Case Story: Lifelong Effects of Chronic Atopic Eczema

Shelley F. Diamond

I speak as a 39-year-old woman who has lived with severe full-body atopic eczema and related atopic conditions since birth. From the entangled twine of memory, I unravel a thin thread to present an incident from my childhood, with hope that it contributes to greater understanding between doctors and patients. I applaud the open eyes and ears of those in the medical community interested in the perspectives of those with chronic illness, for we have something instructive to say about faith, care, and ethics.

As a member of an international group of eczema patients communicating via the Internet, I recently saw a posted message that I'll paraphrase here: “We've had to devise ways of keeping our son from scratching. We call him Houdini because of his ability to get his hands free. A sense of humor is certainly necessary with this condition, isn't it?”

Reading this brought shocked tears, not laughter. As a child I too was put into restraints in vain attempts to prevent me from scratching. Tragically, 30 years later, apparently little has changed for children suffering with this disease.

When the use of restraints began, I was eight or nine years old. The year before, I'd had an operation for removal of a benign cyst on my leg, and I'd developed a staph infection. Now I was in the hospital for an operation to remove another tumor that had appeared on my left clavicle, so close to the bone that I nearly developed osteomyelitis. My left arm was affected and in pain. It was consequently bound in a sling to prevent movement. My right arm was also incapacitated, held straight out and hooked up to an IV.

It was an awkward position to be held in for 24 hours a day, and I felt extremely frustrated at being left without the use of my hands, confined to bed, and restricted in all physical movement. I was in that position for nearly a week.

This situation would be uncomfortable for any child. What must be understood, however, is the context of chronic illness in which it occurred. Because of my eczema, I was accustomed to scratching constantly, so not being able to do so at all was a severe mental and emotional struggle.

Before entering the hospital for this operation, I had just been learning to gain control of my hands. I had recently figured out a self-hypnotic pattern of repetitively touching my fingertips together, and I had had some success tucking my hands under my buttocks as a calming mechanism. I was beginning to hold a handkerchief and other objects to keep my fingers occupied, as well as starting to slap, pinch, or stroke the skin comfortably without using my nails. But I was in the early stages of this control and frequently relapsed into scratching.

Put bluntly, it was torture for me to be unable to use my hands just when I was learning to use them in positive ways rather than destructively. My other good habit, reading, was also denied me because I couldn't hold a book or turn the pages. Lying there, unable to use the few methods I knew for handling my overwhelming feelings, I was in agony.

It was hard to believe I could feel worse than I already did. When I tried to talk about my feelings at home, my mother invariably said, “Honey, thinking about it just upsets you.

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Think about something else. Wait till your next doctor’s appointment, sweetheart. You can talk about it all with the doctor.”

Unfortunately, when I tried to talk to the doctor during office visits, he would be cordial but dispassionate. When I touched upon my misery and distress, he would stand up and say, “We’ll talk more about this next time.” Crestfallen, I would look down and nod, knowing that next time would be no different. When the going gets tough, the visit is over.

Before coming to the hospital, my mother had said, “The doctor doesn’t have time to talk in the office—he’s busy with all the other patients that we see in the waiting room. When you’re in the hospital, there’ll be lots of doctors and nurses and lots of time to ask them all your questions.”

But when hospital staff came in, checked the chart, and “saw” the patient, they didn’t see me at all. On a superficial level they appeared to be concerned, but I could tell they were just being polite, doing a job; they didn’t have time to care about the frustrated soul trapped in my little body. Their kind words were well-meaning but empty, obviously meant to pacify me while they made their escape. I heard many heave a sigh of relief outside my room. Clearly, everyone felt sorry for me, but no one was willing to engage me in conversation about my predicament. All I heard was the murmur of predictable platitudes followed by hushed sessions of unintelligible whispering in the hallway.

They couldn’t say to me what I heard them say to other children: “Just take this, and it will be all better” or “It will hurt for a second, but then it will be all over” or “All you need is an operation and it will be all over.” So as quickly as possible they wanted to move on to someone whose problem could be solved.

In the daytime, there was a certain routine to my hospital stay. My parents made regular visits, and I had meals and examinations for distraction, though I remember shaking my head and legs, the only mobile parts of my body, and sobbing agitatedly. I recall my dad saying, “C’mon, stop that crying. You understand that, don’t you?” For a moment I felt proud of myself for requesting that awkward position in the hospital, sleep was impossible.

I remember mumbling, “There must be a way out” over and over, my mind like a rat in a maze searching frantically for an exit. I tried every mental trick I knew. I promised God I would be good, urgently chanted magical incantations I’d read in a book on Merlin, and tried to remember tips from movies I’d seen about how people escaped prison and concentration camps.

At one point when a physician came in, I gathered my courage and announced, “Doctor, I don’t know what to do. I’m so itching I can’t stand it.” I was hoping that this small sentence would convey my vast, unspeakable anguish and that the doctor, in his great wisdom, would be able to read between the lines. But instead he said (denying my experience), “Now we’re taking care of that with the antihistamine you’re getting, so you shouldn’t be so itchy.”

“But I take the same thing at home, and it doesn’t do any good,” I meekly objected.

“Well, you’re in a different place now, and not being able to use your hands is the best thing for you. A lot of that itching is all in your mind. I think you’ve just gotten into a bad habit, and that’s what you’ve got to work on. OK? [said brightly, as if that solved everything]. You do want to get better, don’t you?” I meekly nodded. “I’m sure that this medication is what you need, but you’ve got to give it time to work, kiddo. I’ll see if I can get one of the nurses to read you a story or something.”

The next time I saw my parents, my mother insisted that I probably didn’t explain what I needed well enough. “There are a lot of people here much sicker than you are,” she said. “You’re not going to die, honey. First they have to take care of the people who’re dying. You understand that, don’t you? Now you’ve got this nice private room, you lucky girl. Look out the window and enjoy the view.”

Later, when a nurse I considered “nice” came in, I spit out my entreaty as clearly as I could, to ensure that I would not be misunderstood. “Can you just sit down and talk to me about my skin?” For a moment I felt proud of myself for requesting
what I really needed. But the nurse’s response dashed my hopes in a way that I will never forget. “That’s not my job, honey. I’m sorry but I have to make my rounds with medications and do my paperwork. What if all the patients wanted me to sit and talk? I wouldn’t have time for all the important work I have to do. If I had nothing else to do, that would be fine, but I’m busy, child. Maybe the morning nurse will have a few minutes to read you a story or something. I’ll make a note on your chart about that, OK?”

But I did not bother responding. I withdrew into myself as the truth sank in. “That’s not my job, honey.” Her words echoed in my ears. I had held on past the point of emotional exhaustion, telling myself that if I just asked the right person at the right moment in the right way so that they understood, then somebody would just listen and talk to me about what was going on. But now I realized it was hopeless. It didn’t matter what I said or did—everyone’s attitude was one of cheerful denial. “Things aren’t as bad as they seem” was the consistent message. I was supposed to feel glad that I didn’t have a terminal illness, when on the contrary, I wished there was an end in sight.

I was nearly out of my mind with desperation, overwhelmed by rage, shame, and the frustration of being trapped like a wild animal. To resist responding to itching is a maddening experience when the itch is all over your body and you are unable to give yourself even a minimum of tactile sensation. I felt my mind drift out of my body, and it seemed as if I was on the ceiling looking down, knowing what “she” was feeling, yet at the same time separated from “her.”

As a final insult, the nurse did not answer my buzzer when I had to pee. I held it in for as long as I could before finally urinating in my bed. The sad thing is that I remember the release as gratifying. At least here was one instinct I was able to express. I remember feeling my body grow cold from the wet spot, and as I looked through the window, my mind floated out to greet the moon.

If I had had only that one bad experience in the hospital, the trauma would have been manageable. But this was the beginning of years of torment. Due to the hospital restraints, my skin did improve. My parents then decided to use restraints at home. Ropes, handcuffs, straitjackets, and other contraptions were used to immobilize my hands or tie me to the bed. I became obsessed with Houdini, the magician, learning his escape techniques. By self-hypnosis and willpower, I often managed to get out of whatever restraint they devised, and, feeling utterly triumphant, would tear my skin to shreds in furious revenge. The frenzied scratching that ensued was orgasmic.

To think of my self as my body was to feel insane. My developing ego had to separate my self from my body in order to survive. “It” was disgusting and doomed, not me. I wanted to destroy my body in order to save myself. I ended up in the hospital a number of times after tearing myself to shreds in a desperate effort to kill this beast who had imprisoned me inside it.

A child cannot articulate the excruciating horror of these experiences—it’s hard enough for an adult. When no one even acknowledges that you’re in a situation that would make anyone crazy, your sanity is on the line. No one acknowledged the difficulty of my position. No personnel were assigned the responsibility of determining my ability to handle the emotional stress of the situation, nor was there anyone responsible for assisting me in doing so.

The use of restraints affected every aspect of my psyche. The limited scope of this essay does not allow for details of the long-term psychological effects. It suffices to say that the mind/body split has been a devastating legacy. I believe my ordeals with eczema led to my suicide attempts, drug abuse, difficulties in school and other restrictive environments, multiple rape and sexual molestation incidents, voluntary sterilization at age 21, continued need to live as a loner, and other post-traumatic stress-related conditions.

My parents were overwhelmed by doctor visits, trips to the pharmacy, and the task of constant care at home: the fruitless use of creams, ointments, pills, shots, tar baths, oils, bandages, massages, humidifiers, special soaps, special diets, herbs, vitamins; trying different clothes, detergents, and bedding; eliminating molds, dust, and so on. A number of quacks were even consulted, with more time and money wasted on useless remedies including eating only apples and meat, wearing only white clothes and redecorating the house in white, sitting on a vibrating machine, and receiving a nearly fatal lye treatment that burned all my skin off. It was all my parents could do to remain optimistic in the face of my increasing despair.

When I reflect on my mother saying “Think of something else,” I now understand that she was speaking for herself. She survived my illness by distracting herself with household obsessions, fantasies of my condition miraculously disappearing overnight, and a passionate concern with pleasing the doctors. My father’s coping skills involved hiding in the basement inventing electrical devices in his workshop and stoically insisting on not letting anything “get to” him. I now understand my parents’ behavior as psychological defense mechanisms. At the time, however, I was profoundly disturbed by their inability and unwillingness to communicate directly with me about my condition.

Most published stories focus on people who become ill at some point after a normal life has been established. Their stories show how illness changes their world and forces them to redefine themselves. What then of people like me who are defined by illness from birth and never get a chance to define themselves in any other way? With temporary illness, emo-
tional trauma heals over time as the body returns to normal. When one is chronically ill from birth, illness is the norm, creating an inverse of reference points.

Living with chronic illness provokes a mental process similar to the five stages that Elisabeth Kübler-Ross outlined for death and dying: denial and isolation, rage, bargaining, depression, and acceptance. The stages occur in random order, over and over again, perhaps with periods of remission. But then illness rises up again, like the tide, and you are once more inundated and swept away.

There is such a large disparity between my world and yours. Communication from each side must be translated into the other’s language, and much is lost in the translation. Emotions are at the heart of the matter, separating doctors from chronically ill patients. Doctors are trained to suppress their feelings, take effective, efficient action, and present an image of decisive competence. In an emergency room this is appropriate; however, the chronically ill require an emotional response. I’m talking about sincere human empathy for physical conditions that must be endured for the rest of one’s life.

The dilemma between doctor and patient can be described as the ultimate clash of opposites. The patient is sunk into her body, with her mind in danger of being completely submerged. She is drowning, not waving at the doctor, who is sunk into his mind and nearly divorced from his body, which is reduced to a tool for his will.

A doctor’s care is especially important when illness must be accepted as a lifelong condition that cannot be cured. To be “in a doctor’s care” is to have faith that the doctor cares enough to initiate and facilitate painful but necessary emotional discussions. The ethics of ignoring emotional care for the chronically ill is an issue that must be debated within the medical community.

As a chronically ill child, I found the doctor to be an important role model. My parents and the doctors were my biggest early influences. On one hand I hated them all for ignoring my feelings, and on the other I wanted to be like them, numb to feelings. But it’s a bitter lesson taught when a child is discouraged from emotional expression by those before whom she stands naked.

I assume that most people who have a temporary illness go to the doctor open to whatever assistance is presented. I carry 39 years’ worth of emotional baggage to any doctor’s appointment and always show up reluctantly, weighed down by melancholy, suspicion, and resentful resignation. The doctor has no clue to understanding my apprehension, distrust, and suppressed fury and has no time for a mournful litany of explanation. Medical schools need to do a better job of preparing students for working with patients like me.

Change can be incorporated in two essential ways. First, emotional intelligence should be developed and cultivated in medical students. When traditional medical intervention is ineffective, students must learn to switch to a different model of care, where what can be done is to sit down, listen, and sympathetically share the grief, frustration, and rage. For the last several years, I have been invited by the medical school at the University of California–San Francisco to lecture to the new medical students on their first day of class. I applaud this recognition of the pedagogy of suffering; however, the first day of class is quickly forgotten, and the patient’s perspective is buried under the accumulated weight of lessons deemed more important. Doctor-patient relations should be an entire course that is required of all students.

A second opportunity for change occurs when it is established that a case is chronic. At that point, the patient, along with critically involved family members, deserves to be given options of talking with professionals or with someone else who has the same condition. As it is now, families assume that the doctor is taking care of everything, and doctors assume that family and friends are providing emotional support. Meanwhile, the emotional needs of the ill person are ignored unless he or she is suicidal. I was told many times that I could get help if I was suicidal; otherwise my problem was deemed insignificant.

The system needs to consider emotional needs as part of basic care for chronic cases, without pathologizing the situation. It is rational to be overwhelmed by the accumulated trauma of severe lifelong illness. If one is to function as a mentally healthy person despite disease, access to emotional support is imperative.

Despite the fact that millions of people have severe eczema, I did not meet another until I was 35 years old, and did so only as a result of a personal five-year outreach effort. I have finally heard from, met, or spoken with over 60 people with lifelong, severe full-body eczema, and I’m sure that my suffering would have been greatly relieved if I had been able to talk to them at a younger age. There are questions and stories that can be fully understood only by those who have shared that experience. Everyone in the eczema patient network has felt immeasurable solace in communicating with each other, exchanging support and information.

I always knew that I was not the only one in the world with severe eczema, but only when I actually met and talked to others, discovering how much we had in common, did I realize what I had been missing. It’s comparable to having a black child grow up in a white world without ever meeting another black person. It’s crucial to self-esteem to meet others who look like you. And it’s important for a child to meet adults with the same condition who can confirm that it’s possible to survive childhood and function as an adult.

I urge the medical community to take responsibility for assisting chronically ill patients in finding emotional support among peers and professionals. Doctors and patients actively working together can diminish the human tragedy of chronic illness.
Commentary: Heeding the Call of Suffering

S. Kay Toombs

Shelley Diamond’s vividly painful narrative provides extraordinary insights into the lived experience of illness. Not only does it convey the excruciating dis-ease endured by those living with full-body atopic eczema, but it also reveals the kinds of suffering that invariably accompany all severely debilitating illnesses. Her descriptions of bodily alienation, profound isolation, inability to communicate, emotional anguish, family disruption, and lifelong struggle transcend her particular physical disorder (Toombs 1992). Although Diamond’s ordeal is uniquely personal, she is (sadly) not an unusual case. In courageously telling her particular story, Shelley Diamond speaks for all chronically ill patients.

Diamond’s narrative is so rich in detail that I must necessarily limit my comments to two aspects of illness: bodily alienation and isolation. Bodily alienation begins with a radical change in the everyday, taken-for-granted relation with the body. Rather than being reflectively lived in, the body that is in pain or that refuses to function necessarily becomes the unwelcome focus of attention. The body must be taken into account. In chronic illness this forced attention to body is ongoing. Everything else recedes into the background. Diamond experiences this radical shift of attention in the constant and unrelenting sensory bombardment that envelops her whole body (and being). Unlike those around her who are well, it is impossible for her to “think about something else,” to “wait till the next doctor’s appointment,” to look out of the window and “enjoy the view.” She is preoccupied with the torture of itching, the helplessness of not being able to scratch, the confinement of her restraints, and the inability to share her experience with anyone.

The loss of bodily taken-for-grantedness leaves one vulnerable and deeply threatened. Illness reminds one that the body is other-than-me in that it is a biological organism with its own nature. At the same time there is a symbiotic relation with one’s body such that one cannot dispense with “it” and remain intact. Diamond recounts this sense of inescapable embodiment with stark images of forced confinement. Her body is a “beast” that has imprisoned her inside it. It consumes her, traps her “like a wild animal,” toys with her as if she is a “rat in a maze searching frantically for an exit.” She tries desperately to get away from her body by remembering how “people escaped prison and concentration camps.” She wants to destroy “it” by tearing her skin to shreds and, thereby, saving herself. Her desire physically to separate from her body is unattainable. If she were to succeed in annihilating “it,” she would inevitably destroy herself.

Although escaping her embodiment is impossible, Diamond does achieve a kind of separation from her body—a consciously willed severing of “body/mind.” “To think of my self as my body was to feel insane. My developing ego had to separate my self from my body in order to survive.” In this act of disassociation her body becomes wholly other—“it” is “disgusting,” and “doomed.” She is not. However, this separation leaves “a devastating legacy.” In becoming that which is wholly other than her self, her body becomes an object which may be abused, molested, sterilized, and (almost) annihilated. This radical detachment from body paradoxically also incurs a loss of self. “I felt my mind drift out of my body, and it seemed as if I was on the ceiling looking down, knowing what ‘she’ was feeling, yet at the same time separated from ‘her.’”

Diamond’s story vividly depicts the experience of the body as other-than-me. It also reveals another equally disturbing experience of bodily alienation: the body-as-other-than-itself. Her body is at once both the tormentor and the tormented. The body that tortures with the excruciating “itch” of eczema is also the body that bleeds and suffers in the frenzied act of scratching. Limbs that are immobilized by “ropes, handcuffs, straitjackets, and other contraptions” attest to the body’s power to wound; yet, in their imprisonment, they contort with the pain of unaccustomed immobility.

Since the body is the means by which, and through which, we interact with the world, unaccustomed physical restriction (be it the result of disease or external restraint) “pains” us in other significant ways. The lived body is always the body-in-situation. Contained in the action of raising my arm is my specific intention to wave to my friend. I raise my arm in order to get her attention. Moreover, the ability to move one’s arm makes it possible to turn the pages of a book, to work at a particular job, to caress a child’s cheek.

The meaning of embodied action cannot be understood in isolation from the person who performs the action or apart from its occurrence in everyday life. When Diamond is temporarily “left without the use of her hands,” this is of great significance in the context of her illness. She tells us that “her hands figured prominently in her eczema” since she scratched constantly. At the time she is hospitalized, however, not being able to use her hands has profound meaning. Diamond had just achieved an extraordinary accomplishment—learning to “use [her] hands in positive ways rather than destructively.” She was even beginning to come to some kind of reconciliation with her body—stroking the skin “comfortingly without using her nails.” Consequently, the loss of her hands is much more than simply the loss of mobility. It is “torture.”

Serious illness not only aliens one from one’s body but profoundly isolates one from others. This estrangement is partly due to the fact that we lack expressive language fully to communicate the subjective experience of bodily disorder. This
inadequacy of language is particularly striking in Diamond's case. For most of us the term itch conveys an annoying, but relatively harmless and short-lived irritation such as a mosquito bite—a meaning that fails absolutely to capture anything of the "vast, unspeakable anguish" that envelops Diamond's whole body and being (Northoff et al. 1992).

The difficulty with language does not, however, mean that it is impossible to grasp anything about another's experience. A seemingly vague statement such as "I'm so itchy, I can't stand it" provides the starting point for further exploration and clarification. If one responds by asking further questions—"Tell me more about the itching. When is it the worst? Is there anything we can do to make it tolerable?"—the patient is encouraged to give more detailed information which may ultimately suggest a different therapeutic approach. Moreover, when a patient says, "I can't stand it," this clearly indicates that the person is finding it hard to cope. One of the most important acts of healing is acknowledging the individual's struggle to endure. Uttering platitudes such as "things could be worse," "others are much sicker," "you're not going to die, honey" demeans the patient's suffering, increases isolation, and obviously makes it impossible to identify and address the patient's particular problem.

Understanding another requires that one pay attention to all components of communication including gestures, facial expression, bodily comportment, tone of voice, displays of emotion, and so forth (Engel 1977; Cassell 1985). It is astounding that Diamond's agitated sobs, her "crestfallen" demeanor, the contorted shaking of the "only mobile parts" of her body, her feelings of desperation, rage, shame, and frustration, and her final withdrawal into silence were apparently invisible (or irrelevant) to those who cared for and about her. These nonlinguistic clues "speak" volumes about her condition.

A further problem with communication in the clinical context occurs because subjective experience is essentially unshareable. As Scarry (1985) notes with respect to sensations such as pain:

For the person whose experience it is, it is "effortlessly" grasped (that is, even with the most heroic effort it cannot be grasped); while for the person outside the sufferer's body, what is "effortless" is not grasping it (it is easy to remain wholly unaware of its existence; even with effort, one may remain in doubt about its existence or retain the astonishing freedom of denying its existence . . .)

This makes it possible for Diamond's doctor to dismiss his patient's privileged and excruciating experiential awareness of her own body in favor of his clinical knowledge regarding the efficacy of a particular drug therapy. Not only does he deny her experience ("A lot of that itching is all in your mind. I think you've just gotten into a bad habit, and that's what you've got to work on."), but he also dismisses her firsthand knowledge about the effects of this particular therapy in her own case ("I take the same thing at home, and it doesn't do any good.").

The doctor's unwillingness to give credence to Diamond's experience is not simply due to the fact that she is a child. Like other chronically ill patients, on many occasions I have found that medical professionals find it hard to trust my personal experience of multiple sclerosis. Some have insisted that my perception of bodily change is incorrect (because no quantitative measurement records it); others have agreed with my assessment but only after a clinical test or examination has "confirmed" it. If medical professionals deny a patient's experience, then meaningful communication between them is impossible.

Diamond's progressive loss of voice chronicles her increasing isolation from all those who care for her. Her growing desperation is reflected in her changing modes of discourse. She begins by "trying to talk about" her feelings to her parents and doctor. After many rebuffs she "gathers her courage" and "announces" her "unspeakable anguish" to the hospital physician. Her final attempt at meaningful communication is to "spit out" her "entreaty" to a "nice" nurse. When even this nurse refuses to respond to her suffering, Diamond's loss of voice is complete. She no longer bothers to respond to questions, having no choice but to withdraw into herself. The only remaining mode of expression is bodily. The child unwillingly urinates in her bed and finds the release unexpectedly gratifying.

It would be many years before Diamond would finally regain her voice. After years of torment, she searched for (and found) other eczema patients like herself. In communion with one another they gain support, information, and "immeasurable solace." Diamond now also willingly gives voice to her experience in the act of telling her story to medical students. As Arthur Frank (1995) says of the wounded storyteller, "The telling does not come easy, and neither does the listening . . . [but] . . . In stories, the teller not only recovers her voice: she becomes a witness to the conditions that rob others of their voices. When any person recovers his voice, many people begin to speak through that story." This is surely the case with Shelley Diamond's narrative.

REFERENCES


