Kathy Charmaz

Loss of self: a fundamental form of suffering in the chronically ill

Abstract   Physical pain, psychological distress and the deleterious effects of
medical procedures all cause the chronically ill to suffer as they experi-
ence their illnesses. However, a narrow medicalized view of suffering,
solely defined as physical discomfort, ignores or minimizes the broader
significance of the suffering experienced by debilitated chronically ill
adults. A fundamental form of that suffering is the loss of self in
chronically ill persons who observe their former self-images crumbling
away without the simultaneous development of equally valued new
ones. As a result of their illnesses, these individuals suffer from (1)
leading restricted lives, (2) experiencing social isolation, (3) being
discredited and (4) burdening others. Each of these four sources of
suffering is analysed in relation to its effects on the consciousness of
the ill person. The data are drawn from a qualitative study of 57
chronically ill persons with varied diagnoses.

Introduction

Physical pain, psychological distress, and the deleterious effects of
medical procedures all cause the chronically ill to suffer as they experi-
ence their illnesses. However, a narrow medicalized view of suffering,
as solely defined as physical discomfort, ignores or minimizes the
broader significance of the suffering experienced by debilitated chronic-
ally ill adults. The nature of that suffering is, I contend, the *loss of self*
felt by many persons with chronic illnesses.

Chronically ill persons frequently experience a crumbling away of
their former self-images without simultaneous development of equally
valued new ones. The experiences and meanings upon which these ill
persons had built former positive self-images are no longer available to
them. Such losses are most marked at the onset of a serious, debilitating
illness or at points when ill persons define former actions, lives and
selves as now precluded by illness. Over time, accumulated loss of
formerly sustaining self-images without new ones results in a diminished
self-concept.

Serious chronic illness also results in spiralling consequences such as

loss of productive function, financial crises, family strain, stigma, and a restricted existence. Over time, many debilitated chronically ill persons become dependent and immobilized. As they suffer losses of self from the consequences of chronic illness and experience diminished control over their lives and their futures, affected individuals commonly not only lose self-esteem, but even self-identity. Hence, suffering such losses results in a diminished self.

In part, I believe, suffering of this sort derives from the 'American Way' of illness.[1] The combination of payment plans, patient–practitioner relationships, cultural beliefs and medical ideologies produces an unwieldy and inflexible framework for thinking, acting and feeling about illness. Practitioners usually treat those with chronic illnesses within a framework of care designed for those with acute illnesses, however inappropriate that framework is. Treating chronic illness within the acute care framework results in fragmented care, incomplete information, overburdened caregivers and isolated individuals left to handle the spiralling problems caused by illness as best they can. The traditional American emphasis on independence, privacy and family autonomy is still evident in the management of chronic illness.[2,3] Although Americans believe that families should be allowed to handle illness of a member in their own way, in fact, serious chronic illness generally proves to be an overwhelming strain on the family unit.[4] Both the framework of care and the American values perpetuate an ideology which, in turn, perpetuates the current system of medical care.[5]

More importantly for present purposes, many ill persons themselves hold ideologies about living with chronic illness, which reveal residuals of the Protestant Ethic.[6,7] They predicate their ideologies on values of independence, hard work and individual responsibility, even though they may not espouse these values in other areas of their lives. Chronic illness becomes the arena in which these values are played out. Maintaining a 'normal' life or returning to one becomes the symbol of a valued self. Under these conditions, chronically ill persons not only view dependency as negative, but also often blame themselves for it.

With such values, the chronically ill question their own self-worth and view their developing limitations as losses. In addition, others generally view the chronically ill through the framework of acute care with its assumption of illness as causing temporary disruptions of self rather than causing continued losses of self. Hence, others' realization of their suffering tends to be absent, limited or minimized.

In this paper, I aim to show how suffering undermines the self and which social psychological conditions contribute to that suffering. Because suffering loss of self develops out of daily life, I analyse its

major sources discovered in the lives of chronically ill persons. These include *living a restricted life, existing in social isolation, experiencing discredited definitions of self* and *becoming a burden.* Each will be treated below. A discussion of the implications of suffering among the chronically ill follows.

Theoretical framework

The following analysis draws upon a symbolic interactionist perspective. In keeping with that perspective I assume that the self is fundamentally social in nature. That is, the self is developed and maintained through social relations. Because of the social nature of the self, socialization is a lifelong process. Due to its fundamental assumptions about the nature of the self, the symbolic interactionist perspective permits examining the ways in which changes in self-concept occur throughout the life cycle. Consistent with this approach, I examine how illness as an experience shapes situations in which the person learns new definitions of self and often relinquishes old ones. Experiencing illness is a social psychological process in which the inner dialogue between the I and the me changes and definitions of experience change.[8,9] The ill individual draws upon past social experiences, cultural meanings and knowledge to engage in a mental dialogue about the meanings of present physical and social existence, specifically, the emergent indications of identity elicited by illness.

Serious chronic illness provides a unique area in which to study the self because self-concern typically becomes so visible. Moreover, ill persons often become highly aware of previously taken-for-granted aspects of self because they are altered or gone.

When I speak of self-concept, I mean the *organization* of attributes that have become consistent over time. Organization is the key to understanding the self. Though the self is organized into a structure, ordinarily that structure ultimately depends on processes to sustain it. In other words, for most individuals, maintaining the organization of the self — that is, self-concept — means empirical validation in daily life. What happens then when images of self reflected to ill persons by others are inconsistent with their core self-concepts? What happens when the ill person's present self-images are wholly incompatible with that individual's criteria for possessing a valued self?

These questions become even more significant in the light of the structure of intimate relations. As Parsons and Fox pointed out, American families are not well structured to handle the strain of caring for an ill member, especially the mother.[10] Paradoxically, serious chronic

illness frequently demands caring from others. American institutions largely fail to offer alternatives to intimates, except the drastic measure of removal of the ill person from the home. It is this context in which the individual confronts and lives with his or her emerging concept of self as a chronically ill person.

Methods and data

This study draws on initial data and analysis from a larger work on relationships between the chronically ill person's experience of time and construction of personal identity, which has been supplemented by further research. Generally, a symbolic interactionist perspective informed the data collection and analysis; specifically, I followed the strategies of grounded theory as outlined by Glaser and Strauss in the analysis.[11,12,13]

The data are drawn from 73 in-depth interviews with 57 chronically ill persons in Northern California who have various diagnoses such as cardiovascular disease, diabetes, cancer, multiple sclerosis, lupus erythematosus and so forth. For present purposes, I have limited the data to interviewees whose illnesses were believed to be severely debilitating and/or who were housebound. Because most chronically ill people remain at home, I usually talked with people in their own homes. Interviews were obtained through referrals from several hospital clinics, a private physician and informally through the recommendations of nurses and colleagues. Several additional interviews were conducted with practitioners and family members. Names have been changed to protect the respondents' anonymity.

Interviewees varied in age, income and type of illness. The age range was from 20 to 86 years, with the largest proportion ranging from 40 to 60 years. Approximately 50 per cent of the persons were middle class in occupation and income. Several had been upper middle class earlier when able to work, but were forced to curtail their lifestyles because of the costs of their illnesses. Ten interviewees currently maintained upper middle class lifestyles; the remaining lived marginally on low-income or welfare budgets. Because more referrals were made to women, two-thirds of the respondents were women.

Sources of suffering loss of self

The sources of suffering loss of self among the chronically ill develop out of the conditions and content of experiencing illness. Further,

experiencing debilitating illness poses questions about, if not a direct assault upon, the self. The sources of suffering are experientially mixed categories. Being discredited, for example, may lead to adopting a more restricted life. In turn, a restricted life leads to fewer opportunities for constructing a valued self. Reciprocal effects are visible too. Living a restricted life causes social isolation and social isolation leads someone to live a restricted existence, both of which limit possibilities for positive validation of self. In the section that follows, I delineate each source of suffering and discuss the ways it produces loss of self. These sources all lead to losses of control and action, the typical foundations on which Americans construct their sense of self.

Living a restricted life

The homebound chronically ill live narrowed, restricted lives, which contrast sharply with the lives of other adults, who have more possibilities for constructing valued selves. Their illnesses become the focus of their lives as treatment regimens, periods of discomfort, medical appointments and the problematics of mundane activities structure and fill their days.

Values of independence and individualism combine to intensify the immobilizing effects of chronic illness. These chronically ill persons become aware that they cannot do the things they valued and enjoyed in the past, or if they are fortunate enough to be able to participate on some level, that level is apt to be much diminished from that of the past.[14] As long as an individual feels that he or she exercises *choice* in valued activities and some *freedom* of action to pursue these choices, everyday life does not seem so restrictive, suffering is reduced, and self-images are maintained.[15] For example, a businessman commented that he still took lengthy walks with his wife, an activity both enjoyed, though he had reduced other activities such as social engagements with business contacts. Several single women remarked that having a car and retaining a valid driver's licence allowed them to view themselves as independent. Driving offered proof that their lives were not entirely restricted because they believed themselves to have freedom and choice even though they could not always exercise it. Conversely, knowing that one can no longer drive or function in other ways that symbolized independence prompts the realization that life is becoming increasingly restricted as previous taken-for-granted activities become precluded. Though she was seldom well enough to drive, one woman's observation illustrates the symbols of independence, choice and mobility afforded by driving. She observed:

> Just knowing that the car is in the garage and I can use it if I want to or have to

gives me a great deal of comfort. Why, I don't think I have driven it in six months, but knowing it is there helps me to feel independent.

Tangible (direct) restrictions become daily reminders of the lessened freedom and, often, diminished self, that these patients experience. Some patients, such as those on kidney dialysis, experience concrete, daily reminders of their restrictions; they frequently feel their treatments govern their lives.[16] The loss of self felt by several patients with advanced renal failure results not only from the intrusiveness of their treatments in their daily lives, but also derives from the knowledge that they are dependent upon the machine to live. One young man revealed his view of the restrictions imposed by dialysis in the following way:

> This [the dialysis machine] is an ego destroyer. You come, and you're depend-ing on a machine to keep you going, and if you don't, then you don't go. I mean that's all there is to it . . . .
> I know that sometimes I feel less than human, having to go through the process. And I would like to take a vacation from it for 2, 3 or 4 weeks and not have to come for that length of time. That's all, I'm not asking that much, just 4 weeks, you know, and then come back, and I'll be ok, but I can't do that. Traveling is very hard, getting away and just normal things that people do. *And so it makes me think from time to time that I'm less than human, and again I work my way out of that, but it is just a constant struggle to* [do so]. [Emphasis mine.]

Loss of control from life restrictions typically results in losses of self. Such life restrictions sometimes derive from the deleterious effects of treatment. The restrictiveness of their lives with subsequent loss of self was concretely and directly felt by several men who experienced treatment-produced sexual impotence.[17] They questioned the relative value of treatment against the losses it induced. Several women found themselves to be as debilitated from their medications as they were from their diseases. As they experienced the spiralling problems caused by conditions brought on by their treatment (usually high dosages of steroids), they suffered a loss of control over themselves and their lives. The ways in which they had known themselves in the past became increasingly remote as present experience differs from the past, particu-larly when dependency characterizes the present.

Restricted lives are sometimes set into motion by professional practices. Not all patients are given sufficient information and treatment to reduce their suffering losses of self. When they rely on information from one practitioner or one perspective, they main remain unaware of possibilities that could increase their participation in life. A man whose medical treatment for myasthenia gravis and peripheral neuropathy failed to include rehabilitation measures exclaimed:

I lost three years and just became immobilized at home because I thought that's what you should do if you wanted to live at all with something like this. If I had just known what a few gadgets and a little exercise therapy could do for a person like me.

Some patients occasionally view the losses that other patients suffer. Their observations cause them to evaluate information and treatment for themselves. A woman who was receiving the latest medication rejected it after observing the debilitated condition of another female patient at the clinic who had followed the regimen for several years. The patient she observed became a living symbol of who and what she herself could become by following the prescribed, and potentially dangerous, regimen. This patient said incredulously, 'She [the other patient] was having a lot of strange symptoms, and I just looked at her and I realized that she was dying . . . it just went through my head this lady is dying from the drugs that they are giving her.'

The lives of the chronically ill are sometimes more restricted than they need to be. The world is set up for the healthy and able, a fact the ill and disabled usually do not question. Hence, they judge themselves and who and what they should be by yardsticks applied to the healthy and able. In that way, they contribute to the restrictiveness of their own lives.[18] For example, it does not occur to a man with a back problem to get up during a movie and walk around for a bit because he cannot sit for several hours straight. It does not occur to a middle-aged worker to take additional rest breaks so he can keep his job. It does not occur to an elderly woman to consider sharing her small house with another person so that someone can give her the minimal assistance she needs to live at home.

The unpredictable course of many chronic illnesses fosters uncertainty and fear, and as a result, some patients voluntarily restrict their lives more than need be. The unpredictability sometimes consists of lengthy episodes of illness followed by periods of relative remission. Or, unpredictability can have a much narrower time frame and consist of 'good days and bad days' or even intermittent 'bad spells' during the day. But due to their unpredictable conditions, these patients suffer disruptions of their lives and selves that go far beyond the physical discomfort they experience. Such disruptions include the felt necessity of quitting work, limiting social engagements, and avoiding activity. While they aim to protect their lives, they may do so at great costs to their self-images.

The situation of an elderly woman, whose chronic illnesses included a heart condition, illustrates self-imposed restrictions. She felt it unwise to be any distance from her doctor so she stopped travelling. She

believed that she needed to reduce stress so she stopped driving, except for occasional short errands. She thought that she might be vulnerable to break-ins so she moved to an apartment with a security entrance. She decided that her dog was too much trouble so she did not replace him after he died. Although she simplified her lifestyle, she did so at the cost of increased loneliness and boredom.[19,20] According to her son, she subsequently focused more intensely on each apparent and each potential symptom.

The greater the loss of control and the amount of potential embarrassment from the unpredictable illness, the more likely that individual's self-concept suffers and he or she will restrict his or her life voluntarily.[21,22] For example, an elderly woman, although alert and steady on her feet, eliminated all outings as she became incontinent. She whispered to me,

> I just can't go out anymore, dear; it's the bladder and you know how embarrassing not being able to control your bladder is. For a while, I tried to control it by timing my liquids and keeping on a strict schedule but it didn't help very much, so I just don't go out anymore, not even to church.

While some voluntarily restrict their lives, others are forced to as they experience the spiralling problems elicited by their illness. Foremost among these problems is the financial burden that chronic illness so often places on an individual or family. When fortunate enough to work, ill persons frequently feel they have to restrict all other activities in order to manage their jobs. But when forced to leave work, they usually just live marginally and leave their prior social worlds entirely. Under these conditions, they suffer a loss of friends and often drastically alter their lifestyles. For example, a change of residence can foster increasing social isolation and a loss of prior self-image.

Most importantly, living a restricted life fosters an all-consuming retreat into illness.[23,24] Ill persons' restricted lives led to constricted concerns.[25] Under these conditions, illness structures their world and shapes their self-concepts. One young man became terrified of swallowing after he almost choked to death on his daily time capsule. His panic increased to the point that his life revolved around swallowing his pill each morning. From then on, he liquidized everything he ate and even so, he was afraid to eat. He recounted:

> My life became so restricted that it revolved around getting that time capsule down. That's all I could think about . . . . What I was thinking about was getting that damn pill down each morning, then the rest of the day took care of itself, even though I was phobic about swallowing.

The combination of tangible restrictions and physical debility causes the chronically ill to experience stress and frustration and also

significantly, fosters an encompassing concern with self. A young man remarked that handling the dialysis treatments and its after-effects 'requires a lot more being on top of what's going on than with normal people, that it adds an extra burden of junk into your life'. Another man on dialysis described himself as a 'captive of the machine.'[26]

Friends and relatives also observe the ill person's consuming thoughts about self and illness. One woman described her father's interests now as limited to his heart and the TV set though he once had lively professional and avocational interests. The sister of a young woman with anorexia nervosa who had been appreciated for her wit, beauty and perceptiveness offered this interpretation of her sister's present life:

> It is like her world is tunneled from here to there [points from her body to the floor], down to where the number points on the scale. I told her that's just a really narrowed version of what your life is all about. You know your life is not your weight and it is not a magical number on a scale and is not going to magically change when a certain number on the scale is reached.

In contrast, for some persons, particularly those who had lengthy episodes of serious illness in the past but later improved, such periods became the foundation for re-evaluation and change of self. These individuals spoke of earlier crises as periods of time when they were free from the ordinary bonds of routine existence. That freedom heightened their consciousness of who they were and who they wished to become. For these people, illness became a tool of self-discovery and a fundamental source of later self-development. Those who currently were seriously debilitated and still in the throes of multiple crises, however, were much less positive about their experience of illness.

Social isolation

Since selves ordinarily are situated in networks of social relationship, social isolation typically fosters loss of self. Social isolation is a major consequence of a restricted life. Lack of participation in work alone resulted in social isolation for most of those interviewed. Few had intimate relationships beyond those developed through work and family. Earlier friendships usually waned as ill persons no longer shared the same social worlds.

When ill persons are no longer able to participate in shared activities such as work, community organizations, or shared leisure pursuits, e.g. sports or games, visitors must come to them, and such visits require extra time and effort on the part of the visitor. Past reciprocity becomes altered and the chronically ill are left behind. The inattentiveness of former friends and relatives sometimes shocks ill persons and their

intimates. A middle-aged housebound woman with multiple illnesses had two daughters in the area who she rarely saw and from whom she never received offers of help. Reflecting upon her isolation, she also noted that her close friends from her working days ten years ago had all drifted away. Similarly, a 68-year-old retired professor mentioned that the social network lasting throughout his lengthy career was gone. And the wife of a 69-year-old man whose emphysema and complications are life-threatening said of her stepson:

> He knows the doctor said his father might not live; he could go anytime or he might live as long as two years. He knows that and you know how much he has been over here in three weeks? Fifteen minutes on Sunday morning! *Fifteen minutes*, that's all. And he only lives two miles away. He only came because I called him and said, 'Every day your father gets worse and every day he wonders if you are coming by..'

Experiences of being discredited, embarrassed, ignored and otherwise devalued also contribute to the growing isolation of ill individuals and to their subsequent reappraisals of self.[27] Sometimes such episodes result in these persons' voluntary withdrawal from the scenes in which devaluation is played out, even if they occur primarily in the family living room. When ill persons feel negatively identified, they may begin to experience emotional isolation while remaining in the immediate presence of those who devalue them. For example, a visitor asks the wife of a man whose recent heart attack has immobilized him, 'Has he been a good boy today?' followed by cooing direct questions to him: 'Have you taken all your medications; are you doing what your doctor tells you?' Through tone of voice, the visitor implies that he is now reduced to four-year-old or puppy-dog status. Rather than feeling comforted by such interest, he feels alienated.[28]

Others may have no intent to devalue an ill person and yet he or she drifts into social isolation. Why? A major reason is that the ill person does not have adequate time, energy or concentration to sustain his or her relationships. Reorganizing priorities results in limited time. Because work comes first and exhausts those still able to manage it, they find that they have no energy for other involvements. In addition, simply managing daily maintenance takes longer when fatigue or discomfort is high, when energy is low and when medical procedures and rest take time. One woman used flex-time to go to work early (6.00 a.m.) when she felt her best so that she could rest in the late afternoon and evening when she felt most fatigued. Additionally, ill persons often drift into isolation when removed from earlier social worlds by lengthy hospitalization and convalescence, particularly when former associates have left these worlds by the time they can return. Unless their role in

former social worlds was a central one, my interviewees discovered that each lengthy absence further weakened whatever bonds had existed in the past.

A young man with renal failure described the difficulties he had in maintaining friendships. He observed:

> I used to be very stubborn, and I'd always stick with relationships and stay with them to the bitter end and work things out, and now I find I don't have as much energy for doing that, and it frustrates me at times because I don't want to lose those contacts and those friendships, but yet they want more from me than I am able to give, and so I can't. And I know that when I feel miserable from dialysis, it is a hundred times harder for me to relate to people in a full way. And I slough off, and I don't throw all my energy into dealing with things that are going on in the relationship and that frustrates other people frustrates me.

Spending considerable amounts of time on a medical regimen is isolating. It is isolating because: (1) the experience alone sets the ill person apart from others, (2) treatment usually takes place in the privacy of the home, and (3) it focuses the ill person's attention upon self. Consequently, chronically ill people tend to experience much loneliness, and the experience of loneliness itself is one of suffering.

Social isolation increases as the ill person wears out family and friends. Continuous immersion in illness, whether from crisis or fear, also takes its toll on involved others. When so immersed, the ill person frequently remains unaware of the strain on them. For example, the wife of a cardiac patient complained to him that he was making undue demands on her, which he said he had not realized. A twenty-five-year-old woman with anorexia nervosa was shocked when her mother told her she was tearing the family apart with her constant crises. Strain on intimates intensifies when they believe the ill person contributes to his or her own suffering by getting the illness in the first place (particularly when thought to be psychosomatic), by not seeking more or different professional help, by not following the regimen, or even, in a few cases, by following it. (Diabetics, for example, sometimes report that their diet planning and preparation is a burden on intimates.) In any case, such strain contributes to whether or not currently involved others will maintain their involvement in the future.

The older sister of the young woman with anorexia nervosa related her own inner turmoil over her commitment to her sister and her commitment to her own pre-med. studies. Her sister's constant crises increasingly disrupted her school-work, yet, currently, she was centrally involved since professionals requested that their mother stay out of her sister's life. When reflecting upon her sister and the resulting situations, she said:

I get angry at both, but I do get angry at her [sister]. I get angry because [as if to her sister], 'How many times − (I sound like my mother here) − how many times before you will listen to what is being told to you? Or what has to happen in order for things to sink in so it doesn't have to happen again?' and how many times do I personally have to go through to live my sister's death? And I've a sense of just fuck it, literally, just wanting to wash my hands of the whole situation because she personally, I have a hard time with family because in some ways I am probably the healthiest [she means psychologically] of all of them and yet it is very hard to keep my life up and positive when I am constantly drained, as I see it, because it does take a lot out of me to deal with my sister on the level that she's on, same with my mother, it takes a lot of energy and I do get angry.

The *cause* of *continuous crises*, their *length* of *time* and *degree* of *family relatedness* form three conditions shaping whether or not others provide sustained involvement and, thereby, help to maintain the ill persons's self. The cause of the continuous crises turns primarily on whether others believe the ill person 'created' them or their physical conditions result in them. Not surprisingly, others tolerate crises better when the ill person is not held responsible for them. The length of time of crises figures heavily in sustaining involvement. Generally, ill persons report that family (and often, friends) readily demonstrate their interest, attentiveness and assistance when illness begins. But as it continues, such involvement tends to dwindle to a few members of the immediate family.[29]

Visibility of obvious suffering typically causes friends and acquaintances discomfort since obvious suffering rips away the previously known public, sociable presentation of self, thereby making sociability problematic. In addition, simply maintaining small comforts consumes the consciousness of these ill persons. They find that they can no longer continue to handle even limited social encounters as they had in the past. Hence, the drift into social isolation typically intensifies as the person's condition worsens. For example, two middle-aged women on kidney dialysis developed an unusual rapport. For several years, they had met occasionally for snacks following their treatments. But as her condition worsened, one woman could not sit for more than a few minutes. Because she felt she could not manage being in public places, even her former limited social contacts markedly diminished. A housebound man found that his social contacts became almost toally limited to his wife. Earlier, his yard work had afforded him many short visits from neighbours. After he became housebound, a tacit understanding developed among neighbours that he was not the same person he had been. In both these cases, the ill persons' physical discomfort and seeming apathy subsumed and permeated their

interactions. Subsequently, those present experienced discomfort themselves because each ill person withdrew into suffering.

The loneliness brought on by social isolation is most visible in those chronically ill persons who live alone. Minimal social contacts, such as the visits from an attentive neighbour or a call from a relative, assume tremendous significance. One housebound woman commented that a wave or call from her neighbour was very comforting; such limited contact alone made her isolation bearable. More importantly, it affirmed that her loss of self was not complete; she was still valued as a person with whom a relationship could be shared, even if only a limited one. Similarly, even the most routine appointment may become an 'outing' of significance if it offered the individual sociability while simultaneously breaking his or her daily schedule. A routine check-up by the doctor may become an event looked forward to before and savoured during the encounter.

When a patient lives in social isolation, the relationship shared with the physician may assume extraordinary significance for the kind of self which that patient may possess. That is, the images of self reflected by the physician become the basis of lengthy self-appraisals. A physician who was attuned to his influence said of his lonely, isolated patients, 'They can take my most casual, flippant remark or suggestion as absolute authority, and a direct reflection upon them.' A patient disclosed the influence that the doctor has on a person with chronic illness:

> More than your medications, it's important to have a doctor that understands you as a person. It is hard to accept chronic illness — maybe a person expects it at 65, but they don't at 49. But any doctor who takes an interest in you makes a difference. [She began to relate an incident in the past.] She said, Dr Lang took care of me — he's okay as a surgeon but as a doctor he upset me more than words. You keep going in with the same problem and they stop listening. One time he sat there opening his mail while I was in the office. I said, 'Go ahead and open your mail, I'll wait.' He felt silly, then he listened.

She continued rhetorically:

> You're [the patient] not saying anything that isn't true [to the indifferent physician]. At that time he wanted to freeze the nerves off because of an aneurysm in the aorta to the left leg — I had very little circulation in the left leg — it hurt terrifically. I let it [the pain] go until the doctor's appointment — then to get in there and have this guy keep opening his mail — it's a little too much.

Later, this woman revealed even more explicitly the importance she attributed to the images of self reflected by the physician. She explained:

What I like about Dr Brenton and Dr Kaye is that they treat you like a person
... that is so important when you are ill, to be taken seriously as a person ....
The thing in Dr Kaye and Dr Brenton I found is a humanitarian ... In a person
with chronic disease who has so many things to handle, not only the sickness,
but just living problems – to be treated like a number is the last thing you need.

When ill persons receive positive reflections of self in interaction and
take them as credible and real, they are more apt to regard themselves
positively. But when demeaned and discredited by those to whom they
attach significance – even during the briefest of interactions – then
maintaining a positive self-image becomes problematic.

Discrediting definitions of self

Suffering loss of self among the chronically ill also results from dis-
crediting definitions of self, including: (1) those arising in interaction
with others and (2) those developing out of unmet expectations of the
ill person. Although not all chronically ill persons suffer the visible
impairments readily resulting in stigmatized identities, many suffer
discreditation related to their decreased and now marginal participation
in the normal world.[30,31,32,33,34,35]

Dramatic discrediting occurs during the course of encounters when ill
persons experience public mortification. The images of self mirrored to
these ill persons can be so unexpected or jarring that they shake the
very foundations of their self-concepts. For example, I once accom-
panied an older woman on a shopping trip whose diabetes had resulted
in amputation of her left leg. Since she did not adapt well to her
prosthesis, she chose to use a wheelchair. While we were meandering
through a department store, we caught the attention of a little girl who
gazed steadfastly at my companion with horror and fascination. To the
mortification of the woman, the child shrieked and pointed, 'Look,
Mommy, that lady doesn't have a foot? Doesn't she look awful?'

The child's pronouncement was far more jarring than the usual
awkward incidents that attend disability and wheelchair use. Since the
woman had prided herself on her appearance, the incident called into
question more general definitions of self. In this case, the incident
raised anew questions that she had long put to rest about who she was
in relation to others, how she saw herself and what she could expect
in the future. Because she had accepted her disability, and moreover,
believed herself to be acceptable to others, this encounter was particu-
larly disturbing to her.

Other persons told how they restricted activities rather than face
potential discrediting. A young woman's flare-ups of rheumatoid
arthritis resulted in a slow, laboured gait. Combined with her extra-
ordinarily small stature, she described herself as a ready target for the

curiosity and hostility of children, especially boys. She commented that she hated to go to the grocery store since tiny toughs (8 to 12-year-olds) had beaten her there several times in addition to their frequent jeers and snide comments about her size and slowness. She observed that she limited such trips and had to 'gear myself up' to go to the store. Though not surprised by rude comments and questions, or even by being pushed or hit, she said each occurrence was somewhat jarring, and a little frightening.

Discrediting is not limited to those with visible impairments. A young man's earlier experiences with peers caused him to hide his diabetes. On a more subtle level, another diabetic said that she avoided parties now because she disliked confronting food and alcohol she could not have and, moreover, because she particularly resented being watched and judged by others present.

The significance of the discrediting encounter depends on its *perceived magnitude*, the *relative importance* of *who discredits*, the *situation* in which *discrediting takes place*, and the *amount* of *repetition* of *discrediting events*. The perceived magnitude of the discrediting intensifies when the ill person either feels forced to accept the discredited definitions and/or feels that these definitions further weaken the foundation of an already shaky self.

Clearly, the relative importance of those who discredit the ill person shape that individual's future self-concept. Images of self reflected by intimates are crucial for sustaining or discrediting of self-concept.[36] Because handling serious illness is so stressful, family members themselves also may experience lack of support at a time when demands on them dramatically intensify.[37] Subsequently, they are unable to give positive images of self to the ill person and may even discredit them. Among the most common reasons for discrediting by intimates is failure of the ill person to fulfil their expectations, whether or not these expectations are realistic. These expectations range from sexual activity to household tasks, regimen compliance and companionship. Unrecognized or unaccepted effects of illness often figure in the inability of the ill person to fulfil the expectations of others.[38] Others frequently pressure them to remain functioning as before. Poor motivation, rather than the individual's physical condition, tends to become the defined reason for not functioning normally.[39,40] Hence, others view those ill persons who cannot fulfil their 'obligations' (often obligations with which they concur) in negative terms and blame them for being inattentive or uncaring. Others may even come to believe that the ill person conspires to undermine them by performing poorly, functioning inadequately or relinquishing responsibility for self-maintenance. A middle-aged woman found that her general slowness of movement

and specific slowness in meal preparation resulted in her husband's continual irritation and outbursts. He attributed her slowness as due to her personality and attitude toward him rather than her illness. A young man found that even his girlfriend implicitly demanded his time and attention when he told her he was physically incapable of giving it. She interpreted his incapacity as evidence of his lack of commitment to the relationship and lack of caring for her. A young woman found that her parents viewed her request to return home as an unreasonable demand since during adolescence her relationship with her father had been full of conflict. In each case, these ill persons later interpreted their intimates' responses as an attack upon their sense of self, one that took months or years to heal.

Even when all acknowledge the presence of the illness, conflicts may still arise, for not all may regard it as a reasonable justification for unmet obligations. When someone claims pain, fatigue or other disabling symptoms, he or she may be countered with, 'You are not doing enough; you don't try to push yourself' or 'You are using it as an excuse.'

Supportive intimates, in contrast, usually bolster the ill persons's self, thereby maintaining continuity with the past pre-illness self. I observed one wife of an elderly man with slowed, slurred speech wait patiently while he attempted to answer questions. She never interrupted or attempted to answer for him. Rather, she engaged him in conversation in much the same way she always had. Supportive intimates also are typically in tune with the ill person's nuances of mood, discomfort and symptom. For example, this wife kept a close eye on whether her husband became irritable, restless or inattentive, which indicated need for medication, not personal quirks. Her husband explained with pride, 'She knows what's happening to me better than I know myself'. Similarly, a young woman noted that her mother was even more alert to her fatigue and incoordination than she was. Her mother often protected her from embarrassment in social situations by signalling to her that it was time to leave. Otherwise, she risked spilling food, knocking objects over or even falling, all of which mortified her since unknowing others usually thought she was drunk.

These relatives placed their ill person's behaviour into a perspective revolving around illness and regimen maintenance without themselves feeling diminished by it. In doing so, they minimized discrediting the ill individual and disrupting ongoing relationships. In addition, supportive intimates do lessen the potential for discreditation when they are comforting about the attributes, functions, and actions now lost and when they emphasize the positive aspects of current existence.

Those without supportive intimates are more vulnerable to new and

discrediting definitions, particularly as they observe their former selves crumbling away.[41] Discrediting definitions of self from medical personnel, especially physicians, become increasingly significant for an isolated ill person. Physicians sometimes treat undiagnosed persons with esoteric diseases as severe neurotics whose symptoms are either nonexistent or psychosomatic in origin. In this circumstance, the patients feel unsupported or guilty of having brought their discomfort upon themselves. A young woman, later diagnosed as having lupus erythematosus, recalled one of her earlier hospitalizations. At that time, she had little asistance from friends or family because no one believed that she had a serious condition. She felt others' disbelief indicated that her own feelings and intuitions about her self and experience could not be trusted. She remembered an encounter with one of the hospital interns with whom she had developed a friendly rapport:

> He came back with some tests and . . . we sat down and he just said 'Well, you know we don't show anything, blah, blah, blah,' and I just looked at him and looked at him and I think this was the first time I said something like, 'Do you think I am lying?' or something like that and he just passed it off. In fact, he didn't really want to talk to me about it. I just broke down: I started crying. And I left there and I felt terrible.

Another woman with multiple sclerosis felt that the psychiatrist to whom she had been referred insulted her fundamentalist Christian missionary work and attempted to demean her. In this case, the patient was angry about the attempt to discredit her. After relating the encounter to her other physicians, who were embarrassed by their colleague's behaviour, one doctor said to her, 'Mrs. Baker, he is only a resident and doesn't know very much about the world. We know that you have seen and done a lot.' Whether or not his remarks were as discrediting as she felt, she held her ground on who she was and her value and won support for doing so.

Discrediting definitions are apt to be adopted when: (1) the ill person feels *vulnerable*, (2) the ill person *identifies* with the individual(s) who discredit him or her, and (3) the discrediting *validates* a *hidden fear* or *recasts* the ill person's *self-images* in new unattractive light.

Much discrediting, however, occurs in more subtle ways such as when someone is tacitly devalued or simply discounted. Tacit devaluation occurs in those situations when others simply *assume* that the ill person is not to be given fully human or adult status.[42] The ill person remains unacknowledged as a bona fide participant in the scene. Tacit devaluation becomes evident as negative definitions are implied or suggested, often indirectly or through nonverbal means. During an interview, a husband frequently interrupted his wife who was being interviewed in

the next room; he repeatedly corrected her responses or requested amplification of a point, thereby subtly devaluating her spontaneous responses to the questions. In another interview, the wife monitored her husband's remarks through stern facial expressions and tense, guarded body positioning. Because he suffered a speech impairment, she took the liberty of 'interpreting' his past for him in a manner that undermined his views and simultaneously discredited his ability to respond appropriately.

Perhaps the most ordinary way that discrediting occurs is simply through being discounted. For example, I observed that a wheelchair-bound woman's family subtly excluded her from conversation and ceased to refer to her as 'Barbara' at points when they discussed the logistics of transporting her to events. They treated her as a problem rather than a participant in the ongoing interaction. Being discounted in this way not only indicated her 'real' status in the family to her but also caused her to feel emotional isolation.

When an ill individual is unable to affirm personal significance through action, affirmation of a positive self-image which others accept and honour is problematic. Thus, being regarded as a 'valid' person requires continual struggle. Being an invalid all too often means acceptance of being discounted and devalued.

Because being discounted is closely tied to inability to function in conventional ways, those who believe they acknowledge and flatter the ill one may actually highlight that individual's limitations and thereby discount him or her. Consider the statement of this wheelchair-bound multiple sclerosis patient who sometimes was treated as an angelic child:

I resent people saying, 'Aren't you lucky; you don't have to do anything.' I know some people would love to sit around and do nothing and let others take care of them, but I don't. I resent being treated like a child and having people fussing over me, saying, 'Isn't she an angel?' I am *not* an angel.

When being discounted is a constant threat, individuals often feel compelled to negotiate their identities, even with family members. Being discounted may go further into the devaluation continuum. They may feel that they are being defaced as they can no longer perform ordinarily expected activities.

When ill persons realize that significant others do not understand or accept the limitations inherent in their present physical conditions, they feel discounted. If others gauge ill persons' behaviour by conventional yardsticks, then their behaviour is apt to be judged inadequate. Consider this young mother's mortification when her mother-in-law confronted her with the undone housework both assumed any good housewife would do:

I had no help — I couldn't do windows. Before I had help, the house looked like a tornado. When my mother-in-law visited, she bawled him out and me out for the way the house looked. I cried and felt terrible.

Further, ill persons often feel discounted and devalued when the arrangements for care reflect a new and undesirable identity. Although designed to aid the ill person, home care arrangements frequently underscore fears of incapacity or incompetence and are often viewed as intrusions of privacy. Examples include the former household chauffeur who no longer drives but must be driven, the mother who feels replaced by the housekeeper and the elderly wife who now is bathed and dressed by strangers with rough hands and patronizing voices. Such changes are, at times, destructive to past family relationships.

The patient quoted above resisted being cared for by her mother-in-law since she had previously known her only in a formal relationship. When she related her feelings and the family crisis it elicited, she recalled:

The thing that did it was that she wanted to come in and take care of me as a nurse. I couldn't accept that. I cried. I told my husband I couldn't take it. She wanted to *bathe* me. I told my husband, 'But she's my *mother-in-law*.' My husband was getting awfully angry with me — he would say, 'But she's a nurse and knows how to take care of you,' which was true. We went on for some time about that. Before, each time she would stay a month. I was able to take care of myself. It was a heartbreak to me — my mother-in-law! I'd always managed to stay on good terms with her which is more than her other in-laws had. But I didn't want my mother-in-law to see me nude. I had always known her as my mother-in-law and that was the way I wanted to know her, and I couldn't accept her as my nurse. When a nurse comes through your door as a nurse, that's one thing. She is a professional and is there to assist you in anything you need assistance with, but to have your mother-in-law cleaning up after you and bathing you, that's another — it is just too much to take.

Handling such dilemmas in order to maintain positive evaluations of self and continue prior relationships with others prompts the ill person to develop new strategies for negotiating his or her position. This woman accomplished this by reversing roles with her husband. She said:

What did it was one time I said to him how would you like it if you were sitting in a wheelchair and *my* mother grabbed your penis and said to you, 'Alright, pee in this jar.' He kept saying, 'Your *mother* — oh no!' I said to him, 'Yes, my mother — what is so different about that than your mother taking care of me?' My mother took care of a lot of people too. Once he stopped thinking of how embarrassing it would be [to him], he got my point and didn't press it.

Ill persons themselves are not always aware of the extent to which their physical conditions intrude upon their lives. Some gloss over their symptoms and minimize their discomfort. Thus, many persons initially develop other accounts to explain their experiences. A woman believes her tendency to drop objects is due to her clumsiness. Another woman thinks her increased falls are due to her lifelong weak ankles. A man thinks his nausea and fatigue are due to a sensitive stomach.

Lifelong stoics may acknowledge their symptoms only after becoming quite incapacitated. Before then, they simply attempt to function. Although unlikely to claim much physical suffering, they are apt to suffer psychologically since they make valiant attempts to live as normally as possible, even at severe costs to their health and, ultimately, to their intimate relationships. For them, failure to live up to the expectations of others is also the failure to live up to their own expectations, which sometimes are even greater. For example, women sometimes bemoan the unclean house, unsorted laundry, uninteresting meals, etc. When surrounded by the visible symbols of their present level of functioning and when compared negatively to past levels and their personal performance standards, these individuals suffer tremendous amounts of self-blame and guilt. Subsequently, they may devote much energy to apologizing to others for their felt inadequacies. Indeed, they may apologize for their very existences because they too share the assumption that in order to be fully human, one must be able to function fully. In this way, they actively participate in their own discrediting.

Occasionally, ill persons will try to function in realms no longer expected by others. When inability to function occurs, the defeat they experience may become more of a burden to the caregivers than the actual physical care. The pathos of the ill person who cannot accept dependency permeates the existence of the caregivers. For example, one daughter said of her aging mother:

> Mother caused us great sorrow and difficulty in the last few years before she
> died. She just wouldn't accept letting us take over the household and take
> care of her. She would overdo, then everyone would feel guilty, even though we
> were doing the best we could with two full-time jobs. Then she'd have to spend
> several days in bed and she would cry continuously. No matter where you went
> in the house, you could hear her crying.

Implicit within the above discussion is one of the most significant sources of suffering from loss of self of the chronically ill: the inability to control one's self and life in ways that had been hoped for, anticipated, or assumed. This inability clearly may lead to self-discreditation and self-blame.[43]

Self-discreditation begins when ill persons can no longer take for granted some valued attribute or function which they view as fundamental for a positive self-image (such as sexual functioning).[44] Self-discreditation continues when they discover that somehow they are incapable of living with chronic illness on the terms they had expected or hoped for. When ill persons attempt to return to the normal world and fail, they usually feel profound disappointment and grief for their lost self-images.

As discrediting events recur, the chronically ill begin to see themselves as permanent failures and as burdens to others. They then cease their attempts to intervene actively with the self that they see shaping before them; in short, they accept a discredited self.

Becoming a burden

The sense of 'becoming a burden' follows closely upon loss of hope and loss of recapturing positive self-images of the past. Becoming a burden essentially involves becoming more dependent and immobilized. Although some interviewees stressed the psychological and economic burdens that their illnesses could conceivably cause others, most felt an overwhelming concern about the burden of physical care.

Becoming a burden typically demeans identity because these ill persons have little power over their situations and the quality of their existences. And as implied above, becoming a burden means onerous and continuous obligations for family members. For example, an elderly woman disclosed:

> One of the worst things about all this is that sometimes I feel so badly about being dependent. It does cause a lot of extra work for everyone else. You're never sure of yourself — never can depend on getting something done. When you don't feel well, wham! — your whole day is shot, and you may not get anything done.

Since becoming a burden is rooted in physical dependency and immobilization, ill persons usually recognize that their illnesses have become their major source of social identity.[45] Fear of the identifications attached to dependency and immobility often propelled these individuals into action. Becoming a burden affirms and intensifies immobility and stands in symbolic contrast to the way these persons wish to conceive of themselves. For example, a young physician who had diabetes expressed his fears of the future in this way:

> The thought of being on welfare is beginning to look very scary. When I think of diabetes, I think of those old men on the back wards. [He paused reflectively.] Death doesn't bother me as much as the process of dying — of disability.

Becoming a burden symbolized that the person can no longer claim identities based upon prior external activities, interests and pursuits. They are gone. Being immobilized in physical dependency generally is sufficient to identify someone as a burden to others. However, what it means to be a burden specifically emerges in ongoing interaction and in relation to the ill person's expectations. For example, for 73-year-old Mrs Price, who no longer goes out of her home at all, being a burden means being unable to cook the evening meal and to perform light housekeeping duties. In contrast, for 27-year-old Charlotte it means being physically dependent on living with her aging mother and simultaneously, not pursuing vocational objectives.

Becoming a burden means that a person no longer fulfils the obligations implicit in past relationships. Even though *what* constituted fulfilling obligations may only be realized when someone is no longer able to do it, guilt and shame about burdening others usually follows. If family relationships are already strained, ill individuals may go to supernormal lengths to maintain the balance of duties believed to constitute their 'part' and so avoid further obligating and burdening an unwilling relative. For example, a young mother who could not walk disclosed to me:

> When I became ill, I nearly killed myself keeping things going. I wasn't going to give him any grounds for saying that I didn't keep my end of the marriage. So I took care of the children and the apartment without asking help from him.

Perhaps the worst part of becoming a burden is the *feeling* of *uselessness* to self and others. Men who felt forced to give up their jobs tended to feel useless earlier in the course of their illnesses than did women. Events such as leaving the job clearly mark the points in time when ill persons define themselves as a burden. One man who had always had a big garden dated his feelings of uselessness from the point at which he relinquished the major portion of the gardening to his wife. He reflected:

> We've [he and his wife] always had a big garden, worked on it together, but I always did all the heavy work. You can't imagine what it did to me this spring to have my wife out there with the tractor while I just sat there in the lawn chair and directed her.

Feelings of uselessness intensify as the strain of illness and physical care take their toll on the caregiver. Few interviewees had any outside help. Because care generally fell to one individual, the ill person may observe the visible strain on the caregiver. Acutely aware of the added obligations her illness imposed on her husband, one woman repeatedly commented on his fatigue and worry as he took over her role with the

children. In another case, a man deeply regretted the fact his wife had to take an outside job besides caring for him and the house. Another person knew that her daughter wished to give her whatever care she needed. Her strained relationship with her son-in-law, however, caused her to feel that any more help from her daughter would threaten her daughter's marriage.

Becoming a burden means more than physical dependency and feelings of uselessness. It means that small things in everyday life become major obstacles, such as using the bathroom or getting to the phone before it stops ringing. It also means an appreciation for little comforts previously taken for granted. Moreover, it means that interactions and relationships shift as the ill person focuses inward on self. A woman with multiple sclerosis expressed these meanings in this way:

> Why wasn't I thankful for these little things [like taking a bath]. Others around you don't realize how much these things mean. One morning I awoke – my husband was already in the shower – I was soiled and laying in it. [By way of explanation:] Oh, I didn't do any damage, the mattress is plastic covered and I always lay on another covered plastic sheet so nothing will be ruined. But there I was laying in this mess, not able to do a thing for myself and needing a bath more than anything else and knowing I'd lay there like that until 7.30 when my attendant came, feeling horrible. My husband came out of the shower wrapped in a towel with his hair wet, the big handsome thing. I asked him, 'How was your shower?' He said 'It was wet.' I said, 'That was cruel [to him].' I turned over and just wept. He said, 'Honey, what's the matter?' But he didn't see it at first. Nobody needed a bath more than I did then. Oh, my attendant washes me from head to toe and I'm clean, but it isn't like having a tub bath or a shower. I felt so miserable. I needed the bath, and he had it. He didn't see that the remark was thoughtless.

Discussion

Clearly, these chronically ill persons evince a heightened self-concern about the person they see themselves becoming and about valued self-images from the past which they have lost, sometimes irretrievably. That heightened self-concern raises several dilemmas precisely because they now see themselves and their lives as fragile. First, they scrutinize encounters with others for hints of discreditation and negative reflections of self. Thus, they become not only particularly sensitive to the intentions and meanings of others toward themselves, but moreover, they begin to read the statements and actions of others in new, and self-discrediting ways, and thereby increase their own suffering.

Second, chronic illness seems to foster greater dependence on others

for self-definition and value while simultaneously it tends to produce siuations wherein relationships become more strained and problematic. That is, the ill person relies more heavily on reflections of self by others at the very time in his or her biography when bonds to others weaken and isolation and loneliness intensifies. Although relatives are more likely to give care and maintain relationships than friends, care may exhaust them and they too may give up and relinquish it. The round of care combined with the direct confrontation with loss and suffering overwhelms many caregivers. In turn, they are unlikely to have substitutes or support, and the American family is not well constructed to provide lengthy, arduous care of a suffering member whose hopes for recovery are nil.

Third, even though the chronically ill may desire and need more intimate social contact to preserve their crumbling self-images and to monitor their images in others' eyes, they themselves often become less capable of maintaining relationships as they become consumed by illness. If they openly reveal their suffering, show self-pity, guilt, anger or other emotions conventionally believed to be negative, they are likely to further estrange those who still take an interest in them. Fourth, in a society which emphasizes doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life.

Last, a word about the nature of suffering. The language of suffering these severely debilitated people spoke was a language of loss. They seldom talked of gaining a heightened consciousness of the world, revelations about self or insights into human nature from their experiences. Instead in their suffering, they experienced the heightened self-concern described above. A striking contrast, however, was apparent among those who had improved and no longer suffered as greatly as they had in the past. These individuals were more likely to see their earlier suffering as a path to knowledge and self-discovery. Perhaps then, the structuring of illness in American society fosters learning from the past retrospectively when the individual defines present experiences as improved and more hopeful.

Gerontology Program
Sonoma State University
California

Acknowledgments

Notes

1 From my studies of chronic illness, I have come to the position that there is an 'American Way' of experiencing and handling illness, as analogous to Jessica Mitford's argument of an American way of managing (and not managing) death. I expand upon this point in my earlier paper, 'Ideologies and the politics of constructing identity: the subjective experience of the chronically ill', paper given at the Meetings of the Society for the Study of Social Problems, New York, 31 August, 1976. Compare with J. Mitford, *The American Way of Death*, New York, Simon & Schuster, 1963.
2 K. Charmaz, 1976, op. cit.
3 K. Charmaz, *The Social Reality of Death*, Reading, Mass., Addison-Wesley, 1980a. My argument does not deny that people from other cultures may share markedly similar values about managing chronic illness. Rather, I limit my observations to the data which I have gathered for this and related work. Surely some parallels can be made. If, for example, Kafka's work *The Metamorphosis* can be taken as a metaphor for cancer as Shlain takes it, that provides one parallel between American and Russian ways of handling disease; others may be observed in Solzhenitsyn's *Cancer Ward* and Tolstoy's *Ivan Ilyich*. See F. Kafka, *The Metamorphosis*, New York, Schocken, 1968; L. Shlain, 'Cancer is not a four-letter word', in C. Garfield, *Stress and Survival*, St. Louis, C.V. Mosby, 1979, pp. 175–85; A. Solzhenitsyn, *Cancer Ward*, New York, Bantam, 1969; L. Tolstoy, *The Death of Ivan Ilyich*, New York, Signet Classics, 1960.
4 T. Parsons and R. Fox, 'Illness, therapy and the modern urban American family', *Journal of Social Issues*, vol. 18 (1952), pp. 31–44.
5 P.M. Strong, 'Materialism and medical interaction: A critique of "Medicine, superstructure and micropolitics"', *Social Science and Medicine*, vol. 13A (1979), pp. 613–19.
6 K. Charmaz, 1976, op. cit.
7 K. Charmaz, 'The social construction of self-pity in the chronically ill' in N.K. Denzin, *Studies in Symbolic Interaction*, vol. 3, Greenwich, Conn., Jai Press, 1980b, pp. 123–44.
8 G.H. Mead, *Mind, Self and Society*, Chicago, University of Chicago Press, 1934.
9 P.M. Strong, 1979, op. cit.
10 T. Parsons and R. Fox, op. cit. See also A. Oakley, 'The family, marriage and its relationship to illness', in D. Tuckett, *An Introduction to Medical Sociology*, London, Tavistock Publications, 1976, pp. 74–109.
11 J.N. Clarke, 'A multiple paradigm approach to the sociology of medicine, health and illness', *Sociology of Health and Illness*, vol. 3 (1981), pp. 89–103.

12 B.G. Glaser and A.L. Strauss, *The Discovery of Grounded Theory*, Chicago, Aldine, 1967.

13 B.G. Glaser, *Theoretical Sensitivity*, Mill Valley, Ca., Sociology Press, 1978.

14 M. Davis, *Living with Multiple Sclerosis*, Springfield, Ill., Charles C. Thomas, 1973.

15 L. Reif, 'Ulcerative colitis: Strategies for managing life', *American Journal of Nursing*, Vol. 73 (1973), pp. 261-4.

16 A.L. Strauss and B.G. Glaser, *Chronic Illness and the Quality of Life*, St. Louis, C.V. Mosby, 1975.

17 B. Zilbergeld, 'Sex and serious illness', in C. Garfield, *Stress and Survival*, St. Louis, C.V. Mosby, 1979, pp. 236-242.

18 Some ill persons do try to restructure events to fit themselves, instead of altering themselves to fit events. Unfortunately, their attempts may be met with resistance. A few years ago, for example, a middle-aged man who had chronic pain attended my class in health and illness. Since he could not tolerate sitting for more than a half hour or so, he sat behind most of the seminar students and occasionally got up, stretched his stiff leg and walked back and forth for a few seconds. Much to my chagrin, I subsequently overheard several students commenting negatively on his actions. One student said, 'Well, I really wish he'd just leave if he has to get up.' Her response was especially disconcerting in this class where one might hope that students could appreciate innovative ways of managing a painful physical condition and ordinary involvements simultaneously.

19 L. Reif, 1973, op. cit.

20 A.L. Strauss and B.G. Glaser, 1975, op. cit.

21 A.A. Alonzo, 'Everyday illness behavior: A situational approach to health status deviations', *Social Science and Medicine*, vol. 13A (1979), pp. 397-404.

22 E. Goffman, *Stigma*, Englewood Cliffs, N.J., Prentice-Hall, 1964.

23 S. Macintyre and D. Oldman, 'Coping with migraine', in A. Davis and G. Horobin, *Medical Encounters: The Experience of Illness and Treatment*, London, Croom Helm, 1977, pp. 55-71.

24 S.L. Star, 'The social psychology of chronic migraine', unpublished paper, University of California, San Francisco, 1981.

25 I do not wish to imply that those who have constricted concerns cannot at some point use their experiences to learn about themselves and the human condition. I do wish to point out, though, that the kind of consuming consciousness I describe later does lead to a loss of self. The young man quoted provides one case example of a person whose life was almost totally restricted by his marked disability and whose consciousness was consumed by the panic he felt about swallowing. Yet later, he felt forced to deal with his fear and because his first wife left him and he had relied on her, he gradually taught himself how to become more independent. The combination of capturing his fear and becoming more independent opened his world so his life became much less restricted. For further accounts of restricted lives due to encompassing pain and discomfort see S.Y. Fagerhaugh and A.L. Strauss, *Politics of Pain Management*, Reading, Mass., Addison-Wesley, 1977, and S.L. Star, op. cit.

26 R.G.A. Williams, 'Logical analysis as a qualitative method. I: Themes in old age and chronic illness', *Sociology of Health and Illness*, vol. 3 (1981), pp. 140-64.

27 J.W. Schneider and P. Conrad, 'Medical and sociological typologies: The case of epilepsy', *Social Science and Medicine*, vol. 15A (1981), pp. 211-19.

28 L. Shlain, 1979, op. cit.

29 R.T. Smith and L. Midanik, 'The effects of social resources on recovery and perceived sense of control among the disabled', *Sociology of Health and Illness*, vol. 2 (1980), pp. 48–63. The relationship in the kinship network is pivotal for the extent and kind of care provided. Generally, wives provided continuous support and care, even though I saw several who did not know how they would continue. Mothers gave care to adult daughters and adult daughters cared for parents. The sibling tie was weaker. These chronically ill persons typically did not feel that they could call upon siblings, as they were 'involved in their own lives' and they did not feel sufficiently 'close' to them to do so. As crises continue, ill persons may evaluate what requests they can properly make; caregivers evaluate what they can give their ill relatives while simultaneously managing their ordinary affairs. Because many of the women were single or divorced, I did not have ample opportunity to see if husbands provided the same kinds of involvements. While several married women expressed fear of greater impairment since their husbands did not like 'sick people', others reported that their husbands were exceedingly helpful, supportive and protective. Only in one case did I find a man who became the primary caregiver to parents. He was twice divorced, retired from the military and saw himself as more available and mobile than his sisters. Of the adult men I interviewed most received care from wives with the exception of a single man who preferred to receive emotional support from friends rather than his 80-year-old aunt and uncle, his only living relatives. Since friends systematically let him down, he was left primarily with what support was given by treatment staff. See also A. Oakley, 1976, op. cit.

30 K. Charmaz, 1980a, op. cit.

31 K. Charmaz, 1980b, op. cit.

32 E. Goffman, 1964, op. cit.

33 S. Hopper, 'Diabetes as a stigmatized condition: The case of low-income clinic patients in the United States', *Social Science and Medicine*, vol. 15B (1981), pp. 11–19.

34 M.S. Knudson-Cooper, 'Adjustment to visible stigma: The case of the severely burned', *Social Science and Medicine*, vol. 15B (1981), pp. 31–44.

35 J. Schneider and P. Conrad, 1981, op. cit.

36 Ibid.

37 T. Parsons and R. Fox, 1952, op. cit.

38 R. Jobling, 'Learning to live with it: An account of a career of chronic dermatological illness and patienthood', in A. Davis and G. Horobin, *Medical Encounters, The Experience of Illness and Treatment*, London, Croom Helm, 1977, pp. 72–86.

39 F. Davis, *Passage Through Crisis*, Indianapolis, Bobbs-Merrill, 1963.

40 M. Siegler and H. Osmond, 'The sick role revisited', in G.L. Albrecht and P.C. Higgins, *Health, Illness and Medicine*, Chicago, Rand McNally, 1979, pp. 146–66.

41 M.C. Knudson-Cooper, 1981, op. cit.

42 K. Charmaz, 1980b, op. cit.

43 T.E. Levitin, 'Deviants as active participants in the labeling process: The visibly handicapped', in G.L. Albrecht and P.C. Higgins, *Health, Illness and Medicine*, Chicago, Rand McNally, 1979, pp. 217–27.

44 S. Hopper, 1981, op. cit.

45 In this case, illness floods identity. The ill person has essentially lost the ability to minimize his or her physical condition. It intrudes upon their lives in visible ways and upon the lives of their intimates. For a description of a condition which can more readily be hidden, see J.W. Schneider and P. Conrad, 'In the closet with illness: Epilepsy, stigma potential and information control', *Social Problems*, vol. 28 (1980), pp. 32–44.