

Illness Behavior and the Sick Role

Illness behavior refers to “the way in which symptoms are perceived, evaluated, and acted upon by a person who recognizes some pain, discomfort or other signs of organic malfunction.” On the surface, it may seem that the nature and severity of an illness would be the sole determinants of an individual’s response, and, for very severe illnesses, this is often true. But many people fail to see a physician or go very late in the disease process despite the presence of serious symptoms, and many other people see physicians routinely for trivial or very minor complaints. These patterns suggest that illness behavior is influenced by social and cultural factors in addition to (and sometimes instead of) physiological condition.

STAGES OF ILLNESS EXPERIENCE

Edward Suchman (1965) devised an orderly approach for studying illness behavior with his elaboration of the five key stages of illness experience: (1) symptom experience; (2) assumption of the sick role; (3) medical care contact; (4) dependent patient role; and (5) recovery and rehabilitation. Each stage involves major decisions that must be made by the individual that determine whether the sequence of stages continue or the process is discontinued.

STAGE 1: SYMPTOM EXPERIENCE

The illness experience is initiated when an individual first senses that something is wrong—a perception of pain, discomfort, general unease, or some disruption in bodily functioning. Suchman states that three distinct processes occur at this time: (1) the physical pain or discomfort, (2) cognitive recognition that physical symptoms of an illness are present, and (3) an emotional response of concern about the social implications of the illness, including a possible disruption in ability to function.

Assessment of Symptoms

David Mechanic (1968) developed a theory of help-seeking behavior to facilitate an understanding of this assessment process and how individuals act prior to (or instead of) seeking a health care provider. Mechanic traces the extreme variations in how people respond to illness to differences in how they define the illness situation and to differences in their ability to cope with the situation. The process of definition and the ability to cope are both culturally and socially determined. As individuals mature through life stages, they are socialized within families and within communities to respond to illness in particular ways. Part of this socialization is observing how others within the group respond to illness and noting the positive or negative reaction their behaviors elicit. Sociologists refer to this process as the social construction of illness. Mechanic identifies 10 (sometimes overlapping) factors that determine how individuals respond to symptoms of illness.

1. *The visibility, recognizability, or perceptual salience of symptoms.* “Many symptoms present themselves in a striking fashion, such as in the case of a sharp abdominal pain, an intense headache, and a high fever. Other symptoms have such little visibility (as in the early stages of cancer) that they require special checkups to be detected in their early stage.”

2. *The perceived seriousness of symptoms.* “If the symptom is familiar, and the person understands why he has the symptom and what its probable course will be, he is less likely to seek care than if the symptom is unusual, strange, threatening, and unpredictable.”
3. *The extent to which symptoms disrupt family, work, and other social activities.* “Symptoms that are disruptive, and which cause inconvenience, social difficulties, pain, and annoyance are more likely to be defined and responded to than those that do no.”
4. *The frequency of the appearance of symptoms, their persistence, or frequency of recurrence.* “The more persistently ill a person feels, other factors remaining constant, the more likely he is to seek help, and frequent or persistent symptoms are more likely to influence a person to seek help than occasional recurring symptoms.”
5. *The tolerance threshold of those who are exposed to and evaluate the deviant signs and symptoms.* “An individual’s tolerance for pain and discomfort and his values about stoicism and independence, may also affect how he responds to symptoms and what he does about them. Persons vary a great deal in how much discomfort they are willing to tolerate and the attention they give to bodily troubles.”
6. *Available information, knowledge, and cultural assumptions and understandings of the evaluator.* “The sophistication of patients about medical matters varies from those who are aware of the latest therapeutic developments even before their doctor to those who cannot identify the basic body organs and who have only very naïve notions of bodily functioning. Such differences in medical knowledge and understanding have considerable influence in how people recognize, define, and respond to symptoms.”
7. *Perceptual needs which lead to autistic psychological processes.* Anxiety and fear may impact on symptom recognition and the decision to seek care in complex ways. Anxiety about illness may prompt quicker care-seeking, but fear of particular diagnoses may delay seeking help.
8. *Needs competing with illness response.* People assign varying priority to health. While illness symptoms might be a central focus for some, family and work-related activities are more important to others.
9. *Competing possible interpretations that can be assigned to the symptoms once they are recognized.* “People who work long hours expect to be tired, and are therefore less likely to see tiredness as indicative of an illness. People who do heavy physical work are more likely to attribute such symptoms as backache to the nature of their lives and work rather than to an illness condition.”
10. *Availability of treatment resources, physical proximity, and psychological and monetary costs of taking action.* The cost of treatment, convenience of treatment, and the cultural and social accessibility of the provider all impact on the care-seeking decision.

Research on Symptom Assessment

There are significant social and cultural influences on the way people interpret and respond to medical symptoms such as pain. For example, variations in response to pain are based on differing

levels of pain tolerance that are culturally prescribed in different ways for women than for men or for members of different ethnic groups.

Zborowski (1969) found that Protestants of British descent tended to respond in a matter-of-fact way to pain, which enabled them to adapt to illness more quickly than other groups. Patients of Irish heritage often repressed their suffering and tended to deny pain. Both Jewish and Italian patients responded to pain with more open emotionality; however, Jewish patients were primarily concerned about the long-term consequences of their illness and were not much comforted by the administration of pain-killing medication, while Italian patients were more oriented to the current pain and were at least somewhat satisfied when the pain was relieved.

Other research focusing on perceived pain in getting one's ears pierced also found significant ethnic differences. Testing both male and female volunteers between the ages of 15 and 25, Thomas and Ross found that Afro-West Indians reported significantly less pain than Anglo-Saxons, who reported significantly less pain than Asians—all for the same procedure.

What causes these patterns? Both role modeling within families and social conditioning are important influences. As one grows up in a family, there are countless opportunities to observe reactions to pain and alarm expressed by family members. Children's anxiety about receiving painful medical treatment has been shown to be strongly correlated with parental anxiety.

In response to the assessment of symptoms, the individual may decide to deny that the symptoms need attention, delay making a decision until symptoms become more obvious, or acknowledge the presence of an illness. Should an illness be admitted, the person may enter stage 2—the sick role.

STAGE 2: ASSUMPTION OF THE SICK ROLE; ILLNESS AS DEVIANCE

If the individual accepts that the symptoms are a sign of illness and are sufficiently worrisome, then the transition is made to the sick role, at which time the individual begins to relinquish some or all normal social roles.

Background of the Sick Role Concept

The **sick role**, one of the most fundamental concepts in medical sociology, was first introduced by Talcott Parsons in a 1948 journal article but elaborated in his 1951 book, *The Social System*. Parsons emphasized that illness is not simply a biological or psychological condition, and it is not simply an unstructured state free of social norms and regulation. When one is ill, one does not simply exit normal social roles to enter a type of social vacuum; rather, one substitutes a new role—the sick role—for the relinquished, normal roles. The sick role is, "also a social role, characterized by certain exemptions, rights, and obligations, and shaped by the society, groups, and cultural tradition to which the sick person belongs."

Parsons viewed sickness as a type of deviant behavior in that it is a violation of role expectations. Functionalist theorists (like Parsons) are concerned about the impact of deviant behavior

upon society and parts of society. Sickness is assessed as being dysfunctional for the family because when one member is sick and relinquishes normal responsibilities, other members are required to pick up the slack—and may become overburdened in so doing. In addition, sickness is dysfunctional for society. The equilibrium that society maintains can be disrupted when individual members, due to sickness, fail to fulfill routine responsibilities. The “lure” of sickness—the attraction of escaping responsibilities—requires society to exercise some control over the sick person and the sick role so that disruption is minimized.

Sickness is acknowledged to be a special form of deviant behavior; however, it is not equivalent to other forms of deviance such as crime. Institutions (law and medicine) are created in society to deal with both behaviors, but while criminals are punished, the sick are provided with therapeutic care so that they become well and return to their normal roles.

Within the context of social control responsibilities of medicine, society allows two explicit behavioral exemptions for the sick person but also imposes two explicit behavioral requirements. The exemptions are

1. The sick person is temporarily excused from normal social roles. Depending on the nature and severity of the illness, a physician can legitimize the sick role status and permit the patient to forgo normal responsibilities. The physician’s endorsement is required so that society can maintain some control and prevent people from lingering in the sick role.
2. The sick person is not held responsible for the illness. Society accepts that cure will require more than the best efforts of the patient and permits the patient to be “taken care of” by health care professionals and others.

In order to be granted these role exemptions, however, the patient must be willing to accept the following two obligations:

1. The sick person must want to get well. The previous two elements of the legitimized sick role are conditional on this requirement. The patient must not get so accustomed to the sick role or enjoy the lifting of responsibilities that motivation to get well is surrendered.
2. The sick person is expected to seek medical advice and cooperate with medical experts. This requirement introduces another means of social control. The patient who refuses to see a health care professional creates a suspicion that the illness is not legitimate. Such a refusal inevitably reduces the patience and sympathy of society and those surrounding the patient.

Criticisms of the Sick Role

Sociologists today are divided on the sick role's current value as an explanatory concept. The four main criticisms are briefly described below:

1. The sick role does not account for the considerable variability in behavior among sick persons. Variation occurs not only by age, gender, and ethnicity, but also by the certainty and severity of prognosis.
2. The sick role is applicable in describing patient experience with acute illness only and is less appropriate in describing persons with chronic illnesses who may not have easily recognizable symptoms and may not get well no matter how much they want to and how faithful they are in following the physician's instructions.
3. The sick role does not adequately account for the variety of settings in which physicians and patients interact; it is most applicable to a physician-patient relationship that occurs in the physician's office.
4. The sick role is more applicable to middle-class patients and middle-class values than it is for persons in lower socioeconomic groups. Not everyone can follow this pathway; for example, lower income persons have less freedom to curtail their normal responsibilities, especially their jobs, and thus have a more difficult time complying with the model.

The Medicalization of Deviance

While Parsons described the role of medicine as an instrument of social control, many believe that the powers of the medical institution have now expanded far beyond areas of genuine expertise. This has led to a **medicalization of deviance**, a concept that has two primary meanings. First, an increasing number of behaviors and conditions are being interpreted in medical terms, giving the medical profession increased powers in determining what is normal and desirable behavior; and second, medical practice is understood to be the proper mechanism for controlling, modifying, and eliminating these "undesirable" deviant behaviors. Bringing behaviors such as alcoholism, drug addiction, compulsive overeating, and compulsive gambling under a medical rubric introduces a "quality of therapeutic mercy into the way they are handled."

Demedicalization

Concern that the medical profession's powers of social control have become too extensive, a counter movement toward **demedicalization** is now underway. It includes such elements as the removal of certain behaviors (e.g., homosexuality) from the APA's list of mental disorders and the deinstitutionalization of mental health patients (mental patients who can survive on the outside and are not dangerous are mainstreamed into society). Ironically, both medicalization and demedicalization are occurring simultaneously in society.

Symbolic Interactionism: The Labeling Approach to Illness

Whereas the biomedical approach assumes illness to be an objective state, **labeling theory** views the definition of illness to be a subjective matter worked out in particular cultural contexts and within particular physician-patient encounters.

Every society has its own particular norms for identifying the behaviors and conditions that are defined and treated as illnesses. These illness definitions are not objective and are not permanently fixed in at least two important ways. First, the definitions differ from culture to culture and change over time within cultures. In the United States, alcoholism was once considered to be a voluntary, criminal act; it is now considered to be a medically treatable illness. On the other hand, homosexuality used to be considered to be a lifestyle choice.

Second, implications of the illness label are influenced by social position. Many people might be considered mentally ill for engaging in the same kinds of behaviors for which college professors are labeled “eccentric.” Cocaine addicts, alcoholics, and people who abuse prescription drugs are all medically defined in different ways even though all may be experiencing chemical substance abuse. The stigma (or lack of it) is certainly influenced by the individual’s social standing.

Application of the illness label is especially important because of the influence labels have on how a person is treated. Individuals who have received mental health care may always be viewed somewhat differently than people who have not received such care, even after treatment ends and mental health restored. Likewise, someone who is diagnosed with cancer may forever after be considered fragile even if the cancer is successfully combated.

STAGE 3: MEDICAL CARE CONTACT/SELF-CARE

When Suchman’s “stages of illness experience” was devised in the mid-1960s, the third stage was labeled as “medical care contact” and described as the point at which an individual sought professional medical care. Today, medical sociologists are much more aware of the variety of options available to persons who have entered the sick role, the increasingly common practice of self-care, and the importance of the individual’s social and cultural environment in shaping the action taken.

The Decision to Seek Professional Care

In the previous chapter, we emphasized both macro (social-structural) and micro (individual decision making) factors as influences on participation in health behaviors. Both factors are also important influences on the decision about seeking professional medical care. Ronald Anderson and Lu Ann Aday, who have helped to guide sociological thinking about the use of medical services, developed a framework for examining access to care that includes both structural and individual factors.

They posit that access to care can best be understood by considering (1) the general physical, political, and economic environment, (2) characteristics of the health care system, including health care policy and the organization and availability of services, and (3) characteristics of the population, including that that may predispose one to use services (age, gender, attitudes about health care); those

that enable one to use health services (income and health insurance coverage); and the need for health services.

Concentrating more on the individual level, DiMatteo and Friedman have specified three factors that influence the decision to seek care:

1. *The background of the patient.* Propensity to see a physician is influenced by such factors as age, gender, race and ethnicity, and social class. For example, men often are more reluctant to see a physician, and many married men schedule an appointment only when pressured by their wives to do so (estimates are that women make 70 percent of all health care decisions). Many (especially older) men prefer to “tough it out” and are embarrassed to discuss such matters as sexual dysfunction, prostate enlargement, and depression.
2. *The patient’s perception of the illness.* Zola (1973) identified five “social triggers” that influence the judgment that the symptoms need professional health care: (a) perceived interference with vocational or physical activity, especially work-related activity; (b) perceived interference with social or personal relations; (c) an interpersonal crisis; (d) a **temporalizing of symptomatology** (setting a deadline—if I’m not better by Monday, I’ll call the doctor); and (e) pressure from family and friends.
3. *The social situation.* Even for pain that may relate to a serious condition, situational factors matter. Symptoms that begin during the week, rather than on the weekend, are more likely to motivate prompt contact with a physician, as do symptoms that appear at work and symptoms that appear when other people are present.

The Concept of Self-Care

Self-care describes the broad range of behaviors initiated by individuals to promote optimal health, prevent illness, detect symptoms of ill health, heal acute illness, and manage chronic conditions. It includes obtaining information about health and illness, doing self-screening exams, managing one’s own illness, including self-medication, and formulating clear goals and preferences regarding end-of-life treatment decisions. Although the term *self-care* implies an individual behavior, these practices occur within a social network and are very much influenced by family, friends, and cultural norms.

However it is defined, it is clear that self-care practices are an extremely common and routine response to illness symptoms and are practices that are pervasive throughout the population. Self-care is certainly not a new concept. Since the earliest civilizations, people have taken personal measures to protect their safety and well being and to deal with illnesses. However, the advent of scientific medicine shifted primary responsibility for managing health and illness from the individual and family to the physician. Now, there is a renewed interest among both the general public and many health care professional in shifting the overall management of health care from the professional back to the individual.

The Self-Help Movement. In the 1960s and 1970s, a self-help movement promoting personal involvement and responsibility in health emerged in the United States. It was part of a larger cultural critique of authority and expertise and a partial contradiction to the prevailing value attached to professionalism. Since that time, personal initiative toward health and the management of illness has continued to grow as a result of several factors.

1. An expansion of alternative medical philosophies and clinical approaches that place primary responsibility for health on the individual rather than on the professional. These include behavioral approaches, concepts of holistic health, and therapies derived from Eastern philosophies (e.g., yoga, meditation).
2. As health care costs have continued to climb, there has been an increased interest in potential savings from more vigorous health promotion and disease prevention efforts. Studies indicate that persons who use self-care practices reduce both the number of visits to physicians and the number of days in the hospital, and that commonplace use of self-selected, over-the-counter drugs saves the nation millions of dollars each year in physician's fees.
3. Increased recognition that advances in health status and life expectancy will come more from changes in personal patterns of lifestyle than from additional technological or scientific advances in medicine.
4. Encouragement from the women's movement for women to reevaluate the quality of care received in a male-dominated health care system.

Self-Help Groups. In recent years, there has been tremendous growth in the number of self-help groups—groups of “individuals who experience a common problem, who share their personal stories and knowledge to help one another cope with their situation, and who simultaneously help and are helped.” An estimated 10 million persons annually participate in the nation's self-help groups. Groups have been organized around almost every conceivable disease, addiction, and disability.

STAGE 4: DEPENDENT-PATIENT ROLE AND STAGE 5: RECOVERY AND REHABILITATION

With the onset of the dependent-patient role, the patient is expected to make every effort to get well. Some people, of course, enjoy the benefits of this role (e.g., increased attention and escape from work responsibilities) and attempt to malingering. Eventually, however, the acute patient will either get well and move on to stage 5 or terminate the treatment (and perhaps seek alternative treatment).

The severity of the illness (and whether is it acute or chronic), culturally influenced reactions to illness, the individual's coping ability, and the nature and extent of social support coalesce to determine the impact of the illness on the dependent patient. For many individuals, spiritual beliefs and the support system offered by a religious group are among the most important mechanisms used to deal with illness and with the concerns and fears that it can create. Illnesses may be interpreted in light of a

spiritual belief system, pain and discomfort may be accepted as an opportunity to demonstrate one's faith, and strength may be gained by one's confidence in the benevolence of a higher being.

The following list identifies the major concerns people have during stage 4:

1. *Impairments of personal cognitive functioning.* Patients may be concerned that their illness will progress to a point that their cognitive functioning ability may be impaired or that medications will have a dulling effect on memory, reasoning ability, and capacity for communication.
2. *Loss of personal independence.* Many people deeply value their independence and appreciate it even more when it is threatened. Reliance on others may be a devastating thought—because of the inconvenience and, in a larger sense, the idea of becoming a burden on others.
3. *Changes in body image.* For patients whose illness creates any dramatic alteration in physical image, a major readjustment may be needed. Many people themselves as physical as much as or more than mental beings; any change in body image is significant.
4. *Withdrawal from key social roles.* Because so many people derive their identity from their work/occupation, any disruption in work pattern or work accomplishment is very threatening. If remuneration is affected, an extra emotional burden is created. The withdrawal from key family responsibilities may be of paramount concern, along with anxiety about creating more work for other family members. This withdrawal and concern about it can jeopardize cohesiveness.
5. *The future.* Any chronic or serious acute condition creates questions about the patient's future and the extent to which there will be further incapacitation or physical or mental limitation, questions about financial indebtedness, and questions about permanent losses in daily activities.

Living with Chronic Illness and Disability

These pressure points are intensified for chronic patients who typically must get accustomed to several significant changes in lifestyle and interaction, prolonged regimens of medication, continuing bureaucratic hassles with the medical care system, and sometimes disabling pain.

Based on more than 100 interviews with 55 persons, Kathy Charmaz (1991) has described how experiencing a progressively deteriorating chronic illness can reshape a person's life and sense of self. People experience chronic illness in three ways: as an *interruption in life*, as an *intrusive illness*, and as an *immersion in illness*.

At first, a person with a chronic illness may notice the disruption in life. There is time spent hoping for the best and trying to convince oneself that things will work out. Difficult times lower hopes

and increase fears that important life events will need to be sacrificed. A bargaining process may occur when the person promises to do whatever can be done to feel better. Not fully comprehending chronicity, ill persons seek recovery, and, in doing so, maintain the same image of self and keep the illness external, not allowing it to become an essential part of one's being. Only through time and through the words and actions of others do the meanings of disability, dysfunction, and impairment become real.

Chronic illness becomes intrusive when it demands continuous attention, more and more time, and significant accommodations. Intrusion happens when the illness is recognized as a permanent part of life—when symptoms and treatments are expected and planned around. The ill person loses some control over life but may work to maintain some control and to boost self-esteem. Limits may be placed on the illness—for example, allowing one's self a certain number of bad days. Efforts are made to prevent the illness from occupying more and more of one's time and being.

Immersion occurs as the illness begins to dominate life. Responsibilities are surrendered, and days are dominated by dealing with the illness. "No longer can people add illness to the structure of their lives; instead, they must reconstruct their lives upon illness." They face physical and maybe social and economic dependency; their social worlds shrink; more and more of each day is ordered by the routines demanded by the illness. People turn inward, become more socially isolated, and begin challenging their own identity ("How can I continue to be myself while having this illness?").

Recovery and Rehabilitation

The final stage of Suchman's schema varies depending on the type of illness. For acute patients, the process is one of relinquishing the sick role and moving back to normal role obligations. For chronic patients, the extent to which prior role obligations may be resumed ranges from those who forsake the sick role to those who will never be able to leave it.