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Stories of Suffering: Subjective Tales and Research Narratives

Kathy Charmaz

The following analysis addresses relationships between suffering and the self. It emphasizes subjects' stories of experiencing chronic illness and their relationship to the construction of self. A symbolic interactionist perspective informs the analysis. Topics include forms of suffering, the moral hierarchy of suffering, relationships between gender and moral status in suffering, and meanings of subjects' stories. The major argument is that suffering is a profoundly moral status. Placement in the moral hierarchy of suffering affects whether and how an ill person's stories will be heard.

The following story is from an interview of Christine Danforth, a 43-year-old receptionist whom I interviewed for 7 years. Christine has lupus erythematosus, Sjögren's syndrome, and chronic pain from old back injuries, and her physical condition had worsened since our last talk. She described the first of eight recent hospitalizations:

I got the sores that are in my mouth, got in my throat and closed my throat up, so I couldn't eat or drink. And then my potassium dropped down to 2.0. I was on the verge of cardiac arrest. . . . That time when I went in they gave me 72 bottles of pure potassium, burned all my veins out.

I asked, "What does that mean, that it burned your veins out?" She said,

It hurts really bad; it's just because it's so strong and they can't dilute it with anything. They said usually what they do is they dilute with something like a numbing

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effect, but because I was 2.0, which is right on cardiac arrest, that they couldn't do it; they had to get it in fast.

I asked, "Did you realize that you were that sick?" She said,

Well, I called the doctor several times saying, "I can't swallow." I had to walk around and drool on a rag. They finally made an appointment, and I got there and I waited about a half hour. The lady said that there was an emergency and said that I'd have to come back tomorrow. And I said, "I can't." I said, "As soon as I stand up, I'm going to pass out." And she said, "Well there's nothing we can do." . . . And then this other nurse came in just as I got up and passed out, so then they took me to emergency. . . . And it took them 12 hours to—they knew when I went in there to admit me, but it took them 12 hours to get me into a room. I sat on a gurney. And they just kept fluid in me until they got me to a room.

Later in the interview, Christine explained,

[When the sores] go to my throat, it makes it really hard to eat or drink, which makes you dehydrated. After that first time . . . when I called her it had been 3 days since I'd ate or drank anything . . . and by the time I got an appointment, it was, I believe, 6 or 7 days, without food or water.

Imagine Christine walking slowly and determinedly up the short sidewalk to my house. See her bent knees and lowered head as she takes deliberate steps. Christine looks weary and sad, her face as burdened with care as her body is encumbered by pain and pounds. Always large, she is heavier than I have ever seen her, startlingly so.

Christine has a limited education; she can hardly read. Think of her trying to make her case for immediate treatment—without an advocate. Christine can voice righteous indignation, despite the fatigue and pain that saps her spirit and drains her energy. She can barely get through her stressful workday, yet she must work as many hours as possible because she earns so little. The low pay means that Christine suffers directly from cutbacks at the agency in which she works. Her apartment provides respite but few comforts. It has no heat—she cannot afford it. Christine does not eat well. Nutritious food is an unobtainable luxury; cooking is too strenuous, and cleanup is beyond imagination. She tells me that her apartment is filled with pictures and ceramic statues of cats as well as stacks of things to sort. Maneuverable space has shrunk to aisles cutting through the piles. Christine seldom cleans house—no energy for that. I have never been to her apartment; it embarrasses her too much to have visitors. Christine would love to adopt a kitten, but cats are not permitted. Her eyes glaze with tears when my skittish cat allows her to pet him.

Christine has become more immobile and now uses a motorized scooter, which she says has saved her from total disability. But since using the scooter and approaching midlife, she has gained 100 pounds and needs a better vehicle to transport the scooter. Christine has little social life by now; her friends from high school and her bowling days have busy family and work lives. When she first became ill, Christine had some nasty encounters with several of those friends who accused her of feigning illness. She feels her isolation keenly, although all she can handle after work is resting on the couch. Her relationship with her elderly mother has never been close; she disapproves of her brother who has moved back in with their mother and is taking drugs. One continuing light in Christine's life is her recently married niece, who just had a baby.

The years have grown gray with hardships and troubles. Christine has few resources—economic, social, or personal. Yet she perseveres in her struggle to remain independent and employed. She believes that if she lost her current job she would never get another one. Her recent weight gain adds one more reason for the shame she feels about her body.

Christine suffers from chronic illness and its spiraling consequences. Her physical distress, her anger and frustration about her life, her sadness, her shame, and her uncertainty all cause her to suffer. Christine talks some about pain and much about how difficult disability and lack of money make her life. She has not mentioned the word *suffering*. Like many other chronically ill people, Christine resists describing herself in a way that might undermine her worth and elicit moral judgments. Yet she has tales to tell of her turmoil and troubles.

Analyzing our subjects' tales and our collected stories of illness teaches us about suffering and how it affects the self. Raw experiences and subsequent stories of suffering tell us about selves laid bare and open to view. To study suffering and the self, we must address the kinds of experiences suffering includes and the moral context in which it arises. Suffering is a category that scholars invoke.¹ What do we mean by suffering? What sense do chronically ill people make of their stories of suffering? In which ways do their stories contribute to continuity and change of self? How do we as qualitative researchers render these stories in our research narratives?

FORMS OF SUFFERING

When we think of suffering in chronic illness, physical distress looms large. Yes, suffering is of the body. It includes malaise, discomfort, pain, and agony. It is immediate and sometimes relentless. Everything blurs as the state of one's body takes over. Drugs dim recall and distort chronological sequence. Markers dissolve as numbers of health crises and disquieting events grow. Events collapse and merge in memory. Accurate accounts fade as recountings become reconstructions.

Joan Sorani is 68 years old. She has chronic bronchitis, emphysema, bronchiectasis, osteoporosis, and a history of lifelong severe asthma and undetected tuberculosis, which was later estimated to have been contracted at age 5 or 6. She often experiences a lack of oxygen because of emphysema and sometimes feels crazy when on high dosages of steroids. During these episodes, Joan feels out of sorts and out of self, as if watching someone else live in her body. Body and self seem separate. Joan remarked, "My brain sometimes gets addled because I can't remember. I think it's because of the loss of oxygen to the brain [laughs]. It's kind of strange that you can't remember all these things that you're supposed to be doing." Even severe physical suffering does not always overpower concerns about self.

As Morse and Carter (1996) suggest, suffering is more than of the body, and it is more than a psychological response. In contradistinction to Illich's (1995) position, suffering involves more than coping. Suffering calls for attempts to control one's life as well as to cope with it. It gives rise to actions as well as feelings. It shapes new stories and moral meanings. Suffering poses existential problems of identity and continuity of self.

Discomfort can become a constant companion. It gnaws at the edges of one's life and sometimes devours it. Yet, awareness of physical suffering dims when it seems

a natural part of one's being and life. Suffering also slips into the background when pressing needs and other people take priority. Keeping a job, raising a child, and caring for a sick spouse may all take precedence. If so, storytellers may mute the extent of their suffering and, instead, try to validate their actions and seek concurrence that they remain in control of their lives. Such individuals may remain unaware of how much they suffer. Should they become aware of it, they feel frustrated and, most likely, guilty when it disrupts everyone's lives.

The consequences of physical suffering spread and accumulate throughout a person's life. Joan Sorani had been ill for 40 years—since she was 28. She was divorced for decades before she married Tom, who then devoted himself as much to her care as to his cherished career. During the many years that Jane was single, she could barely hold a job and care for her daughter. She said, "I do have some guilty feelings. I couldn't—my daughter—I couldn't provide for my daughter the kind of parent I wanted to be because I was sick all the time. . . . It was so difficult." Long years of suffering can keep past regrets locked into the present.

By nature outgoing, Joan wants involvement with family, friends, and community life. However, her health enforces severe constraints, despite Tom's cheerful help. Joan continually has to cut out and cut down involvements. The past echoes in the present as Joan's feelings reemerge. She said, "I haven't done too much in the last 5 years to tell you the truth. I didn't go to my daughter's wedding; I didn't go to my niece's wedding." Her daughter married late in life, just 5 years ago. She reflected on her daughter: "I felt that she was pretty disappointed in her mom."

Joan now has fewer markers of how intrusive her poor health has become because she no longer works and Tom takes over household tasks without being asked. People who gradually limit their activities often keep their symptoms and regimens from intruding on their lives. These individuals scale life down to where their physical distress remains manageable and, likely, invisible, at least to themselves. Retirees do that well. Their social and personal measures of relative distress often fade after meetings, deadlines, and juggling conflicting demands all cease.

What makes muted meanings of silent suffering perceptible? A sudden disjuncture between past and present make the extent and depth of suffering apparent. Like a telescope, a disjuncture sharpens the person's view. Surgical reversals. New medications. Dramatic improvement. Images of past and present appear in sharp contrast. Then I hear comments such as "I didn't realize how tired I was before." "I only became aware of how much pain I had when it stopped." The *extent* of prior loss compared with present health illuminates such disjunctures in physical suffering.²

A present crisis may also explain past liminal changes. At this point, current suffering forces a fresh look at the past. Crises raise questions and demand explanations. Thus, a disjuncture imposed by crisis sparks a review and reinterpretation of the past. A long convalescence after a heart attack caused one man to reflect: "When I realized how much I'd given up in the months before the heart attack, it was startling."

When in agony, suffering is immediate and relentless. Suffering can also be insidious. It steals in and spreads out. It is of the self and it is social. As suffering spreads out, it shapes social relations and limits social worlds. Such suffering means work—for chronically ill people, caregivers, and coworkers. Christine Danforth's life consists of trying to keep her multiple forms of suffering manageable. Her story is one more anecdote in the current saga of mismanaged care. Here, social arrangements produce both mental anguish and physical distress.

Like Christine, many people with advanced chronic illnesses discover that suffering dictates daily life. It shapes lasting meanings. Suffering can seep into and transform the self. Suffering can lead to either development or diminishment of self. Suffering can be a path to finding resolution and gaining wisdom or a route to sinking into depression and slipping into despair.

Although meanings of suffering may begin with the body, they include emotions, accompany losses, and thus, can arise through social as well as corporeal existence. Loss of control, loss of certainty, and loss of an anticipated future all cause suffering. Loss of control over health may include loss of bodily control and personal autonomy. Loss of control merges with loss of certainty because the individual now risks being cut off and cut out—*despite* his or her inherent worth. Furthermore, loss of certainty means losing the collective myth of a taken-for-granted future as well as the personal belief in sustained health.

The people who I interviewed talked *about* experiences of suffering. They seldom used the term *suffering* to describe their present experience. When doing field research, I am much more likely to hear statements such as “I’m in such pain,” “It hurts so badly,” “I was feeling sad,” or “Everything went wrong” than to hear “I am suffering.” Talking about events that indicate past suffering is one thing; identifying self as continually suffering is quite another. The language of suffering may remain implicit; people may tell of pain and talk about problems but limit their view to specific events and situations.

I believe that studies of health and illness echoed the avoidance of suffering in the larger culture for many years. Now, health researchers are looking at suffering more directly. Studies of the experience of illness have moved closer to studying suffering as they address subjective meanings of loss and stigma (Blaxter, 1993; Brody, 1987; Charmaz, 1983, 1991, 1994; Corbin & Strauss, 1988; Herzlich & Pierret, 1987; Jones et al., 1984; Kleinman, 1988; Kotarba, 1983; Morse, 1997; Morse & Carter, 1995, 1996; Plough, 1986; Schneider & Conrad, 1983; Strauss et al., 1984; Wiener, 1975).³ David Bakan’s (1968) article on pain and sacrifice and Elaine Scarry’s (1985) philosophical analysis of the body in pain suggest paths for empirical research. The following four sources advance understandings of suffering: (a) recent studies of the experience of illness (Frank, 1995; Jackson, 1992; Johnson, 1991; Mathieson & Stam, 1995; Sandstrom, 1990; Weitz, 1991), (b) the emerging research literature on the body (Charmaz, 1995a; Leder, 1990; Olesen, 1994; Radley, 1991; Scheper-Hughes & Lock, 1987; B. Turner, 1984), (c) the current interest in narrative analysis (Frank, 1993; Lawton, 1998; Maines, 1991, 1993; Mishler, 1994; Riessman, 1990; Williams, 1984), and (d) autobiographical works on illness and disability (Beisser, 1988; Frank, 1991; Mairs, 1986, 1989, 1996; Murphy, 1987; Register, 1987; Sarton, 1988). All of these works provide insights from which to draw. My analysis below shifts the focus to look at forms of suffering and ways that implicit moral meanings shape relationships between suffering and the self.

THEORETICAL FOUNDATION

To understand how suffering affects the self, we first need a definition of the self. Gecas (1982) distinguishes between concepts of the self as process and the self as object. The self as process assumes unfolding, developing, and becoming—the

emergent nature of self. Here, I adopt the symbolic interactionist assumption that the self is always in process and never a static final product (Blumer, 1969; Mead, 1934).

The self as object takes into account sociological notions of the self-concept. Under ordinary conditions, self-concepts are relatively enduring (Rosenberg, 1979). Individuals can scrutinize and evaluate themselves as they can any other object or person. Following Ralph Turner (1976), I view the self-concept as an organization of attributes, sentiments, values, and characteristics through which people define themselves. Therefore, the self has boundaries as well as contents. Some things are taken as self, many are not. Experience can change more rapidly than the self-concept, particularly when someone has a medical crisis (Charmaz, 1991, 1994). Thus, we may neither adopt nor attend to new images of self given in specific events when these images are inconsistent with our self-concepts.

Images of self arising in interaction may or may not coincide with how we see ourselves. The stability of the self-concept provides a frame of reference for evaluating these images. We may agree with these images; we may reject them. We may slowly adopt them; we may gradually dismiss them. But whatever we think, feel, and do about these images is intertwined with our self-concepts.

The self is inherently evaluational. We evaluate our actions and more generally ourselves. Once we internalize negative definitions of self within our self-concepts, they become part of us and, thus, are difficult to change. Repeated positive images are necessary to alter these internalized negative definitions.

Some years ago I wrote an article titled "Loss of Self: A Fundamental Form of Suffering Among the Chronically Ill." It was a clumsy piece. But in it I tried to direct attention to experiential and conceptual issues of loss to and of the self, not merely of social identity, daily routine, and predictability. I return to these issues, not with answers but with some ideas and more data. The following four points are crucial when thinking about suffering and the self:

1. When and under which conditions does suffering permeate the boundaries of the self? Clearly it does in some instances and not in others; we need to know more.
2. How does an individual gain a strong core of self that weathers crises and will not be buffeted, like a sail in the wind?
3. What sustains the self in suffering and limits or deters its spread?
4. What place does a person's story have? Which moral claims are imbedded in the story? How does the storyteller position self? When do people adopt their stories of sickness as part of their self-concepts?

SUFFERING AS A MORAL STATUS

Hierarchy of Moral Status

Suffering is a profoundly *moral status* as well as a physical experience. A moral status confers relative human worth and, thus, measures deserved value or devaluation. Stories of suffering reflect, redefine, or resist such moral status. The stories form moral parables of right and wrong, of moral virtue and moral flaw, of reason and rationalization. Kleinman, Brodwin, Good, and Good (1991) argue that the current collective and professional language describing suffering takes a ration-

alized, routinized form rather than expressing moral and religious meaning. Granted, moral meanings of suffering may neither be directly evident nor expressed; however, they still shape thought and action.

With suffering come moral rights and entitlements as well as moral definitions—when suffering is deemed legitimate. Thus, a sick person can make certain moral claims *and* have certain moral judgments conferred on him or her, such as

- deserving,
- dependent, and
- in need.

Suffering can award an individual an elevated, even sacred, moral status. This is someone who has been in sacred places, who has seen and known what ordinary mortals have not. His or her stories are greeted with awe and wonder. The self also has elevated status. This person is special; the compelling story casts an aura of compelling qualities on the storyteller.

Bessie Harris's experience transformed her moral status and view of her suffering. Earlier she had plummeted into total disability from emphysema and heart disease. When I visited Bessie, I found her bent over in her electric wheelchair at the kitchen table. She proceeded to tell me of her rapid descent into life-threatening illness. As she began her tale of her risky surgery, her middle-age daughter, Thelma, who had been tidying kitchen counters in the adjoining room, stopped and joined us. Bessie told of her near-death experience when her heart stopped. Thelma listened with rapt attention and awe. Although she had heard the tale many times before, it transformed the moment anew. Bessie told of being in the long dark tunnel, then seeing a beautiful bright light. Bessie believed that the light emanated from the face of God. As Thelma heard her mother's tale again, she gazed on her with reverence. Afterward, Thelma declared that this experience had lifted Bessie's spirits and improved her attitude toward her illness.

Suffering also may present opportunities to play out the myth of the hero who emerges victorious against all odds. Thus, again, suffering elevates status and sets the person apart when viewed as a hero who has emerged from battle. This person has defied death and, perhaps, doctors by resolving to act despite taking risks. Heroic status often follows facing illness and death earlier than one's peers. Such stories then become tales that attract an audience and proclaim a changed identity. A heroic struggle transforms both the person and his or her situation. A 50-year-old woman had a difficult surgical procedure for a condition seldom found among her age peers. She said, "You go into battle and you come out wounded." Her partner marveled with admiration, "Whew, I could *never* go through all that."

An elevated moral status changes. Time, toil, and trouble erode high moral status. Then moral claims from suffering narrow in scope and power. Stories of self within these moral claims may entrance and entertain for a while, but they grow thin over time—unless someone has considerable influence or power. Social circles narrow to the person's most significant others. Love, power, money, or special knowledge sustain moral status. Loss of the crucial element decreases a person's moral status.

There is an implicit hierarchy of moral status in suffering (see Figure 1). A crisis and its immediate aftermath allow the moral claims of suffering to supersede those

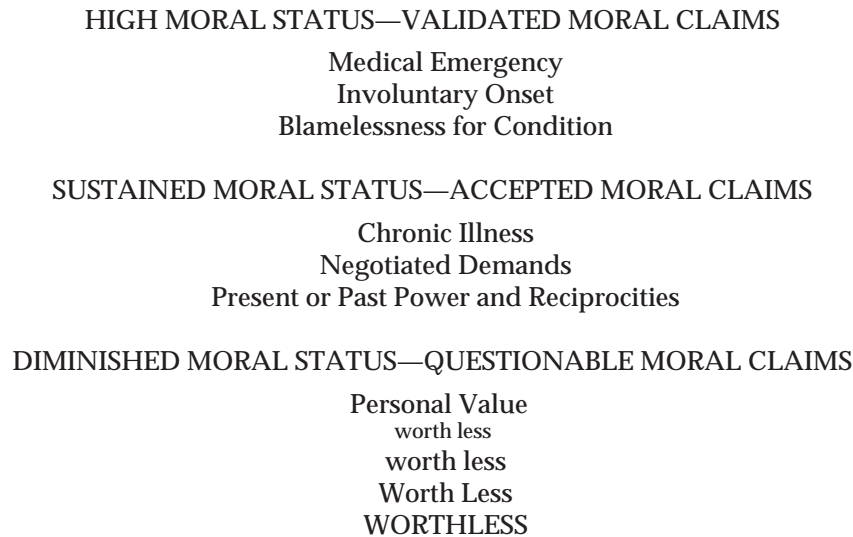


FIGURE 1: Hierarchy of Moral Status in Suffering

of the healthy and whole. Otherwise, a person is less—worth less. WORTH LESS. Two words—first separate—can change as illness and aging take their toll. These words may join, and with them, the person ends up as *worthless*.

The moral status of suffering brings standards of decorum and dignity that reflect a hierarchical position. One has to fulfill these standards or suffer the consequences. However, such standards are usually taken for granted and are relative to specific group and prior understandings. Invoking the standards of one group can alienate another. Christine Danforth went from silence to outburst. Silence does not work in some contexts; it is the only strategy in others. An outburst does demand attention, but it can alienate.

An ill person may also take for granted standards that are or are not shared. One's moral status may emerge in private with spouse, parent, or adult child. It may occur in public settings or at work. A person may gradually feel a subtle devaluation or experience obvious degradation. A groundskeeper had worked as part of a maintenance team for years with the same men. They had shared an esprit de corps. But now his workmates refused to help him on the very tasks that everyone agreed were two- or three-man jobs. A professor in an understaffed department suffered a rapid decline that resulted in his colleagues taking over his classes. Although they said they did so willingly, he sensed how burdened they were and felt that he had let them down. Meanwhile, his colleagues banged at the dean's door, saying, "How can we get him out of here?" Moral claims of suffering seldom long preserve a person's public status.

Moral claims and moral status become contested. Almost every aspect of Christine Danforth's life is problematic—living arrangements, family, medical care, income level, and work relations. After being on a disability leave, she went back to work. She said,

And so I went back to work on March 1st, even though I wasn't supposed to. And then when I got there, they had a long meeting and they said I could no longer rest during the day. The only time I rested was at lunchtime, which was my time; we were closed. And she said, my supervisor said I couldn't do that anymore, and I said, "It's my time, you can't tell me I can't lay down." And they said, "Well, you're not laying down on the couch that's in there; it bothers the rest of the staff." So I went around and I talked to the rest of the staff, and they all said, "No, we didn't say that; it was never brought up." So I went back and I said, "You know, I just was talking to the rest of the staff, and it seems that nobody has a problem with it but you," and I said, "You aren't even here at lunchtime." And they still put it down that I couldn't do that any longer. And then a couple of months later one of the other staff started laying down at lunchtime, and I said, you know, "This isn't fair; she doesn't even have a disability and she's laying down," so I just started doing it.

Christine made moral claims not only befitting those of suffering but of personhood. She claimed a right to be heard, a right to just and fair treatment in both the medical arena and the workplace.

The paradox? Christine worked at a nonprofit agency that provided advocacy services for people with disabilities.

Risk, Gender, and Moral Status

Protecting moral status involves risks. Not uncommonly, people with illnesses give precedence to preserving continuity of self over illness and regimen. They may risk more suffering to preserve themselves and to sustain their moral status. Preserving one's moral status as a competent worker can result in risks. A construction worker ignores his symptoms to keep up with the other men. A secretary takes half of her medication so that she can still drive to work and back without getting sleepy. Initially, someone may take naive risks. Later, as people learn about their altered bodies and develop viewpoints on their illnesses, taking risks becomes a choice, or an act of defiance.

As the body becomes contested territory, autonomy of self becomes tied to keeping control of the body. Control. Autonomy. Self-respect. If people predicate their self-respect on having control and autonomy, losing them means a diminished self. Thus, some people, particularly men, choose to suffer physically rather than lose control. Don Dietz, a 61-year-old man, walked regularly with a group of friends. Despite having sharp chest pains during a walk, Don kept up with the group. Then he insisted on going to a friend's house as previously planned instead of going to the hospital.

[During the walk] I was white and sweating like crazy. I was in obvious pain. You didn't have to be a genius to figure out something was wrong. . . . [Later] I lay on their couch for a couple of hours while they harassed me. . . . They finally said, "You're not going to die on my couch. Get out of here" [laughing]. . . . I was just so sick of listening to them. I was extremely uncomfortable, and they're just at me and at me and at me like pitbull terriers or something, you know, so I thought, "Okay, just to shut them up."

Then it took medical staff 13 hours to stabilize Don. He resisted succumbing to the drugs. He wanted to stay in control. While in the midst of crisis, Don Dietz tried to remain himself: the man who could think for himself and take control. He said,

One, I think it's my nature [to stay in control]. You have to agree to what you are. That's number one. Number two, I was married to a surgery supervisor for 22 years, and there used to be some very interesting statistics. Fifty percent of the people that die in hospitals die of drug induction. Now how many of those would have died anyhow? Nobody knows. . . . But there's a fair chance that if you go in the hospital, they'll kill you.

I don't like doctors. . . . [Bill, an old friend who had recent brain surgery, drove up to see Don, who was still in intensive care. Bill's eyes rolled back, then he collapsed. Don jumped up to help. Out came his monitors and needles; blood splattered all over the place.]

[I thought] I'm not coming back here; I'd rather die.

Don stopped taking the heart medications cold turkey.

In my study, men took many more knowing risks and engaged in more death-defying actions than women. Don Dietz deferred getting to the hospital when he knew he was having a heart attack. Granted, he saw going to the hospital as a substantial risk. It is also a heavy risk not to go—the longer one waits, the more likely permanent damage or death will occur. One man in my study left the hospital against medical advice. Another man fired his doctor while in the midst of a medical crisis. And yet another refused all medical care for 14 years.

The bravado and risk in these men's stories are not simply push-button John Wayne reactions. Their stance represents more than male jockeying to have the best story, to have taken the greatest risk, to have emerged the clearest victor. Taken another way, these men assert moral claims to rights due moral beings. Their stories echo with their claims to moral rights and struggles to preserve their moral status. An implicit view of rights, a quest for control, and an insistence on autonomy define how these men know themselves and wish to be identified by others.

Not everyone can articulate a logical language of rights, but most people can act. Moral claims and moral rights may not always be framed in clear statements or cogent arguments—particularly when one is in crisis. Should patients interpret a relationship with a practitioner as a provocative challenge rather than as a working partnership, the likelihood increases that they will take risks with their health. To them, the challenge undermines control and autonomy and, however tacitly, their moral claims and moral rights. A contest for control ensues—control of the person's body, but moreover, control over moral status. A patient's quest for control of moral status may be masked in a language of obstinance and expressed through anger. Among its other functions, however, anger also serves as the emotion of injustice—of betrayed trust, broken rules, and unmet expectations (see also Tavis, 1988).⁴

STORIES OF SICKNESS, TALES OF SUFFERING

Subjective tales have meaning. They place the experiencing person in the center of the story and, thus, provide a perspective on events. Simultaneously, the storyteller now has some distance from these events. That distance gives a new perspective on them and, by extension, on self. The storyteller's moral status given in the original event may not seem so immutable. It may be reconstructed. Storytelling makes possible a review and reevaluation of the person's life. By piecing the past together, a storyteller makes sense of the present and future. Stories create pattern, coherence,

and sometimes, resolution. A subjective tale can take different forms: a chronicle, a narrative, a report, an evaluation, a mystery, or a fable. Weaving a narrative of any kind entails a certain amount of choice (Brody, 1987). Choices may grow as time elapses. New moral claims can be imbedded in the tale, and a revised moral status may be proclaimed through the drama of the story. Hidden benefits may follow narrative reconstruction. The storyteller may learn new ways of managing life that transcend immediate suffering. With these gains, the storyteller's moral status may rise.

Storytelling is part objective, part subjective. It is objective in that a person (and perhaps other participants) takes past actions, events, and images of self as objects to examine. It is subjective in that the story becomes one way of knowing self (Charmaz, 1999). This story gives self a history. It makes past events real and believable, although this may take effort. The more incongruous the story is with self at the time, the more narrative work is needed to examine, to understand, and to resolve it.

Should suffering become etched on the self, it shapes not only stories but views and feelings as well. At this point, a story of suffering has become the story of self. If suffering has long been a part of life, it merges with life. When reflecting on the place of her illness in her life, Joan Sorani wondered, "How could I know? You know, I've had this for so long, I don't know any other way."

Stories are emergent and open-ended; people talk of the past but speak in the present. As George Herbert Mead (1932) pointed out long ago, the present is always novel; it is new. Our experience and knowledge of the present provide the lens through which we view the past. In turn, our present view of the past shades current interactions. A story of the past differs from a story unfolding in the present. The storyteller has a different stake in the outcome and in the audience. He or she can reconstruct a story of suffering so that it reflects heroism without contamination. Then any hint of past suffering contrasts with the current portrayal of self. The person remains in control; the self remains intact and untouched by suffering. Here, the person not only preserves moral status but may claim moral superiority for remaining in control and not caving in to suffering.

A story can change over time as the present reshapes images of the past (Mead, 1932). When a person reels in shock about being ill, the story may just spring out at any opportunity (Charmaz, 1991). Later, this story becomes measured, recast, and perhaps entirely repackaged for different audiences.

Viewing one's story of suffering as a story of self holds varied meanings, depending on how this melding occurred. It makes a huge difference whether people endorse this story themselves instead of having it enforced by others. It also makes a difference if a confidante understands and accepts the story. To illustrate, a middle-age African American professional woman had to leave her high-powered job because of disability. She developed a friendship with a fellow support group member who happened to be a younger White housewife. Their stories unfolded through daily phone calls. She said, "I don't know what I'd do if I didn't have her. We don't look the same. We've had very different lives. We don't even see each other that often. Yet so many times, she's the only person who really understands what I'm going through."

A story of sickness can take on life of its own. Arthur Frank (1995) views some stories as overdetermined: The person views illness as pivotal at every interval in his or her life and attributes every misfortune to it. Yet, when we researchers get close to the phenomena, we find that chronic illness does start a chain of misfortunes. The

direct causal links make sense in some stories. Illness combines with and complicates additional disadvantages in other stories. For example, Christine Danforth could chart her woes as emanating from her illness, her lack of education, and her low income.

A changed relationship between self and suffering follows altered definitions of illness. Sara Shaw was an angry young woman when I first met her. She saw her illness then as unjust punishment for being different from her siblings and for causing her parents distress. Sara next viewed her illness as dues paid for having suffered. At this point, she addressed suffering directly but placed it in the past. Several years later, Sara began to see illness and suffering as opportunities for knowing. Sara was an artist; she understood that different positions provided certain perspectives, and not others, to see, know, and construct images of the world. When I last saw her, Sara viewed illness as a source of transformation when one surrenders to the flow of experience while suffering (Charmaz, 1995a).

Chronically ill people may try to maintain moral status, personal dignity, and control by remaining silent, by neither acknowledging suffering nor allowing a story of it to take form. Silence is a strategy to keep both suffering and story from becoming real. Don Dietz recalled,

I was ignoring certain truths. . . . I don't know if this is a man thing or not. I would ignore obvious aches and pains that were warning me that it was more than getting a little older. That kind of thing. And if I wanted to do something, I did it. If I wanted to climb a mountain with a friend, I did it. And I had to pay for it. I would pay for a lot of things I would do. And ultimately, that was stupidity.

Silence poses medical perils. Yet telling stories of suffering also raises moral risks. Stories can turn back on their storytellers. If so, these stories provide fuel for judgments, for denied moral claims and reduced moral status. A story that initially elevated a storyteller's moral status may sink it into a source of shame. What started as news becomes an item of gossip to pick up or pick apart, and it ends as a tale to deride or simply dismiss. As an audience imparts new negative meanings to a tale, so they cast the storyteller as well. Sad tales, as Erving Goffman (1961) pointed out long ago, are supposed to captivate listeners. But sad tales do not always work this way. And they may wear out sympathetic audiences.

Telling the story of suffering is a way of creating continuity and wholeness in the face of disruption—a life torn apart. It is a way of understanding what happened. It is a way of coming to terms with a changed life (Corbin & Strauss, 1988). Moreover, the evolving story points a way to accepting a changed self. The story leads the person toward resolution of loss. Joan Sorani said,

I think the main thing is liking yourself as you are and being happy that you're not any worse. Because I have seen people who are, I feel, are three times, four times, five times worse off than I am. And, and my particular problem is, so the doctor tells me and I feel sometimes, is very severe. So, accepting yourself and living with yourself and liking yourself and being positive I think are the main guidelines.

The frame for a story may assume as much significance as the story itself. A frame provides context and confers meaning. Then the person can account for what happened. In Don Dietz's case, the frame meant the life story that he had been piecing together for years.⁵ After Don's son died 12 years ago, he became a hospice

bereavement counselor. He viewed his hospice work as a huge undertaking but also as a way of coping with his son's death.

So the work was going on prior to the heart attack. If the heart attack had come with none of this other work, I probably would have been the person who took it as disaster and went downhill. Probably would have been dead already. Just a guess. Because I would have taken all the negatives, the negatives of my life in the past, and put it all together . . . but because of this other process that had been going on, the heart attack was really a force to say, hey, here's how to cement it all together.

In Don Dietz's story, suffering presented challenges. Don's view of the self as work superseded his view of his heart attack as an object outside himself. In his view, one had to grapple with and work through suffering. A functioning self is not a given for him. Nor is life. Rather, Don worked to construct a self that he believed would allow him to live. His story reveals a new twist on meanings of suffering. Like many others, Don adopted a metaphor of illness as an external object or force. By referring to "the heart attack," Don objectified his condition and distanced himself from suffering. Yet that distance allowed him to reclaim suffering and illness as part of his life story on his terms in his own time. He integrated fragments of his experience with illness bit by bit into his life story and into his understanding of self. Don reflected, "The heart attack, in effect, created all the processes that I still had not been totally willing to integrate into myself. I now had to look at things that I had been ignoring."

Stories of suffering evoke reflection, reevaluation, and redirection. They contain wisdom and provide lessons in living. These respondents' stories may have begun with claims for moral rights and moral status, but they end with sage advice and moral principles. A 41-year-old woman described herself now:

I'm tolerant. . . . I don't criticize people. . . . I don't like petty little things to get in the way, that so many people let get in their way. 'Cause life is so short, and it—it's people that have health don't realize how much time they waste.

Don Dietz stated,

It taught me to go with the flow. . . . If you fight it, it'll probably win because when you fight there's a winner and a loser. Very rarely is there a draw, you know. And the process that created the heart attack is a little more powerful than I'd ever be.

CONCLUSION

Stories of suffering are consequential. The words, characters, action, plot, and point shape meanings for the storyteller and for his or her audience. A story provides a way of making sense of suffering, of locating self in life, and of coming to terms with an altered existence. The story makes claims for both storyteller and audience. The storyteller makes identity claims for being a certain type of person and reality claims for the audience to support. Both types of claims may be buttressed with a moral righteousness that enhances the significance of the story and, moreover, the moral status of the storyteller. This story grabs attention, at least for a while. Strong claims and moral righteousness have limits and hold risks. If participants treat this

story and the claims within it as true and immutable, other possible meanings of the experience become muted.

Any story must fit the audience if it is to be heard. The same story told the same way may win some hearts and close other minds. Strong claims and moral righteousness may raise doubts of audiences that view them as overstatements. As a storyteller becomes committed to one version of the story, he or she may remain unaware of how it seems and sounds to the audience.

Audience and storyteller may blend as partners and friends join in crafting the story. If so, the ill person's account may be revised and edited before being entirely articulated. Still, these stories offer chronically ill people ways of seeing themselves and their situations from fresh perspectives. When suffering remains relentless in the story, these perspectives may be shaded by sadness and loss. Paradoxically however, awareness and acknowledgment of the tragic elements in one's story can be the first step toward transcending suffering and loss.

Silent or ignored suffering may be reclaimed as story and as part of self—when it becomes safe to do so. Thus, renewed health or signs of improvement alter a person's stance on suffering. Someone who could not or would not acknowledge earlier suffering may later celebrate it in stories because he or she can place it in the past. The framing of the story makes suffering intriguing but removed from current experience. Earlier suffering empowers people who emerge as victors; then their moral status rises. The distance between past suffering and present self mitigates potential threats of devaluation. The situation differs markedly, as does the story, if the storyteller claims to be a person who suffers now and who deserves the compassion of others. The weight, time, and meaning of the story shift. For this story to work, the storyteller must act as if the story of suffering is close to the present to maintain its compelling narrative edge.

Whose suffering matters? Not everyone's. The suffering of someone with high moral status is assumed to be significant on face value and awarded unrequested attention when illness first begins or dramatically worsens. The suffering of someone with low moral status may be ignored or minimized. The moral equation for compassion and care only partly rests on one's status in the moral hierarchy of suffering. A person's moral standing also reflects prior relationships and the web of reciprocities within them. Hence, moral claims of suffering wither when relationships are strained and reciprocities have waned. A story that otherwise might evoke sympathy can elicit shame or remain silenced. When relationships are strong, shared stories affirm bonds and can transform both storyteller and listener. These tales may also inspire us to transform our research by going deeper into the story and further into the experience that shaped it.

METHODOLOGICAL EPILOGUE

How do we tell an analytic story about our respondents' stories? Which research and writing methods can we use to portray their stories? Our subjects tell a tale and piece together puzzles from their past. They may need to re-view and restitch events to weave a seamless tale. What sounds seamless and complete to them may not to us. The meaning of the tale may be invisible, incomplete, or even incomprehensible. Then we have to piece their tales together to discover what they mean

from our vantage point. Finding analytic meaning requires that we listen for cues, look for clues, and then pursue them. It entails being willing to go back to people—sometimes again and again. The further we delve into implicit meanings, the more we may need to wonder and watch.

The predominant method of studying the experience of illness consists of conducting one-shot interviews. An initial interview may not elicit complete information, much less implicit meanings. Researchers cannot expect to get beneath the surface with every respondent in one visit. We need to build trust and to create a safe place in which they can disclose thoughts and feelings as well as facts and acts. Researcher and respondent more or less co-construct interviews from which a respondent's story emerges. This story is neither absolute truth nor fiction. Through our interviews, however, we should aim to gain an inner view of our respondents and how they see their worlds (Lofland & Lofland, 1994).

Conceptions of moral claims and moral status in suffering did not jump out of the data into my ready hands. If the ideas were right there, they eluded me. However, much material that indicated such concerns did reside on the surface of the interviews. Many respondents divulged tales of feeling stigmatized, of being judged negatively, and of feeling different and separate. A few hinted at their moral superiority vis-à-vis their diagnostic peers. They made invidious comparisons between how they and others handled their conditions. I sensed their claims to superiority, but I did not connect them to the moral status of suffering. Only through hearing multiple voices and comparing many tales did these ideas take form. To see these moral issues involved going into a liminal place deep within the experience rather than surveying its surface.

My analysis of suffering developed from a grounded theory study of the body and self. In keeping with the grounded theory method, I wrote memos about my emerging ideas during the data collection (Charmaz, 1995b; Glaser, 1978; Glaser & Strauss, 1967; Strauss, 1987). These early memos focused on the body in illness, not on suffering per se, but they moved me toward developing ideas (and memos) about suffering later. Memo writing is the pivotal intermediate step between coding data and writing the first draft of the analysis. Memo writing helps researchers to define and delineate theoretical categories and to focus further data collection. This analytic step is crucial because it keeps researchers in control of their studies. The following list describes the advantages of memo writing (see also Charmaz, 1995b).

Memo writing helps researchers to

- stop and think about data;
- develop a writer's voice and writing rhythm (Memos can read like letters to a close friend; there is no need for stodgy academic prose.);
- spark ideas to check out in the field setting;
- avoid forcing data into extant theories;
- treat qualitative codes as categories to analyze;
- clarify categories—define them, state their properties, and delineate their conditions, consequences, connections with other categories;
- make explicit comparisons—data with data, category with category, and concept with concept;
- develop fresh ideas, create concepts, and find novel relationships;
- demonstrate connections between categories (e.g., empirical events and social structures, larger groups and the individual, espoused beliefs and actions);

- discover gaps in data collection;
- link data gathering with data analysis and report writing;
- build whole sections of papers and chapters;
- keep involved in research and writing; and
- increase confidence and competence.

The lines between the analytic and writing phases of research blur. Discovery processes and conceptual development proceed into the writing. Researchers may act as if their writing is mere reporting. However, writing is a way of learning and of gaining precision and clarity. Qualitative researchers can find that their arguments and emphases arise in their written drafts rather than in earlier memos and conceptual maps.

Like essayists and storytellers, scientific writers use rhetorical devices, metaphors, and writing strategies to explain their findings to their audiences. We can also adapt writing strategies from fiction writers to improve our craft as long as we remain faithful to our studied experience in the field. I developed the following guidelines for writing research stories.

GUIDELINES FOR ETHNOGRAPHIC WRITING⁶

Pulling the Reader In

The writer

- invites, entices, and involves the reader to stay with the story;
- provides the context of the story or implies what might follow;
- makes implicit or explicit claims from the beginning; and
- reproduces the power of his or her experience.

Re-creating Experiential Mood

The writing

- keeps the reader engaged;
- unifies the scene and tightens the story;
- provides a view of the action or feeling with minimal distractions;
- distills experience to those narrative details that bring the scene to life; and
- gives priority to an effective story over efficient writing (i.e., narrative description).

Adding Surprise

The writer

- shows how unforeseen events pile on each other;
- observes when ordinary rules, values, expectations are discarded;
- provides tension and surprise by recounting a predicament; and
- adds elements of surprise by revealing implicit meanings and rules, assumptions, subtle worldviews, and hidden social processes.

Reconstructing Ethnographic Experience

The writer

- presents images that resemble the experience;
- strives to be faithful to the experience;
- shows readers what he or she wants them to know; and
- does not simply tell readers what is important.

Creating Closure for the Story

The writing

- builds tension;
- makes the entire piece cohere;
- implies the closure from the beginning; and
- moves the reader toward the conclusion through style, imagery, and voice.

The following excerpt was written some years before I delineated the guidelines above. However, I made explicit efforts to preserve the mood of the described experience in my analysis. The analytic emphasis in grounded theory can mute mood and flatten meaning. Thus, building experiential mood into a theoretical treatise requires blending imagery and analysis of the experience. Note how I included the story and then moved on to the analysis. I began with a statement by Ernest Hirsch (1977) of a telling moment that transformed his life. Subsequently, I picked up the rhythm and feeling in his story to re-create its experiential mood in my analysis.⁷

Example: Building Experiential Mood and Theory Into the Narrative⁸

Because of my illness, patients might feel sorry for me, so that I could not have optimal effectiveness as their therapist. . . . This pronouncement came altogether unexpectedly. . . . But I found out that I was simply to finish the psychotherapy cases that I was carrying and that I was then to end my psychotherapeutic activities for good and all. What had been at the center of my professional life was no longer to be even at the periphery. I could not imagine what my professional life, or even just my life, would be like without doing this type of work. (Hirsch, 1977, pp. 71-72)

Significant Events as Turning Points

Relived moments. Retold stories . . . recurring feelings. Significant events echo in memory. Whether validating or wholly disrupting, a significant event reveals images of present or possible self and evokes feelings. Thus, these events mark time and become turning points.

A significant event stands out in memory because it has boundaries, intensity, and emotional force. Furthermore, a significant event captures, demarks, and intensifies feelings. Frequently, those feelings are unhappy ones such as bewilderment, humiliation, shame, betrayal, or loss. The event flames and frames these feelings. The emotional reverberations of a single event echo through the present and future and therefore, however subtly, shade thoughts and feelings about self and alter meanings of time (cf. Denzin, 1984).

Significant events transcend the actors within them and the stage on which they occur. These events are emergent realities, events *sui generis*; they cannot be reduced to component parts (Durkheim, 1951). Thus, a significant event reflects more than a relationship or another's actions. When, where, and how the event occurs and who participates in it contribute to the force of the event and affect its subsequent interpretations. Sorting what the event means and the "correct" feelings to hold about it shapes self-images and self-worth.

A significant event freezes and enlarges a moment in time. Because of inherent or potential meanings of self within the event, people grant obdurate qualities to it. They reify it. To them, the event supersedes past meanings and foretells future selves.

The Reader as Interpreter of the Story

Whether we aim for recapturing experiential mood or for creating novel analyses, readers put our writing to the test. What we intend to accomplish in our works may not be what they learn. Readers come to our stories with their own knowledge, experience, and meanings—including readers who are our colleagues. They have views; they offer interpretations. But do they interpret our works as we might wish? Arthur Frank (1995, p. 99) used the following excerpt from my book to describe what he called "The Chaos Narrative." Nancy Swensen had a life-threatening chronic illness, difficult relationships with her adult children and tenants, continual financial problems, and cared for her mother who has Alzheimer's disease. Nancy stated,

And if I'm trying to get dinner ready and I'm already feeling bad, she's in front of the refrigerator. Then she goes to put her hand on the stove and I got the fire on. And then she's in front of the microwave and then she's in front of the silverware drawer. And—and if I send her out she gets mad at me. And then it's awful. That's when I have a really, a really bad time. (Charmaz, 1991, p. 173)⁹

Frank (1995, pp. 99-100) makes three points about Nancy's statement. First, he points out that it is without narrative sequence—the present is so pressing that the reader does not sense the order of a story. Yet the reader's fears are evoked because we might experience similar misfortunes. Second, Frank sees Nancy's situation as overdetermined; her illness creates and complicates a whole range of life problems. Third, he observes that her syntax and staccato pacing of her words "pecks away at the reader just as Nancy's life pecks away at her" (p. 99). Readers feel chaos and sense that Nancy's life is out of control. Frank caught the urgency that I wished to portray in several of my stories about Nancy. He perceived the mood and noted how having a chaotic life kept Nancy in an endless present where past and future blend.

My concluding advice to qualitative researchers: Try the guidelines above. Adapt them. Write memos—many of them. Aim to recapture lived experience in writing. With a few tools and much effort, our suffering with writing dissipates. Then we can hear our subjects' voices more clearly and understand their tales more completely.

NOTES

1. However, the British use the term and refer to people with illnesses as sufferers (see, e.g., Anderson & Bury, 1988).

2. An analogous experience for those who have not experienced much physical suffering occurs in loss of a relationship through death. The bereaved may not realize how deeply the loss affected them until the sorrow, anger, and self-pity of grief begin to lift. (Of course, they may not realize it at all. When people suffer from physical illness, they likely invoke some reminders—through comparisons with others and self in the past.)

3. Indications of this shift can be seen in Charmaz and Olesen (1997).

4. Sociologists of gender (Connell, 1987; Messner & Sabo, 1995; Sabo & Gordon, 1995) have argued that men view themselves through their independence and measure themselves in hierarchies of men as well as through dominant hierarchical relations with women. If so, it follows that they may enter into competitive relations with professionals for control of their bodies, and they may risk their health and their lives in the process.

5. A person may adopt or create a frame from varied meaningful aspects of his or her life, such as the web of relationships, cultural identity, or a sense of community.

6. For further analysis of these points in ethnographic story writing, see Mitchell and Charmaz (1996). Adapted by permission of Sage Publications.

7. The copy editor changed my final wording about relived moments and recurring feelings without consulting me. My original rendering is included here.

8. Slightly adapted from Charmaz, Kathy. *Good Days, Bad Days: The Self in Chronic Illness and Time*. Copyright ©1991 by Kathleen C. Charmaz. Reprinted by permission of Rutgers University Press.

9. Charmaz, Kathy. *Good Days, Bad Days: The Self in Chronic Illness and Time*. Copyright ©1991 by Kathleen C. Charmaz. Reprinted by permission of Rutgers University Press.

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