

## **Adding Insult to Injury: How Physicians Fail Women in Pain**

by Halle Rose

Though I spent the majority of my early years in a dance studio, I was always drawn to stories. One of my favorites, which I listened to as an audiobook when I couldn't have been more than seven or eight years old, was *Alice's Adventures in Wonderland*. Thoroughly enthralled by Lewis Carroll's vivid descriptions and whimsical characters, several quotes and poems from the nineteenth century novel have resonated with me throughout the years. One, which became unexpectedly and abruptly relevant to my own life barely two weeks after I had turned sixteen years old, is from the scene in which Alice is confronted by the Caterpillar. "Who are you?" asks the Caterpillar, prompting Alice to answer the question most of us spend a lifetime trying to figure out for ourselves. She proceeds to tentatively retort: "Well, I--I hardly know, sir, just at present-- at least I know who I *was* when I got up this morning, but I think I must have been changed several times since then."

I knew who I *was* when I got up on the morning of February 8, 2015. My entry for the New York City Dance Alliance Pittsburgh Convention read my name, followed by "Independent Teen, Erie Dance Conservatory." A pale face with a long blonde ponytail stared back at me from the mirror in the hotel bathroom as I got ready that morning. While I was getting dressed, I picked out the pink top that I wore for every convention audition, in favor of some subconscious superstition that was common among dancers. Before the audition began, I drank fruit punch-flavored gatorade, as always, and took six hundred milligrams of ibuprofen to ease the dull pain that had been developing under my left kneecap. I mentally ran through the choreography once more, concluding that I definitely knew the ballet combination better than the modern, which made sense considering I had spent the majority of my life in a classical ballet

studio. I remember it crossing my mind that this was my last year of competing for scholarships for fun before I had to start seriously and strategically thinking about competing for a spot in a collegiate program. I stood in the front right corner of the room for my audition, as always.

The details of my physical incapacitation are clinical in essence, devoid of any character that distinguishes my experience from that of any other orthopedic-trauma patient. *Torn medial patellofemoral ligament* and *patellar avulsion fracture* do little to convey the assault on my identity that took place the day that I dislocated my patella in front of a room of two hundred people and, though I was unaware at the time, suffered a femoral nerve lesion that would leave me with severe quadricep atrophy two years later. I knew who I *was* when I got up that morning--a dancer--disciplined, physically strong, focused and capable; however, by the time I was sitting in the waiting area of the Pittsburgh Children's Hospital's Emergency Room, my left knee so swollen that it could hardly be distinguished where the joint ended and the quadricep began, I had undoubtedly changed several times since then.

Chronic injuries are not uncommon in young athletes. Serious dancers, who typically begin to practice their craft between the ages of three and six, are particularly susceptible for repetitive strain injuries, in accordance with the tendency to overuse muscles and ligaments. Tendinitis is essentially a colloquial term in the ballet studio; most students are afflicted to some degree in their knees, ankles, and/or hips. Additional injuries, which range from nuisance to debilitating in nature, include lower back strain and muscle spasms, snapping hip syndrome, and impingement of tissue in the feet and ankles. The pre-professional dancer will typically strive to meet the demands of his or her training regime, which often parlays into practicing and performing despite the limitations imposed by his or her injury. This tendency mirrors the

mentality of collegiate athletes--the competitive nature of the individual combined with the limited opportunities for success in the respective field often drives young athletes and dancers to inflict further injury upon themselves once initially afflicted.

The prevalence of these injuries is undoubtedly linked to the culture surrounding collegiate athletics and pre-professional performance. Even the youngest dancers are praised for pushing through pain, for conquering injury, for persevering despite facing an implicit challenge. In dance, there is an inherent sense of validation when one triumphs over her body. Dancers and athletes alike are cultivated in an environment that glorifies heroism and enforces unspoken rules, such as: "injury is not allowed, pain is ignored and unacceptable, and there are no complaints about 'minor disabilities' until they interfere with training programs to such a degree that it is apparent to coaches and teammates alike" (Shuer and Dietrich 104). "No pain, no gain" has exponentially manifested from a mantra to a mindset, despite the counterintuitive nature of this premise. For many dancers, self-preservation and career longevity involve a delicate balance of knowing when to push through pain and when to withdraw, risking losing flexibility, muscle equilibrium and stamina, in the interest of their ultimate maintenance of physical capability. "We're not masochists," states Tamara Rojo, artistic director and lead principal dancer of the English National Ballet. "We don't enjoy the pain. It's not some kind of religious ritual. You do not and should not think you have to suffer for the art" (Gramilano).

On the contrary, it appears that the true suffering that arises from chronic injury is psychological, cumulative, and most debilitating when an individual is inhibited from pursuing her sport or craft. In a study conducted by M.S. Shuer and M.S. Dietrich, a significant degree of emotional distress was found to be evident in athletes who experience chronic "minor" injuries.

Fostered by the socialization of competitive sport and performance, serious athletes are considerably less likely to acknowledge a state of physical disability, or to seek psychiatric treatment for the mental ramifications that may consequently ensue. Shuer and Dietrich describe the typical athlete as “training in a constant state of pain or injury while meeting the demands of an elite level program,” and deduce that the psychological trauma experienced by injured athletes is comparable to that which is evident in survivors of natural disasters (Shuer and Dietrich 105). Because elite athletes are expected to endure various degrees of musculoskeletal pain in addition to aerobic and anaerobic discomfort, they have been conditioned to simultaneously endure the accompanying emotional distress--on an anatomic level, most athletes who suffer from chronic injuries can even be found to have a prolonged stress-response system (106). Once an injury has been experienced, however, psychological consequences are inevitable. Dietrich and Shuer conclude that the typical elite athlete will struggle to cope with the events surrounding a debilitating injury, particularly in regards to coming to terms with a “...sudden change in status [and] abilities” (106). The crux of a chronic injury forces an athlete to admit failure of physical and mental fortitude, to relent despite being immersed in a culture where injury and rehabilitation are heavily stigmatized. This conclusion suggests the potential of an attenuating physical injury to wreak havoc on an athlete’s sense of self when so much of the athlete’s identity is invested in what they practice.

From the time I was two years old, I had always identified as the dancer. Perhaps it was because this identity was so deeply ingrained within me that nobody had to break it to me that my time as a dancer was over. The words “You might never dance again” never left the mouths of my physical therapists or physicians; this cold, hard fact was something I was inherently

aware of from the moment my patella slid out of place. I found it interesting how, from my initial treatment in the ER, it was immediately apparent that the interactions between an injured athlete and her physicians are cautious, weighted even. The physician withholds from making any potentially-false assertions of prognosis, and the athlete, who is undoubtedly more physically conscious than most, hesitates to ask questions that she is fully aware may have devastating answers. Everyone tiptoes around the injured athlete because nobody wants to bear the news that she is no longer the same person that she was when she woke up that morning.

I never sought empty promises that my livelihood could be restored, but I was struck by the inability of the orthopedic resident to look me in the eye as he explained the rehabilitative course of action. Surely this man had to have delivered worse news in his career, news that somebody had not made it, that another would never wake up. Regardless of his experience in the discussion of sensitive subjects, this doctor evaded my leading questions that dared him to state out loud what I already knew to be true. It felt as if although the resident knew I would survive my injury, that there was never any real danger of a lasting consequence like death, that he also knew that a lasting consequence had still occurred as part of my identity abruptly dissipated.

To the same degree that I knew I would not readily recover from the injury I had sustained, I knew that the extent of the damage to my leg extended far beyond what my original physician predicted. My first inkling of the fallibility of the white coat came when my orthopedic surgeon dismissed my inability to lift my leg from the hip. "It's in your head," he told me. "You're just afraid that it's going to hurt." Vulnerable, hurting, and emotionally exhausted, I certainly didn't meet this accusation with the emotional fervor that perhaps it deserved. At the

time, I didn't take as much offense at this man accusing me of falsifying my pain as I felt shame at succumbing to my body's weakness, at failing to overcome the current physical challenge I faced. After all, who was I to question someone who far surpassed me in education and experience with orthopedic trauma? I remember my mother agreeing, if somewhat hesitantly, that perhaps I was apprehensive of the pain that might come from attempting to use my leg. It was not until I lost feeling down the front of my left thigh and my foot turned blue that she, and I myself, began to take my pain seriously.

As it turns out, I am not the only patient to have experienced a consequential dismissal of pain from a physician. More specifically, I am not the only female patient to have been told that my pain was superficial, and that addressing it was medically unnecessary. There is readily available literature that suggests the inadequate treatment of pain in Western culture; furthermore, there are prevalent and sinister undertones among these sources that imply the higher likelihood of women to be underdiagnosed and treated for their pain when compared to their male counterparts. As published in the *Journal of Law, Medicine, and Ethics*, Diane E. Hoffmann and Anita J. Tarzian survey several facets that surround the portrayal of symptoms by both male and female patients, and the eventual analysis made by physicians. Hoffmann & Tarzian first consider the biological differences in pain perception between genders, discrepancies that arise as a result of reproductive hormones, variations in stress-induced analgesia responses, and brain and nervous system structure. It was concluded that women were more likely to report "more severe levels of pain, more frequent pain, and pain of a longer duration than men" as a "direct result of physiological differences" (Hoffmann and Tarzian 15). They continued to examine the psychological and cultural factors that influence pain perception

and behavior, and found that differences exist in the manifestation of male versus female pain expression in addition to the manner in which pain is communicated to health-care providers. In Western culture men are typically socialized from a young age to repress expression of pain and emotions. Women have been found to adopt a more “relational, community based perception of the world,” and are more likely to not only fully describe their pain sensations than men, but to “[include] contextual information, like the pain’s effect on their personal relationships” (Hoffmann and Tarzian 17). This research prompts investigation not only into the difference in how men and women communicate pain to health-care providers, but also in how health-care providers respond to these descriptions of discomfort.

Alarming often, women fall subject to “The Yentl Syndrome,” a documented phenomenon in which female patients are more likely to be treated less aggressively in their initial encounters with the health-care system until they “prove that they are as sick as male patients.” In a study conducted by Karen L. Calderone, male patients undergoing coronary artery bypass graft received narcotics more often than female patients, while the female patients received sedatives more often, suggesting that female patients were more likely to be perceived as anxious than in pain (Calderone). This observation suggests that when my first orthopedic surgeon claimed that my pain was fabricated, he was merely echoing the sentiments of generations of physicians before him who hold preconceptions about female pain. This tendency to expect exaggeration and forgery of symptoms traces back to the Freudian perception of “female disease.” Up until the twentieth century, hysteria was a viable and likely justification for a woman’s physical and mental discomfort (Tasca). It was common practice to disregard women who expressed pain that could not be readily diagnosed, to render them “sexually unfulfilled”

and more often than not, to institutionalize them. In her short story, “The Yellow Wallpaper,” Charlotte Perkins Gilman immortalizes the experience of a misdiagnosed woman subject to a 19th-century European health-care system:

If a physician of high standing, and one’s own husband, assures friends and relatives that there is really nothing the matter with one but temporary nervous depression—a slight hysterical tendency—what is one to do? (Perkins)

Gilman initially wrote *The Yellow Wallpaper* as an exaggerated account of her own experience with medical mistreatment, intending to address the oppressive patriarchal nature of health-care at the time. Unfortunately, the experience of female misdiagnosis and dismissal is not limited by the confines of history.

Another study conducted by Calderone followed the case of Cynthia Toussaint, a former professional ballet dancer whose pain following a hamstring injury was consistently dismissed by her physicians until she was eventually diagnosed with Complex Regional Pain Syndrome, a chronic condition characterized by the amplification of pain receptors following an initial incidence of injury (Complex Regional Pain Syndrome). Throughout the course of her treatment, or lack thereof, Toussaint was told that her pain was “all in her head,” that she was “making it all up,” that she “had stage fright,” that all she had to do was take aspirin. Toussaint claims that when she asked doctors how to address the pain she was experiencing, she was told to “shoot herself in the head” (Vesely). Today, Toussaint is wheelchair-bound, though she remains a steadfast advocate for the validation of female pain.

Stories that parallel Toussaint’s have always been prevalent, but are now becoming increasingly accessible with the widespread use and distributive power of the internet and other



communicative technology. Jennifer Brea, a then-PhD student in political science at Harvard, former TED Fellow, and current prolific advocate for invisible illness and autoimmune disease, first fell ill in 2010 after suffering a 104.7 degree fever that persisted for ten days. Throughout the next year, she grew increasingly less coherent as her fine-motor skills rapidly deteriorated. She fell susceptible to infection after infection, only to be told at each doctor's visit that there was nothing wrong with her. After visiting numerous specialists, a psychiatrist told her: "It's clear you're really sick, but not with anything psychiatric. I hope they can find out what's wrong with you. The next day, a neurologist diagnosed her with conversion disorder--a mental illness caused by a stress or psychological trauma that she was unable to recall (Brea). Her symptoms, he claimed, were real--the neurological, cardiac, and numerous other deficits were obviously debilitating, but they did not appear to have any biological cause. It was later that day that Jennifer collapsed after walking home from her appointment, and so began her next two years of bedrest. She took to the internet, and to her surprise, found a community of others like herself, who she described as "similarly isolated, similarly disbelieved" (Brea).

Jennifer was ultimately diagnosed with Myalgic Encephalomyelitis, also referred to as ME, or chronic fatigue syndrome. The common symptoms among sufferers of ME are the debilitating consequences of physical and mental exertion. In a speech at TEDXSummit 2016, Jennifer described being unable to walk half a block without being bedridden for the next week (Brea). Despite the frequency of ME (there are over a million sufferers in the United States alone), the general population is grossly uninformed. "Doctors do not treat us, science does not study us," Jennifer stated at the conference. She continued to remark on her experience as a woman with an invisible illness. "When my doctor diagnosed me with conversion disorder, he

was evoking a lineage of ideas about women's bodies that are over 2,500 years old," Jennifer explains, putting her experience (which was eerily similar to my own) in the context of modernized perceptions of hysteria. "Why has this idea had such staying power?" Jennifer attests the tendency of physicians to attribute invisible illnesses partially to sexism, but primarily to the average physician's authentic motivation to help (Brea). Evoking diagnoses such as conversion syndrome, or any other modified version of hysteria, allows physicians to solve problems that are otherwise unsolvable. Women are two to ten times more likely to receive the diagnosis of "conversion disorder" when science falls short of diagnosing a potentially crippling illness (Brea). This statistic is reflective of a much bigger conundrum that is ultimately harmful--when physician preconception inhibits, or even halts, research and progression, patients are neglected. Statistically speaking, women are considerably more likely to fall victim to this neglect.

The profile of a female victim of physician preconception includes not only those who suffer from chronic disease, but also those who fall subject to acute injury. Rachel Fassler, a young woman who suffered from ovarian torsion, waited upwards of fourteen hours before her pain was addressed by physicians at the Brooklyn Hospital Center Emergency Room. Ovarian torsion, which is considered a medical emergency, is characterized by the rotation of a woman's ovary so that the blood supply to the organ is impeded; afflicted patients typically complain of sharp and sudden pain in the lower abdomen. If left untreated, the condition may result in ovarian loss, intra-abdominal infection, sepsis, and even death (Ovarian Torsion). As recalled by Rachel's husband, Joe Fassler, they were assured in the emergency room that Rachel's case was "*not* an emergency;" rather, a nurse pronounced her diagnosis as "stones," and began the standard pain-management course of treatment for kidney stones soon after. When Rachel's pain

failed to subside, however, her husband pressed for more aggressive treatment. When she requested stronger painkillers, Rachel was told “Lot of patients to get to, honey...don’t cry” (Fassler). It wasn’t until several hours later that Rachel’s CT scans were reviewed, by a different physician than the one that had initially diagnosed her with kidney stones. It was only then that a considerable mass was found, and that Rachel was rushed into surgery to remove the cyst that was weighing down her ovary. Joe Fassler attests the delay in Rachel’s treatment primarily to the gynecological (and consequently, inherently female) nature of her condition. “This particular ER,” Joe states, in an article published in *The Atlantic*, “like many in the United States, had no attending OB-GYN. Every nurse’s shrug seemed to say ‘Women cry, what can you do?’” (Fassler). The common ground between Cynthia Toussaint’s, Jennifer Brea’s, and Rachel Fassler’s stories, in addition to my own, is the consistent condescension and dismissal bestowed upon us by the professionals we entrusted to take care of us, condescension and dismissal that is just as integral to the culture of Western culture health-care today as it was 2,500 years ago.

I knew my surgeon was wrong. It was a bold assertion, especially given the status and prestige of the man in question, and I admittedly failed to challenge his treatment of me at the time. Regardless, I knew his diagnosis was incorrect. When I got up, on the morning of February 8, 2015, I knew who I was. I was a ballet dancer, and therefore I was resilient, persistent, and extremely in-tune with my body--despite being unable to dance, I hadn’t fully lost those aspects of my identity. It was actually later in my course of treatment, while waiting to consult with a neurologist at the Cleveland Clinic, that I stumbled upon empirical evidence that reinforced these qualities that I had thus far defined myself by. In his book *Complications*, Atul Gawande, a prominent surgeon at Brigham and Women’s Hospital in Boston, addresses what he calls “The

Pain Perplex.” In his attempt to rationalize the elusive nature of pain and sensation, he references a study conducted on fifty-two ballet dancers and fifty-three university students. The study utilized a cold-pressor test, in which a subject’s hands are first submerged in a bowl of ice water, and are then withdrawn once the subject feels pain. On average, female dancers were able to keep their hands submerged three times longer than female non-dancers, and though male dancers were able to withstand a longer duration than female dancers (consistent with the earlier study conducted by Hoffmann and Tarzian), they were able to withstand a still longer duration than male non-dancers. Gawande assumes the heightened pain-tolerance of dancers can be attributed to the psychology of the craft (Gawande 121). The psychology of ballet is analogous to the culture of competitive sport. Distinguished by self-discipline, physical fitness, and competitiveness, dancers have been conditioned to tolerate the type of discomfort that accompanies chronic injury. “Their driven personalities and competitive culture evidently inure them to pain,” states Gawande, upon review of the study (Gawande 122). These qualities aligned with those I felt as though I had inherently attained through being a dancer, characteristics that were deeply intrinsic and withstanding parts of my identity. To have these assertions of character undermined by someone I trusted to remedy me was unprecedented and unnerving in the face of coping with my injury.

Almost six months after I first lost sense of who I was, I finally knew what had happened to me. Thanks to persistent physicians and physical therapists who operated on possibility instead of preconception, it was determined that I had undergone a patellar dislocation with an associated femoral nerve lesion, a neurological complication of the dislocation that was virtually unheard of in medical literature. Almost two years later, I was given a fleeting glimpse into the

possibility of why this injury had happened to me. I am currently being tested for Ehler-Danlos Syndrome, a genetic, hypermobility-spectrum disorder that would explain the neurological deficits I experienced. Ehler-Danlos Syndrome is often referred to as a “medical zebra” because for years, medical students have been taught that, “When you hear hoofbeats behind you, think horses not zebras,” meaning that the likely diagnosis is what is common and usual. In the case of conditions like Ehler-Danlos, Complex Regional Pain Syndrome, and Myalgic Encephalomyelitis, however, sometimes hoofbeats really are zebras.

The identification of the already underdiagnosed chronic illness that I am likely affected by was further inhibited by the preconceptions held by the physicians who treated me. Because I am female, I am statistically more likely to have my complaints of pain dismissed and to have my symptoms rendered as medically insignificant. To face this adversity at a point in my life where my assertion of my own identity had been compromised was nearly insurmountably challenging, but ultimately defining. There was some inevitable impact on me by the injury itself, as Leslie Jamison mentions, in her essay entitled “Grand Unified Theory of Female Pain:”

[There] are the dangers of a wound: that the self will be subsumed by it (“personal vanishing point”) or unable to see outside its gravity (“everything led to it”). The wound can sculpt selfhood in a way that limits identity rather than expanding it—that obstructs one’s vision of others’ suffering rather than sharpening empathic acuity (Jamison).

Figuring out how to rebuild my identity from the pieces my injury had left behind was especially difficult, considering that my experience was largely driven by the preconceptions of others. To be questioned and condescended to at a point in time when I was most vulnerable challenged which aspects of my identity were unconditionally inherent, and which would waver in the face

of change. I found that despite being superficially stripped of the “dancer” identity, there were qualities I had gained from my years in the studio that were only fortified when placed in the context of overcoming an injury. I found that as a female patient, there were common expectations of me from others that contradicted those I held for myself, and that whether I defied or accepted those expectations would ultimately determine the modified identity I would forge. I have certainly changed several times since I got up on the morning of February 8, 2015, but through the triumph of possibilities over preconceptions and through the support of the stories of others, I have finally attained a better sense of who I am today.

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