Self, Sickness, Somatization, and Systems of Care

The scope of health psychology is very broad, including concerns with the promotion and maintenance of health, the prevention and treatment of illness, the psychological correlates of health and illness, the individual's relations with the health-care system, and the use of psychological knowledge in the formulation of health policy (Taylor, 1995). Perhaps because of its roots in social psychology, health psychology has focused on the sociocultural contexts of illness and health. For example, a recent review of the field (Taylor, Repetti, & Seeman, 1997) emphasized the unhealthy environment and discussed the role of such factors as race and socioeconomic status, the community, family, peer groups, work relations, and social networks in determining the level of disease-inducing chronic stress experienced by individuals, their vulnerability to mental illness, their coping skills and resources, and their health habits and behaviors. Interestingly, in all the literature in this new and exciting field, relatively little attention has focused on the role of the self in the genesis and maintenance of health and disease and in moderating an individual's health-related behavior, including his or her interactions with health-service providers.

It is true that concepts of self-regulation are implicit in much of the psychosocial literature on health (Carver, 1979; Carver & Scheier, 1982, 1985, 1991; Leventhal, Nerenz, & Steele, 1984). Monitoring one's own symptoms and other bodily states, whether on one's own, or by consulting a physician or using biofeedback devices, is essential to achieve and maintain good health. Only when we are aware of the dis-
crepancy between our current state and the state we wish to attain can we engage in the kinds of behaviors that will reduce this discrepancy. This bifurcated knowledge of our current states, and of our ultimate goal states, constitutes an important aspect of self-awareness. Moreover, our motivation to engage in effective self-regulation may be determined by self-efficacy (Bandura, 1977, 1997), our belief that we are capable of engaging in the kinds of behaviors required to achieve the goal state in the first place, or return to it after we have drifted away. Physical disease can have a profound impact on one’s self-image, as when scars, disfigurements, and amputations create a divergence between the current appearance of a patient’s body and the way he or she remembers appearing in the past. The visible stigmata of disease, and disease-related inability to return to work or to pursue other accustomed activities, may pose a grave threat to one’s self-esteem (Jones et al., 1984). (For detailed analyses of how physical illness influences self-related contents and processes, see Charmaz this book, chap. 9, and Leventhal, Idler, & Leventhal, this book, chap. 8).

Thus, the self plays an important role in health and illness, but most theoretical work in this area seems to rely on a rather informal, or even implicit, construal of the self and does not refer to any specific theoretical formulation. Consider, for example, the biopsychosocial model of health and illness that lies at the core of most health-psychology theory (Engel, 1977, 1980; Schwartz, 1982, 1984). The biopsychosocial model attempts to show how illness arises through the interaction of biological factors such as viruses and bacteria, psychological factors such as beliefs and coping strategies, and social factors such as socioeconomic status and social support (and how illness can be prevented by systematic attention to the same interaction). The self is somewhere in the biopsychosocial model, surely, but it is not represented explicitly anywhere in that model. Similarly, the health belief model (Becker, 1974; Rosenstock, 1966) invokes such factors as people’s perceptions of their susceptibility to illness to explain their health-related behaviors, but does not otherwise talk about their beliefs about themselves. Even Leventhal’s self-regulation theory of illness behavior, which has self in the title, does not invoke the self at any of its stages, except implicitly in the perception of symptoms and the appraisal of coping strategies (Leventhal & Cameron, 1987; Leventhal, Meyer, & Nerenz, 1980; Leventhal & Nerenz, 1985; Leventhal, Nerenz, & Steele, 1984). Put bluntly, if we want to entertain the concept of self-regulation, we need to know what the self is and what it looks like.

The Self as a Knowledge Structure

The social intelligence view of personality and social interaction (Cantor & Kihlstrom, 1987) defines the self as one’s mental representation
of his or her own person and personality. It is part of the repertoire of declarative knowledge on which one draws to guide his or her social interactions. In other words, the self is an organized knowledge structure representing people's own individual understandings of themselves (their appearance, their characteristic beliefs, motives, values, attitudes, and behaviors, and their typical relations with other people). In addition to this more or less abstract self-knowledge, the self also includes some reference to one's autobiographical record of events and experiences in which he or she was the agent or patient, stimulus or experiencer (Kihlstrom & Cantor, 1984; Kihlstrom & Klein, 1994, 1997; Kihlstrom, et al., 1988; Kihlstrom, Marchese-Foster, & Klein, 1997). This is especially the case for those autobiographical episodes that exemplify one's self-concept. But every episodic memory is linked to the self (Kihlstrom, 1997).

More specific descriptions of the self as a knowledge structure are derived from more general theories of knowledge representation within cognitive psychology (e.g., Kihlstrom & Klein, 1997). For example, when considering the self-concept, one may begin by asking how other concepts are structured in the mind and assume that the self-concept is structured similarly. Viewed as a concept, then, the self does not appear to be a monolithic mental representation composed of defining features that are singly necessary and jointly sufficient to distinguish the self from all others. Rather, it appears to be a fuzzy set of context-specific exemplars representing what one is like in each of a number of salient social contexts: with parents or with friends, at work or at home, in sickness or in health. These exemplars may be united by a principle of family resemblance, resulting in a prototypical self representing a person's most characteristic features. Or they may be unified by an overarching theory of why we seem to be the people we are, or why we seem to be one person in one kind of situation and quite another person in others (Epstein, 1973).

In a similar way, consider Schilder's definition of the self-image as "the picture of our own body which we form in our own mind" (1938, p. 11). That idea is very close to folk psychology, and most scientific psychologists today are reluctant to talk as if there are pictures in the head because a homunculus would be needed to view them. On the other hand, recent research on mental imagery and perceptual memory suggests that it might be quite appropriate to view the self, construed as an image, as a perception-based mental representation that stores knowledge about the visual features of one's face and body, the spatial relations among these features, the acoustic properties of one's voice, the characteristic sweep of one's gestures, and so on. People have perception-based representations of others, which allow them to recognize these others on the street or on the telephone. And they have similar perception-based representations of themselves, as well: for example, people with eating disorders often rate themselves as fatter than they
really are. This is a clear indication of a conflict between self-image and reality.

Other forms of mental representation are applicable to the self. For example, Pennington and Hastie (1993) have shown that jurors organize the evidence presented to them into a story structure representing initiating events, goals, actions, and consequences. More generally, Schank and Abelson (1995) have argued that knowledge is commonly represented as stories, not as lists of facts, beliefs, and features. Accordingly, the self can be viewed as a kind of narrative, or perhaps an interlocking set of narratives, told to self and others, about where one came from, what one is doing now, and where one is headed in the future (Charmaz, this book, chap. 8; McAdams, 1997; Pennebaker and Keough, this book, chap. 5).

Last, but not least, we can think of the self as part of a large associative network of memories—a bundle of sentence-like propositions representing semantic knowledge of one’s own physical and psychosocial traits and episodic knowledge of specific experiences, thoughts, and actions. This idea has been pursued most vigorously by Klein and Loftus (1993), who have used sophisticated priming paradigms to show convincingly that episodic self-knowledge is represented independently of semantic self-knowledge.

All of this is admittedly quite abstract, and if we faulted models of health and illness behavior for having little to say about the self, we could, and should, equally fault models of the self for having little to say about health and illness behavior. Thus, we turn to some psychosocial problems of health and illness and consider where the self might play a role.

The Somatoform Disorders, the Self, and Abnormal Illness Behavior

The self would seem to be particularly relevant to health and illness behavior in the problem of abnormal illness behavior. As defined by Mechanic (1962), illness behavior refers to how symptoms are perceived, evaluated, and acted upon by a patient (McHugh & Valis, 1986). As such, illness behavior is neither normal nor abnormal. On the other hand, some illness behaviors are clearly less appropriate, or less adaptive, than others (Pilowsky, 1967; Pilowsky & Spence, 1975). For example, even after receiving a satisfactory explanation of his or her symptoms, and an appropriate prescription for treatment, an individual may remain highly concerned about the state of his or her health. Or a person may become annoyed at other people’s reactions to his or her illness or envy those who are healthier. Or one can retain a strong conviction that he or she is ill, even though the findings of physical exams, laboratory tests, and exploratory surgeries are negative.
Perhaps the most dramatic manifestations of abnormal illness behavior are the mental illnesses known as somatoform disorders: somatization disorder, conversion disorder, pain disorder, hypochondriasis, and body dysmorphic disorder.\textsuperscript{1} In these syndromes, individuals complain of physical symptoms in the absence of any general medical condition that would account for these symptoms. In all these cases, physical illness is a salient feature of a person’s self-presentation; in somatization disorder and malingering, physical illness seems to be a central feature of the self-concept. From a cognitive point of view, some of the somatoform disorders can be thought of as conditions in which the attribute \textit{sick} is a central feature of the self-concept in which descriptions of the self as a sick person, and of illness episodes, are highly accessible in memory, or where the self-narrative is organized around stories of sickness. Such a characterization seems particularly appropriate to somatoform disorder, pain disorder, and hypochondriasis. But these are verbal views of the self, descriptions and narratives composed of words, phrases, and sentences that are highly convenient for cognitively oriented personality and social psychologists to study, perhaps, but not the only way to represent the self. As it happens, there is another somatoform disorder, \textit{body dysmorphic disorder}, which permits analysis in terms of nonverbal, perception-based forms of self-knowledge.\textsuperscript{2}

The somatoform disorders are considered \textit{mental} illnesses, and health psychology has traditionally been concerned with \textit{physical} conditions such as cancer and hypertension. At the same time, the somatoform disorders are mental illnesses that masquerade as physical illnesses, and they are primarily encountered, and treated, by primary-care physicians. As such, they may offer a unique perspective on how people’s self-concepts and self-images are related to their health and illness behavior, including their interactions with health-care professionals and other elements of the health-care system.

\textit{The Self as Ugly Person}

In body dysmorphic disorder, originally called dysmorphophobia (Morselli, 1891), a person is preoccupied or excessively concerned with imagined or exaggerated defects in physical appearance, rather than with imagined or exaggerated symptoms and sickness (for reviews, see Phillips, 1991, 1996; Phillips & Hollander, 1996). These defects cause the person significant distress and cause considerable impairments in role functioning, even though they do not exist, or are hardly noticeable by others. In body dysmorphic disorder, a person’s self-image is discrepant from the way in which he or she is perceived by other people.

A recent clinical study of 30 cases found that the most frequent complaints were of imagined defects with the patients’ head hair, beard
growth, body hair, nose, skin (including acne and facial lines), eyes, head or face shape, body build, or bone structure; somewhat less frequent were complaints about the size or shape of body parts below the neck (Phillips, McElroy, Keck, Pope, & Hudson, 1993). The average age of onset was mid-adolescence, and the course was chronic, with new imagined defects added over time. At the time they were interviewed, most of the patients had multiple concurrent complaints. Only a small minority had any insight that their defects were imagined rather than real: for most of the rest, their preoccupation with self-image usually had the quality of an overvalued idea, whereas for a large minority, the self-image was frankly delusional. Patients in this last class might qualify for a diagnosis of another syndrome relevant to the self-image, delusional disorder, somatic type (de Leon, Bott, & Simpson, 1989). Almost three quarters of the patients had sought treatment from plastic surgeons, dermatologists, or dentists. Most of these requests were refused on the ground that there was nothing to treat. However, eight patients had undergone a total of 25 procedures, most of which, as might be expected, only made the symptoms worse.

At the expressly subclinical level, Fitts, Gibson, Redding, and Deiter (1989) found that 70% of college students were dissatisfied with some aspect of their physical appearance, and 28% met all diagnostic criteria for body dysmorphic disorder. Young people with body dysmorphic disorder could become overconsumers of health-care services because, for some people, troubled interactions with health-care professionals may begin with the perception of the self as ugly.

The Self as Sick Person

For some time now, we have been interested in the problem of somatization disorder, formerly known as Briquet's syndrome (Briquet, 1859; Guze & Perley, 1983). In somatization, an individual complains of multiple physical symptoms that cause significant impairment in role function, but for which there are no demonstrable organic findings or known physiological mechanisms. Onset is typically before age 30, and the multiple unexplained complaints generally persist for several years. Somatization is a common cause of absenteeism from work, and an extraordinarily large portion of physician time and effort is spent with individuals who seek medical attention, not simply because of the nature of the symptoms, but more as a result of their frequency, severity, and persistence (Kellner, 1990; Kirmayer, 1986). Somatization has been called "medicine's unsolved problem" (Lipowski, 1987).

For example, a group of patients studied by Smith, Monson, and Ray (1986a) were identified in midlife by histories of chronic illness averaging 30 years in length, including multiple unexplained symptoms and multiple hospital admissions, and major diagnostic and surgical proce-
dures. For the population as a whole, the 1980 census indicated that the annual per capita expenditure for health care in the United States averaged $543, including $123 for physician services and $385 for hospital care. By contrast, the individuals in the somatization study sample spent, on average, $4,700 per year, including $1,721 for physician services and $2,382 for hospital charges (Smith et al., 1986a). For one patient, the quarterly average was $13,067 in charges, including 42 days in the hospital. These individuals also spent an average of seven days per month in bed (the population average for this variable is slightly less than half a day). Over half of the somatization group said that they had been "sickly" for most of their lives, and 83% claimed that they had quit work because of poor health.

**Mechanisms of Somatization** In somatization disorder, there is positive evidence, or at least a strong presumption, that the person's physical complaints are linked to psychological stress or conflict (Cloninger, 1986, 1987, 1996; Guze, 1967; Kirmayer & Robbins, 1991; Smith, 1991). Somatization has frequently been defined as the tendency to experience or express psychological states as somatic symptoms (Lipowski, 1968). Thus, somatization contrasts with psychologization (Kirmayer, 1984). However, somatization should not be characterized as simply a function of the transfer of emotional distress into somatic complaints. Other mechanisms that bias perception and shape expression may be crucial to the individual's experience of self as sick (for a review, see Kirmayer, 1986).

For example, the complaints in somatization disorder may reflect the somatic component, as opposed to the subjective feeling component, of an individual's negative emotional states. That is to say, an individual under stress might be expected to have cardiovascular or gastrointestinal symptoms. In this case, however, we would expect that medical tests might reveal a physical basis for the person's symptomatic complaints (e.g., tachycardia, muscle tension, or excess gastric secretion). But this is precisely what is not found in somatization disorder. In somatization disorder, the person complains of symptoms that cannot be objectively confirmed.

As another example, cybernetic self-regulation theories posit that one's awareness of one's internal state is a function of control processes that monitor the availability and urgency of internal compared to external information (Carver, 1979; Carver & Scheier, 1982, 1985, 1991). This cue competition theory posits that a varied external environment will reduce attention to internal information and so will decrease reporting of somatic sensations. Similarly, individual differences in public and private self-consciousness (Fenigstein, Scheier, & Buss, 1975) will determine the degree to which one is aware of, and responds to, his or her own internal physical states. According to this point of view, indi-
viduals most likely to report multiple unexplained symptoms are less likely to experience an external environment that focuses attention away from internal states. Again, however, the cue-competition theory assumes that somatizing patients are attending to actual physical changes that should be detected by appropriate medical testing, but that has not been found to be the case in somatization disorder.

More likely, somatization tendencies arise from basic processes affecting the social construction of the self (Kirmayer, 1984, 1986; Kleinman and Kleinman, 1985). Broadly speaking, people have two means for expressing emotional distress: somatization and psychologization. In somatization, distress is referred to, and expressed by, the body; there is something wrong with one's heart, stomach, and so forth. In psychologization (which might be more appropriately labeled "psychosocialization"), there is something wrong with a person's mind and social relations. For example he or she is unhappy, his or her marriage is unsatisfactory. Medical anthropologists tell us that psychologization is something of a Western invention while somatization is closer to the norm in the rest of the world, and that this difference has to do with peculiarly Western modes of construing the self (Lock, this book, chap. 3; Shwedler & Bourne, 1982). Thus, cultural factors will help determine the extent to which a person uses somatic complaints as a vehicle for emotional communication and social control. According to this point of view, because emotions are related to the bodily, as well as the social, aspects of self, somatization cannot simply be the misdirected expression of psychosocial distress. Rather, somatization may be an emphasis on one aspect of all distress (Kirmayer, 1986). It can be construed as symmetrical to psychologization—the emphasis on personal and social dimensions of suffering. Somatization and psychologization perhaps can best be understood as contrasting methods of constructing the meaning of illness that assimilate emotional experience to either the bodily or the social realm.

Yet another mechanism underlying somatization involves the very structure of the health-care system. For example, medical procedures for diagnosis and treatment maintain a focus on the body and encourage somatic attributions of symptoms (Kirmayer, 1986). In the United States, mental illnesses and disorders are still stigmatized to a relatively high degree and therefore the benefits of the sick role tend to accrue to physical illnesses rather than psychiatric or psychosomatic illnesses (Blackwell, 1967). Individuals who emphasize somatic distress may be pursuing the most direct path toward reaping the benefits that may be derived from the sick role (Charmaz, this book, chap. 9).

*Somatization in Young Adults* Although somatization disorder is commonly identified during middle age, it should be noted that one of the criteria for the diagnosis is a long-standing history of multiple, unex-
plained medical complaints. Thus, the natural history of somatization probably begins much earlier than middle age. Indeed, somatization disorder probably begins in adolescence, or even childhood, as a person develops a mental representation of illness and its personal and social consequences and begins to incorporate "being sick" into his or her self-concept and the sick role into his or her repertoire of social behaviors. Accordingly, it seems important to develop means by which people with somatization disorder, or those at risk for somatization, can be identified early in their careers as medical patients, so that their utilization of medical services can be tracked prospectively and effective interventions can be devised.

To this end, a series of studies, conducted at a major university in the Southwest, involved a total of 2,797 undergraduate students, who completed a survey of medical problems and complaints during their introductory psychology course (Canter Kihlstrom & Marsh, 1994). The subjects were nineteen years of age on average, much younger than the typical somatization disorder patient.

For purposes of the survey, Canter Kihlstrom and Marsh (1994) constructed a medical problems and complaints (MPC) questionnaire based on the 35 symptoms considered in the diagnosis of somatization disorder, according to DSM-IIIR (American Psychiatric Association, 1987). The questions covered a variety of problems in the gastrointestinal (e.g., vomiting, nausea), cardiopulmonary (e.g., heart racing, shortness of breath), sexual (e.g., impotence, painful sex), and female reproductive spheres (e.g., menstrual pain, irregular periods); conversion and pseudoneurological symptoms (e.g., blurred vision, fainting); and pain (e.g., back pain, joint pain). The subjects were simply asked to indicate whether they had ever been "bothered" by each symptom, on a 3-point categorical rating scale. A student's somatization score was simply the number of items to which he or she gave a rating of 3 ("definitely yes"). The DSM-IIIR also requires that there be no medical explanation for the complaints, of course, but this question was omitted on the survey so that the questionnaire, intended as an initial screening device, would not become too cumbersome.

The results of these studies, conducted from 1993 to 1994, were very striking. In the first study, the 683 subjects endorsed a mean of 5.91 of the thirty-five symptoms listed. The gastrointestinal symptoms were among those most frequently endorsed, while back pain and pain in the extremities were also common. Cardiovascular symptoms were frequent in a population that is, overall, quite healthy and active. Except for dizziness, pseudoneurological or conversion symptoms were relatively rare. Menstrual symptoms were fairly frequent among the women. Women yielded significantly higher somatization scores than men, even after the four genitourinary symptoms that can be endorsed only by women were eliminated. According to DSM-IIIR, the thresh-
old for somatization is crossed by individuals who endorse 13 or more relevant symptoms, with no restrictions on their distribution: 13% of the sample (38% of this group was male) met this criterion and were considered to be at least at risk for somatization.

In a follow-up study, a much larger sample of 1,557 subjects completed a 15-item version of the MPC based on earlier studies that validated brief screening instruments for somatization (Othmer & De-Souza, 1985; Smith & Brown, 1990; Swartz et al., 1986). The subjects identified as at risk for somatization disorder reported a higher number of medical consultations in the past year than subjects with low scores on the short MPC questionnaire. Moreover, they reported higher levels of abnormal illness behavior on a brief version of the Illness Behavior Questionnaire (IBQ; Pilowsky & Spence, 1975). Within the somatization group, there were no differences in either utilization or abnormal illness behavior between men and women. In other words, within the at-risk group, men and women were similar. These findings were confirmed in a third study employing the full 35-item version of the MPC questionnaire.

As a general finding, the National Institute of Mental Health (NIMH) Epidemiologic Catchment Area (ECA) study reported a prevalence of somatoform disorder (a broad diagnostic category including conversion disorder and hypochondriasis as well as strict somatization) of about 0.3% for women and 0.1% of the population at large (Robins et al., 1984). By contrast, about 6% of women seen in one outpatient psychiatric clinic exhibited somatization disorder (Othmer & DeSouza, 1985), and other reports from various hospital consultation and liaison services report a prevalence ranging from 2% to 8%. Among primary care physicians (i.e., specialists in family practice, internal medicine, pediatrics, and obstetrics/gynecology), unexplained medical symptoms may account for as much as 10% to 30% of patient visits. In a recent study of psychiatric disorders in primary care, Kellner (1990) found evidence of somatization disorder in about 26% of medical patients. Thus, although somatization disorder may be relatively rare in the general population, it seems to be overrepresented in various health-care settings.

Somatization can be characterized as a problem of identity: an individual identifies himself or herself as a sick person, and it is this self-concept that colors the interpretation of percepts and feelings as symptoms of disease and, ultimately, leads to vigorous, persistent requests for medical services and treatments. A physician, on the other hand, identifies that individual not as sick, but perhaps as mentally ill, an identification that the individual vehemently rejects. In other words, somatization disorder involves a fundamental conflict between an individual’s self-concept, “I am a sick person,” and a physician’s impression of that individual, “No, you’re not,” or even “You’re crazy.” Resolving
this conflict is the key to more appropriate treatment of these patients by health-care providers and more appropriate utilization of health services by individuals.

_Treatment of Somatization_ Individuals who suffer from somatization are difficult to treat because their self-perceptions do not match the way they are perceived by others. They think that they are physically ill and seek help from a physician or other health-care professional. That provider, in turn, will try to determine what is the matter, employing the full armamentarium of modern medicine. After numerous laboratory tests, and perhaps even exploratory surgery, the health-care professional may conclude that this patient is not ill after all. He or she may even refer this individual to a psychiatrist. The patient then interprets that referral as evidence that he or she is not being taken seriously, and the relationship spirals downward. Successful intervention requires that a physician and an individual be in the same consulting room. That is, either a physician must adopt an individual’s view of self, or an individual has to change his or her self-concept.

Challenging an individual’s self-concept seems an unlikely prospect, so some practitioners have adopted the strategy of embracing that self-concept. For example, Wickramasekera (1995) offers individuals with somatization disorder biofeedback and other “high tech” treatment modalities. Biofeedback at least resembles a medical treatment (after all, it is intended to help the patient control bodily processes), and therefore it communicates to the individual that the health care professional is taking the physical complaints seriously. According to Wickramasekera, this treatment focuses on physical symptoms, builds rapport in turn, and lays a foundation for additional referrals such as psychotherapy.

Similarly, Smith and his colleagues have devised a consultation-liaison procedure in which services continue to be delivered by a primary-care provider (Kashner, Rost, Smith, & Lewis, 1992; Smith, Miller, & Monson, 1986; Smith, Monson, & Ray, 1986b). Instead of being referred to a psychiatrist or other mental-health practitioner, individuals with a diagnosis of somatization disorder who are first seen in primary care settings are scheduled for regular physical examinations by their general practitioner every four to six weeks. This is intended to make contact with a physician independent of symptomatic complaints. The physician, in turn, is discouraged from going further than the routine physical. For example, special diagnostic tests or hospitalization are not ordered unless they are clearly indicated by the physical exam. He or she is also encouraged not to tell individuals that their symptoms are “all in their head.” Rather, as with Wickramasekera’s biofeedback procedure, the physical examination is intended to communicate that an individual’s self-perception as sick is being taken seriously.
Results of an initial randomized controlled study showed a clear advantage for the new approach, with health-care charges declining by about 50% over 18 months, mostly due to the controls on hospitalization (Smith et al., 1986b). Unfortunately, a later study showed a decline of only about 12% (Kashner et al., 1992), and suggested that the effects on utilization were likely to extinguish over about two years. Perhaps this outcome is related to another finding of the studies: the consultation-liaison program may save some money, but it does not lead to any improvement in overall outcomes such as physical or mental health, perceived health, or psychosocial adjustment. The physical complaints seen in somatization disorder may reflect one’s psychosocial difficulties. And, if this is the case, individuals will continue to have these complaints, identify themselves as sick people, and seek and use medical services, so long as these psychosocial difficulties go unattended. Successful treatment may depend on finding a way to change these individuals’ modes of self-identification, so that they will more readily accept the psychosocial interventions that they really need.

The Self, Self-Regulation, and Compliance

Paying attention to a person’s self-concept and other psychosocial realities also may be the key to success in other interactions between consumers and providers of health-care services. Consider the problem of compliance with medical treatment regimens (Haynes, 1982; Haynes, Sackett, & Taylor, 1979). Once a disease has been diagnosed, and treatment involves a medication regimen, what can be done to encourage and promote adherence to that regimen? This is a particular cause of concern regarding individuals who suffer from chronic diseases such as asthma, depression, diabetes, and hypertension.

Many attempts have been made to promote adherence by improving communication (e.g., Ley, 1989). As one recent example, a new organizational form has emerged, the pharmaceutical benefit management (PBM) firm (see Canter Kihstrom, 1996a, 1996b, 1997a, 1997b; Reissman, 1995), which specializes in managing prescription benefits for employers and managed care organizations. A PBM verifies clients’ eligibility for benefits, processes claims for reimbursement, and handles communications with pharmacists on the retail level. However, it also engages in physician and patient education programs designed to enhance adherence to medication regimens. For example, the pharmacy staff of the firms will mail patients informational brochures pertaining to their disease and its treatment, and physicians will receive information about the drugs and their proper doses. The pharmacy staff also examines refill patterns using a computerized database as a way of monitoring adherence to the regimen.
Most recently, PBM firms have adopted an approach to care, known as disease management (DM), which carves out an entire illness for specialized management (Terry, 1995). While DM goes beyond strictly pharmaceutical concerns and focuses on the entire spectrum of care for a particular condition, including outpatient, inpatient, and ancillary services, PBM firms that develop DM programs continue to focus on pharmaceuticals.

A specialized focus on drugs, or on specific disorders, may improve the quality and outcome of care generally and adherence to therapeutic regimens in particular. However, the DM strategy, as used by PBMs, seems to be based on perhaps invalid assumptions about adherence. The focus on providing information to individuals seems to be predicated on a communication model of compliance that holds that adherence will occur if individuals receive, understand, remember, and believe the correct information about their illnesses. Unfortunately, research suggests that whereas informational and educational efforts can enhance adherence over the short run, these same efforts may not have much effect in the long run (Haynes, Wang, & Gomes, 1987). It seems that effective management of pharmacy benefits, or of whole diseases, will require a better understanding of the complex compliance process.

It is in this context that we return to the self-regulation model of compliance developed by Leventhal and his colleagues (Leventhal & Cameron, 1987; Leventhal, Nerenz, & Steele, 1984). According to this model, compliance and other adaptive illness behaviors involve a sequence of three stages: interpretation, coping, and appraisal. At the interpretation stage, a person develops a cognitive representation of his or her illness, its symptoms, etiology, course, prognosis, treatment, and prevention. Based on this representation, one then considers the available coping strategies, selects one or more for implementation, and puts it into action. Finally, one engages in an appraisal of the action plan’s outcome, which then feeds back to affect both the representation of the problem and the action plan itself.

Leventhal and his colleagues have been particularly interested in the role of emotion in this process. For example, fear appeals may increase the salience or threat value associated with the cognitive representation of the disease, but may actually interfere with coping by making one afraid to find out whether he or she has a disease in the first place. However, aspects of the self clearly play an important role as well. Thus, one’s autobiographical memory for previous illness episodes, his or her own and other people’s, may affect the representation of the illness, the selection of coping strategies, and the appraisal of outcomes.

Other aspects of selfhood may also be critical to effective self-regulation of compliance and other illness behaviors. For example, self-regulation begins with a cognitive representation of one’s current state,
or a mental representation of one's current self, and a cognitive representation of the goal state. This is what Markus and Nurius (1986) might call the "possible self." Receiving a medical diagnosis, especially of a chronic condition, will likely alter one's mental representation of self, and so it is necessary to understand how such new knowledge gets incorporated into the self-concept. And, of course, there are other possible selves to consider, including the one that lies waiting in the future if a person does not effectively comply with doctor's orders.

An illness like hypertension, with no symptoms identifiable without special equipment, may be especially hard to incorporate into the self-concept. There is no pain, or lump, or gastric distress, or difficulty breathing to remind one that he or she does, in fact, have an illness. And the act of compliance itself may involve changes, such as medication routines, side effects, and activity restrictions, which have to be incorporated into the self-concept: cat lovers with cat allergies, people with diabetes who no longer can eat what they want, and asthma sufferers who can no longer jog with their friends, must alter their self-concepts if they are to get healthy and stay healthy. Further, in the case of diseases like cancer that often have chronic deteriorating courses, and for which treatment is sometimes risky and uncertain, one actually has to choose between two goal states or two possible selves. Given compliance, the treatment may work, leading to remission of the disease, but have such a profound impact on physical appearance and quality of life that individuals no longer feel like themselves; or individuals can retain their current sense of self and lifestyle through noncompliance but pay for it with a shorter life, and perhaps a more difficult end. Thus, in order to understand how one comprehends an illness, or complies with a prescription, it is necessary to understand not only how he or she represents the disease and its treatment but also how he or she represents himself or herself as concept, as memory, as story, and as image.

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Notes

1. J. Kihlstrom (1992, 1994) has argued that conversion disorder properly belongs in the category of dissociative disorders, along with psychogenic amnesia, psychogenic fugue, and multiple personality disorder, on the grounds that conversion symptoms reflect pseudoneurological disorders of consciousness affecting the special senses and voluntary motor function. These are divisions of
consciousness ultimately involving the mental representation of the self (J. Kihlstrom, 1997). By contrast, somatization disorder, body dysmorphic disorder, and hypochondriasis involve the types of symptoms that, if organically based, would be diagnosed and treated by internal medicine. This argument was considered (Martin, 1996), but ultimately rejected, in the framing of DSM-IV (American Psychiatric Association, 1994).

2. Additional examples, outside the domain of the somatoform disorders, are anorexia nervosa and bulimia nervosa, where in addition to disordered eating behavior, a person may actually perceive certain body parts (e.g., the abdomen, buttocks, thighs) as too fat. In such cases, where one's perception of his or her own body shape is so out of proportion to objective reality, we can think literally of a disturbance in self-image. Transsexualism, the feeling of being a woman trapped in a man's body, or vice versa, may also reflect a discrepancy between self-image and perceptual reality.

References


ple unexplained symptoms. Paper presented at the annual meeting of the American Public Health Association, Washington, DC.


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