Identity Dilemmas of Chronically Ill Men

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Commentary

This chapter was written by an extremely skilled researcher who has always used grounded theory in her highly regarded work. Dr. Charmaz has also published articles about grounded theory methodology and methods, including her innovative combining of these with a phenomenological approach. She is known for her valuable contributions about people who suffer from chronic illnesses; indeed, she is one of the few sociologists who have directly written about human suffering. In this particular chapter, her focus is on men’s responses to their severe, long, terminal illnesses.

Let us examine the chapter’s style of presentation in terms of the author’s grounded theory analyses. First, note how clearly and early in the chapter she poses several theoretically oriented substantive questions. Then, she mentions directly (really locating for us) the sources and nature of her data, as well as her use of several grounded theory “steps.” The latter consisted of examining

the interviews for gender differences, studying the men's interviews and written accounts for themes, building analytic categories, refining these categories, making comparisons with the women on selected points.

Her analytic and descriptive analysis is simultaneously integrated through discussion of “four major processes in men's experiences of chronic illness.” These are explicitly listed in her introductory remarks and soon mentioned as integrating the analysis. Discussion of each is supplemented with a discussion of comparisons of “preserving a public identity” and “changing a private identity.” This is followed by another short discussion of “strategies for preserving self.” Both discussions are directed at illuminating her principal categories of identity and self (her enduring theoretical interests in her research on experiences with chronic illness). The concluding section of this chapter consists of a brief general “discussion” about male identity and men's responses to their illnesses. The entire chapter incorporates the central emphases of the grounded theory mode of research, emphasis on theoretical formulation, constant and multiple comparisons done for theoretical purposes, and undoubtedly a useful of theoretical sampling. You should particularly note the clarity analysis, signaled not only by the overall presentation, but the systematic clarity of her conceptual classifications, labeling, and ordering within each analytic section. From her other works on grounded theory methods, and in this particular chapter, the variety of labeled concepts, we know that she has used the usual ones (coding, memos, and so on), to produce an admirable theoretical analysis.

Chronic illness frequently comes to men suddenly with immediate intensity, severity, and uncertainty. Because men contract more serious and life-threatening chronic illnesses than women, experiencing illness causes men different identity dilemmas. This paper explores men's identity dilemmas by studying how men experience chronic illnesses and by looking at how assumptions about masculinity affect their identity. The paper explores four major processes: (1) awakening to death after a life-threatening crisis, (2) accommodating to uncertainty as men realize that the crisis has lasting consequences for their lives, (3) defining illness and disability and (4) preserving self to maintain a sense of coherence while experiencing loss and change. The data are derived from forty in-depth formal interviews of twenty men, informal interviews with these men, and an extensive collection of published and unpublished personal accounts. The data were analyzed through the strategies of grounded theory.

Introduction

Chronic illness frequently comes to men suddenly with immediate intensity, severity, and uncertainty. Typically, men contract more serious and life-threatening chronic illnesses than women who experience a higher incidence of degenerative diseases such as arthritis and multiple sclerosis (Conrad, 1987; Verbrugge, 1985, 1989). Hence, men have heart attacks and strokes earlier in life and die significantly more frequently and quickly than women (Verbrugge, 1985). Thus, the suddenness of illness, its intensity, and timing in the life course (usually middle-aged and older) pose special identity dilemmas for men. Identities define, locate, characterize, categorize, and differentiate self from others. Identities develop in stable roles and in emergent situations (Goffman, 1963; Weigert, 1986). Following Hewitt (1989), social identities derive from cultural meanings and community memberships and are conferred upon the person by others. Personal identities define a sense of location, differentiation, continuity, and direction by and in relation to the self. When identities are internalized, they become part of the self-concept. What Turner (1976) defines as the relatively stable, coherent organization of characteristics, evaluations, and sentiments that a person holds about self (cf. Charmaz, 1991; Gecas, 1982).

Identity dilemmas result from losing valued attributes, physical functions, social roles, and personal pursuits through illness and their corresponding valued identities, i.e., positive definitions of self, including socially conferred and personally defined positive identities. These dilemmas include the knotty problems and hard decisions arising as people experience trials, tribulations, and transitions during their illnesses that affect who they are and can become. Serious chronic illness threatens men's taken-for-granted masculine identities and leads to identity dilemmas that can recur again and again. Men's identity dilemmas include the following oppositions: risking activity vs. forced passivity, remaining independent vs. becoming dependent, maintaining dominance vs. becoming subordinate, and preserving a public persona vs. acknowledging private feelings. Whichever direction a man takes has costs. For example, a man may take enormous risks with his health to remain active, independent, and dominant. At each turn, trying to maintain former identities may take more effort while potential social, psychological, and physical losses simultaneously multiply.

To date, the sociological literature has not explicitly addressed the special circumstances that chronically ill men face (see, for example, Charmaz,
1987, 1991; Corbin and Strauss, 1988; Johnson, 1991; Kelleher, 1988; Kleinman, 1988; Strauss, Corbin, Parghaugh, Glaser, Maines, Suescek, and Wiener, 1984). Nor have earlier researchers looked at men's experiences from the standpoint of gender-based conceptions of masculinity. Instead, the literature has largely remained gender-neutral and, thus, not only missed seeing the particular emergent structure of men's experience of chronic illness, but also the identity dilemmas that they confront.

This research is an initial attempt to open the discussion of gender and identity in chronic illness. In my depiction of men's identity dilemmas, I build on earlier analyses of (1) experiencing chronic illness first as an "acute interruption" followed by an "intrusive illness" (Charmaz, 1991) (2) developing narratives of self-change through illness (Frank, 1993) and (3) recapitulating the past (Charmaz, 1991).

"What is it like to be an active, productive man one moment and a patient who faces death the next? What is it like to change one's view of oneself accordingly? Which identity dilemmas does living with continued uncertainty pose for men? How do they handle them? When do they make identity changes? When do they try to preserve a former self?"

This research explores these questions by looking at four major processes in men's experience of chronic illness: (1) awakening to death after a life-threatening crisis, (2) accommodating to uncertainty as men realize that the crisis has lasting consequences, (3) defining illness and disability, and (4) preserving self to maintain a sense of coherence while experiencing loss and change. Here, uncertainty means awareness of imminent or eventual recurrence, degeneration, or death. Although uncertainty has long been a key theme in the chronic illness literature, the focus has been on uncontrollable embarrassing, incapacitating, or painful symptoms and further episodes (cf. Reif, 1975; Schneider and Conrad, 1983; Wiener, 1975). By also studying men with potentially life-threatening conditions, uncertainty in relation to death in chronic illness becomes explicit.

Methods and Data

This study is part of a larger qualitative research project on the situations and perspectives of people who have chronic illness. The data are derived from forty in-depth formal interviews of twenty men, seven of whom were interviewed more than once, informal interviews, and a collection of personal accounts. For comparative purposes, the analysis also draws upon eighty interviews with chronically ill women. The criteria for being interviewed included: (1) adult status (over twenty-one years of age), (2) a diagnosis of a serious but not terminal chronic illness, (3) a disease with an uncertain course, and (4) effects of illness upon daily life.

Grounded theory methods were used to analyze the data (Charmaz, 1983; 1990; Glaser, 1978; Glaser and Strauss, 1967; Strauss, 1987; Strauss and Corbin, 1990). The steps included: (1) examining the interviews for gender differences, (2) studying men's interviews and written accounts for themes, (3) building analytic categories from men's definitions of and taken-for-granted assumptions about their situations, (4) conducting further interviews to refine these categories, (5) rereading personal accounts from the vantage point of gender issues (e.g., Fiore, 1984; Hirsch, 1977; Hodgins, 1964; Kelly, 1977; Murphy, 1987; Zola, 1982), (6) studying a new set of personal accounts (e.g., Beissel, 1989; Frank, 1991; Zink, 1992), and (7) making comparisons with women on selected key points. The processes in the major themes served to integrate the analysis.

Awakening to Death

Consider this story. A forty-five year old man had had a serious heart attack three years before while cycling. Being a competitive cyclist had complemented and extended his identities as a hard-driving, no-nonsense businessman, a former military man, and the traditional breadwinner and head of his household. These masculine identities—male athlete, competitive businessman, Viet Nam veteran, and breadwinner—formed the boundaries and content of his self-concept. A business failure just before his heart attack forced his wife to go to work. After his heart attack, his doctor prescribed a rigorous cardiac rehabilitation program. Without my asking, he mentioned, "I didn't know who I was for a while. I'd kind of [think], 'God, if I can do this exercise, I'll die again,' [he saw doing strenuous exercise as risking death]. How to identify?" I asked, "How did you come to identify yourself?" He said:

Well, what's the alternative? If death is on the one end or do you want repeated heart attacks? We had one of our friends in the group [cardiac rehabilitation] who was in there for the second heart attack and he lasted two and a half years and he's my age but he let himself go—back to smoking and drinking and bad eating habits.
So there is—I’ve heard this before—you get this invulnerable feeling—this invincible feeling and all of a sudden the hardest thing to accept is, “Hey, you are vulnerable. You can be hurt. You can die.” You know, which you never thought of that before, or I never did. So that’s still in the back of your mind.

Like other men who participated in cardiac rehabilitation programs, this man had gained a sense of leaving death behind, and regained a feeling of moving on with his life. But reminders of the fragility of life come more frequently and forcefully, as occurred with the sudden death of his friend.

Death. The first identity dilemma comes when men realize that death could occur—now. Chasing to former identities in hope of minimizing the threat of death could risk their lives. Acknowledging the threat of death could cost them their most valued identities. When wholly unanticipated, the threat of death shakes men to their very core. Within moments or brief hours, the disruptive crisis removes them from familiar former identities to that of patient, possibly of dying patient. Crisis can overtake them without earlier warnings. Even illnesses like diabetes or cancer may not become manifest until a crisis. Occasionally, like the athlete above, another man’s crisis awakens or reawakens a man to his own vulnerability, aging, and death (cf. Karp, 1988).

Some men invoke gender-based reasoning such as the male midlife crisis (Jaques, 1965; Levinson et al., 1978; Sabo, 1990) to account for what happens to them even as illness develops. One man believed he was having a midlife crisis—that his life was falling apart. “There’s a point I was thinking, ‘This is a midlife crisis; this is just a state, or this is a stage you’re going through.’” Later, his doctor told him that his aorta was literally ripping apart.

Awakening to death comes as an unbelievable shock when a man (1) sees himself as too young to die, (2) defines himself as exceptionally healthy, or (3) has had no earlier episodes or heralding symptoms. A young clinical psychologist, Neil A. Fiore, (1984) sought help for what he believed was an infection on his testicle only to find the physician talking “calcification,” “surgery,” “cancer,” “death.” When younger men have heart attacks, particularly the first one, they often do not know what is happening to them (cf. Cowie, 1976; Frank, 1991; Johnson, 1991). The athlete above recounted his heart attack at age 42. “I was on my bicycle going on just a routine ride for me and . . . I just went down. I didn’t know what happened. . . . So I had no indication that I [was having a heart attack]—no chest pains, no shortness of breath, no typical [symptoms of] how you feel. I couldn’t even tell you what it feels like.” This man awoke in the hospital to find himself to be partly paralyzed. The paralysis did not faze him but he became furious when his doctor told him that he had had a heart attack. When I asked him what raised his fury, he juxtaposed the futility of heart disease with the injustice of having paid his dues already by stopping smoking, limiting drinking, getting in shape, and losing weight. All this work and then, the biggest injustice, “It’s just I’m too young. . . . Why me?”

Once these men realized or were told what had happened, identity dilemmas emerged. When men believed that they had narrowly survived their crisis, at least at first they assumed it meant vulnerability. A greatly increased risk of dying. A radically altered life. A substantially foreshortened future? Death? Now real and perhaps soon. At this point, they connected death with personal identity. Several men made statements like these: “I know that I am mortal.” “We all know we are going to die, but when you come close to death, you see it is true.” “I am not immune to death.”

The prospect of immediate death darkens the present and shades the future. While in crisis, men see living and dying as discrete categories. Their sense of betrayal by their bodies evokes anger, self-pity, and envy of the healthy. Once certain futures now look uncertain, even ended. Though premature death now seems possible, these men remain unaware of lasting illness and disability if they are unfamiliar with their diagnoses, their disease process, and other men who have the same condition (cf. Charmaz, 1991).

When men define awakening to death as only a discrete, immediate event, they limit the critical period to the initial crisis. Like Speedling’s (1982) men who had heart attacks, these men initially saw getting through this crisis as the passage to an unchanged future. Several men who had bypass surgery or other circulatory procedures questioned whether they should participate in a study of experiencing chronic illness. They believed their surgery had effected the necessary repairs. For them, not only the threat of death was over, but also the illness. A referral to my study, especially if by their nurse, undermined their construction of illness as an acute episode.

Eventually, men’s routine interactions and unforeseen daily obstacles turn early glimmers of awareness into growing consciousness that illness remains. They learn lessons in chronicity during everyday routines that have become much more arduous and time-consuming than before. For example, mowing the lawn or simply getting himself bathed, groomed, fed, and dressed for the day can overwhelm a man who has had a heart attack or stroke. Lessons
chronicity can challenge men’s assumptions about male mastery and competence, thereby leading them into depression (cf. Dahlberg and Jaffee, 1977; Hodgins, 1964). Treating illness and its consequences as problems to solve is consistent with men’s gender-related behavior (Tannen, 1990). Inability to solve these problems undermines their personal identity. A forty-five-year old man with heart disease disclosed that for six months, “I thought my life was over. Cardiac Cripple.”

The identity issues emerging in awakening to death are not limited to men, but they are imbedded in the medical diagnoses these men received and the social conditions they experienced. Women responded similarly when they found themselves facing unanticipated life-threatening crises. However, women, even heart patients, reported much more difficulty in getting physicians to view their symptoms as real. Despite severe symptoms, these women suffered disruption without a legitimizing diagnosis. Subsequently, practitioners, relatives, and the women themselves wondered if they fabricated their symptoms. Hence, these women met serious diagnoses with relief (cf. Charmaz, 1991). In contrast, men who had crises acknowledged their symptoms but initially glossed over their meaning and present or potential seriousness. Further, they seldom had trouble in getting practitioners to attend to their developing symptoms.

What mitigates the overwhelming implications of awakening to death for identity? When might a man gain through having a crisis?

Awakening to death can result in direct, positive consequences for identity. Not only do moments of crisis crystallize when defined and met with a spouse or partner, so also do identities. During crisis and its immediate aftermath, most married men felt tremendous affirmation of their valued identities in the family as they awakened to death (cf. Johnson, 1991; Speedling, 1982). They received an outpouring of care, comfort, and love from their wives and families. These men often bragged about how supportive and helpful their wives had been. Even men who had had troubled marriages felt that their wives affirmed, valued, and supported them. Statements like these were common: “Patty was really great through the whole thing.” “Marge was right there every minute; she even stayed at the hospital those first few nights.” To these men, their wives had provided the essence of “being there” for them. They were vigilant, attentive, helpful, advocates, and loving companions throughout the crisis. The women provided their mates with a continuing link to both past and future identity through the intensity of their involvement in the present.

Thus, these men received identity validation, or confirmation of positive social identifications and private definitions of self. More than affirming men’s personal identity and worth, this identity validation also implicitly affirmed their gender identities as men in the household. Paradoxically, that validation came when they were most physically dependent but derived from their central positions as husbands (which also validates the wife or partner’s identity and role as helpmate and caregiver).

Identity supports to provide validation for single and divorced men, however, usually were much less available. They weathered crises largely on their own. Here, their situations resembled those of single women who often had to fend for themselves during crises and within the health care system. Older widowed and divorced women, however, typically received more caring and comfort from adult children than their male counterparts. The occasional exception occurred when divorced men’s first wives, or gay men’s friends, gave them care and support through their crises. (The few gay men with whom I talked did not currently have love relationships.) Generally, if single men had no caring children or close friends, they were particularly bereft. Thus, constructing a personally valued, and socially validated, identity became more problematic for them than for those who had access to families.

accommodating to uncertainty

In which ways do men define and handle uncertainty? A casual observer might find that men often accommodate to uncertainty by ignoring, minimizing, or glossing over it. But what do such actions mean to men who do so? Their way of accommodating to uncertainty assumes “bracketing” (Husserl, 1970) the event which elicited it. Bracketing means setting apart this event by putting a frame around it and treating it as something separate and removed from the flow of life. The impact of the event upon identity lessens when this event is separated from social and personal identity. Through bracketing, men define uncertainty as having boundaries—those limited to crises. Such bracketing coincides with medical definitions when both patient and practitioner use the same measures. For example, when a man has a successful surgery and treatment for cancer, both he and his physician may bracket the earlier uncertainty and limit it to the duration of the five-year survival rate. Conversely, the patient’s bracketing conflicts with the physician when they invoke different measures. To the extent that men put boundaries on uncertainty and
limit it to flare-ups and crises, they avoid letting it permeate their thoughts and alter their identities. Thus, bracketing raises identity dilemmas because it poses maintaining past identity at cost to health against taking illness into account at risk to social and personal identity.

Bracketing reduces awareness of uncertainty. But why might men who remain at least partly aware of continued uncertainty not make the prescribed lifestyle changes because of it? First, these men cannot envision themselves as dead, and may see themselves as risk-takers and winners. Second, their earlier habits merge with their conception of masculine identity. Third, they have lost hope of genuinely affecting change and decide to live on their own terms for whatever time they have left. In each case, they usually do not foresee the possible kind or degree of disability and debility. Rather, they see themselves as remaining the same or as dead. Yet men can use uncertainty to retain power and privilege in their homes. Then, wives who cajole and try to control them get responses like this one: "Why should I care what I eat? I'm going to die anyway." Fertile grounds for marital strife develop in each case (cf. Peyrot, McMurty, and Hedges, 1988). Subsequently, identity dilemmas arise when spouses disagree on bracketing or acknowledging uncertainty.

Eventually most men realize that their bodies have changed. Subsequently, they become aware of uncertainty—uncertain episodes, uncertain treatment effects, uncertain complications—an uncertain life. Awakening to death and acknowledging continued uncertainty is sobering. Reappraisals follow. These reappraisals can lead to epiphanies marking major turning points for men and their families (cf. Charmaz, 1991; Denzin, 1989; Gordon, 1990). When men acknowledge continued uncertainty, their reappraisals bring reflection and self-appraisal. Men who had attended much more to work than to their families decided to devote more time to them. Men who described themselves as driven by their "Type A" behavior believed that they had to relinquish it before it killed them. The man above who had viewed himself as a cardiac cripple for six months saw his heart attack quite differently two years later. He said, "I would say, 'Thank you, thank you,' type of thing. But you know, had it not been for my heart attack—I'm grateful it happened now, 'cause it changed my life considerably and so I have a lack of words to describe it. Yeah, I thank my heart attack for that. In one way I'm grateful.”

Reappraisals of productivity, achievement, relationships all altered what these men defined as valuable. Their forced reappraisals led to setting priorities, making decisions, and also, coming to terms with their pasts and presents.

A middle-aged executive regretted his behavior in his first two marriages and resolved to maintain his third. These appraisals lead to assessments of self and identity. The middle-aged attorney reflected:

When you are on the brink, so to speak, you begin to look at what things in your life are valuable and which aren’t. And you begin to—and one of the things is real clear was I was glad that I did work where I tried to help other people rather than having a garage full of Mercedes. And it made me feel not like a saint, or anything, but it made me feel like not a bad person, not even like I was a good person. But I was alright. I was alright.

A resolve to live in the present frequently follows these initial reappraisals. The man above said, "I reflect on the past, leave the sadness and parts of myself that I don’t consider functional anymore and try to live in the present." A young man believed that his earlier struggles to sift through and to sort out the past had kept him from attending to the immediate present and from knowing himself within it.

For young men, reappraisal can open paths to self-discovery. Getting a kidney transplant and being released from thrice-weekly dialysis treatments resulted in reappraisal by the young man above. At that point, he suddenly had much more unstructured time. He reflected, "And part of it is getting used to myself. . . Getting used to myself; yeah, two words, because I didn’t really have that much time to find out who I was before. I’d get glimpses now and then, and I would, ‘Oh, you,’ or ‘Yeah, far out,’ you know, or ‘Maybe,’ . . . [I] caught a lot of those [glimpses]."

Not uncommonly, men will be shaken by the initial crisis then gradually resume normal lives. Concurrently, they normalize their symptoms and regimen if they follow one. But before they resettle into a normal routine, they reevaluate their lives and their actions.

After awakening to death and defining uncertainty, lifestyles, and also habits, rapidly change—at least for a while. Men quit working, change jobs, renegotiate their work assignments, or retire early. They follow a regimen, lose weight, stop smoking, and reduce drinking. Making permanent changes, however, means acknowledging uncertainty and treating its consequences as lasting. Several men with diabetes disclosed that they hadn't attended to their conditions until shocked by a diabetic crisis. One middle-aged manager previously had ignored his diet, his doctor's warnings, and his wife's nagging. After a harrowing struggle against death followed by loss of his foot, he not
only acknowledged his own uncertain future, but also tried to instruct unaware relatives and friends about the negative consequences of their lifestyles... "because, look what happened to me."

As young men grow older, their accommodations to uncertainty can form the foundation of their identities. As he looked back on having been a diabetic for more than two decades, a professor viewed his regimen not only as the means of reducing uncertainty by staving off further complications but, moreover, as the way he identified himself. He reflected:

I would not want to have to be preoccupied with it [diabetes] the way I was the first year or so. Ah, but at the same time, it is the ground of my life. I have no idea who I would be, in a way if I hadn't become diabetic... Just to have to internalize this regime must have made a great difference to my personality, I think... I was a person who didn't eat unless someone sort of sat him down. And I like to drink and drink and sometimes got quite intoxicated. Stay up all night, and not sleep, go days without sleeping. And I've now become the opposite of all that, like a field and ground thing (emphasis mine).

Defining Illness and Disability

As they accommodate to uncertainty, how do men define their conditions? How do these definitions affect their personal identity? These men viewed their conditions in four major ways: an enemy, an ally, an intrusive presence and an opportunity. At different points in time, a man may hold each definition. Similarly, he may view his physical condition as the enemy but the treatment as an ally. Hence, his definitions reflect and simultaneously shape narratives of knowing self through illness (Frank, 1993; Herzlich and Pierret, 1987) and thus can result in raising or resolving identity dilemmas. Definitions of enemies and allies both explicitly create personifications. However, viewing one's illness as an enemy objectifies and externalizes it and thus distances and separates it from at least personal, if not also, social identity (cf. Goffman, 1961, 1963). Viewing illness as an ally emphasizes subjectivity and identification with it and thus, integrates it with personal and, if disclosed, social identity.

Changing definitions and revising the stories that frame them reveal new identifications. Yet these definitions are not always stories of self-change as Frank (1993) describes. Rather, definitions of illness as an enemy typically testify to a man's continuity of self. Here, the narrative framing of the man's definition proclaims that he remains the same though his body and situation may have changed.

Definitions of the illness spread to specific symptoms, treatments, and even to the body itself. A young man who had defined the dialysis machine as an enemy tried to make an ally of his new kidney transplant, which his body began to reject. To him, the transplant meant a direct route to his preferred identity as an involved graduate student. He said, "Rejection is a very scary time... a very scary time because you have all these hopes and then the kidney—your body is saying, 'Well, I don't agree with you, you don't need—this isn't your kidney.' And you're saying, 'Well, agree with me, this is [my kidney]'—and you get into conversations. I got into conversations with my kidney and my body."

Images of enemies and allies are present, although sometimes implicit, in the competitive discourse of victories and losses that middle-aged and younger men frequently invoke when talking about their illnesses. Norman Cousins (1983) titles his chapter on dealing with his heart attack, "Counterattack." Lee Foster (1978, p. 526) states, "The record for longevity on a kidney machine, the last time I checked, was thirteen years, and if I stay on dialysis I aim to break the record.

Arnold R. Beisser (1989), a psychiatrist who became quadriplegic due to poliomyelitis, took a similar stance toward his disability:

When I became disabled, I even tried to turn my disability into a competitive sport. I did everything possible to deny the cripple in me. I had no use for him, and no place in my concept of myself for disability. Much of what I have written here has been about my search to find something of worth in that image of the cripple, something with which I could identify without regret. (p. 80)

Beisser wrote his book at age sixty-two; he became ill at twenty-seven. Visible disabilities such as Beisser's wheelchair use result in social identifications that cause or complicate problems in self-definition. If so, definitions of illness and disability as an intrusive presence are likely to follow. Anthropologist Robert F. Murphy had had a productive career before a benign tumor left him progressively paralyzed. He (1987, p. 104) comments:

From the time I first took to the wheelchair up to the present, the fact that I am physically disabled has been in the background of my conscious thoughts. Busy though I might be with other matters and problems, it lingers as a shadow in the corner of my mind, waiting, ready to come out at any moment to fill my meditations.
It is a Presence. I too, had acquired an embattled identity, a sense of who and what I was that was no longer dominated by my past attributes, but rather by my physical defects.

Murphy’s wheelchair use permeated his consciousness of self, as well as others’ consciousness of him, and symbolized his loss of power. Other meanings and symbols emerge when the context and situation are different. When first ill, Beisser (1989) lay flat on his back for a year. He recalled when he first sat in a wheelchair, “I felt as though my power had been restored. I had far greater difficulty in breathing, and it lasted only three or four minutes. But who cared! It was position that counted, and I associated this one with being able to take care of myself” (p. 24).

Visible disability typically becomes a master status and a master identity. It is a master status because this position overrides and subsumes others; it is a master identity because it defines every other identity. Beisser later experienced rudeness, stigma, invaded space, and loss of privacy because of his disability, which raised and reinforced identity issues. Like Beisser, several of my middle-aged and younger interviewees took years to reconcile the identity dilemmas that illness thrust upon them. Older working-class men were resigned to their situations and rebuilt lives around illness. Middle-class men sought to make illness and disability meaningful, to recast them into something through which positive identification could be made. Their quest resembled that of the younger and middle-aged women respondents (both middle- and working-class) but these women ordinarily articulated their concerns more directly and arrived at positive conclusions more readily. Nonetheless, by seeking to make illness meaningful, these men changed their definition from illness as an enemy or an intrusive presence to an experience with positive consequences. The professor above first received his diagnosis while he had a diabetic crisis and nearly died. Afterwards, he viewed both his body and his illness as enemies who were trying to kill him. But over the years, his definition changed, “It’s [his illness] an enemy that I’ve made an ally of. Really, I don’t think I’d still be here, if I hadn’t been diabetic. It’s like the paradox of the return of the prodigal son. It kicked me out of Eden alright, having to, you know, be on my best behavior so much and think about when to shoot up and all that. But it was what I needed.”

From this vantage point, this man’s awareness grew of how central being diabetic was to his sense of identity. He remarked, “Probably if I were less narcissistic and obsessive, I would be a poorer diabetic. It’s sort of like diabetes and me, we were made for each other.”

By making illness an ally, men can use it as an opportunity for reflection and change. Arthur Frank (1991, p. 1) refers to illness explicitly as “an opportunity, though a dangerous one.” He writes, “Illness takes away parts of your life, but in doing so it gives you the opportunity to change the life you will lead, as opposed to living out the one you have simply accumulated over the years” (p. 1).

Whether men treat their conditions as enemies, allies, intrusions, or opportunities, their definitions are seldom mutually exclusive or static. That is, a man who sees illness as an ally because it led him to set priorities can still see it as an intrusive, even ominous presence in his life. Similarly, a man can treat his illness as an ally for a number of years only to redefine it as an increasingly intrusive presence if it steadily limits his activities. Which definition holds sway depends upon the context and situation, the man’s self-definition, and his responsibilities, actions, values, goals, and plans. As a result, many men appreciate what they learn while ill, but still struggle with preserving defining aspects of self from the past before illness.

Preserving Self

Although certain major identities change such as that of worker to part-time retiree, men with chronic illnesses try to lead normal lives. In doing so, they implicitly, and often explicitly, devote much effort to preserving self— aspects of a self known and valued in the past (see also Charmaz, 1991; Johnson, 1991). Preserving self means maintaining essential qualities, attributes, and identities of this past self that fundamentally shape the self-concept. Thus, ill people relinquish some identities but retain others. By preserving self, men reconcile the identity dilemmas that chronic illness thrusts upon them. Johnson (1991) stresses roles and lifestyles in preserving self, but it means more than that. Rather, preserving self means maintaining a way of being in the world and a way of relating to and knowing self, others, and social worlds. Through preserving self, men maintain continuity throughout the past, present, and future. After he qualified for a disability benefit, Ernest Hirsch (1977), a clinical psychologist with multiple sclerosis, still maintained continuity with the past and forged a future. He retained valued identities through
remaining in the same organization, community, and close friendships. His former employer provided him with free office space and clerical help to enable him to do research and writing. Despite earlier worries about losing his masculinity and independence, he managed to preserve essential qualities of self although he endured profound physical and social losses. He writes, "Whatever changes have occurred in me do not touch the core of my 'self,' which has remained pretty much the same. As far as other people are concerned, I think I've remained much as always. Although I realize some changes have occurred, I feel a continuity with the past and have no difficulty recognizing myself as myself, and neither does anyone else" (pp. 169-170).

As men come to terms with illness and disability, they preserve self by limiting encroachments from illness in their lives and controlling definitions of their illness and any disability, as suggested above. They also intensify control over their lives when they can and develop strategies that minimize the visibility and intrusiveness of illness which I discuss briefly below. This reconciling of identity dilemmas takes illness into account, whether or not others believe that these men do it in a healthy way.

Recapturing the Past Self

Before men learn these new ways of preserving self, many of them assume that they will recapture the past self, or explicitly aim to do so. Here, they aim to reclaim the same identities, the same lives that they had before illness. Nothing less will do. For these men, their "real" selves are and must be only the past self (Charmaz, 1991; Turner, 1976). They lapse into invalidism and despondency if they cannot recapture their past selves. Jean B. Zink (1992, p. 60), who has long been disabled, now suffers from post-polio syndrome. She compares herself with a male friend.

Identity Dilemmas

Except for women whose diseases caused severe mental impairment, women showed more resilience and resourcefulness than men in preserving aspects of self, even though women were less likely to have spouses to bolster their efforts (see also, LaMaistre, 1985; Lewis, 1985; Prizele, 1985; Register, 1987; Wulf, 1979). Women rarely told their futures to recapturing their past selves.

Trying to recapture the past self does provide strong incentives to fight illness and to stave off death. When men believe in their doctors and in their treatment, their resolve to struggle maintains their hope. If so, then a man assumes that his past self will be preserved when his physician promises marked improvement. A middle-aged father of young sons commented about having cardiac bypass surgery, "I felt—I was going to do everything I did before, otherwise it wasn't worth having the surgery. . . . I wanted to be just the same as before. And, like for these children, it would be really devastating to them if I were to go ahead and say, 'Well, I can't do this because of my heart. I can't do this.'" You know, you don't want to teach your children to be like that.

Attempting to recapture the past self has its pitfalls when all valued social and personal identities remain in an irretrievable past. Being unable to measure up to the past self results in further preoccupation with it, and heightens identity dilemmas. Arnold Beisser (1989, p. 56) recalls how his desire to recapture his past self affected his courtship. "One big thing separated us. I was in love with someone else. That someone else was me. Or rather, my image of what I used to be. My past was my standard and I carried it with me like a Pepsi generation commercial. And, of course, I assumed that everyone else, including Rita, was attracted to that same image."

Drastic lifestyle changes following illness, such as reduced employment, forced retirement, rigid regimens, and broken marriages evoke or collapse former identities entirely, one after another, like dominoes. Simultaneously, despondency about not recapturing the past self increases and renders preserving valued aspects of self more arduous. A middle-aged man with heart disease felt overwhelmed, immobile, and depressed, when he compared his present precarious physical, financial, and marital statuses with his past fitness, financial security, and stable marriage. His fear of another heart attack, combined with his lassitude, led him to withdraw from everyone. He said, "I'd say I hit rock bottom about October, November last year. I got to where I don't care what happens to me, you know; I don't care what happens to anybody."
The distance increases between a man’s past self, by now reconstructed in memory in idealized form, and present identities, as valued former identities collapse and new ones are viewed as negative. With each identity loss from chronic illness, preserving valued past “masculine” identities becomes more difficult. Not surprisingly then, Brooks and Matson (1982) found that the self-concepts of men with multiple sclerosis changed more negatively over time than those of women. Men draw upon the existing cultural logic that currently defines masculinity as they try to make sense of their altered selves and situations (cf. Denzin, 1991). When sexual performance forms the foundation of their conception of masculinity, impotency undermines their identities as men. Preserving a past identity becomes particularly problematic when the basis for that identity is lost. After his heart attack, the man above was financially devastated. Subsequent crises put more responsibility on his wife to get a full-time job, as his identity as the wage-earner rapidly eroded. He said, “She was fine throughout that [the financial crisis]—she didn’t work [before then]; she worked part-time; now she’s working full-time. So yeah, she blamed me for that, me being the provider and that type of thing. That hurts me too, you know.”

Under these conditions, illness becomes the symbol of identities lost and the reason why attempts to preserve self flounder. This man explained, “This is the worst year of my life. In one month I lost health, a career. In a year I lost my capital; I almost lost my marriage—you could almost say that year I lost my marriage. My oldest daughter moved.”

Problematic health strains an already strained marriage. It also strains a stable marriage when erosion of valued identities continues. Like retirement, chronic illness allows men who cut back or leave work to become new critics of their wives’ and children’s activities. Loss of control outside of the home leads to efforts to preserve self by exerting more control within it. To the extent that a man takes for granted that masculinity is imbedded in power, the more likely he will tighten his control within the household as access to other arenas decreases. For example, as a retired bartender became house-bound, his scrutiny of his wife’s day increased and he became more critical and controlling. She could incur his wrath by failing to anticipate or to satisfy his dictates about the smallest household or personal care task. Such men want to be in control. Illness marginalizes their sense of masculinity (cf. Connell, 1987; Mossner and Sabo, 1990;). They cannot accept physical dependence, except, perhaps, upon wives. The demeaning nature of seeking help, being evaluated (“his doctor found out he was smoking again and read him the riot act”), of living on new—much less on someone else’s—terms does not come easily. Rather than give up old habits, these men may flaunt them. If they cannot control their health, they may try to control someone else’s response. To do this, they will take risks—often many of them and, likely, cast their wives and physicians into the role of adversaries to put out. In this way, they maintain their assumed status in the hierarchy of men and simultaneously, exert dominance over women (cf. Sabo, 1992). At this point, they also risk being identified as obstreperous, unmotivated, and mentally unstable by their practitioners (cf. Albrecht, 1992; Ploog, 1986).

Dependency strains relationships and plays havoc with identity. But identity develops and is maintained through interaction. Partners often find themselves in an elaborate dance around dependency. Wives and partners may find themselves anxiously trying to protect shreds of their husbands’ former identities while feeling overwhelmed by the escalating demands placed upon them (see, for example, Lear, 1980; Strong, 1988).

These wives and partners provide pivotal identity supports for their husbands that mate the identifying effects of dependency and loss. As illness and disability persist and progress, identity supports dwindle for men in troubled marriages and for single men (cf. Hirsch, 1977). Several single men who became ill in their twenties lost their families of origin through death and divorce. By their thirties, they had become quite isolated. For example, one thirty-eight-year old man with multiple sclerosis had markedly deteriorated during the past five years. His parents divorced during his childhood; his father died long ago, and his mother remarried a man in another state and could not afford to visit him. His move to the West Coast at eighteen had weakened his ties with his siblings who did not travel. By the time he became bedridden, his mother’s occasional letters provided his only family contact. Like isolated elders, his main support came from a volunteer. After many life and death crises, he felt disconnected from the world and from almost everyone. He said of his illness: “It’s everlasting. It’s perpetual, and it just goes on and on and on, and it doesn’t stop. . . . I don’t think of death as gloomy; I see it as a release. I was wishing so much for it. And now it doesn’t scare me at all, at all. But I wish and I wonder when it will happen.”

This man disclaimed the self he witnessed in illness. To him, it was not worth preserving. When talking about his teen-aged years, his present immobility contrasted strikingly with his past activity. He said in wonder, “You know, I could do anything I needed to do. Like baseball, or football, or basketball. You know I did all those things—swimming. Now it’s no more.”
For him, the halcyon days of healthy youth remained in a faded past. But for others, the disparity between past and present identity enveloped the immediate present and foretold the future. A young man whose kidney transplant was failing questioned the value of living on the dialysis machine. The middle-aged attorney above discovered that his condition was far more serious and complicated than he had initially thought and probably had resulted in minimal brain damage. Another surgery became necessary but his health had deteriorated too much to risk doing it. Losses accrued. No stamina for backpacking. Memory losses canceled work. Social Security denied him a disability benefit. A legal victory against Social Security still did not result in processing his benefit. His doctor refused his pleas for more painkillers and less blood pressure medication. The side effects kept him groggy and uncomfortable. He attempted to control his medical care by firing his doctor. Despondent and unable to function as in the past, he said, “I don’t do anything but sleep now.” Six months later, he hung himself in the room that had come to be his bedroom, office, and sanctuary.

These three men saw their lives shrinking and their chances for creating valued identities diminishing. Under these conditions, they each saw suicide as a reasonable way of resolving the identity dilemmas in which they found themselves. In contrast, possibilities for expanding identities foster hope and support desire to stave off disability and death. The self to be preserved is a developing self, ripe with the potential for new, positive identities. For example, one man had recently won an award in his field which brought him substantial recognition and travel, in addition to renewed friendships. For him, the world was opening up to him, not closing down upon him. Quite spontaneously, he disclosed, “I don’t want to die. I’m just a baby, a fifty-two-year-old baby boy. I’m just starting. I don’t want to die.”

Preserving a Public Identity. Changing a Private Identity

Some men claim public identities that reframe their pasts and demonstrate continuity with that past. They minimize the effects of chronic illness on their public persona by offering a public narrative of their lives in which chronic illness plays a minor or post role. To keep this narrative credible, they may have to devote vast amounts of energy to keeping illness contained and disability invisible or less obvious (cf. Charmaz, 1991). Their efforts are founded on assumptions of preserving masculinity. A man struggled to use crutches for far longer than his condition permitted because he wanted to remain in the “manly” position of being on his feet, rather than in a wheelchair. A man with diabetes could not manage both his wheelchair and a tray in the cafeteria. He could not bring himself to ask his co-workers for help and skipped lunch. He risked a coma rather than request help.

Simultaneously, men may maximize the significance of illness and disability in their private identity. At home, the identities derived from illness and disability engulf them and may engulf the entire household. Roger Ressmeyer (1983) revealed that he involved himself in unwise relationships because he needed a partner’s support and back-up work. Ironically, the independent public man can transform himself into a dependent patient at home. This stance allows the tyranny of the sickroom, promotes self-pity, and encourages physical dependence. Even when men do not become overly dependent, wives add hours to their day as they manage or collaborate in care by preparing special diets, assisting in bathing, dressing, grooming, completing the daily medical regimen, and providing rides (cf. Corbin and Strauss, 1984; Gerhardt and Brieskorn-Zink, 1986).

Strategies for Preserving Self

Whether or not a complete disjuncture exists between the public and private identities, most men tried to mute the effects of illness on socializing or working. They drew upon both taken-for-granted actions and explicit strategies to preserve their earlier selves and thus, maintain or recreate public and private identities. Their strategies involve careful considerations of timing, pacing, and staging to maintain appearances to others, and often, to self. Wives and partners are often collaborators in preserving self, as well as in care (cf. Corbin and Strauss, 1984, 1988).

When they needed to keep working, men attended closely to ways they could quite literally preserve themselves to do so. These men planned and managed their appearance because looking sick could cost them their bosses’ confidence, co-workers’ support, or even their jobs. When they felt that they would be disadvantaged in their hierarchy of men, they told no one that they had a serious illness (see also, Ressmeyer, 1983), avoided disclosing further episodes, or minimized their significance. When their co-workers demeaned them or complained that illness brought them special privileges, ill men came to view them as competitors or management spies. One middle-aged man with renal failure worked in a maintenance crew for the county. His crimes of thirty years turned against him for receiving less strenuous tasks for a few months
after he had a heart attack. This man decided not to be beaten by his co-workers’ attitudes and kept his job. But he refused his supervisor’s offers to reassign him to prove that he could still do the strenuous work.7

Being able control the logistics for doing work, as well as the amount and type of work itself, allows men to preserve their work and themselves, including their assumptions about masculinity. Part of that control rests on also being able to control other people and the definition of the situation. An executive masked leaving the office early for his dialysis treatments by “attending meetings out of the office.” Not even his secretary knew he was a dialysis patient. He believed that knowledge of his illness in the business community would reduce his stature as an aggressive competitor in the hierarchy of businessmen (cf. Sabo, 1992). A salesman completed his sales calls in the morning when he felt and looked fresher, and did paperwork at home in the afternoons when he could take rest breaks. A professor referred questions to several bright students when he felt short of breath. An administrator moved his office to a wing closer to the parking lot. In all these cases, controlling time, pace, space, information, and people gave these men more control over ensuring interaction, impression-management, and identity.

How do men preserve self when they cannot exert this type of control? Their embarrassment about visible markers of illness results in avoiding encounters beyond their inner circles. The executive above maintained a policy of not socializing with business associates. By not attending cocktail or swim parties, he hid his restricted diet and his dialysis shunt. A craftsman with emphysema hid how hard walking had become. He lagged behind anyone who might observe him struggling to climb a few stairs. Later, as his coughing and spitting fractured ordinary conversation, he refused social invitations and reduced his work to a few projects that he could complete alone at home.

Not everyone assumes that illness and disability will become melded with identity. Some men remain strikingly resourceful in finding ways to remain vitaly involved and simultaneously to avoid having a stigmatized identity. Wheelchair use, for example, can give rise to developing a host of clever strategies for preserving self. One man arrived at social events early to position himself in an opportune location to see and greet friends. He found that people treated him as a commanding man when seated across from him but did not when they towered over him. When others were seated, he could position his body more forcefully in ways associated with manliness (Connell, 1983; Whitson, 1990). Such strategies preserve self as known in the past and, moreover, preserve assumptions about masculinity.

Discussion

Traditional assumptions of male identity, including an active, problem-solving stance, emphasis on personal power and autonomy, and bravery in the face of danger form a two-edged sword for men in chronic illness. On the one hand, these assumptions encourage men to take risks, to be active, and to try to recover, which certainly can prompt recreating a valued life after serious episodes of illness and therefore bolster self-esteem. On the other hand, these assumptions narrow the range of credible male behaviors for those who subscribe to them. Hence, they foster rigidity in stance and set the conditions for slipping into depression. Men’s assumed difference between masculine identity and the “lessor” identities of women and children shrink as they lose ordinary “masculinizing practices” (Connell et al., 1982; Whitson, 1990).

Thus, an uneasy tension exists between valued identities and disparaged, that is, denigrated or shameful, ones. A man can gain a strengthened identity through experiencing illness or can suffer a diminished one. These are not mutually exclusive categories. Men often move back and forth depending on their situations and their perceptions of them. The grieving process in men may be negated or cause those who witness it such discomfort that they cannot give comfort. Men may express their grieving in tears and rage as well as in tears and sorrow. But for many men who experience progressive illness and disability, grieving, instead of being a process, sinks into becoming a permanent depression. Life becomes struggling to live while waiting to die.

What are the conditions that shape whether a man will reconstruct a positive identity or sink into depression? Certainly, whether or not a man defines having future possibilities makes an enormous difference. The men in my study primarily focused on their preferred identities in action. Subsequently, if they could define no valued realm of action available to them and no way to preserve a valued self, the likelihood that they would slip into depression increased.

A final point: A more exacting look at the differential experience of men and women who suffer from serious chronic illnesses will deepen sociological and professional understandings of how they make sense of their lives. As the research in chronic illness grows, studying men and women comparatively in conjunction with marital, age, and social class statuses in addition to the type of illness can substantially reframe sociological interpretations of the narratives of chronically ill people.
Acknowledgments

A version of this article was presented at the annual meetings of the Society for the Study of Social Problems in Pittsburgh, August 18-20, 1992. I am indebted to Candee Nagle, Norman K. Denzin, David F. Gordon, Mark Mikkelson, Don Sabo, and three anonymous reviewers for their comments on an earlier draft. I thank David F. Gordon and Don Sabo for encouraging me to work in this area.

Notes

1. Chronic illness means experiencing ongoing or intermittent, recurrent, irreversible, and often degenerative symptoms of a disease process (cf. Freund and McGuire, 1991). It focuses on what it means to have a disease, not on objective medical definitions, and addresses two of Conway's (1975) subtypes of chronic illness: "lived with illnesses" (e.g., multiple sclerosis, chronic fatigue syndrome, renal failure, diabetes, post-polio syndromes), which force adapting without immediate life threat, and those "mortal illnesses" (e.g., heart attack, stroke, cancer) that sufferer view as life-threatening and that have lasting consequences whether or not they (1) know about these consequences and (2) experience immediate symptoms.

2. When I first met the men, their ages ranged as follows: three below forty, six between forty and fifty-four, four between fifty and sixty, five between sixty and seventy, and the remaining two men were seventy-three and eighty-five. Ten men worked at least part-time; others had retired or were too ill to work. Their social class statuses include: eight men were working class or poor, six were middle class, and four were upper-middle class. Ten men were married. Status attributes of the one-half of the sample with whom I kept in touch (5-8 years) changed slightly over time (e.g., financial and marital).

3. Structured interviews elicited respondents' views of and feelings about their conditions, their course and implications, and effects on daily life (e.g., regimen, limitations, symptom control). These interviews frequently elicited disclosures that the men had not made to family or friends. For guidelines on intensive interviewing, see Lofland and Lofland (1984) and Silverman (1991).

4. Also, men report fewer illnesses and doctors' visits than women; men may not seek early care or routine checks that might result in detecting crises (Freund and McGuire, 1991; Nathanson, 1989; Verbrugge, 1980; Verbrugge and Wingard, 1997; Waldron, 1976). Some men misattribute conditions like diabetes or high blood pressure until they become crises.

5. Note that I refer to "initiated crises" here. A man who becomes identified as a trouble-shake, crack, mental illness, mental incompetence, or an alcoholic will be hard-pressed to have his symptoms and views of treatment taken seriously (cf. Albrecht, 1992; Leidnerman and Grisso, 1985; Millman, 1996, Morgan, 1986).

6. Despite working-class jobs permitting little flexibility, middle-class jobs, in contrast, allow more control over timing, scheduling, pacing, and using space during work. Kotabe (1983) suggests that working-class labors may be relatively uncritical about staying on the job because they can net 80% of their pay if they can claim a job-related disability. Ten years later, many working-class jobs are without access to benefits and even if they are available, workers are hard-pressed to prove that their illness or disability is job-related. Thus, workers try to remain in their jobs.

References


