CAMPAIGN AGAINST STIGMA: PATIENTS AND THE ONGOING THERAPEUTIC REVOLUTION

CARL A. MAIDA
University of California, Los Angeles

ABSTRACT

Focusing on stigma as a sociocultural phenomenon, particularly in context of the modern hospital as bureaucratic as well as therapeutic institutions, the characteristics of sick role and stigmatization are considered. Patient depersonalization, illness "careers" and power-dependence relationships are noted. A number of forms of self-help, as in management of chronic illness, in coping with serious physical disability, in independent living, AIDS, and other serious conditions are examined, including hemodialysis and lupus.

The modern hospital expanded along with other features of the industrial city in the late 19th century to become the very model of a helping organization. It soon became the primary place where the crisis of illness was to be controlled, or at best managed, as both hospital facilities and professional staffs became more specialized. Moreover, the culture of the hospital also became universally recognized and accepted by lay people as the preferred context for the resolution of their major life crises of birth, acute illness and death. To this day, patients and doctors interact and construct their relationships within treatment settings with a distinct cultural context based upon the premises of scientific medicine, epidemiology, and the management of complex organizations. The complexity of the illness itself, but also the social reaction that many chronic conditions carry with them, produce a considerable emotional burden for both the provider and the patient, and this also influences the culture of care. For example, stigma represents one of the fundamental human costs of chronic illness. Its chief emotional consequence is the

barrier of psychological and social distance established between stigmatized patients, their health providers, and the rest of society.

Stigma is a sociocultural phenomenon, and has its origins in the fact that all, and any, human differences are potentially stigmatizable. It derives much of its force from being embedded in culturally determined beliefs and symbols of illness and deviance. But what is stigmatized in one culture may not be stigmatized in another. Stigma is thus a social construct, in that each society validates what its members regard as a "spoiled identity." Our culture has had a long history of stigmatizing illnesses, such as tuberculosis, polio, leprosy, and more recently, AIDS. In these conditions where contagion is a factor, stigma leads to some form of restriction. While they are indeed contagious, so is the fear that surrounds them and, many times, the fear of the disease goes far beyond the epidemiological consequences.

Stigmatized patients and their families, friends, even their caregivers, suffer the social consequences of the stigma. These include stereotyping, discrimination, social isolation, alienation, and rejection. Patients experience fear and shame as a result of these unfortunate reactions to a stigmatizing illness. In fact, many take responsibility for their devalued identities and blame themselves for their situation. However, others suffering the same stigma turn to self-help groups to redefine their identities as worthy and to learn skills in self-mastery and emotional self-care. As chronic conditions are managed, not cured, and a major component of these illnesses is often stigma, health providers can help to relieve the unnecessary rejection and suffering. Providing non-stigmatized medical care to chronically ill persons requires both clinical and interpersonal skills, and a better understanding of the nature of stigma. In this article, case studies describe professional and lay initiatives on behalf of persons with end-stage renal disease and lupus to exemplify the difficulties that surround the management of care for patients with chronic medical conditions.

MODERN HOSPITALS AND THE THERAPEUTIC REVOLUTION

In the decades following the Civil War, only the disenfranchised visited hospital clinics and dispensaries when they were sick. Hospitals were stigmatized as houses of infection and contagion and "a place where the poor went to die" [1, p. 116]. Their patients were also stigmatized because disease and social deviance were linked in the minds of the elites of the time. In Victorian America, "moral causes and pathological consequences still fit together" [1, p. 120]. In a society where disease was closely associated with poverty and personal morality, the hospital was "a refuge for the unfortunate and the inadequate" [1, p. 120].

During this era, most middle-class Americans avoided hospitals, choosing instead to be treated at home. The general hospital was run as a public or private charity to provide care for those in the lowest socioeconomic groups. These included many of the strangers visible in late 19th century American cities, such as

immigrants and itinerant workers, the urban poor, and others without familial support. The hospital thus treated people who were new to city living and its risks, including industrial workmen injured on the job. Like the public school, it was a place where those unfamiliar with urban institutions were socialized to comply with the governing elites and their demands for moral uplift. Because it was a charitable institution, hospital staff continually reminded patients "that they were enjoying a privilege and their gratitude was expected in return." Hospital patients also provided most of the nursing care to their peers and did routine hospital chores like cleaning and maintenance work.

By the turn of the century, many urban hospitals had been transformed from custodial institutions offering mostly care to medical workplaces dedicated to cure. The modern hospital developed through innovations in technology and organization. They grew and flourished within the Progressive cities of New York, Philadelphia, Baltimore, and Boston, where the movement for reform addressed not only public health care but also municipal government, public education, social welfare, the penal system, and the mental asylum. The application of Pasteur's germ theory and Lister's antiseptic principles to medical science led to improved surgical practices. The use of X-rays, improved techniques of anesthesia, and the ability to provide blood transfusions greatly enhanced medical diagnosis and treatment. These innovations along with other rapid advances in medical technology, the professionalization of medicine and the introduction of formal nursing training contributed to the therapeutic revolution that transformed the hospital from a charity to a profitable enterprise.

Following the lead of English nurse-reformer, Florence Nightingale, upper-class women founded the State Charities Aid Association in New York in 1872 to monitor public hospitals and almshouses. Their efforts in reorganizing the hospital ward and in vigilantly monitoring the institutional environment to diminish the risk of hospital-generated infection led to overall better sanitary conditions. In 1873, the first nursing school was established at New York's Bellevue Hospital, the former New York Almshouse. Nursing education soon flourished as more middle-class women sought out careers in the service occupations. Hospitals grew increasingly reliant upon this cadre of disciplined and skilled student nurses who would work for virtually nothing during their two years of nursing school.

In the early 1900s, Progressive reform and corporate philanthropy contributed to the hospital's transformation from almshouse to a center for medical research, teaching, and professional care. The Flexner Commission, sponsored by the newly established Carnegie Foundation for the Advancement of Teaching, investigated abuses in medical education and called for a closer linkage between medical science, the universities and the hospital. John D. Rockefeller established the Rockefeller Institute for Medical Research in New York to wed the clinic to the laboratory. The medical profession also underwent reform, as physicians reorganized the American Medical Association, formed state licensing boards and created a more scientifically based medical curriculum. The sum of these measures

led more physicians to affiliate with a general hospital and their patients would more often visit them at the hospital's clinics or in their offices near the institution. As a result, the hospital became the preferred medical workplace and the number of house calls diminished.

Throughout the Gilded Age and Progressive Era, the elites supporting these projects envisioned medicine and the modern hospital as scientific enterprises. This followed a trend toward professionalization in other science-based industries, such as chemicals, electronics, and production engineering. A concurrent effort to support these endeavors came about through the convergence of government, corporate, and endowment funds. With this support, scientists and physicians began working together in university and industrial laboratories to seek cures for the diseases plaguing humanity. This collaboration yielded breathtaking advances in medical science so that by the early 1930s, the nation's infant mortality declined by two-thirds and life expectancy increased from 49 to 59 years. The death rates for many diseases dropped significantly: tuberculosis dropped from 180 to 49 per 100,000, typhoid from 36 to 2, diphtheria from 43 to 2, measles from 12 to 1, and pneumonia from 158 to 50. After the successful eradication of yellow fever and smallpox, public health waged campaigns against malaria, pellagra, and hookworm and similar scourges [2, p. 469].

Impressed with these advances, ambitious young men entered the modern hospital's wards and classrooms to pursue careers that would afford them prosperity, status, and greater autonomy in an occupational world increasingly being controlled from above by administrators and managers. The middle classes fully supported these advanced hospital facilities with their expanded range of medical and nursing services, by electing to give birth, to undergo surgery and perhaps to die within their white walls. This sense of confidence has not eroded among succeeding generations of middle-class Americans. Their faith in the medical profession and their satisfaction with hospital care increased dramatically with the discovery of antibiotics in the late 1930s. Prior to this, physicians had been powerless in the face of bacterial infections. After 1940, technological innovation and the growth of the pharmaceutical industry further increased the power of medicine to treat a variety of diseases.

As medicine's therapeutic revolution progressed, hospitals became increasingly bureaucratic in their organizational design. Health bureaucracies have required increasingly more supervisory and managerial personnel to monitor technical and human resources, costs of service delivery, forms of reimbursement, and compliance with government regulations. Between 1946 and 1989, hospital personnel per occupied bed multiplied nearly sevenfold.

Since 1980, health care's share of the U.S. gross national product rose from 8% to 15%. This surge is comparable to the expansion of the railroads in Victorian America and the ascendancy of the aerospace and defense industries after World War II. The health care industry currently employs some eight and one-half million individuals. In post-industrial Pittsburgh, health care has replaced steel as

the dominant sector of the local economy. In post-Cold War Los Angeles, the health sector was one of the few places with job openings. This trend is also apparent in New York where health care has become the city's fastest growing business. Since 1989, New York City has accounted for about 40% of the nation's net job losses. While many production and service jobs have disappeared from New York, the health care sector has expanded dramatically. With an aging population and at least 200,000 HIV-positive individuals, according to *The Economist,* "more than one in ten New Yorkers works in the business, most of them in hospitals, nursing homes or home health care; in the Bronx that proportion rises to more than one in four" [3, p. 24].

While dominating the local economics of many deindustrialized regions, the health sector has appropriated systems of control that developed in mass production industries [4]. Technical control methods were used to maintain a continuous flow of production and to increase the output of both the machines and the workers. This form of control is embedded in the design of machinery, the industrial architecture and the organization of work to maximize efficiency of the physically based aspects of production.

Bureaucratic control, by contrast, is embedded in the organizational structure of the company: its job classifications, promotion policies, work rules, and disciplinary procedures. This second form of control stratifies the workforce by creating new distinctions among employees based upon their technical function and their power within the work setting. The number of supervisory personnel also increases because of the need to regularly monitor and evaluate every worker's performance. Supervisors routinely penalize workers who do not comply with company rules and reward those whose behaviors are in accord with established protocols. Bureaucratic control methods are clearly intrusive, as they impose new behavioral requirements on employees. Like the mass production factory in 1920s America, the hospital is central to understanding how these forms of control are enacted in a core industry of late modernity, namely the care and repair of sick bodies.

IDEOLOGY AND INTERACTION
IN THE HOSPITAL

Philip Rieff has observed that the hospital has succeeded "the church and the parliament as the archetypal institution of western culture" [5, p. 390]. As such, it is central to managing forms of behavior that had been previously regulated by familial, religious, and legal domains. In today's hospitals, physicians create and control the symbolic categories of health and illness, organizing diagnostic and therapeutic activities around their images of professional life. A sense of personal autonomy, or individualism, is central to their clinical self-image. As physician-driven institutions, hospitals are likewise organized around an individualistic image of patient care. Central to hospital life is the

individual's welfare, so that the patient serves as the reference point for most transactions. This patient-centered attitude is the basis for care and help giving, and both the professionals' and their patients' actions derive from it.

Modern hospitals, like other bureaucratic service institutions, have rules that govern clientship. Both physicians and patients call upon these rules to serve their self-interests. Patients negotiate treatment based on their level of need for health care, but also on their personal attributes. Physicians and other health providers use a central tenet—the individual's return to health—to justify their professional activities. Transactions are negotiated from a core of a few significant rules in hospital care, but the rules are tenuous because it is impossible to project accurately the shifting needs of individuals. An element of uncertainty precipitates countervailing diagnoses and treatment plans, and each health provider operates on the basis of this sense of indeterminacy [6].

The rationale for individualism as a core value can be found in the origins of scientific medicine. Since the late 19th century, physicians have sought to understand disease as a process analogous to a mechanical breakdown. The triumph of mechanism and of a naturalistic worldview during the second industrial revolution gave rise to this positivistic conception of the human organism. Since that time, disease has been conceived as an imbalance and dysfunction of the component parts of a machine-like body. Medical intervention proceeds along similar lines, restructuring an individual organism to restore balance or functional regularity. A mechanistic conception of illness, coupled with the germ theory as an explanatory model, led medicine away from a social understanding of disease origins.

Functionalist conceptions of breakdown and intervention to restore homeostasis have also been used to explain patient illness behavior. The "sick role" is a form of ascribed deviance, which absolves patients from blame for having become ill, but holds them responsible for seeking medical treatment. The explanation of illness as a form of social deviance derives from a mechanistic view of "somatic dysfunction" as the incapacity for relevant task-performance, [7, 8]. Somatic illness is thus dysfunctional because it incapacitates an organism's productivity in an industrial society. Disease also threatens healthy persons because sick bodies routinely deviate from social norms, producing undesirable and potentially contagious results. However, the sick must rely upon the healthy for care so that they can return to their productive capacities. To control this potentially conflict-laden situation, the physician takes the role of arbiter and oversees the mutual obligations of the sick and the healthy.

The "sick role," a functionalist construct, has four specific features. A person is absolved from responsibility for his incapacity and exempted from normal role or task obligations. A person's illness is deemed legitimate on two conditions. An individual must recognize the role as undesirable, and must take responsibility for seeking care. With the support of family members, an individual must seek only legitimate professional care. The sick are thus obliged to seek help only from

physicians and hospitals, and health care providers are equally obligated to treat them. Physicians are required to stigmatize the sick through diagnostic labeling, and to insulate them from normal interactions with the healthy to avoid both physiological and behavioral contagion. Despite the threat of contagion, the physician must initiate treatment that compels a patient to depend upon the healthy for care and recovery.

A functionalist framework places intervention and cure of illness at the center of hospital life. In fact, most hospital routines are negotiated to meet the individual needs of patients whose careers progress from initial diagnosis to intervention in disease processes. A physician decides to intervene based upon symptoms that are presented and noted during a routine consultation. The intervention requires calling on personnel from other specialties to attend to a sick patient's welfare. The emergent team of health care workers establishes a focus and an alliance on behalf of a patient at a specific point in time. However, since hospital life is subject to recurrent crises, these temporary arrangements are terminated, quickly forgotten, renegotiated, and forgotten again in a seemingly endless cycle of patient care. The hospital milieu is thus characterized by ongoing conflict and indeterminacy.

Professional and organizational interests in medical care are somewhat concealed from the patients and staff because of a common assumption that the hospital's primary function is the restoration of the individual to health. These social interests are most likely concealed, as well, from younger physicians who often enter the profession with similar beliefs. The mystique may result from medicine's success in implementing a professional project that unifies its socialization practices and its cognitive base. The joint production of physicians, as producers and users of medical knowledge, and of the knowledge itself are at the core of this project. Medicine's knowledge base is thus constructed and standardized to assure cognitive exclusiveness and to facilitate training for mastery of a body of specialized knowledge.

Medical socialization has a goal of developing a clinical mentality based upon an action-image, rather than solely on a knowledge-image of disease. In medicine, the scientific method is construed as a cognitive process of diagnosing, treating, and managing disease symptoms. Physicians organize a patient's career through labeling behavioral responses to diagnostic and therapeutic transactions. That career is constantly being negotiated because medical decisions change as symptoms manifest, are labeled and controlled. Such decisions then are always made with an eye toward treatment interventions, and this blend of cognitive and therapeutic activity has come to define medicine's professional project.

Hospital work is organized as a team effort. Physicians and allied health workers form a team for the purpose of treating a particular disease or condition. Physicians are the highest-ranking team members and therefore wield the most power. Their loyalties are vested in a particular medical specialty and to the clinical chief who oversees their work. By contrast, the loyalties of allied health workers, such as nurses, physician's assistants, dietitians, physical and

occupational therapists, social workers, and health educators, are often vested in a specific treatment setting. However, command and control styles of management, whereby nurses and other team members receive unilateral orders from physicians, limit their influence in their work settings. They are bound to follow these orders by their contractual obligations to the hospital and in more subtle ways to the physician.

The organization of staff as a team that physicians control sustains hierarchies within hospital work settings. Similar arrangements organize the relationships between physicians and their patients. These are dyadic relations between persons of unequal status. While physicians strive to maintain autonomy and control over their work, patients are generally passive and dependent in the sick role. This may explain in part why a physician will remain detached and impersonal when interacting with a patient. For a physician's interest in a particular patient is often determined by that person's compliance to a narrow, professionally defined role. If an individual follows the treatment protocol and maintains this role, conflict tends to be minimized. By contrast, when a patient manipulates the physician or fails to comply with a treatment regime, the physician will often refer the case to other colleagues. Physicians are bound by an ethical code to do everything in their power to maintain alliances with patients who are chronically or acutely ill. However, a patient may breach an alliance because of any number of factors and will thereby become estranged from a particular caregiver.

The physician thus controls medical intervention, the dominant approach to patient care. A doctor views a patient's condition as a technical dysfunction that can be cured by physical and chemical treatment. The physician is active and dominant in the transaction. The health care team is organized such that there is control over the patient, and that the physician's orders are followed expediently. The patient is expected to be passive in the healing transaction. Such passivity may increase the probability of patients becoming alienated from medical professionals and of failing to comply with their treatment. Hospitals reflect this mode of care in their organization. Clinical transactions are thus arranged to expedite service delivery within such hierarchies and most relationships are governed by regulations and sanctions. The rationales for this impersonal style are treatment success, efficiency, and a lowered risk of malpractice litigation.

Therapeutic intervention, an alternative form of care, encourages the patient to actively participate in treatment. The physician is crucial to this approach, but must be prepared to accommodate a patient's more proactive role in a treatment alliance. Negotiation and reciprocity in the healing process are central to this approach and these dynamics limit the monopoly of power held by the physician. The patient joins with a team of physicians and allied health workers to realize an alliance. Rehabilitation facilities, rather than acute care hospitals, are more likely to use this approach to treatment.

The demands made upon physicians in acute care facilities preclude the enactment of a therapeutic intervention approach. The more personal interactions

associated with private practice or rehabilitation settings are usually dispensed with or delegated to allied health workers. However, these workers are usually trained only to perform specific tasks in an efficient and detached manner. Their education may not have included formal training in counseling and other supportive techniques. Their limited understanding only increases their anxieties over not being able to fully handle the emotional aspects of care. Moreover, they will often view emotional support tasks as those of higher paid psychiatric staff that routinely consult to hospital medical services. Allied health workers may also harbor resentment toward the physician who dropped the matter into their hands without yielding any of the physicians' customary demands for sole autonomy in and dominance over the medical workplace. Although the health workers are powerless to act beyond their specified role, they are expected to undertake the additional tasks of emotional work assigned to them by professionals who have restricted their activities in most other treatment-related domains.

When a patient encounters a physician, the nature of the transaction is usually confined to diagnosis and treatment of physical symptoms. A key element in a clinical transaction is the way in which the discourse flows from the superior to the subordinate. The physician is expected to control the flow by actively seeking information from the patient or allied health staff. A diagnostic interview is arranged in a manner such that the physician's legitimacy is conveyed to the patient but also to subordinates in the setting. The physician often delegates preliminary routines and social amenities to subordinates—a procedure that might allow more time with patients, but also displays the primacy of the physician's role as the key manipulator of the patient as organism. The transaction is further mystified by the physician's down-to-business style, which is sometimes framed by patronizing forms of address and the use of technical jargon to convey symptoms and diagnoses. A patient may try to regain control of the encounter through confrontation or by actively negotiating treatment. These breaches in protocol may indicate a potential loss of control in front of colleagues and staff. A physician will then usually withdraw from the patient and begin to comment directly to others on the health care team often referring to the patient in the third person.

Medical intervention, as a form of interaction, only reinforces the profession's mechanistic bias and thereby dehumanizes the patient. By narrowly focusing on presenting symptoms, disease is reduced to a strictly organic dysfunction. The patient then becomes an object to be manipulated through one or more task functions. Failure to account for the patient's view of disease symptoms and of the relationship of symptoms to non-organic factors increases the risk of diagnostic failure and of depersonalization.

Depersonalization is symptomatic of a concern for order and efficiency at the expense of flexibility and compassion. It occurs frequently when staff perceives patients as helpless, non-compliant or not fully cognizant of their condition. Depersonalized care also results from tensions between administrators and

professionals over control over treatment. Physicians regard the hospital as a workplace that should be under their professional control. But the hospital is also a bureaucracy operated by administrators where service delivery is formally organized. As such, the hierarchical arrangements characteristic of most bureaucracies may also depersonalize interactions between hospital staff and patients.

ILLNESS "CAREERS," STIGMA,
AND SELF-CARE

The goals and assumptions of both medicine and the hospital are embedded in most diagnostic and therapeutic transactions. A patient's career will be constructed to reflect these interests along with the presenting symptoms and health care needs. The hospital as a work organization is likewise influenced by the social interests of its dominant professionals. Physicians have the "legally sustained jurisdiction" to exclusively perform the work of physical healing [9]. This sanction also assures their professional autonomy and right of self-regulation, and their technical authority over a body of knowledge and therapeutic skills. These social interests not only dictate standards of professional behavior but also directly influence relations with other hospital personnel and with patients.

Hospitals are places where staff and patients are continually negotiating treatment and these transactions come to define the life of the organization. Hospital life revolves around numerous "small worlds" created by interactions of health care personnel and their patients. These organizational networks are based upon a set of manifest rules and implicit meanings. For example, physicians expect compliance with their treatment plans. Their initial affiliation is often contingent upon the new patient's acceptance of this responsibility. A "power-dependence relationship" is thus established between professional and client on the basis of control vested in the role of the practitioner. This form of interaction is designed to transform a person into a patient. Repeated clinical visits can thus foster dependency in patients, especially those with a chronic illness.

In contrast to the short-term affiliations associated with acute care, chronically ill patients may grow increasingly more reliant on a number of services available to them. They become well socialized in the role of help-seeker and learn to use strategies to manipulate the system for a variety of medical and non-medical services. Patients will negotiate services on the basis of attributes, such as health, age, wage, household size and composition, and their self-presentation. They will typically reinforce their worthiness through deference and other dependent behaviors as an anticipated trade-off for participation in entitlement programs.

Physicians, nurses, social workers, and even administrative personnel will advocate on behalf of a worthy patient to organize and sustain a network of care for their material support. The network usually renders a client dependent upon public entitlements for the satisfaction of his basic needs. The hospital will mediate on behalf of a client for services that governmental bureaucracies routinely deliver to

worthy recipients, including disability benefits. A social worker will be assigned to counsel a patient who is incapable of determining a suitable strategy for community living. As case manager, the social worker develops a series of ties with other agencies, negotiates and makes decisions by proxy. Dependent networks of care are thus mobilized on behalf of low-income incapacitated patients who are undergoing a change of status and often lack the requisite skills for negotiating with bureaucracies. These longer-term affiliations give the hospital and its staff greater control over non-medical aspects of a patient's life.

However, a new situation may emerge out of the strategies that patients use to manage their identity as people who are worthy of care. While diversifying demands for health and related services, a patient may become structurally dependent upon many units of the system of health and human services [10]. A number of providers then become committed to the patient's career as a multiple recipient. The institutional field is thereby widened to include exchanges between the hospital and other agencies, including rehabilitation, nursing homes, federal and state disability and welfare programs.

Hospital staff's attitudes toward "dependent" patients who have become embedded within a nexus of diverse services can affect their interpersonal relations with them. Allied health workers will often resent these patients who require additional supportive services and record keeping satisfying government reimbursement guidelines. They begin to withdraw when these patients make continued demands upon them or when they complain to them about poor quality care. Hospital staff will often state that disadvantaged patients, who cannot afford to pay for their medical care, should be satisfied and grateful for *any* care bestowed upon them. They will often question why general hospitals maintain "semi-permanent" patient populations rather than providing short-term treatment and referral to private practitioners.

Physicians and others governing the routines of the hospital organize a patient's medical condition into an illness "career." This is meant to facilitate control of both the disease and any changes in a patient's behavior that are a consequence of the illness. Each stage of this career is managed through both diagnostic labeling and the requisite therapeutic techniques to control disease symptoms. Physicians thus have the legitimate power to understand, label, and intervene in the disease process, and to sanction personal behavior. However, the power of the profession extends beyond physical healing to include the social control of deviance and the stigma that will often accompany an illness. Medicine's status thus permits it to define the need for service and how that need will be organized. In Eliot Freidson's words, "the social organization of treatment may be seen to create the conditions by which the experience of being ill, the relationships one has with others when ill, and the very life of the sick person becomes organized" [9, p. 302].

As an applied science, the creation of new medical labels will evolve with innovations in medical technology. Each innovative diagnostic or therapeutic technique fosters new careers for professionals and their patients. It is in the best

interests of the medical profession to increase the number of diagnostic labels and thereby the range of illness behaviors to which the sick role can be imputed. Medicine's dominant role is thus maintained through such professional expansion, with each new discovery serving to reaffirm its status as the key legislator of healing in the society.

The physician has become a moral arbiter responsible not only for identifying the cause and prescribed treatment of a condition but also for designating the consequences of a patient's illness behavior on his family, school, or workplace, and the wider society. In this role, the physician is often called upon to sequester the sick person, perhaps by temporarily or even permanently prohibiting the individual from engaging in certain routines in the home, or in public places. While utilitarian in motive, over time such restrictions in everyday activities may stigmatize a person, render him discreditable, and cause him to lose whatever "social margin" he had attained prior to becoming ill. In the words of Jacqueline Wiseman,

> Social margin refers to the amount of *leeway* a given individual has in making errors on the job, buying on credit, or stepping on the toes of significant others without suffering such serious penalties as being fired, denied credit, or losing friends or family. . . . Social margin also encompasses the human resources a person can call upon in case of disaster, such as an incapacitating accident, losing a job, or being arrested. A person with margin can get help from his family, employer, or friends at such times [11, p. 223].

Once lost, a person's social margin is difficult to regain as it is built up over time, much as a credit history. After a while, members of the sick individual's social network may no longer view him as capable of giving or worthy of receiving the benefits accrued through social relations. They will then relate to him according to a diminished set of expectations. When a sick person engages with the world as a stigmatized individual, he may come to expect a certain response from those outside the immediate family or the caregivers within clinical settings. The stigmatized individual may even anticipate such derision and ostracism from former associates as well as from strangers and this sense of shame may then become a part of his defensive structure. That person will then forge a character that is capable of managing his "spoiled identity" and his subsequent behavior will emerge from this defensive stance.

The physician's role as a moral arbiter is evident at the onset of a chronic illness. Upon diagnosis, the patient and family members express fears to the physician regarding the illness and its consequences, the treatment regimes and prognosis, and their concerns to provide for medical care. These are temporary reactions that disturb psychological homeostasis, and they follow Selye's classical paradigm of stress [12]. Coping during this phase means perceiving the illness as a threat, mobilizing resources to meet it, and diminishing the crisis through adaptive behaviors.

Although most hospitals are organized around acute care, chronic illnesses affect some 10% of the American population, more than infectious or parasitic diseases, and cause 80% of all deaths. Patients are hospitalized during the acute stage of a chronic illness and then sent home to manage subsequent phases. Longer-term issues will arise once the immediate crisis has past. In contrast to the hospital-managed acute phase, subsequent phases of the illness will significantly alter a person's everyday behaviors. Upon discharge from the hospital, a chronically ill person must proactively manage the illness, a drastically changed life situation, and a new personal identity.

Home and family life will have to change dramatically in order to accommodate major alterations in everyday routines and vocational activities. In 1981, legislation passed that gave states the option to apply for Medicaid waivers on behalf of home care services. As a result, Medicaid spending on community-based services doubled between 1989 and 1993. In 1993, home care expenses totaled $31 billion, and averaged $2,575 per person [13, p. 2]. Recipients paid one-third of their costs out of pocket. Federal and state government programs financed over 60% of these services. However, most patients will rely on informal, unpaid caregivers since two-thirds of those with disabilities do not receive paid home care services.

The primary requirement in chronic illness behavior is adjustment: an individual must adapt everyday life and social functioning to a less-than-normal health status. Coping during this phase will require one to learn how to manage intermittent medical crises and to control symptoms, including pain. Those with a chronic illness will also have to reorder time and the spatial dimensions of their lives, learn to minimize social isolation and, thereby bring about a gradual return to "normal" routines. Chronically ill persons use a variety of coping strategies to enhance their adaptation. However, successful adaptation often requires them to continually work on, test, and modify these strategies.

Professional and peer counseling are widely used by patients and their families during the onset and initial treatment of a disease. There has also been a trend toward patient self-care. Self-care describes activities carried out by an individual, sometimes with the help of others, to deal with somatic and emotional problems arising from an illness, to improve health status or to prevent illness from occurring. The major components of self-care are health maintenance, disease prevention, self-diagnosis, self-medication, and other forms of self-treatment and patients' participation in professional care. Recently, there has been a clear preference for specific stress reduction techniques, including biofeedback, meditation, visualization, and guided imagery, which help individuals gain more control over the healing process.

There is considerable evidence that psychological attributes play a significant role in mediating health outcomes in chronic illness. Three such cognitive factors are internal locus of control, the sense of coherence and self-efficacy. Locus of control refers to the degree to which an individual perceives that consequences arise from their own actions, efforts, or characteristics as opposed to forces beyond

their control, for example, which they may characterize as fate, luck, chance, powerful others, or the unpredictable. Persons with a strong sense of external control tend to see little if any relationship between their own actions and subsequent events. By contrast, "internals" believe that some control lies within themselves. They are more likely to perceive self-care behaviors as efficacious.

The sense of coherence refers to an individual's perception of the internal and the external environments as predictable. Persons with a strong sense of coherence view the world as comprehensible, manageable, and meaningful. They believe in the possibility of working through challenging situations and, as a result, that things will work out as well as can reasonably be expected. They are thus more likely to engage in self-care behaviors because of their confidence that such efforts will yield positive results. Self-efficacy refers to an individual's sense of personal ability to perform tasks or to cope with new or challenging situations. Persons confident in their ability to carry out demanding activities and aware of their coping strengths are more likely to actively pursue self-care behaviors.

Chronically ill persons will often participate in health-oriented self-help groups to meet their self-care objectives. These groups are a way to get information about effective coping with both the physical and psychological difficulties associated with their condition. They also provide a setting for obtaining social and emotional support by sharing problems with their peers. Individuals who participate in self-help groups often report increased self-esteem and self-reliance. They appear to have a better understanding of their illness and to be more capable of negotiating and maintaining therapeutic alliances with professionals.

SELF-HELP AND DISABILITY RIGHTS
AS SOCIAL MOVEMENTS

The contemporary impetus toward mutual help and self-care in health has its roots in the women's movement. A central concern of the women's movement was in the area of health. In consciousness-raising groups, women soon discovered that they knew relatively little about their bodies, their sexuality, or the ways medical institutions defined and controlled important phases of their lives. Critical of the medical school's near exclusion of women and of male physicians' condescending attitudes toward their female patients, women's health activists established independent health care clinics run by and for women, and lobbied for the legalization of abortion. They established support groups to come to terms with the dependency, sense of powerlessness, and victim blaming that women frequently experienced in health care organizations. Feminists also developed self-help groups focused on particular aspects of health, including know-your-body courses, alternative health care, and post-mastectomy recovery. Other self-help groups were established to provide mutual support in parenting and family crises, during menopause and widowhood, and in coping with the range of mental and emotional disorder [14, pp. 35-36].

Parallel with the women's movement, people with serious physical disabilities organized self-help groups during the post-war decades. The disabled shared many of the same concerns of the feminists, including stereotyping, stigmatization, and increased dependency on professionals. Both movements flourished in the late 1960s when people began to view medical care more critically and to de-mystify its premises and procedures. There was also an upsurge of consumer activism focused especially on the pharmaceutical industry, and on the health-related regulatory agencies in the federal government, such as the Food and Drug Administration (FDA) and the Occupational Safety and Health Administration (OSHA) [15, p. 49]. Each movement developed as a result of an increasing mistrust of the professionals sanctioned to look after the public interest in the areas of science, technology, and health, and of the diminishment of personal control as more of people's lives became subject to professional managements [16, pp. 20-21].

The late 1960s also witnessed the flourishing of self-help organizations of parents of chronically ill and handicapped children, although most of these groups had begun to surface two decades earlier. In fact, by the early 1950s, parent-organized groups developed into state and national organizations as local groups coalesced to publicize their particular condition, especially through the new medium of television [17, p. 14]. By the late 1960s, many of these disease-specific organizations increased in both membership and influence. The National Association for Retarded Children had over 1000 local units and a membership of 130,000. The United Cerebral Palsy Associations of America had about 260 local units, over 100,000 members, and more than 50,000 volunteers. The Muscular Dystrophy Association of America had over 400 chapters and 500,000 volunteers [14, pp. 17-18]. From the early 1970s onward, many self-help organizations spearheaded effective campaigns on behalf of their diverse constituencies in the courts and in state legislatures. They eventually realized their goal of integrated schooling when Congress passed the Education for all Handicapped Act of 1974, which guarantees the right to public education for all children with a physical or mental disability who are living in the community [17, p. 87].

The 1970s brought about the creation of a new type of self-help group: the independent living organization. Usually organized by young adults with a variety of disabilities, these local groups provide mutual support and specific help with a range of problems. As they developed, they offered many of the services of established health and welfare agencies and added some innovative ones. They took a critical posture toward the conventional forms of service delivery and had a strong orientation to advocacy and social action to achieve changes in policies. In Berkeley, California, the prototypical Center for Independent Living (CIL) originated in 1970 among a group of physically disabled students at the University of California, who organized to obtain more accessible buildings, classrooms, laboratories, and other academic facilities so they would not be hampered in pursuing an education. The students' success in bringing about changes in the university's facilities led them to extend their activities into the

community, on behalf of other persons with disabilities. By the mid-1970s, the Berkeley CIL had become a major resource for independent living, jobs, and personal services for young adults with disabilities who were living in the San Francisco Bay Area [18].

As soon as these local-level, self-help organizations banded together to form national coalitions, they realized considerable political influence. The National Council of Independent Living Centers (NCILC), a coalition of over 200 local self-help organizations of persons with disabilities, lobbied hard to improve the quality of life for disabled persons. The national organization campaigned for improved procedures for disabled Social Security recipients, and for the recruitment of personal attendants for disabled persons. It also worked to assure that public transportation and housing facilities are wheelchair accessible, and for increased job openings for persons with disabilities. The NCILC's extensive campaign on behalf of the Americans with Disabilities Act (ADA), including several years of lobbying, public education, media campaigns, and mass demonstrations in Washington, D.C. and in state capitals, eventually led to the act's passage in 1990 [17, p. 88].

Like the NCILC, the National Alliance for the Mentally Ill (NAMI) was established along self-help lines to provide assistance to discharged patients and their families. Originally a loosely structured coalition of small family groups, the NAMI established a strong policy advocacy presence through its campaigns on behalf of the civil liberties of the mentally ill, and for improved conditions in both community treatment facilities and in the state hospitals. By the late 1980s, the NAMI had nearly 1,000 affiliates and an annual budget of over $1 million. Its fully staffed national office in Washington, D.C. was established for the purpose of policy advocacy, most notably the National Institute of Mental Health (NIMH), on behalf of federally funded social programs that benefit the mentally ill, such as Social Security and the Community Support Program [17, pp. 47-49].

By the late 1980s, AIDS activists went beyond each of the considerable achievements of the other activist groups in spearheading policy advocacy on behalf of patients with a condition, which the medical profession was virtually powerless to cure. In the AIDS epidemic, gay activists clearly indicated that such passivity should not be taken for granted. They numbered among their members articulate individuals with considerable intellectual skills who also had experience in political activism. Their counterparts in the lesbian movement brought similar skills and experiences, but also feminism's fundamental questioning of the motives of health care providers. Both groups share a fundamental ideology of personal empowerment and of control over their own health care. Together with other constituencies, such as parents of persons living with HIV, especially children, they created a powerful coalition that could not only organize but also deliver funds, protesters, and votes. Clearly, the politicization of health has challenged notions of stigmatization for at least these specific subcultures and their supporting institutions.

Because of their involvement in, and access to, the arts and other cultural institutions, AIDS activists had developed the skills to present their definitions of the epidemic and to express what it means through powerful images. In the area of research, AIDS activists with scientific training were also able to influence all aspects of the research process, from the funding to the conduct of clinical trials. More significantly, they have been able to influence what constitutes good science in AIDS research. They mobilized public interest in the ways persons living with HIV are treated, anti-retroviral therapies and other AIDS drugs are marketed, AIDS-related research is funded, even how the epidemic is defined. The powerful AIDS lobby convinced Wellcome to slash prices on the controversial drug, AZT, and persuaded the Food and Drug Administration (FDA) to release unapproved drugs that were thought to be effective in treating AIDS. Advocacy groups obtained the release of information about experimental treatments, "overcoming the FDA's insistence that to do it would violate commercial confidentiality" [19, p. 19].

What weaves together these diverse social action practices is the resurgence of populism in the social movements of the late 20th century. Like its 19th century predecessor, the "new populism" implies a reliance on self-initiated activity, based on both participatory democracy and experiential forms of knowledge. Most contemporary movement organizations emphasize the creation of social environments, such as self-help groups, support networks and experiential learning situations, where participants solve problems by "taking action together." Within these settings, the change process is relational, rather than individualistic, emphasizing the connectedness and mutual involvement of participants in meaningful activities. This emphasis may account for the success of many voluntary social action initiatives, from neighborhood organizations to broad-based citizens coalitions.

Similarly, the "social model" programs that frequently emerge from populist initiatives differ considerably from their professional counterparts because of their experiential knowledge base. These programs strive to transform the knowledge, gained through life experience rather than that of experts, into an institutional ethos that is shared by all participants. While they appear similar in their organizational and administrative structures to the more formal expert-driven programs, social model programs differ with respect to their perspective toward a specific issue or situation. Their alternative approach, based largely upon populist values of self-control and self-determination embedded in their practices, is itself continually transformed and reconfigured through the open-ended experiences of participants [20].

The following cases describe how patients with chronic conditions obtain support from self-help groups. The first case describes how one such group helps renal patients cope with the move from hospital-based hemodialysis to CAPD, a self-care modality that gives them greater independence and control over their treatment. The second case describes how self-help groups help persons with lupus

achieve greater emotional self-care as they learn to adjust to the cyclical flare-ups and remissions characteristic of the disease.

RENAL DISEASE, DIALYSIS, AND MEDICAL SELF-CARE

End-stage renal disease (ESRD) is a chronic life-threatening condition that requires ongoing medical treatment [21]. Renal disease indicates that a person's kidneys, as the body's filtering system, are unable to remove metabolic waste products from the blood. Chronic renal failure was once considered untreatable and its sufferers faced a slow death. However, major advances in medical technology in the 1960s diminished the threat of death to renal patients. Multiple dialysis treatments with an artificial kidney machine once reserved for only acute and potentially reversible cases have become standard therapy for all ESRD patients. Another key breakthrough is the arterio-venous shunt. Usually implanted in the forearm, the shunt provides access to the blood without permanently damaging the vessels. Renal patients are now kept alive through dietary management, medication, and long-term dialysis techniques, and in some cases, organ transplantation. The major cost of treatment for kidney failure is borne by publicly financed Medicare and Social Security programs.

Incenter hemodialysis (HD) is the predominant treatment for adults with renal disease. Patients must visit a hospital three times a week to use a mechanical kidney. The treatment requires about four hours to complete. During this time, a patient is passive and dependent upon the machine and the hospital staff. He or she remains immobile in a reclining armchair while his blood is pumped through clear plastic tubes to an artificial kidney, which removes impurities, controls electrolyte levels, and eliminates excess fluids.

Continuous Ambulatory Peritoneal Dialysis (CAPD), an alternative dialytic technique, uses the abdomen as a dialysis machine. CAPD cleanses a patient's blood by filtering it through a solution in the abdominal cavity. The technique uses a small tube or catheter to infuse and drain the abdominal cavity of a cleansing liquid. The tube is surgically inserted into an incision in the abdomen. After surgery, patients learn how to dialyze themselves during a five to ten day training course. They are taught how to filter their blood by running a sterile solution through the catheter. The infusion takes up to 30 minutes to complete. Several hours later, the patient extracts the old chemical solution and inserts a new supply of the liquid. CAPD patients usually have fewer fluid and diet restrictions, but must perform the fluid exchange procedure four times a day. There are complications associated with CAPD, especially peritonitis, an infection in the abdomen, but also back pain, hernias, and accumulation of high levels of fat in the blood.

ESRD patients are required to perform a daily regimen that may be restrictive and unpleasant. This varies from dietary restrictions to performance of dialysis

exchanges to taking a number of medications. Patient noncompliance with the HD regimen is quite common. ESRD and chronic dialysis are associated with acute and chronic adverse biological effects on almost all organ systems. Many patients have impairments that limit both their performance of routine physical activities, including self-care, and their ability to work. Restrictions on social and leisure activities and vocational disability are ubiquitous in chronic HD patients. They frequently have psychological symptoms of anxiety and depression, but also more severe psychiatric syndromes. HD patients' family lives are marked by serious marital conflicts resulting from decreased libido and sexual dysfunction, and their children also experience high levels of psychological distress.

CAPD patients are able to engage in more routine physical activities. Because they are not dependent upon the hospital dialysis unit, they have more independence and control over their treatment. They can set their own schedules and travel without making special arrangements. They have a less restricted diet. Although these patients express boredom with performing CAPD exchange procedures, they have increased freedom and ease of travel and are thus capable of sustaining a fuller vocational life. As a result, their families suffer less treatment-related stress. However, CAPD patients report both chronic pain and fear associated with peritonitis. They show little improvement in sexual function even though many men report a greater libido and many women see the recurrence of their menstrual periods. These patients must also cope with a changed body image as a result of the 2-inch long catheter protruding from their abdomen. The abdomen will often distend as a result of the procedure, and patients will usually gain weight because of their increased caloric intake.

Although they are capable of performing a wider range of activities, CAPD patients report only marginal improvements in their psychological mood, sense of well-being, and overall life satisfaction. This probably results from the initial apprehension and malaise that accompanies the transition to self-dialysis. As renal patients move out of the dialysis unit, they relinquish a world of caregivers who have surrounded them since the onset of their illness. Patients become a regular part of a unit three times a week, very often for years. They grow attached and dependent upon staff for their medical, nursing, dietary, and rehabilitative care. The social worker mediates many of these transactions within the hospital, but also with the federal agencies that finance dialysis and other entitlement programs. This network of emotional support and "hands-on" care was expected and delivered to them whenever they enter the hospital. Once they initiate CAPD, however, they lose the ongoing support of the health care team and will often become anxious about their ability to handle the physical crises that are a part of renal disease.

The dialysis unit is also a place where patients routinely gather to discuss their condition and other aspects of their lives. Patients tend to rely on the unit for more than their health care needs. It is a source of ongoing support, providing both social relationships and a sense of belonging. Patients routinely socialize

and discuss various aspects of their treatment. They frequently compare notes about members of the staff and discuss at length their family lives. After so many years of thrice-weekly visits, patients tend to find their primary support on the unit where close friendships evolve and are celebrated on birthdays and other occasions. As patients switch to CAPD, they become isolated from their peers and thus relinquish the support provided them by the dialysis unit as a "treatment family." This is particularly distressing at a time when they are confronting an altered physical appearance and doubts about whether they are capable of managing self-dialysis.

Harry Brey and Joyce Jarvis established a support group to help HD patients cope with the transition to CAPD [22]. The group met twice each month at a community hospital in the New York metropolitan area. Patients joined the group during the training period just after surgery to insert the catheter. However, some joined the group after they decided to adopt CAPD but before they made the change to the new treatment. Group members shared medical information about CAPD and confronted the challenges of self-care. They also took turns recounting their struggles with renal disease and their treatment experiences. Strong emotions would often accompany the retelling of their medical histories, and the group was a source of support and clarification of these emergent feelings. As patients disclosed more of themselves in the group, they began to experience a revived sense of themselves as individuals.

The individuation process begun in the group was especially important. These patients had grown dependent upon a hospital treatment milieu for their continued survival. They also accrued "secondary gains" from their illness. These included an increased dependency upon members of their social networks, but also upon the hospital-based network of care and entitlement programs that became available to them. For many patients, dialysis resolved many of the conflicts that had beset them before becoming ill. For example, they would use the sick role to justify abdicating both work and family responsibilities. The group discussions thus validated and supported their newly felt sense of personal autonomy as they moved toward greater self-responsibility for their treatment. This independent stance was an essential part of the move away from the dialysis unit and its myriad forms of support.

Self-care meant going home to a life apart from the medical setting. As patients engaged more in their treatment, issues that had been resolved or at least occluded by dialysis resurfaced. As CAPD reduced their opportunities to further accrue secondary gains, patients were forced to confront their personal lives. The group encouraged greater independence in resolving treatment-related difficulties. Peers helped each other adjust to their changed family worlds now that they were spending more time at home. Members also reinforced one another's greater engagement with the world outside of the home and the hospital. They supported each other's search for part-time and full-time employment, but also for volunteer opportunities. Perhaps the most important forms of support were provided in the

areas of body image and sexuality. While some reported an increased libido after their catheter was implanted, others had difficulties accepting a changed body image resulting from abdominal distention. Just as the challenges of self-care and of survival apart from the hospital focused earlier phases of the group, help in resolving pre-dialysis issues of intimacy and family life formed the basis of later phases. During each phase, however, the emphasis was clearly on the possibilities of living independently of the medical environment and of seeking and gaining mutual support from peers in coping with the change.

LUPUS, SELF-HELP, AND EMOTIONAL SELF-CARE

Systemic lupus erythematosus is a chronic, inflammatory autoimmune disease; it damages the connective tissues and can affect any organ of the body [23]. Lupus occurs in all races and ethnic groups; it is far more common in women than in men. Typically, the onset of the disease occurs during the childbearing years. Those with lupus develop blood cell abnormalities, including the overproduction of the antibodies that normally help protect the body against infectious environmental bacteria and viruses. In the absence of outside infectious agents, these antibodies attack the body's healthy cells, setting off an allergy-like reaction. In effect, the body's immune system turns against the body itself, attacking and sometimes destroying bodily tissue. Like arthritis, lupus causes swelling and inflammation of muscles and joints. It often affects the kidneys, but it can also involve the heart, lungs, central nervous system, liver, or other organs or systems. Patients experience extreme fatigue, lose hair, develop mouth sores and skin rashes, and run low-grade fevers. Swelling of the hands and feet, pain in the joints, and sensitivity to the sun, heat, and cold are also common.

To date no cause of lupus has been established. Because there is no single pattern of onset and no single set of symptoms, the diagnosis may take several years. Lupus is difficult to diagnose because early indications are vague and diffuse. Patients often experience symptoms long before there is physiological evidence from blood tests or other clinical assessments. If there is no change in organ functioning or blood tests are normal, physicians may conclude there is no real disease. Until a definitive diagnosis is made, patients receive no specific corroboration that something is physically wrong with them. Lupus patients report that some physicians described them as "hysterical," "nagging," "inquisitive," "demanding," and "anxious." Before the diagnosis, patients may thus doubt their own judgment and feel that their problems are psychosomatic and self-induced. In 1982, 11 criteria were established for diagnosing lupus. These criteria include both the results of blood tests and physical symptoms. If a patient has four or more of the signs and symptoms on the list, a diagnosis of lupus is made.

The symptoms of lupus are unpredictable and erratic. One day, the patient feels relatively well and energetic, but the next day, he or she feels ill and enervated. The

erratic course tends to evoke counterproductive behavior in patients. On "good days," patients attempt to accomplish as much as possible to compensate for past and future "bad days." The tendency to overdo things exacerbates their symptoms, causing them to feel ill for several days afterward. This "vicious cycle" may even be life threatening, and it usually prevents patients from achieving a relatively normal way of life. Because of the cyclical exacerbations and remissions, lupus creates stress for patients and their families. The chronic stress with which lupus patients live helps create episodic "flare-ups" of the disease and adds to the discomfort of the symptoms. The physical pain can cause severe fatigue and interrupted sleep. The usual medications alleviate or control specific symptoms but often produce adverse physiological and emotional changes, and troublesome side effects. How to differentiate physical and psychological symptoms caused by the disease and from those caused by the treatment is, at best, difficult.

Cortisone is most frequently prescribed to alleviate or control specific symptoms. The corticosteroids, however, will often produce adverse physiological and emotional changes, and side effects that are experienced as distressing. These include mood swings, insomnia, depression, nausea, weight loss and gain, increased appetite, bloating, water retention, personality changes, anxiety, memory impairment, mood lability, mental deterioration, obsessive reactions, and sometimes psychosis. If the dosage of the corticosteroid is changed, abnormal behavior is apt to occur, ranging from "steroid psychosis" to physiological withdrawal symptoms. Because cortisone both stimulates and simulates bodily stress, the drug also detracts from the body's natural ability to counteract stress and to maintain the fight/flight response.

Lupus is a serious and presently incurable illness. To a great extent, the prognosis depends on the patient's psychosocial adjustment, since the state of mind, emotional stress, and immunological factors are closely linked in the disease process. Patients frequently have psychological or technically psychiatric symptoms. These symptoms are of two kinds: a mild form of emotional distress that is manifest in neurotic depression, anxiety, tension, phobias, or obsessional behaviors, and a severe form that manifests in such florid symptoms as hallucinations, delusions, disorientation, and psychosis.

Depression is pervasive. As was just noted, medications used in the treatment of lupus may have depressive effects. Some clinicians believe that the patient's anger at having lupus is expressed in a depressive style or in self-destructive behavior: anorexia, the tendency to be suicidal, noncompliance with medical regimens, the abuse of medication, and the denial of physical limitations imposed by the disease. Patients experience a loss of positive self- and body image, lowered self-esteem, heightened stress, and depression. They fear that they will be rejected by others and hence, isolated.

People with any chronic illness have periods of reactive depression. At the point of diagnosis, patients with lupus may need help in coping with the unpredictable assaults of the disease on the body and with the associated psychological distress.

Anxiety, fear, and stress tend to be greater when the causes and nature of the illness and the prognosis are unknown. Lupus is mysterious and unpredictable, and many nonpatients react negatively to it. Some withdraw because they are afraid of "catching" the disease; others deny its impact on the patient.

Withdrawal by others is not the only form of isolation the patients with lupus experience. Because of physical pain, exhaustion, and emotional fatigue, these patients may isolate themselves. Divorce rates among patients with lupus are higher than the norm, in part, because of the limitations or inability to engage in sexual relations, either owing to pain or to the tendency of medications to suppress the libido. Sexual dysfunction may add to reluctance of unmarried patients to socialize or to become involved in intimate relationships. Another reason for this flight from intimacy is the fear of bearing children who might have lupus too. That genetic forces play an important role is clear, in view of the fact that lupus develops regularly and spontaneously in certain inbred strains of mice. In humans, there is a moderate tendency for lupus to occur in more than one family member.

Many patients with lupus experience anxiety and distress about the financial burdens that the disease imposes, both the direct medical costs and the loss of income arising from the erratic course of the disease, which makes regular employment difficult. Patients who are employed full-time fear the consequences of missing too much work. Those who can no longer work full-time experience distress about having to rely on others for financial help. Those with family obligations may feel they have failed when they cannot provide consistent financial support for their dependents.

Local chapters of the Lupus Foundation of America hold regular meetings and organize support groups for patients. Members of these local self-help organizations also develop and implement community outreach programs, and work with hospital staffs, professionals, and the local media. The goal is to transmit accurate scientific information about lupus. The local chapters, in sum, help the individual members through traditional self-help techniques that support peer relationships in dyads and in group settings. They develop a cadre of members who, despite their illness, develop and use skills in community organization, mutual support and the education of patients; thus, they are a model of the self-help principles of the importance of activity to overcome stress and anxiety and the reciprocity of giving and receiving help.

Groups of lupus patients may be dichotomized into two main types that function differently according to the characteristics and needs of their primary members. The first type, which may be termed "primary support" groups, are made up of members who, for a variety of reasons, are not receiving support from their immediate families and intimate friends. The second type, which may be termed "supplementary support" groups, consist of people with relatively intact and satisfying primary supports but who wish to establish and maintain contact with peers who are experiencing a similar problem.

The Lupus Foundation set up self-help groups in two southern California locations: a large urban neighborhood and a smaller suburban community. The urban group was largely a "primary support" group and the suburban group was mainly a "supplementary support" group. The two groups differed in such aspects as the breadth of participation, the proportion of trivia to significant content, and the frequency of conflicts or disagreements. Probably because of the greater homogeneity and personal security of its members, the suburban group allowed for rapid and intense discussions of significant issues surrounding the illness, rather than for a focus on procedural and status questions, as in the urban group. There was also a more positive mood at the end of the sessions in the suburban group, and members reported greater satisfaction with the group process than in the urban group.

The urban group had a higher proportion of small talk than "significant" talk during its sessions compared to the suburban group. In fact, group procedures were frequently discussed in the urban group. These procedural issues, nonsubstantive so far as the disease is concerned, involved such questions as who should be invited to address the group, who should do the inviting, the frequency of meetings, and so forth. Furthermore, the startups of the discussions were more difficult in the city than in the suburbs. Fewer members participated in the urban group's meetings than in the suburban group. Antagonistic, critical, or indifferent moods were observed at the end of many of the urban group's sessions, but none in the suburban one.

Such differences in content, level and functioning of the group discussions and group functioning as a whole are related to differences in the composition of the two groups. The majority of the urban group's members were single, separated, or divorced women, most of whom had to work. Their various kinds and levels of situational life stresses were substantial and continuous, and this situation was reflected in the often-acrimonious group sessions. In contrast, the other group's members were mostly married, lived in middle-class suburbs, and generally had supportive husbands; fewer of them worked, not because they were too ill but because they chose not to.

The participation of lupus patients in health-oriented, self-help organizations is a form of emotional "self-care." The purposes of such participation are several: to get information from others with lupus about how to cope effectively with psychosomatic difficulties; to obtain emotional and social support by sharing problems in a group setting; and to bolster self-esteem and self-reliance, both in understanding one's illness and in relationships with the health care system and its professionals.

Although conscious self-care, in the form of necessary changes in lifestyle is required to improve their physical and social adaptations, the lupus patients' major problems seem to be in the mental health sphere. Self-care cannot "cure" the disease or change its course, but participation with others in self-help activities seems to alleviate the greatest stresses of lupus and to improve the patients' ability

to cope with the disease. Self-care is not a substitute for needed medical interventions; rather it is a desirable form of parallel social treatment for this severe, often life-threatening, chronic disease.

PARTNERS IN HEALING

Medical self-care is thus sustained through active participation in close-knit networks of care, including self-help groups and mutual aid organizations [16, 21]. Self-care skills learned through these networks include symptom recognition, treatment of minor illness and injury, and negotiation and advocacy skills. Individuals may also decrease their dependency by engaging in self-care activities, such as risk reduction, health promotion, and preventive health practices. The sum of these skills and activities can empower chronically ill persons to take greater control over their bodies and their lives.

Knowledge of self-care practices is especially important to informal caregivers because they provide most home care services for persons with a chronic illness or disability. By participating in self-care networks, family members and other informal caregivers can also learn how to recognize, encourage, and employ lay resources in managing everyday routines. Lay caregivers will then be better informed and capable of supporting individuals as they learn to use problem-solving and other self-management skills.

Self-help, self-care, and other lay initiatives clearly affect a person's morale. They have also been found to provide important emotional and material sustenance because these resources offer models of successful coping. Together with such cognitive factors as self-efficacy, internal control and the sense of coherence, they foster empowerment, or an individual's sense of mastery of the skills necessary for a return to productive living. Studies suggest that self-care, motivated through a support group, is more effective than individually practiced self-care. The most promising outcomes of self-care and peer self-help groups in chronic illness are those that convey stress-buffering, supportive, and socializing effects. These are processes that encourage a sense of personal empowerment through modeling healthy behaviors and engaging in voluntary action. Those who mobilize self-care networks or who participate in self-help groups may thus have found additional resources that enhance their resistance to emotional and somatic disorders.

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Direct reprint requests to:

Carl A. Maida
Public Health–Comm Den, UCLA
63-023 CHS
Los Angeles, CA 90095-1350
e-mail: cmaida@ucla.edu