


Erasure of the Credible Subject: An Autoethnographic Account of Chronic Pain

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Abstract

In this autoethnography, I provide a firsthand account of living with severe chronic pain in an effort to begin to fill an absence in the scholarly literature. I intend to demonstrate how the performative nature of pain and the way in which people in pain are treated can contribute to the slow and steady erasure of their credibility and sense of effectiveness in the wider world. In this way, I underscore the “public issues” inherent in the chronic pain experience, something that is traditionally seen as the most private of “personal troubles.” I conclude that qualitative health research would benefit if more “insiders” were to give expression to some of the devastating social effects of living with chronic pain. Pain sufferers need a common language through which they can begin to resist shame, reclaim a sense of agency, and raise their voices as part of an empowered collective.

Keywords

pain, chronic, disability, stigma, autoethnography

Researchers across many disciplines have made chronic pain the subject of exhaustive study, and countless qualitative health researchers have faithfully documented the experiences of pain patients and the stigma they so often face (e.g., Good, 1992; Jackson, 2005; Kugelmann, 1999; Werner, Isaksen, & Malterud, 2004). However, to truly understand pain, we also need to listen to the unmediated words of those who live in it. Pain sufferers inhabit a world where their strained voices are too easily invalidated and rarely even heard. I aim to begin to fill this void in the scholarly literature by providing an autoethnographic account of what it is like to live in and with severe chronic pain, the threat to one’s credibility that it represents, and the promise of both sociological insight and political agency that it embodies.

I am someone who can speak on the topic of pain with some authority, having had over a dozen, often emergency, surgeries on my legs and hips; months of hospitalizations; and scores of visits to doctors and physical therapists. I almost lost first my right leg and later my left, as the doctors were just hours away from needing to amputate. Initially, the wound on my right leg stretched almost 10 inches (25.4 cm) long and gaped open 4 inches (10.16 cm) at its widest point. The subsequent grafts remained unclosed and required daily dressing changes for close to a year. I was bound to bed for several weeks, in a wheelchair for many months, and on crutches for over 4 years. The pain has haunted me in one form or another every day since September 13, 1991. At some indistinct point in the years

that followed, the original “organic cause” of my pain resolved. However, the pain had by then become, if not more intense, more exhausting due simply to its unrelenting chronicity. Most of the time, the chronic pain was unaccompanied by any external signs of its presence. There was nothing, in other words, to validate my internal experience outside of my own description.

These are my “credentials” as an authority on pain. It is fitting that I enumerate these to you, for the need to establish credibility is at the very center of the chronic pain experience. People in pain live with a largely invisible disability or “concealable stigma” (Pachankis, 2007). Because they are usually able to “pass” as able-bodied (Joachim & Acorn, 2000), others often question their claims of suffering. To confront challenges to their credibility, the invisibly disabled must rely on continual impression management and strategic self-disclosure (Matthews & Harrington, 2000), but the unrelenting nature of credibility work is inherently wearing.

As a White, well-educated, upper middle class woman, the otherwise intact narrative of my privileged subject position has been profoundly ruptured by pain. Yet it is this position that has situated me in such a way that any injury

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to my privilege comes as a surprise, an instance of cognitive dissonance. Thus my advantaged social status—while blinding me to the many ways in which race and class can compound and complicate the effects of disability—does enable me to see with some clarity the distinctive features of oppression based on disability that distinguish it from other forms of oppression.

The many personal journals I have kept over the years, as well as my voluminous medical records, gave me the rich wealth of data from which I reconstruct the experiences narrated here. Like many scholars of illness (Ettorre, 2005; Defenbaugh, 2008; Poulos, 2012; Uotinen, 2011), I have chosen to employ the autoethnographic method as a form of “systematic introspection (Ellis, 1991) that articulates the social, cultural, and even political aspects of one’s own personal experience. In doing so, I hope to “make it possible to converse about previously silenced and unspeakable topics” (Ellis & Bochner, 1996, p. 25) in a way that “deepen[s] our capacity to empathize with people who are different from us” (Ellis, Adams, & Bochner, 2011). After all, autoethnography aims to bridge the divide between art and science—and I would add mind and body—by providing “evocative narratives” that help readers “see and sense” the subject matter in ways that reach beyond what traditional disembodied scholarship can do (Tillman-Healy, 1996, p. 80).

An autoethnographic approach to illness studies also speaks to Ellingson’s (2006) appeal to qualitative health researchers to acknowledge the embodied nature of knowledge production by writing their own bodies into their research. Indeed, Spry (2001) calls the body a “site of scholarly awareness” (p. 706) and Defenbaugh (2008) views the wounded body in particular as “a corporeal site for understanding the liminal space between health and illness” (p. 1402). Autoethnography, especially autoethnographic illness narratives, is uniquely suited to acknowledge the role of one’s own body in knowledge production and reflexivity. As Richards (2008) argues, “The expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness” (p. 1717).

What I hope to demonstrate is that chronic physical pain—despite its traditionally being seen as the most private and personal of experiences—is also a public, even political issue. Pain is political in the sense that bodies in pain represent a potential site of social critique and resistance that, if mobilized, could result in persons in pain as a political interest group. Many in disability studies have already demonstrated the ways in which the medicalization and personalization of disability focus attention on the individual and her “pathology” or “deficiency” rather than on the many social structures that exclude her and constrain her life. For instance, our culture tends to view a woman’s paralyzed legs or her reliance on a wheelchair as “the problem,” while not attending to the debilitating lack of curb cuts in her town that would enable her to more ably live and

work as a productive member of society. When our attention is focused at the individual level, society is protected from the disruptive social critique and political upheaval that might otherwise erupt in the face of such injustices (Charlton, 2006; Conrad & Schneider, 1980; Garland Thomson, 1997, 2006; Linton, 2006; Siebers, 2006; Waitzkin, 1989; Zola, 1972). Critical disability theorist Simi Linton (2006) writes:

The medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit and significantly, as an individual burden and personal tragedy . . . [Society] colludes to keep issues within the purview of the medical establishment, to keep it a personal matter and ‘treat’ the condition and the person of the condition rather than “treating” the social processes and policies that constrict disabled people’s lives (p. 162).

Chronic pain claims a unique status among other disabilities in this regard. Such pain is distinctively political because it involves three modes of alienation—or sociopolitical isolation—that are intrinsically silencing and that make it exceedingly difficult for persons in pain to speak with the strength of voice and the coherence of message required for self-advocacy. Part of the aim of this article is to draw attention to a “problem that has no name” (Friedan, 1963)—a problem that resists signification in its context of isolation and that thus masquerades as a personal matter—and to give its sufferers a common language with which to voice their collective political critique.

First, chronic pain is largely invisible. It is poorly understood and all too often medically unexplained. Moreover, at least at this point in time, such pain is only claimable through self-report and pain behavior. As such, scholars have amply documented that persons in pain struggle terribly to retain some semblance of credibility in the face of all those—even medical caregivers—who have doubts about the veracity of their complaints (Kleinman, 1988, 1992; Kugelmann, 1999; Skuladottir & Halldorsdottir, 2008; Ware, 1992; Werner et al., 2004). When the sufferer’s credibility has thus been challenged, she can become, as Susan Wendell (2006) puts it, “invalidated as knower” and her voice effectively repressed (p. 254)—as evidenced by the dearth of firsthand accounts of persons in pain in the literature.

Second, the contested and invisible nature of chronic pain as a disability does not translate well into the language of medicine, which prefers disorders with straightforward organic etiology. The biomedical model of Western medicine resists recognizing symptoms that do not fit neatly into one category or the other of Cartesian mind–body dualism. In the absence of a true understanding of the complex mutuality of mind and body, physicians often cope with diagnostic uncertainty by pushing unintelligible symptoms into the realm of psychology. The pain is, put simply, “all in your

head.” The medical professionals who treat it may or may not deem it as “real.” The root cause of such pain is commonly called “psychogenic” or of psychological rather than physical origin. The person in pain, in turn, searches relentlessly for a viable meaning to make sense of the pain. Lacking any legitimate medical explanation, she may accept the psychological interpretation of her suffering. Once psychologized, such individuals are frequently subject to the damaging stigmatization often associated with mental illness (Holloway, Sofaer-Bennett, & Walker, 2007; Jackson, 2005; Kleinman, 1988, 1992; Lillrank, 2003; Werner, Steihaug, & Malterud, 2003). The stigma, in turn, shames pain sufferers into silence and cuts them off from one another. As many scholars have argued, disability on the whole invites its own brand of oppression that operates primarily through “psychological internalization” and the promotion of “false consciousness and alienation that divides people and isolates individuals” (Charlton, 2006, p. 220). Pain only amplifies this isolation.

Finally, pain is at base a phenomenon that is inherently resistant to language. Physical agony itself can reduce the individual to a preverbal state of screams or moans (Scarry, 1985), while many medications that treat pain distort one’s speech and thought. In this way, pain robs its sufferers of their voice and all but extinguishes their hope of articulate protest. Too often, it precludes its sufferers from speaking in the lucid and intelligible manner that political agency necessitates. Moreover, pain is an existential crisis that demands to be communicated even as it disables one’s capacity for such communication. Of course, this paradox only works to deepen the suffering of the person in pain.

These three modes of alienation of persons in pain work in concert with the medical model as a “major institution of social control” (Zola, 1972). They disempower people in pain by securing their silence and ensuring their isolation, thus eliminating the possibility of collective resistance that could disrupt the status quo. In this way, pain is a unique phenomenon within the world of qualitative health research, and scholars would benefit from attending to pain as a public issue, and not only a personal trouble, that can best be elucidated by pain sufferers themselves. Just as researchers of mental illness have been criticized for inadequately including the voices of individuals actually living with mental illness (Karp & Birk, 2013), pain researchers need to make room for “insider” accounts in the literature. Critical disability theorist Tobin Siebers (2006) noted, “The greatest stake in disability studies at the present moment is to find ways to represent pain and to resist current models that blunt the political effectiveness of these representations” (p. 177). I seek here to begin the process of constructing language with which people in pain might develop their collective voice.

I have chosen to use the female pronoun when referring to persons in pain throughout this article. In doing so, I wish

to gesture toward the fact that women are more likely than men to experience severe bouts of chronic pain in their lives (Hardt, Jacobsen, Goldberg, Nickel, & Buchwald, 2008). Moreover, I use the female signifier as a self-conscious rhetorical device to underscore that oppression based on disability intersects and intertwines with oppression based on other factors, including gender.

Cry Baby

It all started when I was 16. I had finally made it to the varsity soccer team of my small private high school, and the preseason had just begun. During a scrimmage one beautiful early autumn afternoon in 1991, I suddenly felt an extraordinary pressure in my right leg—the same leg that had been taped up earlier for what we had all thought were “shin splints”—and realized I could not lift my ankle. As I looked down in horror, a flood of pain overtook me. It came on so intensely, I raised my hand to indicate to my coach I needed to come off the field. She gave me a look of puzzled frustration—I hardly remember what came next. My teammates told me I “crumpled” to the ground, seemingly without warning, and was carried to the bench where bewildered coaches and trainers tried to put ice on my leg as I writhed and howled incoherently. I felt as if my eyes went black and I could not see. Somebody called the school’s emergency medical responders.

What I had was a very serious, as yet undetected, muscular disorder that had become acute. Though no one knew it at the time, this meant the doctors had roughly 6 hours to operate or I could lose my leg. Left untreated altogether, as I learned later, I could have even died. The problem was that my condition, Acute Exertional Compartment Syndrome, was at that time very rare, so rare in fact that two of my doctors later wrote up my case in a medical journal (Fehlandt & Micheli, 1995). At the time of my injury, mine was one of only a handful of recorded cases in medical history. Moreover, because many medical diagnoses can masquerade as psychological disorders (Schildkrout, 2011), it is not uncommon for perplexed doctors to view certain somatic symptoms as “not real.” Thus the attending emergency room doctor’s misdiagnosis and dismissal of my pain: I presented with no breaks to the bone, no visible swelling, and an intact pedal pulse. Having ruled out broken bones, sprained tendons, and such, he looked at the whimpering, twitching teenage girl before him and determined I was overreacting. “I don’t see anything wrong with you,” he said to me. To my parents he said, “The films show no break in the bone. Honestly, I think she’s being a bit of a crybaby. You should just take her home.”

This was the beginning of the slow and steady annihilation of my identity as a credible subject. After that first day in the emergency room, the doctors did eventually figure out my diagnosis and admit that it was “real,” but the

process of my erasure had already begun. I had entered into the world of the “hysterical patient”—a world in which profound physical pain is denied, truth is silenced, and resistance is interpreted as symptom. Over time, chronic physical pain beats people down, exhausts them, and frightens them, but when they arrive at medicine’s door, their despair, fatigue, and fear are often read as a somatization of internal conflict, a manifestation of a purely “psychological” problem (cf. Lipowski, 1988 and Faucett & Levine, 1991). They become, in a word, suspect.

Memento Mori

Once the initial diagnosis had been made, “Acute Exertional Compartment Syndrome” was my new name. I had never heard of this muscular disorder before, but suddenly I found myself explaining to anyone who visited me in the hospital how there are four compartments in each of their lower legs. If the internal pressure of one of the compartments rises too high, as it mysteriously does for people with this unusual syndrome, the result is excruciating pain, choking off of the blood supply, and the subsequent death of the muscular tissue. Naturally, the doctors were fascinated by my leg. They hushed me when I spoke so that they could talk to one another as they pointed to the exposed tendon, palpated the lump of leftover muscle, and poked their pocket scalpels into the necrotic flesh. In so doing, they converted me and my humanity into what disability theorists Frazee, Gilmour, and Mykitiuk (2006) call a “medically interesting case.” As the theorists observed, the disabled women in their study complained that as their physicians “talked over [their] heads and bodies,” the women were made the “centre of [the clinician’s] gaze but [were] not involved as a participant in the conversation or judgment” (p. 235). It was as if my doctors were debriding not only my wound but my sense of sovereignty over my own body as well.

After my first 6-week hospitalization, I was desperate to restore some sense of normalcy to my life and so returned to school despite my doctor’s initial concern that it was too soon. Back in 1991, my private high school was not yet wheelchair-accessible, but I was at the time using a wheelchair. Given the inaccessibility of the school campus, the principal opted to house me in the school’s infirmary until I was “well enough” to rejoin the other students, a duration that turned out to be the rest of the school year. Even the school’s infirmary did not have a wheelchair ramp, and so every morning, my mother drove me in, and we commenced the long, grueling practice of transferring me from the back seat of her old Mazda to the first step of the infirmary. From there, I would head butt-first up to the second step, then the third step and so on, the two of us being absolutely vigilant about keeping my leg elevated the entire time. Once at the top step, she handed me my crutches, and by then adept with them, I got myself from the entrance to my designated

bed with my leg screaming in pain from “being down.” At night, as my mother returned from work, we would do the whole process in reverse. Unfortunately, only later did I understand that—as disability activist, Liz Crow (2010), put it—“It wasn’t my body that was responsible for all my difficulties, it was external factors, barriers constructed by the society in which I live” (p. 124).

One morning, as I was maneuvering myself up the steps, a Saab convertible flew past us, a group of boys inside. Amidst blaring music and shouting, one boy hurled a single word at me, producing the delighted laughter of his friends: “Cripple!” I remember looking up in astonishment, having been yanked so abruptly from my private ritual of quiet, tortured ascent. I felt the pain emanating from my heavily draped and carefully extended leg pulsate with even sharper cruelty. As I heard the car race around the drive, I was consumed by utter silence, a void so complete as to leave me no words, even for my mother, whose worried eyes pored over me. When I gave the signal, we continued our climb to the top of the stairs.

As critical race theorist Charles R. Lawrence III (1993) argues, nothing silences a person more effectively than hate speech:

The . . . invective is experienced as a blow, not a proffered idea, and once the blow is struck, it is unlikely that dialogue will follow . . . [Such] insults are undeserving of first amendment protection because the perpetrator’s intention is not to discover truth or initiate dialogue, but to injure the victim (p. 68).

Lawrence’s discussion is concerned with hate speech based on race. However, his central argument illuminates the social structural component of my experience that is otherwise hidden from view. In particular, displays of broken bodies in pain can be so rattling to the able-bodied community as to invite speech designed with the same intent to injure—and silence—its object. “Cripple!” did both.

The construct of “racial microaggressions,” borrowed from its original, culturally specific context, elucidates how enduring and cumulative consequences can result from “subtle insults” directed at a person “often automatically or unconsciously” (Solórzano, Ceja, & Yosso, 2000, p. 60). For instance, one classmate, a gawky 11th grader at the time, walked up to where I was sitting one day in between classes. It was the first time after my injury that I had dared to wear shorts despite the 10-inch (25.4 cm) long, 4-inch (10.16 cm) wide angry red scar that marked my leg. Without speaking to me, he knelt down to investigate. After an exaggerated shudder, he declared to a friend across the room, “Have you seen this, man? Seriously, come look at this. It’s gross.” The dehumanizing effect of such insults added up, so humiliating me as to make me want nothing more than to disappear.

I had become a *memento mori*. My body, broken and needy, represented pain, dependency, and ultimately the

inevitability of death. Hateful speech and the marking of my difference perhaps enabled my classmates to dissociate themselves from the fact of our shared mortality. They were probably trying to prove their own normalcy by carving out the bounds of my deviance. In Rosemarie Garland Thomson's (1997) words, these boys were patrolling the borders of their "normate" selves by declaring me "other."

I had no voice with which to fight my classmates and no capacity to chase Saabs full of boys. By the time I had graduated to crutches and gone on to college, I had no energy to be the self-advocate I needed. Despite the privilege afforded me by my race and class, the "sense of entitlement" that Annette Lareau (2002) argues is the hallmark of the middle class had been so undermined by the mediating factor of disability as to have been replaced by its opposite, the "sense of constraint" Lareau associates with the working class. In other words, the broken body has the power to diminish or even partially reverse the effect class privilege has on one's sense of agency. I did not think to complain. Over time, the day-to-day injuries frequently escaped even my notice. For instance, the sidewalks and campus pathways at my small liberal arts college were often shoveled after a snowstorm just wide enough for a "normal" student to pass through. They were, however, too narrow for a person on crutches, whose total girth was extended by the long arc of the sticks under her arms. I had to turn my body sideways and crutch awkwardly that way down the icy pathways to get around campus on such days which, in New England, were not infrequent. *You are not normal. Your kind is not welcome here.*

Pain as Performance

Years passed. Over the course of many surgeries, the doctors had miraculously saved both of my legs, even though the few people with the same syndrome are often not so fortunate. Yet my pain continued. It spread in fact. Not only my legs but also my hips became sites of almost unbearable pain—searing, shooting, haunting pain. It had become the kind of pain that frequently prevents you from going out at night or sometimes during the day—the kind of pain that makes it difficult to stand and wash dishes, to walk down the hall, or even to just finish a sentence.

In the eyes of the medical establishment, however, as soon as it was evident that my pain had lost its original referent, I became categorically suspect. As with phantom limb pain, a person can experience unbearable pain even when the "organic cause" for that pain has long disappeared. I think of my pain as the neurological vestige of the original injury, a record of my body's history kept in excruciating detail, a well-worn path in my brain recalling the length, depth, and meandering route of every prior trip with perceptions as sharp as they were the first time.

Pain cannot be as yet scientifically measured, and so doctors must rely on the patient to signal that he or she is in

fact in pain (Borsook, 2012). In the absence of objective markers of physical pain, persons in pain can only make claims on their suffering through self-report and pain behavior. Put simply, patients must perform their pain. To be credible, the sufferer must act out her pain at the doctor's office, or as in the example that follows, while utilizing a "handicapped" parking status. Yet it is the inescapably performative nature of the behavior that actually kills the very credibility one seeks to guarantee. Literary scholar Elaine Scarry (1985) articulates the crux of this catch-22:

So, for the person in pain, so thought of as the most vibrant example of what is to "have certainty" while for the other person it is so elusive that "hearing about pain" may exist as a primary model of what it is "to have doubt." Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed (p. 4).

No one can definitively verify that a person is in pain, and so they require her to act it out. As soon as she does, her "acting" immediately becomes a reason for discrediting her. Jean Jackson (2005) articulates this argument in her work on pain patients: "Pain is doubly paradoxical: It is a quintessentially private experience that depends on social action to make it real to others, yet that very same action can also arouse suspicions about its reality" (p. 342). This catch-22 effectively alienates the person in pain as a discredited subject, thus preventing her resistance to any negative treatment she may subsequently experience.

Several years ago, when my pain was severe enough to necessitate use of a cane but my pride too wounded to admit it, I had an experience that drove home for me the performative nature of pain. On a day that I was in significant pain and in particular need of solace, I went to visit my mother who was working in Harvard Square at the time. It was very busy, and there were few if any free parking spaces. I circled the area two or three times in the vain attempt to deny my disabled status before giving up and taking a handicapped spot. Due to my foolish insistence on the pretense of normalcy coupled with the stubborn vanity of youth, I left the cane in the trunk and gingerly exited my car (with HP placard visible). With great pain, I took the quick steps necessary to cross the street without being hit by the cabs and cars that do not slow down for young people who look capable of running out of harm's way. Just as I did this, a taxi driver craned his neck out of the window and yelled at me with tangible venom, "Yeah, you look fuckin' handicapped! Stupid kid!"

Ironically, I looked just as I had hoped to look: like a normal, able-bodied young person. How could anyone ever have guessed my pain? Yet the man's implicit question lingered not merely as a challenge to my honesty but as an injury to my very credibility. I learned that day that I needed "props" if my pain was to be taken seriously. Without crutches or a cane, for instance, I noticed children running

down a narrow hallway would not take care to avoid bumping into me, despite the concern with which I battled the pain in each halting step. Even doctors, in many cases, do not take pain seriously unless they are offered the grimaces and moans when and where expected.

“Credibility work,” as it has been called (Werner & Malterud, 2003), is often simultaneously necessitated and called into question by medical professionals treating unexplained chronic pain. The patient must act a certain way. However, this performance is frequently met with rejection or ridicule, both of which function as “effective mechanisms of medical and social control” of the behavior of the patient (p. 1416). By trying to “live up to” the hidden norms that oppress them, the patients squander their scant energy on trying to appear a credible patient rather than on managing or improving their pain.

There are high stakes to failing in one’s credibility work. Wendell (2006) argues if the patient’s condition is not validated by the “cognitive authority of medicine,” then she is categorically “invalidated” and her confidence “radically undermined”—for “what can you know if you cannot know that you are experiencing suffering”? (p. 254). Not only are the stakes high when one fails in one’s credibility work, but also when one succeeds, thus the catch-22. After all, the more successful and convincing one’s performance of pain is, the greater the harm done to one’s own sense of self. How can I feel authentic when I always have to play-act my credibility for others?

All in Your Head

The surgeries done, the wounds healed, and the original impetus removed, my pain no longer spoke with what Elliot Mishler (1984) has called “the voice of medicine.” Without realizing there was this language barrier firmly wedged between us, I returned to the doctors again and again, desperate for them to treat the pain that had become utterly incapacitating. What I did not anticipate was that not only would they fail to see, much less be able to cure, the pain, but that they would turn their gaze on me. When pain can be neither measured objectively nor explained medically, it is not only the credibility of the person in pain that suffers damage, but also her mental health status. Without any other means of making sense of it, many puzzled health care providers relegate pain of unknown etiology to the realm of psychology. The person in pain then frequently finds she is subject to the subtle stigma associated with mental illness (Link & Phelan, 2001).

Erving Goffman (1963) famously defines a stigmatized individual as one who is seen by others as having an “attribute that is deeply discrediting” and that demotes the bearer “from a whole and usual person to a tainted, discounted one” (p. 3). Medically unexplained chronic pain functions in this way, given its widespread reputation as being

“psychogenic” or emotional in origin. Many scholars have written about the prevalence of the view that the only “real” pain is that which can be explicated biologically or physiologically and that pain regarded as psychogenic is “not real” (Hoffmann & Tarzian, 2001; Kleinman, 1988; Lillrank, 2003; Ware, 1992). In this way, pain patients have become what Arthur Kleinman (1992) has called the “modern pariahs” of society (p. 181) whose chronic conditions health care providers find “messy and threatening” (Kleinman, 1988, p. 17). Their illness narratives are exceedingly difficult for physicians to listen to and treat with patience and compassion (p. 9).

It is not my intention to delineate the difference between “real” and “unreal” pain, nor do I think it is impossible that certain kinds of pain are indeed psychogenic. Rather, I simply wish to highlight two things: First, regardless of the source and mechanism of the pain itself, any pain that is viewed by others as psychological in origin automatically subjects the sufferer to the stigma—or what Richardson (2005) refers to as “delegitimation”—associated with psychiatric instability. Second, the stigma in turn can produce as an effect the very psychiatric symptoms such as depression and anxiety that medical professionals believe are causally prior. Whether or not they are preexisting, such symptoms are without a doubt common responses to being treated as if one were “crazy” (Jackson, 2005). As such, the person in pain who experiences depression or anxiety as a result of her stigmatization begins to wonder if she is in fact crazy. After all, the symptoms are there. She is tired. She is anxious. She is demoralized. How can she argue against the claim that the pain is “all in her head”?

At the nadir of my experience with unexplained, unrelenting pain sometime in the years immediately following college, my well-meaning but by then rather exasperated primary care physician referred me to a neurologist. I had high hopes for what light he (and it was in my particular case almost always a “he”) might shed on my dilemma, and more to the point, what relief he might offer. Unable to walk without the assistance of a cane at that time, I made my way slowly, agonizingly into the elevator and up the several floors to his office with my mother by my side. After a quick series of neurological tests, the doctor declared me “normal.”

I was devastated. How could the medical world help someone it deemed medically “normal”? Then the doctor asked a series of questions. “Would you say you are depressed?” he asked. “Anxious?” Well, yes, I had to mutter, thinking of how much angst lay just beneath the surface of interactions such as these. Then he nodded wordlessly as he rose from his chair. “I’m afraid there is nothing I can do for you,” he told me. I had gathered myself and stepped gingerly out into the hallway, aching sore from the exam. He turned to my mother then, who was pale with the same deflated hope I felt, and offered dryly, “You really should

take her to see a psychiatrist. I've seen this kind of thing before. Sometimes it's all in their head." Deeply shamed, I recall suddenly needing to lean against the wall for support. Pondering the depth of my despair, I concluded, he is right—I *do* need to see a psychiatrist.

Echoes of the "hysterical" privileged White women of times past reverberate today in the simple fact that much of the medication that treats unexplained neuropathic pain works because it acts on one's "nervous" system. In Charlotte Perkins Gilman's (1997) *The Yellow Wallpaper*, the heroine's enigmatic illness is understood by her physician husband to be a bad case of "nerves," connoting the fabled diagnosis of hysteria common in that day (see Showalter, 1998). He "treats" her by constricting her existence to certain rooms inside the house and securing her isolation from outside stimulation, everyday sociality, and the even the rewards of work. In so doing, he brings about the very symptoms he claims to treat, seemingly justifying both his evaluation and his management of her. In my darker hours, I believed that the medical and psychological models formed a tag-team that created a similar situation: the former exacerbated my suffering by declaring me noncredible and mentally unstable, while the latter confirmed the assessment of the former by documenting the reactions to my resulting stigmatization as evidence of my illness. Clearly my pain was not caused by my run-ins with the worlds of medicine or psychology, but the suffering surrounding my pain was certainly exacerbated by them.

Writer's Block

It is critical to clarify at this point how it is that I am able to speak with relative fluency about pain, if pain is as I contend, so inherently silencing. I recently came across a statement by writer Leon Weiseltier (as quoted in Flaherty, 2004) that resonated powerfully with my experience: "If you can write about the wreckage the wreckage is not complete" (p. 119). In short, I am writing from a place of relative wellness, where my pain has receded far enough from the shores of my being so as to enable me to speak about it.

At the height of my pain, I found myself time and again unable to find words that could articulate the shape of my suffering. It was as if I could not relay the coordinates of my existential location to others, no matter how many ways I tried. Arthur Frank (1995) writes eloquently in *The Wounded Storyteller* about the ways in which chronic illness, including pain, troubles the ability of the sufferer to share her story coherently and intelligibly. People in pain, like all seriously ill people, are in Frank's words "wounded not just in body but in voice" (p. xii). Thanks in large part to the biomedical industry about which I had developed so many critiques, one gracious doctor led me to a neurological medication that has, more or less, lent me some control of my pain. Now, as a recent and at least temporary member of

what Frank (1991) refers to as the "remission society," I wish to leverage my status as partially recovered to tell my story.

Those whose pain dissipates may redeem their voice, but they rarely want to use it to recall the suffering that had so subdued them. So pain remains, more often than not, unspoken. I do not wish to speak for these others, nor would I ever claim that I could. Instead, I endeavor to serve as a sort of retrospective voice to my younger self who suffered in silence for so long. During the peak of my crisis, I frequently said that someday I wanted "something good to come out of something hard and painful." In the words of Audre Lorde (1980), "It only remained for me to give [the illness] voice, to share it for use, that the pain not be wasted" (p. 16). However, despite the pages and pages I poured out in my journal, I could not communicate my experience to anyone other than myself, for my language had become too chaotic and nonlinear for others to follow. Looking back, it is no longer a mystery to me why I suffered from "writer's block" for so long.

Virginia Woolf ([1929] 1991) legendarily argued that one cannot write without "a room of one's own," or the means to support a life uninterrupted by work and the tyranny of gendered expectations. I would add that it is also exceptionally difficult to write without a body that feels like one's own, to write from an internal space that is constantly and unpredictably assaulted by the chaotic circuitry of a body in trouble. The shots of pain here and searing aches there cannot help but to distract the writer's train of thought and so to punctuate the text in question.

Conversely, when one is writing from a healthy, complaint-free body, that body erases itself as the material conditions out of which the writer's thoughts and arguments become possible. Just as Whiteness enables White individuals to deny race as a significant factor in American society, the able body is quick to delude its inhabitants into believing that they, as thinking, theorizing, scholarly subjects, are the sole authors of their thoughts. Pain, however, makes such illusions impossible.

All ideas arise from within the walls of the body. All thoughts are shaped by the contours of our ultimate material condition. No idea or experience is free from the constraints of the absolute structures of skin, muscle, and bone. Broken bodies whose wounds have been sustained through trauma often produce narrators whose voices are as halting as their gait and whose narratives are as fractured as their bodies. Pain not only ruptured the coherence of my narrative, it precluded coherence as a narrative possibility. My speech could never resound with the smooth confidence of those whose faith in the absolute sovereignty of their bodies is as seamless as their words. People can tell only embodied stories (Frank, 1995), but like the body that produces it, the embodied narrative of the person in pain is unpredictable, unreliable, and seemingly unsuitable for communication.

The body as author of one's thoughts, however, is invisible, a ghostwriter, to those whose able, painless bodies make embodiment feel effortless.

Just before I graduated from college, a professor told me about a call for submissions by an anthropologist working on a book project about what it means to be a "wounded ethnographer." I wrote in and was delighted to find out my brief abstract had been accepted. In the months following graduation, I worked feverishly on my contribution to the anthology. Although I wrote over a 100 pages, none of it made any sense. I was simultaneously more prolific and more blocked than I had ever been. My ideas did not flow and were in some cases circular and in other cases truncated. The text was tortured, littered with ellipses and ambiguities that made it impossible for readers to follow a consistent narrative thread. I have retrospectively come to see my problems in writing that chapter as representative of the immense physical pain that I was in at the time. With every searing reminder of my unequivocal embodiment, pain disrupted the cogency of my narrative, elided my thoughts, and called into question everything I tried to argue.

Doctors told me at the time that I was not to trust the neurological fireworks I was experiencing in my body. They were vacant signifiers of pain that "meant nothing." So how could I ever trust anything I perceived to be real? Fortunately, the consequent nonlinearity and complexity my writing had taken on actually served me well in college because I could write layered analytical essays on any topic so long as I did not attempt to narrate my own experience. To my enduring regret, I was never able to finish the autobiographical piece and had to back out of the project. Sadly—and in this light, not surprisingly—it seems this may have been the case for many of the other contributors, as the book never came to fruition.

Even today, so many years later, I still struggle to write about my injury. I have found the process of writing and revising this article revealing. While I can write with relative fluidity in the active voice when I discuss pain in abstract terms, I tend to shrink back into the passive voice and mangle my words wherever I speak about and from my body. I have even resisted editors' calls to eliminate the passive voice at certain points in the text: given the very real experience of pain as something that happened *to* me, I find the passive voice feels more honest, more reflective of my subjective experience. I see my resistance as a desire to remain true to the voicelessness of pain, which is, after all, at the heart of my argument.

The inherent contradiction between the invisible, unspeakable nature of pain and its undeniable materiality for the sufferer creates a schism between the person in pain and all others, destroying community and negating the possibility of any collective voice with which to resist. The excruciating paradox of pain is that its utter incommunicability is paralleled only by its absolute demand to be

communicated and its longing to be understood. Sufferers wish in vain to break free from what Byron Good (1992) calls the "unshared and unsharable" world of chronic pain (p. 47). Scarry (1985) argues that physical pain is in this way a unique category of existence, "physical pain—unlike any other state of consciousness—has no referential content. It is not of or for anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language" (p. 5).

Arthur Frank (1995) calls the attempt to signify the unsignifiable, to tell a story of that which is at base unsharable, "the chaos narrative." The chaos narrative is a story in which "words necessarily fail" the author as she "traces the edges of a wound that can only be told around." It is ultimately paradoxical by nature: "A true chaos story cannot be told" (p. 105). As I have framed it elsewhere, "the story that can be told, the story that can be taken in, is never the whole story" (Birk, 2007, p. 38). The best one can do is to tell *a* story, one that attempts to make meaning of the experience retrospectively and to communicate something of the chaos with enough fluency to break its silence but not so much as to dishonor its ineffability.

As a person in pain, I longed for the words that would cohere the ruptures of my broken body-narrative, and yet I could never trust stories that were woven into a perfect fluidity. As with the pain itself, my longing to communicate that which defies communication made true rest impossible. The only resolution was to keep writing, writing as I am now—in, through, and beyond pain—until the page is filled with layers upon layers of words, all of which are haunted by the ghost of pain, the vestigial reference for which there is still no referent.

Conclusion

Those in chronic physical pain are uniquely situated to discount their own critical insights, and thus to relinquish their position as a site of potential resistance. This is only in part because it is so easy to "psychologize" the pain sufferer into feeling guilty for her own suffering. Individuals must have words to name the injuries they sustain as they navigate the world as persons in pain and encounter the people, structures, and discourses that constitute them as flawed subjects without credibility, efficacy, or agency. If pain is political power in want of a coherent voice, persons in pain will need language to fashion an identity capable of collective political power. In order for such language to be found, scholars of chronic pain need to make more room in the literature for the research of "insiders." After all, people who themselves suffer from chronic pain have the most light to shed on what it is to live with severe physical pain. The scholarly community would benefit from more firsthand accounts of individuals attempting to hold onto their fragile credibility in the face of pain. Those who endure the subtle alienation

mirrored in the eyes of their doctors, friends, and strangers have a unique ability to reflect back on the society that struggles to understand them. When pain is no longer understood as simply a private, personal matter, its political agency can be realized and its sufferers can embody more empowered narratives of endurance and strength. It has been my aim here to begin to give pain a voice, so that other persons in pain can come out from under the shadows of false shame, join their voices to the collective, and resist that which endeavors to secure their silence.

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Author Biography

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