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Epistemic Injustice, Endometriosis and Dance/ Movement Therapy: An Autoethnographic Investigation

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THESIS APPROVAL FORM

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Expressive Therapies Division
Master of Arts in Clinical Mental Health Counseling: Dance/Movement Therapy, MA**

Student's Name: Kevana S. West

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

Thesis Advisor: _____ **Meg H. Chang EdD, BC-DMT, LCAT** _____

Epistemic Injustice, Endometriosis and Dance/
Movement Therapy: An Autoethnographic Investigation
Capstone Thesis
Lesley University

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Kevana S. West

Dance/ Movement Therapy

Meg Chang

Abstract

As the field of dance/ movement therapy evolves to meet the demands of a rapidly changing social landscape, it is imperative that clinicians think critically about the degree to which our work is steeped in oppressive frameworks and ideologies. This investigation uses testimony to explore epistemic injustice as it relates to the author's experience of living with endometriosis and the pursuit of professional licensure. Considering the limited amount of research on the condition, along with the perceived absence of literature within the field of dance/ movement therapy, further study is warranted. The experimentation phase of this research incorporated the use of social media in the process of recording daily movement improvisation and written journals. The results, analyzed through the video editing process and autoethnographic exploration, draw attention to the impact of epistemic injustice and oppression on the body. Specifically, this work seeks to illuminate the perils of implicit bias and Eurocentric standards within the field of dance/ movement therapy. As we move beyond the performative allyship of multiculturalism toward a landscape of vehement social justice, it is essential that we do more than simply name the problem, we must elevate the embodied wisdom of individuals occupying marginalized identities.

Keywords: epistemic injustice, Endometriosis, dance/movement therapy, testimony

The author identifies as a black queer southerner of multicultural lineage.

Epistemic Injustice, Endometriosis and Dance/ Movement

Therapy: An Autoethnographic Investigation

I come from a lineage of storytellers, community healers, and generations of oratory wisdom; for this knowledge I have no reference or citation, it is simply fact because my body knows it to be so. I am who I am because of who I was and who I will be; similarly, I am who I am because of where I have been and where I am going, and on the way to becoming the person I am today, many versions of myself had to die. Just as the I that enrolled in this program, the one with the code-switch stuck in the on position, has come and gone, soon the I, that speaks to you in this text will perish to make room for another. Although we share a connection through memory and intuition, I do not ascribe a sense of selfness to the people I was in the past or the persons I will become. The I that speaks to you within this text exists at the intersections of blackness, queerness, and disability; I am they, sometimes she and often we.

With the above statements I seek to inform you of my cultural positioning through the expression of my embodied sense of time, which like many aspects of my personhood is nonlinear, outside of the binary and seemingly elusive. Elusive is a word that does not fully describe what I was meaning to convey, but it was the most applicable on hand. In his 1994 publication, Somé aptly describes this phenomenon when he categorizes Modern English as being good for “quick fixes” and the maintenance of consumerism, but often fails at communicating multicultural perspectives (p. 2). Here I sit at the intersection of many marginalized identities with the directive to communicate in this academic form of English, a language that was never meant for me and has often been employed in direct opposition to my safety, wellbeing, and right to exist (Caldwell & Leighton, 2018; Okun, 2021). I’m reminded of Audre Lorde’s quote that states “the master’s tools will never dismantle the master’s house”

(1984, p. 2). My thoughts become cacophonous, and resentment threatens to overwhelm me as I acknowledge the fact that these words will seldom fall on the eyes of readers who look like me, speak like me, live like me. I can't help but *feel some type of way*¹ about this demand for intellectual property; any way you look at it, I, a Southern Black Queer have been tasked with the challenge of producing work to be consumed by an audience that is/ will be largely made up of the dominant culture (Lorde, 1984).

This single research assignment has shifted time and time again; still I am unaware of where I stand, unaware of the purpose of this and growing more resentful with each word that is birthed from the fingertips of this exhausted body. Throughout the process of obtaining this degree, I have asked myself countless times, “how did we get here; why did we willingly subject ourselves to enduring the trauma that is academia?” The short answer is that I, along with several of my peers, were called to Lesley to fulfill a divine purpose and this period of turmoil served as an initiation of sorts, (Somé, 1994) but how do we even begin to justify the level of oppression that is enacted on marginalized peoples through the simple pursuit of knowledge? (Caldwell & Leighton, 2018). One might even call into question if the impetus for enrolling in institutions of higher learning is a drive toward self-actualization or simply a means for obtaining social capital: for better assimilation into a culture dominated by European patriarchal ideals (Caldwell & Leighton, 2018). Countless times during the thesis writing process, I have asked myself “what am I doing, what is it that I am trying to say?” Truth be told, I do not possess the answer to these questions, at least not in the form that is required of me; for the story I set out to tell is one of pains so deep that they escape the written word (Caldwell & Leighton, 2018; Okun, 2021). With

¹ Colloquialism within the African American community. Throughout the text, phrases of this sort will be italicized, but never translated to safeguard that which is sacred.

each attempt to translate the visceral of implicit memory, I get further away from coherence, there are just some things that “knowledge can’t eat” (Somé, 1994, p. 8). I find it ironic that the I of three years ago enrolled in a dance therapy program only to spend the time in between then and now, intellectualizing processes that were of the viscera. I find it insulting that academia has placed claim on the work that indigenous peoples have been conducting for millennia and then has the *audacity* to demand that we academize that which is of the soma; that which is unspeakable (Okun, 2021; Somé, 1994). Is this not but another example of white supremacy in action? Is this not an act of perpetuating the notion that, that which is of the flesh is primitive, and subordinate to the cognitive prowess of the mind (Caldwell & Leighton, 2018)? We as a profession tout the benefits of movement only to sell our work short via our incessant “worship of the written word” (Okun, 2021). But what can I, a person without any credentials, possibly know? It is with heuristic inquiry, that I will attempt to analyze and translate the knowledge gleaned during the experimental phase of this research into a form that is deemed credible by the institution that is holding my calling for ransom. What follows is a nonlinear testimony that leverages corporeal wisdom as a form of epistemic justice for individuals living with endometriosis (Akinyela, 2014; Rosen, 2021).

Before we embark on our journey across space and time, we must first define epistemic justice by exploring its antithesis. Rosen defines epistemic injustice as “the wrongful discrediting of someone’s capacity as a knower” (2021, p. 1) and cites the phenomenon as a causal factor of the disparities in treatment outcomes associated with individuals belonging to marginalized communities. Within her critique she leverages the established research that denotes the differences in healthcare experiences between black patients and their white counterparts and specifically draws attention to the variances in pain assessment and treatment (Rosen, 2021; Tait

& Chibnall, 2014). Further, Rosen names narrative and person-centered approaches to treatment as means for minimizing the impact of implicit bias in healthcare settings (2021). As I transcribe this sterilized explanation of healthcare realities for marginalized peoples (specifically black people with uteruses), I am enraged. The resentment is palatable, and I notice that the speed of my typing increases, my brow furrows and my lips come to a purse. It is an undeniable fact that healthcare professionals (and western society at large) do not acknowledge the embodied wisdom of black people in pain; this is a fact, because my body knows it to be true. However, for my lived experience to be valid in an academic context, it must be punctuated by the last names of white presenting academics. The above passage does not encapsulate the full magnitude of endless nights spent in the ER, the missed days of work, the late assignments, or the microaggressions and gaslighting that emerge from being chronically ill and undiagnosed, but neither does this one (Caldwell & Leighton, 2018; Mieres, McNally, Duarte & Grossman, n.d.). Some experiences take up residence in our implicit memory and are “stored solely on the physiological level” (Caldwell & Leighton, 2018 p. 21). These memories often “remain unintegrated by the higher processing areas of the brain” and thereby resist the trap of language (Caldwell & Leighton, 2018 p. 21; Somé, 1994). It may be bold of me to speak on this with such candor, in the very text on which my ability to graduate hinges, but I feel that we as dance/movement therapists have lost our way in pursuit of legitimization. We have relinquished our reverence for the body in favor of using “the master’s tools” of literary discourse and intellectualization (Lorde, 1984; Somé, 1994).

At the start of this investigation my intentions were to provide a functional definition of endometriosis, explore common psychiatric comorbidities, and determine the effectiveness of utilizing dance/movement therapy (DMT) to address the psychological symptoms associated

with the condition. However, as the process of data collection unfolded, my interest shifted toward the investigation of my own relationship with movement; specifically, I found myself exploring the parameters and limitations of my mobility in search of movements that did not inflict harm on my body. However, the act of listening and learning from the body's wisdom does not make for an academically rigorous investigation, and for that reason another shift had to occur in support of data analyses. I can acknowledge that earlier drafts of this work were flailing attempts at finding the central thread that would expose the unspeakable, but it was not until I let go of my desire to control and intellectualize that I stumbled upon the concept that would ultimately become the mediator between endometriosis and DMT (Okun, 2021; Rosen, 2021; Somé, 1994). The force that called me to Lesley, is one that communicates via visceral sensation, and it is my belief that it is the same force that led me to focus on testimony as epistemic justice (Akinyela, 2014; Rosen, 2021).

As my time at Lesley approaches closure, I know that I am accompanied by all the versions of myself that have existed and can see plainly how each moment of this life has led us here. This is the story of how I came to share a body with an angry uterus and how her unbridled rage led me to pursue a career in dance therapy. Within this testimony, I will leverage corporeal knowledge and lived experience to explore the etiological factors associated with endometriosis, investigate the potential impact of body-based psychotherapies on the symptoms associated with the condition and demonstrate the act of meaning making through embodied storytelling (Akinyela, 2014).

I vividly remember the first time my uterus let me know that she was angry; I was 12, it was in the wee hours of the morning on a school night, and I was doubled over in pain. The first time I heard the word endometriosis I was 16 and despite having a familial history of the

condition, I remained undiagnosed until the age of 25. For 13 years I went to provider after provider and carried the burden of the insinuation that I was exaggerating or worse that it was all in my head (Culley, et al., 2013; Emad, 2006; Harris, et al., 2018; Grundström, et al., 2020; Mieres, McNally, Duarte & Grossman, n.d.; Ong, 2011). I have been living with this diagnosis for three years at the time of writing this, and I can attest that the effects of medical gaslighting are long lasting. In fact, I often still question if I made the whole thing up, if I'm somehow fabricating immobilization, chronic fatigue, and volatile mood swings. Shortly after these thoughts emerge, I think of the images I received after my diagnostic procedure; these are my only tangible proof that the wrath of my womb is real. Therein lies the insidiousness of epistemic injustice; I have internalized the insatiable need to prioritize the cognitive over the corporeal, to invalidate my own body's experience. (Caldwell and Leighton, 2018; Mieres, McNally, Duarte & Grossman, n.d.; Okun, 2021).

Endometriosis is a reproductive disease that is often characterized by inflammation and experiences of chronic pain within the pelvis, abdomen, and back. (Culley, et al., 2013; Dibenedetti, Soliman, Gupta, & Surrey, 2020; Harris et al., 2018; Ong, 2011; World Health Organization, 2021). While some individuals living with the condition are asymptomatic, those who present with chronic pain often experience a host of other physical and psychological symptoms like heavy menstrual bleeding, gastrointestinal discomfort, fatigue, anxiety, and depression. (Culley, et al., 2013; Dibenedetti, et al., 2020; Ong, 2011; World Health Organization, 2021). Although the rate of occurrence is indeterminable due to the difficulties associated with diagnosis, the prevalence of endometriosis is estimated to effect in between two and 17% of people with uteruses (Culley, et al., 2013; Dibenedetti, et al., 2020; Harris et al., 2018; World Health Organization, 2021). Additionally, considering the disparities in treatment

outcomes for members of marginalized communities, it is likely that some individuals remain undiagnosed throughout their lifetime (Tait & Chibnall, 2014). Presently, there is limited research on the condition, however considering the physical, psychological, and social impact of endometriosis, further research on the condition is warranted.

Before I enrolled in the program, I was a barista, a virtual personal assistant, a costumer, and a performer, all at the same time. I have a memory of that version of myself expressing that it didn't matter what career she chose, so long as she was good at it; this was the moment that I gave up on my dream of becoming a DMT. I'm uncertain of who or what I angered when I decided to let my dream die, because shortly after I spoke those words, my health took a drastic turn for the worse. The cosmic author(s) guiding my journey made it abundantly clear that abandoning my calling was not a desirable option.

In case you were wondering, I was a great barista, but with endometriosis often comes chronic fatigue, a symptom which made it extremely difficult for me to arrive to my morning shifts in a timely manner (Dibenedetti, et al., 2020). I was also moderately successful in my other roles but was often undermined by my tendency to over function. We were running a losing race against disability, determined to get as much living done before our body demanded its rest. If only I knew then that we were running headfirst into the very thing we were trying to escape. As I record this testimony, my hand moves away from the keyboard to apply pressure along my right side and I am aware that in this moment, I am running a similar race (Akinyela, 2014). My right ovary feels as if someone has it imprisoned within the grip of a clenched fist. My organs protest as I pull another all-nighter, in service of completing this assignment before I am ultimately incapacitated by the very thing I am writing about. I tell my body "not now, we can rest later, we're almost finished." I ignore the pleas of my flesh because my brain has

important work to do; epistemic injustice rears its ugly head yet again as I prioritize the cognitive over the corporeal (Caldwell & Leighton, 2018; Rosen, 2021).

As you may have gathered from the above testimony, the condition about which I write is characterized by a host of disruptive symptoms and has both a physical and psychological component (Akinyela, 2014; Culley, et al., 2013; Dibenedetti, Soliman, Gupta, & Surrey, 2020; Harris et al., 2018; Ong, 2011; World Health Organization, 2021). The current body of literature asserts that the symptoms associated with endometriosis cause significant distress in many areas of functioning (Dibenedetti, et al, 2020). However, despite its prevalence and impact, there is limited research on the condition, and to my knowledge, there is no established research within the field of DMT. Considering that the current body of literature suggests that both psychological and physiological factors contribute to the etiology and maintenance of endometriosis, it is the author's hypothesis that body-based psychotherapies and specifically DMT may provide opportunities for better management of the disease through its holistic approach to treatment. This theory is supported by a recent randomized control trial that indicates that mindfulness-based DMT interventions may aid in the reduction of perceived pain and the associated psychological distress (Majore-Dusele, Karkou, & Millere, 2021). Specifically, the study suggests that treatment interventions prioritizing the cultivation of a "safe therapeutic environment, mindfulness skills," interoceptive awareness, "relaxation," increased tolerance of discomfort, "meaning making, self-regulation, acceptance and creative process" were effective in reducing anxiety and depressive symptoms associated with experiences of chronic pain (Majore-Dusele et al., 2021, p. 5). It is important to note, that this trial was conducted on individuals diagnosed with chronic headaches that were not a characteristic of another primary disorder i.e., chronic primary pain (Majore-Dusele et al., 2021). This distinction may negatively impact the

transferability of the findings to individuals living with chronic secondary pain (pain associated with a medical condition) as is the case with endometriosis.

By the time we made it to college, we had already been forged in the fire; after experiencing 18 years of consecutive traumatic experiences, I entered adulthood with a full ride and a diagnosis of complex PTSD. I also came equipped with two superpowers: the ability to forget, and the ability to freeze (Van Der Kolk, 2015). More specifically the ability to detach from the emotional brain and physical body in service of reaching a desired goal (Caldwell & Leighton, 2018; Van Der Kolk, 2015). It was around this time that I had my first experiences with psychotherapy, which were ultimately unsuccessful in treating the trauma that was recorded within the physical structures of our body (Caldwell & Leighton, 2018). It was in that all grey studio and the Quaker church out north, that I found healing; specifically, it was through contact improvisation and Authentic Movement that we regained a connection to our physical self and the ability to tolerate touch. Additionally, it was through Alexander Technique that I discovered the work of Dr. Emoto and began to understand the ramifications of admonishing my body for being differently abled; specifically, it was while studying the Alexander Technique that I became aware of the harm caused by the internalized ableism that was manifesting as negative self-talk.²

This body, my body, knows that we had to take that ballet class, endure those years of institutionalized violence, and make another trip back through academia to fulfill our inherited

² Dr. Masaru Emoto is known for his research on the impact of emotions on the environment; specifically, Emoto conducted several investigations exploring the effect of prayer, meditation, and music on the crystallization patterns of water molecules. While Emoto's research has been discredited by the larger scientific community, my body holds it as truth.

task (Somé, 1994). Further, it is with this embodied wisdom that I make sense of the many hardships I have experienced during my short time on this earth; for without it, the trauma I endured would be rendered meaningless, my entire existence would be swiftly and retroactively enveloped and catapulted into self-destruction (Majore-Dusele et al., 2021). I have survived all these years because my purpose is to witness the testimony of bodies wounded by oppression and this is a fact because my body knows it to be true (Akinyela, 2014; Caldwell & Leighton, 2018; Rosen, 2021).

While the etiology of endometriosis remains unclear, research conducted by Harris, et al., (2018) suggests that childhood and adolescent exposure to physical and sexual abuse is associated with diagnosis of endometriosis later in life. Further, the study concludes that “abuse severity, chronicity, and accumulation of types of abuse [are] each associated with increasing risk in a dose–response manner” (Harris et al., 2018, p. 1660). It is important to note that the results of the cohort study were in direct contradiction of an earlier investigation on a similar topic (Schliep et al., 2016). However, considering the increased sample size and internal validity measures associated with the Harris et al., (2018) article, it is likely that there is an association between adverse childhood experiences and later diagnoses of endometriosis.

Although there exists conflicting discourse on the role of early trauma in the development of the condition, the position taken by Harris et al., (2018) is supported by the established research that associates adverse childhood experiences with poor long-term health outcomes (Vézina-Gagnon et al., 2021). Specifically, a recent analysis of administrative data spanning the time frame of 17 years investigated the differences in health outcomes between survivors of childhood sexual abuse (CSA) and the general population (Vézina-Gagnon et al., 2021). While there is ample research that correlates adverse childhood experiences, and specifically CSA, with

“proinflammatory responses that ultimately foster chronic diseases,” the article seeks to investigate how the relationship develops amongst individuals diagnosed with genitourinary conditions (Caldwell & Leighton, 2018; Van Der Kolk, 2015; Vézina-Gagnon et al., 2021, p. 105). The results of the matched-cohort study suggest that unresolved psychiatric complaints associated with CSA could contribute to the later onset of genitourinary diseases specifically through the “chronic activation of the hypothalamic–pituitary–adrenocortical axis” (Vézina-Gagnon et al., 2021 p. 109). Because these findings establish a clear relationship between early psychological stress and the development of endometriosis, it is the author’s hypothesis that the development of coping skills related to stress management may be an important consideration in the treatment of the psychological symptoms associated with endometriosis (Harris, et al., 2018; Vézina-Gagnon et al., 2021).

As we approach the end of this chapter, I am reminded of how this story began. We were a sad and anxious child, often left to our own devices from an early age. The ones that birthed us claimed we were, at our core, an embodiment of evil and deserving of punishment; the phrase was always “spare the rod, spoil the child.”³ As we grew, we learned deceit and mistrust, which only further reinforced the belief that we were inherently bad. It was there, in what seemed like an eternity of darkness that we learned to cope with stress through creative practice. We drew, sewed pieces of paper together with yarn, we sang songs and held movement demonstrations for our imaginary friends. Because we were often unattended, isolated and without social skills we were an easy target for many forms of abuse. We were accused of being seductive, and too

³ Excerpt from Proverbs 13:24 as found in the Hebrew Bible and Christian Old Testament. This passage speaks to the concept of original sin, or the belief that humans are evil from birth. Further, this passage is often used to glorify acts of child abuse in the form of corporeal punishment within the Christian community.

willing of a participant; we were constantly reminded of the things “little girls shouldn’t do.” We were taught to hate our body, to hide it in shame, to constrict and minimize that which was “unclean”⁴ (Caldwell & Leighton, 2018; Okun, 2021). We inherited hypervigilance on the bodily level. However, it was there in the fire that we developed some of the very skills that carried us here. We gained resilience, learned to invoke laughter, and to express the darkness through creativity.

Presently, there is no cure for endometriosis and current treatment strategies largely focus on managing the symptoms of the disease; subsequently The World Health Organization (2021) advocates for a multidisciplinary approach in the treatment of the condition. Despite this recommendation, there are many obstacles for those seeking care (Culley, et al., 2013; Emad, 2006; Grundström, Danell, Sköld, & Alehagen; 2020, World Health Organization, 2021). In addition to the complications associated with chronic fatigue, chronic pain, and diminished mobility, a common theme amongst affected individuals is a distrust for healthcare professionals (Culley, et al., 2013; Emad, 2006; Grundström, et al., 2020; Ong, 2011).

Any endo warrior (a colloquial term for individuals living with endometriosis) could tell you plainly that mistrust of healthcare professionals is an act of reciprocity. In the face of countless experiences of being invalidated within healthcare settings, the body’s natural response is to resist (Caldwell & Leighton, 2018; Rosen, 2021). For me, the experience of entering any healthcare facility is one of visceral terror. My heartrate increases, the muscles in my hands, feet, and abdomen contract, my flesh begins to perspire as I scan my environment in search of the

⁴ References anti-menstruation and anti-womb sentiments found in Leviticus from the Hebrew Bible and the Christian Old Testament. A common belief held within the Christian community is that the desires of our body are evil, and most evil of all are the feminine and queer bodies.

nearest exit. I want to flee from both my physical location and my body itself. This is not suicidality; this is the despair of living with a body in protest, the despair of possessing a wisdom that falls on deaf ears. As I fumble with these words, far too primitive to ever truly, capture a real visceral moment, I am aware of my slightly elevated heartrate. My skin is somehow hot and cold all at once; feeling the restriction within my abdomen, I want to flee. I want to close my laptop and say, “I’m sorry *fam*, I couldn’t do what you asked of me.” To the best of my ability, I have attempted to articulate what it feels like to encounter epistemic injustice in ways that the academic literature *could never*. However, you shouldn’t take my word for it, I’m no expert, I just have 16 years of lived experience.

In their 2020 publication, Grundström, et al. contextualize the experiences of 16 Swedish females seeking care for endometriosis and identify a consensus of having difficulties obtaining treatment due to the “normalization [and] trivialization” of symptoms by healthcare providers, family members, and society at large (p. 21). The ability to generalize the content within this study is questionable due to its small sample size and purposive sampling methods, however, similar findings are reported within the relevant research (Culley, et al., 2013; Emad, 2006; Grundström, et al., 2020; Ong, 2011; Rosen, 2021). Due to the limited availability of research on endometriosis, affected individuals may encounter obstacles when searching for knowledgeable practitioners and are at risk for being misdiagnosed as having psychosomatic symptoms (Culley, et al., 2013; Emad, 2006; Harris, et al., 2018; Grundström, et al., 2020; Mieres, McNally, Duarte & Grossman, n.d.; Ong, 2011). Considering the prevalence of repeated exposure to adverse healthcare experiences, which further the development of low self-concept, anxiety associated with health care providers and establishments, and resistance to treatment, it is imperative that person-centered approaches be utilized when engaging with individuals presenting with

symptoms related to the condition. (Culley, et al., 2013; Grundström, et al., 2020; Rosen, 2021). While specific person-centered approaches vary across disciplines, Majore-Dusele, Karkou, & Millere (2021) define them as being characterized by “warm relationships built on empathy, support, validation, and the acceptance of the patient as [they are]” (p. 5). Specifically, it could be beneficial to engage in extensive rapport building at both the cognitive and corporeal levels to address client mistrust of healthcare professionals and to allow time for client stories to be told and incorporated into treatment (Caldwell & Leighton, 2018; Rosen, 2021). With this goal in mind, it is the author’s hypothesis that mirroring interventions may be especially impactful in the early stages of treatment.

In the months leading up to enrollment, I underwent a procedure, called a laparoscopic ablation. The purpose of the surgery was twofold: to diagnose and treat what was suspected to be endometriosis. I remember being so excited to finally regain what was lost to that invisible monster without a name. I imagined that post-surgery, the fatigue would dissipate, the pain would be manageable, and the mood swings would subside. To my dismay, the only positive outcome associated with the procedure, was that it served as a naming ceremony for the monster that lived in my belly. The surgery confirmed what many physicians failed to acknowledge and investigate: that my symptoms were associated with an anatomical condition a not purely a manifestation of psychological distress (Caldwell & Leighton, 2018; Mieres, McNally, Duarte & Grossman, n.d; Okun, 2021; Rosen, 2021). The rage of my womb now had a name, but within a month’s time, I would learn that the ablation only made it angrier.

By the end of the year, I had quit one of my jobs as a barista and decreased my creative work as I prepared for the next chapter of my journey, graduate school. It was around this time that the last version of myself began to make way for the version that is reluctantly conducting

this investigation. By the close of our first semester at Lesley, we had left the coffee industry all together. This was an important shift for me, I was starting to acknowledge the impact of endometriosis, specifically I was becoming aware of how the condition was affecting my professional functioning. Rather, I finally had clarity and proof, that my pain was real; I was now able to hear the wisdom of my body. Finally, I had started to accept the truth of my flesh and began to organize my life around that knowledge (Rosen, 2021). However, it is important to acknowledge that this shift was only possible because of my academic privilege. Specifically, without access to the increased financial security afforded by eligibility for student loans and the promise of the increased earning potential that is associated with advanced education, this transition could have never occurred. This is important to name because the process of applying for disability benefits is never easy and given the lack of research and awareness on endometriosis, the process is made that much more complicated. Meaning that individuals living with my same condition but without the same level of academic privilege are at risk, for underemployment, poverty conditions and increased barriers to compassionate, knowledgeable healthcare.

Another consideration specifically related to the field of Dance/ Movement Therapy (DMT), is the prevalence of experiences of chronic fatigue amongst individuals living with endometriosis. In their 2020 qualitative study, DiBenedetti, et al., conducted twenty-two interviews to gain insight into the impact of endometriosis related fatigue. While the severity of fatigue varied from mildly disruptive to incapacitating each of the participants reported that the symptom had an impact on their functioning in 6 categories: day-to-day activities, social engagement, physical activity, mood and emotions, interpersonal relationships, as well as engagement in work and school (DiBenedetti et al., 2020). Further it was suggested that there may

be a causal relationship between experiences of chronic pain and fatigue (DiBenedetti et al., 2020). This is important to note because resistance to movement interventions may be an adaptive approach to managing experiences of chronic pain and fatigue. Further, considering that there is significant overlap between the impact of chronic pain, chronic fatigue and the symptoms associated with major depressive disorder, additional consideration may be required when evaluating the psychological symptoms of individuals diagnosed with endometriosis (American Psychological Association, 2013; DiBenedetti et al., 2020). Specifically, experiences of hopelessness, diminished interest, changes in weight, sleep routines, and diminished ability to think or concentrate could be better explained by the presence of endometriosis, which may not be apparent in individuals living without a diagnosis (American Psychological Association, 2013; Culley, et al., 2013; Dibenedetti, et al., 2020; Ong, 2011; World Health Organization, 2021). Additionally, successful treatment of the mental health symptoms associated with the condition, hinges on the effected individuals access to pain management interventions and the availability of systems that can be restructured to support their physical needs.

Before we arrived on campus that first summer, I remember we were asked to delineate the events that carried us to Lesley. I told the tale of a late comer to the field, an accidental dancer who fell in love with the form after enrolling in a ballet class on a whim. This was a truth, it was her truth, but not mine. At some point during early childhood, we developed a superpower: the ability to forget entire chapters of our life. I like to think of this ability to forget, as a force that has protected me from that which might cause us to unravel. However, just like any superpower, ours is not perfect; with it comes an altered relationship to the physical self and the loss of pleasant memories that were stored too close to the painful ones (Caldwell & Leighton, 2018; Van der Kolk, 2015).

Although my mind remains a place littered with blank spaces where memories should be, I'm thankful to have recently reencountered those that feature the performances I would stage for my imaginary friends. My truth is, that I was a born dancer, I was sold the myth that without training, I was nothing (Rosen, 2021). It just took nearly two decades to acquire the means necessary to purchase said myth, and another decade to realize that I had voluntarily welcomed violence against my body and paid a hefty price to receive it. To fully understand how undergoing dance training caused more harm than good, we'll have to take the scenic route through the trauma epidemic of 2020.

That year, I remember all I could say was “wow, what a time to be alive,” between the pandemic, the isolation, and the blatant disregard for black and brown peoples, that was all the optimism I could muster. Despite the many challenges we faced that year, I understood that the unfolding events plainly depicted why we were all called to Lesley the previous summer; we were needed to respond to an impending mental health epidemic. I learned many valuable lessons in 2020, the most salient being that coping skills are effective in managing stress, but only up to a certain level. As the year inched to a close, I noticed an increase in physical symptoms and despite having a strong aversion to healthcare settings, I decided to pursue medical care for the first time since undergoing diagnostic laparoscopy. I arrived at the gynecologist's office with my partner, in hopes that his presence would make the physician more likely to accept my request for a hysterectomy. Somehow, she was still able to talk me down, and I left the office with a prescription for pain medication and a referral to a pelvic floor therapist. During my initial exam, the therapist informed me that my pelvic floor muscles were weak; nothing about the statement felt accurate, but I ignored my better judgement and mistook my intuition for anxiety (Okun, 2021; Rosen, 2021). I was desperate for relief and decided that it

couldn't hurt to try; I was wrong, it did hurt, and the result was additional physical therapy to reduce the harm that had been done. What the first physical therapist mistook for a weak pelvic floor was atrophy from chronic activation of the muscles in that region.

When I began pursuing dance "training," it was already suspected that we had endometriosis; at that point we had been experiencing symptoms for seven years but would not receive a formal diagnosis for another six. I remember taking that first dance class on a whim; I needed just a few more credits to reach full-time status and maintain my scholarships, but I wanted to keep my academic course load light. During that first week of classes, it was announced that the department would hold auditions for the company; I had taken *all of* three dance classes and initially only signed up because, in my mind, auditioning meant attending an evening of free classes. To my surprise, I was cast in two pieces and invited to join the company; the head of the department said "you're a good mover" when delivering the news and I just assumed he took pity on me, a peasant, without any formal training. I spent the next three and a half years training in modern, ballet, jazz and tap, learning to engage my pelvic floor and forsaking the movement that had carried us to that point.

During those years spent in the all-grey studio, I sustained many injuries, specifically stress fractures within both hips and feet, and countless injuries to the muscles in my legs. At the time, I believed that these injuries were evidence of my deficiency; I was *thick* and untrained, always fatigued and visibly behind my peers. Today, I acknowledge that the injuries we sustained represent the battle our body fought against the forms of movement that were not for us. Although I cringe at the thought of being sold my birthright, I am aware that within the current system, this is the path I must take. For this reason, I do not wholly regret studying dance at the collegiate level. Similarly, I only halfheartedly resent the time I have spent at Lesley

pursuing those coveted letters that will deem me credible enough to walk alongside others on their path to healing.

When I was 9, my mother, grandmother and I went out for ice cream. This was the day that I had to record a video testimony to strengthen the legal case against my mother's boyfriend. I remember, as we walked hand in hand my grandmother leaned down and said something like "sometimes God allows bad things to happen to us, so that we may help others in similar situations." I grew to resent that and questioned what kind of God allows children to be harmed just so they could help the other children he allowed to be harmed. I no longer serve that god, but the sentiment remains the same; all my experiences up until now, all of the hardships, have prepared me to do this work, more than any institution ever could. I have walked the path and with the kindness of my grandmothers and the help of a couple of good therapists, I am now able to venture back, and walk hand in hand with those on similar journeys. This is the story of how we got here, the story of how we developed endometriosis, the lived experience that informs the practice.

Method

Materials

The primary means for data collection was video recording using the front facing camera on the Google Pixel 3 (8 MP camera with a 75° shot at 1080p and 30fps). During the recording process the device was mounted using a 62" Ubesize tripod with an illuminated ring light. The 27 verbal processing videos were stored privately on the social media platform TikTok, the 16 Authentic Movement videos and the unedited digital collage videos were stored on Google photos and the 16 finished video collages were stored on Google photos and displayed publicly on Instagram. The 16 digital collage videos were edited using the VIP version of the Android

application VivaVideo. Journaling for the 16 Authentic Movement videos was done using a pen and college ruled paper journal, while the journaling for the 16 digital collage videos was conducted using the caption feature on Instagram.

Procedure

As mentioned earlier in the text, when I began this investigation, I sought to explore the efficacy of using DMT as a form of treatment for individuals living with Endometriosis. Initially, I intended to conduct an experiment following an ABA single subject design. However, as the research began to develop so did my resistance towards such strict parameters around my creative process. For this reason, an autoethnographic approach better suited my need for increased creative freedom, and as the methodology changed so did my relationship with the data collection process. At the start of this inquiry, I anticipated that the data analysis would be deductive in nature; however, as the data collection progressed, I became more curious about the theories that were naturally emerging. For this reason, the creative aspects of autoethnography and the inductive nature of grounded theory was most applicable to the amended research design (Tie, Birks, & Francis, 2019).

Data collection began on the first day of my menstrual cycle on January 5th, 2022; I focused on verbal recording and processing of both the physical and psychological symptoms associated with endometriosis, with the intention of using this dataset as a baseline of symptoms. The first dataset was collected using the “Only Me” feature on TikTok and was comprised of 19 videos collected in between January 5th and January 29th; each video varied in length from 30 seconds to two minutes and 57 seconds and were collected every one to two days. Initially, I had considered using Instagram for this portion of the data collection process, however, I anticipated that the public nature of the platform would limit the authenticity of the descriptions provided

within the dataset. The rationale for posting the first set of videos to TikTok was that its “Only Me” feature provided private cloud-based storage that was easily accessible. Specifically, by design the platform allows for a series of videos to be played consecutively, allowing for a more streamlined data reviewal process.

Collection of the second dataset began on January 30th and was associated with the start of a new menstrual cycle. My recording of verbal data became less consistent and because I was no longer interested in measuring the effect of movement on the psychological symptoms associated with endometriosis, this method of data collection was discontinued on the 12th day of the menstrual cycle following the collection of eight videos using the same method as outlined for dataset one. Verbal processing videos within the second dataset ranged in length from 10 seconds to two minutes and 41 seconds; due to their irrelevance to the amended research design these videos were reviewed but not included in the data analysis process.

The second set of data collected in between January 30th and March 2nd consisted of a total of 40 videos. Specifically, eight of the videos were verbal processing recordings collected via TikTok, 16 were video documentation of single subject Authentic Movement collected offline ranging from three minutes and 36 seconds to 13 minutes and 47 seconds in length. The final 16 videos were digital collages collected and edited offline and later posted publicly using Instagram’s Reels and post features. Unedited videos varied in length from three minutes and 13 seconds to 12 minutes and 50 seconds, and the edited videos varied in length from 43 seconds to one minute and 44 seconds. The video editing process served as a means for witnessing my own movement and highlighting the phrases, shapes, and qualities that felt safest in my body. Further, because the editing process requires meticulous reviewal of the footage, the process elucidated the patterns of movement that were likely to result in injury. Accompanying the 39 videos were

32 journal entries, 16 of which were recorded using a pen and paper journal; the remaining 16 journal entries were recorded in the “Caption” section of the related Instagram post.

Initially, Authentic Movement was chosen as the sole treatment intervention because of my previous experience with the form and its focus on shifting toward comfort. During the opening stages of the intervention phase, the form was supportive and adaptive because it accommodated the limited mobility associated with heightened endometriosis symptoms. However, as the investigation progressed, the strict parameters of the form became a hindrance to creative exploration. While these videos and the accompanying journal entries were not reviewed or analyzed, the improvisations that followed greatly benefited from the daily movement practice that was established during the process. In short, engagement in a low impact form of movement for 16 consecutive days, allowed for habit formation to occur; this could be an important prerequisite intervention for individuals who are resistant or unaccustomed to movement.

The shift from the privately stored Authentic Movement videos to the publicly available digital collages happened organically and unexpectedly and the transition served as the impetus for the change in methodology and guiding theory. Specifically, the creation of the first collage was an act of creative expression or movement for movement’s sake; it was posted to Instagram (Albatross, n.d.) merely because it was art that I wanted to share with my community. The community witnessing that occurred without provocation within the comment section of that first collage was the deciding factor in amending the research design. I had offered my testimony in the form of movement and my community bared witness; the interactions were of great similarity to the therapeutic use of narrative, only in this context the narrative prioritized and centered my body’s wisdom. Although I was initially hesitant to make such a personal process accessible to

the public, it was ultimately the presence of community support that informed the changes made to the research design. Further, I would like to name that healing in community, rather than in isolation is consistent with the values of Africanists traditions, and I speculate that my reservations towards involving others in my research were indicative of my own internalization of oppressive ideologies.

Results

It was the combination of witnessing my own movement from a third-party perspective and my lived experience of sustaining injury that allowed me to define my movement parameters and limitations. This was a significant outcome because the unpredictability at which my body functions is a major deterrent to movement and represents a causal factor in my tendency towards sedentariness. Further, because an overactive pelvic floor is one of the characterizing features of endometriosis, I found that the training that lives in my body has a deleterious effect. We speak of transference and countertransference in the counseling realm, and I am curious to know if these phenomena manifest on a bodily level. Consequently, I am eager to learn if the oppression that lives in the bodies of dance therapy practitioners has the potential to enact harm. As I worked to forsake the training that I once viewed as a badge of honor, the movements that made my body feel most like home were characterized by softened hips, relaxed glutes, and a slightly tilted pelvis. I found healing there as I shook and gyrated; I found healing while I was *throwin dat ass*.

Discussion

The implications of the above findings have applications beyond individuals living with endometriosis or similar conditions. Namely this form of heuristic inquiry, elevates the participant's bodily wisdom and places the individual in the role of researcher, interpreter, and

expert, with the relinquishing of power by the dance movement therapist being in and of itself an act of epistemic justice. Further, because our culture prioritizes the cognitive over the corporeal, we are implicitly (and often explicitly) taught to ignore the wisdom of our flesh. We are socialized to dissociate and are largely unaware of how our individual bodies respond to different qualities of movement. Additionally, considering that white supremacy permeates every aspect of our culture, it is safe to assume that by extension, the way we organize our physical selves in space is governed by Eurocentric patriarchal standards. Because of this, research within the field of DMT could benefit from exploring the physical ramifications of corporeal code-switching within marginalized communities.

Despite my blatantly obvious feelings of resentment towards this process, academia, and all related systems of oppression, it was through completing this capstone that I had the opportunity to think critically about how European patriarchal standards impact and distort all that we do in this cultural setting. More specifically, it has been an illuminating experience of unearthing how white supremacy assumes residency in my body. Prior to conducting this research, I had not danced consistently in over a year. Due to the years that I spent training in Western forms of movement, dancing had become an act of violence against my body. While the initial aim of this investigation sought to explore the impact of DMT on the psychological symptoms associated with endometriosis, the research ultimately became an exploration of endometriosis, epistemic injustice, and its manifestations within the field of dance/ movement therapy.

It appears to me, that as a field our move toward legitimization is a double-edged sword. Part of me acknowledges that there is benefit in being deemed credible by the established healthcare system, but at what cost? Who misses the opportunity to be deemed as a credible

practitioner of dance therapy due to limited access to educational resources, or difficulties with expression via the written word? How many communities remain underserved because their resident healers were not born with enough privilege to pursue education at the graduate level? There are born healers, who come from healing lineages like mine, who are enduring under-fulfilling (and likely exploitative) labor, just to practice this work in whatever form they are able. It is our dance instructors, our volunteer coaches, and our community elders that are (and have been) doing this work, but it's not dance/ movement therapy because the American Dance Therapy Association has not had the opportunity to recognize their brilliance (American Dance Therapy Association, n.d.). I acknowledge that this is just the way things are, that this is the path to becoming the village healer, because *This is America*. But my heart longs to know what this process could look like if we were to abandon the "master's tools" (Lorde, 1984, p. 2). If we were to accept our duty as makers of change and say, "let's do something different;" I can only imagine how our work might be transformed, I can only imagine how many communities might finally be able to break the chains of oppression.

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