historical roots among indigenous people. Thus, dance itself has been ascribed to have a curative power whereby dance (movement) therapy has been developed in the last decades and follows a specific approach of treatment” (Kiepe, Stöckigt & Keil, 2012, p. 404).

DMT comes in many different forms, including the Chace approach with body action, kinesthetic empathy and group circles, Mary Whitehouse’s authentic movement approach with its witness and mover method, the Psychodynamic Oriented Dance Therapy approach with “in-depth psychological concepts and theories” (Bräuninger, 2014, p. 446), and Integrative Dance Therapy approaches that incorporate a number of different forerunners’ concepts. (Bräuninger, 2014, p. 446).

Dance/movement therapy’s fluidity and the core belief that DMTs should meet clients where they are at, has helped touch the lives of countless individuals. There are even more potential clients out there in the world who could benefit. Research has found that “dance can improve quality of life by strengthening the immune system through muscular action and through the activation of various physiological responses” (Blázquez, Guillamó & Javierre, 2010, p. 285). Patients also have the opportunity through DMT to “verbalize and express

experiences, feelings, and thoughts that make their situation clearer, and free them from unconstructive repertoires that limit improvement” (Blázquez, Guillamó & Javierre, 2010, p. 290).

Dance/movement therapy is also a strength-based approach to therapy, meaning that individuals are given the opportunity to “discover and connect with their innate strengths and resources” in order to achieve “personal growth and healing” (Shim, et. al., 2017, p. 28).

Bridging the Gap Between DMT treatment and TOS

A literature review of the effectiveness of physical treatments in reducing clinical symptoms of TOS determined that “clinicians should consider exercises as a major part of conservative treatments” and “the combined treatment effect of physical treatments and medications should also be considered in the treatment plan” (Lo, et. al., p. 62). Because this research does not address the mental or emotional side to treatment and recovery, I am hopeful that there could be movement-based research approaches to TOS. I became more hopeful when I found a study that investigated quality-of-life scores of nTOS patients following FRR surgery, and while I learned that “surgical intervention for nTOS remains controversial due to uncertainties in diagnosis and outcome” (Rochlin, et. al., p. 436), this study made no mention of any mental health diagnoses nor did it investigate any mental or emotional component of surgical recovery as part of their research.

I finally understood that there would likely be no research currently available to me that investigates dance/movement therapy within the context of the physical, mental and emotional components to thoracic outlet syndrome recovery. To bridge this gap, I looked at the physical disorders that share symptomology with TOS and mental diagnoses that often arise in chronic illness sufferers, then looked at how DMT was used to service of these conditions. I made several connections between TOS and other conditions that have had DMT interventions

researched, such as fibromyalgia, chronic illness, chronic pain, chronic fatigue syndrome, depression, stress, anxiety and other health-related psychological outcomes.

Dance/movement therapy is a method of healing that is “used therapeutically to strengthen the emotional, cognitive, physical and social integration of the individual” (ADTA, 2013), and can be an effective psychological and physically-integrative method in combating chronic illness. A 2014 meta-analysis study by Koch, Kunz, Lykou and Cruz regarding DMT and its therapeutic use in the treatment of health-related psychological problems found that dance and DMT were effective in improving quality of life, well-being, mood and affect, and body image. DMT and dance also had a positive effect on depression, clinical outcomes and anxiety. The study “supports DMT and dance as an effective and useful treatment method in clinical and preventative contexts” (Koch, Kunz, Lykou & Cruz, 2014, p. 63).

Chronic illness. Thoracic outlet syndrome, particularly nTOS can be a chronic condition, but in some cases the treatments can alleviate symptoms or eliminate them entirely. However, many sufferers of TOS have their condition misdiagnosed or mistreated and must deal with the associated symptoms chronically. Some research shows “living with chronic illness as a continually shifting process of wellness-in-the-foreground or illness-in-the-foreground” (Robinson, 2017, p. 447), and that “wellness and illness co-exist and have overlapping aspects but either wellness or illness is the focus of attention at any moment” (Robinson, 2017, p. 447), indicating the heavy mental health component to living with conditions like TOS. Even if a full recovery is never possible, Robinson found that “when there was an active choice to walk down the positive road, the more negative emotions were acknowledged and dealt with or set aside rather than being the focus of attention” (p. 454), but this ability to make that choice may require a psychoeducational component for many people. Because chronic illness is tied so heavily to an

individual's physical body, dance/movement therapy could be effective in helping a sufferer achieve this, especially since so much of learning to live with a chronic condition regards understanding one's body and the condition, as well as listening to one's body to know what it needs and when. Robinson explains that:

Accepting the condition (in some measure) and making space for it opened up the sense of a new body and a new family. It was a body that had something attached, like a shadow, which also became part of the family. The distance between the body and the illness varied depending upon the depth of accepting that had been achieved. (p. 454)

Additionally, as humans experience longer life spans than ever before in our existence as a species, even in spite of a chronic illness, there is a "critical need for interventions that add life to years in the context of chronic illness" (Robinson, 2017, p. 460).

Fibromyalgia. While categorized as a chronic illness, fibromyalgia specifically shares many unique characteristics with neurogenic TOS, and I believed it warranted its own special attention in this investigation. Symptoms of fibromyalgia include "chronic widespread musculoskeletal pain, sleep disturbance, fatigue, morning stiffness, bilateral tender points, memory and concentration problems, numbness and tingling, and others" (Armentor, 2017, p.462), many of which are also prevalent for TOS sufferers. Additionally, individuals with fibromyalgia often face skepticism about the pain of their disorder and the "medical field is not in agreement on the diagnosis as it is one based on subjective rather than objective criteria" (Armentor, 2017, p.462), sentiments which many sufferers of nTOS (and other forms of TOS) know all too well.

Armentor goes on to explain that living with a chronic illness that is often contested, such as fibromyalgia and TOS, can lead to stigmatization (p. 463), which leads to sufferers to

sometimes feel discredited and discriminated against. Fibromyalgia sufferers included in Armentor's research also expressed sentiments similar to those of TOS sufferers, specifically "the difficulty that family, friends and coworkers had in understanding their new restrictions that included needed more rest, limited ability to lift heavy items, sensitivity to pressure and touch, and avoidance of certain social settings and events" (p. 468).

Through her study of fibromyalgia and stigmatization, Armentor found two specific manners through which many sufferers communicate their symptoms and their well-being: Being direct and comparing their symptoms with other illnesses. (p. 465). However, her study makes no mention of any non-verbal means of communication, which dance/movement therapists have proven time and time again can be beneficial in expressing what may be difficult to say. Dance therapy innovator Marian Chace states that:

The arts, whether painting, music, drama or dance, are well recognized as being of importance to people as a means for communication of emotions or ideas that are difficult to translate into verbal forms. The dance, in particular, is perhaps more potent than any other of the art forms. Man lives his life in rhythm and expressive body action, and these are the elements that are involved in dance. (Chace, 1993, p. 256).

Additionally, Chace advocates that dance/movement therapy sessions can help bring about a closeness with other people that many in our modern society lack, whether suffering from mental or physical illnesses or not, even "in a culture where distance between people is more usual than closeness" and when "the adult overwhelmed with emotional problems reveals the extreme aspect of this isolation and consequent loneliness" (Chase, 1993, p. 257). Those who live with fibromyalgia, TOS or other chronic illnesses, who are so often burdened with verbally trying to express their pain and their suffering, would greatly benefit from a method of

communication, understanding and healing that removes the need for verbal expression or explanation.

Depression. Individuals with thoracic outlet syndrome and other chronic illnesses can develop depression, a persistent feeling of sadness, low self-esteem and a loss of interest in activities once found pleasurable (American Psychiatric Association, 2013). Even if TOS is not the direct cause of the depression, and an individual was already experiencing depressive symptoms or had a genetic predisposition for developing depression, the addition of a new physical diagnosis like TOS can exacerbate those feelings. Due to the rarity of TOS, it is not uncommon for those with this diagnosis to feel alone and isolated in their experience. This can further deepen feelings of depression.

Dance/movement therapy offers an opportunity to alleviate depression symptoms. A pilot study by Pulkanen, Saarikallio and Luck found that a “short-term group form of DMT intervention may help people with mild, moderate or severe depressive episodes improve their level of depression as well as comorbid anxiety” (2014, p. 496). Additionally, the research found that “the DMT decreased the participants’ measure of neuroticism and increased their measures of extraversion, secure attachment style, and satisfaction with life” (2014, p. 496) and participants were more able to identify their feelings (2014, p. 496). Throughout their study, they also found that participants in the DMT study had a high attendance rate (with an average attendance of 17 out of 20 sessions) despite the intervention being in a group setting, “which could be especially challenging for severely depressed patients” (Pulkanen, Saarikallio & Luck, 2014, p. 497). While there was no control group for this study, which puts some limitation on the significance of their findings, the results make a promising connection for those suffering from TOS and depression.

A systematic review of DMT interventions by Kiepe, Stöckigt and Keil (2012) found a “statistically significant increase in plasma serotonin concentration, a decrease in plasma dopamine concentration and a decrease of symptoms of disease severity after twelve weeks of dance therapy compared to the control group” in a study of adolescents with mild depression, which further supports DMT as a viable intervention for those with depression symptoms.

Stress and Anxiety. Dealing with thoracic outlet syndrome, like any other diagnosis, can often cause significant stress and anxiety. One study explained the burden of such a diagnosis and the stress and anxiety it can cause in the following way: “People with chronic illnesses strive to be regarded as full members of society and to be accepted by others, that is, to pass” (Äsbring & Närvänen, 2002, p. 154). Personally, I found this stress to be overwhelming at times, because I didn’t know what the future would hold. I worried that I would fall behind with work and my studies. I stressed daily about whether I would ever be normal. I was kept up at night, stressing about what responsibilities I wasn’t able to get accomplish due to my TOS symptoms. I was anxious that my health would never be the same. I didn’t know if the surgical interventions would work or if more blood clots would present. My saving grace was my time practicing dance/movement therapy with my class at Lesley. I literally and figuratively stumbled into the dance studio week after week, and so greatly looked forward to the moments of stillness, breath, reflection and movement that I found in our lessons. And this research has demonstrated that I am not the only one who has found relief of stress and anxiety through DMT.

The study by Koch, Kunz, Lykou and Cruz (2014) found DMT to be an effective intervention for reducing anxiety. In fact, DMT interventions included in their meta-analysis “were found to be comparable to effects of other types of therapies including pharmacology and verbal psychotherapies.

Iris Bräuninger states that previous studies on DMT and dance interventions demonstrated that they “reduced stress and improved psychological parameters, such as emotional states, life energy and negative affect. Hence, DMT fosters emotion-oriented stress and coping strategies.” (2012, p. 444). Her randomized control trial also concluded that “DMT is a successful treatment in the short- and long-term to reduce psychological distress and improve stress management strategies and is significantly more efficient than non-treatment.” (Bräuninger, 2012, p. 448).

Chronic pain and pain management. One significant challenge facing many individuals experiencing chronic illnesses and pain such as TOS is the day-to-day management of their affliction. Some pain is manageable day-to-day, while other pain requires medication(s) in order for sufferers to perform even the simplest activities of daily living. Chronic pain is a “multifaceted condition that can inflict a profound and debilitating impact on individuals’ entire personhood” (Shim, et. al., 2017, p. 27). Often, this pain can greatly impact someone’s ability to move, making more overt dancing and movement challenging. However, “dance movement therapy may prove to be as important as other forms of therapy and pharmaceutical treatments for patients with long-lasting and chronic pain” (Blázquez, Guillamó & Javierre, 2010, p. 291), potentially because participants in one study reported that “DMT helped them to recognize some of the misconceptions they had had about pain, movement, and personal efficacy for physical activity, which in turn motivated them to adjust/correct their thoughts, beliefs and behavioral patterns” (Shim, et. al., 2017, p. 34).

A number of dance/movement therapy techniques implement multisensory and multidisciplinary approaches to using the body in different ways, demonstrating an impact on “body image, mood, stress, mobility, life energy, movement pain, sense of agency, meaning

making and overall quality of life” (Shim, et. al., 2017, p. 28). While working with children in hospitals, dance therapist Suzi Tortora has found that incorporating breathing techniques, guiding imagery and focused attention can redirect the clients’ attention from their pain. She has also used touch, such as massage and rhythmic rocking, musical instruments, vocalization, tactile props such as scarves and stuffed animals, and heated or cold packs. (p. 175). Tortora further explains the need for utilizing multiple senses in the treatment of individuals presenting with a medical condition:

Adding a multisensory focus to medically related illness is essential for the invasive and painful treatment methods... Despite the tenderness and kindness of the medical professionals caring for these patients, they experience a constant barrage of assaults on their bodies as treatment requires both internal and external probing, poking, and surgical investigations that can include the removal of body parts and the ingestion of unpleasant-tasting medicines. (p. 173-174).

Trained dance/movement therapists have many tools at their disposal during their sessions with clients, and often a DMT intervention can incorporate small elements that may not always look like traditional dance and movement to the untrained eye. The ability to adapt to the needs of clients, especially when their medical conditions restrict their movement, is an essential skill for DMTs. Even if the interventions just involve breathing, tactile experiences, or other forms of artistic expression such as art or music, the essence of movement exists and there is always the opportunity to explore and expand even the smallest movements to help clients better understand their mental, physical and emotional states.

Discussion and Further Steps

There is a much room for expansion and improvement in research regarding DMT and individuals experiencing symptoms of thoracic outlet syndrome, because a direct study does not exist, as far as I could tell from my months of extensive research. While a rare condition, TOS causes sufferers like myself to experience a number of physical symptoms and additional mental and emotional states that can wreak havoc on the person as a whole. Individuals with rare disorders are no less deserving of holistic healing and wellness.

Hope exists. Thanks to existing research that demonstrates the efficacy of DMT interventions with chronic illness, fibromyalgia, depression, stress, anxiety and chronic pain, similar outcomes may be possible for TOS. Thus, my literature review indicates that there are a number of positive correlations that could exist between DMT and TOS, meaning that TOS sufferers may have an additional treatment option to complement and potentially improve their journey to recovery, in addition to the medication, physical therapy and surgery already utilized within the current medical treatment model.

Further research is certainly needed to truly explore the relationship between DMT and TOS and after concluding my investigation for this capstone thesis, I have a few ideas to expand research in this area. The following paragraphs explain the method I propose to better understand DMT and TOS and to test my hypothesis that it is an effective complementary treatment.

I would first compile three groups of sufferers of TOS. Each group would have an equal number of people with neurogenic, venous and arterial TOS. All three groups would also feature individuals with a wide range of causations for their TOS, including overuse, athletic endeavors, physical abnormalities and traumatic injury. Ideally, the gender identities included in the groups would also reflect the percentage in the general TOS population at the time of the study.

Prior to the groups convening, each participant would be interviewed to find out more about how they are feeling physically, mentally and emotionally. Responses would be cataloged through both a Likert scale and open-ended responses. All three groups would then be examined over the course of ten weeks, then interviewed about their experience in the months and years after the conclusion of the active study to see how their physical, mental and emotional states had evolved after the intervention, using the same Likert scale and open-ended responses.

The test group in the study would be provided with dance/movement therapy interventions weekly as an in-person group. The therapists and researchers conducting the group would have the physical needs of the TOS sufferers at their disposal, but would evolve the DMT portion of the group to meet the needs of the developing group. Specific interventions would address living with chronic illness and pain and the underlying mental and emotional toll of the physical disorder. The control group in the study would be provided with a traditional talk-therapy group that addressed the same issues but without any DMT or other expressive therapies component. The third group of study participants would not be included in any group therapy intervention and will simply be interviewed over the course of the same time period as the two groups meeting weekly. Their responses will help the researchers see how physical, mental and emotional states evolve naturally for TOS sufferers, without any therapeutic group intervention.

Due to the rarity of the condition, getting the individuals in these groups to physically meet face-to-face may prove challenging, but the researchers could investigate options for digital connection, such as video conferencing. It is important, however, that both groups receiving therapy interventions in this study meet in the same manner, whether that be in-person or via online portals.

The DMT intervention and the control group's intervention would purposely be conducted in a group setting. Due to the isolation felt by many who experience chronic illnesses and rare disorders, being together in a group setting may have therapeutic impact by itself, so it is important that the study would be able to test a DMT group's results against the findings from a more traditional talk therapy counseling group. In my opinion, this is why face-to-face meetings would be preferable to online connections, but as discussed earlier, this ideal may not be feasible.

The third group would be studied without their involvement in any in-person group experience. This is designed to make sure that the results of the DMT group's interventions was solely due to the DMT interventions themselves and not simply because the participants felt better being in a group with other individuals who finally understood what they were going through. This phenomenon is demonstrated in a study by Blázquez, Guillamó and Javierre regarding DMT group therapy with chronic fatigue syndrome, another oft misunderstood syndrome like TOS, which found that "participation in the group provided social support and allowed the patients to express themselves in a secure environment. The chance to communicate with each other through their bodies was positive for their perceptions of well-being" (2010, p. 287).

It is my belief that any clinical mental health intervention for people suffering from thoracic outlet syndrome would be more beneficial than no intervention at all, because the sudden onset or slow degeneration of a chronic, life-altering syndrome has an impact on more than just the physical self and the mental and emotional needs of these individuals must be addressed if they are to recover, cope, survive or thrive as a whole self. Given the physical nature of the syndrome and my own personal experience with TOS recovery, dance/movement therapy

offers a unique opportunity for sufferers to incorporate the body that physically betrayed them into the overall mental health recovery process. TOS often strikes in active and otherwise healthy individuals, meaning this diagnosis can have a startling impact on those affected. This also means, however, that the individuals seeking treatment (and particularly those who are elite and recreational athletes) had a positive working relationship with their physical body prior to a diagnosis and this mind-body connection could be utilized in their recovery efforts.

I still struggle almost daily with chronic physical symptoms, new and evolving bodily limitations and the emotional and mental toll such a shocking diagnosis took on me, but I am a living and breathing testament to the healing power of dance/movement therapy. The strong mind-body connection I have forged since starting my study of DMT has helped me immensely as I evolve through my recovery, and I hope that further research and development can bring these interventions to a wider audience of TOS sufferers.

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Figures



Figure 1. A picture of Cara Spilsbury recovering from TOS surgery at Boston's Beth Israel Deaconess Medical Center in February 2017.



Figure 2. A picture of Cara Spilsbury's TOS surgical scar in March 2017, three weeks after the first rib resection procedure.

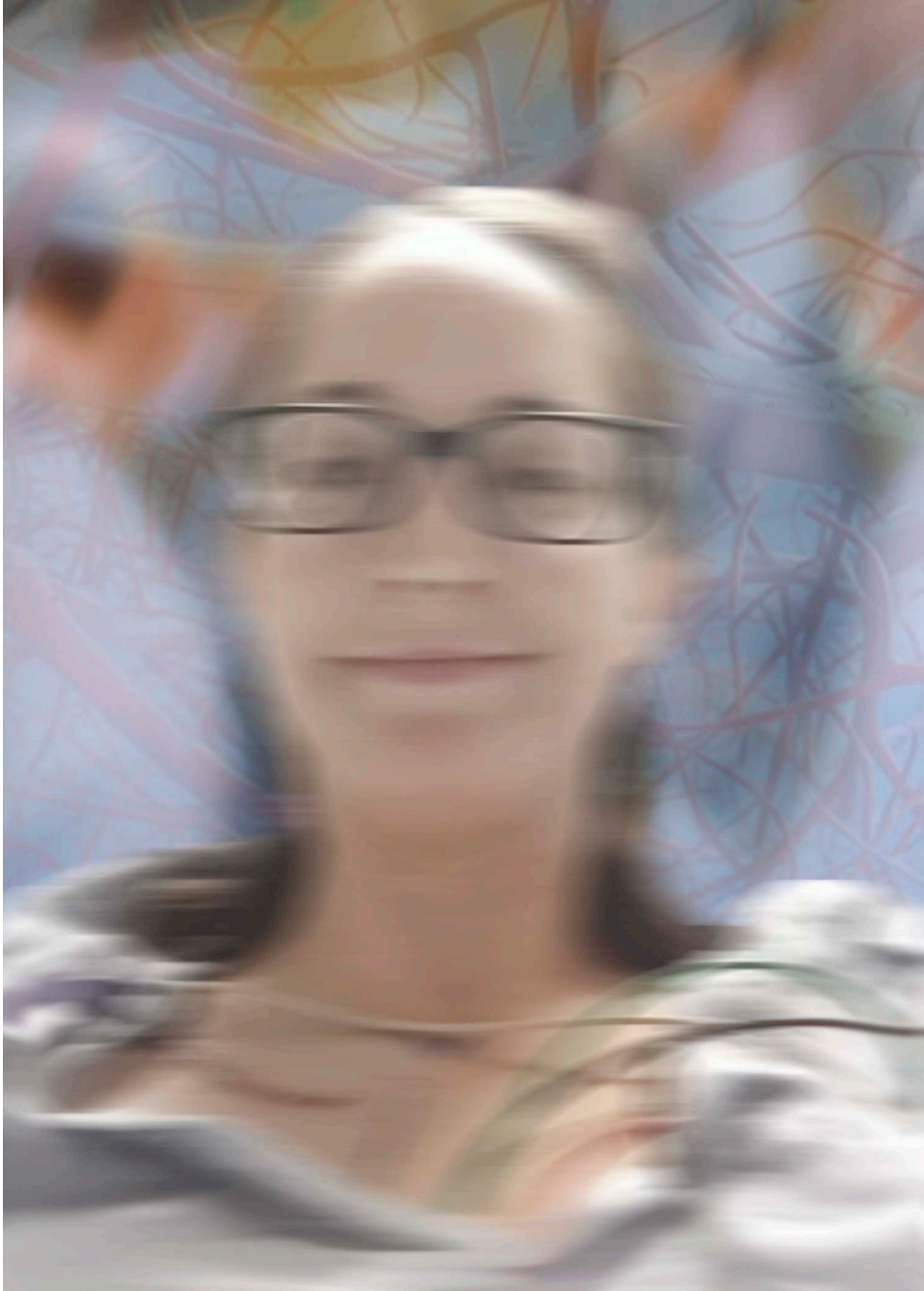


Figure 3. An artistic representation of the physical, mental and emotional toll of TOS diagnosis, surgery and recovery, created by Cara Spilsbury utilizing Photoshop and phototherapy techniques.

THESIS APPROVAL FORM

**Lesley University
Graduate School of Arts & Social Sciences
Expressive Therapies Division
Master of Arts in Clinical Mental Health Counseling: Dance/Movement Therapy, MA**

Student's Name: ____ Cara M. Spilsbury _____

Type of Project: Thesis

Title: ____ Utilizing Dance/Movement Therapy to Help Alleviate the Physical and Emotional Effects of Thoracic Outlet Syndrome: A Literature Review _____

Date of Graduation: ____ May 18, 2019 _____

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: ____ Meg Chang, EdD., BC-DMT _____