Zbigniew J. Lipowski

PHYSICAL ILLNESS, THE PATIENT & HIS ENVIRONMENT

PSYCHOSOCIAL FOUNDATIONS OF MEDICINE

American Handbook of Psychiatry

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Introduction

The dominant focus of this Volume is on mind-body-environment interrelationships as they determine health and disease. Whether we talk of psychosomatic medicine, of organic brain syndromes, or of psychosocial aspects of physical illness, we are looking at different facets of the same basic theme, namely the interplay between man as a psychobiological unit and his environment as it pertains to health and disease.

The present Chapter has a twofold purpose: to outline briefly the contemporary conceptions of disease, and to provide a comprehensive framework for organizing our knowledge about human experience and behavior in physical illness and disability. The writer’s approach to both these topics is both *holistic* and *ecological.* The holistic viewpoint sees body and personality as two integral aspects of a larger whole: *The person.* Soma and psyche are constructs reflecting two different modes of abstraction and methodological approaches to the study of man, the biophysical and the psychological, respectively. These different approaches involve two distinct languages for description of the phenomena studied and for the formulation of relevant explanatory statements. Human body and personality constitute a unit shaped by continuous interplay between man's genetic endowment and his social and physical environment. The ecological perspective stresses the ways in which environment influences man and he in turn affects it. Mind, body, and environment are viewed as elements of a dynamically interacting system. Human health and disease are a continuum of psychobiological states determined to a varying extent by biophysical, psychological, and social variables. These states involve all levels of human organization, from the molecular to the symbolic. This view is equally valid for what, in our dualistic language, we call psychiatric and physical, or mental and organic disorders.

A traditional approach in medicine has been to distinguish sharply between etiological and reactive factors in disease. This distinction still has some practical value in the search for specific causal agents and for preventive action. Yet dichotomies like "etiological" versus "reactive," "organic" versus "mental," or "psychosomatic" versus "somatopsychic," are becoming less sharp now with the emergence of multicausal and dynamic conceptions of disease and the recognition of complex feedback mechanisms. For practical purposes, however, it is still useful to talk of psychological responses to physical illness, while keeping in mind that they are an integral part of it.

To reflect contemporary trends in both medicine and psychiatry it is appropriate to introduce this Volume with a conceptual bridge between medicine and behavioral sciences, and psychiatry, which has its roots in both. We shall call this approach *psychobiological ecology* of man. To develop it, we need to cross interdisciplinary boundaries in quest of a unified knowledge of mind-body-environment transactions. This quest has emerged as one of the most important scientific challenges of our times.

The major sections of this chapter are:

1. Contemporary conceptions of health and disease in man.
2. Determinants of psychological reaction to disease.
3. Modes of psychological response to physical disease, injury, and disability.
4. Personal meanings of illness.
5. The stages of illness and related challenges.
6. Terminal illness and management of the dying patient.

The above schema is an attempt to organize a complex and fragmented field for didactic purposes. It is a formidable task, but it is worth attempting to bring together a body of observations, concepts, and hypotheses equally relevant for the psychiatrist and other health professionals, as well as for behavioral scientists concerned with matters of human health and disease.

Contemporary Conceptions of Health and Disease in Man

The concept of disease has undergone repeated changes throughout the history of medicine. A *unified concept* of it has been gaining ground in the 1970s. It reflects the influence of psychosomatic and ecological thought, as well as of social pressures for both personalized and universally available medical and psychiatric care. Current emphasis on a *comprehensive* approach to the prevention of disease and management of patients favors the holistic and ecological approaches. Social trends and involvement of behavioral scientists in medicine have combined to endorse psychosomatic thought which enriched the medical model of man as a biological *organism* with a psychosocial perspective of him as a person and a member of a given social group with which he interacts. The definition of disease in a recent medical dictionary reflects a contemporary concept of it. Disease is the “sum total of the reactions, physical and mental, made by a person to a noxious agent entering his body from without or arising within . . . , an injury, a congenital or hereditary defect, a metabolic disorder, a food deficiency or a degenerative process.”

The above definition conceives of disease as a state having no separate existence apart from a patient, a person. This is still a controversial point. Feinstein advocates a distinction between the meaning of the terms “disease” and “illness,” respectively. The former refers to data described in *impersonal* terms: anatomical, chemical, microbiological, physiological, etc.; the latter designates *clinical phenomena,* such as the host’s subjective sensations (i.e., symptoms), and certain objective findings (i.e., signs).

In this writer’s opinion the dictionary definition of disease is preferable to Feinstein’s. For one thing, his concept of disease leaves out many psychiatric disorders which are not at this time describable in “impersonal” terms and would thus constitute nondiseases. Feinstein’s distinction between disease and illness has a limited application and does not do justice to the contemporary trends to define disease, at least in part, by subjective and social as well as biophysical criteria. To avoid semantic confusion we use the terms “illness” and “disease” interchangeably.

The concept of disease is intimately related to prevailing views on etiology and pathological mechanisms. We note that the dictionary definition quoted above confines the range of causal factors to the biological, physical, and chemical ones. This leaves out *psychosocial factors* as a class of potentially noxious and pathogenic agents. *Symbolic stimuli* emanating from man’s environment and impinging on him as information may be no less noxious than the other etiological factors listed. Information evaluated by the recipient in terms of personal threat, loss, failure, or punishment, or eliciting conflicts and frustration with their concomitant affects, may result in disturbed homeostasis and some degree of adaptive failure. The latter involves biological, psychological, and social aspects. These facts reflect man's unique capacity to create symbols in thought and language, and respond to them at all levels of his organization. This capacity is predicated on cerebral activity which not only subserves mental activity but also mediates between man's environment and his internal milieu which it controls and on which it is also dependent. We shall elaborate these concepts further while discussing psychological stress. They are also mentioned in Chapter 2 (p. 97), in which causes and psychological effects of cerebral damage and dysfunction will be discussed.

A unified concept of disease, elaborated by Dubos, Engel, and Wolff, takes full cognizance of man's capacity for symbolic activity, which adds a crucial dimension to his adaptation to the social and physical environments, and to maintenance of health, as well as susceptibility to disease. As Wolff put it: "It is unprofitable to establish a separate category of illness to be defined psychosomatic or to separate sharply—as regards genesis—psychiatric, medical, and surgical diseases." This view has been influenced by the general system theory and is rapidly replacing earlier, reductionist concepts of static, single-factor, unilinear causal sequences, be they expressed as germ theory or psychogenesis.

The characteristics of the unified approach to disease may be formulated in the following postulates, equally applicable to somatic and psychiatric disorders:

Relativity of the Concepts Health and Disease

There is no sharp boundary between health and disease, between normality and abnormality. They are relative concepts defined by changing statistical, subjective, and social criteria, as well as by abstract, utopian notions of an ideal state and varying degrees of deviation from it. For Dubos health implies “a modus vivendi enabling imperfect men to achieve a rewarding and not too painful existence while they cope with an imperfect world.” Disease connotes “failures or disturbances in the organism as a whole or any of its systems.” Thus health and disease are viewed as states constituting a continuum divided by an arbitrarily and conventionally defined boundary.

Multifactorial Etiology

No disease is caused by a single factor, although one factor may outweigh all the others in determining a given disease state. Etiologic factors include enduring predispositions or vulnerabilities of genetic and acquired origin, as well as current susceptibility, psychic and/or somatic, of the individual to noxious agents ranging from physical, chemical, and biological to symbolic, which exert a strain on his current adaptive capacities. These causal factors vary in their respective relevance from case to case, and evaluation of their relative contribution to a patient's malfunction and discomfort constitutes the process of comprehensive diagnosis.

Ecologic Viewpoint

The study of every disease must include the person, his body, and his human and nonhuman environment as essential components of the total system. This involves the employment of methodologies, explanatory concepts, and terminologies derived from physical, biological, and behavioral sciences. For reasons of research strategy these different components are broken down and studied in isolation from those belonging to the other levels. But the determinants of health and disease in an individual always involve complex interactions between him and his total environment (See references 38, 64, 74, 75, 122, 174, and 201).

Disease as Dynamic State

It is customary to distinguish etiological and reactive aspects of disease as if they represented two different categories of phenomena. This is largely an artifact, although it has some heuristic value. The whole constellation of factors listed under *Multifactorial Etiology* above continues to influence the course of any disease. There is dynamic interplay among these factors and numerous feedback loops having a beneficial or deleterious effect on the disease as a process and on its outcome. This is particularly true of the currently prevalent chronic diseases, in many of which the point of onset cannot be identified. In them it is quite arbitrary to distinguish between causal and reactive factors.

Psychosocial Stress

When the meaning of any information input, internal or external, is construed by the subject in terms of threat of, or actual loss or injury to his psychic and/or physical integrity, we talk of *psychological stress.* This theoretical construct has been plagued by ambiguity, despite numerous attempts at its clear formulation. The most lucid and comprehensive discussion of psychological stress has been given by Lazarus, that of social stress, by Levine and Scotch. Semantic confusion, however, should not obscure the mass of accumulated evidence, clinical and experimental, that events and situations in an individual’s life affect his health. When such events are interpreted by the subject in terms of meanings mentioned above and result in disturbances of his psychological and/or somatic homeostasis straining his current adaptive and coping capacities, we can apply the term psychological stress. It is a general concept encompassing disturbing stimuli (stressors), their cognitive assessment, and the resulting emotional, physiological, and coping responses.

Psychological stress need not have pathological consequences unless it is sustained, or of such a magnitude for a given person at a given time that it results in a breakdown of adaptive mechanisms, somatic, psychological, or both. Such a breakdown has been expressed in the concept of *general susceptibility* to disease. Whether the latter occurs and what form it takes is determined by a variety of factors, enduring and current, residing within the individual (host) and in his social and physical environment. Recent psychosomatic research has used a three-pronged approach to the investigation of the chain of events leading from a social stimulus to disease. The first approach emphasizes epidemiological methods, and focuses on temporal relationships between specific *life changes,* or demanding *life situations,* e.g. family or occupational, in groups of individuals and their morbidity. The second approach takes as its starting point an individual's *psychological state,* the realm of thought and feeling, in response to life events and situations which are disturbing to him. The third approach aims at identifying *physiological mechanisms and pathways* mediating between symbolic stimuli, a disturbed psychic state, and evidence of pathology and/or dysfunction in a given organ or tissue.

Enge distinguishes three broad classes of psychologically stressful events: *loss* or threat of loss of psychic objects, i.e. people, possessions, ideals, etc., having ego-sustaining value for the person; actual or threatened *injury* to the body; and *frustration of drives.* This list is not exhaustive. One could add to it the disorienting rate of social change; value, choice, and decision conflicts; wants, created by the existing economic system, coupled with aroused expectations and inability to meet them; status inconsistency, and a host of other social situations and events which cannot be reduced to Engel’s three main categories. It must be emphasized, however, that despite observed similarities of people’s responses to external events, the ultimately decisive factor is the *individual’s* evaluation of his perceptions, and his personal interpretation of them.

Bodily injury or illness, or threat of either, constitute one of the major sources of psychological stress. This view links etiological factors with reactive ones. Thus, psychosocial factors may not only contribute to disease onset, but illness itself includes psychosocial responses which may increase or reduce the initial psychological stress and thus influence the course and outcome of the illness (See references 20, 36, 40, 64, 74, 75, 82, 92, 94, 111, 121, 126, 171, 204, 210, 211, 215, 216, 224, and 226).

Determinants of Psychological Reaction to Disease

The multiple determinants of every patient’s psychological reaction to his physical illness, injury, defect, and/or disability may be assigned to the following classes:

1. Intrapersonal factors, which include biological variables, such as age, sex, and constitution; and psychological, i.e., personality in all its aspects, past experience with illness in oneself and others, etc. Both these classes of variables inherent in the person include his enduring psychobiological predispositions and states as well as those obtaining at the onset of illness and throughout its duration.

2. Interpersonal factors, i.e., nature of patient’s relationships with other people, especially family and health professionals, both before and during his illness.

3. Pathology-related factors, i.e., spatio-temporal characteristics of disease or injury and the subjective meaning they have for the patient in relation to his past history, knowledge, values, and current adaptive capacity.

4. Sociocultural and economic factors, i.e., values and attitudes toward illness as such and specific diseases prevalent in the patient’s social milieu; beliefs about medical care delivery and its practitioners; economic consequences of illness for patient; etc.

5. Nonhuman environmental factors, i.e., physical aspects of

environment in which patient lives during his illness.

The varying influence of the above factors determines the unique quality of the experience and behavior of every patient in any given episode of illness. No single set of generalizations can fully account for the individual nuances of response to illness. Yet generalizations are practically useful to allow grouping of patients showing common features and as a basis for the clinical approach to every individual. Each of the five classes of determinants must be taken into account for a *comprehensive* diagnosis and management.

Intrapersonal Factors

These are the *psychobiological characteristics* of the patient and his premorbid life history as experienced by him. Those aspects of his past experience are relevant which influence the meaning for him and his attitude toward his particular illness or disability and its consequences.

The psychological impact of any illness differs depending on its timing in a person’s life cycle. The experience of being sick and the psychological resources to cope with disability are different in a child, adolescent, or an old person. Thus *age* is an important variable.

Illness, disability, or injury in *childhood* (See references 32, 105, 109, 138, 169, and 208) deserve special attention. They may interfere with the child’s maturation and optimal psychological development. The quality of the illness experience, influenced by the behavior of the important adults toward the sick child, may determine his reactions to illness in later life, such as excessive fear of, sense of weakness and shame in relation to, or, on the contrary, eager acceptance and even simulation of illness as a psychologically rewarding state. A child has a limited repertoire of cognitive and other coping strategies available to him, and his usual defense is regression. Yet, as Langford points out, such regression is “strategic withdrawal for regrouping of strengths” rather than a pathological development. Most children cope with illness surprisingly well and may come out of it with increased maturity and vigor. To achieve this favorable outcome, however, the child needs the understanding and support of those taking care of him, particularly if the illness is severe, prolonged, and requiring hospitalization.

Physical illness during *adolescence* imposes an additional stress at a time when the tasks of gaining independence from the parents and developing a stable body and self-image provide a formidable challenge. Some adolescents tend to fear the passivity and dependence imposed by the illness and may readily interpret it as a punishment for sexual and aggressive feelings and activities. Others may welcome it. Physical illness during adolescence is particularly likely to engender intense conflicts and anxiety. They may be manifested directly or take the form of lack of cooperation with health professionals, and denial of and attempted flight from illness.

Examples of this are provided by juvenile diabetics and adolescents suffering from malignant neoplasms.

Illness, even relatively mild, in a *middle-aged* person who has enjoyed good health, may trigger off thoughts of approaching old age, infirmity, and death. Such associations may evoke an emotional response more intense than the nature of the illness would warrant. This intensity may be further enhanced if the illness occurs close to the age at which a parent or other significant person died.

Old age frequently adds an important variable influencing the response to illness: some degree of brain damage and consequent proneness to cerebral decompensation. The latter often complicates physical illness and hospitalization in persons over 65 years. Cognitive disorganization impairs rational evaluation of the illness and environment, and adds a source of psychological stress and disorganizing anxiety. There is also the grave hazard of extension of the irreversible brain damage.

Thus, the psychological impact of illness or disability varies with the developmental phases of the human life cycle. A congenital deformity or functional handicap will help shape a person’s body image and influence the direction of growth of his personality. Acquired at any stage from birth on an injury or illness carries a potential for psychological growth as well as for crippling maladjustment. Anything that disturbs functions of the body affects the psyche and vice versa.

The patient’s sex influences reaction to diseases which impair bodily attributes or functions valued for their enhancement of the sex role. Injury or deformity which mars esthetic quality of the body is likely to have more serious emotional significance for a woman than a man. He is more likely to be affected by any chronic illness which enforces dependence on others and interferes with capacity for work, a source of gratification in its own right. In either sex, disease affecting sexual function or secondary sex characteristics may undermine his or her sexual role and identity, and intensify related unconscious conflicts. Unconscious symbolic meaning of the affected body part may have a sexual connotation, and injury to it, the nose for example, may be unconsciously interpreted as castration with consequent anxiety or depression.

The patient’s *personality style* influences the meaning and experience of illness, as many authors have emphasized. Myocardial infarction, for example, evokes different responses in an obsessional, schizoid, paranoid, hysterical, or impulsive personality type. Personality attributes comprise the individual’s *cognitive and perceptual style,* such as field dependence or independence; his unconscious *conflicts,* characteristic *ego defenses,* and *coping styles* with psychological stress of any type; *ego strength, intelligence, values,* and *knowledge; body image* and *self-concept;* and other relatively enduring qualities which all play a major part in determining the total psychological response to disease. These factors influence behavior to all facets and at all stages of illness, and hence their assessment should be part of a comprehensive diagnosis as a basis for an individually tailored management plan for every patient. The clinical relevance of these variables will be discussed in more concrete terms in the subsequent sections.

Apart from enduring personality characteristics, the patient's *psychobiological state* at the onset and during the course of his illness must also be taken into account. His level of consciousness and his cognitive and perceptual capacity, will influence his ability to appraise his illness, diagnostic procedures, etc. His ability to cope with the illness also depends on his current mood, state of unconscious and conscious conflicts, and stability of life situation. It has been observed that the greater are the magnitude of *life change* and the related conflicts, adaptive demands, and affective arousal, the more likely is an illness to occur and be severe. This suggests that psychosocial stress plays a dual part in that it both enhances susceptibility to illness and impairs the host's capacity to cope with it physiologically and psychologically. Since illness itself changes the quality of subjective experience, producing unpleasant mood and disturbing perceptions and thoughts, a vicious circle results. Increasing psychophysiological arousal and distress may readily ensue and add to the initial psychological stress (See references 9, 42, 82, 83, 102, 143, and 193).

Interpersonal Factors

The quality of the individual’s interpersonal relationships before and after the onset of his illness exerts a profound effect on his experience and coping capacity. When illness comes on, as it often does, in a setting of interpersonal, say marital, conflict, or of loss of a close person, or work-related stress, its impact tends to be greater, its course more stormy and the recovery protracted or absent. Findings of higher than average morbidity and mortality rates among the recently bereaved, for example may reflect both increased susceptibility to disease and reduced ability and/or willingness to cope with it. Loss of an important relationship, whether actual, anticipated or even imagined, is said to be a common trigger for the so-called *giving up-given up complex.* That psychological state, consisting of negative appraisals of self and environment, and concomitant affects of helplessness or hopelessness, has been observed to be a *common antecedent* of many illnesses. It appears that the more intense those affects are, the greater the tendency to give up the struggle for survival, psychologically and biologically.

Increasing attention has been given lately to the crucial importance of *family relationships* in influencing the course and outcome of illness. These factors will be discussed in more detail later. It suffices to stress at this point that viewing the patient apart from his social context results in an incomplete picture of illness and its deficient management.

Relationships between the patient and the health professionals with whom he comes into contact invariably influence, for better or worse, the course and outcome of his illness. Other relevant relationships include those with employers, friends, neighbors, etc., who constitute the patient's social milieu. All these factors will be considered in some detail in the later sections.

Pathology-Related Factors

The nature and characteristics of the pathological process or injury are a class of biological variables pertaining to the integrity of the body and its functions. These factors acquire psychological significance as they, and/or their consequences, give rise to perceptions, thoughts, feelings, communications, and actions. There is some indication that subliminal interoceptive stimuli may influence conscious psychic processes and dream contents and thus provide clues to a still covert pathological process. It would be valuable for preventive medicine if such clues could be reliably identified, but this is not yet feasible.

Variables, such as the site and extent of the lesion, rate of onset and progression, the kind and degree of functional derangement, as well as duration of the pathological process, all influence the patient's emotional response. Specific organs and physiological functions have different psychological significance and symbolic value for each person, related to his unique life experience, body image, and personality. These values may have little relevance to the issue of survival. Injury to the face or an abdominal scar may have greater subjective significance than impairment of organs essential for survival. The particular experiential history of the patient, his conscious and unconscious conflicts and beliefs, sociocultural influences, and other factors, determine what significance and value he attaches to the given body part or function. The extent to which the disease process changes one's *somatic sensory input and body image* also influences how one responds to disease or injury. Last but not least, *impairment of cerebral function* by disease, its nature, and the degree of its reversibility or compensability, is important (See references 11, 23, 32, 52, 78, 124, 125, 129, 177, 183, 186, 194, 202, 210, 216, and 218).

An organ or biological function has especial subjective significance for a person when it:

1. constitutes a source of pleasure, pride, self-esteem, and effective coping with the environment;
2. helps maintain satisfying relationships with others;
3. helps alleviate intrapsychic conflicts and thus protects against experience of painful affects;

4. enhances sense of personal identity, self-concept, and stability of his body image;

5. helps maintain social roles and occupational capacity;

6. has unconscious symbolic meaning which imparts to it a vital value in his psychic economy.

Any disease, injury, or disability which jeopardizes or destroys such personal values has an intense subjective meaning for and emotional effects on the patient.

Sociocultural and Economic Factors

This is the domain of *values, beliefs,* and *attitudes* related to matters of health and disease. They are generally shared by members of a given social group and class, and affect every patient's emotional response to illness, as well as his illness behavior. These factors have been studied extensively by medical sociologists (See references 84, 98, 146, 147, 161, and 206).

Everyone holds views about the significance, etiology, likely effects, and prognosis of the more prevalent diseases. Such beliefs influence the meaning of his illness for the patient and what he does or fails to do about it. His behavior also expresses his image of the health professionals and medical institutions. If this image is largely unfavorable, the patient tends to avoid seeking medical help and resorts to folk medicine and self-medication. Members of the lower socioeconomic groups tend to be wary of doctors and hospitals, less likely to evaluate symptoms as indicative of disease, and more likely to trust their own understanding of health. Poor people from city slums or rural areas have often different medical values and customs from those of health professionals and other members of the higher socioeconomic groups. These factors, combined with the cost of medical care, contribute to the medically deprived position of the poor.

Attitudes in a patient’s social milieu toward being sick, as well as derogatory and fearful views of certain diseases, influence his willingness to accept the sick role, and reveal his symptoms to others. Some diseases carry a *stigma* and to suffer from one of them may evoke shame, guilt, self-devaluation, and social withdrawal. Such responses add to the other stresses of illness, and promote attempts at its concealment. Venereal diseases, epilepsy, leprosy, or tuberculosis are often stigmatized because of their negative moral connotation, fears of contagiousness, and/or frightening outward manifestations. Cancer is so dreaded at all levels of American society that about 60 percent of adults queried in a large poll stated that they would conceal it from others. Many people believe that cancer is contagious and fear contracting it from or transferring it to members of their family. Such fears are particularly strong in patients suffering from an illness believed to be contagious who harbor conflicts over hostile impulses and feel guilty about them. If such an illness intensifies the patient’s hostility, he may have unconscious wishes to infect others and suffer intense guilt as a consequence.

Knowledge of scientific medicine varies with socioeconomic grouping and is usually lowest in those with a low level of education and income. Yet irrational beliefs about medical matters are not confined to any class. Nor does possession of medical knowledge automatically ensure rational behavior in illness, as any physician who has treated his colleagues can testify.

Nonhuman Environmental Factors

Psychological effects of the physical environment in which the sick person lives, be it home or hospital, are an important, although neglected subject. Various hospital environments affect the patients. Esthetic qualities of the surroundings, quantity and quality of the sensory input, and appearance of diagnostic and therapeutic implements may influence the patient’s mood and at times arouse anxiety or facilitate cognitive disorganization on account of their novelty, unfamiliarity, monotony, etc.

The above list of determinants of psychological reactions to disease is not meant to be exhaustive. Their outline underscores the large number and diversity of variables which influence the experience and behavior of the sick.

Modes of Psychological Response to Disease

We will describe patients’ responses to disease, in both their *subjective* and *observable* aspects. Three such overlapping aspects will be distinguished:

1. The intrapsychic (experiential), which refers to what the patient perceives, thinks, and feels, that is to perceptual, affective, and cognitive components of his subjective response to his illness;
2. The behavioral, that is, how the patient communicates with others and acts in regard to his illness;
3. The social, which concerns his interactions with others, particularly his family and the health professionals.

The Intrapsychic (Experiential) Aspect

Disease and the suffering it causes are universal components of the human condition. Stripped of its abstract, scientific connotations, “disease” and “illness” are labels for an essentially personal experience, one known only through introspection. It may be communicated to others and has to be received with empathy to result in meaningful information. Such procedure is often dismissed as unscientific and the data as anecdotal. Yet this is not a valid reason to leave out of account what matters the most to every patient, to every one of us, personally. The subjective aspects of illness may be described and studied in two distinct ways: as a *total experience,* by obtaining introspective reports; and *atomistically* by applying scientific psychological terminology and observation methods, and breaking down the patient's experience as an integrated whole into its *perceptual, cognitive,* and *emotional* components. The former method will be briefly discussed first.

An illness colors to some extent the sick person's experience of his body, self, and environment, his values and goals. Novelists, like Proust or Chechov, writers of diaries, and some existentialists, have written sensitive accounts of how the sick feel. Of particular interest are autobiographical descriptions of specific illness experiences written by physicians. While every episode of illness is a unique experience, certain common trends may be discerned. Narrowing of interests, ego-centricity, increased attention and responsiveness to bodily perceptions and functions, irritability, increased sense of insecurity and longing for human support and closeness, are commonly reported inner changes. There is often an unpleasant change in the general body feeling, or coenesthesis, experienced as malaise or the feeling of sickness, usually associated with an active pathology. Negative emotional experiences are not invariably reported, however. Some sufferers from chronic illness or disability experience an increased awareness of esthetic and intellectual values and enhanced intensity of spiritual life in general.

Perceptual, Cognitive, and Affective Components of Response

Perception of all the sensory input relevant to one’s illness depends on the *attributes of the perceiving individual,* the *characteristics of perception* itself, and *the situation* in which the patient finds himself. The quality, intensity, and spatiotemporal features of the perception are important. A sudden attack of vertigo, bleeding, severe pain, or marked shortness of breath are more likely to force an appraisal of what is happening with greater urgency than a painless lump or transient bowel dysfunction. Yet already at this stage the characteristics of the perceiving individual come into play.

One such characteristic is the *perceptual style,* whether conceptualized as *perceptual reactance,* that is, augmentation or reduction of what is being perceived; as *repression-sensitization*; or some other hypothesized continuum of perceptual reactivity. Habitual augmenters tend to perceive somatic sensations, such as pain, more keenly and appraise them more readily in terms of threat or harm than the reducers. The latter find it easier to ignore and deny the significance of their symptoms. Sensitizers are liable to report greater frequency and/or severity of symptoms, and higher total numbers of complaints and visits to physicians, than repressors. These observations seem to represent differences in perception concerning illness and corresponding responses to it.

Individuals differ with regard to their responsiveness to somesthetic stimuli. Some may mislabel their interoceptive cues. These individual differences reflect early learning of both somatic responses and their symbolic, linguistic equivalents. The latter are influenced by sociocultural and ethnic factors.

Cognition refers to thinking, concept formation, and problem-solving. *Cognitive aspects* of the psychological response reflect an individual's *cognitive style.* Two such styles pertain to illness experience: *vigilant focusing on and need to explain* illness-related perceptions and events; and *minimization,* that is, a habitual tendency to play down the significance of any perceived bodily changes, etc.

Cognitive evaluation of illness is partly conscious and partly unconscious. Unconscious cognition involves primary process thinking, that is one characterized by distortions of facts according to the person's wishes, conflicts, fears, repressed memories and fantasies, etc.

Different organs and bodily functions have unconscious symbolic meanings derived from early childhood experiences and never influenced by factual knowledge. Thus, perception of abdominal distension due to a malignancy may arouse unconscious fantasies of pregnancy, for example. Much has been written about unconscious sexual symbols of the nose, neck, eyes, or teeth. Any body orifice may symbolically represent a female genital. Illness may be interpreted, consciously or not, as just or unjust punishment for repudiated wishes or actions which had aroused feelings of guilt; as enemy; challenge; weakness; irreparable damage; or as value. Such subjective views of illness or injury influence the patient’s conscious attitude, feelings, and overt behavior.

An almost universal cognitive response to illness is an attempt to *explain its origin.* Two most common modes of explanation are to *blame* oneself or another person or nonhuman agent for having caused the disease. Such beliefs about etiology may vary from rational and scientifically sound ones to irrational and delusional. In any case, to “explain” the origins and mechanisms of the illness may offer a comforting illusion of mastery over it and help reduce ambiguity, uncertainty and anxiety. Yet this is not always so. Sometimes the evolved explanation may result in a sense of guilt, grievance, and anguish.

The emotional responses to illness vary in quality, intensity, and duration. They both reflect and influence the personal meaning of illness, the nature and degree of symptoms and disability, and the degree of support the patient gets from his environment. *Anxiety, grief, depression, shame, guilt, anger*—these are the affects most often elicited. Less common are *apathy, indifference, elation, or euphoria.* Whether one judges a patient’s affective response as normal or not depends on its *appropriateness,* that is, degree of correspondence to the severity of the pain, losses, and suffering. Such judgment is obviously value-laden and the borderline between normal and abnormal responses is an arbitrary one. Practically more important is the degree to which the affective response impairs a patient’s capacity for recovery and/or adjustment. Pathological emotional responses which are components of identifiable psychiatric syndromes, neurotic or psychotic, are discussed in detail in a paper devoted to the psychopathology related to physical illness.

The Behavioral Aspect

The *communications* and *actions* of the patient in relation to his illness comprise the behavioral aspect of his total psychological response. Mechanic introduced the concept “illness behavior” to designate “the ways in which given symptoms may be differentially perceived, evaluated, and acted (or not acted) upon by different kinds of persons.” Yet perception and evaluation of symptoms do not logically belong to behavior as usually defined in psychology, but communications and actions do. Illness behavior should be confined to the latter.

Communicative Behavior

What the patient communicates regarding his symptoms or distress, when he does it, to whom and how, is important for delivery of medical care and a satisfactory doctor-patient relationship. Communication is a two-way process, modified by the manner in which messages are responded to by the recipients. In the case of illness, the patient’s communications influence and are influenced by the responses of his doctors, family members, or other concerned persons. This aspect of illness behavior has attracted considerable attention in the 1970s because of its relevance to the diagnostic decision and the patient’s compliance with medical recommendations (See references 1, 39, 149, 196, 213, 228, 230, and 231).

Only selected examples of studies in this area are mentioned here. Zola emphasizes the influence of *sociocultural factors* on the manner in which patients communicate their symptoms to the doctor. He found that Irish and Italian patients attending outpatient clinics of a general hospital presented their complaints differently. The Irish tended to understate their difficulties, to refer their complaints mostly to the eyes, ears, nose, and throat, and to deny that they felt pain. Italians, on the contrary, dramatized their complaints, referred symptoms to many parts of the body, and claimed that their distress interfered with their social relationships. More Italians were labelled as “psychiatric problems” by the doctors, suggesting that the way in which symptoms are communicated tends to influence diagnostic reasoning. Zola observes that the doctor “can block or reject the patient’s communication by his very reaction, or lack of reaction, to the patient’s concerns” and thus obtain inaccurate and misleading information. Similar conclusion was reached by Duff and Hollingshead from their study of medical inpatients.

Zborowski studied responses to *pain* manifested verbally and nonverbally by patients of Old American, Jewish, Irish, and Italian origin. Patients of Jewish and Italian origin tended to be more emotional while experiencing and communicating pain than the Anglo-Saxons (Old Americans). They also tended to emphasize their perception of pain and its severity. The Old Americans and Irish tended to play down pain, report it unemotionally, and describe it typically as stabbing and sharp. The Irish were vague and confused in their description of perceptions and feelings about pain. Italians related more often than others that their pain was constant rather than intermittent. They and the Jewish patients made no effort to conceal their pain, and manifested it by crying, moaning, etc., suggesting their desire to communicate their suffering both verbally and nonverbally.

Patients often communicate selectively what they believe the doctors are interested in, namely somatic complaints. This expectation may make the patient express his psychological distress in terms of somatic complaints and metaphors. Such skewed communication readily leads to diagnostic errors, and unnecessary and costly investigations of nonexistent organic disease. Another source of diagnostic error is provided by patients who complain in terms of psychological distress and withhold information about their somatic symptoms. Others habitually express their disturbed feelings in *somatic* terms. Such somatizing patients predominate in the lower economic classes and the rural areas.

Special problems are presented by patients suffering from disorders of communication, for example aphasia, or those who communicate in an idiosyncratic idiom, as many schizophrenics do, or overdramatize their symptoms as an expression of hysterical personality. Such patients may fail to make themselves understood or believed with possible errors in diagnosis.

COPING BEHAVIOR

The *actions* taken by the patient in relation to his illness are an aspect of his overall *coping behavior.* The concept of coping designates “instrumental behavior and problem-solving capacities of persons in meeting life demands and goals.” A narrower definition confines it specifically to strategies of dealing with psychological stress. Physical illness and disability are a category of psychological stress with one crucial characteristic: the primary source of stressors lies within the person’s body boundaries. Coping in this context may be defined as cognitive and psychomotor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function, and compensate to the attainable limit for residual irreversible impairment. One may distinguish behavioral coping *styles* and *strategies.* The former refer to *enduring dispositions* to act in a certain manner in response to threat or loss involving one’s body. Strategies refer to the *actual techniques* which the patient employs in dealing with a particular illness or disability. They are a resultant of both his coping style and current situational constraints. The latter include the particular form of disability suffered from, say paraplegia or aphasia, as well as the whole constellation of intrapersonal and environmental factors accompanying a given illness episode. Behavioral coping styles may be classified as *tackling, capitulating,* and *avoiding.*

Tackling means a tendency to adopt an active attitude toward challenges and tasks imposed by illness or disability. In its extreme form, it is manifested by a tendency to “fight” illness at any cost. The patient acts as if the disease was an enemy to be combated and may engage in behavior inimical to his health, for example by continuing strenuous physical activity in the presence of coronary artery disease or rheumatoid arthritis. Adaptive manifestations of this style include rationally modulated activities aimed at early recovery, or compensation for residual disability. Timely seeking of medical advice, compliance with therapeutic regimens, active information-seeking, searching for substitute skills and gratifications to replace the lost ones—these are desirable coping strategies reflecting the tackling style.

Capitulating refers to one’s habitual way of dealing with threats and losses by adopting a passive stance and either withdrawal from or dependent clinging to others. Patients displaying this style create problems for physicians because of their inadequate cooperation, or excessive demands for support, reassurance and care-taking, respectively. This way of coping should not be confused with adaptive passivity during the acute stage of any serious illness.

Avoiding pertains to active attempts to get away from the exigencies and challenges of the illness. It is characteristically displayed by individuals for whom acceptance of illness, hospitalization, treatment, etc., signifies a severe threat to their self-concept as independent or invulnerable, or, on the contrary, excessively vulnerable. Its intrapsychic concomitant is usually either a marked degree of denial of illness or of manifest anxiety.

Coping behavior in patients has been studied in particular detail in relation to such conditions as chronic illness and disability, severe burns, acute poliomyelitis, diabetes, and other illnesses. It is a clinically useful universal concept as it allows the physician to identify a given patient’s dispositions and actual techniques for dealing with his illness, and intervene to encourage adaptive ones. Excellent examples of such intervention are given by Hackett and Weisman who describe psychiatric techniques of managing psychological disturbances related to surgery.

The Social Aspect

The social aspect of the patient’s response to illness refers to his interactions with concerned others, especially his family and health professionals. This aspect has been studied extensively by sociologists, who have proposed relevant explanatory hypotheses and introduced organizing theoretical constructs. The most influential of the latter has been that of the sick role, developed by Parsons. As Kasl and Cobb put it, “Parsons observed with great insight that when one becomes ill, one does not simply drop one’s customary roles—the role of parent, spouse, or provider; one actually adopts a new role which supersedes the others.” Parsons called this the *sick role.* This concept is reviewed here as it is pertinent to the patient’s interactions with his social environment.

The concept of any role involves two kinds of expectations: That the individual will adopt certain attitudes and follow certain actions; and that others should behave toward him according to explicit and implicit rules. The sick role implies the following expectations: 1. Exemption from the responsibilities and obligations of the premorbid social roles (for example, as wage earner) in relation to the nature and severity of illness; 2. Obligation to seek the health and comply with advice of competent persons; and 3. Surrender of the sick role as soon as possible. It is thus expected that playing the sick role has a time limit and the patient should do his best to achieve functional recovery. This is in accordance with the prevailing values and norms of the American society, which extol self-reliance, individual initiative, efficiency, and achievement. The sick role is a deviant one, but distinguished from other deviant roles by the fact that the sick person is not held responsible for his condition.

The sick role is a heuristically fertile concept, which provides a *sociological* framework for the study of illness as an indispensable complement to the biological and psychological approaches. The concept has been criticized on theoretical and practical grounds. The main criticisms are that it is inadequate for the study of minor as well as of incurable and stigmatized diseases; and that it is not applicable to illness behavior not involving contact with physicians. It is also not applicable to the characteristics of other cultures. These criticisms do not detract from the originality and methodological value of Parsons' contribution.

The patient may take one of several courses of action with regard to acceptance of the sick role: (1) He may accept it realistically, as society expects him to do, and surrender it upon recovery; (2) He may attempt to reject or avoid it, even if this is harmful to him; (3) He may adopt it readily and refuse to give it up despite the doctor's opinion that he is fit to do so; and (4) He may strive to avoid it, then give in to and cling to it. All these patterns of sick role behavior are encountered in clinical practice and influence the course, duration, and outcome of any illness or injury. They are determined by the interplay between the patient, his illness, and his social environment. A person who views dependence, helplessness, and physical incapacity as threatening or degrading has difficulty in accepting the sick role and engaging in rational illness behavior. Interaction between the patient and members of *his family* on the one hand, and the *health professionals* on the other, influences his sick role behavior and will now be discussed.

The Patient and His Family

The relationship between illness and family dynamics may be approached from several overlapping points of view: (1) The influence of family interaction, say marital conflict, on the development of illness or injury;

The role of the family in the learning of particular modes of illness behavior. For example, children may adopt through identification and imitation specific attitudes toward the sick role as well as predisposition to evaluate given symptoms or types of disability as threatening, shameful, etc. Children rewarded for being ill may acquire a tendency to view illness as a potential source of gratification;

The impact of illness in a given family member on the stability of the family as a whole; (4) The interactions between the sick member and other members of the family as they affect the patient and his spouse, children, parents or siblings; and (5) The influence of the family dynamics on the timing of seeking medical consultation and hospitalization.

All these aspects of the relationship between illness and family interactions have been studied and there is growing appreciation of their importance for medicine. Only selected observations and theoretical formulations may be touched upon here.

An influential set of theoretical formulations in this area has been contributed by Parsons and Fox. They pointed out that the modern American family by virtue of its small size and relative isolation is exceptionally vulnerable to the impact of illness of one of its members. The illness in the mother is disturbing because of her unifying and emotionally supporting role within the family. Her illness may deprive husband and children of her customary support, while imposing additional stresses and demands on her. Illness of the father, as the main provider and status-bearer, undermines the social and economic position of the family as a whole, and by attracting mother’s concerns deprives the children of her support. Illness of a child could increase marital strain and enhance sibling rivalry, for example. The intrafamily dynamics could be further disturbed if the sick member used his illness as a strategy aimed at escape and relief from obligations and demands within and outside the family. The adjustment to illness and disability involves learning by the patient how to be sick and by the family how to respond to his sickness. Both these tasks are demanding and may evoke disruptive emotional responses.

Many studies have focused on the impact of severe illness in a child on family dynamics. Friedman et al. (See references 30, 57, 138, 169, and 208) made a detailed analysis of parents' reactions and coping strategies in response to neoplastic disease, mostly leukemia, in a child. The common sequence of parental reactions began with a feeling of shock when diagnosis was disclosed, followed by a tendency to self-blame and guilt for imaginary errors of omission and neglect with regard to early manifestations of disease. Such guilt feelings tended to be transient and gave way to seeking of information about the illness and its etiology as an attempt at mastery of an uncontrollable situation. The coping behavior of the parents included defense mechanisms of isolation of affect, intellectualization, and, less often, denial. Poor operation of such defenses was associated with manifest anxiety and depression which hampered a parent's ability to care for the sick child. Hope in the parents was common and gradually gave way to anticipatory grief, manifested by somatic symptoms, apathy, and preoccupation with thoughts about the ill child.

As part of this study an attempt was made to assess the degree of psychological stress in the parents by determining urinary 17-hydroxycorticosteroid levels and relate them to the observed coping behavior and affects. It was found that the excretion rates were relatively stable and the investigators concluded that the more any defense mechanism protected the individual from the impact of the chronic stress of a child's illness, the lower and less fluctuating would be the associated 17-OHCS levels. Such levels were among the lowest in parents who displayed marked denial mechanisms.

This study stands out as one of the most thorough of its kind and is using a psychophysiological approach. It shows that a person’s coping strategies have *both psychological and physiological* aspects and consequences for him.

The impact of specific diseases and disabilities in *adults* on the family interaction has been less extensively studied. A few representative examples will be cited to emphasize the diversity of the related problems which await further research.

Disability in *husbands and fathers* has been studied from the point of view of the patients. The latter reported the main changes in their family relationships in the following order: (1) greater responsibilities for the wives in the management of the home; (2) reduction of social and recreational activities; (3) more duties for the children around the house; (4) incurred debts; (5) changed plans for a larger family; (6) necessity of wife’s employment; (7) increased marital discord; (8) changed plans for children’s education; and (9) changed living accommodation. The disabled head of the family perceived significant shifts in the respective roles of the family members, with his own role being undermined in the process. There was also evidence of marital friction and decline in social and economic status of the family. Shifts of roles within the family may create conflicts when the husband eventually recovers and claims his previous dominant role and its prerogatives. This writer has observed psychological decompensation in several wives as a result of such repeated role reversal.

The impact of chronic illness upon the *spouse* was studied in a sample of men and women belonging mostly to the lower class. The healthy spouses reported new or increased symptoms, such as nervousness or fatigue. There were indications of increased interpersonal conflict (role tension) expressed by irritability and readiness to feel depressed in both partners. Greater symptomatic distress of the patient caused more emotional tension in the spouse, and vice versa.

An interesting relationship has been observed among physical disability, and need and marriage satisfaction in couples in which the *wife* was severely disabled. “Severe disability” was defined as a physical impairment interfering with homemaking activities. Some of the women were bedridden and unable to move. The physical condition of the disabled woman was not a reliable predictor of need or marriage satisfaction in either partner. Greater mobility of the wife did not invariably result in greater need or marriage satisfaction. There was no simple relationship between the wife’s level of functional mobility and the husband’s need satisfaction. Severe disability provided the patient with a less ambiguous role and thus less conflict and demand for efforts to improve her ability to meet obligations. The disabled woman’s sexual satisfaction was positively correlated with her marriage satisfaction. Physical condition of disabled persons had little effect on marital sexual activity. Similar observations have been made in paraplegics and quadriplegics.

In general, the following conclusions may be drawn from the available studies: (1) Evaluation of any patient is incomplete without a detailed inquiry into his family interactions and the ways and degree in which they are affected by the patient’s illness and, in turn, affect him; (2) The quality of *communications* between the patient and his family members should be assessed in a marital couple or family interview. There is often skewed communication, and in cases of fatal illness a conspiracy of silence, which imposes a strain on all concerned; (3) In the case of a married patient it is essential to inquire into the effect of the disabling illness on the respective *roles* of the couple, their sexual adjustment, and the related marital tensions. The sense of sexual identity of either partner may be undermined as a result of illness and reactivate related intrapsychic conflicts. This may occur if the wife is forced to play a more active role both as breadwinner and sexual partner (for example, husband’s paraplegia or painful back may preclude his taking an active role during sexual intercourse). The reverse situation and role shift may occur if the husband of a disabled woman has to assume housekeeping and other functions conflicting with his self-concept as a male;

(4) The response of a "healthy" family member may aid and abet the *maintenance of the sick role.* Or, on the contrary, a hostile response toward the ill member may prompt him to attempt to give up the sick role prematurely. When the former interaction is at play, the healthy member, be it parent or spouse, may derive gratification from playing a supporting and nurturing role. He or she may then interfere with treatment of the patient, foster his dependence, and decompensate psychologically if the patient recovers; (5) Chronic or fatal illness and disability often tend to accentuate *ambivalence* in the relationship between the sick member and the one most concerned with his care. Negative aspects of the ambivalence are then a source of guilt and provoke renewed attempts at compensation with resulting increased resentment leading to more guilt, etc. Such a vicious circle is commonly observed, increases psychological stress for both partners, and predisposes to pathological forms of grief when the sick member dies; (6) Illness *does not always disorganize* a family, but at times helps it to rally together and consolidate itself.

The Patient and Health Professionals:
The Doctor-Patient Relationship

The importance of the *doctor-patient relationship* for the course and outcome of the illness has long been recognized and there is extensive literature on the subject. Only some salient theoretical models and studies are mentioned here.

Henderson proposed an early model of doctor-patient interaction. He defined it concisely: “A physician and a patient taken together make up a social system. They do so because they are two and because they have relations of mutual dependence.” Parsons has carried a *sociological* analysis of the doctor-patient system further. He points out that the role of the physician “centers on his responsibility for the welfare of the patient in the sense of facilitating his recovery from illness to the best of the physician’s ability.” A doctor’s judgment confers on a sick person the status of a “patient.” This is a prerogative of the physician’s social role.

The *social role* of the physician is only one aspect of the doctor-patient relationship. The analysis of the latter should include three basic elements: (1) The individual predispositions of the physician, including his unconscious motivations and responses; (2) His internalized standards of professional behavior; and (3) The specific stimulus complex provided by the patient.

Szasz and Hollender describe three types of doctor-patient relationship: *activity-passivity,* in which the patient is helpless and passive and the physician treats him in a manner similar to that of the parent of a helpless infant; g*uidance-cooperation,* implying that the patient is capable of following directions and exercising judgment. He is, however, expected to comply with the physician as a competent guide. This model has its prototype in the relationship of the parent and his child (or adolescent); *mutual participation,* a model most appropriate for the management of chronic illness in which the patient is largely responsible for his care and consults the doctor only occasionally. The physician helps the patient to help himself. This is a relationship between two adults.

While each of the above models is appropriate for certain types or stages of illness as well as in relation to the patient’s age, intelligence and cognitive clarity, the actual relationship may be inappropriate for the given patient and situation. Thus a comprehending adult may be treated as if he were a child. Such a relationship may be initiated by either doctor or patient, but willing cooperation of both is needed for the inappropriate relationship to become established and flourish. How can this happen? The answer lies in the fact that neither doctors nor patients are just rational adults and that both are influenced by unconscious motives related to dependent, sexual and/or power needs. The degree to which such elements enter into the doctor-patient relationship influences its quality and therapeutic efficacy. We speak of *transference* and *countertransference* in this relationship to mean distortion of the mutual perceptions of the doctor and patient, respectively, and consequently of their relationship, by the significant past relationships of each of them. Such influence is usually unconscious and may result in intense feelings of attraction, suspicion, hostility, competition, regressive dependence, etc., which tend to impair the professional relationship. Transference and countertransference do not mean conscious feelings of liking, trust, sympathy, or antipathy which are universal aspects of human relationships. They refer only to *distortion* of present relationships in terms of the past, usually childhood ones.

A common aspect of the doctor-patient relationship is *ambivalence,* which may be mutual. The doctor lends himself to contradictory feelings by virtue of his role itself. He is in some respects an authority, a judge and bearer of good or bad news related to the patient's future, to matters of suffering and death. The doctor may feel attracted to a patient, or repulsed and exploited by his demands, lack of progress, irrational behavior, or ingratitude. A physician's knowledge and therapeutic efficacy are limited, giving rise to doubts, sense of failure and other self-devaluating feelings which for some are hard to bear. The hallmarks of the patient's situation are *uncertainty* and, if treatment is undertaken, *dependence* on the doctor's judgment, competence, and information he chooses to transmit. This unique type of social relationship may arouse mutual mixed feelings in both partners. Whether such feelings remain within manageable bounds, or acquire disturbing intensity, depends both on the personality of the patient and the doctor's maturity, attitude, and conduct. A measure of self-awareness can certainly help the physician to avoid countertransference reactions burdensome for him and antitherapeutic for the patient.

One of the crucial aspects of the doctor-patient relationship is the quality of their mutual *communications,* verbal and nonverbal. This subject was discussed in an earlier section dealing with the patients' communicative behavior (see p. 20). The other side of the dialogue is what the doctor communicates to the patient, how he does it, where and when. Studies relevant to this topic lead to the following conclusions: Information given by physician to patient affects the quality and course of treatment. The patient's compliance with medical advice is closely related to the degree of his satisfaction with having his need for information met. Insufficient, contradictory, or confusing information results in the patient's dissatisfaction and noncompliance. The patient's postoperative course is improved by providing information before surgery. The degree of the information about illness transmitted by the physician to the patient depends on characteristics (personality, ethnic, cultural) of the physician and patient, and on the situation in which the information is communicated. If the doctor succeeds in giving accurate information in a manner understandable and emotionally acceptable to the patient and his family, he has a better chance of obtaining a meaningful history and cooperation.

The quality of the doctor-patient relationship influences—for better or worse—the patient's response to his illness and its course and outcome. To some extent the same holds true for other health professionals, especially nurses involved in his care during hospitalization.

Personal Meanings of Illness

The central unifying concept in a discussion of psychological response to disease, injury, or disability is that of the *personal meaning* which illness in all its aspects has for the patient. It refers to the subjective significance of all the information input, internal and external, which the patient receives and appraises in the light of his values, beliefs, memories, conflicts, etc. The meaning is a product of the interplay between the patient, his illness and environment. It links conceptually the determinants and modes of the psychological response to disease. Symptoms, diagnostic label, lesion, functional impairment, doctors' statements, and other facets of the total illness experience are appraised by the patient, consciously and unconsciously. This process of evaluation, resulting in meaning, continues unabated throughout the course of every illness. It is a dynamic process reflecting continuity of the information inputs. One could talk of many changing meanings, but it is helpful to identify a dominant personal meaning of the illness or disability as a whole.

What his illness means to a patient is influence by the determinants listed earlier (see p. 7), as well as by the quality of the emotional response elicited in and results of actions taken by him. The evolved meaning modifies and is in turn modified by the patient's emotions and perceptions. The dynamic interplay among these factors and the related feedback effects contribute to the complexity of this subject and the difficulty in explaining it clearly. Some clinical examples may illustrate it.

To understand why a patient feels and acts in a particular manner it is necessary to gain insight into what his particular illness or disability means to him. For example, people who value their *physical* appearance highly are prone to psychological breakdown as a result of mutilation or disfigurement. Impairment of *intellectual* or *perceptual* functions by disease of the brain, or sensory organs or pathways, will disrupt the main adaptive coping mechanisms and source of pride and security in any individual for whom intellectual achievement or perceptual clarity are indispensable conditions for self-esteem, pleasure, a sense of competence, and economic security. A man whose major source of gratification is *sexual* prowess and ability to procreate is likely to be disturbed by impotence due to spinal injury, diabetes, or prostatectomy, for example. Mastectomy, hysterectomy, or masculinization induced by hormones in a woman may have similar emotional effects, as well as revive latent intrapsychic conflicts over her sexual identity and role. Persons who attach particular importance to personal *cleanliness* as part of an obsessional personality style are liable to feel dirty and devalued after construction of a colostomy. Urinary or fecal incontinence may have similar effects. Some paraplegic patients seen by the writer were more disturbed by loss of sphincter control than by paralysis.

Such examples may be multiplied. In each of them the specific personal meaning of the disease, dysfunction, etc., for the particular individual is a crucial factor in determining his emotional and behavioral responses. The latter are also influenced by the attitudes of the patient’s environment to both his illness and behavior. In general, there is no organ or physiological function whose disturbance, damage, or loss could not disturb a given individual’s sense of security and personal worth because of its personal value-laden meaning for him. The psychological impact of illness or disability depends in part on the individual’s vulnerability related to his personality and past experience.

Categories of Meaning

It is helpful for clinical assessment of patients to distinguish four broad categories of subjective meaning of illness, injury, disability, and its consequences for the patient:

1. threat 2. loss 3. gain or relief 4. insignificance.

Threat implies anticipation of harm to one’s physical and/or psychic integrity whose occurrence would cause suffering. Such anticipation may follow perception of any bodily change if this is interpreted by the person as signifying danger to him. At times, no threat is perceived until the patient is told by a doctor that an illness is present. Tendency to interpret somatic perceptions as threatening varies widely and appears to be an enduring personality trait acquired through earlier learning. Some people respond with alarm to any novel somatic perception or even one, say palpitations, which they may have been told repeatedly to disregard as harmless. Others equally consistently minimize and ignore even obvious and painful bodily changes.

Anticipation of danger, whether realistic or not, characteristically evokes *anxiety* or fear. To avoid semantic confusion, the term anxiety is used exclusively in this discussion. This affect is accompanied by individually varied patterns of physiological arousal which may give rise to somatic perceptions, such as palpitations, sweating, shortness of breath, etc. These may, in turn, be interpreted as danger signals and result in augmentation of anxiety—an example of a positive feedback. Anxiety tends to increase vigilance to threat and to set off cognitive and behavioral activities aimed at avoidance, tackling, or minimization of the anticipated danger, and thus reduction of the unpleasant experience of the anxiety state itself. The coping strategies employed by people to reduce or eliminate anxiety include the unconsciously operating ego mechanisms of defense as well as deliberate actions, such as intake of drugs or alcohol, compulsive overwork or sexual activity. Thus threat and anxiety have both physiological and behavioral consequences which may be adaptive or harmful. Excessive physiological arousal may complicate and exacerbate an existent pathological process, and precipitate cardiac decompensation or fatal arrhythmia in a patient with heart disease, for example. Coping with anxiety may harm the individual, if he engages in actions inimical to his health. Excessive intensity of the aroused anxiety may lead to delay or, on the contrary, undue haste in seeking medical help. A moderate degree of anxiety results in optimal adjustment to illness and its consequences.

Loss in this context means not only actual damage to the person's bodily integrity, that is loss of body parts and functions, but also *symbolic losses* resulting from disease or disability. Such losses refer to deprivation of personally significant needs and values. The latter are related chiefly to *self-esteem, security, and gratification of needs.* Any illness or disability may result in partial or total loss of gratification derived from eating; from physical, sexual, or intellectual activities; esthetic qualities of physical appearance, and so forth. These various activities and attributes lost evoke an emotional response *in proportion to their subjective value and importance to the individual.*

The common emotional response to real or anticipated loss, whether concrete or symbolic, takes the form of *grief.* This may merge imperceptibly into a depressive syndrome. Less often, reaction to loss may take the form of any psychiatric disorder, neurotic or psychotic, or antisocial behavior, or somatic illness. Grief is a normal affective reaction to any type of loss, including that of a bodily part or function. Its intensity and duration are roughly proportional to the subjective importance of the loss. Grief is considered by many authors as a necessary step in the work of mourning which results in eventual acceptance and adjustment to what is irreparably lost. The desirability of grieving is often taken for granted in the literature, especially that inspired by psychoanalytic theory. Lack of grief in the face of loss is usually assigned to the working of the mechanism of *denial,* which is also invoked when a person shows no anxiety in response to threat. Yet absence of anxiety may be a sign of good adjustment and is not always presumptive evidence of the operation of denial. Lack of grief may mean that the given event was not perceived by the patient as a loss. More systematic research is needed in this area to validate the prevailing hypotheses and caution is indicated in accepting them as universally valid facts.

Gain or *relief* refer to a personal significance of illness, conscious or unconscious, as a source of psychological, social and/or economic advantage for the patient. From the psychological viewpoint, any illness or disability may facilitate resolution, gratification, or avoidance of intrapsychic conflicts over disavowed impulses: aggressive, sexual, dependent or power-seeking. Illness may provide a legitimate reason for avoidance of conflictual situations and actions. An epileptic, for example, may avoid contacts with the opposite sex on the grounds that he might develop a seizure in the presence of his partner, or that he is unfit to be married, have children, etc. Another patient may justify outbursts of anger or avoidance of competitive situations by invoking his particular illness or disability. Open expression of dependent needs and demands for their gratification may be legitimized in the patient's view by the special status conferred on him by his disease or disability. Thus illness may provide rationalization for either avoidance of or indulgence in behavior which the patient could not otherwise face or engage in without conflict. In other cases, a painful or otherwise disabling illness may satisfy a psychological, usually unconscious, need for suffering as atonement for unacceptable impulses or fantasies. When such psychic factors are present, the patient may have a vested interest in maintaining his illness and react adversely to its improvement. The patient's manifest attitude to his illness may be entirely at variance with his unconscious view of it and its psychological advantages. He may deplore in good faith that he is ill and clamor for relief and cure, while his nonverbal behavior may express the opposite attitude of which he is unaware and which he may explicitly deny.

From the *social* viewpoint, illness may provide a patient with a strategy used to avoid social demands and responsibilities, and secure attention, support, and compliance of others, especially his family members. Some patients derive a sense of identity, pride, and satisfaction from being ill, particularly if the illness is unusual and attracts attention and curiosity of others, including doctors. A patient with a rare disease may attract much medical attention, be repeatedly displayed and discussed by physicians, and puzzle them. He may learn to enjoy the exhibitionistic aspects of such interest and the perplexity of the doctors. For some individuals this may be the only claim to distinction. They are not likely to give up these advantages readily.

One may propose this generalization: A patient’s overall response to illness and disability, and his motivation to get well, are related to the subjectively experienced losses and/or gains derived from the illness.

Insignificance refers to a relative absence of personal meaning of one’s illness or symptoms. Early symptoms of a neoplasm, for example, may be ignored by the patient if they do not signify a threat to him. This may be a result of incorrect appraisal due to lack of medical knowledge, but may also stem from indifference to symptoms in someone who is withdrawn, depressed, apathetic, or who believes himself invulnerable.

Illness experience and behavior change as illness progresses and full recovery, a downward course, or some degree of permanent disability follow. The view of illness as a *process* involving a *time dimension* may be clarified if we describe it as comprising a series of *phases* or stages. As the patient moves from one stage to the next, he faces novel tasks which impose demands upon him.

Stages of Illness

The terms “acute” and “chronic” are commonly used in medical and psychiatric practice and connote rate of onset, duration, and reversibility of disease. These terms are ambiguous. It is difficult to identify clearly any group of individuals as the chronically ill, or the acutely ill, or those with disabilities. Within most diagnostic categories there are patients who are more disabled than ill, more acutely ill than chronically ill, and so on. The term “chronic illness”, as commonly used, is synonymous with disability.

We will attempt to give a meaningful presentation here of a patient’s progress, the changing tasks, stresses, and pitfalls he has to face on the road to recovery, or when chronic illness, disability, or fatal disease preclude return to full health. Not every patient goes through all the stages. His illness may become arrested at any of them. An acute phase may never occur. There are only three possible outcomes: recovery, chronicity, or death. The following stages will be described:

1. symptom perception,

2. decision making,

3. medical contact,

4. acute illness,

5. convalescence or rehabilitation,

6. chronic illness or disability.

The Symptom-Perception Stage

Psychological characteristics of this phase of any illness are: *perception* of change within one’s body boundaries and its *evaluation.*

Traditionally, a *symptom* has been defined as a manifestation of disease apparent to the patient himself; a *sign* denotes a manifestation of disease that only the physician perceives. This distinction is misleading. Enge proposes that “the presence of a complaint must be regarded as presumptive evidence of disease.” A symptom is a phenomenon belonging to the realm of subjective perception which may or may not be observable by others, or communicated to them as a complaint. A *sign* connotes an *inference* made by a qualified observer that what the patient reports and/or the observer notices directly, or discovers by means of special techniques, indicates the presence of a particular disease. Such an inference may be made not only by a doctor, but at times also by a lay observer, and may be at variance with what the patient perceives, reports, or even explicitly denies.

A person’s interpretation of the significance of his symptoms determines his affective responses and subsequent action or lack of it.

Symptoms are perceived and evaluated differentially by different individuals and in different social situations. Such differences reflect both culturally and socially learned responses, and the subject’s personality.

Sociocultural differences result in different patterns of response to symptoms of illness. For instance, upper-class persons are more likely than lower-class members to see themselves as ill when they experience particular symptoms. Ethnic factors were discussed before in relation to studies by Zola and Zborowski. As symptoms become more severe, continuous, unfamiliar, and unpredictable in their course, however, the sociocultural and ethnic factors become less important. Pain, the commonest symptom, is likely to motivate a search for a medical consultation.

A different approach to the perception and evaluation of symptoms uses the concept of *body image* as a basis for explanatory hypotheses and research methodology. Every individual has a unique concept of his body as a psychological object. Alterations of body perception which occur in illness are responded to cognitively and emotionally in a manner and intensity which are partly dependent on the subject’s body concept. Sensations arising from areas assigned high significance in the person’s body gestalt are more likely to be registered and interpreted. The vast literature on the body image has recently been reviewed by Fisher, and the concept itself critically analyzed by Shontz. The reader is referred to these sources as well as to Chapter 33 of this

Volume.

A *psychodynamic* approach to somatic symptoms is represented by a study by Silverman. He claims that the development of physical symptoms, regardless of whether they are due to organic disease, is related to “an insufficiency of the psychological systems for handling the stimulus influx mobilized by stress.” This study represents an attempt to explore an important dimension of somatic symptoms, namely their *unconscious symbolic meaning and determinants.* This area of investigation still suffers from the lack of reliable methods of validating the proposed links between observation records on the one hand, and inferences made from them, on the other. In general, the more the meaning of perceived symptoms is influenced by unconscious needs, fantasies, and conflicts, the more irrational, idiosyncratic, and unpredictable is the patient’s overt response. Panic, massive denial, and disregard of the likely significance of symptoms, their delusional misinterpretations, marked delay or, on the contrary, undue haste in seeking medical help—these are familiar examples of responses to symptoms which are more influenced by unconscious factors than by rational reasoning and knowledge.

Experiential factors related to previous illness episodes in oneself, or in a person close to the patient, tend to influence the meaning of symptoms and affective response to them. One who lost a close relative by cancer or heart disease may become sensitized to and fearful of any associatively linked symptom in himself. This may be an expression of identification with or guilt toward the deceased individual.

Physicians commonly speak of “organic” or “functional” symptoms. This distinction is meaningless since every illness has both physiological and psychic components and the crucial question is *how much both of them* contribute to the patient’s clinical picture. It may help the clinician to assess such a relative contribution if he has a clear grasp of complaints which indicate *psychic distress* regardless of whether a physical illness is present. The following classification may serve as a guide to complaints or symptoms pertaining to the body, but indicative of psychological distress or disorder. Such symptoms are variously referred to as “psychogenic,” “psychophysiological,” “psychosomatic,” or “somatization reactions”—all vague and misused terms.

1. Physiological correlates of *affective arousal* such as anxiety or anger, or somatic manifestations of an *affective disorder,* mainly depressive or anxiety syndromes, e.g., pain, palpitations, diarrhea, hyperventilation syndrome, polyuria, etc. Of course, none of these symptoms is pathognomonic of a psychiatric disorder.

2. Somatic expression and communication of ideational, often conflict-

related, mental contents, which originate at the symbolic level of organization and attempt to imitate a physical illness to meet the patient's psychosocial needs. These are the *conversion symptoms*.

3. Secondary symbolic elaborations, manifested as conversion symptoms, of perceived somatic changes of any etiology, e.g., hysterical fits coexisting with epilepsy.

4. Excessive preoccupation with bodily sensations, functions and appearance, often accompanied by increased sensitivity to normally subliminal somesthetic sensations. This is *hypochondriasis* (See references 96, 97, 128, 167, and 177).

5. Nosophobia, that is morbid fear of disease, such as cancer, venereal or heart disease, etc.

6. Somatic delusions, that is, *false convictions* of bodily change, disfigurement or disease, e.g., of changing one's sexual characteristics or having parasites, expressive of unconscious fantasies and signifying schizophrenic or depressive *psychosis,* or occurring transiently in *delirium.*

7. Communication of psychological distress in *bodily metaphors,* e.g. "my heart is heavy," "my head is empty."

8. Psychogenic *body image disturbances,* that is, subjective sense of change in color, shape, weight, size, position, etc., of the body and/or its parts. Such symptoms occur in association with schizophrenia, depression, severe anxiety states, and the depersonalization syndrome.

9. Somatic symptoms representing *residues* of earlier responses to stress, or memories of somatic symptoms experienced during a forgotten childhood illness and re-experienced through associative links with a current psychosocial stress.

The above symptoms may be present alone or coexist with and mask those of a physical illness, just as the latter may be present as a disorder of mood or higher mental functions. At any given time, symptoms may be manifestations of primarily organic pathology, the affective response to it and the associated physiological arousal, and of the symbolic meaning of the other symptoms. A patient may experience combinations of symptoms having different mechanisms and diagnostic significance.

The Decision-Making Stage

A patient's response to his symptoms has a bearing on his *decision to seek medical help*. studies of medical care in the United States and England show that in a population of 1000 adults over sixteen years of age, in an average month 750 experience an episode of illness, but only 250 of these consult a doctor. In certain population groups, such as the aged, nine out of ten illness episodes are not treated by a physician. At least three sets of factors influence the patient’s decision to seek medical help: (1) his objective clinical disorder and symptoms, as well as his perception, knowledge, beliefs, and attitudes about having a particular disorder; (2) his attitudes and expectations of the doctor and medical services; and (3) his definitions of “health,” “sickness,” and need for medical care. These factors vary in the population and reflect individual, ethnic, and sociocultural variables discussed earlier.

Many people seek medical consultation during periods of *life* stress. Psychophysiological reactions evoked by such stress are a source of discomfort and may also prompt attention to symptoms which were previously ignored. Life stress may foster the adoption of the sick role regardless of presence or absence of a physiological change or dysfunction. The onset of a psychiatric disorder in response to psychosocial stress may bring the patient to a doctor, but be expressed in terms of the somatic complaints listed earlier.

The patient’s decision-making process is practically important for two reasons: (1) It has a bearing on *preventive medicine* and *timely* utilization of medical facilities; and (2) It is related to *overuse* of medical care. The former problem has been studied lo identify psychosocial causes of *delay* in seeking medical help for serious conditions, mostly cancer and heart disease (See references 19, 27, 61, 63, 67, 71, 90, and 91).

Delay may be computed from the date of first appearance of symptoms or from the time a symptom is recognized by the patient as requiring medical attention. It is this latter, "avoidable," delay which has attracted particular attention. Many different factors have been suggested as influencing delay: 1. *age,* older patients being more likely to delay; 2. *ethnic factors;* 3. *lower socioeconomic status; 4. site of symptoms,* those noticeable by others may lead to greater delay; 5. *personality variables.*

Most studies identify two sets of relevant factors: *excessive anxiety* related to the appraisal of symptoms as highly threatening; and ignorance, minimization, and/or denial of the significance of symptoms accompanied by *low anxiety* (See references 19, 27, 61, 63, 67, and 71). Denial and extreme anxiety may not, however, be the only relevant factors. *Severe depression* related to a life crisis may make some patients relatively indifferent to somatic symptoms, or be accompanied by self-destructive or masochistic tendencies with resulting inaction. A *schizophrenic* may be indifferent to pain of a myocardial infarction, for example.

Excessive use of medical facilities has been less often studied than delay, even though undue tendency to respond to subjective discomfort by seeking medical help contributes to the cost of medical care. Such behavior may be a manifestation of hypochondriasis. Some patients suffering from *anxiety neurosis* may displace their anxiety from inner conflicts onto somatic concerns and fear of disease. A doctor may reinforce such fears by telling the patient that he has a “weak heart” or “tired blood,” for example. Many patients come to medical clinics or doctors’ offices because they need sympathetic advice about *psychosocial problems.* If the doctor ignores this need, the patient may continue to return to him and present ever new somatic symptoms until a doctor opens up a discussion of the patient’s real concerns, or attaches a medical label to his complaints. In the latter case the patient may “organize” his illness and enter a long-term “patient career.” Such patients are likely to become chronic attenders of clinics, etc., and are often called “crocks” by the exasperated doctors. Early inquiry into the reasons underlying the patient’s complaints and the timing of his visits may lead to a talk about his psychosocial problems, usually family or job related. This may satisfy the patient’s need and prevent repeated and fruitless attendance.

The Medical Contact Stage

Once a person has decided to consult a doctor, a new element enters the picture: *patient-doctor interaction.* This aspect of illness has been discussed earlier and only a few additional comments need be added.

Both the patient and physician bring certain expectations into their encounter. They are partly related to their respective *social roles* which consist of conventionally defined attitudes, rights, and duties assigned to each participant. Patients tend to evaluate the physician by nonprofessional criteria which are influenced by their cultural background and conceptions of what constitutes a *good doctor.* Surveys indicate that people single out competence, interest in patients, and a sympathetic and concerned manner, as the chief qualities of a good doctor. The success of a visit to a physician, judged by the patient's satisfaction and willingness to comply with the doctor's advice, depends to a large extent on whether the patient's expectations are met.

For the doctor, the purpose of a consultation is to arrive at a diagnosis. "The satisfaction felt by the physician when he is able to assign a name, hopefully the correct one, to the patient's illness is matched only by the layman's relief when he hears that he is suffering from aplastic anemia and not leukemia." This wry comment reflects a deplorable aspect of current medical practice. To diagnose means more than attach a medical label. It also includes an assessment of the patient's personality and current level of psychological functioning; his family, occupational, social, and economic situation; and his attitude toward his illness and symptoms. To achieve a *comprehensive* diagnosis the doctor observes the patient's appearance and verbal and nonverbal behavior, takes an extensive history, and performs a manual and instrumental examination. These aspects of a medical consultation cannot be discussed in detail here. The reader is referred to selected references (See references 14, 45, 46, 49, 108, and 154).

The doctor's diagnostic reasoning process and the decision reached are influenced by his interaction and communication with the patient. These, in turn, are affected by the doctor's personality and whether he is *physical-minded* or *psychological-minded,* respectively. The former is typically less reflective, introspective, and interested in abstract psychological ideas than the latter. These personality characteristics determine if the doctor pays attention and tries to deal with his patients' psychosocial concerns.

Whatever the result of the doctor's diagnostic reasoning may be, he has to convey his opinion and advice to the patient. The manner in which he does it influences the patient's affective response and his cooperation or lack of it. The doctor should state his findings and opinions clearly, bearing in mind the kind of person he is dealing with. The patient's ability to comprehend and his need for information and likely reaction to it have to be assessed. An intelligent, obsessional patient needs more information to allay his anxiety than one whose intellectual capacity and need for understanding are less. Medical jargon, ambiguous statements, or vague innuendoes may increase the patient's anxiety and open the way to misinterpretations. A patient who habitually minimizes and denies the significance of danger must be recognized and given an unambiguous statement of what the physician thinks and recommends. Disclosure of diagnosis of a serious and potentially fatal illness will be discussed later (see p. 50). When no evidence of organic disease is found, the patient should be told so and asked about other possible reasons for his symptoms. To tell him that his complaints are “imaginary” or “functional” and he is really well, only serves to antagonize him and belies his subjective perception of ill health. The doctor should state that while there is no evidence of organic illness, there must be a reason for the patient’s discomfort, possibly related to his life situation. In this way an inquiry into the latter and possible preparation for a psychiatric consultation may be broached.

The Acute Illness Stage

An acute illness implies relatively sudden onset and brief duration. A mild, commonplace acute illness is usually self-limited and may not even bring a patient to the doctor. If the illness is serious, however, it drastically interrupts a person’s way of life and readily arouses fears of death, incapacity, dependence on others, and personal losses discussed earlier. Pain, if present, adds to the other stresses. The patient often responds with shock, disbelief, and sometimes attempts at escape from the threatening situation. Thus a patient with an acute myocardial infarction may attempt to continue his activities and dismiss his symptoms as “indigestion” or some other harmless condition. He may display unconcern and even bravado which mask his anxiety and may be mistaken for courage. An acutely ill patient needs the doctor’s emotional support and reassuring firmness.

The characteristics of this phase, or type, of illness are: adoption of some degree of *dependence* on others; *confinement* at home or a hospital; and *uncertainty* about the outcome. The latter may be full recovery, death, or some degree of irreversible damage and thus chronicity. An acute illness may be a transient or terminal phase of a chronic one. Since the other aspects of illness have been discussed before, we will focus on one common feature of acute illness: *hospitalization* and the hospital as a *social milieu* with which the patient interacts.

Response to Hospitalization

Admission to a medical ward is for many a novel and anxiety-provoking experience, for some a welcome respite. As an inpatient one becomes a member of a specific social milieu in which the chief roles are played by the health professionals. A person accustomed to privacy and independence has to surrender them, and his freedom of action is curtailed by the authority of doctors and nurses. He is subjected to often irksome rules. Members of the clinical team decide what is wrong with him, what investigations and therapies he is to undergo, what restrictions to observe, and what behavior is acceptable or not. The physical environment itself is for many unfamiliar and often frightening. The patient brings to this situation his habitual attitudes toward and modes of coping with novelty, dependence, passive submission, authority figures, and uncertainty—hallmarks of his condition as a hospitalized patient. Most people manage to adjust to this situation, some enjoy it, some find it distressing. The patient engages in interactions with other patients and ward personnel, and the more *anxious* and/or angry he is, the more likely is he to fall into conflict with some member of the ward community. He is then liable to be branded a “management problem” or a “difficult patient,” and referred for a psychiatric consultation.

The mere event of admission to a medical ward may be a source of stress. Corticosteroid and catecholamine responses, respectively, were studied in two groups of normal adults admitted to a hospital research ward. Urinary 17-hydroxycorticosteroids, epinephrine, and norepinephrine values were higher on the day of admission than later in hospitalization. This suggests that hospital admission involves elements of novelty, threat, and unpredictability which are associated with stress and psycho-physiological arousal.

Ward rounds and laboratory procedures may be emotionally stressful. Yet predictions of what may disturb a given patient are not easy. This is illustrated by a study of women awaiting breast biopsy for suspected cancer.

Despite the obvious uncertainty and unpredictability of this situation for the patients, the majority of them did not show manifest breakdown of psychological defenses. This was reflected in the normal range of hydrocortisone production rates. Thus it is incorrect to assume a priori that what to an observer may appear as “stress” actually evokes emotional *distress* in a given individual or group. The distress depends on how a potentially threatening situation is individually perceived, interpreted, and defended against. Some patients react with excessive emotions to hospitalization, investigations, surgery, etc.

It is largely up to the doctors and nurses to ensure that a medical ward should have a therapeutic effect. To prevent psychological crises in the ward milieu it is important to ensure maintenance of *communication* between patients and staff. This helps prevent interpersonal conflicts related to fears, mutual distrust, and distorted perceptions among members of the ward community. Some physicians and nurses readily provoke in many of their patients unduly dependent, hostile, anxious, or seductive responses which interfere with professional relationships. Such complications are avoidable and may call for a clarifying and mediating intervention of a psychiatric consultant.

Understanding of the patient’s personality and some degree of psychological self-awareness on the part of the staff facilitate therapeutic and preventive actions. The latter, called by some “adaptive intervention” or “therapeutic manipulation,” involve *personality diagnosis, suggestion,* and *clarification.* The use of such methods need not be confined to psychiatric consultants. Properly trained nurses may apply some of these techniques, for example in *group therapy* sessions for the inpatients in a general hospital. Such intervention may help them adjust to hospitalization, illness, investigative and therapeutic procedures, etc.

There is a growing trend to create a *therapeutic social milieu* in the general hospital. This involves attention by the staff to the patients’ emotional needs and their fears and uncertainties, which are often either unexpressed spontaneously or acted out in behavior disruptive of ward routine.

The Convalescent or Rehabilitation Stage

Physiological recovery from illness should lead to surrender of the sick role. This applies to all acute and fully reversible illness as well as that which leaves physically nondisabling residual damage. When convalescence and/or rehabilitation is indicated, the patient should cooperate. Yet psychosocial factors may interfere with these goals and prolong disability beyond the physiological recovery and despite the doctor’s judgment that the patient is well. A physical illness or injury may be followed by some degree of disability due to psychosocial factors, that is, by *psychological invalidism.* Intrapsychic as well as socioeconomic factors may contribute.

Intrapsychic Factors

Ruesch studied a sample of patients with *delayed recovery.* He frequently found conflicts over dependency and aggression in men, and conflicts related to self-love and the feminine role in women. The men tended to be dependent and passive, the women dominant, aggressive, and overprotective. The sick role provided these patients with a *primary gain,* that is reduction of intensity of intrapsychic conflicts and related unpleasant affects. When physical illness or injury occurred in a setting of *psychological stress* or *interpersonal conflict,* recovery was delayed. Psychologically traumatic implications of disease or therapeutic procedures had the same effect.

Other studies of patients with delayed recovery from a variety of infections, or cardiovascular and other diseases generally concur with Ruesch’s findings. Severe psychological trauma in their early lives, proneness to depression, and a disturbed life situation and depression before or after illness, characterizes many patients who have prolonged convalescence. Slow recovery from infectious mononucleosis was correlated with lower scores of ego-strength. Protracted convalescence in women who underwent radical mastectomy could be predicted by Bard. He found a correlation between the extent of dependence and that of the delayed recovery after surgery. A sample of patients who had suffered a myocardial infarction showed that the subjective meaning of the heart attack was an important determinant of disability. They believed themselves to be damaged, fragile and vulnerable.

Thus enduring *personality* factors as well as the concurrent *affective* state related to illness and/or interpersonal problems may delay recovery. The concepts of *primary and secondary gains* are important. *Secondary gains* refer to psychological, social and/or economic advantages which a patient may derive from *any* illness. One should make a distinction, however, between conscious or unconscious *predilection* to illness on the one hand, and persistence of somatic symptoms related to *affective arousal* on the other. In the first case *motivational* and *attitudinal* factors play the primary role; in the second case, the patient's physical illness merges with a *psychological* one, such as anxiety, depressive, conversion, or hypochondriacal neurosis, and related perception of symptoms. This distinction is important for treatment. If the patient suffers from an anxiety state, for example, psychotherapy and use of psychotropic drugs may help accelerate his recovery.

Social and Economic Factors

The doctor-patient relationship plays a part in delayed recovery and rehabilitation. The amount and quality of *information* which the physician transmits to the patient is important. This is well illustrated by the effects of the extent of medical information given to patients suffering from a first coronary occlusion. The nature and adequacy of information given to such patients is associated with the frequency and timing of return to work. Anxiety and depression are common in these patients and related to the inability of doctors to confront and answer patients' questions about the meaning and implications of their illness. Treating patients' symptoms related to psychological distress as if they were manifestations of continuing physical illness is a common blunder which fosters psychological invalidism. The whole area of the personal meaning for the patient of the doctor's therapeutic methods; of prescription for drugs and the drugs themselves; of placebo effect; and the patient's compliance with therapeutic regimen, such as intake of prescribed drugs, is attracting more attention because of its relevance for the evaluation of treatment and its cost.

Many studies illustrate the importance of *adequate information and instruction* given to patients by the doctors. Lack, vagueness, or incorrectness of such information is a highly significant factor in avoidable prolonged disability. Ambiguity and uncertainty often enhance anxiety and foster unduly cautious, if not frankly phobic, attitudes in the patients toward resumption of their premorbid occupational, sexual, and recreational roles (See references 12, 101, 141, 155, and 221). Close follow-up after discharge from the hospital is crucial for prevention of such invalidism.

The response of the patient's family may also contribute to delayed recovery. A healthy member may reinforce the patient's secondary gains from being sick by meeting his dependent needs to a much greater extent than when he was well. Anxiety in the spouse may increase that of the patient. If there is convergence between the latter's motivation, conscious or unconscious, to remain ill and a gratifying family response to his persisting complaints, prolonged psychogenic disability may ensue.

Social security disability programs, workmen's compensation insurance, compensation and medical malpractice suits, and other *economic* incentives may contribute to the patient's secondary gains and invalidism.

The Chronic-Illness Stage

Chronic illness implies a significant degree of *irreversibility* of the pathological process or damage to the body and the related *disability.* It is an ill-defined category and includes such diverse conditions as congenital defects, acquired injuries and illnesses leaving residual damage, and incurable diseases with a progressive or remitting course. It is difficult and misleading to generalize about such diverse pathological conditions. Their importance lies in the fact that chronic illnesses are the leading cause of morbidity in advanced societies. The literature on the psychological aspects of specific types of chronic illness and disability is extensive (See references 6, 32, 60, 144, and 225).

To discuss meaningfully psychological responses to chronic illness or disability, one has to classify categories according to several criteria:

1. Time of onset. It is important if the given defect, disease, or disability was present at or acquired after birth. If the latter, then at what point in the person’s life cycle did it appear? We do not deal here with congenital defects or deformities, since they must be considered part of the individual’s somatic endowment and not a stage of an illness.

2. Rate of onset: acute or gradual. The latter allows the patient more time to develop coping mechanisms and is usually less traumatic psychologically than the former.

3. Presence or absence of progression. If the disability results from an accident, for example, and a *stable* condition ensues, the patient is dealing with some form and degree of permanent disability, loss of function, or disfigurement, to which he has to adjust. If the pathological condition is potentially *progressive,* this adds an element of *uncertainty* about the future. Many people find uncertainty more distressing than a serious but definite loss. Sufferers from many chronic illnesses, such as multiple sclerosis, find it hard to plan for the future which for them is unpredictable. A terminal illness adds the challenge of facing early death.

4. Degree of reversibility of and/or compensability for the impaired function. These factors determine realistic planning for

> rehabilitation and adjustment, and the setting of goals toward which the patient may strive and whose achievement may be a source of pride and enhanced self-esteem.

We will describe some of the more commonly observed *response patterns* to *severe disability* and *fatal illness,* especially *cancer,* respectively. Much of what was discussed in relation to the other stages of illness is equally relevant to the present stage and will not be repeated.

Chodoff offers a classification and description of *patterns of psychological adjustment* to chronic illness and disability. It will be used as a general framework and basis for discussion. The proposed three major response patterns are:

1. *Insightful acceptance,* characterized by a lack of bitterness and hostility, and of a sense of personal devaluation. The patient copes adaptively, cooperates with rehabilitation plans, tries to learn substitute skills, and find new sources of gratification. This is the most desirable response both for the patient and those concerned with his care.

2. *The denial pattern,* characterized by negation of objective facts of illness, for example of paralysis; of significance of disability, such as the need to be cared for or to avoid certain activities; and of one's emotional response to illness, like anxiety, depression, or anger. Denial may be applied to one or

all of the above aspects of illness and vary in extent. It may be explicitly or implicitly expressed. As such it is neither necessarily pathological nor maladaptive. Some degree of it may help maintain optimal psychic adaptation. Denial is pathological only if it concerns obvious facts and/or prevents the patient from behaving in a manner respecting his limitations and requirements of treatment.

3. *The regressive pattern* is characterized by exaggerated *dependence* and *passivity,* often with thinly veiled anger and hostility. A regressed patient plays up his disability and demands maximum attention and care from his environment. He exaggerates his helplessness and suffering and uses his illness as a strategy to manipulate others by playing on their sympathy or feelings of guilt. This pattern is most often observed in hysterical personalities who are typically overly dependent and dramatize their feelings, as well as is some people who overemphasize their physical prowess and independence.

Such classifications are deficient in several respects. They are static and obscure clinical observations that the chronically ill and disabled go through various *phases* of psychological response. Patients may experience shock, denial, grief, anger, apathy, and euphoria, that is, display a wide spectrum of emotional reactions and defensive strategies before settling in one or another response pattern. In practice one must consider the changing, *dynamic* aspects of every patient’s illness behavior. General classifications tend to ignore inherent personality *assets* which are present to some extent in *every patient* and must be used to the best advantage in his rehabilitation. If a patient is just labelled as a “denier” or “regressed,” this may lead to therapeutic nihilism and failure to tap whatever usable personality resources he may possess. Even small gains in a sense of self-esteem and meaningful existence in the severely disabled are a worthwhile goal of rehabilitation efforts. Categorizing patients in terms of their ego mechanisms of defense gives no indication of what specific affects they are defending against. Is it anxiety, grief, shame, guilt, envy, resentment, or hopelessness? Identification of the specific affective response in the individual patient may offer important clues for therapeutic intervention, be it individual or group psychotherapy, behavior therapy, or use of psychotropic drugs.

In conclusion, generalizations or labels should not obviate the need for repeated evaluation of each patient’s psychological assets and liabilities as a basis for an *individually tailored* and periodically reassessed management approach (See references 26, 53, 59, 60, 81, 144, and 225).

The same holds for every patient regardless of the nature of his disease or disability. Patients suffering from *cancer* provide another important example. There is a vast literature on psychological aspects of cancer, with 126 citations in English between 1970-1973 alone. There too we see attempts to classify psychological response patterns which cancer patients evolve. Such descriptive categories may serve only as guidelines in evaluating a given patient’s most dominant concerns and emotional reaction at a given time. Few patients display an invariable response pattern throughout their illness and its treatment. One must be sensitive to shifts in the psychological responses and encourage the most adaptive ones. Problems of communicating diagnosis of cancer, patterns of communication, and psychological aspects of the management of cancer cannot be discussed here. The question whether psychological factors influence prognosis of cancer patients has attracted attention. In one study, those with a most favorable outcome had a high proportion of individuals who had strong *hostile* drives without loss of emotional control. Others report that cancer patients who were *aware* of the nature of their illness lived longer than those who were not, while those who suffered from concomitant *depression* tended to die sooner than those not depressed.

Conclusion

The same general determinants of psychological responses operate at all stages and in all types of physical illness. A multifactorial scheme for the clinical evaluation and study of such responses has been proposed in this Chapter. This general model is applicable to any disease or injury, acute or chronic, mild or severe. The relative weight of the different factors obviously varies from patient to patient, but they all contribute to illness experience and behavior. Assessment of these factors is a necessary part of comprehensive diagnosis as a basis for efficient clinical management of all patients.

Terminal Illness and Its Management

Terminal illness connotes impending death. Finality replaces uncertainty about the future. It is the last phase of the human life cycle evoking intense psychological responses in patients, their families, and the health professionals. Its specific problems justify a separate discussion.

The scientific study of attitudes toward death and the experience of dying has a short history. Few systematic studies had been published until about twenty years ago. By 1964, a bibliography on death and bereavement listed 321 entries of which about one-third had been published after 1960. A more recent annotated bibliography on death and dying deals with the more important works which had appeared up to 1969. This upsurge of scientific interest in death and dying continues and is one of the most remarkable developments in contemporary culture. We now have a body of factual knowledge which allows formulation of guidelines for the management of the dying. We first discuss briefly some salient observations and then principles of management.

One should first distinguish different foci of studies related to death and dying: (1) of psychological and cultural *attitudes* toward death in the general population; (2) of the *fear* of death, one's own or of others; (3) of the *concept of death* in various populations, such as children; (4) of *thanatophobia;* (5) of the attitudes, experiences and communications of the *moribund patient;* and

(6) of the actual *experience of dying.*

Only the last two types of studies can be considered here. The reader is referred to several recent books which together offer comprehensive coverage of the whole subject (See references 13, 48, 107, 165, 220, and 219).

Weisman and Kastenbaum have written a lucid account of a study of the terminal phase of life. Their method, “the psychological autopsy,” was an interdisciplinary conference that attempted to reconstruct the preterminal and terminal phases of life of a recently deceased patient and evaluate the role of psychosocial factors in his death. Their patient sample consisted of eighty elderly men and women, inmates of a hospital for the aged.

The authors emphasize that dying is a *natural event* in the life cycle. There is a distinct *preterminal period* that may be regarded as a developmental phase serving as preparation for and adaptation to impending death. The dying process must not be viewed as a “mental health problem.” Four attitudes toward death could be distinguished: 1. *acceptance;* 2. *apathy;* 3. *apprehension;* and 4. *anticipation, i.*e. acceptance plus an explicit wish for death. Acceptance was more often the attitude of well-adjusted patients, while death anxiety was associated with moderately severe organic and psychiatric deterioration.

Those findings were obtained retrospectively and from a restricted patient population. It would be erroneous to generalize from them. Thus, observations of terminal cancer patients revealed that nearly all of them were deeply concerned about dying, depressed, and frightened. Kubler-Ross, in her valuable book *On Death and Dying,* reports on a study of over 200 terminal patients. She describes five major stages in the psychological response to the awareness of dying: (1) *Denial and isolation.* This initial phase was present in both those who were told that they would die and those who came to this conclusion independently. A characteristic verbal response was: “No, not me, it cannot be true.” Denial was at least partially used by almost all patients during the first stage of terminal illness, and intermittently later on. It was, for a time, a healthy way of dealing with an uncomfortable and inexorable situation. Denial sustained to the end did not bring distress. Most patients, however, gradually gave up denying the reality of their situation and displayed other responses; (2) *Anger.* When denial could no longer be maintained, it was often replaced by feelings of anger, rage, envy, and resentment. The typical question at this stage was: “Why me?” The patients readily projected their anger and blame on family and staff. They were aggrieved by and found fault with everything. Such hostile behavior was aggravated by angry responses of family and the ward staff; (3) *Bargaining.* This stage was characterized by patients’ attempts to avert their fate by being amiable and cooperative as if this could be rewarded by postponement or warding off death; (4) *Depression.* When progression of his disease was unmistakable, the patient reacted with a sense of loss and grief. *Reactive grief or depression* was related to the losses of body parts through surgery and the symbolic losses of self-esteem, etc., accompanied by feelings of guilt or shame. *Preparatory depression,* on the contrary, signified anticipation of the ultimate loss of life itself. This second type of depression was a necessary stage in coming to terms with the impending loss of all the love objects; and (5) *Acceptance.* This stage required time to be achieved and help in working through the preceding stages. The patient was neither depressed nor angry, but almost devoid of feeling and increasingly detached. He tended to be silent and wished to be left alone. *Hope* usually persisted through all the stages. If a patient gave up hoping, it was usually a sign' of imminent death.

Death has different *meanings* for different individuals: the personified destroyer; relief from pain; reunion with one’s family; loss of control; punishment; loneliness. *Attitudes* toward death can vary in the same individual, ranging from fear, defiance, and denial, to uneasy resignation and calm acceptance. For some, the approach of death may become a stimulus to psychological growth and creativity.

Descriptions of the subjective *experience of dying* have been obtained from patients resuscitated after cardiac arrest. They related a pleasant feeling as though they were entering a peaceful sleep. None of them recalled any fear or other unpleasant feeling while losing consciousness. It seems that “biologic death” is not an unpleasant experience. Psychological complications tend to occur if the dying person suffers from unresolved feelings of *guilt;* a sense of *unfulfillment* or wasted opportunities; and a marked susceptibility to *separation anxiety.* These are conditions in which psychiatric consultation, sometimes supplemented by talks with a clergyman may help alleviate the patient’s anguish. The incidence of “psychopathological” reactions in terminal patients is unknown. Some patients are delirious or comatose in the final stages of life.

The Management of the Dying Patient

The doctor’s personal attitude toward his own death influences his views on how the dying patient should be managed. Death is an ultimate challenge to the physician’s knowledge and skill and a disturbing reminder of their limitations. Some doctors experience their failure to save the patient as a personal defeat and humiliation. They may respond with feelings of guilt, shame, and resentment. To cope with his own emotions, the doctor may simply avoid the patient, or become awkward and detached in his contacts with him. The doctor’s withdrawal tends to increase the patient’s sense of helplessness and loneliness. Often the patient, his family, and the doctor attempt to maintain the denial of the impending dissolution and an awkward game of mutual deception and avoidance of facing the facts takes the place of open communication. How can this common and regrettable situation be avoided? We may offer some general clinical guidelines.

1. The issue to be faced and settled by all concerned is that of *communication of diagnosis* and its consequences. The perennially controversial question is: “To tell or not to tell?” It is remarkable that extensive polls conducted among physicians and laymen, respectively, reveal almost diametrically opposite views on this issue. Eighty to ninety percent of healthy subjects, as well as cancer patients, questioned responded that they wished to be told that they had cancer or another fatal illness. However, 40 percent of dying patients, who were asked if they wanted to be told *when* they would die, answered in the negative. And how about the doctors? Of 219 physicians questioned by Oken, ninety percent said that they did not disclose diagnosis of cancer as a usual policy. In a general poll of 5000 American doctors, twenty-two percent said that they never told patients that they had cancer. Yet doctors usually affirm that they would personally want to be told if critically ill.

Whether or not the patient is told that he has cancer, or another fatal illness, he sooner or later guesses the truth from the nonverbal cues. How should this problem be handled? The question is *not* whether to tell, but *who should do it, how and when.* Communication should be the responsibility of someone close to the patient and his family. Time must be allowed for the facts to sink in and for questions to arise. The patient should not be told that there is no more that can be done for him. The way the news is broken should depend on the patient's personality, intelligence, religion, and the indirect clues he provides about how he is likely to deal with the disclosure. Some should not be told until a strong relationship with a staff member has developed. Clearly, a general rule of thumb has no place here.

2. The management involves sustained and supportive *communication* after the disclosure of diagnosis.

3. Some patients benefit from psychological intervention and counseling. The latter should have the following aims: *Encouragement of competent behavior,* that is, helping the patient maintain his remaining competence and capacity for achievement; *preservation of rewarding relationships* with the family and friends; *maintenance of a dignified self-image* by providing environment, activities, and relationships enhancing the patient's sense of his own worth; *attainment of an acceptable death* by helping the patient resolve his intrapsychic conflicts and emphasizing his achievements and autonomy.

4. Communication with and support of the patient's *family.*

In summary, management of the dying patient is one of the most important and demanding tasks for all health professionals involved in his care. Adequate communication with the patient, sustained contact and emotional support *to the very end* are mandatory. These tasks belong to the health professionals in attendance, and *not* primarily to the psychiatrist. His role should be confined to consulting and therapeutic intervention in selected cases only. The management of the dying must be adapted to their individual needs and capacities. The physician must also at times face the decision when to withhold treatment and distinguish between prolongation of life and prolonging dying.

Conclusion

There is a major increase of interest in the psychological aspects of death and the process of dying. This area of study is far from finished and its results are still inconclusive. It imposes serious emotional demands upon the investigator, who can hardly remain detached and separate research from therapy. There are many modes of dying. The patient’s age, sex, personality, circumstances of his terminal illness, his religious beliefs, the degree of support he receives from his environment, his state of consciousness, and amount of physical pain are all significant factors.

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