THE BODY, IDENTITY, AND SELF:
Adapting To Impairment

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Serious chronic illness undermines the unity between body and self and forces identity changes. To explicate how the body, identity, and self intersect in illness, one mode of living with impairment, adapting, is explicated in this article. Adapting means altering life and self to accommodate to bodily losses and limits and resolving the lost unity between body and self. It means struggling with rather than against illness. The process of adapting consists of three major stages: (1) experiencing and defining impairment, (2) making bodily assessments and, subsequently, identity trade-offs, as ill people weigh their losses and gains and revise their identity goals, and (3) surrendering to the sick self by relinquishing control over illness and by flowing with the experience of it. Adapting seldom occurs only once. Rather chronically ill people are forced to adapt repeatedly as they experience new losses. The data consist of 115 interviews about experiencing chronic illness and 25 more focused interviews about the body in chronic illness. The strategies of grounded theory provided the methods for completing the analysis.

Chronic illness assaults the body and threatens the integrity of self. Having a serious chronic illness shakes earlier taken-for-granted assumptions about possessing a smoothly functioning body. It also disturbs a person's previous assumptions about the relation between body and self and disrupts a sense of wholeness of body and self (cf. Bury 1982; Brody 1987; Charmaz 1991; 1994a; 1994b; Gadow 1982; Monks and Frankenberg n.d.; Murphy 1987). Thus, chronic illness with impairment intrudes upon a person's daily life and undermines self and identity. What happens when people have chronic illnesses that weaken, challenge, or negate valued images of their bodies? How do beliefs, images, and expectations of one's body affect present identity and future hopes and plans? What kinds of goals do people form for their future identities after they have experienced loss of bodily function or disability?

To explicate how the body, identity, and self intersect in illness, I outline *one* mode of living with impairment or loss of bodily function: adapting. By adapting, I mean altering life and self to accommodate to physical losses and to reunify body and self accordingly. Adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways. Bodily limits and social circumstances often force adapting to loss. Adapting shades into acceptance. Thus, ill people adapt when they try to accommodate and flow with the experience of illness.

Other ways of living with illness include ignoring it, minimizing it, struggling against it, reconciling self to it, and embracing it (see Charmaz 1991; Radley 1991). People ignore and

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minimize illness when they do not experience its effects on their lives or can control those effects. They also ignore and minimize when other goals take precedence, such as keeping a job or attending to an intimate's needs. Through ignoring and minimizing, ill people may preserve the sense of unity between body and self that they had before illness. Preserving that unity becomes much harder when they constantly struggle against illness—they fight it and the identifications that come with it. Many people reconcile themselves to illness for years. They tolerate it—within limits. Hence, they define going beyond those limits such as "needing a wheelchair" or "going into a nursing home" as more than they can handle emotionally (see Charmaz 1991). When reconciling self to illness, people acknowledge and attempt working around it, but they neither accept it as defining them nor do they accept others' pronouncements of whom they now should be. In contrast, embracing illness means seeking refuge in it.

People with chronic illnesses often experience all these ways of living with impairment at different times. All may be necessary and natural responses to their experience, depending on their situations. After long years of ignoring, minimizing, struggling against, and reconciling themselves to illness, they adapt as they regain a sense of wholeness, of unity of body and self in the face of loss.

Modes of living with impairment are embedded in social definitions of "appropriate" *attitudes, actions,* and *activity levels.* Such judgments take into account *dependency* and *deviance.* Hence, negative definitions result when others view ill people as failing to reveal "correct" feelings or to take the "right" stance, engaging in "too much" or "too little" activity than physically warranted, becoming more independent or dependent than expected, or sinking into depression, drugs, or drunkenness. Some people never adapt to impairment; others refuse to admit that they have suffered losses (see examples in Albrecht 1992; Herzlich 1973; Radley and Green 1985; 1987; Williams 1981a; 1981b). Still others adapt to their impaired bodies only long after suffering losses. Many people, however, must adapt time and again as they progressively experience failing health, whether they slowly decline or rapidly plummet during acute episodes, crises, or complications. In whatever way people live with impairment, they prefer to have certain future identities over others, although their preferences may be wholly unattainable. Some chronically ill adults hold fast to regaining their unimpaired selves. Others pursue contradictory identities. For example, a stroke patient may simultaneously want to be the passive patient today and the fully recovered worker tomorrow without realizing that the latter requires concerted effort right now.

Adapting to an impaired body means resolving the tension between body and self elicited by serious chronic illness. It also means defining integration and wholeness of being while experiencing loss and suffering. These meanings of adapting to an impaired body become implicit criteria for "successful" adaptation with the taken-for-granted proviso that the person also remains as independent and autonomous as possible. Hence, successful adaptation means living with illness without living solely for it. Adapting to physical loss ebbs and flows and repeats itself in similar forms as further episodes, complications, and additional illnesses occur.

Studying adaptation to loss through impairment illuminates tensions within continuing metaphors of opposition:[1] the self versus the body, struggle versus surrender, the idealized body versus the real, experienced body, social identifications versus self-definitions, objective reality versus subjective experience, struggling with versus struggling against illness, invisible disability versus obvious impairment, freedom of bodily movement versus physical constraint and dependence, and bodily control versus loss of function. Though quelled before, these tensions reemerge with each disruptive episode or with deteriorating social conditions.

Adapting to impairment consists of three major stages. First, it depends upon experiencing an altered body, that in turn leads to defining impairment or loss and to making reassessments. Whether chronically ill people objectify their bodies and struggle against illness or subjectively integrate their ill bodies with self shapes whether or not they create a sense of wholeness of body and self and of their lives. Bodily appearance affects social identifications and self-definitions and, therefore, how an individual experiences an altered body. Second, assessing one's altered body, appearance to self and others, and the context of life results in changing one's future identity accordingly. Ill people make identity trade-offs, in other words, opting for one identity over another, as they weigh their situations and losses and gains. Even when forced to accept a lesser identity than previously, they often redefine their decisions as positive and find value in their restricted lives. Third, surrendering to the sick body means the end of the quest for control over illness. At this point, people open themselves to experiencing their illness; they define unity of body and self through this experience.

THEORETICAL FRAMEWORK

This article takes a symbolic interactionist perspective on identity (Blumer 1969; Cooley 1902; Lindesmith, Strauss, and Denzin 1988; Mead 1934; and Strauss 1959) and builds upon the emerging literature on the body (DiGiacomo 1992; Frank 1990; 1991a; 1991b; Frankenberg 1990; Freund 1982; 1988; 1990; Gadow 1982; Glassner 1988; 1989; Kotarba 1994; Olesen 1994; Olesen, Schatzman, Droes, Hatton, and Chico 1990; Sanders 1990; Scheper-Hughes and Lock 1987; Zola 1982; 1991). I draw upon the philosopher Sally Gadow's (1982) clarification of the relation between body and self and on my earlier work on the self in chronic illness (Charmaz 1991) and the effects of loss upon identity (Charmaz 1987).

In keeping with symbolic interactionism, personal identity means the way an individual defines, locates, and differentiates self from others (see Hewitt 1992). Following Peter Burke (1980), the concept of identity implicitly takes into account the ways people *wish* to define themselves. Wishes are founded on feelings as well as thoughts. If possible, ill people usually try to turn their wishes into intentions, purposes, and actions. Thus, they are motivated to realize future identities, and are sometimes forced to acknowledge present ones. However implicitly, they form identity goals. Here, I define identity goals as *preferred identities* that people assume, desire, hope, or plan for (Charmaz 1987). The concept of identity goals assumes that human beings create meanings and act purposefully as they interpret their experience and interact within the world. Some people's identity goals are implicit, unstated, and understood; other people have explicit preferred identities. Like other categories of people, some individuals with chronic illnesses assume that they will realize their preferred identities; others keep a watchful eye on their future selves and emerging identities as they experience the present (see also, Radley and Green 1987).

Gadow (1982) assumes that human existence essentially means embodiment and that the self is inseparable from the body. I agree. Mind and consciousness depend upon being in a body. In turn, bodily feelings affect mind and consciousness. Yet, as Gadow points out, body and self, although inseparable, are not identical. The relation between body and self becomes particularly problematic for those chronically ill people who realize that they have suffered lasting bodily losses. The problematic nature of such realizations intensifies for ill people who had previously pursued and preserved an endless youth through controlling and constructing their bodies (Turner 1992). Thus, meanings of loss are embedded in assumptions and discourses about the body. Not only do individuals assume bodily control through rational practices, but they also assume their practices achieve and, quite literally, embody individualism (Shilling 1993).

As Victor Kestenbaum (1982) observes, illness threatens a person's sense of integrity of self and the body and of self and the world. People who have serious chronic illnesses find progressive losses repeatedly threaten their body and self-integrity. They risk becoming socially identified and self-defined exclusively by their impaired bodies (Bury 1988; Goffman 1963; Locker 1983; MacDonald 1988). Thus, chronically ill people who move beyond loss and transcend stigmatizing negative labels define themselves as much more than their bodies and as much more than an illness (Charmaz 1991).

Gadow argues that illness and aging result in loss of the original unity of body and self and provide the means of recovering it at a new level. She assumes that an original unity existed and implies that loss and recovery of unity is a single process. However, what unity means can only be defined subjectively. Some people may not have defined themselves as having experienced such unity before illness, or as only having partially experienced it. Further, with each new and often unsuspected bodily impairment, people with chronic illnesses *repeatedly* experience loss of whatever unity between body and self they had previously defined or accepted. Thus, at each point when they suffer and define loss, identity questions and identity changes can emerge or reoccur. Throughout this article, I deal with the loss of body-self unity and its recovery through acknowledging bodily experience and opening oneself to the quest for harmony between body and self.

In order to understand how loss and recovery of body-self unity occurs, we must understand ill people's meanings of their bodily experiences and the social contexts in which they occur (Fabrega and Manning 1972; Gerhardt 1979; Radley and Green 1987; Zola 1991). Such meanings arise in dialectical relation to their biographies (Bury 1982; 1988; 1991; Corbin and Strauss 1987; 1988; Dingwall 1976; Gerhardt 1989; Radley 1989; Radley and Green 1987; Williams 1984) and are mediated by their interpretations of ongoing experiences. Consistent with symbolic interactionist social psychology, present meanings of the ill body and self develop from, but are not determined by, past discourses of meaning and present social identifications (Blumer 1969; Goffman 1963; Mead 1934).

As chronic illness encroaches upon life, people learn that it erodes their taken-for-granted preferred identities as well as their health. Further, they may discover that visible illness and disability can leave them with a master status and overriding stigmatized identity. Because of their physical losses, they reassess who they are and who they can become. Subsequently, they form identity goals as they try to reconstruct normal lives to whatever extent possible (Charmaz 1987; 1991). Frequently, people with chronic illnesses initially plan and expect to resume their lives unaffected by illness, or even to exceed their prior identity goals. As they test their bodies and themselves, ill people need to make identity trade-offs at certain points, or even to lower their identity goals systematically until they match their lessened capacities. At other times, they may gradually raise their hopes and progressively increase their identity goals when they meet with success. Therefore, both raised or lowered identity goals form an implicit identity hierarchy that ill people create as they adapt to bodily loss and change (Charmaz 1987).

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METHODS AND DATA

Grounded theory methods provided the strategies for collecting and analyzing data (Charmaz 1983; 1990; 1995; Glaser 1978; Glaser and Strauss 1967; Strauss 1987; Strauss and Corbin 1990; 1993). Consistent with the emergent character of grounded theory methods, my analysis evolved as I collected and interpreted data. While completing a study of the experience of chronic illness, I found that issues about having a problematic body arose repeatedly. This study included 115 intensive interviews of fifty-five adults with serious, intrusive chronic illnesses (cf. Charmaz 1991; Lofland and Lofland 1994; Seidman 1991). Sixteen of these respondents were followed longitudinally from five years to over a decade. After analyzing the earlier interviews for content about the body in illness, twenty-five additional highly focused interviews were conducted (including twelve interviews with respondents from the longitudinal portion of the original study) of two to three hours in length. I also collected personal accounts of experiencing chronic illness and disability to examine them for statements about the body (see, for example, Beisser 1988; Fisher, Straus, Cheney, and Oleske 1987; Frank 1990; LeMaistre 1985; Mairs 1989; Murphy 1987; Pitzele 1985; Register 1987). The first set of interviews stimulated my initial ideas about the body and self; the focused interviews elicited detailed information about the body and self, and the personal accounts provided independent sources of data for checking my ideas.

The respondents' characteristics varied by gender, age, and socioeconomic and diagnostic statuses. Two-thirds of the first set of respondents were middle-aged women (all respondents were over age twenty-one and white); two-thirds of the men were middle-aged; three-quarters of all respondents were working or middle-class. Two-thirds of those under age sixty worked part-time, full-time, or intermittently; other respondents quit work, attended school, went on disability, or retired early. Slightly over one-half of the respondents were married. Their chronic illnesses include heart and circulatory disease, cancer, emphysema, diabetes, chronic fatigue syndrome, rheumatoid and collagen diseases (arthritis, lupus erythematosus, Sjögren's syndrome, mixed connective tissue disease), and other auto-immune diseases such as multiple sclerosis. Almost one-third of the second sample of focused interviews were conducted with men. Except for one respondent in his twenties, respondents' ages ranged from forty to sixty (twelve respondents) and older, 61-75 years old. Half of all respondents were married; three were single; the remainder were divorced or separated. All were white.

I provide a stage analysis of adapting to impairment as a heuristic device to understand experiencing illness, not as an ultimate truth or as a prescriptive tool for practitioners and patients, as Elisabeth Kübler-Ross's (1969) stage analysis proved to be. Depending on their physical condition and social resources, individuals may tumble through the stages rapidly and repeatedly, or they may plateau for years before moving into the next phase of adapting. A constructivist grounded theory perspective that emphasizes respondents' lived experience and stories (cf. Dawson and Prus 1992; Denzin 1988; Prus 1995) informs my analysis, rather than a more positivistic approach such as that of Anselm Strauss and Juliet Corbin (1990). The analytic steps included: (1) examining the first set of interviews and personal accounts for statements about the body, self, and identity, (2) developing themes around these topics that were explored in detail in the second set of interviews, (3) building analytic categories from the themes, and (4) linking the categories into a coherent process.

EXPERIENCING AN ALTERED BODY

Experiencing an altered body means that people with illnesses note physical changes and diminished bodily functions (cf. Charmaz 1991; Kahane 1990; Kelly 1992; Yoshida 1993). Thus, experiencing an altered body means more than having or acquiring one. It means that these people begin to *define* bodily changes or the illness itself as real (if already diagnosed) and to account for how changes and symptoms affect daily life.[2] Distressing bodily sensations and impaired functions as well as disquieting feelings about body and self give rise to defining bodily changes. The unity of prior embodied experience has been shaken; assumptions about body and self have been jolted (see also, Olesen et al. 1990). At this point, people with illnesses compare their present body with their past body; they assess the differences between then and now, and they measure the costs and risks of ordinary activities. Before becoming ill, most people took their bodies for granted as functioning instruments or vehicles subjugated to the self. This taken-for-granted instrument becomes the yardstick against which they compare their altered bodies. A forty-one-year-old woman who had asthma described the bodily changes she experienced within the last year:

> By that time I really couldn't go for a walk, um, the way I used to, so I felt like my body had betrayed me. By that time I had, even though I hadn't really been diagnosed, I felt that even a little strain—I was pushing myself and I knew it, you know. I knew that things that I used to do easily without any strain at all were a challenge. And so I was real aware of it. And also, probably at that time, I'd probably been running a low-grade fever for a long-time, and I knew it. . . . So I mostly felt like my body was sort of foreign territory—it was not the body that I knew.

Like others, this woman experienced her body as more than altered—she felt it was alien. Thus, she experienced a radical disruption of body and self. Experiencing this bodily alienation leads people to rethinking explicitly their previously held notions of body and self. This woman and several men with respiratory disease found that rapid weight gain accompanied plummeting physical activity. Mirror images of the body further call into question a previously taken-for-granted self. She said, "So I'm heavy—I'm heavy in a way I've never been before." Experiencing multiple bodily losses in a short period intensifies feelings of estrangement, of separation from one's past familiar body, and of loss of self. The body once viewed as a taken for granted possession to control and master has spun out of control. At best, the body is now a failed machine, an obstacle to be repaired, overcome, or mastered. At worst, it has become a deadly enemy or oppressor (cf. Charmaz 1980; 1994b; Gadow 1982; Herzlich 1973; Herzlich and Pierret 1984; Williams 1981a; 1981b).

When wholly unanticipated, even middle-aged people may view their bodily changes with a sense of betrayal. They may describe their past bodies as "invincible," "indestructible," and "immortal" and express regret and anger about their losses. In turn, their anger and regret intensify when ill people feel that their illnesses control them. They have lost control of their body as an object they assumed they could master. Moreover, they view themselves as overtaken by an alien force. The woman mentioned above stated:

> It has probably slowed me down, and I'm very aware that I have this and if I really want to be as healthy as I can be, it's—it will control where I live; it will control what kind of work I do; it will control who I can be around—I can't be around someone who insists on

> wearing perfume; I can't be around anyone who smokes anything at all; I can't be around people who insist on having . . . certain kinds of chemicals.

Perhaps more destructive than the anger is the guilt and shame followed by self-abasement that ill people with failing bodies experience: guilt because they share cultural standards of ageless bodily perfection and correct appearance (cf. Glassner 1988); shame because their very existence testifies to a failure to meet these standards. Self-abasement follows and intensifies the humiliation. Robert F. Murphy (1987, p. 111) observes:

> In my middle age, I had become a changeling, the lot of all disabled people. They are afflicted with a malady of the body that is translated into a cancer within the self and a disease of social relationships. They have experienced a transformation of the essential condition of their being in the world. They have become aliens, even exiles in their own lands.

For a time, people with chronic illnesses may make firm separations between their impaired bodies and their self-concepts (cf. Charmaz 1991; Register 1987; Weitz 1991). That way they can keep their illness separate from themselves and their lives. The extent to which they keep it separate and their stance about doing so is crucial. By keeping illness separate, they allay disquieting feelings about themselves and their bodies.

Struggling against illness differs from struggling with it. When people struggle *against* illness, they view their illness as the enemy with whom they must battle (cf. Charmaz 1980; 1994b). They hope to regain their past identities and to restore a now missing sense of self. Usually at this point, they can neither face nor accept more restricted lives and lesser identities than what they had before illness.

When people struggle *with* illness, they struggle to keep their bodies functioning and therefore, their lives "normal" to whatever extent possible. Hence, they do not give up. In struggling against and with illness, they try to take control over their illnesses and their bodies. Gregg Charles Fisher (1987, p. 13) describes how he and his wife struggled with chronic fatigue syndrome, implying that they learned to differentiate between body and self, despite their struggles: "Through the long years of this illness, we have had to struggle every day to cope with our affliction. As the years go by, we are more determined than ever to remain strong. The saying that time heals all wounds is true, not because wounds, like sand castles, wash away with the first tide but because in time you learn to survive your wounds."

Through struggling with illness, these people eventually integrate new bodily facts into their lives and their self-concepts (cf. Charmaz 1991; Corbin and Strauss 1987). But until they define the changes as chronic and experience their effects daily, ill people look for recovery and can keep illness and therefore their bodies at the margins of their self-concepts (Charmaz 1991; 1994a). Subsequently, they continue to objectify their bodies and distance themselves from them.[3] Not only do their bodies become objects to mend but they are also worksites in which to do it. The situation differs for people who have already struggled with bodily oddities or "psychological" quirks now redefined and legitimated as bona fide physical symptoms. Their initial diagnostic relief turns into the sobering experience of adopting their medical label and of defining what it means to them. As they do so, they may make the label their own while simultaneously objectifying their symptoms that fit the diagnostic label. The writer Nancy Mairs (1989, pp. 235-236) redefines herself and her body as a woman with multiple sclerosis but also objectifies her body:

> Now I am who I will be. A body in trouble. I've spent all these years trying alternately to repudiate and to control my wayward body, to transcend it one way or another, but MS [multiple sclerosis] rams me right back down into it. "The body," I've gotten into the habit of calling it. "The left leg is weak," I say. "There's a blurred spot in the right eye." As though it were some other entity, remote and traitorous. Or worse, as though it were inanimate, a prison of bone, the dark tower around which Childe Roland rode, withershins left, withershins right, seeking to free the fair kidnapped princess: me.

The horror of the unknown—disability and death—prompts the distancing inherent in objectification. Distancing continues as long as the person assumes that mastering his or her wayward body is necessary to make it acceptable. Relinquishing notions of mastering one's body, in contrast, allows a receptivity to bodily experience. Arthur Frank (1991, pp. 60-61) reveals the moment when he shifted from objectifying his body to embracing it as subject: "I wondered at what the body could still do for me, as diseased as I knew it must be. That day I stopped resenting 'it' for the pain I had felt and began to appreciate my body, in some ways for the first time in my life. I stopped evaluating my body and began to draw strength from it. And I recognized that this body was me."

As ill people objectify their bodies less, they are more open to attending to the cues their bodies provide. They learn how to protect their bodies and therefore are able to extend their control over their lives. For example, a woman with lupus erythematosus learned that she could work at home while she was sick. At home, she could control the temperature, light, seating, and interruptions, as well as the pacing of her tasks. When she worked at her clients' offices, she could control little of that. She said:

> But see, I've always gone to the client's place to do the work and now, when I don't feel good, I'm finding that it's much easier to do it here at the house. And then I can just do—I can just do it at night; I can do it early in the morning. Yeah it's too hard to go and sit—sometimes the chairs they make me sit on or the—and it's too cold or it's too hot, or it's just real hard. I don't have the patience I used to have. I lost that. I used to have a lot of patience; I could bear anything. I don't think I was even aware of it. But now my body tells me. I can't control my body.

Before her illness, this woman had ignored bodily discomfort. At that time, she had committed herself, not only to a demanding work and social life but also to a rigorous fitness routine. She had pushed her body to be slim, strong, and taut, as she put it, "like a jungle tiger." She had internalized and met the prevailing standards for appearance. But as she learned to listen to her body, she had to abandon those standards. Uncontainable sickness forced adopting other priorities for her body. Like this woman, other people cease to measure their body against past perfection, or past hopes of perfecting it, and begin to live with it. The sick body becomes familiar and perhaps even comfortable. This familiarity and comfort increases if treatments, regimens, or health practices seem to work. If so, the sick body becomes predictable and manageable. The ill person may feel that he or she is beginning to unify the altered body and the self. Arthur Frank (1991, p. 87) identifies this unity of body and self, "As soon as cancer happened to me, not just to anyone, it ceased to be random. I am a bodily process, but I am also a consciousness, with a will and a history and a capacity to focus my thoughts and energies. The bodily process and the consciousness do not oppose each other; what illness teaches is their unity."

Typically, however, this unity has limits, albeit unstated, taken-for-granted limits. Ill people often believe that they have already suffered beyond tolerable limits. Thus, they see themselves as having filled their quota of human misery and earned their right to a just reprieve. They often said, "I've paid my dues [of suffering]." If so, then new, foreboding symptoms or conditions shock them. Moreover, these people experience the unpredictability of their bodies afresh as they grapple with new or intensified distress. Their uncertain lives and their frail grasp on health again takes center stage. For the past year, a middle-aged woman with multiple sclerosis had fought constant, debilitating infections. She said:

> My body is distressed, and it needs attention, and I'm working very hard to give it that. . . . I really feel with MS, I have a much better hold on it, handle on the MS, much better visualization where I'll be in—what I'll do with it in five years, ten years, because I can adapt as I go along. The problem with infections is that infections going on with MS can alter the disease severely in a negative way, and so I want to get more of a handle on the infections.

After being diagnosed and experiencing her condition for over fourteen years, having multiple sclerosis with some residual disability had become familiar and manageable. This woman had had several extremely debilitating exacerbations but after each one had improved considerably. For lengthy periods, she struggled with keeping her illness contained by maintaining and protecting her body (cf. Charmaz 1991; Monks and Frankenberg, n.d.). Although she always acknowledged that her MS could take a downhill course at any time, she expected to have ups and downs. The belief that she had faced the worst before and improved, gave her hope and caused her to view her MS as predictable and manageable. The infections, however, posed grave uncertainty. She said, "The aging with the MS really doesn't bother me. Aging with chronic infections—the infections can just screw up your body in so many ways, and so I'm more frightened by that because it's unknown."

The unknowns of the past echo in the uncertainties of the present. Ten years before, this woman's MS symptoms had rapidly worsened. She had said then, "I'm just so frightened . . . by the unknowns. If I knew that this was the worst, I could deal with that. But not knowing . . . My legs are getting weaker and I'm so frightened because of the unknowns. My doctor says I may have to go into a wheelchair. That's my bottom line. I won't go into a chair."

COPING WITH CHANGES IN BODILY APPEARANCE

Having a visibly altered body provides the experiencing person, as well as family and friends, with immediate images of change. Such changes occur throughout the course of illness. I use the term "appearance" symbolically as well as literally since knowledge of loss can cast new light and force new self-images upon an individual. But not all people with serious chronic illnesses have visible symptoms and disabilities. Looking healthy can undermine a person's credibility with health practitioners. Women particularly have difficulty being taken seriously. One woman who had a recent angioplasty, angina, an old spinal injury, and bowel disease was told by two of her physicians and her pharmacist, "You don't look like you're old enough to have anything like that happen. You don't look like there could be anything wrong." Even those closest to ill people may not understand their conditions and so expect them to function as before. A middle-aged man had an automobile accident while having a heart attack. Although he sustained some injuries, afterwards, he looked healthy and fit. He lost weight, exercised, and his injuries slowly healed. Yet he had residual fatigue, occasional memory loss, emotional swings, and lethargy from his multiple medications. Because he seemed to have regained health, his losses remained masked. Subsequently, his wife lost patience with him as his business declined and he withdrew from the family. She saw him as shirking responsibility.

Relatives and friends may not be able to fathom debilitating changes in a person who shortly before had functioned with extraordinary competence. Youth and beauty render an invisible illness even more invisible. While in her early thirties, a woman's youth disguised her debilitating arthritis. Her much older boyfriend saw her as healthy and beautiful. For years, her constant complaints of pain mystified him. She could not enforce her identity claims as ill as long as she appeared healthy, pretty, and able. Because of her appearance, both her private and public identities belied how she defined her self. She said:

> I may look like I'm healthy and all this stuff and I get—all these guys start making catcalls and I'm in pain and it just seems incongruous. I go, "What are they whistling at?" I usually identify with how I *feel,* even though I go through a lot of effort to make myself look good, I still identify with how I feel. It's like being—feeling like an old person in a young person . . . . It's like only an old person is entitled to have all this pain.

By four years later, this woman's disabilities had become apparent. Although she had long identified herself as in pain and disabled, she also had been accustomed to other people noting only her beauty. Being socially identified as disabled undermined her self-worth and sense of wholeness. She said:

> I think it's real embarrassing. You know, like say if someone can see that I can't walk or something, I'm all stooped over, you know, I catch a glimpse of myself in ah, like a window, it's very shocking sometimes what I see. [I asked, "In which way?" She said:] Well, I can see that, other people can see is that, you know, my leg, I can hardly walk on it. And I feel like somehow I'm not a whole person and . . . people can look at it and feel sympathetic, but they can look at you and see you as less than whole, you know. (Charmaz 1991, p. 111)

She added, "Somehow it's almost like a defect to me. And . . . , it's frightening, I guess." Five years later her disability was quite marked. Because she questioned whether she still was attractive to men, she had several affairs, which she regretted.

Ill people may evince few problems about impairment or loss of function until a hidden loss becomes visible. For example, impotency can be a problem known only to a man's wife unless the marriage dissolves. The tension between invisible disability and visible impairment becomes evident. Lesley Fallowfield and Andrew Clark (1991, p. 66) show how some British women with mastectomies rejected their altered bodies when their breast amputation was visible:

> *Interviewer:* Can you tell me how you felt about your appearance since your operation?
> *Patient:* Mm, that depends—I think I look OK when I'm wearing my false one, don't you? I don't think anyone could tell.
> *Interviewer:* And without your clothes?
> *Patient:* That's rather different—I tend not to look at myself—it upsets me that I don't look like a woman anymore.
> *Interviewer:* What about when you're with your husband?
> *Patient:* Oh, I don't let him see me, oh no. I couldn't. He'd be horrified. I always undress in the bathroom now.

Like the woman above, other ill people tried to reduce the effects of visible disability on their pursuits and relationships. And like her, they could then reduce the effects of it on themselves and their social identities. One man on kidney dialysis always wore long sleeves and usually a jacket to hide his dialysis shunt. Feelings about visible disability influenced both men's and women's identity goals. When men could not hide or minimize their changed appearance, they often withdrew. Hence, their identity goals plummeted. Women withdrew less but dwelt upon appearance issues in the interviews much more than men. They tried to manage their appearance to handle their feelings and to bolster their confidence. Nancy Dyson, who had a mastectomy, said:

> Wearing bright colors and makeup and pulling myself together before I go out is a way of protecting my vulnerability so people don't make assumptions. It's like camouflage. It's sort of like the camouflage is the door and I can open it or not. It is another way of having control over my disease. I choose whom I share my vulnerability with. (Donnally 1991, p. D5)

Women under fifty evinced much concern about the effects of illness on their appearance. I asked a forty-one-year-old woman with lupus erythematosus if her thoughts about her appearance had changed at all in the last five years. She replied with fervor, "I hate my body; I hate my body. Mostly because I've gained so much weight and—and then my face breaks out [lupus has a characteristic rash]. People look at you like something's wrong [with your character]. I don't hate it because it's sick; I hate it because it's ugly . . . . You're supposed to be skinny and pretty."

When changes in appearance are sudden and visible, particularly women may define those changes as tests of their love relationships. A forty-two-year-old woman suffered a devastating reoccurrence of mixed connective tissue disease when she was pregnant three years ago. She had not had such a serious episode for eighteen years, long before she had met her husband. During that previous episode, her boyfriend had left her and her parents had ignored her. She described herself and her concerns during this second flare-up:

> Oh, I was just a disheveled lump, I mean I was a disheveled lump. I'm sort of still a disheveled lump, I feel like in a lot of ways. But it doesn't much matter to me. Yeah, I mean I think in some ways this was a little bit of a test of me with Bob [husband]. It's like, "Here's the worst I can possibly be," you know; "I'm sick; I'm vomiting; I look like crap." And then I gained so much weight, so it's like, "Here's the worst I can be. Are you going to leave me now?" you know. "Are you going leave now? When are you going to leave? Are you going to leave next week?"

CHANGING IDENTITY GOALS

Bodily Changes and Identity Goals

Bodily changes prompt changing identity goals. Upward changes allow ill people to entertain possibilities and try new ventures. A successful transplant, cardiac rehabilitation program, or medical regimen means feeling better and more able. Then people reentered the worlds they left or embarked on new pursuits. They readily moved on with their lives when they had alternatives and when their identity goals throughout illness had assumed moving beyond it. Thus, these people returned to work, or if working, increased their work hours, pursued sports and hobbies, and planned to redirect their lives. Men returned to their careers. A few women started new businesses. Several men and women went back to school.

Bodily changes, including noticeable improvement, do not automatically result in changed identity goals. Emotions and social relationships influence choices and actions. When fear of failure or further sickness permeates ill people's thoughts, they proceed slowly in forming or changing their identity goals. A young married woman who had had cancer feared a recurrence. She resisted investing herself in a valued pursuit because she could not tolerate the possibility of losing it. Her husband's income allowed her to experiment with college courses and low-paying, part-time jobs. Relying solely on self led some people to measure their options, situations, and bodies carefully when they prized their autonomy. These people could not risk becoming immobilized. Paradoxically, they risked becoming social captives of their sick bodies.[4] Under these conditions, people made changes very slowly and avoided taking risks. They often needed substantial encouragement to reach for more challenging identity goals. After spells of sickness, they had difficulty imagining themselves going beyond their current situations. For example, a woman who had lupus erythematosus had wanted just to be able to work enough to remain self-supporting. Her appalling encounters with eligibility workers and social service employees resulted in her avowals never to depend on public assistance. She recounted:

> I didn't think—didn't have any wide horizons. My friend Ken, he told me last year, "Bonnie, I just can see you managing a business," right? I said, "Oh, give me a break," you know. And he even probably said it to me in February. "You know, Bonnie, you ought to open an office and blah, blah, blah." I said, "Don't even talk about it; I'm not interested in it." But it just happened. One day I had too much work and I said, "Wait a minute." So I got up, called the *Times* [local paper] and as I was walking away from the phone, I went, "What did I do?" That's the way it all happened. And my friends gave me [money] to get started in my business.

In contrast, a downward spiral, or sudden serious episode can force lowering identity goals. Ill people must either adapt because they cannot handle the lives they had—even in the recent past—or they realize that they now have a tenuous hold on managing their lives. How do they do it? What social context affects their choices?

Certainly, markedly altered bodily functioning and feeling can undermine present identities or force lowering identity goals (see, for example, Albrecht 1992; Dahlberg and Jaffe 1977; Pitzele 1985; Plough 1986). People with chronic illnesses resist lowering their goals if they believe others need them to function as before. They put their bodies and their lives at risk when they view their identity losses as too great or when they remain unaware of the extent of their physical losses. For example, several heart patients abandoned their diets and regimens after a few months because they no longer felt sick. In addition, people who recognize but cannot account for their reduced capacities tenaciously try to function. One middle-aged woman said, "It was scary at times. I didn't know what was wrong. [I was] not feeling well, and always having to push, push, push. Always behind the eight ball, always tired, always pushing against this wall of fatigue. And trying to keep up, you know."

The Social Context of Changing Identity Goals

Identities bring commitments and responsibilities. In turn, how individuals define these commitments and responsibilities in relation to other people deeply affects their identity decisions. Changing identity goals then takes into account (1) the individual's definitions, (2) significant others' views and wishes, and (3) the interactions and negotiations among them. Once chronically ill people have altered their lives to accommodate to limited identity goals, it takes substantial support to move beyond them.[5] Given their definitions, ill people may only relinquish their identities and their accompanying identity goals when forced to do so. They may develop intricate strategies to preserve their identity goals. For years after having been immobilized by illness, a single woman had balanced her work productivity with her energy limits. When necessary, she simply took time off from work to avoid a full-blown exacerbation or to regain her energy. By carefully monitoring and maintaining her body, she could realize her overriding identity goal of remaining independent. But keeping bodily needs and identity goals in balance can prove to be arduous. Now married, this woman has two young children as well as farm animals to care for in addition to a part-time university teaching job seventy miles away. Her identities as mother, wife, and teacher supersede any illness identity and cause her to persevere beyond her bodily limits. Her children need her; she and her husband committed themselves to not using child care. The family's need for her income also tugs at her, especially since her husband lost his main job. Thus, by realizing her identities, she risks being forced to relinquish them. She compared how she handled illness when she was single with her current situation, "Going through that whole period in my life when I was real sick, I got very used to just listening to my body and how it's feeling and totally going how—by how I was feeling from day to day. And I can't really, I can't always do that now. There's sometimes when I have to push it much more than I would have before."

Before her marriage, this woman was a successful independent entrepreneur. Her autonomy combined with her control over employees' work assignments permitted her to take time-outs from work to nurture her body. More frequently, middle-class and professional men, not women, can fit their work around their bodily needs. When they can control the social context of work, they can realize and further their identity goals concerning it.

A major part of the social context revolves around spouses or partners. In long-term marriages among older couples, loyalty and attachment typically remain unquestioned although spouses may have sharp differences about health monitoring (cf. Johnson 1985). Wives of all ages willingly saw their husbands through crises, even when marriages were shaky. Problems generally arose later as the long-term effects of illness emerged. In contrast, support from husbands and boyfriends of middle-aged and younger women was more tentative throughout illness. These men did not take over tasks as readily as wives did, and they abandoned their relationships emotionally, if not completely, more quickly than women. Women with illnesses sometimes relied on adult children, friends, and health-care workers for emotional support and practical assistance .

Multiple crises and disabilities that cut into pivotal roles (e.g. breadwinner, sex partner) undermined middle-aged and younger spouses' support. Previously conflicted marriages may break at this point. Subsequently, taken-for-granted identities as companion and parent may also dissolve. Conflicts about identity goals may develop in strong relationships. The type of identity goal and rate and intensity with which the sick person pursues it can all become points of contention (see also Peyrot, McMurry, and Hedges 1988; Speedling 1982). A woman with multiple sclerosis wants to do volunteer work in a busy hospital; her husband feels her body cannot handle the stress. A man with heart disease waits for his health to improve; his wife believes that he is becoming an invalid and should go back to work.

Certainly age, gender, work, and marital status shape, but do not determine, the context in which chronically ill adults change identity goals. As Alan Radley (1989) states, what people with chronic illnesses adjust *with* is as important as what they adjust *to*. Their ways of changing identity goals and adapting to the changes also reflect the content of their lives and the meanings they attribute to their ongoing interactions. Money and help make an enormous difference as to how, when, and why people will or will not lower their identity goals. Single mothers often sacrificed their health for sustaining their identities as workers and parents. Money and help also affect how people feel about changing identity goals (see, for example, Albrecht 1992). Possessing sufficient funds allows older men and women to retire early, a socially acceptable disengagement for the affluent. Having financially secure spouses permits others to leave their jobs or to reduce their work hours. In short, money and help allow ill people more choices about which identity trade-offs to make and when to make them.

The social context of changing identity goals may itself change. The designated "patient," financial resources, and potential help may change and thus result in shifting identity goals. For example, one older woman with a mild heart condition felt forced to seek employment when her husband's health declined (after two heart attacks and bypass surgery) and he lost his job (and his pension) three years before his expected retirement. Two years later, however, she suffered a small stroke. Though she had little lasting impairment, she took the stroke as a warning that she had been under too much pressure. She then became the designated patient in the family. Fortuitously, her husband had become re-employed and could again support them. The move of an adult daughter back into their area also meant help with household tasks and errands. Subsequently, this woman relinquished her identity goal of being fully employed.

Identity Goals and Identity Trade-offs

Identity goals emerge and change through mediation of subjective and social meanings. Hence, ill people sacrifice some identities in favor of retaining others. Noted anthropologist Robert F. Murphy (1987) suffered from a progressive paralysis. He did not endure the professional and financial devastation common to many adults with disabilities because he could continue to work in a field in which he had already established himself. Nonetheless, he felt pressured to remain a productive scholar to validate his worth and to command his colleagues' respect. He writes about returning to teaching in a wheelchair:

> My overreach beyond the limits of my body was a way of telling the academic world that I was still alive and doing what I always did. And all my feverish activities in both academia and my community were shouts to the world: "Hey it's the same old me inside

> this body!" These were ways of protecting the identity, for preserving that inner sense of who one is that is an individual's anchor in a transient world. (p. 81)

Feeling devalued results in weighing interactional costs and in balancing necessities against possible identity trade-offs. To the extent that these identity issues are direct and explicit, people will construct explicit identity goals. Murphy's interactions formed an unspoken yet unyielding mirror that reflected the renegotiation of his preferred identities. Because Murphy's strained interactions with acquaintances at work reduced his self-worth, he avoided meetings and receptions. He knew that he could not conduct field research so he became a textbook author. He preserved his sense of self by choosing his activities carefully and by making identity trade-offs. Murphy viewed textbook authorship as a lesser identity than ethnographer but also saw himself as "too old" for ethnographic forays, which mitigated his identity trade-off. As people shift their identity goals laterally or downward, they may relinquish what others view as the more socially valued identity. They feel their losses. They think about their lives. They assess the costs and benefits of relinquishing activities and responsibilities and, therefore, identities. When costs to their bodies and intimate relationships exceed relative gains, they give up valued identities. A middle-aged woman related:

> I'd come home and I was in such pain—you have to work [on the job] seven hours but you put in eight or nine. It's very stressful. But I never succumbed to stress but once or twice. It was doable because I only worked three days a week . . . But Alan [husband] would come home and I'd be on the couch in such pain I couldn't get off, too tired to fix dinner and he was just wonderful. He'd call at work, "Well, what should I bring home tonight?" And some nights I'd cook, but not many. And so I decided, this isn't a way to live. I don't have to work . . . . So it was with great regret, and not something I planned, I turned in my resignation. It's the best thing I ever did.

Concurrence from others strengthens the person's belief in having made the right choice. The woman above agreed with former associates' appraisals of her appearance. She recalled, "I went to a wine tasting that we put on a couple weeks ago . . . and some of the Board members were saying, 'Gee, you look so much better. You were all bent over; you looked terrible.' I did look awful. I need more rest; you have to pace yourself."

After making identity trade-offs, people often try to redefine their identity choices in positive ways. Similar to other kinds of decision making, they want to view their choices as sound. At this crucial point, the tension becomes apparent between acknowledging bodily limits and needs and constructing a preferred identity for those who must make significant changes of activity and direction in their lives. In order to handle their lives, they must integrate self and illness without having it consume their self-concepts. Thus, like the woman above, they may, in effect, view identity loss as identity gain. In essence then, people can move up their identity hierarchy while they move down their bodily hierarchy.

By this time, these ill people account and care for their altered bodies while viewing themselves as residing in their bodies but not as wholly defined by them. Part of redefining personal identity depends upon seeing one's self as more than one's body and the illness within it (Charmaz 1991). The woman above defined the place of illness in relation to identity:

> Fibromyalgia does not define who Ellen Thomasen is. It's baggage I've got to carry along. We've all got baggage. Some of it's light and some of it's heavy. And we'd like to check it in a locker awhile. And sometimes you can do that and sometimes you can't but it's not going to stop me from going on a trip. That's the way I feel.

Simultaneously, she recognized her limitations and her need to care for her body while creating her life and facing an uncertain future. She said, "I wonder if I'm going to be able to be active with my grandchildren . . . I'm wondering—we don't know what the symptoms are going to do, you know. I plan to fight as long as I can. And by fighting—it's an attitudinal thing—it's also resting and doing the things you need to do. I don't—I've always been so active that I don't like this at all. But it's doable, you know?"

Finding the balance between struggling with illness and relinquishing identity goals permits ill people to construct valued lives. A woman with multiple sclerosis once felt deep regrets about lost chances and dashed hopes. She feared then "that having MS will affect my life in a negative way," as well as affect her husband and children seriously. Although ten years later she had relinquished some earlier dreams, she had also realized several, including traveling, which she had expected to forego. Deeply imbedded in her family life, she could now say, "I'm comfortable with who I am, where I am."[6]

SURRENDERING TO THE SICK BODY

Surrendering means to stop pushing bodily limits, to stop fighting the episode or the entire illness. The quest for control over illness ceases and the flow with the bodily experience increases. Surrender means awareness of one's ill body and a willingness and relief to flow with it (cf. Denzin 1987a; 1987b). A person ceases to struggle against illness and against a failing body at least at this specific time. Through surrendering, the person anchors bodily feelings in self. No longer does he or she ignore, gloss over, or deny these feelings and view the ill body as apart from self.

Conditions for surrender to occur include (1) relinquishing the quest for control over one's body, (2) giving up notions of victory over illness, (3) affirming, however implicitly, that one's self is tied to the sick body. Ill people may surrender and flow with the experience in the present but hope for improvement in the future. Yet they are unlikely to entertain false hopes. At this point, the person views illness as integral to subjective experience and as integrated with self (see also LeMaistre 1985; Monks and Frankenberg n.d.) .

Surrendering differs from being overtaken by illness, resigning oneself to it, or giving up (cf. Charmaz 1991; Radley and Green 1987). Being overtaken occurs without choice; surrendering is an active, intentional process. However silently and tacitly, ill people agree to surrender. When surrender is complete, the person experiences a new unity between body and self. Mark Kidel (1988, p. 18) advocates "reclaiming our illnesses as expressions of our own being," to gain authenticity. Like Arthur Frank (1991, p. 1), who views illness as "an opportunity but a dangerous one," Kidel also recognizes that doing so risks opening "ourselves to the full and unpredictable impact of the unknown" (p. 19). Hence, ill people define their experience as newly authentic when they realize that having an ill body is part of them and they allow themselves to experience it. They also may define their past ways of relating to illness as inauthentic. Several people echoed this man's view, "I was just a phony, pretending I didn't have it [kidney failure], trying to do everything everyone else did when my body was telling me I couldn't."

Surrendering also can be distinguished from becoming resigned and losing hope. Becoming resigned means yielding to illness, acquiescing to its force, or to the devalued identities attributed to it. Such resignation means accepting defeat after struggling against illness. When people give up, they lose hope and crumble inward. Passivity, depression, and debility follow. They are overtaken by illness. Under these conditions, people with chronic illnesses can become much more disabled than their physical conditions warrant. They lose interest in their regimens and, perhaps, in living. As they give up, they give in to fear and despair. In contrast, surrender means permitting oneself to let go rather than being overtaken by illness and despair.

Resisting surrender means holding on and, with advanced illness, refusing to die. Fear may propel critically ill people. When they struggle against illness and try to impose order upon it and their lives, they are unlikely to surrender during the midst of crisis. But later, learning to live with residual disability can teach them about surrender. As Arnold Beisser (1988) acknowledges, he learned about surrender through facing defeat. Like many other men, Beisser had earlier believed, then later hoped, that his sustained effort would force change to occur and victory to prevail. Yet no amount of effort changed the fact of his disability. Beisser (1988, pp. 169-170) reflects:

> Defeated on all fronts, I had to learn how to surrender and accept what I had become, what I did not want to be.
>
> Learning to surrender and accept what I had not chosen gave me knowledge of a new kind of change and a new kind of experience which I had not anticipated. It was a paradoxical change.
>
> When I stopped struggling, working to change, and found means of accepting what I had already become, I discovered that that changed me. Rather than feeling disabled and inadequate as I anticipated that I would, I felt whole again. I experienced a sense of well-being and a fullness I had not known before. I felt at one not only with myself but with the universe.
>
> This was not the change that had been wrought by struggle, work and effort, but by learning not to struggle, how to give in, to stand aside and let truth emerge. It was not the tragic truth I expected at all.

For Beisser, surrender meant stripping away the fantasy of recovery, the wish for recovering former wholeness. Still, surrender allowed for being in the flow of the moment rather than wishing and waiting for a mythical future. No longer could pressing symptoms, marked disability, and progressive illness be ignored or redefined. When surrendering, illness merges with subjectivity; it *becomes* subjectivity. Surrendering to illness opens the possibility of transforming the self. By reentering the present anew and flowing with it, ill people gain fresh views of themselves and their situations. External social mandates melt away as the person gains voice from within. Subsequently, a new sense of wholeness of self can emerge.

When an individual is very sick, surrender permits unity with the diseased body. Fighting illness at this point may amount to fighting *against* oneself instead of *for* oneself. One woman struggled against Hodgkin's disease for twelve years; she resisted being constrained and defined by her illness. During her last hospitalization for a bone transplant, her last hope of recovery, she realized that her body could handle no more. At that point, she relinquished her struggle and surrendered to illness and death. How do people know when to surrender and to what to surrender? When overtaken by illness, the woman who resisted relinquishing her responsibilities said of surrendering:

> It means that I don't have—I can't control it [ill body] and [it means] to look at what it has to teach me. Just . . . let it tell me what it needs to tell me. You know, that willingness and that acceptance . . . . So it didn't come instantly, but I was willing to surrender and to look at what was going on. But it did come; it did happen. And I'm always much more at peace after I'm able to do that anyway.

Fighting for her meant fighting for control over an unwilling body. Surrender allowed her to find new integration of body and self. She disclosed, "I become more when I surrender, I mean I become more; my spirit's able to grow. And it can't do that if I'm holding on to control."

In this sense, by freeing the self from a quest for control, it becomes possible to experience the moment and to allow the boundaries of self to flow and to expand. Yet self also anchors the person to continuity with past, present, and future. And that anchor itself becomes problematic while surrendering to sickness. Another woman reflected upon this problematic relationship between body and self:

> To me it's [immersion in illness] sort of moving toward spiritual states where you do lose a sense of self and time as a release. I mean, self is a kind of bondage in a way—so it's wonderful—you move toward heaven—to not have that burden. But the other thing, of course, is that we are here. I exist as Jane so Jane comes back and wants to exist. So that's the hellish side. (Charmaz 1991, p. 104)

CONCLUSION

The process of adapting outlined above offers a window on unity between body and self in illness. Illness presents the possibility of developing new and deeper meanings of the relation between body and self. Such possibilities remain more hidden and implicit in ordinary adult life. But as ill people go through and emerge from crises, complications, and flare-ups, they also reenter mundane adult worlds. Meanings gained through experiencing surrender may fade and recede into the past. Yet these meanings and their accompanying feelings may be reawakened and remembered when illness progresses and health again fails.

Appearance issues affect women more heavily than men. However, compared to men, women show greater resilience in the face of illness and greater ability to adapt and flow with the experience of illness. Men more often than women take an all-or-nothing approach to identity goals. They place a higher stake in recapturing the past and with it, their past identities (cf. Charmaz 1994). If they cannot reclaim all of their past identities, they drop the struggle. Failing to achieve their preferred identities becomes tantamount to complete failure. Under these conditions, such men give up.

How might adapting affect those whose lives are intertwined with an ill person? Whether they welcome adapting or define it as defeat depends on their views and interests. Adapting can cause havoc in the lives of people who depend on the ill person and who cannot or will not renegotiate or relinquish earlier reciprocities. If family and friends believe the proper stance toward illness is struggling against it or politely ignoring it, then they will be displeased to witness their ill person adapting to it. More likely, however, family and friends are relieved when the ill person begins to adapt. As he or she does so, earlier anger, self-pity, guilt, and blame dissipate. Adapting leads to taking responsibility for self. Hence, spouses and partners may feel much less need to monitor the ill person and to patrol his or her activities. Moreover, chronically ill people who adapt do not require their friends and family to construct a fictional present and mythical future with them. Adapting fosters candor and openness. And ultimately, surrendering to illness permits grave illness and death to be a part of life for the survivors as well as the sick person.

Adapting to impairment takes people with serious chronic illness on an odyssey of self (cf. Charmaz 1991). Their bodies become alien terrain. Their altered lives can transport them into unfamiliar worlds where they feel estranged. Furthermore, the familiar becomes strange when altered bodies pose new constraints, require careful scrutiny, and force attending to time, space, movement, and other people in new ways. By struggling *with* illness while constructing their lives, chronically ill people feel that they regain lost control over their bodies and their lives. By regaining control and coping with bodily changes, these people learn to live with their illnesses. As they do, the strange becomes familiar. Because surrendering to the sick body strips the journey of routine distractions and obstacles, conditions exist for ill persons to experience self anew and to continue the odyssey with renewed clarity and purpose. In this sense then, adapting to impairment fosters redemption and transcendence of self.[7]

Through struggle and surrender, ill people paradoxically grow more resolute in self as they adapt to impairment. They suffer bodily losses but gain themselves. Their odyssey leads them to a deeper level of awareness—of self, of situation, of their place with others. They believe in their inner strength as their bodies crumble. They transcend their bodies as they surrender control. The self is of the body yet beyond it. With this stance comes a sense of resolution and an awareness of timing. Ill people grasp when to struggle and when to flow into surrender. They grow impervious to social meanings, including being devalued. They can face the unknown without fear while remaining themselves. At this point, chronically ill people may find themselves in the ironic position of giving solace and comfort to the healthy. They gain pride in knowing that their selves have been put to test—a test of character, resourcefulness, and will. They know they gave themselves to their struggles and lived their loss with courage.

Yet the odyssey seldom remains a single journey for these chronically ill people. Frequently, they repeat their journey on the same terrain over and over and, also, find themselves transported to unplanned side trips and held captives within hostile territories as they experience setbacks, flare-ups, complications, and secondary conditions. Still they may discover that each part of their odyssey not only poses barriers, but also brings possibilities for resolution and renewal.

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NOTES

1. I am indebted to Margaret Purser (personal communication, 1993) for the term "continuing metaphors of opposition."

2. Olesen et al. (1990) refer to this type of self-appraisal as the self as knower. They argue that through a hurting body, people view their bodies as significant reference points in relation to self and illness.

3. When someone does not understand the diagnosis and its implications, the possibilities for objectifying the body increase. This process intensifies if the person and those around him or her also have little understanding of chronicity. If so, the person may detach self from his or her impaired body. In any case, illness can be such an assault upon the self that the person views his or her bodily changes as unreal (cf. Manning 1991).

4. Physical loss can consume caregivers as well as their patients. Maggie Strong (1988, p. 254) reveals how her husband's continued physical losses steadily consumed *her* self and body:

> Ted's hearing wasn't improving at all. Was he going to lose hearing next? Stunning, a stunning loss.
>
> Would I now become his senses, not just his hands and legs and fingers? Stunning, a stunning possibility. . . . My sorrow for Ted's hearing faded into a growing panic and rage. He was climbing right into my body. I was climbing right into his, into his sensory lobes, into his auditory cortex and he into mine. This was a gradual total body transplant in which my own self would be entirely usurped.

Ian Robinson (1988) invokes Strauss et al.'s (1984) concept of "identity spread" to address similar themes. Robinson quotes the wife of a man who had multiple sclerosis: "At this time [when her husband was badly affected] I felt completely overtaken by MS. I saw it, spoke it, lived it, hated it, all day, everyday. Any outside contact was MS; any visitor was to see Walter and see how his MS was" (p. 57).

5. Formal and informal social support for changing identity is geared more to the young and middle-aged than the old. Thus, younger and middle-aged adults have more access to formal support through rehabilitation counseling and therapy than older people and more incentives and prods from others to reconstruct their lives. As people get older, decisions once set into motion, like retirement, become increasingly difficult to undo. The social structure affords older people fewer alternatives for change.

6. The comfort that chronically ill middle-aged people gain with their bodies and their identities echoes studies in aging that demonstrate greater self-acceptance of professionals in their fifties (Karp 1988; 1992). Similarly, marital and occupational status may greatly affect this self-acceptance. Middle-aged men and women in long-term stable marriages, for example, seemed most self-accepting.

7. I am indebted to Norman K. Denzin (personal communication, 1993) for reminding me of the cultural myth of redemption after loss followed by transcendence of self (see also, Charmaz 1991).

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