

Journey to the ‘new normal’ and beyond: reflections on learning in a community of practice

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Through poetry and strips of narrative, this paper discusses the embodied experience of chemical sensitivity and the anthropologist author’s and other patients’ journey through altered perception towards knowledge, community and transformation in the context of a medical clinic. The narratives are situated in several strands of relevant theory, including Merleau-Ponty’s work on the primacy of perception, feminist perspectives on embodied experience and standpoint epistemology, disability studies, identity creation through narrating the self, and Lave and Wenger’s situated learning in a community of practice.

journey

I—before
in the cold embrace
of chemical damage
since childhood
i pushed through pain and fatigue
through unpredictable blanks in thought
indistinct sight, warped hearing
i hid dysfunction
and no one suspected

yet in the dark when explanation fails
fear like shadow grows
chills body and heart
narrows hope

i thought to outrun, outwork
outlast illness
clinging to moments of light

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struggling to find a footing
 survival the goal, denial the means
 all the while
 quietly sliding, sliding
 as the long years spun out their tale

*This illness is the pits. My husband died of it, I'm sick with it, I don't have any money, and I've lost everything. Nobody cares. They think we're crazy. (Jo, 35 years old)*¹

On 8 August 1994, an elderly woman trying to kill a tree-sized squash plant on a fence at the back of her garden in Honolulu saturated the plant, fence and surrounding area with a powerful but readily available commercial herbicide. I was sitting on the opposite side of the fence in front of an open bank of louver windows at my rented studio in my friends Peter and Jean's house, less than six feet away. The spray came through in a wet, pungent cloud. Although I jumped up to close the windows, within minutes my lungs began to burn. As the fumes continued to circulate through the open-design studio over the next two weeks of humid drought, I fell ill with alarming symptoms that increased day by day: nausea, diarrhea, distortions in vision and hearing, insomnia, fatigue, difficulty thinking and accessing words, loss of short-term memory and problems with balance. Suddenly odors of all kinds—six-month old dried paint, carpeting, household cleaners, perfume, cigarette smoke, auto exhaust, plastics, mold—became overwhelming and caused immediate shortness of breath, dizziness, disorientation, adrenaline surges, inflammation and uncontrollable trembling. I became allergic and reactive to nearly all foods, and my weight fell precipitously. Physicians at my HMO said that although according to the *Physicians' Desk Reference* my symptoms were classic signs of pesticide poisoning, I couldn't be really poisoned because the exposure was insufficient. They insisted the symptoms would pass, even as they multiplied.

My friends (university professors) and I felt we were living in a nightmare. Unsuccessfully they tried to find a place I could stay where I would feel relief even temporarily. One night I ended up unconscious in the emergency room at the hospital, within minutes of dying, according to the physician reading the results of a test showing almost no saline in my blood. Then through a biologist whose wife had been stricken with the same condition a decade before, we learned of a medical clinic and hospital in Dallas that treats patients in crisis with a variety of immune disorders related to (multiple) chemical sensitivity (MCS), the 'disability' I had suddenly (it seemed) developed.

Arriving in Dallas in late August on an overnight flight from Honolulu, Peter and I entered the clinic as caregiver and patient. Soon my husband at that time replaced Peter, and we remained in Dallas until I was released from treatment six months later to return to California.

On arrival I was ignorant about the nature of chemical sensitivity, and most of the chronic illnesses I was subsequently diagnosed with that together constitute my 'disability.'² Acutely ill, the question of whether and to what extent I might recover

remained unknown for many weeks. Yet as an anthropologist in education, from the moment of my exposure and immune system 'crash,'³ my perceiving and knowing mind split into a kind of double vision—a variation on the 'double description' my former teacher Gregory Bateson (1955, 1972) theorized as involved in the framing and reframing of experiences and meaning in the processes of learning and learning how to learn (deutero-learning). As a full participant in the illness, clinic treatment and life in a community of people with a disability, all that happened was critical to my survival and future. I was at first a new and clueless patient who depended on others to get through the system, later an experienced patient who could guide others through it. And I was observing in a sometimes deeply passionate and compassionate way, other times almost dissociated or detached way, everything that I and others were experiencing. I was surprised that several theoretical strands important in my work were dramatically being lived out by me and other patients: the primacy of perception (Merleau-Ponty, 1964), embodied experience and standpoint epistemology (Alcoff & Potter, 1993; Grosz, 1993), identity creation through narrating the self (Heilbrun, 1988; Eakin, 1999), and situated learning through legitimate peripheral participation in a community of practice (Lave & Wenger, 1991; Resnick, 1991). Running away from chronic illness since early childhood, I had never applied these theoretical positions to disability, learning and knowledge in my own life—a stunning lacuna in my thinking.

Here I want to talk about the embodied experience of chemical sensitivity and my and other patients' journey through altered perception towards knowledge, community and transformation. I situate that journey in the ongoing multilogues in the literature on the 'normal' and 'disabled' body, narrating our lives and learning in a community of practice. As chemical sensitivity is little known compared with other illnesses, I provide some contextualization, though I don't attempt to capture the trauma of the events and experience. Instead I want to be faithful to what I and other patients were trying to do with the experience—survive and overcome it, and observe what was happening to us so that we could make sense of it. Some narratives of disability turn the experience into beauty (e.g. Ehrlich, 1994). My intent instead is to describe some of what happened physically to me and other patients, while focusing on the change in awareness I underwent, because that change was both embodied and spiritual.

I was far too ill in Dallas to take field notes or even keep a journal—and it was only towards the end of the six months that other patients began asking me whether I would consider writing about our experiences. Only a few of them had a college education and only two of the 200 I knew during my stay had earned a Ph.D. (environmental science, physics). Their insistence that I write to give voice to our experiences and lives was a request I took seriously. During my first month back in California while still extremely ill, I lay in bed with a tape-recorder every day, speaking into the microphone everything I could remember. The traumatic nature of each day at the clinic had left me with intense recall of conversations and events, including details about the case histories told me by 75 patients I came to know well. (My physicians in California diagnosed this recall as resulting from post-traumatic stress

disorder.) It is on these recalled data (twelve 90-minute tapes) and supporting notes I wrote on clinic social organization and patient discourse that I am drawing here.⁴ The poem 'journey' that frames sections of this paper, written in 1999, was my first attempt to express what happened and what I have come to understand.

The normal body, disability and narrating the self

For decades the medical model of disability dominated disability discourses, and still holds sway in most social institutions where decisions are made on the treatment, benefits and possibilities for those defined as 'disabled.' Today, however, the literature on disability is vast and growing, especially since passage of the Americans with Disabilities Act in the US in 1995. The new literature includes work that counters the medical model, including the social model of disability that originally came out of England, the disability rights activist perspective, and feminist, queer and other identity perspectives (e.g. Goffman, 1963; Sontag, 1978; Oliver, 1990, 1996; French & Oliver, 1993; Barnes & Mercer, 1996; Davis, 1997; Thomson, 1997; Wendell, 1997; Nast & Pile, 1998; Shakespeare, 1998; Butler & Parr, 1999; Corker & French, 1999; Crutchfield & Epstein, 2000; Deutsch & Nussbaum, 2000; Barnartt & Altman, 2001; Smith, 2001). Thomas's definition incorporates the primary stance of social disability theorists:

... disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being. (1999b, p. 1)

Corker and French (1999, p. 6) argue that disability theory has failed to 'conceptualize a mutually constitutive relationship between impairment and disability which is both materially and discursively (socially) produced.' Discursive practices are central to the ways disability is conceived and represented, and at the heart of these discursive practices is a continuing debate over labels, categories and definitions—normal(cy), (disa)bled/ity, (en)abled/ment, ableism, disabled people/people with disabilities, illness, disease (Kleinman, 1988; Oliver, 1990, 1996; Davis, 1995; Corker, 1998a; Linton, 1998)—because labels, categories and definitions literally shape thinking, attitudes and actions. Other discursive practices are underplayed. Butler and Parr (1999, p. 5) argue that the social model of disability's emphasis almost entirely on discriminatory social positioning of people with disabilities, and the discourse associated with that social positioning, often fails to recognize the 'pain and inconvenience that an impairment can cause an individual,' not to mention the diversity of people's experiences with impairments and illness. There is no question, however, of the social stigma and oppression experienced by people with disabilities.

In the past decade disability studies has shifted to narrating lives as a source for creating theory (Kleinman, 1988; Couser, 1997; Rogers & Swadener, 2001). The outpouring of personal narratives of those with chronic conditions and illnesses has begun to create a substantial literature reflecting the formerly missing diversity of lived experience (e.g. Hannaford, 1985; Murphy, 1987; Grandlin, 1992, 1994; Williams, 1992; Gold & Duval, 1994; Marris, 1996; Moss, 1999; my friend Britt Robillard,

2002, and one chemically sensitive fellow patient and friend at Dallas, Millar & Millar, 1995). Narrative offers the possibility of *transformation* of perception through the expression of *altered* perception, and the opening out of awareness through unexpected encounters with an unexpected world.

Somers (1994, pp. 613–614) argues that 'social life is itself *storied*,' and 'narrative is an *ontological condition of social life*.' For people with disabilities, this means joining with feminists to write from the standpoint epistemological position of embodiment (Alcoff & Potter, 1993; Moss, 1999; Tyler, 1999–2000; Anderson, 2001). We know that our memories are always new constructions of what we think occurred, and these reconstructions vary over time and context. With feminist poststructuralists we also know that 'essentialist notions of disability'—or of lives, for that matter—are problematic (Corker, 1998a). Nevertheless, I believe that the current emphasis on 'narrating the self' as a continual (re)construction of the self—that in a sense, we are not selves until we construct a narrative that tells us who we are and where we have been (e.g. McAdams, 1988, 1993; Bruner, 1991; Kerby, 1991; Neisser, 1993; Eakin, 1999)—ignores the impact of acute trauma and the realizations that are born in the moment of suffering, challenge, altered perception and connection with others. I also believe that it is impossible to forego all essentialism: making a statement of any kind, taking a position on anything at all requires essentialism to some degree, including arriving at a sense of self necessary for making sense of our lives. I agree with Tyler (1999–2000) and Frank (1995) that writing about suffering can be healing. I especially resonate to Barone's (1990, p. 314) argument that 'Good narrative texts ... offer an occasion to conspire about, and so make visible, new worlds that are both desirable and possible.' As Thomas (1999a, p. 55) states in laying out the use of identity narratives by women with disabilities to talk back to 'the story-lines of the prevailing [normality] narratives,' through storying our lives 'we strengthen the counter-narrative, and the dominant and oppressive social narratives begin to crumble....' That crumbling happens in ways that scholars and/or activists who theorize the lives and suffering of people with disabilities (including their own) may not always recognize as aligned with the discursive practices of social disability theory.

Yet narratives by people with disabilities are not of a single person or really even by a single author. As I write I am acutely aware of the presence of my friends (many with whom I am still in contact) of multiple ethnicities and social classes from all over the world who gathered in Dallas for treatment, and whose voices echo through mine. Ellis's argument speaks deeply to me, even though in the space of this one article I cannot touch on all she says that connects to the experiences I talk about here:

The inner workings of the self must be investigated in reciprocal relationship with the other: concrete action, dialogue, emotion, and thinking are featured, but they are represented within relationships and institutions, very much impacted by history, social structure, and culture, which themselves are dialectically revealed through action, thought, and language. (1997, p. 133)

What I talk about here is change in ontology through expanded perception, the development of community, and learning and transformation in a community of practice. In so doing, I will be reflecting the way we talked about 'disability,' 'impairment' and

'normality' in the Dallas patient communities, which will mean at times contradictions and ambivalence about the issues, terms and meanings that may and do differ from the social disability research literature produced by disability scholars, activists and allies.

Some may argue that the ambiguity and inconsistencies in this account are evidence of how 'disabled people still freely subject themselves to control through the scrutiny of others, especially "disability experts" and "the media"' as well as 'through internalizing our oppression [as disabled people]' (Corker, 1998a, pp. 231–232). Corker's construction is one possible reading of what was going on at Dallas. However, people's realities are not fixed, or as easily categorized as the dichotomies in the social disability literature seem to suggest. As a 'person with disabilities' myself since birth, who grew up in a home with a mother seriously impaired by rheumatoid arthritis and other chronic illnesses, I find myself sometimes agreeing and sometimes disagreeing with scholarly theorizing on 'disability' even as I now enter the theoretical conversation myself; yet this issue goes far beyond what I am trying to accomplish here. Among the patients I knew in Dallas and later in Northern California where I live, our experiences and our ways of making sense vary. We did not then and have not now arrived at final discursive positions on the issues of 'disability,' 'normalcy,' etc., whether for our illness(es) or the chronic illnesses and conditions of others (I discuss these issues at greater length in Watson-Gegeo, 2003).⁵ Our lives are and will continue to be works in progress. I maintain that patients' attempts and expressed desire to 'get well' and return to what constitutes for them 'being normal' (again) should not be read as a failure to '[repudiate] such cultural master narratives as normalcy, wholeness,' etc. (Thomson, 1997, p. 279) if, by 'normal,' patients are actually talking about healing and hope. For MCS it is simply not known whether 'full recovery' is possible or not. In any case, my primary concern here is to faithfully represent how I and others perceived what was happening to us and how we responded.

Fractured normality: when the perceived world changes

II—crisis

from the heart of the ordinary
comes the avalanche that ends illusion
the biochemical cascade
to the edge of death

when the tacitly-assumed in an instant
shatters and falls to shards
the known shrinks, chaos threatens
faith is eclipsed

years of waking nightmare
in a reality outside definitions
of normal, experience, disabled, ill
danger, safety, breathe, touch

stripped of possessions
nearly jobless and homeless

supported by the compassion of friends and strangers
at last no choice but to see
we are only part of the ongoing story
of love
and loss is the key
to freedom

I woke up one morning, and the world was changed. (Wendy, 45 years old)

Two days before our flight to Dallas, there seemed nowhere I could be that I was not reacting, not struggling to breathe. Around noon, Peter suggested that maybe we could go to the beach and I could breathe the air off the ocean. Maybe I would finally fall asleep there, as I hadn't slept for several nights. I was so weak that sitting up in the passenger seat was difficult. At the beach Peter put down the seats in the back of the van, and covered the carpet with a sheet he had washed that morning. I lay down with a pillow and closed my eyes, breathing the sea air. I began to gratefully drift to sleep. But suddenly I woke with a start. My arms, lying directly on the sheet, were slowly turning numb. Now the smell of laundry detergent became acute. Too exhausted to even be afraid, with wonder I realized I was now reacting to something new, detergent—and again, my body had taken on a strange set of behaviors that I could neither understand nor control. Later I would learn I had experienced 'peripheral neuropathy' from skin contact with the laundered sheet.

We know the world through the body, and we know the body through the world. The body is both 'a surface for social inscription' and 'the locus of lived experience' (Grosz, 1993, p.188). The body-mind is the place from which we construct knowledge about the world; and, as feminist standpoint epistemologists have convincingly argued and disability narratives illustrated, differences in bodies are fundamental to *how* we experience the world (Harding, 1993; Nelson, 1993). For Wendy, me and many others, 'I woke up one morning, and the world was changed' is not a metaphor. One moment we knew the sensate world as 'normal' people know it. In the next moment our contact with and understanding of that world through smell, taste and touch had been abruptly and irrevocably altered: normality was fractured for us.

The philosopher Merleau-Ponty (1964, p. 3) argued that human beings have a relationship with the perceived world that they take for granted: 'The perceived world is the always presupposed foundation of all rationality, all value, and all existence' (1964, p. 13), the foundation of our ontology and epistemology; and our 'experience of perception' is 'the moment when [everything is] constituted for us' (1964, p. 25; emphasis added). Embodied perception is self-referential (Rosenfield, 1988). When his perception altered due to an accident that temporarily erased his 'normal' body image, Oliver Sacks (1994, p. 50) realized that 'One has oneself, one *is* oneself, because the body knows itself, at all times by [the] sixth sense [of proprioception].' Most people have known moments in which their *social* presuppositions were suddenly laid bare (a topic of interest to the late sociologist Erving Goffman, and to cross-cultural/ethnic, feminist and gender studies scholars in many disciplines).

However, the experience of having our ontological presuppositions of the *physical world* laid bare and challenged is less common.

Nothing is as profoundly taken for granted as breathing and what we can and cannot smell. Being suddenly able to smell things no ‘normal’ person can smell—and smelling them at an intensity that overwhelms the brain and dislodges the possibility of any other thought—takes one into an altered state of consciousness that frighteningly challenges lifelong assumptions about the nature of physical matter and our relationship to the physical world. The human olfactory apparatus carries molecules of what is breathed directly to the limbic system deep in the brain (Ashford & Miller, 1998). Thus MCS patients correctly feel that a whiff of formaldehyde (ubiquitous in, e.g., paper, cosmetics, new clothing, pressed wood furniture) or gasoline fumes ‘goes straight to the brain’ (Walsh & Emerich, 1988). For me, cerebral and neurological symptoms of toxicity (dizziness, disorientation, seizures, central nervous system tremors) instantly follow the inhalation of a chemical incitant, with symptoms (numbness, pain, weakness, fatigue) elsewhere in the body following later.

It is not only the *intensity* of odors that sets MCS experience off from ‘normality.’ We are hypersensitive to particular chemicals, such that odors may be *distorted*, their components detected individually and heightened according to sensitivity. In the cascade of increasing sensitivity I endured in 1994, each day brought a new altering of my perception, a new experience of ‘losing’ something I had taken for granted I could use or be around. The first night in Dallas, for example, I started to brush my teeth before bed with the toothpaste I had used for years. Only this time it no longer tasted like mint and sugar. Suddenly it tasted primarily of formaldehyde, food coloring and preservative, and I vomited into the bathroom sink; that was the end of my ability to use commercial toothpastes. For many years, laying my hand down on a wooden table was problematic; molecules move, and the varnish on wood is full of the solvents to which I am very sensitive. Most people value pleasurable smells, as the popularity of air fresheners, potpourri and colognes indicates. For MCS patients, these odors are distinctly non-pleasurable, and produce (in me) dizziness and seizures.

Our relationship to the physical world having been changed, each new encounter with a situation requires us to ask, ‘Is this X [item, activity, situation] something I can have/do/tolerate, or not? Has it changed from what it was for me back when I was “normal”?’ The question must be asked of our own bodies, too, which have become something of an unknown. As one patient, Trey (36 years old), put it:

I feel that my body is a stranger. I don't know what it will do, how it will react. There's a gap between the person I was and who I am now. I'm different, but I can't tell you how.

The anthropologist Robert Murphy (1987, p. 85) referred to this sense of difference as ‘the damaged self,’ remarking that after he developed the progressive paralysis that ultimately took his life, ‘I had changed in my own mind, in my self-image, and in the basic conditions of my existence.... [It was] a diminution of everything I used to be.’ The loss of status and identity through loss of employment is another component experienced by many with MCS. Such changes in identity are faced by people with other disabilities and are common ground—an intersection (Collins, 2000)—between

them and other minoritized peoples. Yet the altered perception of the physical world and serious impairments from exposure to ordinary 'things' experienced by MCS patients extends theoretical notions of standpoint epistemology and difference into new territory beyond even what is typically assumed to be 'disability.' For the chemically sensitive, the differences of race, class and gender can be suddenly collapsed into the more acute bond of a shared altered perception of the nature of the material world.

Fractured normality is social as well as physical, for it also applies to MCS patients' inability, for the most part, to return to the taken-for-granted lifestyles of their social peers. Recovery of good health ('getting well' in contrast to 'getting cured' in patient discourse) greatly depends on isolation and avoiding further exposures. One of the most difficult aspects of fractured normality is the social disbelief and disdain towards MCS as a disabling illness that patients too often face. Here is where our perceptions of *social* presuppositions about family, friends and other relationships are challenged.

Cultural disbelief and ambiguity

Cindy has done everything she can. I have done everything I can. This illness doesn't make sense. None of it makes any sense. So what are you supposed to do? (Martha, patient's mother/caregiver)

Dealing with this illness is like being in a paper bag. You keep punching and punching, but you can't punch your way out. (Matt, patient's husband/caregiver)

Tomorrow night Peter and I would be flying to Dallas. As we drove to the windward side of the island to spend the night on the beach, all my attention was focused on using as little energy as possible so I could make it through the next 24 hours. By now I was very thin and weak. Peter parked the van to allow the breeze off the ocean to flow through; he pitched a small tent on the sand for himself, but Jean and I were sleeping in the van. She stretched out on the floor in back, I was in the tipped-back passenger front seat with the window down. I knew they didn't understand that because the herbicide was in all our clothing and the van itself, each moment was misery for me. Constant tremors, nausea, inflammation throughout my body, and later I would learn that the horrible feeling in my brain was due to continuous low-level seizing. My ears were ringing and I felt wired.

We said goodnight, and then as I was trying to relax towards a sleep that never came, Jean said quietly, 'You know, Karen, I just have to be honest.' She laughed softly. 'I don't really believe you are ill. I was trained in psychology and I just think you are imagining it all.' I was stunned. She and Peter were paying for the trip to Dallas (over my protests), but she didn't believe I was ill! She had seen me hospitalized with Lupus in the past, and just a few days ago when I almost died from low blood saline, but she didn't believe I was ill! I tried to understand it. Her father had been a famous psychiatrist and head of a major mental institution on the East Coast, and Jean held a graduate degree in psychological anthropology. Given her generation, she had been thoroughly socialized into earlier interpretations of Freudian attitudes about women's 'problems,' as I knew from previous conversations with her, but she herself suffered from inherited bipolar disease. Jean went on to say that there was nothing she had ever learned about medicine that would explain the symptoms I had except

that they were psychological in origin. She wanted me to know this, adding that 'I know you won't agree.' I felt like she was trying to create an academic discussion, where the outcome of the debate was merely the scoring of an intellectual point, while I was struggling to get through the night.

I murmured something about appreciating her honesty. That she had the right to think what she would. That despite what she thought, I was not imagining anything. I said nothing more. I told myself to let go of it. All my focus had to be on maintaining my will to stay alive, even though I felt no fear anymore of dying. It had ceased to matter. Two years and many laboratory tests lay between this night and Jean's retraction of her statement of disbelief.

People react in many different ways to illness and/or 'disability': denial, embarrassment, scorn, sympathy. Chemically sensitive patients typically look pale, but often they appear to be 'normal.' They are not usually physically impaired in a visible way, although some with multiple chronic conditions suffer forms of disabling arthritis, fibromyalgia, multiple sclerosis, cancer, blindness or deafness. Even the initially sympathetic may come to doubt that we are so sensitive or are getting sick from something that a 'normal' person cannot smell or detect. Surely we must be imagining it, must be phobic, depressed or psychosomatic, probably are stressed out, need to be in therapy or don't love ourselves (as the psychotherapist in the film *Safe* argued about the chemically sensitive female protagonist). We live with several levels of stigma (Goffman, 1963). One is being 'disabled.' As Murphy (1987, p. 90) pointed out, 'Disability is not simply a physical affair for [the disabled]; it is [their] ontology, a condition of [their] being in the world.' Another is the strong cultural suspicion that the illness is psychological rather than physical. Like many patients, I have been accused by colleagues at my university of being a 'malingerer' who just doesn't want to go to campus, or who is 'getting away with something' because I teach, attend meetings, serve on committees, and do research from home as an accommodation to my disability. The diminishing of the self and the social ostracism experienced by all people with disabilities is given a special twist in this case. We are not only marginalized by a society uneasy with or hostile towards chronic illness and fearing contamination (Davis, 1961; Chesler, 1965; Sontag, 1978), but our health *depends* on just such an isolation on the margins of the social world.

We also confront layers of ambiguity in trying to undertake treatment that will help us. The variety and character of symptoms chemically sensitive patients experience is perplexing. Often we are unsure of what caused a reaction, and as with all chronically ill patients, we are socially accountable for our own illness somehow, especially because of the ambiguity of its causes and treatment. Even when a patient has, as I do, a large number of laboratory and neurological tests that show serious brain, central nervous system and immune disorders, it can be hard to defend our personal experience of physical impairment—and our altered perception and knowledge about the nature of the physical world—against the weight of conventional medicine and social judgment. Frustration at ambiguity was a focal topic among patients at the Dallas clinic. As Dominique (28 years old) said in one of our conversations about her seizures and peripheral neuropathy:

It's always such a guessing game as to what causes my reactions. It's hard being better, then being worse, because I don't know what the trigger was.

Treating physicians are necessarily in a discovery posture with individual patients, and patients with each other, with regard to what is going on, what works, what doesn't. The change in perception, the loss of self and 'normal' life, often the loss of family and friends, the search for answers—all these contributed to the building of communities of practice among patients at the Dallas clinic focused on doing the ontological, epistemological, emotional, medical and spiritual work required to support healing.

In search of the 'new normal': (re)constituting the world in a community of practice

III—the turn
inured to crisis as life's sole certainty
in a shifting sea of doubt
i took the chance
and looked into the void

in the beginning is our end
in the end is our beginning
washed to the edge of the world
we are returned by the incoming tide

We just want to go home and get back to a normal life again. I told Beth, we're going home to the new normal. Not the old normal—the old normal is gone forever. (Roger, patient's husband/care-giver)

It was my second day at the Dallas clinic. I fainted in the bathroom in front of a patient's mother who was a registered nurse; she found a paramedic and I was transported by wheelchair to an examining room. The treating physician checked me over and told the male nurse to hook me up to an eight-hour IV of amino acids and other ingredients. I shakily walked with him to the chilly IV room, and sat down in a wooden chair with reclining arms, seat and back. It took seven sticks with butterfly needles before the nurse found a vein that did not infiltrate, and shaking his head, he ordered me not to move that arm for the next eight hours because he didn't think he could find another usable vein. I leaned back in the chair, already dizzy from the needed infusion of saline and aminos. I was alone with a bell on my lap in case of trouble. A few minutes passed, and then a paramedic came to the door carrying a severely emaciated young woman who was unable to even hold up her head. He laid her on an IV table and soon had her hooked up to an IV with the same composition as mine. Leanne, the woman with the patient, introduced her as Lynn, her sister-in-law; they had just arrived on a direct flight from Canada. Leanne said she had not yet registered Lynn at the main desk, and could I keep an eye on her and ring the bell if she needed help. The paramedic covered Lynn with a cotton blanket, and he and Leanne left.

Lynn and I were alone. A few minutes passed in silence. Then I noticed that Lynn was beginning to tremble, and concerned that she might dislodge the butterfly needle in her arm,

I asked, 'Are you cold, Lynn?' She replied weakly, 'Yes.' I looked out the glass wall into the hall and saw that the three nurses on duty were all occupied with other incoming patients, and were very busy. Then I noticed a cotton blanket on a table in the corner several feet from where I was sitting.

I looked at the blanket and became acutely aware that the world had stopped, and the clinic was silent, as if time itself had halted. 'I'm not supposed to try to stand up,' I thought: it would be very difficult because of the angle of the back and seat of my chair, my weakness, and the likelihood of dislodging the butterfly needle in my arm. But Lynn needed help now. 'Am I really too sick to help someone else?' It was an existential question, not a factual question. It was for me a defining moment on that, my second day in the clinic. I felt—I knew—that everything that was to follow would flow from the decision I would make at this moment. I knew without hesitation or question that I had to stand up, get the blanket, and cover up Lynn with my usable arm, and do this without dislodging my IV, even though I was weak, had no experience with butterfly needle IVs, and had plenty of excuses for not moving. I got up, I retrieved the blanket, I covered up Lynn, I asked her if she needed anything else, and then I collapsed into my chair. The needle in my arm moved but did not infiltrate. I then endured seven hours of extreme pain as the vein in my arm cramped, a pain so intense I was fighting nausea. Seven hours of intense pain and intense joy. It was the beginning of healing and what would become, for me, transformation.

In the act of covering up Lynn with the blanket, I entered a community of practice that, while it was connected to the physicians and staff, consisted of patients and, for the fortunate, caregivers. Patient communities in the clinic and environmentally controlled condos were locuses for situated cognition and learning. *Situated cognition* means that 'every cognitive act ... [is] a specific response to a specific set of circumstances' (Resnick, 1991, p. 4). *Situated learning* refers to the 'relational character of knowledge and learning,' the 'negotiated character of meaning,' and the 'concerned (engaged, dilemma-driven nature) of the learning activity for those involved in it' (Lave & Wenger, 1991, p. 33). By the end of the second day I was integrated into an ongoing group of patients who socialized new arrivals, shared information and taught each other medical and many other types of knowledge, worked together to create new knowledge based on experience and readings in medical research, helped those who were there without caregivers and needed basic physical assistance, shared resources, created a social life within the condos where we lived, discussed perception, symptoms, realizations, transformation and how to 'get well,' rushed members to the emergency room in the middle of the night in cases of anaphylactic shock, and provided emotional and sometimes financial support to each other. Patient communities served as brokers for those patients who, for reasons of class or nationality or language, found negotiating the complex clinic environment especially difficult (e.g. Angelica and her mother, see below in text).⁶ During my six months in Dallas, there was always at least one ongoing self-identified patient community within the clinic population, and there were at times as many as three, with overlapping memberships. Many patients chose not to participate in any of these communities. Initially I was in one that was ongoing when I arrived, and when I and another patient were the last remaining members as people left in December, we became the nucleus around

which another formed in early January with close ties to yet another group that had started in November. Patient communities typically included patients whose treatment schedules overlapped (e.g. they were in testing, IV, or sauna at the same time) or who had similar interests and perspectives, and arranged their schedules to coincide so that they could spend time together.⁷

Incorporation into and learning within the patient communities or cohorts (as we sometimes called them) are classic examples of Lave and Wenger's notion of 'legitimate peripheral participation.' In fact, our patient experience might be a more prototypical example than classroom learning or skill apprenticeships, because patient communities were about reciprocal teaching/learning that embraced the whole person and life experience. Legitimate peripheral participation refers to 'the incorporation of learners into the activities of communities of practice, beginning as a legitimated (recognized) participant on the edges (periphery) of the activity, and moving through a series of increasingly expert roles as learners' skills develop' (Watson-Gegeo, 2001, p. 24). Members of an ongoing patient group observed new arrivals, and typically were quick to incorporate anyone who was willing and seemed open, although no one was ever turned away. New patients were at first often confused by the complexity of clinic bureaucracy, the sometimes unclear instructions they were given by professional staff, the degree to which they needed to take initiative in their own medical care, the routines they needed to establish to press towards healing, and especially with how to handle the contradictory and sometimes devastating emotions they felt. Cohort members listened as we told each other our life stories—of how we 'crashed' quickly or over time from exposures due to occupation, legal and illegal pesticide sprayings, participation in the Vietnam and Gulf wars, nuclear power plant exposures and other kinds of accidents. We helped new members and each other through periods of intense pain, grief, fear and sickness; we honored the tears and the silence; we encouraged humor, calm, acceptance without giving in, and turning away from denial, turning towards awareness, incorporating our changed perceptions into a new ontological relationship with the world. We disagreed, argued, some relationships became intolerable. Those who were my closest friends and I distanced ourselves on occasion from patients who we felt were 'buying into the illness' or not willing to take risks in the hope of getting better (as most of our treatment was experimental medicine). We tried to be caring, courageous, hopeful, and to celebrate who we were. There were moments of beauty that we created for each other. One of the most touching to me personally was when the 15-year-old son of a very sick patient in the condos came to visit her at Christmas. In a casual conversation with him when we met, I mentioned that what I missed was the lights, because light is about hope. And the next day, secretly while I was at the clinic, he strung lights in the young fuchsia tree growing a few feet from my bedroom window. He turned them on that night, and in surprise, wonder, realizing immediately who must have done this, I sat down on my bed and cried. Every night at sunset he turned them on until New Year's Day when he had to return to his home state to go back to school.

Within the group we spent hours talking about how to reconstitute the world for ourselves in such a way that we could understand our lives, survive and make a

difference in changing the larger society's attitudes towards products, chemicals, toxins. Our way of knowing the world was different from 'normal' people, yet what did the term 'normal' mean? We talked of Roger's idea of the 'new normal,' a remark he had made to me one day in the IV room. For us the 'new normal' meant changing the way we lived in order to 'get well' and protect ourselves from 'crashing' again. We rarely used the term 'disability' or 'disabled,' not because we positioned ourselves as superior to others who suffered impairments—if anything our awareness of the social stigma of chronic physical conditions was heightened by our own experience, and our compassion intensified. Instead, our focus was on survival, on relief from physical pain, on being self-sufficient again, of awakening to a new realization of what interdependence in the world meant, of figuring out what 'getting well' would mean for each of us individually. We came to perceive and conceive our lives differently. When we were physically able, we talked for hours, because we spent hours each week at the clinic—it was a full-time job from 9 a.m. to 5 p.m., and some people continued treatment until the clinic closed at 8:30 p.m. We sat for hours together on IVs or in the allergy testing rooms. We talked ontology (the nature of the world) and epistemology (how we find out about and know the world), though we never used these philosophical terms.

In the moment and reflecting back now on what happened in those endless conversations, what is striking is the holistic nature of learning in the patient communities. We talked across the borders of race, class, gender, sexual orientation, ethnicity and educational level. We talked in ordinary language about highly abstract, often medically specialized, and deeply analytical issues and concepts. We talked from, around and about texts (medical charts, books on alternative medicine, immunology, allergy and even cellular research). We shared specialized funds of knowledge that each of us had about a huge range of topics, so that sometimes the talk was not even about health at all, it was about the biology of the natural world, about human development or philosophical systems in other cultures. Always the education that was happening in patient communities was integrated into people's feelings, aspirations, aesthetics, imagination and lived experiences. Always we were mutually urging—or helping to urge those around us—to think beyond the constraints we currently faced, isolated in a medical clinic from a social world that we would never experience the same way again. Situated learning, yes; and also the ritual process of transformation—and the Dallas clinic was liminality (Turner, 1969) writ large and long for those of us who were there for several months. As the weeks and months passed, I came to realize that those patients who did not do this kind of ontological, epistemological and educational work while at the clinic were not really prepared to return to the world they had left when they came.

Coming full circle, moving beyond: transformation and transition to the outside world

IV—new horizons
voices call from over sea

to take leave of grief
not that weeping dies
for crisis does not die
but perspective moving we
feel a focus here
in the center of void is the only light
we can ever know

one more life to live
and i have made it mine
between and beyond definitions
somewhere floating in space
barely tethered to the earth
though not yet sure of the way
feeling a surge of unruly joy
hope staking claim to its rightful place

So many things I thought were important aren't important to me any more. This illness has helped me realize that faith and love are what is truly important.... We must have faith that God will heal us, and that love will heal us. And we need to keep beauty in our lives. (Alisa 42 years old)

'Learning involves the construction of identities' (Lave & Wenger, 1991, p. 53). The sudden altering of perception, life in an extreme environment, fundamental questioning of the nature of reality and oneself, and learning in a community of practice can be transformative and empowering (Tedeschi & Calhoun, 1995; Greenleaf, 2001). *Communitas*—community—develops partly out of being forced to stop and reassess one's life and what is important, going through a profound experience together, sharing a common traumatic experience, and the need for new relationships for those who may be losing friends, family or occupation (Lyons *et al.*, 1995). For the Dallas clinic patients, the necessity of seeing the world as a potentially harmful and dangerous place, of having no place to be that is safe, of trying to generate hope in the face of tragedy, raised cosmological as well as ontological questions. Spirituality deals with cosmology, and spirituality became a major focus of conversation in the cohorts to which I belonged.

Many patients at the clinic experienced dramatic changes in their sense of self and purpose in the world. Most became open to if not engaged in a deeper level of spirituality. Others did not experience the kind of transformation that empowers (and granted, 'transformation' and 'empowerment' are concepts that slip away when we try to define them). Some patients ended up bitter, defeated, angry, still in denial—and often these patients 'crashed' again and had to return to Dallas later but at a more serious level of illness. Most of those I knew, however, and especially those who participated in one or another of the patient communities of practice, experienced a positive transformation and were able to make the kinds of changes in their lives that promote health. In this sense, the cohorts were effective socializing and transformative groups.

Still, 'positive transformation' is open to interrogation. In the cohort with evolving membership that I fully belonged to in the fall and winter, people's experience and

conception of transformation—a term we all used—varied. For some transformation meant a further narrowing of their beliefs, or a journey inward whereby they moved away from engagement with the sociopolitical world. A few experienced a fundamentalist religious conversion. Most felt an opening out and liberation from their prior narrow beliefs, and a desire to become involved in reaching out to other ill patients, or to environmental causes, including concerns with the poor, oppressed and low-income people who might be ill with chemical sensitivity but unaware of the existence of the clinic and unable to afford treatment there. One of the central organizers of the group I was primarily in, Marianne, viewed her transformation as an extension of what she was already trying to do with her life:

I believe God put me here to help others. Now that I'm sick there are so many other things I can't do. It's really important for me to feel I can still help. With this illness, we really need to help each other.

Marianne and her husband subsequently moved to Dallas, where although she is nearly recovered now, she continues to help patients at the clinic and in the surrounding community.

I think of the complexity of transformation at the clinic as well illustrated in an event that happened about two weeks before my departure for home. That Sunday morning my cohort gathered in a member's condo for a spiritual meeting. We talked about our caring for each other, what this experience was giving us and taking away from us, how our perception had changed, our awareness grown, our eyes opened to realities and understandings we had never guessed before. As we went around the circle describing what we felt and saw, we decided to have a few moments of silence, in which each person could offer a prayer or statement that transcended the human condition. We had in our group an atheist, a Buddhist, a practicing Jew, Christians of several denominations, and others who identified as spiritual but not connected to a formal religion. When the time came for the silence and the seeking, two of the group got up to leave, saying that as Christians they could not pray if the prayer was not to Jesus. After they left, one of the other Christians remarked:

They have a long way to go to understanding the real meaning of their faith, and what it means to be transformed. The first step in crisis is to open your heart. This experience has made us all part of one family. It doesn't matter if we have different beliefs.

It seemed to me that the group meeting (which involved members from different countries and cultures) summarized well the patient community experience, its strengths and limitations, the possibilities of transformation, and the variation of where people might be on their life journeys when crisis strikes. Later that day, Brianna—who had been at the meeting—came to visit me. We talked for several hours. She was returning to New York that night to continue her ongoing work opposing the use of pesticides in apartment buildings (hers had been sprayed with a lethal product that resulted in everyone in the ground floor apartments dying of acute leukemia within two years of the spraying, and she herself—who had lived on the second floor—was now sick with advanced leukemia; a lawsuit was underway). Brianna and I talked about our future work, about the need for us to tell our stories

to a wider public, about how this experience wasn't about us individually, it was about human beings' relationship to the natural world, about sustainability, health, recognition of disability and chronic illness, social justice for those who could not afford medical treatment. That while chemically sensitive patients are often called 'canaries in the coal mine' because we are sick typically from low-level exposures (as such things are measured) to chemicals, eventually the increasing use of chemicals would affect everyone. Her face alight in an expression of transcendence and realization, Brianna said gently but passionately:

We are the canaries in the mine, yes. But we're more than that. We'll be the survivors who teach the world how to live.

In crashing into illness and hypersensitivity, my perception of the physical world was altered; but like Marianne, the crash had not altered my commitment to help others. Rather, it changed my sense of what helping meant. In the extreme environment of the clinic, when it seemed that my life had been destroyed forever, I broke through to a new level of awareness about what my life had meant up to now, and how that couldn't be taken away if I refused to let it go—at least, not yet. It was then that what I was experiencing became for me not just an interruption to and derailing of my life, but part of my spiritual journey. It all came together for me in a few brief moments on my final day in the clinic.

Wednesday 18 February 1995, last day at the clinic. I was feeling very nervous about leaving the safety of the environmentally controlled condos and clinic, and the support system I had there with physicians, the patient educator, the nurses, the staff. And my new friends. Walking down the clinic hallway as I went through the checking out process, I wondered how I would manage the flight from Dallas to Oakland, whether I could tolerate my brother-in-law's car when he picked me up, or the house I'd rented sight-unseen and paid a contractor US\$6000 to 'make safe' for me, whether I would crash again and be back in Dallas like some other patients I'd met. I was saying goodbye to all the clinic rooms and staff I knew so well, and then I came to the IV room.

As I walked past, glancing through the glass wall I saw that the room was full of patients, at least a dozen in that small space, due to an influx of new patients on Monday. Then I heard my name called—the voice was Kathy's, one of my favorite friends. I reluctantly turned back and stood in the doorway. Kathy looked at me expectantly. 'Karen, Angelica is a new patient,' pointing with her free hand to a young Mexican woman lying on an IV table, weeping. An older woman was standing next to her, a hand lovingly on Angelica's side. 'Her mother doesn't speak English. They're immigrants from Mexico. Angelica is very scared, Karen. She's feels so ill she's afraid she'll die. She needs your help.' Surprised and embarrassed, I saw that the others, many of them new patients, had stopped talking and were looking at me. Kathy said to them, 'This is Karen who I told you about.' She turned back to me. 'You got well, Karen, you're going home. Tell Angelica what she needs to do to get well.' Kathy's face was lit with admiration and concern, her eyes were intensely focused on me, and then with great embarrassment I saw that everybody in the room was looking at me the same way. A few were saying, 'Yes,' and 'We all need to know how to get well.'

Once again the world changed for me as the room fell silent. I saw myself in this same room six months before on my second day at the clinic, the day I covered up Lynn with the blanket. Two hours later that day the IV room had been full of continuing patients, and Lynn was asleep. A patient who had been pointed out to me the previous day came into the room—Heather, a very attractive young woman who I'd been told had gotten well and was leaving for her home in Canada in a few days. Other patients said I needed to talk with her because she could tell me what to do to get well. I thought it strange that a fellow patient should be regarded as knowing as much or more than the doctors, and I was naturally skeptical as well as curious.

Everyone greeted Heather, and she greeted them back as she looked around the room. Placing a chair next to mine, she introduced herself as the nurse hooked her up. 'You're Karen, aren't you? I heard you'd come. I'm Heather.' We sat there exchanging brief comments about the Dallas weather and clinic as I continued to fight the pain in my arm. Heather began to look at me seriously. 'There's something different about you,' she said. And she probed to find out who I was, where I'd come from, what I did for a living. I had hoped to escape anyone's knowing about my background. But Heather was unstoppable, and gradually she extracted from me that I am an anthropologist. With excitement she exclaimed, 'I knew it!' She told me about her own work learning about the medical practices and beliefs of Mexican immigrants on the outskirts of San Antonio where she'd worked as a registered nurse at a hospital until she crashed.

Then Heather abruptly said, with a mix of gentle kindness and enthusiasm, 'You can get well, Karen. I can tell you how to get well. I'm leaving this week, and I'm going to write a book about my experience and how to get well. Do you have a notebook?' I did, as I'd learned the first day that having somewhere to record the multitude of instructions we were given was essential. I brought it out, and Heather began telling me what to write down: an entire program for healing the immune system based on what she'd learned as a long-term patient at the clinic, what her mother had read in the medical and health research literatures, what she'd tried and what had worked for her. As I wrote I began to feel that an angel had dropped into my life to give me hope. Heather's departure was a blow to me and many other patients; we all looked to her as a guide, a hero, someone who we desperately hoped we could become, one of what the chief physician called the clinic's 'miracle cases.'

Now on my last day at the clinic, with a wave of surprise and elation, I realized that, in a sense, I had become Heather. I came to the clinic ill and ignorant about my illnesses and disability generally. Over six months I was socialized into all that I needed to know of patient discourse, the causes of my illness and its multiple symptoms, where to obtain the products chemically sensitive patients require and what those are, what to eat, what to wear, how to live, how to help, how to create meaning, how to 'get well,' how to function in a dangerous world of ambient chemicals. And this education wasn't unique to me. It was the goal of the clinic to foster this kind of knowledge and attitude transformation in all its patients, although the medical staff hadn't a clue as to how to make it happen. It was the patients who, out of mutual need, determination, confusion, despair, humor, more determination and hope had managed to construct a community of learning and practice. Sometimes that community became transformative, because as Brianna had said to me, we had also learned how to live, and with this knowledge we could transform the world.

All this flashed through my mind in an instant. I reluctantly returned my focus to the present, my last day at the clinic and now in the IV room. I looked at Angelica lying on the table. I could help Angelica, but again I hesitated as I had before helping Lynn that day six months earlier. This time it wasn't out of fear for my own condition. This time it was a deep resistance and almost a revulsion: I did not want to be part of a disabled community. I didn't want to (re)construct my identity around the very concept of illness from which I had been fleeing all my life. I didn't want to be an expert, or to take on the task that I knew in fact I would have to take on when I arrived home, of receiving phone calls sometimes from total strangers from all over the country, asking me to help them in whatever way I could.

I looked at Angelica, and then I felt again the love that is the foundation of who I am, who I have always been. The love that had been severely challenged by everything that had happened since I crashed. The love that had been transformed by this experience, and that would continue to be transformed by what I would face over the next several years of struggling to heal. Though at that moment I could never have anticipated fleeing from my just-rented house to escape a major chemical incident in the neighborhood, losing everything I owned from chemical contamination in that incident, living in a stranger's bedroom essentially homeless for a time, fighting to keep my job and obtain accommodation, filing bankruptcy, divorce, and all the other struggles that disability and chronic illness had in store to make my soul grow. Here in the IV room I was very aware of how weak I still was, of the tentativeness and unclear prognosis of my own health, and that truly 'getting well' was years away if it was going to happen at all; of how very little I actually knew; and ... and of how essential to healing just a little hope can be.

I walked over to Angelica and took her hand. 'Hi Angelica, I'm Karen. Don't be afraid. You're safe here. What's in your IV?' She was still weeping, and stammered that she didn't know. I reached up to steady the IV bottle and looked at the label on the side. 'Amino acids, vitamins, minerals, half-normal saline,' I read aloud. 'That's what you should have, it's what I had, too.' 'It is?' she asked with relief. 'You can get well, Angelica. Here,' I said, taking a small notebook and pen from Kathy's lap. 'I'll write down for you what you need to do....'⁸

Conclusion: the journey continues....

morning

a green canyon morning
washed in golden light
we cannot know the path
until we dare to walk it

rustling expectant breeze
in newly opened leaves
echoes wind through hills
to summon listening ears

suspended at the inbreath
here on eternity road

startled, elated, and in wonder
at the moment of epiphany

Life is full of miracles. You're already a miracle by still being alive. Do the program, have faith, meditate, listen to music, and teach your students in love. And write, Karen. Writing will heal you. (Patient Educator, on my final day at the clinic)

The journey of transformation is about ontology and epistemology, and the human mind, heart and soul. It is about the physical, social, political and spiritual experience of living in the world sometimes in the context of great suffering, and always as a learner/teacher on a path into the unknown. I would not claim that my experience as a working-class mixed-ethnicity (white and Native American) woman who passes as white is equivalent to a Third World woman scholar's experience of discrimination and suffering simply because I am chronically ill with a little-recognized set of conditions. For one thing, I am deeply aware that there are at least thousands of chronically ill and chemically sensitive people of color in the US and elsewhere who are not getting treatment because of poverty and lack of access to those few available and expensive medical resources they need. This was a topic of discussion often in Dallas, but also here in Northern California where some of us are talking about finding ways to work with inner-city populations in the oil refinery/chemical factory neighborhoods of the East Bay, and farmworkers on the heavily pesticided farms of the Central Valley. Moreover, race and ethnicity and poverty are inscribed on the body in deeply profound ways; adding disability to this inscription is overwhelming. Until I fell ill in 1994, I had spent my career committed to and working on issues of education, economic development and consciousness-raising about pesticides in communities of color in the Third World cities, towns and villages of the South Pacific, Southeast Asia and the US. I am very aware of the inequitable physical, emotional, psychological and spiritual suffering of the situations I lived in and observed—and yet, even though I nearly died several times while doing fieldwork, I could still get on an airplane and go home to better medical care, and white skin still brought privilege even in Third World villages. Even so, in making a powerful argument for Black feminist thought and theory, Patricia Collins's (2000, pp. 257–265) work also speaks to the ontological and epistemological basis for knowledge-under-construction in the MCS community, whatever the patient's race, ethnicity or social class. Although our historical and contemporary experiences and situations may be very different, we share with African-American feminists a specific set of criteria as the basis for constructing and evaluating knowledge that differs from conventional social science criteria: lived experience, dialogue, the ethic of caring and the ethic of personal responsibility. Our 'subjugated knowledge' (p. 251), like other subjugated knowledges, talks back to the objective generalizations demanded in most conventional research (e.g. MCS physical experiences vary tremendously). Our personal stories talk back to the values and expectations of the 'normal' or conventional lifestyle endorsed by and expected in our society.

Since I left Dallas in February 1995, so much has happened, so much struggle, suffering and tragedy—all of what is alluded to in the above narrative and more—that there is no way I can talk about it all here. Over time it may find expression in other writing. Certainly my lifelong political commitment to marginalized peoples and social justice has if anything deepened from my experiences as a chronically ill person who is 'out of the closet' now by the force of circumstances. And as I am now beginning to write about disability, I am having to rethink all of what we thought about and said in Dallas.

Yet what I have just said is only part of my story. The greater part is more than transformation: it is transcendence through understandings, epiphanies and spiritual experiences that have fountained from within, and poured down on me like silver rain in winter, like golden rain falling through sun. And among my friends, whatever their 'disability,' I am not alone in this movement into transcendence. For the past eight years, I have been on an accelerated spiritual journey beyond anything that I might have imagined at the moment I was sprayed with herbicide. For every tragedy and moment of trauma, a gift of support, protection or hope has appeared seemingly out of nowhere, whether through friends or complete strangers. And the string of miracles and epiphanies goes on and on, affecting every aspect of my life. Teaching for transformation all my career, I now find my teaching transformed in ways that are difficult to describe because they are ineffable, just as my research is also changing in surprising, profound ways. My spiritual journey has been cyclical. In so many ways I have come back to where I was 25 years ago to acknowledge, understand and reclaim what I consider to be—within my hybridity and multiple subjectivities—the 'real me.' That includes suddenly beginning to write poetry again after a 25-year hiatus in which words simply would not come. It happened one morning completely unexpectedly in 1999, and 'journey' is one of the first poems I wrote. Poetry, like all art, comes from the soul. Most of what I write now is about joy, love, hope and wonder; very little is about suffering or sorrow, even though the struggles continue. I am re-learning balance, centeredness, serenity.

The source of all these changes and realizations is a new understanding of love and compassion that cannot be expressed in academic writing, and is only approximated even in narrative and poetry. All there is *is* love after all. Beyond that, there are no words, as Brianna (one of the two scientists among the Dallas patients) understood:

How can we explain where we have been, where we are, and what we know? Theory cannot hold it. Maybe we are at the door of a new world.

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Notes on contributor

Karen Ann Watson-Gegeo is a professor in the School of Education at the University of California, Davis. Her research interests are in critical ethnography, critical discourse analysis, indigenous epistemology, identity, and first and second language socialization. She is currently working in collaborative projects on identity transformation, a criticalist perspective on child development, and language socialization theory.

Notes

1. All names have been changed to protect identities, with the exception of Heather Millar, co-author of a book cited here (Millar & Millar, 1995).
2. I have had multiple severe allergies and systemic lupus erythematosus (SLE) since early childhood, and visible genetic abnormalities since birth. The new diagnoses include: autoimmune thyroiditis (Hashimoto's), idiopathic thrombocentric purpura (involving blood platelets), chronic immune dysregulation, central nervous system disorder, and seizure disorder (partial epilepsy) The first three are inherited, and the latter three are believed to have been caused by repeated chemical exposures (particularly, growing up in a paper-mill town with my father's work involving heavy use of solvents—my family lived behind his shop; and periodic, substantial exposures to pesticides and herbicides over several decades).
3. MCS patients and their physicians participate in a complex discourse community in which the vocabulary is drawn primarily from allopathic and complementary medicine (especially allergy and immunology), medical research and professional nursing. Concepts, phrasings and terms from these professions are integrated into an MCS patient discourse (a separate discourse community that overlaps with that of treating physicians and staff). Patient discourse is highly creative and metaphorical. When I use terms such as the 'new normal' and 'crash,' I am referring to the meanings these terms have in patient discourse. I learned more than 100 such terms while I was at the clinic but I have come to understand since then that patient discourse is nationally and internationally shared, and spread through social networks that include a dozen or more journals and newsletters produced for and/or by the MCS patient community. 'Crash' refers to the patient's sudden descent into crisis with a variety of disabling symptoms, including some or all of the following: a significant drop in T-cell count or major dysregulation of the

immune system, becoming allergic or reactive to a wide variety of incitants in the environment, suffering extreme fatigue accompanied usually by headaches, joint or muscle pain and inflammation, seizures, central nervous system symptoms, difficulty breathing, talking and thinking, etc. In a severe crash, patients are bedridden and occasionally die.

4. The audiotaped and written notes I made after returning to California from Dallas might be regarded as 'recollected field notes.' More than field notes taken on site during a project, there are bound to be omissions and distortions in recollected field notes, and all research is selective and biased anyway, often in multiple ways. While my physicians regarded my (temporary) almost photographic memory as post-traumatic stress disorder, I was aware that while going through the experience, everything felt to me to be fundamentally important to my life in ways I could not at the time articulate. Because of that awareness, I found my mind automatically positioned in a kind of intense 'record' mode that has made me a strong ethnographer in previous research experiences in my work with Native Hawaiians, Solomon Islanders and mixed ethnic populations on the mainland US. My brain seemed to be 'videotaping' every detail of what was going on around me, even though I didn't think of what I was doing as 'research' or that I would ever write about what happened. Instead, learning all I could was essential, it seemed, to survival, sensitivity to others and making sense of what was happening to me. I was in a meditative posture through much of this process: time seemed to have slowed down in general, and there was a calm in me that I could not explain. I have been very careful in writing this article to stay very close to what I am sure happened, was said by myself and others, and was experienced by me at the time. The interpretations I make are based on those I made then, extended with understanding that comes with time; but I have been careful not to do a lot of (re)interpreting that goes beyond what I recorded in the original audiotapes and hand-written notes in California, February-March 1995. I have also cross-checked some of my recall with Dallas patients with whom I am still in contact; two of these individuals visited me in the past five years and we were able to talk about our shared experiences. I found that my recall of events and interactions was far more extensive than theirs were, although what they did recall coincided with what I recalled. They would frequently say to me, 'Yes, I had forgotten that happened!' and they were surprised I had made audiotapes on returning home.
5. I am following Thomas's (1999b) move to reclaim the terms 'disability' and 'impairment' as legitimate, for the purposes of this paper, although I sometimes put quotations around these terms to problematize them, depending on context. 'Disability' and 'impairment' in the Dallas patient communities are problematic for reasons different from the arguments made by social disability theorists and activists. In Dallas the issue was posed as 'buying into the illness' versus 'being in denial' as two unhelpful positions patients might take, in contrast to 'being sensible' or 'realistic' about one's illnesses as real and impairing (see Watson-Gegeo, 2003) Being declared 'disabled' was for many ill MCS patients a desired medical label because many could no longer work and needed to find support through their disability insurance policies and/or Social Security Disability, Section 8 housing, etc. This was a matter of survival, not a mere convenient or cynical adoption of the term while ignoring the real disability issues of people with other kinds of impairments. At the Dallas clinic patients did not debate the politics of the label 'disability,' and many were engaged in protracted legal struggles to get recognition of their illness so that they could have accommodation and/or financial support. Those less ill rejected the label 'disabled' because they were working hard to 'get well' in so far as they were able—even as someone would try to overcome a bad viral infection or some other curable illness. Patient discourse distinguished between 'getting well' and 'getting cured,' so that there was an MCS version of what 'well' and 'whole' meant that neither denied the general notion that we are all whole human beings, whatever our physical condition, nor bought into the 'perfect body, perfect health' expectation of the larger society.
6. Due to the cost of clinic treatment and the nature of social networks that are often class or ethnicity based, very few working-class ethnic minority patients (although quite a few white working-class patients) come to the clinic. During my six-month stay, the only ethnic minority

patients there were middle-class professionals, with the exception of Angelica and her mother. A number of patients came from other countries, and some of these had low English skills. Patient communities often rallied around those with language or social class-related difficulties at the clinic; however, clinic staff included Latino, African-American, and gay/lesbian members who also acted as bridges and brokers for these patients. A key figure at the clinic was the Patient Educator and activist, who was a recovered patient and native Texan with a serious sense of caring and advocacy. Her role in securing patient assistance was so key to many of us that we called her 'our other doctor.'

7. Watson-Gegeo (2003) discusses membership in patient communities in more detail. The complexity of my treatment schedule readily placed me in three ongoing groups for some of my stay. The membership of these groups overlapped considerably, but two tended to have within them many of those of us who were 'sicker' or 'very sick' (in patient discourse), and the other those who were 'not as sick' and/or (from the point of view of the other group) 'in denial.' In the above-cited paper, I analyze aspects of patient communities that lie beyond my focus in this article.
8. For several years I received phone calls, as mentioned here, from strangers several times a month. As I was writing this account on an evening in May 2002, the telephone rang; the caller was a woman I had never met. She had been given my name and phone number by a former IV nurse who knew me, and was calling for advice and help. This was the first such call I had received in two years, and it was riveting to have it come just as I was writing the sentence about receiving phone calls.... Interestingly, however, since then I have again begun receiving calls and have also met new patients who have sought me out for advice.

References

- Alcoff, L. & Potter, E. (Eds.) (1993) *Feminist epistemologies* (New York, Routledge).
- Anderson, R. (2001) Embodied writing and reflections on embodiment, *Journal of Transformational Psychology*, 33, 83–98.
- Ashford, N. A. & Miller, C. S. (1998) *Chemical exposures: low levels and high stakes* (New York, Van Nostrand Reinhold).
- Barnartt, S. N. & Altman, B. M. (Eds) (2001) *Exploring theories and expanding methodologies: where we are and where we need to go* (New York, JAI [Elsevier Science]).
- Barnes, C. & Mercer, G. (1996) *Exploring the divide: illness and disability* (Leeds, Disability Press).
- Barone, T. (1990) Using the narrative text as an occasion for conspiracy, in: E.W. Eisner & A. Peshkin (Eds) *Qualitative inquiry in education: The continuing debate* (New York, Teachers College Press), 305–326.
- Bateson, G. (1972) *Steps to an ecology of mind* (New York, Ballantine) (Original work published 1995).
- Bruner, J. (1991) The narrative construction of reality, *Critical Inquiry*, 18, 1–21.
- Butler, R. & Parr, H. (1999) *Mind and body spaces: geographies of illness, impairment and disability* (New York, Routledge).
- Chesler, M. A. (1965) Ethnocentrism and attitudes toward disabled persons, *Journal of Personality and Social Psychology*, 2, 877–892.
- Collins, P.H. (2000) *Black feminist thought: knowledge, consciousness, and the politics of empowerment* (2nd edn.) (New York, Routledge).
- Corker, M. (1998a) *Deaf and disabled, or deafness disabled?* (Buckingham, Open University Press).
- Corker, M. (1998b) Disability discourse in a postmodern world, in: T. Shakespeare (Ed.), pp. 221–233.
- Corker, M. & French, S. (Eds) (1999) *Disability discourse* (Philadelphia, Open University Press).
- Couser, G. T. (1997) *Recovering bodies: illness, disability, and life-writing* (Madison, University of Wisconsin Press).

- Crutchfield, S. & Epstein, M. (Eds) (2000) *Points of contact: disability, art, and culture* (Ann Arbor, University of Michigan Press).
- Davis, F. (1961) Deviance disavowal: the management of strained interaction by the visibly handicapped, *Social Problems*, 9, 121–132.
- Davis, L. J. (1995) *Enforcing normalcy: disability, deafness, and the body* (New York, Verso).
- Davis, L.J. (Ed.) (1997) *The disability studies reader* (New York, Routledge).
- Deutsch, H. & Nussbaum, F. (Eds) (2000) *'Defects': engendering the modern body* (Ann Arbor, University of Michigan Press).
- Eakin, P. J. (1999) *How our lives become stories: making selves* (Ithaca, NY, Cornell University Press).
- Ehrlich, G. (1994) *A match to the heart: one woman's story of being struck by lightning* (New York, Penguin).
- Ellis, C. (1997) Evocative autoethnography: writing emotionally about our lives, in: *Representation and the test: re-framing the narrative voice* (Albany, State University of New York Press), 115–142.
- Frank, A.W. (1995) *The wounded storyteller: body, illness, and ethics* (Chicago, University of Chicago Press).
- French, S. & Oliver, M. (Eds) (1993) *Disabling barriers, enabling environments* (London, Sage and Open University Press).
- Goffman, E. (1963) *Stigma: notes on the management of a spoiled identity* (Englewood Cliffs, NJ, Prentice-Hall).
- Gold, G. & Duval, L. (1994) Working with disability: an anthropological perspective: introduction, *Anthropology of Work Review*, 15, 1–2.
- Grandlin, T. (1992) An inside view of autism, in: E. Schopler & G. B. Mesibov (Eds) *High-functioning individuals with autism* (New York, Plenum Press), 105–125.
- Grandlin, T. (1994) *Somebody somewhere: breaking free from the world of autism* (New York, Times Books).
- Greenleaf, L. (2001) *Successful coping strategies of people with environmental illness/multiple chemical sensitivities*. Ph.D. Dissertation, Center for Psychological Studies, Albany, CA.
- Grosz, E. (1993) Bodies and knowledges: feminism and the crisis of reason, in: Alcoff & Potter (Eds), pp. 187–216.
- Hannaford, S. (1985) *Living outside inside: a disabled woman's experience—towards a social and political* (Berkeley, CA, Canterbury Press).
- Harding, S. (1993) Rethinking standpoint epistemology: 'What is strong objectivity?', in: Alcoff & Potter (Eds), pp. 49–82.
- Heilbrun, C. (1988) *Writing a woman's life* (New York, Ballantine).
- Kerby, A.P. (1991) *Narrative and the self* (Bloomington, IN, University of Indiana Press).
- Kleinman, A. (1988) *The illness narratives: suffering, healing, and the human condition* (New York, Basic Books).
- Lave, J. & Wenger, E. (1991) *Situated learning: legitimate peripheral participation* (New York, Cambridge University Press).
- Linton, S. (1998) *Claiming disability: knowledge and identity* (New York, New York University Press).
- Lyons, R. F., Sullivan, M. J. L., Ritvo, P. G. et al. (1995) *Relationships in chronic illness and disability* (Thousand Oaks, CA, Sage).
- Marris, V. (1996) *Lives worth living: women's experience of chronic illness* (London, HarperCollins).
- McAdams, D. P. (1988) *Power, intimacy, and the life story: personological inquiries into identity* (New York, Guilford Press).
- McAdams, D. P. (1993) *The stories we live by: personal myths and the making of the self* (New York, Guilford Press).
- Merleau-Ponty, M. (1964) *The primacy of perception* (Evanston, IL, Northwestern University Press).

- Millar, M. & Millar, H. (1995) *The toxic labyrinth* (Vancouver, BC, NICO Professional Services).
- Moss, P. (1999) Autobiographical notes on chronic illness, in: Butler and Parr (Eds), pp. 155–166.
- Murphy, R. F. (1987) *The body silent* (New York, W. W. Norton).
- Nast, H. J. & Pile, S. (Eds) (1998) *Places through the body* (London, Routledge).
- Neisser, U. (Ed.) (1993) *The perceived self: ecological and interpersonal sources of self-knowledge* (New York, Cambridge University Press).
- Nelson, L. H. (1993) Epistemological communities, in: Alcoff and Potter (Eds), pp. 121–160.
- Oliver, M. (1990) *The politics of disablement* (London, Macmillan).
- Oliver, M. (1996) *Understanding disability* (London, Macmillan).
- Resnick, L. B. (1991) Shared cognition: thinking as social practice, in: L. B. Resnick, J. M. Levine, & S. D. Teasley (Eds), *Perspectives in socially shared cognition* (Washington, DC, American Psychological Association), 1–20.
- Robillard, A. R. (2002) *Meaning of a disability: the lived experience of paralysis* (Philadelphia, Temple University Press).
- Rogers, L. J. & Swadener, B. B. (Eds) (2001) *Semiotics and dis/ability: interrogating categories of difference* (Albany, State University of New York Press).
- Rosenfield, I. (1988) *The invention of memory: a new view of the brain* (New York, Basic Books).
- Sacks, O. (1994) *A leg to stand on* (2nd edn.) (New York, HarperPerennial).
- Shakespeare, T. (Ed.) (1998) *The disability reader: social science perspectives* (New York, Cassell).
- Smith, R. M. (2001) View from the ivory tower: academics constructing disability, in: Rogers & Swadener (Eds), pp. 55–74.
- Somers, M. (1994) The narrative construction of identity: a relational and network approach, *Theory and Society*, 23, 605–649.
- Sontag, S. (1978) *Illness as a metaphor* (New York, Farrar, Strauss & Giroux).
- Tedeschi, R. G. & Calhoun, L. G. (1995) *Trauma and transformation: growing in the aftermath of suffering* (Thousand Oaks, Sage).
- Thomas, C. (1999a) Narrative identity and the disabled self, in: Corker & French (Eds), pp. 47–55.
- Thomas, C. (1999b) *Female form: experiencing and understanding disability* (Philadelphia, Open University Press).
- Thomson, R. G. (1997) Feminist theory, the body, and the disabled figure, in: Davis (Ed.), pp. 279–92.
- Turner, V. (1969) *The ritual process* (Harmondsworth, Penguin).
- Tyler, L. (1999–2000) Narratives of pain: trauma and the healing power of writing, *JAEPL: Journal of the Assembly for Expanded Perspectives on Learning*, 5, 14–24.
- Walsh, T. & Emerich, D. (1988) The hippocampus as a common target of neurotoxic agents, *Toxicology*, 49, 137–40.
- Watson-Gegeo, K. A. (2001) Mind, language, and epistemology: toward a language socialization paradigm for SLA. Invited Plenary, *Pacific Second Language Research Forum*, 5 October, Honolulu. Published as a videotape by the National Foreign Language Research Center, Honolulu, No. VD12.
- Watson-Gegeo, K. A. (2003) Masking disability, transforming awareness: the dialectic of identity and situated learning in a patient community. Presented at the *Annual Meetings of the American Educational Association*, 23 April, Chicago, in the session on (Re)doing Identity: Problematizing Education and Transformation in the Margins, co-organized by D. A. Quijada and K. A. Watson-Gegeo.
- Wendell, S. (1997) Towards a feminist theory of disability, in: Davis (Ed.), pp. 160–78.
- Williams, D. (1992) *Nobody nowhere: the extraordinary autobiography of an autistic* (New York, Times Books).