

Illness Narratives: Positioned Identities

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Narrative Inquiry: A critical overview

The personal narrative as an object of inquiry in social research has reached a level of popularity few of us would have predicted twenty years ago, when we began analyzing “stories” participants told in research interviews and medical consultations. What accounts for the popularity of the “personal”, and the “narrative” or story of experience? Kristin Langellier (2001a:699) identifies four contemporary U.S. movements: 1) the “narrative turn” in the human sciences away from positivist modes of inquiry; 2) the “memoir boom” in literature and popular culture; 3) the new “identity movements” — emancipation efforts of people of color, women, gays and lesbians, and other marginalized groups; and 4) the burgeoning therapeutic culture—exploration of personal life in therapies of various kinds. I would add to Langellier’s list other post-World War II events: the development of miniature recording technologies, the impact of recorded testimonies of survivors of state-sponsored violence and, in the post-Soviet era, the turn away from class analysis, i.e. Marxian and other macro-structural theory which views class inequality as the central problem. As Langellier writes (2001a: 699-700):

“...diverse sources converge on stories of experience, indicated by the term narrative, and the performance of identity, as indicated by the term personal. Embedded in the lives of the ordinary, the marginalized, and the muted, personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities, and ‘get a life’ by telling and writing their stories.”

My paper focuses on narratives of illness, a genre that has received increased attention over the last 15 years. The illness narrative—a form of case study—emerged in

response to biomedicine's focus on disease, and consequent neglect of patients' embodied experience (Bell 1999, 2000; Langellier 2001b; Mishler 1984). Medical sociologists distinguish between disease (the diagnostic entity) and illness (the way that disease is perceived, enacted, responded to by a person, in relationships with others). In his study of written accounts of illness, Arthur Frank (1995) shows how the ill person resists narrative surrender—the medical chart offers only the official voice. Building on Mishler's (1984) theory about the different (and often competing) voices in a medical consultation, Hydén (1997:49) puts it well: "patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice."

Whatever the issues with personal narrative (and I will turn to these shortly), physicians and other health practitioners are increasingly recognizing the value of narrative for practice and teaching. Recent articles by physicians in the *Annals of Internal Medicine*, one by Abraham Verghese (2001) and another by Rita Charon (2001), articulate how knowledge emerges (otherwise unobtainable) when physicians think about their patients narratively. Cheryl Mattingly (1998) shows how health professionals use narrative thinking to re-vision a patient's life after, for example, a stroke or spinal cord injury. As practitioners are developing narratives about patients, so too are patients and relatives of patients writing narratives about hospital stays (Rier 2000; Weitz 1999), and health researchers are publishing analyses of illness narratives at a fever pitch. In Europe—the U.K. and the Scandinavian countries particularly—narrative-based medicine and nursing research have experimented with "the story" as a mode of interrogating the intersection of patients and practitioners in various health care settings (Hurwitz 2000; Greenhalgh and Hurwitz 1998; Launer 2002; Edvardsson, Rasmussen and Riessman,

forthcoming). The practical importance of the knowledge produced cannot be overestimated: diagnosis is improved, patient satisfaction and adherence rise, and litigation appears to decline as communication improves (Clark and Mishler 1992). As I describe in the two cases below, narratives of illness can provide a corrective to biomedicine's objectification of the body and, instead, embody a human subject with agency and voice.

Narrative approaches are not without their critics, however. Speaking as someone who has been working in the field for many years, even I am becoming uncomfortable with the popularity of the genre—the tyranny of the narrative, as I called it elsewhere (Riessman 1997). To briefly identify some of the critiques: First, some sociologists question the “naturalness” of the personal narrative as a form of meaning making. They ask, in what contexts does personal narrative emerge? What are the social structures that produce particular autobiographical narratives? Zussman (2000:6-7) argues that there are “special” occasions, not part of everyday life, when “we are called on to reflect in systematic and extended ways on who and what we are.” Of course, conversation analysts and others who examine “naturally occurring” stories (told around the dinner table, for example) would disagree—narrative forms are ubiquitous in everyday life, and rules of turn-taking, gaze, and other communicative features have been studied in everyday settings. But there is something different, as Zussman rightly believes, about the *extended* reflections that have come to characterize modern notions of self-hood, called forth on autobiographical occasions: psychotherapy, social work interviews, criminal investigations, and the Oprah Winfrey show! The narratives produced in commercial and state-sponsored therapeutic settings are “broader in scope” and attempt

to account for lives, not merely episodes or events. Certain social structures that involve medical or corporate scrutiny—what Dorothy Smith (1987) calls relations of ruling—generate extended stories. Think, for example, of medical consultations when a practitioner asks “what brings you here today?” or when a prospective employer surveying a resume asks an applicant to “explain the gaps in your work history.” Under conditions when institutional orders are most visible, extended stories are occasioned, even required. There are additional contexts that mandate an extended account of “the self,” and the talk produced takes particular narrative forms. Social movements (such as gay liberation) and self-help organizations call forth particular kinds of stories, and the way they are told has been studied by Ken Plummer (1995) and others. In Alcoholic Anonymous groups, for example, the narrator can take few liberties with her story about drinking and its consequences (Cain 1991). Social structures work on the autobiographical self, and constrain how it may be legitimately constructed.

Besides lack of attention to social structure, narrative has been criticized for lack of attention to historical, class and cultural contexts—the contemporary trend is to over-personalize the personal narrative (Langellier 2001a). Paul Atkinson’s (1997) critique is even stronger: Individual agency has been idealized, rooted in the Western Romantic impulse and its assumptions about the interior self. We have reified the authenticity of biographical experience, replacing ethnographic observation (“deep hanging out”) with single in-depth interviews. As a narrative analyst, I would add that the narrative produced is typically asked to “speak for itself”; language is viewed as a resource, not a topic of inquiry. “Meaning” is assumed to be self-evident, that is, what any competent user of language would find in a story. What the listener/reader brings to her encounter

with a text—theoretical perspective, historical context, and biographical experience—is typically unexamined.

In our therapeutic society (perhaps UK is different than US here), it is no wonder that the “over-personalized” personal narrative has found a congenial—if misguided—home. Stories of illness, in particular, have been stripped of their class and historical bearings. Alan Radley (1989:243) puts it eloquently: “becoming chronically ill does not remove one from society; if anything it amplifies one’s position in it, so that what people adjust *with* is as important a matter as what people attempt to adjust *to*.” Social class and gender, in addition to nationality and race, are the primary determinants of physical and mental health, as medical sociologists have documented for decades. Locating the social in “personal” narratives of illness deserves equal attention.

How can narrative researchers deal with these criticisms? As a beginning we can situate personal narratives in their contexts of production, including historical circumstances. As C. Wright Mills (1959) said long ago, what we call “personal troubles” (e.g. illness) are located in particular times and places. Individuals’ narratives about their troubles are works of history as much as they are about individuals, the social spaces they inhabit, and the societies they live in. We can also locate narratives in the social relations of production, that is, in their class, institutional, and interactional contexts. We can include and interrogate our positions as interviewers and investigators—the audiences for the narrative—using the insights of reader-response theory (Iser, 1978, 1989). And we can go beyond looking primarily at verbal communication.

Several years ago in my graduate seminar on narrative methods, a psychology Ph.D. student, Makiko Duguchi, raised a question that pushed me to think beyond verbal

communication. Speaking from her position as a Japanese-American, she asked how she could include in her transcript of an audiotaped interview (an assignment I gave) her observations about gesture, silence, and the displays of deference her Japanese-American subjects used to communicate with her. She observed that Americans seem to put all their faith in the spoken word. Since the seminar, she has taught me about *ishin denshin*, akin to “tacit understanding”—the ideal communication in which shared understanding occurs, but never spoken. Japanese people do not trust the spoken word: “somehow profound feelings and emotions are more authentic if not said... There is a lot of ambiguity in speech because of Japanese aesthetic of leaving things vague as more genuine, because words never capture the ‘true’ essence” (Deguchi 2003). Radley and Chamberlain (2001) recently articulated the same issue for health research: we need to attend to the presentational features through which illness experiences are reflected, the “displays” of identity, illness and health that can be observed, but are not verbalized in a formal illness narrative. As I look back on narrative research over the past 20 years, I sense we have relied too much on our “holy transcripts.” Mishler (1999:19) says “we speak our identities,” but much remains unspoken, inferred, shown and performed in gesture and association, and in action. What narrators show, without language, constitutes a way of making claims about the self.

My current research attempts to respond to some of these criticisms of narrative studies. It is an effort to locate the contemporary wellspring of work on the illness narrative in a long-standing sociological literature, begun in the UK by Gareth Williams (1984) and Mike Bury (1982), about biographical disruption. Illness (and other life events, such as divorce or infertility), interrupts lives that many individuals assume will

be continuous, ordered, sequential. The interruption of life by a chronic illness must be accounted for, placed in context of the life before and after, at least by Westerners embedded in cultures that privilege modernist notions of a continuous “self.”

In my current work, I am also trying to locate myself explicitly as investigator/interpreter in my representations of the “other”, drawing on the wellspring of work in anthropology on reflexivity. I bring contemporary developments in narrative theory and gender research to my re-interpretive work on the illness narrative, and it is to examples that I now turn (see Riessman [2003] for extended analysis).

Narrative (re)vision

I examine two narratives developed in conversations with two men with multiple sclerosis. I returned to these “accidental cases” (they appeared in my 1990 study of gender and the divorcing process) as part of a new research project on narrative identities. Returning to data one collected in the past with new questions in mind is common in medical research when new knowledge about a disease process emerges. It is less common in social research (Riessman 2002a). Here I bring contemporary theories of masculinity and its performance to my re-interpretation of the illness narratives. I also bring contemporary developments in identity theory, viewing it as a performative act. Analysis shifts from “the told” —the events to which language refers—to “the telling” (Mishler 1995), specifically the narrator’s strategic choices in illness narrative about positioning of characters, audience, and self, and to the listener/reader’s response. I ask, why was the tale told that way? In what kind of a story did the narrator place himself? How did he strategically make identity claims through his narrative performance? What

was the response of the audience, how did she influence the development of the illness narrative, and interpretation of it? How might it be interpreted differently with historicity and social structure in mind?

To illustrate what this angle of analytic vision offers, I analyze and compare two illness narratives.¹ Each man carries a diagnosis of multiple sclerosis, and each performs a version of masculinity that is agentic and positive. Beyond these similarities, the two men could not be more different. An obvious difference I will not dwell on here is stage of the disease.

“Do it now”: Randy’s version of masculinity

At the time of our interview, Randy² was a 38-year-old white academic, who had received his diagnosis 3 years earlier (see Appendix for edited version³). The news of his disease slipped out during a conversation about his divorce. Mid-way into a long meditative response, developed to answer my question about the reasons for his separation, Randy mentioned “the other thing.” After several false starts, he said simply, “I have MS myself.” I was jolted by the revelation. He had no symptoms I could discern. He was vigorous and fit. He described how “it’s kind of a funny disease, the diagnosis goes from possible to probable to certain, so there’s a period of finding out.” The lengthy process of getting a diagnosis—“coping with the uncertainty of the MS”—prompted him to evaluate his life and what he wanted out of it. He decided he didn’t have “time to dally around about things...putting off things for 5 or 10 years like many people do.” He and his wife had discussed separating before he began having symptoms (things in the relationship had “gone flat”). After the diagnosis his mantra became “do it now.” He

initiated change in many areas of his life: he and his wife agreed to separate and begin other relationships, while maintaining their friendship; he decided not to pursue tenure in a teaching university and he began a research career; he traveled to Asia and spent time hiking in remote areas. Traveling to “exotic” regions of the world, “just the experience of traveling alone, it was kind of discovering that I could do it alone...I just feel stronger as a person that I’ve been able to do those things.” As he reasoned, it was all “part of the MS thing, doing things now.” Discovering “strength” by redefining challenge, and the meaning of “strength,” was his response to disease.

I now wonder whether Randy performs a classic masculine tale. As all narrators do, Randy draws on cultural stories to form his personal one, and the “lone hero on the move” is a familiar Western storyline. As Nigel Edley (2002:16) says, the lone hero on the move has many referents in popular culture; it is a “widely available resource for the imaging of masculine selves.” Randy is not quite Clint Eastwood riding off from human connections, but a variant—the lone trekker. As other men in my divorce sample suggest, such leisure activities “vivify breaking away from the confines of domesticity and the breadwinner role” (Riessman 1990a:189).

While drawing from contemporary cultural motifs, Randy’s narrative is also a variant of the classic epic: mortal man endowed with god-like courage, choosing risk in place of safety, defying morbidity, facing danger to discover “strength.” Relationships are muted, even marginalized in Randy’s account. He says “I particularly love traveling alone...I can spend 4 weeks alone and enjoy my own company.” But he turns to company with others in the next breath: “you meet people when you travel alone very easily, rather [than] traveling as a couple.” The wandering hero with intermittent ties,

unencumbered by the constraints of family: a romantic image, I think, that finds its way into the identities of many an ancient and modern man—independent, self-sufficient and determining. But the paradox is palpable: Randy and I both know how fleeting his “strength” and physical independence will probably be.

But how gendered, really, is Randy’s narrative performance? To be sure, ancient woman has no parallel to ancient man—the extended and adventurous travels of Odysseus after the fall of Troy, for example. But contemporary women do have cultural motifs of travel they can draw on to compose their story lines—remember the film “Thelma and Louise?”⁴ I resist a stereotypic masculine reading of Randy’s performance. I can imagine myself enacting his tale; its form may be familiar to women and men who face adversity, refuse to give in, and go on a journey to find strength. “Do it now” is a shared mantra that draws on Western modernist notions of the “self.” And how might one think about Randy’s pull away from committed relationships: Is it one version of masculinity? Is it an aspect of character? Is it an aspect of situation, a way of dealing with illness and (most likely) a premature death? Interpretive questions a health professional might consider.

Continuing our conversation, in a long meditative narrative account, Randy resists stereotypic conceptions of masculinity. First, he spontaneously raises the topic of sexual activity since his divorce, especially the discovery that he was “attractive to members of the opposite sex.” He adds: “I guess I feel more masculine.” I ask, “What do you mean by being more masculine?” He responds with a list of “things that come to mind”: sexual performance, abilities in bed, and attractiveness to women at parties. I get it, and think classic guy stuff. Then Randy says “I’ve also become more comfortable...with my

femininity,” saying he feels freer to do things that are feminine than he would have been when his “masculinity felt more tenuous.” I am totally confused: “What do you mean? The feminine side?” He explains: he feels free to talk personally to others. Again, I think I get it—sex role stuff. Randy then adds “I think I have a component of bi-sexuality to my sexuality...which hasn’t happened yet.” But he says, “sooner or later it will happen” because he’s more “comfortable.” In the past, he says, his “masculinity was threatened by homosexuality,” now he has a “more tangible sense of masculinity.” Twenty years ago I was probably totally confused. I moved quickly to the next question.

Looking back at the interview segment now, there are several ways to think about this interactional sequence. Obviously, it can be analyzed as a classic case of misunderstanding, similar to others in the research interviewing literature (Riessman 1987). The abrupt change of topics at the end, perhaps, reflects my discomfort at the time with the open discussion of bi-sexuality with a male interviewee, a peer who was nearly my age, also divorced. During the 1980s there was questioning in some communities about sexuality and gender identity (the Stonewall protest in New York had occurred 10 years earlier), but my perspective at the time reflected the dominant discourse—gender and sexuality were binary.⁵ Although I moved away from Randy suggesting otherwise, I did hear his strategic choice in the first line of his response about how to organize his experience (“rank order”). With this opening, he positions me as an academic peer; he performs with a specific audience in mind. He does identity work with me, as I do meaning work in my repeated probes (“what do you mean by...”). The resulting co-construction remains abstract—an intellectualized account. The relationship between narrator and audience has influenced the account we produce together.

Trying now to re-interpret Randy's statements about masculinity and bring to bear historical context, there are (at least) three ways to think about the performance of masculinity in the excerpt.⁶ Perhaps Randy was voicing the sex and gender practices of a bi-sexual community, not visible or accessible to a straight researcher. Or perhaps Randy was enacting a common form of "gender-bending"—everyone was doing it—that was unnoticed by academics, until gender theory and queer studies named it in the 1990s. Current readers might be struck by how contemporary his performance of gender is (although his language about it certainly isn't), and how current theory can illuminate it. Recent research on gender identity—one's sense of belonging to either the female or male category—shows that this aspect of identity develops early in life, but is not invariably tied to biological sex, or to gender attribution—what others perceive you to be (Fausto-Sterling 2000; Foucault 1980; Kessler 1998). Randy goes even further by emphasizing both sides of his gender. In the current historical context, he would have postmodernists and social movements on his side, but then—20 years ago when essentializing concepts of gender were dominant within feminist scholarship—I simply did not understand. Randy was not embedded in a set of relationships or community familiar to me—I could not position him—and consequently the illness narrative we produced together remained abstract and distant.

Looking back, I now speculate about the meaning of masculinity and sexuality in the life of a 38-year-old man who is 3 years into an illness career. I wonder: Has medical uncertainty about the probable course of his disease opened up uncertainty about other aspects of his persona, including gender identity and sexuality? Does he wonder how long his body will be able to perform heterosexually? Randy resists the idea of a

continuous essential self, performing instead a multiplicity of selves, a stance that anticipates contemporary research on adult identity: it is neither continuous, coherent, nor universal in its stages (Mishler 1999). Randy speaks of components of identity shifting. Binary categories give way to fluid boundaries. If interpreters insist on constructing a consistent self, and resist the uncertainty Randy performs, the mantra with which he began his meditation on “the MS thing” provides a key—“do it now”: divorce, travel, change careers, explore the boundaries of masculinity and sexuality.⁷

Wanting a job and someone to love: Burt’s version of masculinity

The second man, Burt, was 43 years old when I interviewed him. He was white, had a high school education, and advanced MS. I went to Burt’s home to interview him about his divorce, having obtained his name from court records, and I was surprised when an aging man in a wheelchair answered the door. I wrote in my field notes, “He looked much older than 43 years.” He asked for my help at several points to handle activities of daily living (for example, he could not easily reach his urinal from the wheelchair). I conducted the usual interview, but Burt redirected the conversation at every opportunity to the topic most salient to him: how MS over the previous 8 years had altered his life. Taking charge of the interview early on, he told story after story, each recounting a time since the diagnosis when he had been a responsible husband, father, or worker—a representation of ‘self’ that was the basis of a case study I published many years ago (Riessman, 1990b). Then, I analyzed his construction of a positive identity, how he claimed the status of hero, against all odds—a reading I now view as incomplete.

Similar to other white working-class men, the job had provided a secure masculine identity. Burt had been the breadwinner in a traditional marriage that lasted 21 years. As the disease advanced, his wife left him for another man. Burt had worked for a large well-known company for 20 years. When he got sick, he said with pride “they got me an electric wheelchair”; they also gave him a desk job. He continued to work until he “couldn’t sit for too long in a wheelchair.” Within the first five minutes of the interview he told me he was “planning on going back to work part time.” Sitting across from him, it was hard to imagine. He said he had gone to see his boss several weeks earlier but had been told “things were kind of slow...there was nothing open right now...they would get in touch with [him].” I now wonder if they were putting him off. (I learned after our interview that the plant was downsizing; within a year, another acquired the company, and the plant closed. Thousands of line semi-skilled workers were let go. Unlike executives, these were local people who couldn’t move elsewhere).

I now wonder if Burt wanted to return to work for status, and for human connection—an antidote to the isolated life he described at home. Looking back on my research materials with historical context in mind, I sense Burt’s extreme isolation in a time when the disability rights movement had not yet secured wheelchair access in communities—disability had not yet become politicized. Burt said that “being alone” was his greatest difficulty. A personal care attendant, who helps him with “hygiene...exercises...housecleaning ...food shopping,” is his “closest relationship.” With the attendant’s aid, he is able to get out of the house several times a month only, to play bingo or go to a movie. Otherwise, he watches TV alone. To be sure, the disability movement can accomplish much more, but as I think about Burt’s illness narrative now, I

can imagine how his mobility, at least, might have been greater. Burt's illness narrative (and experience of MS) would have been different in the context of current policies in many settings for wheelchair access.

Because of physical isolation, Burt's social contacts are extremely restricted. He longs for companionship and pines for his former wife: he continues to carry her picture in his wallet and shortly before we talked he had sent her a Mother's Day card, "but she has not responded."

Sometimes I watch a TV show that she liked to watch, 'Love Boat' or something like that. She was always here Saturday night watching it with me. I sit here and I see these things and I feel depressed. Sometimes I hope that she would still be sitting here on the couch.

Other sources of companionship, tied to the marriage, have been lost. Contacts with in-laws have "gone down the drain": "they don't call and they don't even write," and his adult son and daughter have moved out. It is unclear what led to estrangements, especially the relationships with children. Whatever the reasons, the limited possibilities for a public life, and the loneliness of the private sphere, are grimly apparent to me now as I re-examine the research materials. I am reminded of Irv Zola's (1982) meditative narrative about his discovery—an American sociologist with polio—as he did ethnographic research in a village of the disabled in the Netherlands. Extreme social isolation need not accompany polio or multiple sclerosis, except as social arrangements and physical barriers make it so.

Lacking fraternity and community, Burt is institutionalized at home. I now wonder whether he looked to the research relationship as a potential source of

companionship. Musing in the interview about how the younger generation has changed, he reaches out to me—his audience—in a kind of plea for understanding. It was the first of his many attempts to position me as a friend:

Kids today are a lot different than they were in our time. I don't know—I am—I don't know how old you are. In your early forties, too? (I nod). We used to take the kids to the drive-in, something like that, but today-forget it, everything has changed. Now they have to go down to the Cape and spend the weekend down there. You are saying to yourself, "what is going on down there?"

There is a hint of intimacy, even sexuality here—topics Burt returns to many times in our conversation. He describes "growing fond" of a nurse who took care of him during a recent hospitalization:

I wish I could have some kind of real close relation with her, but she is married and has five children. That just about throws everything down the drain. I like the girl very much, she is more my age and I wish I could have some sort of relation with her. I feel something like that. That's what I need, a good woman companion.

He continues:

You know what I mean, you used to sleep with a woman for 21 years and now I'm sleeping in my own bed and there's no one beside me to keep warm, let me put it that way. Nights are cold- something like that. Somebody to hold onto, I miss that.

Burt wants “someone to talk to, you know, someone to love.” Perhaps the research relationship offered a fleeting “woman companion,” someone who listened, gave support, and expressed interest in his life world. Re-examining the transcript now, I see how Burt repeatedly tries to position me in a common world of meaning, sometimes creating openings to do so in the closed-ended question format (used to collect demographic information at the end of the interview):

CR: How often do you attend religious services? Do you attend- [I hand a card with frequency response categories].

B: Never

CR: Never? Not at all, not even on Easter Sunday?

B: Not since I been sick. I watch it on Sunday at 10:30 on TV.

When I can- when I can get somebody to get me up early enough to watch it. Are you Catholic?

CR: I was raised as a Catholic.

B: They have that passionate mass on Sunday at 10:30. Have you ever seen that? Channel 25 has it.

I resist religious positioning, as I resist any promise of a continuing relationship.

As the long interview was ending, I asked another standardized demographic question, this time about income. I learned he had no pension, and was living on meager Social Security disability payments. Burt, resisting the constraints once again of the fixed interview format, inserts a long story that recounts his last day at work several years previously—an association that suggests the huge significance of employment for his masculine identity. In the story he positions himself as the central character in a heroic

drama, with his boss and several doctors as supporting characters. He positions me, his audience, as witness to a moral tale depicting a man who wants to be a workingman.

INTERVIEW EXCERPT

I had told my boss ahead of time that I was goin' to see him [the doctor]. **SCENE 1**
And he said "well, let us know, you know, as soon as you find out so we can get your
wheelchair all, you
know, charged up and fixed up and everything."
So I had seen him [doctor] on a Friday
and I'd called soon as I got back Friday told him [boss] I'd be in that following Monday.
And he said, "oh, it's goin' to be so good to have you back, you've been out of work so
long."

So I went in there [factory] **SCENE 2**
(p) and before I used to be able to stand up in the men's room
you known, and urinate that way
but this one time I took the urinal with me
just in case I couldn't do it.
So I got up, I get in there at 7 o'clock that morning
and at about 9 o'clock I felt like I had to urinate.
And I went over to where I usually go to try to stand up
I couldn't stand up the leg wouldn't hold me.
They have a handicapped stall.
So I went into the handicapped stall to try and use the urinal.
Couldn't use it.
I had the urge that I had to go but nothing was coming out.
So back to my desk I went and I continued working.
And about fifteen or twenty minutes later I get the urge again.
So back to the men's room I go
back to the handicapped stall.
All day long this is happening.
I couldn't move my urine
everything just blocked up.

When I get home I figured well maybe it's because I'm nervous **SCENE 3**
coming back to work the first day on the job.
So I get home (p) I still couldn't go.
So I called my doctor, Dr George
and he said "well, can you get up to [name of hospital]?"
I said, "well, I'm in my pajamas."
He said, "well, I'll send an ambulance."

So they sent an ambulance and brought me up there. **SCENE 4**

And he put a catheter on me
soon as he put that on I think I must have let out maybe two pints.
Everything just went shhhhh.
You know, I felt so relieved.
And he said "well, I'm goin' to keep you in," he says
"I want, I want this uh (p) urinologist to take a look at you."
So it was Dr Lavini
I don't know if you know Dr Lavini he's one of the best around.
He looked at it and said, "we're going to have to operate."
Everything just blocked up.
They had to make the opening larger
so the urine would come out, you know, freely.
So I was in [name of hospital]-

I had gone to work for that *one* day ...

CODA

This poignant narrative about the failure of the masculine body is a classic story in a formal sense.⁸ It moves us: me—the original listener—and you, listeners and readers, perhaps. Looking beyond the events to which the narrative refers, how does the process of storytelling so engage us? Burt claims an identity through the narrative devices of setting, plot, and characters (including dialogue between them); they draw us into his point of view. Performatively, he stages a dramatic representation: the plot moves temporally through the fateful events that transpired on his last day at work. His representation includes discrete scenes: the Friday before (scene 1), Monday, the beginning of the workweek (2), that evening (3), and the final hospital scene. There is characterization: he gives speaking roles to his boss, the two doctors, and himself. Burt positions himself in a moral story about what it means to be a virtuous man. As the interview was ending, he performed his preferred self—responsible worker—not other “selves” he had suggested earlier (e.g. lonely man wanting a woman to love). He sustains a reality, and a preferred identity, displayed inside the narrative performance.

As I muse now about the identity Burt performs in the closing narrative, I am reminded of another character and another scene—Willy Lowman, in Arthur Miller’s *Death of a Salesman*, telling off his corporate employer when he is fired. A salesman for 34 years who was tired and aging, he too wanted to be known as a workingman. The employer, who extracted Willy’s labor for 34 years, took his work identity away. Burt’s corporate employer is not portrayed so harshly, but he also used up the able-bodied man. Nor does Burt confront corporate power, as Willy did: “You can’t eat the orange and throw away the peel [he says]... A man isn’t a piece of fruit.” Thinking now about Burt’s lack of a pension after 21 years with the same employer, learning about downsizing and subsequent closure, I see a vivid instance of how market capitalism and job loss have ravaged American workers. People in management and upper levels of the plant were given employment opportunities and generous benefit packages. Line workers were not. The post-industrial wasteland of the entire Northeastern US, produced in the 1980s by acquisitions and mergers, capital flight and the search for corporate profits, eclipsed the power of working class men, dealing an invisible blow to masculinities defined by factory labor.

Comparison of the Illness Narratives

There are many ways to compare the two illness narratives and I develop several elsewhere (Riessman 2003). Viewed from a biomedical perspective, the men are at contrasting points on an uncertain illness trajectory. Each man resists being a “case” in biomedical terms alone. Each negotiates the balance of healthy and ill aspects of his life. Each actively engages in complex strategies to manage illness, at times creatively

resisting disease designations. Each positions himself in a narrative account as a man with agency and choice, even as there was no choice in getting the disease. Randy and Burt are exemplars of men with a disease that has a downward trajectory, yet they “do” illness in vastly different ways. They illustrate points on a continuum of response—illness experiences. Randy hints that illness offers an opportunity for personal growth. Burt offers a counter-narrative to that (largely North American) storyline.

Illness narrative as a discursive form allows each man to connect strands of his existence: health, illness, self-identity, and the life world. For each, “the illness is articulated and positioned in time and space, and within the framework of a personal biography” (Hydén 1997:56).⁹ But there are critical differences between the two. Burt’s illness narrative pivots on the breakdown of the physical body and, more fundamentally, the breakdown of a social world. He does not reconfigure his thinking as he confronts the biographical disruption of chronic illness (Bury 1982), but engages in a form of biographical reinforcement (Carricaburu and Pierret 1995). The closing narrative segment reinforces prior components of identity (working man) that connect him to a collectivity (other factory workers). “By arranging the illness symptoms and events [on the last day of work] in temporal order and relating them to other events in [his life], a unified context is constructed and coherence is established” (Hydén 1997:56). A fragile coherence, to be sure, but self-positioning in the closing narrative shores up the identity of working man, momentarily eclipsing other “selves” Burt performs in the broader illness narrative—disabled man living in isolation.

Randy’s illness narrative, by contrast, recomposes the life. The diagnosis of MS has called into question his constructed identities as husband and academic, including the

associated life project: getting tenure. The illness narrative allows him to re-imagine identity and a life world, regenerating both. By interpreting illness narratively, he can re-establish a relationship between the “self”, the world, and his body. Illness is cast as an epiphany, a kind of wake up call, which allows him to re-order everyday life. Illness narrative allows him to remake the self-narrative (Hydén 1997).

Not only do the men “do” illness differently, they also “do” gender in vastly different ways. Contrasting versions of masculinity are performed in the illness narratives. As gender theorists now argue, we need to speak about *masculinities* and *femininities*, rather than assuming singular notions about gender (Connell, 1995; Berger, Wallis, and Watson 1995; Edley and Wetherell 1997). Contrary to gender stereotypes about men and relationships, there is variation here: Burt craves connection, whereas Randy keeps enduring emotional ties at bay. Both men emphasize action—doing—but differently. Each is trying to stay active in the face of the disease, Burt with his dogged attempts to return to work and Randy with his trekking. But the centrality of doing paid work for self-identity distinguishes them. Remember, Randy had left his academic job, collected his university-sponsored pension, and was making a transition to part-time research. I did not sense any grand plans for work, but instead a “balanced” life filled with some work, lots of travel to “exotic” lands, new friendships and sexual exploration, until disability hits. In contrast, Burt’s life, which had been structured by a traditional marriage and working class job before MS stopped him in his tracks, had lost both marriage and job. He did not have the resources to begin a new life, nor perhaps the inclination, and there was little community support at the time for a person with his level of disability. Burt could have narrated about new hobbies, the achievements of his adult

children, and other topics, but he didn't. The closing narrative segment he constructs about going to work does not break the frame that structured life before the disease—the centrality of paid work for self-identity. The narrative represents a protagonist who tries to push ahead, doing the things he's always done, retaining a past identity; when he can't, he becomes the suffering victim. Illness "spoils" self-identity (Bell 2000).

Randy, in contrast, narrates about breaking the frame of a previous life (and that life is already more "bendable" because he has role flexibility that Burt lacks). His activity involves shifting the set, freeing his mind of the constraints of the past, and forging a new life based on different principles—self-development and pleasure. He affirms his physical health with trekking. In the context of an encroaching illness, he constructs a "supernormal" social identity (Charmaz 1991). Burt performs the man that was, Randy the man that is becoming.

Both men stand as exemplars of versions of masculinity. Their gendered selves are storied into being through illness narrative. Both tell familiar American cultural tales from the early 1980s—pursue pleasure, do it now (on the one hand) and get to work (on the other). Hanging out in the piazza drinking espresso and talking politics with other men is not part of the cultural plot for either.

Why do the men "do" gender and illness so differently? There are character differences that probably distinguish them, and stage of the disease is clearly important. More important, social structures are deeply embedded in each illness narrative. The contrasting way men bear illness is realized through the body. Drawing on Radley (1989) for insight here, I would say that the men used their bodies in distinctive way in the course of their working lives. Working-class men, like Burt, earn a living by bodily

labor, a body that is “fit for work” displays health. A particular work ethic runs through Burt’s identity performance; his vigorous attempts to return to work (and to the topic of work in our interview) serve to minimize illness and embody the value of a man in his economic world. As Radley says, “There is every reason to return to heavy work (in spite of ‘more informed’ expectations) if, in the labour of one’s body, one can recover the forms of relationship which give meaning to one’s place in the social structure” (Radley 1989:244). Physical identity for Randy, in contrast, is not tied to work but, rather, to self-development, embodied in trekking, travel, and sexual exploration, activities that cultivate the body’s expressive use. In contemporary times, the bodily practices of middle-class, academic men revolve around the gym, not the job. Randy goes further and steps off the treadmill of his university—moving off the tenure track—preferring instead to minimize paid work in his life, and maximize pleasure and self-discovery. He wants distance from instrumental roles, in contrast to Burt who wants to perform tasks that are central to masculinity in his class context. Because the two men are embodied so differently in social class position, their illness narratives take different forms. Social practices and “styles” of response distinguish the two men’s identity performances that, in turn, are located in discourses about the body and the self (Radley 1989). Material conditions and power over space shape the freedom of each man, a comparison that contrasts two sociological theories—the dramaturgical and social structural—which I develop elsewhere (Riessman 2003).

Conclusion

To return to the ideas with which I began, narrative research has been criticized for “over-personalizing” the person narrative, for lack of attention to historical context, the social structures that occasion extended accounts of the “self”, for bleaching research of class relations, and for relying too much on the spoken word, to the neglect of observational methods. I have illustrated, by looking back and re-interpreting two illness narratives, how one narrative researcher has taken these critiques seriously, even in the context of limited, single research interviews. A promising development in narrative studies involves extended collaborative relationships with research participants, and use of photography and videotaping (Bell 2001; Mattingly and Lawlor 2001; Radley and Taylor 2003).

I have argued that gender, class, and historical context matter in the construction and interpretation of illness narratives. The two men’s engagement in the economic world and the resources at the disposal of each made important differences in the scope of lives, and in possibilities for narrating them. Historical context shaped topics that could be introduced into each narrative (e.g. sexuality), audience response, and assumptions about illness itself (e.g. disability inevitably brings social isolation). At the global level, Randy can be the “lone hero on the move” exploring the developing world, while Burt cannot move around his own community without a paid attendant, because of structural conditions—social arrangements that are historically sensitive and class-specific—which are however subject to change.

Through the examples, I provide a glimpse into my current project— “looking back” and re-working narratives I collected long ago, in light of contemporary critiques of narrative and new developments in theory. I emphasize changing conceptions of gender, disability, and the discursive construction of illness identity, which informed my re-readings. I introduce the idea of a “performative self”, which contrasts with the essentialist “self” of my earlier research.

Approaching illness narrative performatively opens up analytic possibilities that are missed with static conceptions of identity, and by essentializing theories that assume the unity of an inner self. Because narrators control the terms of storytelling, they occupy “privileged positions in story worlds of their own creation” (Patterson 2002: 3); the performative approach emphasizes narrative as action, an intentional project (Skultans 2000:9). Individuals negotiate how they want to be known by the stories they develop collaboratively with their audiences, and by their performance of health and illness in social interaction. When ill, individuals do not reveal an essential self as much as they perform a preferred one, selected from the multiplicity of selves or persona that we all switch between as we go about our lives (Harre and van Langenhove 1999:17).

My narrative would not be complete without a homage to Goffman’s use of the dramaturgical metaphor (1959, 1981): social actors’ stage performances of desirable selves to preserve “face” in situations of difficulty, such as chronic illness. Going beyond Goffman, structures of power work their way into what appears to be “simply” talk about lives affected by illness (Sarangi and Roberts 1999).¹⁰ To emphasize the performative is not to suggest that identities are inauthentic, but only that they are situated and accomplished in social interaction. Performances are expressive; they

constitute appeals to an audience, they are “performances-*for* others” (Young 2000:109). Hence the response of the listener (and ultimately the reader) is implicated in the art of narrative (Iser 1978; 1998). I positioned myself as a figure in the illness narratives (as interviewer and audience, and as a current voice asking new questions of them). In all three roles I am interpreter—active and positioned—as we all are when we listen to narrative in professional contexts, construct case presentations, or develop narrative studies of lives.

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APPENDIX: RANDY'S ACCOUNT

The text is edited from four pages of interview transcript. I tried to observe the structure of the account, which is organized into a rank ordering of benefits, in the selection of utterances to delete (marked "..."). Where substantial deletions occur I summarize content (marked "[]"). Other transcription conventions: "-" is a break-off in an utterance; speakers are identified by my initials (CR) and the informant's pseudonym.

CR: What are the greatest benefits that have resulted from your separation?

Randy: Getting close to lots of people...I feel this need to put them [benefits] in rank order...Getting close to lots of people and I started to travel places alone...Discovering that I had the resources to do things ... [describes traveling to several 'exotic' places]... This was part of the MS thing, doing things now...[describes enjoyment of traveling alone]-

CR: Tell me more about that, what is that- discovering that you 'have the resources to do things' alone?

Randy: Oh- To me there's some kind of, oh, strength...[describes trekking in Asia]. I just feel stronger as a person that I've been able to do those things...I can spend 4 weeks alone and enjoy my own company and meet people, because you always meet people when you travel alone, you meet people when you travel alone very easily rather than traveling as a couple...I guess competencies. The last one is- something about the benefits of separation- is becoming somewhat more outgoing in terms of meeting people, somewhat more comfortable with myself. So what I have mentioned, I've mentioned close friendships, travel in terms of personal growth...I feel I've learned more about things—relationships, people...I certainly find that a benefit-

CR: What do you mean by that, "you learned more about-"

Randy: It might be part of getting close to [people]...learning more about people...getting in contact with more people than was ever true when we were married. Doing things- I don't do it often, in fact I've done it very infrequently- but even a thing like a one night stand...[refers to sexual experience before marriage and after separation]. There's been a whole benefit related to that, in terms of masculinity. So sexually I think there's been a lot of change...relationships with members of the opposite sex...I think my feelings of masculinity are certainly- A better way of putting this is that I'm more comfortable with the whole thing about how masculine I am...So I guess I feel more masculine, I guess that's it.

CR: What do you mean by being more masculine?

Randy: Well, the obvious- I'm still with that thing of rank order...Things that come first to mind are sexual performance, abilities in bed and attractiveness, just in a sense of being at a party and other women relating to you as someone sexually attractive. I've also become more comfortable- I guess this has to follow- with my femininity. So I feel

freer now to do things that are feminine or to joke about things like that than I would have when my masculinity- I guess I felt- was more tenuous.

CR: What do you mean? The feminine side?

Randy: I'm certainly freer about talking- that's funny, that's not really femininity- but the first thing I was going to say- I'm freer about talking to people- close people- about that I think I have a component to bi-sexuality to my sexuality and that sooner or later- I haven't- but sooner or later it will happen. I'm not sure though why, if it's there, it hasn't happened yet. But at least I'm freer about talking about it, because I'm more comfortable perhaps with that. My masculinity was threatened by homosexuality [describes loving to cook dinners, expressive movement]. And those are consequences, I guess, of some more tangible sense of masculinity. There are probably others.

CR: [asks next question on interview schedule]

NOTES

¹ I use an expanded definition of illness narrative here, to include speech during the interviews (discrete narrative segments, or stories, and other utterances related to illness and its effects), and unspoken “displays” of illness and health. The definition of illness narrative is the subject of considerable debate, as is the definition of narrative itself (Riessman 2002b).

² “Randy” and “Burt” are pseudonyms.

³ It is questionable whether the text in the Appendix meets even minimal criteria of personal narrative, although there may be brief embedded narrative segments. The response is told primarily in the present tense, not the past, and consequently not organized temporally. As a unit of discourse it has a structure, organized as an elaborated listing of “benefits” (prompted by my initial question) that Randy—the academic—repeatedly tries to “rank order” for me, another academic, who repeatedly interrupts with questions about “meaning.” There is an abstractness to our conversation—two academic talking—that defies easy categorization. As I suggest, my discomfort with (and confusion about) Randy’s sexuality probably affected the “narrative.”

⁴ Films about women on the road exist, but generally do not represent woman as solo traveler. Relational ties are dominant in the genre when women travelers are represented, and in some cases when men are as well (“Easy Rider.”).

⁵ I thank Susan E. Bell for helpful comments here.

⁶ I thank Lars-Christer Hydén for helpful comments here.

⁷ See Riessman (2003) for more on interview with Randy.

⁸ For more on the “classic” uninterrupted bounded story, see Labov (1982), Riessman (1993).

⁹ Good (1994) argues that illness narratives are, by definition, incomplete and ambiguous because the ending is missing, and unknowable: how much deterioration will there be? Will the illness lead to death?

¹⁰ See Riessman (2003) for development of a structural re-reading.