

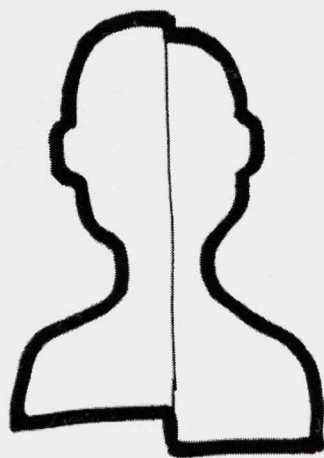
Your Body Tells Me Stories: Living Pain, Flirting Madness, Transforming Care

Maureen, a body worker, and Tom, a person with chronic pain—life partners and academics—offer a narrative description and interpretation of their respective experiences. Together, in a “braided narrative” format, they examine how a person’s relationship with chronic pain can either reproduce or transgress the social codes of an ableist culture and how an embodied practice of care can transform their relation with the particular “body we live.”

by
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Introduction

In this narrative, by engaging and critiquing the invisible codes of the body in pain and presenting our ongoing dialogue with each other, we hope to challenge readers to enter the discussion of how we engage the insidious presumptions of a disembodied status quo.¹ This introductory section will introduce us; describe our respective locations relative to chronic pain; and present the issues and nagging questions that structure our response to living pain, flirting madness, and transforming care.

Maureen

I am a certified chronic pain therapist trained in an “alternative” (i.e., non medical) model of health care and have worked with pain clients for the past five and a half years. I blend my work as a pain therapist with my academic interests, teaching, and scholarship, and I have been working with Tom, who is in his late forties, for more than three and a half years. He has lived for the past 11 years with the adult onset disability of Myalgic Encephalomyelitis, or ME (also known as Chronic Fatigue Im-

mune Dysfunction Syndrome or CFIDS, and Chronic Fatigue Syndrome or CFS).² He also lives with Meniere’s Syndrome (an inner ear disorder), Chronic Sinusitis, and Obstructive Sleep Apnea, in addition to a variety of structural/skeletal issues which together contribute to intractable joint and muscle pain—one short femur, a mild scoliosis, Degenerative Disc Disease (L3/L4, L4/L5), and Osteoporosis Penne. Tom’s diagnosis of ME was protracted for several months because the presentation of symptoms and characteristics did not typically “add up” to a single discrete pathology; neither did it respond to conventional medical intervention. In most cases, ME will not allow the body to return to some “fixed” pre-trauma state, nor to as “remediated” a state (Greenwood & Nunn, 1992, Craig, 1998; Toombs, 1995). ME continues to present in episodic, fluctuating bouts of pain, nausea, dizziness, weakness, neurological and cognitive confusion, environmental sensitivities, sensory overloads, and disordered sleep (among other symptoms). Persons living with this kind of intractable bodily betrayal are

sooner or later challenged either to repress or to accept the unacceptable, that is, to reconcile themselves with the great mystery of their bizarre new existence—that, in most cases, will not be “cured” and to embrace the ongoing consequences that a wildly out of control body may bring.³

Tom

As others with ME, I live with a sleep disorder (among other bizarre symptoms) that has been described in a constant, unbearable state between being not fully awake nor fully asleep at the same time!⁴ As if relegated to living the terrifying cultural nightmare of non-productivity, people with ME often cannot “do” very much in the waxing and waning, sleeping and waking actualities of our existence. Yet, though the neuromuscular field of our lives has become overwhelmingly constrained in once unthinkable ways, understanding the fluctuating character of our disability is not simply an administrative problem of how to handle the “malingerer” or “complainer” who refuses to “get well.”⁵ No, unfortunately, the nature of our disease runs much deeper than a prickly case of patient “non-compliance.” We represent, rather, disturbingly concrete exemplars of the failure of contemporary Western medicine (and the severely able-bodied ideal of Western culture in general) to face the abject horror of the wild, uncontrollable, heterogeneous side of being (Kristeva, 1995, 1984; Merleau-Ponty, 1968).

Maureen

After an agonizing first year of

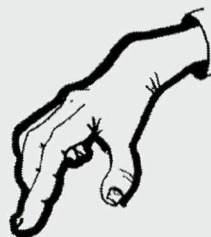
numerous prescription drugs that seemed to have few positive consequences and a barrage of predictable “side effects” (increased dizziness, nausea, steroid “rage,” etc.), Tom gradually shifted to herbal medications, finding conventional medications to be too extreme for his highly sensitized system. He presently receives chiropractic and chronic pain therapy and is also consulting with a neurologist and a new family physician about his skeletal, structural, and chronic sinusitis issues. His family physician is able to prescribe more conventional medications for his allergies and upper respiratory infections which sometimes are not managed by the herbal medications; however, he must then deal with the heightening of responses which invariably accompanies his use of standard prescription medications. Tom’s appointments with his neurologist occur once every two to three months, and usually last between 30 and 40 minutes. He sees a chiropractor once every week and a half. His original consultations (during an acute state of low back and hip pain) were 30 to 40 minutes, three times a week for six weeks. His weekly appointments initially lasted from 15 to 30 minutes but now are typically 15 minutes or less, except during bouts of acute pain or discomfort. This particular chiropractor uses spinal manipulation, trigger points,

massage, touch assessment, and passive stretching. He also advocates regular exercise.

Since Tom and I are life partners, I as a chronic pain therapist am able to work with him almost daily. Our pain therapy sessions last between thirty and forty minutes and include light touch assessment of muscle tension and energy blocks, myofascial release, light and firm muscle re-patterning and pressure, and energy work.

With his treatments, Tom has manageable pain, is able to work part time, and participates in regular and even intense exercise. However, he constantly wrestles with the cultural irony of looking “healthy” while not being able to meet the productivity demands for full-time employment and financial independence. He continues to need ongoing care, modifications in his activities of daily living, and rest times during the day. Tom is also aware that his recalcitrant condition often is perceived as an affront to most practitioners (both conventional and alternative) who have committed themselves to the feel of success (Wendell, 1996; Toombs, 1995) in the face of their clients’ discomfort.

Curiously, the notion of pain management (rather than cure) is still a radical notion within what Julia Kristeva (1984, 1995) calls a productivist teleology and what Wendell (1996,



p.9) refers to as "the myth of control of commercial-media-soaked societies of North America." Wendell goes on to say that the idealization and objectification of the body create demands that persons control and attempt to perfect their bodies. She writes that "refusal to come to terms with the full reality of bodily life, including those aspects of it that are rejected culturally, leads people to embrace the myth of control whose essence is the belief that it is possible, by means of human actions, to have the bodies they want and to avoid illness, disability, and death" (1996, p.9). While presenting exceptional challenges in daily living, Tom's experience with disability and chronic pain over the last eleven years also has proven to be a remarkably fertile ground for ongoing scholarship based in narrative and ideology critique.

As a practicing body worker and body educator, I have come to believe that the denial of the irrational, biophysiological (Kristeva, 1984) parts of the body-self will eventually lead to illness or chronic pain, or worsen them. Furthermore, I have seen how grappling with despair and feeling pain can lead to transformative lived relation with the body that is. My work with clients is invaluable in my research and teaching, and working with Tom has been the major inspiration for my contribution to this paper.

**Living Pain, Flirting Madness,
Transforming Care
Tom and Maureen**

We believe that challenging the dominant discourse of disembodied "health" begins with a commitment to finding expression and giving voice to pain. Furthermore, embodied practices of care which acknowledge the textured character of pain also must provide a viable context for authentic expression while challenging normative discourse and oppressive bodily codes. Encountering chronic pain or illness face to face creates a paradoxical situation. If people are always sick or in pain, sooner or later they are challenged to confront the failed cultural ideal of a stable,



healthy, and productive body they no longer can take for granted. The simplest way to avoid facing the profound failure of this paradoxical ideal is to deny the reality or permanency of one's own chronic condition. That is, though a person may be chronically ill, he or she can ignore or repress the daily signs of illness and continue to hold out for someone, somewhere, who can provide a cure. Denial is the easiest, most attractive, and most natural response to facing the overwhelming breakdown of the body.⁶ It allows persons to continue to think that they have rational control of their life and to avoid

the terrifying issue posed by the embodied contradiction they must now live: the horrifying awareness that they might have to continue to live with illness for the rest of their life, that there may be no cure, and that, however offensive, chronic illness now defines a large part of who they are.

In many cases, honoring the actual body we live in is the greatest risk for persons negotiating chronic pain because it may mean that, by virtue of their departure from "normal," they forfeit the rights and privileges that accompany membership in a productive community, i.e., they pose a nagging challenge to the normal pattern of lived relation with others.

Tom

When we no longer can take our actual body for granted, we are forced into a new way of being in the world that conflicts with normal, impersonal perceptions of how the body should continue to be both invisible and silent. By learning not to speak about the life-altering rupture and chaos of a radically disabling condition, I found myself giving in to the curious cultural expectation of keeping my ailing body absent and invisible by refusing to allow any transgressive experience to come to expression. As I discovered after years of repressing my own sense of chronic pain and disability, surrender to such impersonal cultural expectations led to progressive shrinking of my own space of experience, to internalized oppression of the actual body I live, and to an insidious kind of madness that

comes from trying to force a non-conventional (un-stable, un-healthy, non-productive, i.e., "abnormal") body into a stable/healthy/productive life-script.

Chronic pain/immune dysfunction disability does not work toward that kind of recovery. It does not comply with anybody's demands for transition back to the cultural ideal of "normal" life. My own experience of fluctuating bodily rhythms and demands constantly subverts the invisible replications of such culturally acceptable expectations of what counts as proper and productive comportment.

Often I have wondered about the strange silences which my unhealthy reflections have evoked in the last few years. Many times I have been puzzled and disappointed by the sudden appearance of awkward distance by those to whom I had felt close enough to share my "secret" life of chronic illness. In other more sanguine times, I could (barely) imagine the unexpected contamination of social space I must have unleashed, somehow subverting the unspoken boundaries between health and illness.

Maureen and Tom

We have found that the consequences of lived relation are often overlooked in discussions of the embodied significance of chronic illness and pain. Too often, however, the relational risk of expressing the unbearable weight of human suffering takes its toll in the breakdown of what little support may be already in place.

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 former wife had worked so hard to find, negotiate, and buy in the first agonizing year of my illness in 1987. 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, the long hours of packing and moving boxes, and the months of unpacking one at a time in our new place of residence. One sunny day, taking a short break from our two boys (ages three and a half, and two), 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 seven 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 mar-

riage 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, 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." Nor can I forget my frustrating attempts over the years to garner family support 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.

As I write now from the

unexpectedly political and subversive location of my body, I remember the days of overwhelming tension in my neck, back and hips; of the pain firing in syncopated rhythms through my connective tissue; and of the deep, unbelievably knotted muscles restricting my movements, the constraints on my thoughts, and the radical altering of my daily activities intensified by the threatening (and so damn corrosive!) cultural taboos against giving voice to such "negative" and "abnormal" body disclosure.

Curiously, my body has become a postmodern, thematic, deconstructing of the cultural ideal of disembodied minds and unperceived bodies, in short, "normal subjects" in capital-producing contexts. Paradoxically, as human beings who necessarily interact with each other in intercorporeal ways, we must return continually to the actual—but sometimes unbearable—bodies we live and face the humbling realities of wild being.⁷ We must challenge the stable/healthy/productive body of contemporary consumer culture as an insidiously sedimented ideal whose unjustifiable certitude and impartial claims no longer can be tolerated.

Maureen

I do not offer my practices nor those of other somatically trained practitioners as superior or more genuinely or inherently caring. I do suggest, however, that the modalities of touch and the sensitized practice of touch have been under-explored by conventional medical prac-

tice, and that the kinds of knowledge and insight available through these modalities could have far-reaching consequences for people seeking dignified, body-honoring treatment and for health care workers committed to providing this kind of treatment.

Tom's illness and pain are highly resistant to conventional treatment, and his ongoing struggle with a chronic illness that works across several bodily systems (and the new way of being in the world that it demands) have had both personally empowering and relationally devastating effects.

As a practitioner, I use light pressure and deep pressure massage, therapeutic touch, assisted stretching, gentle manipulation, movement patterning, tension-release techniques, and energy work. Initially, there was so much congestion in Tom's muscles that I could not feel his bones, nor distinguish one muscle group from another. My hands met a wall of protective tension and firmness developed out of years of attempting to contain physical and emotional anguish. The joints and muscles were locked into tight range-of-motion patterns, taking up as little space of motion as possible. Here was a person for whom even the everyday acts of breathing, weight bearing, weight transfer, and motion could carry intense pain. Conversely, there were fluctuations in the illness when he could participate proficiently in the high-level athletic demands of activities of tournament-level tennis.

I have become acquaint-

ed with Tom's body—his joints, muscles, gestures, patterns, breathing, energy. I can tell the difference between his "old pain" (pain that has been stored from long before the onset of his disability and which has deepened during his disability) and his present pain; I can feel the muscle knots and the connective tissue textures; I can feel scar tissue, inflammation, the unpredictable traveling of pain impulses from one site of the body to another, the quivering and trembling of tissue as it feels pain or moves into relief. I can feel muscle relaxation; I can feel everyday soreness. I can feel the thick, distinctive, saturating presence of ME. I have worked with Tom as he has experienced loss of mobility, myoclonic vibration, and myofascial release. Together we have experienced his body stories and inextricably embodied insights. Some he tells me with his voice, some I feel in his tissues. I am not his psychotherapist; rather, I know his body and what it has experienced. It is knowledge forged by trust and prolonged engagement over time. We do not work on curing or healing; we work on acknowledging and caring for the body that is today, now, and all that body brings. It is this unconditional respect and regard that makes these touch modalities so powerful. Kristeva (1995) claims that love is what ought to inform psychoanalytic practice. I am inclined to agree, and in my practice I work at embodying love in such a way that every touch is a caring touch. I bring all my focus, energy, knowledge, imagination,

and attunement to this moment of touching, and I make myself available for what it offers.

Recently, during a bodywork 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.⁸

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). The interaction Tom and I had about whether his pain is "real" is a good starting point. 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, 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 bodywork sessions together.

Another example which illustrates connection to bodily rhythms is a recurring experience which I call "following the fish." At one of our bodywork sessions, I was working on Tom's upper arm and elbow joint—at his request. He was experiencing simultaneous 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 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 when the tremor eludes me. We "followed the fish" for 20 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 go with what is, 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 to 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.

Tom

Facing the phenomenal body of disability can be overwhelming—especially when it is one's own. Most of us have been so thoroughly trained to leave our body behind (by repressing any sense of deficiency or inadequacy)⁹ that we simply accept the stable/healthy/productive body code regardless of its detrimental consequences to actual, personal experience. Such remarkable negation of bodily dysfunction, however, need not always take the leading role in our lives. My own experience with an aching, unpredictably functioning body, for example, leads me to believe that the overwhelming cultural refusal to embrace anything but a stable/healthy/productive ideal of living may itself be refuted and dismissed as both naive and dehumanizing. When I am tempted to commonplace thoughts of transcendence above the fray of the fluctuating rhythms of disability that I live, I can never breathe in that disembodied fantasy of "rare air" for long.¹⁰ I am soon forced back down to the carnal, practical bedrock of daily activities, to face the once invisible challenges of walking and driving, of moving in and

out of upright posture, of avoiding the piercing invasion of chemicals and noxious perfumes, cigarette smoke and bright lights, and of negotiating the relentless onslaught of pain migrating systemically through all of my joints and connective tissue. While I often have been discouraged by the stubborn linear demands of productivity which conflict with the fluctuating rhythms of my own lived body, I am reminded that though "the abyss of uncertainty" is perhaps more visible in chronic pain disability, it is "...not necessarily broader or more dangerous" (Mairs, 1989, p.236) than that foreboding object of repression that everybody always/already lives.

Embracing the open sphere of the lived experience of bodily transgression can help to lead us to new places of self-reflection and transformation. While those of us who live within the open spaces of chronic pain disability continually breach the cultural presumptions of stable bodies and productive scripts, we offer a distinctive ontological clue to the concrete essence of wild being,¹¹ different bodily rhythms, practical rationalities, and the very possibility of existential freedom that breaks through the well-worn repressions of a disembodied status quo.

In a fragmented age of increasing medicalization and dismissal of the living body, we can no longer afford the flight from our own bodily existence nor can we afford the indulgent luxury of refusing to move to radical self-reflection on what it

means to live with others in the world whose non-conventional bodies are different from our own. We can no longer allow ourselves to flirt with madness by living within the paradoxical rhetoric of a culture that refuses our actual bodies. Isn't it time we found some place together where we can learn to accept all the neuromuscular variations of human experience and embrace them as our own?

Closing Thoughts Maureen and Tom

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” disregard and dismiss non-conventional/non-“productive” subjects as failures in a culture of normally absent and distant bodies.

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? Instead, what would happen if 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 syncopated 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?

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. Choosing to engage in self-reflective 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, we must begin to ground our expression and perception of care in honoring the actual bodies we live.

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¹Tom has addressed more of the academic (phenomenological, semiotic, and communicological) issues of living with disability in his, “Disrupting the Disembodied Status Quo” (Craig 1997).

²In order to preserve the ambiguity and profound political consequences of the naming of this disease, we mention all three of its competing designations. The name, “Myalgic Encephalomyelitis” (ME) is the dominant Canadian designation, which emphasizes both the distinctive muscular and neurological symptoms of the disease. “Chronic Fatigue and Immune Dysfunction Syndrome”

(CFIDS) is the preferred designation by the leading advocacy group and many others in the U.S., who attempt to define it by its immunological differences from other diseases. "Chronic Fatigue Syndrome" (CFS) is the official U.S. designation chosen by an informal group of physicians selected by the Centers for Disease Control in order to characterize its non-discrete character. This trivializing name defines the disease curiously by its similarities with many psychological and other conditions. For further information on the intriguing political agenda of the CDC and other government organizations in naming this disease, see Holmes, et al (1988) for the original "working case definition" of the "syndrome of unknown cause that has been the subject of interest in both medical and popular literature, particularly since 1985" (p.387) and the curiously delayed follow-up report in Reyes, et al (1997), based on government sponsored "Surveillance for Chronic Fatigue Syndrome—Four U.S. cities, September 1989 through August 1993." The journalist Hillary Johnson (1996) has documented the politically volatile history of CFS/CFIDS/ME in a massive, ten-year project finally published in 1996. See also Williams (1990) for another early journalistic account on the difficulties in tracking and treating this disease.

³In the recent anthology, *When Pain Strikes* (Burns, et al 1999), Kecia Larkin characterizes this critical existential choice in an interview with Cathy Busby, one of the editors of the book. Lar-

kin style: "I think a lot about pain. In respect to this disease [AIDS], that's where all this comes from. I had to decide at some point if I was just going to lie down and die spiritually and emotionally and just walk around like a shell, or if I was going to try and change, to try and live. It's a constant, never-ending thing, learning how to live. This disease woke me up in lots of ways" (Burns, et al, 1999, p. 69-70).

⁴Harvey Mudolfsky (1992) has proposed that persons with CFIDS demonstrate an "arousal disturbance within sleep" that causes them to live in a twilight world where they are "never fully asleep or entirely awake."

⁵Unfortunately, such dismissive portrayals of persons with ME have been typical since it was first addressed by the Centers for Disease Control in 1988 (Johnson, 1996).

⁶The psychologically trained phenomenologist, Maurice Merleau-Ponty (1962, pp.80-82), asserts that for "normal subjects" who do not have to think about disruptions in their engagement with the world, the full-scale refusal of any kind of deficiency leads to the ongoing repression of illness or disability whereby persons can replay the myth of a fully functional body as a more "natural" way of being in the world.

⁷Merleau-Ponty, developed the notion of "wild being" later in his career (see Merleau-Ponty, 1962, 1968; Craig, 1997), in part, to offer a contrast with the assumptions of the largely "concordant" world of the mathematically and philosophically

trained founder of modern phenomenology, Edmund Husserl (see Husserl, 1962). In my own work (Craig, 1997, 1998) and in our ongoing collaborations together (Craig & Connolly, 1997, Connolly & Craig, 1999), Maureen and I attempt to demonstrate that such able-bodied presumptions of posture, ongoing sensory integration, stability across bodily systems, and production of capital are always complicated by our actual bodies.

⁸Postmodern theorists (Foucault, 1972; Bakhtin, 1981) 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 bodywork 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."

⁹Merleau-Ponty (1962, p.81)

writes about "the refusal of deficiency" as a problem with the individual and her or his own body. As we have attempted to demonstrate in our narrative reflections here, we can see that the sense of "deficiency" presented in chronic illness and disability has both profound personal and social consequences. It affects the very fabric of our most intimate encounters.

¹⁰*Rare Air* is the title of a popular autobiography of the now retired basketball superstar, Michael Jordan, which includes the famous picture of Jordan "flying" in mid-air from the free-throw line on his way to his famous monster dunk. Such cultural icons of athletic prowess represent (in typical mythic hyperbole) the glorified ideal of the incomparable heights that are possible for the severely abled body.

¹¹ While able-bodied subjects can maneuver through the world with the presumption of being on automatic pilot, it is the person with disabilities who can teach us about the freedom to choose to be authentic subjects in the living present. Unfortunately, those of us who can still pretend to rise above the fray of bodily existence never seem to get this message until we are confronted with our life-altering rupture face to face (see Merleau-Ponty, 1962, pp. 126-128).

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