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**PHYSICAL ILLNESS,
THE PATIENT
& HIS ENVIRONMENT**

PSYCHOSOCIAL FOUNDATIONS OF MEDICINE

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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 to 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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