

Tales from the Abyss: Unlearning Not to Speak Embodied Expressions of Pain

*Tom Craig and Maureen Connolly
Brock University, Ontario*

Prelude: A Summary of Theory

Our present work is influenced by a number of theoretical frames across several disciplines - choreology, phenomenology, third-wave feminism, semiotics. In order to preserve our narratives of rupture, healing, and wild being - that is, our embodied "tales from the abyss" - as a whole, we mention briefly here the most notable among them before moving directly to our stories:

Mikhail Bakhtin (1981) and his notions of competing authoritative and internally persuasive discourses.

Samuel Ijsseling's (1976) philosophical history of rhetoric and his postmodern question, "Who is speaking whenever anything is said?"

Julia Kristeva's (1995, 1986, 1984, 1980) post-Lacanian psychoanalytic frame of the subject living in an impossible dialectic between law and transgression, on trial, in crisis, and - sometimes through revolutionary practice - in process.

Maurice Merleau-Ponty's (1962) de-structuring of the so-called "normal" subject who refuses any sense of "deficiency" or disability and his later recognition of "wild" or "savage being" as an existential contrast to so-called "reflective" philosophies which play themselves out everywhere in unreflective presumptions of concordance and stability.

Richard Lanigan's (1992, 1988) semiotic phenomenology of communication, especially his existential propositions about the emancipatory "choice of context" which makes being human possible, and the constraining, imposing, dehumanizing "contexts of choice" which we continue to construct and which drive persons and worlds mad.

Nancy Mairs (1989) and other hyper-graphic, rhetorical artists (Kat Duff, Arthur Frank, Kay Toombs, Susan Wendell, among others)¹ who write about the abyss of uncertainty and unlearning not to speak of the "bone house" erotics of space and place we all live.

We also draw upon our own ongoing collaborative work in the politics of pain, disability, and the utterly subversive practice of reconciling ourselves to the body we actually live.

I. Introduction

Pain is a story that is often untold or interrupted, but which needs both to be told and to be heard. Ironically, while yearning for expression, it is a story that reaches for words to unfold while learning to silence itself in the face of too many who grow tired of confronting the ruptures of stability that pain can bring.

In this paper we will explore a braided narrative told by two phenomenologists and long-time insiders in the lived experience of pain: one who has lived with chronic pain for over a decade and the other a chronic pain therapist who works with the body in a variety of touch modalities. Our description will include excerpts from a month long pain chronology (kept for submission to a neurologist) and corresponding rich descriptions of the actual lived experience of pain.

As we have discovered slowly over the years, pain narratives can work subversively by presenting an alternative to both the medical drama of diagnosis and treatment (usually presented in the neutral, detached and apolitical voice of third-person "objectivity"), and a personal story at once too private, too risky, and too difficult to find words to express. In the first strand of our discussion of the braided narrative of pain, we necessarily utilize medical

discourse to convey its so-called symptomology, but we recognize that the textured nature of the reported chronology also subverts medicalized expectations of a body detached from the swirling contexts of the actual experience of pain.

In the second strand of our analysis, we discuss the paradoxical messages of nurture and tolerance which appear to encourage the authentic expression of persons living with chronic pain, but which also outline the consequences for speaking too much, for being too visible, too resistant or recalcitrant. As we will demonstrate, medical and productivist codes of the body govern much of what is considered to be legitimate exhibition of disturbing experience.

Using textured descriptions of a variety of bodily expressive modes (including detailed medical chronology, autobiographical narrative, touch, myofascial release/unwinding, gesture, posture, and vocalizations) we will explore the intersections of pain and the transgression of cultural codes that an authentically speaking body can bring.

II. Selections from a Pain Journal (Maureen)

25-11-98: extreme fatigue in afternoon (3:00 P.M.); Tom is almost unable to finish teaching class; low back pain, neck pain, leg pain; sleep distress.

27-11-98: pain in Lumbar, S.I., and down into both legs; difficulty walking, rising; able to [weight] train - gets some relief.

5-12 to 6-12-98: Tom is barely able to drive me to work; has trouble dressing, walking, moving in and out of positions; severe pain in arms, elbows, hands (massage); able to sit at desk, but this is followed by severe back pain; high level pain in Lumbar, SI, ITB, QL and some sub scapular (ice and massage); Tom is tender to the touch, swollen, and muscularly asymmetric even in the prone position. Cannot take any heavy pressure [from massage]; agonizing two days; fluctuating and shifting pain all over Tom's body; lots of sleep distress.

30-12-98: Tom sees my chiropractor (a new one for him); no reflex in Tom's L knee; Chiropractor is concerned about pelvis, upper back and Lumbar - would like the results of x-rays and bone scan; we see Neurologist today; Tom has sleep disruption.

2-01-99: training in morning - quite good; Tom has shooting pains in L shoulder and L knee; huge myofascial release in evening before sleep; pain in SI (R) C no movement in stretch position; sleep distress.

3-01-99: pain in both knees and feet; pain surges in afternoon in legs; Tom is able to sleep in afternoon; noise in shoulder joints; some motion in SI / coccyx after massage during stretching; motion again during turnover during night; breathing distress.

Common patterns: pain surges - ongoing; disrupted sleep (breathing distress and/or stoppage); elevated heart rate and temperature; pain in SI and radiating down into legs; joint pain (shoulder, knee, pelvis); difficulty moving in and out of stable positions.

III. Capitalistic Expectations (Tom)

Shortly after experiencing the first few months of the bizarre neurological and muscular symptoms of my chronic pain disability, I recall a particular walk in front of the large, quaint, dusty old house my wife had worked so hard to find, negotiate, and buy in the first agonizing year of my illness in 1987-88. I had been sick through the entire process and remember the multiple trips with our two toddlers and Realtors, detailed questioning by bankers and then, ultimately in 1989, the long hours of packing and moving boxes, and the months of unpacking one at a time in our new place of residence.

Taking a short break from our two young boys (aged three and a half, and two) one sunny day the following year, my wife and I walked slowly up the cracked sidewalk outside our house and talked about issues of devastating illness and changes in our marriage. Then, in an unbearably intimate moment that I will never forget, she reluctantly confessed to me, "I

never thought I would be a single parent." Through the next several years of our marriage, I was reminded again and again that my own symbolic death had become the prominent theme of our relationship.

Ironically, I was not physically "dying" any more than D. was (although I sometimes think that a diagnosis of "terminal" rather than "chronic" illness might have been easier). No, on that day and beyond - for at least one of us - I ceased to be a legitimate and equal partner. I could not hold up my end of the unwritten marriage contract of perceived exchange of equal goods and services. I abdicated once mutually shared household and parenting responsibilities. I became, in sum, dead weight.

In the last months of our marriage and especially after moving out of the house in 1996, I could look back and recall a disturbing pattern of unbearable disregard and repression of the illness that had so disrupted our lives. I remember the concerned conversation on the front porch and the encouragement that I consider the power of "psychosomatic" disorders. I think back to the day I reluctantly shared an abbreviated version of my first attempt to write about the experience of my own life-shattering illness and can still feel and hear the startling response, "No one can say you don't write well."

I will never forget my years of frustrating attempts to garner family support to follow an allergist's advice to keep our dogs and cats out of the house to help alleviate the severe allergies and chronic sinusitis I had developed. One evening, not too long before the physical dissolution of the marriage, I remember standing in the kitchen after dinner and feeling a sharp, intense surge of pain at the top of my right hip and blurting out an involuntary yelp. D. was there washing dishes and stated with apparently humorous intent, "I hope that wasn't a commentary on dinner." While I had expressed pain in that way before at various times over the years, that night I felt particularly alone.

Today I am aware that all that I speak and write is in answer to deeply embodied disruptions within the chronic disabling culture I once helped to construct as "home." As I write now from the unexpectedly political and subversive location of my body, I am aware of relentless days of overwhelming tension in my back, hips and neck, the intensification of pain firing in syncopated rhythms through my connective tissue, and of the deep, unbelievably knotted muscles restricting my movements, constraining my thoughts, and radically altering my daily activities. I am also reminded of the cultural taboos against giving voice to such "negative" and "abnormal" body disclosure. I must clarify, then, that I am not making any metaphysical claims² here for "politically correct" communication about chronic illness and disability, nor for family responsibilities left unattended, narcissistic self-absorption, or intellectual work left undone.

IV. Hands-on Reflections of a Chronic Pain Patient

Recently, during a body work session, Tom asked me how I knew he was not "making it up," i.e., how I knew his pain was real? Aside from my own lived experience of feeling the textures of his pain with my hands, I believe him. It is inconceivable for me not to believe him. I believe his pain exists and I believe it is my responsibility to honor it.³

Here I will describe several experiences which are typical of Tom's treatment sessions (typical in the sense that they are aspects of Tom's pain profile though the profound heterogeneity of Tom's pain defies generalizing or predicting).

About a year into our pain therapy sessions, Tom had asked how I knew whether his pain was "real." As a practitioner, I have to ask myself, "how is it possible that this question can be asked at all?" or, "what experiences with treatment has Tom had so that this question is a possible one for him to ask?" I also must acknowledge that ongoing responses to Tom's expressions of pain have planted a seed of doubt in his experience about the validity of his own pain. My training and practice have taught me that no matter what the source, the pain exists. As I work with pain clients, I begin with the reality of their pain and we work on

developing a profile of, and relation with, their pain. In this way, we are able to explore its physical, emotional, psychical, and spiritual character.

Tom's earlier narrative reflection of living in a relationship as "dead weight" tragically illustrates particular relational consequences of living with chronic pain and disability which do not add up to a discrete, measurable pathology. When I work with Tom, I have to take into account the decade of disregard he has experienced and realize that talking about what he feels and what he needs is not a habit for him. Indeed, he has been "trained" to be silent and pathetically grateful for what little care he has been able to acquire. As the pain therapist, then, I must initiate the questioning, I must provide openings and opportunities for him to ask questions and make requests, and I must respond verbally, gesturally, posturally, and in tactile ways which demonstrate that his questions and requests are welcome, necessary, "normal," i.e., I want his questions and requests to be an ongoing component of our body work sessions together.

Another example which illustrates connection to bodily rhythms is a recurring experience which I call "following the fish." At one of our body work sessions, I was working on Tom's upper arm and elbow joint at his request. He was experiencing a simultaneity of pain sensations in that area: sharp jolts of pain, underlying throbbing, tremor and vibration, and reflex flicking of the hand. I was using deep pressure, soft pressure, smoothing, and myofascial release techniques in an alternating, repetitive sequence in order to keep up the with skin-level and under-the-skin sensations and patterns, and in order to bring some level of relief. Tom was somewhat distressed by the heterogeneity and fluctuating intensities of the pain, but was his usual engaged and calm self. At my request, Tom was describing the shape, temperature, depth, mobility, and other features of the pain sensations he was experiencing.

I am able to discern the different kinds of pain by virtue of their presentation. For example, throbbing pain actually does "throb" or pulse with a regular rhythm, spasm feels completely different, like a piece of rope, rubber or plastic pulled taut, tremor feels like something wiggling or quivering beneath the skin or a fish swimming beneath my hands. We had brought the sharp pain to a manageable level with the deep pressure and the throbbing had subsided to a dull ache, however, the tremor unexplainably began "moving" from the upper arm down into the lower arm, then back up into the shoulder, then the upper back, then suddenly, the other arm. I am "following the fish," staying with the tremor wherever it goes and following Tom's directional cues for when the tremor eludes me. We "followed the fish" for twenty minutes until we were able to achieve a stable location and stillness. At no time did I feel that this was an affront to my abilities, or a challenge to be "overcome." Rather, it was how Tom's pain was presenting and we were working together on a relief strategy. Had the movement not subsided, we would have explored other options, such as letting the fish "swim" and shifting our focus to breathing or energy while the tremor had its time and voice.

Sometimes pain is like that - it wants its time and voice, and we have to work on relief and dignity within the context of the presence of pain. In our discussion of this event, Tom revealed that he had been reluctant to say that the pain was moving and was actually surprised that I was able to follow it. His reluctance is grounded in his experiences of being dismissed - tremor is not supposed to behave this way, so saying what is happening makes the client seem unbelievable, naive, and unattuned to more "objective" observation. Even though I know that the pattern of Tom's pain is not the usual presentation of tremor, I have go with what is, with what his pain is presenting, now regardless of whether it is consistent with conventional descriptions of bio-physiological processes.

Finally, in a recent conversation, I mentioned to Tom that I would be using our "following the fish" experience as an example of being attuned to bodily rhythms and overturning authoritative discourse of how pain is "supposed to happen." Tom's comment was that as remarkable as attunement to bodily rhythms and pain textures is, what remains most remarkable to him is the freedom to speak, to say that the pain has moved, and feel secure in

his sanity, his dignity, his own relationship with his pain and his body.

In my own training and sensibility, the person living with pain is the authority. The pain therapist is charged with creating an environment within which the client and therapist can develop a relationship with, understanding of, and respect for pain and the body in pain. Pain management allows us to work with pain in the textured context of lived relation while at the same time honoring the complexities of ongoing bodily contingency.

V. (In)Conclusion

Unconditional respect and regard for the actual bodies we live make touch modalities powerful. The distinctive tactile presentations of pain: all the kinds of soreness, tension, vibration, texture, density, shape, direction we have described are not accessible to Maureen because she is a particularly gifted body worker. They are available to her because they are there, manifesting themselves in the body. They can be felt and their distinctive features can be learned. The different modalities of touch promote therapeutic resonances across the boundary of the skin and enable both authentic expression and perception of pain through a non-linguistic code.

Such a focus on working authentically out of our bodies also compels questions about how medicine and other institutions of production - the health care industry, the workplace, the "academy" being some of them - are complicit in contra-indicated colonizing practices. We wonder what would happen if instead of disregarding and dismissing non-conventional/non-"productive" subjects as failures in a culture of normally absent and distant bodies, we posited a continuum of inclusion that honors the absolute uniqueness of one's own body which can be known by no other way than by living it as one's own?

We no longer can allow ourselves the privilege of pretending that the "normal" codes of production, invisibility, repression, and dismissal accurately account for the tremendous spectrum of differing bodies. Those of us who know what it means to live with synco-pated rhythms of pain across severely able-bodied cultural codes (which function to keep difference at bay) have learned many of the lessons that the rupture of a stable, healthy, productive ideal can teach. What would it take for others to understand and incorporate these lessons into their own habitual ways of being in the world?

Despite the best of intentions, might not medical, capitalistic, and even scholarly projects which address different bodies be seen as evidence of a residual colonizing mentality? The unreflective "use" of one way of being in the world to understand another (more privileged) way of being in the world demonstrates how pervasive - and seemingly innocent - colonizing practices can be. How will we respond to the largely unexamined presumptions and accompanying privileges of persons with so-called "able" - that is, productive - bodies within the implicit hierarchies that govern our lives?

We can begin to unravel the dismissive problematic of our own detached perceptions of chronic pain and disability by asking what radical new directions human practices of caring might take if we refused to accept the "natural" attitude of our "normal" conventions as the ground of our practice and interpretation of treating others. For example, if we were to "bracket" and then examine the presumption of our so-called "normal" engagement with the world (e.g., our movement, vision, breathing, hearing, speaking, upright posture and invisible expectations of sensory integration), could we continue to conduct our business as usual, look on from the outside, and let our own severely able-bodied "objectivity" lie? Or would we have to alter our typically disengaged codes of interaction with the subjects we appraise and, more critically, re-evaluate the curiously detached relationship we express with our own lived body?

Choosing to engage in self-reflexive embodied practice means taking seriously the body we live (the body that is, here and now, at this moment) in our institutional and interpersonal lives. These choices are risky. Contingent bodies pose threats to powerful agendas

and authoritative discourses, but if health care and institutional conduct are to be examined and re-imagined otherwise, we must begin to ground our expression and perception of care in honoring the actual bodies we live.

Endnotes

1. Duff 1993, Frank 1993, Toombs 1995, Wendell 1996.

2. Merleau-Ponty (1962, 126) writes ironically about how to think phenomenologically about the neurological patient, Schneider, who suffered brain dysfunction as a result of shrapnel embedded in his head during his participation in the Second World War. "After all," he claims, "Schneider's trouble was not initially metaphysical...."

3. Postmodern theorists (Foucault 1972 and Bakhtin 1981, among others) critique medical science and capitalist modes of production as forms of discourse with great power to sanction how we talk and what we know and believe about the body, self, illness, and pain. These forms of discourse have the colonizing effect of internalized oppression, as well as the larger effects of colonization: invisibility, erasure, denial and tokenism. Bakhtin suggests that discourse may be characterized in terms of the authoritative and the internally persuasive. The authoritative discourses in our lives determine/govern our beliefs and behaviors. In contrast, internally persuasive discourse engages us from within rather than imposes itself from without. Individuals who experience internally persuasive discourses discover awakened consciousness. In my own body work practice, I recognize this as connecting with a primordial bodily rhythm, or knowing the shape/texture of a pain experience, or what Levin (1985) calls "a mytho-poetic truth."

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