





COPING WITH SERIOUS ILLNESS: A Conceptual Overview

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PREFACE

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I. INTRODUCTION

People who have a serious and possibly life-threatening illness are faced with a number of concerns. Foremost of these include pain, symptoms, and finding an appropriate medical treatment. Additional concerns have to do with the psychological and social impact of the illness, for example, facing possible death, not being able to work or care for one's children, and simply trying to be happy.

<u>Coping</u> with illness refers to what a person does in response to all the concerns associated with the illness. It is increasingly recognized that how people cope with their illness may be as important as the medical care they receive in determining satisfactory outcomes.

Research on illness has focused on determining optimal medical treatments. We know very little, however, about which psychological and social responses will provide optimal conditions for recovery.

If researchers could determine that certain coping responses improve a person's quality of life, facilitate healing, or lengthen life, patients can be assisted in planning coping strategies that will increase their • chances of achieving these outcomes.

MODELS OF HEALTH AND ILLNESS

Until relatively recently, concepts of health and illness largely conformed to what is sometimes referred to as the medical model. This model emphasizes the physiological and biological aspects of disease. Within the medical model, health is generally defined as the absence of disease, the patient's role is to seek medical care in response to

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illness, and the physician's role is to diagnose and treat illness (Parsons, 1951).

This medical model is gradually being modified in favor of a broader model that includes mental, emotional, and spiritual aspects of disease and health, in addition to the physiological and biological aspects. This emerging model focuses on the "whole mind-body-spirit personality, with emphasis on life-style, well-being, and wellness" (Yahn, 1979). Health is increasingly being defined in terms of positive well-being (in addition to the absence of disease). For example, optimal health has been defined as a synthesis of body, emotions, mind, will, and spirit (O'Regan and Carlson, 1979).

Several researchers have suggested that this new model should be thought of as a hierarchy of models rather than as a single allencompassing model (Engel, 1979; Howard, 1975; Antonovsky, 1979). Thus, an individual's health can be evaluated at any of several levels such as physiological, biological, psychological, social, environmental, or cultural. At each level, an autonomous model can be conceived (Engel, 1979). For example, at the physiological level, the introduction of a virus may cause a sign of illness to occur. In this hierarchical scheme, each level is related to other levels, and a breakdown at one level may influence variables at another level. For example, the loss of a job (environmental) may result in emotional distress (psychological) which in turn disrupts the digestive process (biological).

Health is defined by Engel in terms of the "relative intactness and functioning of each component system on each hierarchical level" (1979,

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p. 161).

Within this hierarchical conception, the medical model represents an attempt to view health and illness on only two levels, the physiological and biological. Consideration of psychological, social, environmental, or cultural influences has largely been out of the realm of traditional medicine.

Within the new model, the promotion of health and the treatment of disease become a joint effort of the individual, the family, the medical community, and society. An example of a conflict in such effort occurs when the medical community urges people to take personal responsibility for their health by not smoking, yet society allows a proliferation of alluring cigarette ads.

This new and broader approach to illness and health is not a new one; it was commonly advocated in the early days of medicine, is today the underlying philosophy of much nonwestern medicine, and has for many years fallen under the rubric of "psychosomatic medicine." It has suffered from a considerable lack of reputability, and even today stirs up controversy within the medical community. Although it is commonly termed holistic medicine, even this term stirs controversy as connoting quackery. Critics of the holistic viewpoint frequently point to the lack of "scientific" evidence, often with justification. Nevertheless, concepts of holistic medicine are rapidly gaining recognition and respect (Challes 1979; Holden, 1980; Yahn, 1979).

Because of the increasing recognition given to concepts of holistic medicine, research on how psychosocial and other factors relate to health and illness will undoubtedly increase in the next decade. One of

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the challenges that researchers in the holistic medicine arena face is to conduct methodologically sound research.

In conducting research based on the holistic model, an important first step is to develop a strong conceptual framework. This should include a thorough clarification of the concepts involved, as well as a preliminary understanding of how the concepts are organized. Once this framework is established, the operationalization of the concepts can follow, i.e., the development of reliable and valid measures of the concepts. Finally, tests of the relationships among the various concepts can be made using these measures.

PURPOSE OF THIS PAPER

This paper presents a conceptual framework of how people cope with serious illness. Within this framework, concepts are identified and defined. Such a conceptual overview is necessary before the concepts can be operationalized and measured in a patient population.

II. AN OVERVIEW OF COPING

DEFINING COPING

There are many definitions of coping. Some refer to coping in general, and some are specific to coping with illness. For example:

Coping refers to strategies for dealing with threat (Lazarus, 1966).

Coping is the instrumental behavior and problemsolving capacities of persons in meeting life demands and goals (Mechanic, 1968).

Coping is all cognitive and motor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function and compensate to the limit for any irreversible impairment (Lipowski, 1970).

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Coping is any response to external life-strains that serves to prevent, avoid, or control emotional distress (Pearlin and Schooler, 1978).

Coping is what one does about a perceived problem in order to bring about relief, reward, quiescence and equilibrium (Weisman and Worden, 1976).

Coping is to deal with and attempt to . . . overcome problems and difficulties (Webster, 1975).

Coping is adaptation under very difficult conditions (White, 1974).

Coping is the cognitive and behavioral efforts made to master, minimize, tolerate, reduce, or minimize internal and environmental demands and the conflicts among them (Lazarus and Launier, 1978).

Coping is viewed as a response in nearly all of these definitions, where the response could be either a behavior or a cognition.

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Many of the definitions include reference to a particular outcome, usually a positive one, e.g., "to bring about relief," "to recover . . . impaired function," or "to avoid distress." There are several problems with this. First, a person may be making a response that is intended to lead to a particular outcome, but for some reason the outcome is not achieved (e.g., the person meditates to reduce distress but it doesn't work). Nevertheless, the response should be considered as a coping response. A second problem with defining coping in terms of outcomes is that many desired outcomes may be distant in time from the response, thus whether the response is a coping response could not be assessed until that time. In fact, it may be necessary for a person to tolerate a short-term undesirable outcome (e.g., distress of surgery) in order to achieve a long-term desired outcome (survival). In this example, one would probably want to refer to the response of facing up to surgery as coping, even though the short-term outcome is distress. A third problem is that people differ in the outcomes they desire. One person may choose to face a great deal of initial distress to achieve a longer life, whereas another may prefer to risk a shorter life to maintain a certain quality of that life. Again, one would want to be able to define both of these responses as coping.

For these reasons, it is preferable to limit the definition of coping to the responses and describe the outcomes separately.

A simple definition of coping is presented here that takes into account some of the problems discussed above, and is appropriate in describing coping with a serious illness:

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Coping is any behavioral response (thought or action) to concerns associated with the illness.

Whether the coping responses are effective or not can thus be dealt with as a separate issue. The word "concerns" was chosen over "problems" because not all illness-related concerns are problems (e.g., the concern about the meaning of one's life is not necessarily a problem).

SCHEMES FOR ORGANIZING COPING RESPONSES

In describing coping responses, one must decide whether to simply list the specific responses or organize these responses according to some apparent underlying scheme.

Most researchers who have attempted to organize coping responses have done so based on the <u>purpose</u> of the coping response. Many investigators consider the essential purpose of coping responses as the reduction of **emo**tional distress (Lazarus, 1974; Moos, 1976; Pearlin and Schooler, 1978; Wolff, Friedman, Hofer, et al, 1964). Lazarus (1979) classifies coping responses into two types: 1) problemsolving responses, which are aimed at changing the situation; and 2) emotionfocused responses, which are intended to make the person feel better. Pearlin and Schooler (1978) classify coping responses according to three purposes, two of which parallel Lazarus': 1) responses that change the situation; 2) responses that control the stress itself; and 3) responses that control the meaning of the situation. Hamburg and Adams (1967) suggest five purposes of coping behaviors as those that: 1) keep distress within manageable limits; 2) maintain a sense of personal worth; 3) restore relationships with significant other people; 4)

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enhance prospects for the recovery of bodily functions; and 5) increase the likelihood of working out a personally valued and socially acceptable situation after maximum physical recovery has been attained. Lipowski (1970) suggests that the purposes of coping are to: 1) preserve bodily integrity; 2) preserve psychic integrity; 3) recover reversibly impaired function, and 4) compensate for any irreversible impairment.

There are two problems with organizing coping responses according to their purpose. First, many responses may serve more than one purpose. Second, such an organization scheme should be derived empirically (e.g., using factor analytic methods) rather than according to an investigator's a priori theory. In order to do this, measures of the separate responses must first be obtained. Because of these problems, it is preferable to first assess specific coping responses without attempting to organize the responses into a scheme.

AREAS OF CONCERN REGARDING SERIOUS ILLNESS

Coping is defined here as a response to concerns associated with the illness. A number of areas of concern to people faced with a serious illness have been suggested. A summary of these is presented in Table 1, based on the work of Cohen and Lazarus (1979); Moos and Tsu (1979); Straus and Glaser (1975); USDHHS (1980); Weisman (1979); and Yager and Robinson (1980). These areas of concern are highly interrelated, i.e., problems in one area clearly affect other areas. Different concerns will be foremost for different people depending on the nature of the illness, the particular life situation, and the

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personality of the individual.

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Table 1

SUMMARY OF AREAS OF CONCERN REGARDING SERIOUS ILLNESS

Area of Concern	Example
Survíval	Desire to live Fear of dying
Bodily integrity	Pain Bodily function Tumor size Symptoms
Self-concept	Self-esteem Sense of competence and mastery Body image
Social role	Ability to work Ability to be a mother
Finances	Money for medical care, drugs Money for household help, child care
Family	Relationships with family, separation from family Burden on family, dependency
Friends	Relationships with friends and associates, isolation, separation, rejection
Religion	Concern with life after death Desire to be closer to God Feelings of remiss
Existential, belief systems	Evaluation of the meaning of the illness Concerns of life, death, destiny Regrets about the past
Feelings, emotions	Avoid depression, anxiety Maintain feelings of well-being, pleasure, hope Express negative feelings
Dependency	Burden on others Need for help vs. need for independence

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Sexuality	Desirability Ability to function sexually
Preparing for uncertain future	Financial support for family Change in life goals
Dealing with hospital environment and special treatment procedures	Chemotherapy, radiation Unknown procedures Rules of hospital Adjust to new surroundings
Developing relations with care givers	Doctors, nurses Appropriate behavior, how to deal with disagreements
Dealing with treatment regimens	Learning and maintaining prescribed treatment regimens (e.g., change in diet, lifestyle, giving injections)

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OUTCOMES OF COPING

These areas of concern to some extent provide the basis for describing the outcomes that could be used to assess the effectiveness of various coping responses. That is, some of the areas of concern are also categories of outcomes. Outcomes that might be of interest include: 1) length of survival; 2) physiological (e.g., functioning of immune system, sedimentation rate, tumor size); 3) physical (e.g., symptoms, pain, bodily functioning); 4) feelings (e.g., positive wellbeing, depression); 3) social (e.g., role and social functioning); and 4) self-concept (e.g., self-esteem, competence).

The relative value of each of these outcomes may differ among individuals. For example, one person may consider the most valuable outcome being able to work, even at the cost of a shorter survival time, whereas another person may hold the reverse values. For most people, lowered emotional distress will almost certainly be a valued outcome. However, other outcomes may be equally valued, such as relating to friends or continuing to work. To obtain some of these other outcomes may require at least a temporary state of increased distress. The consideration of the value of various outcomes to the individual has implications in assessing the effectiveness of various coping responses. An investigator may not be able to objectively define one outcome as more valuable than any other. This again illustrates the importance of defining coping responses separately from the outcomes of those responses. It may in fact be necessary to evaluate all of these outcomes in order to assess the effectiveness of coping.

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CONTEXT WITHIN WHICH COPING RESPONSES OCCUR

The coping responses a person makes depend on many things such as the nature of the illness, the person's beliefs about illness, the person's self-esteem, and the availability of friends or family. In other words, the person's coping responses occur within the context of that person's life and illness situation. To adequately assess how people cope with serious illness, this context must be recognized. The holistic approach considers this context as an essential part of the person's illness, and of the person's responses to that illness.

Some of these contextual variables may facilitate certain coping responses (e.g., having friends facilitates seeking emotional support) and can be considered coping resources (Pearlin and Schooler, 1978; Antonovsky, 1979). Other factors may limit the availability of certain coping responses (e.g., a physician who is unwilling to allow the patient to participate in the decision about treatment hinders that person's sense of control); these become coping hindrances.

Seven general categories of contextual variables are: 1) psychological (e.g., sense of control, self-esteem, self-sufficiency); 2) sociocultural (e.g., availability of friends); 3) medical (e.g., type of treatment, information imparted by the physician, expectations of physician); 4) environmental (e.g., cost of medical care, life events); 5) sociodemographic (e.g., age, income); 6) illness (e.g., nature of illness, prognosis); and 7) constitutional (e.g., general resistance, genetics).

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COPING AS A PROCESS

Clearly, any discussion of coping must consider its dynamic nature, that is, different coping responses may occur depending on the stage in the process (Lipowski, 1970). Most investigators who allude to such a process suggest that denial is more common in the early phases of coping (Hamburg and Adams, 1967; Lazarus, 1979; Moos, 1976; Visotsky, Hamburg, Goss, et al, 1961), followed by a recognition and reorganization phase in which the new situation is faced and incorporated into the person's life (Moos 1976; Visotsky, Hamburg, Goss, et al, 1961). The transition from denial to the recognition phase is not accomplished at a single point in time, but is gradual (Hamburg and Adams, 1967). The denial stage is viewed as preventing people from being overwhelmed, allowing a gradual transition to the recognition and reorganization phase (Hamburg and Adams, 1967; Moos, 1976). This recognition and reorganization phase may be viewed as containing the adaptive tasks, such as those outlined in Table 1.

Before one can describe the <u>process</u> of coping, however, the basic concepts must be clearly understood. Thus, we continue with a more detailed description of some of the elements of coping.

FRAMEWORK OF COPING WITH SERIOUS ILLNESS

<u>Coping responses</u> to the concerns associated with the illness must be viewed within a particular <u>context</u> and can be evaluated according to a number of <u>outcomes</u>. This is the framework within which coping responses can be viewed. A summary of the elements of this framework is presented in Table 2.

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The elements identified within this framework are based on a synthesis of the literature on coping, and on the author's discussions with social workers, nurses, physicians, and counselors who work with ill people. These are discussed in detail in Section III.

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III. CONCEPTUALIZATION OF COMPONENTS OF COPING

Each of the elements that appears in the framework of Table 2 will be discussed below. These will be grouped into sections corresponding to the three categories that appear in the framework (context, coping responses, outcomes). In some instances, a particular element may appear within two categories, with a subtle difference in meaning distinguishing each appearance. For example, although <u>feelings</u> of anger properly belong under mental outcomes, the actual <u>expression</u> (or nonexpression) of anger will fall under coping responses. This example illustrates the importance of the framework. That is, the framework forces a careful look at what is meant by each element when discussing its role in coping.

Where empirical studies have been done using any of the context variables or coping responses in relation to health outcomes, they will be mentioned. Such studies will be referred to even if they did not specifically address coping with illness, as long as the findings illustrate that a particular contextual variable or coping response may relate to health outcomes.

OBSERVABLES VERSUS CONSTRUCTS

The elements of coping defined here vary in terms of whether they represent specific responses or more global constructs. A construct is an abstraction, something that cannot be observed, but which is hypothesized to explain a set of observable events (Nunnally, 1978). For example, anxiety is a construct that is commonly hypothesized to

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explain such observables as wringing of hands, sweaty palms, and increased pulse. Constructs can be of increasingly higher order. For example, specific responses of reading about one's illness, asking questions of the doctor, and talking to a friend who had a similar illness may (if they all occur together) form a construct pertaining to information seeking. If information seeking, positive outlook, and having a sense of purpose in life occur together, they may define a higher order construct such as the will to live.

In this paper, most of the concepts are described either as observables or as lower order constructs. When a concept is difficult to define, it is often because it is a higher order construct. For example, control is a higher order construct and must be broken down into lower order constructs and observables before it can be adequately defined.

CONTEXTUAL VARIABLES

Psychological

<u>Knowledge about Health Matters</u>. The degree of familiarity or cognitive complexity regarding health terminology, disease, and treatments should be taken into account in evaluating a person's coping responses. People who have had little experience with the medical system may not understand commonly used medical terms; even welleducated people may not have this understanding (Yager and Robinson, p. 90). <u>Beliefs about Health and Illness</u>. A person's beliefs about what causes health and illness, and what affects recovery from illness may strongly affect how that person copes. Health, illness, and recovery from illness may be attributed to: 1) the medical care system (e.g., medications); 2) one's own behavior (e.g., nutrition, exercise); 3) one's thoughts and emotions; 4) one's environment (e.g., stresses, cold weather, viruses); 5) fate or God (e.g., predetermination; retribution for certain behavior); and 6) chance.

A belief that the medical care system affects recovery from illness has been termed a belief in the efficacy of medical care (Lau and Ware, in press).

A belief that one's own behavior can influence recovery from illness has been termed a belief in the efficacy of self-care (Lau and Ware, in press).

That one's thoughts and emotions can affect health and illness is a relatively new concept in our culture (Simonton, Simonton, and Creighton, 1978).

<u>Sense of Control</u>. People may view the occurrence of life events in basically four ways: 1) as under their own personal control; 2) as under the control of powerful others; 3) as due to chance; 4) as up to fate, i.e., predetermined. How a person experiences life events depends on that person's interpretation of those events, i.e., a given event may be experienced as aversive or not depending on how the person appraises and interprets the event.

A sense of personal control has classically been referred to in terms of the occurrence of life events: an internal locus of control

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(believing one is in control of events) is opposed to having an external locus of control (believing events are due to chance, fate, or powerful others) (Lefcourt, 1976; Rotter, Seeman, and Liverant, 1962). Personal control can be viewed in terms of control over the events themselves. The "availability of a response that may directly influence the objective characteristics of a threatening event" has been labeled behavioral control by Averill (1973) and refers to this sense of personal control over the events themselves. One could also, however, consider personal control in terms of how one interprets life events. A person could feel a sense of personal control if he or she was confident that potentially aversive events could be interpreted in a way so that the aversive experience was minimized. Thus, feeling in control of the experience of the events (e.g., one's feelings) may occur regardless of whether one felt in personal control of the occurrence of the event. Averill (1973) has labeled this latter aspect of personal control as cognitive control: "the processing of potentially threatening information so as to reduce the net long-term stress and/or the psychic cost of adaptation." Averill has also distinguished "decisional control" as the opportunity to choose among various courses of action. The existence of such opportunity may enhance one's sense of being in personal control, but is probably more indicative of the person's sociocultural context (e.g., socioeconomic status) than of the person's psychological sense of control. Having an internal locus of control (i.e., a sense of personal control) was associated with less illness in a sample of executives under high stress (Kobasa, 1979).

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The extent to which people believe they can affect their own health and illness (i.e., through their behavior, thoughts, and emotions) determines the extent to which they feel a sense of personal control over their health. If they believe that medical care influences recovery, people can still have a sense of their health being under control, although the source of control is external in this case. The belief that health is up to chance, fate, or uncontrollable external influences (e.g., environment) all pertain to having no sense of health being controllable. These concepts have been referred to as health locus of control (Lau, in press; Lau and Ware, in press; Wallston, Wallston, Kaplan, et al, 1976). Lau and Ware (in press) using factor analysis found three dimensions of health locus of control: 1) a belief in the efficacy of self-care (i.e., viewing one's health as a result of one's own behavior); 2) a belief in the efficacy of andical color (i.e., viewing one's health as a result of medical care); and 3) a belief that health was due to chance, i.e., that no one could do anything about it. They did not include items pertaining to health being due to environmental influences, being predetermined, or being up to fate.

Very little is known about the relationship between the various aspects of control and health. It would be interesting to determine the relationship of each aspect of control to health separately (e.g., belief in personal control, control by powerful others, fate, and chance), as well as to determine how various profiles of these beliefs are related to health outcomes (e.g., it may be that nonextreme belief in all four aspects is associated with better health outcomes).

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One study is known that tested the association between a belief in the efficacy of medical care and health. The belief that emergency room care would be effective for chest pain and heart attack was positively associated with relief from chest pain following such care (Linn, Ware, and Greenfield, 1980). However, questions regarding efficacy were asked after the emergency room visit, thus the direction of prediction is unclear.

Sense of Coherence. Returning to the basic concepts of control, another way of classifying these concepts is according to whether events are seen as occurring by chance or according to some overall scheme. Perceiving the world as coherent (i.e., predictable, lawful) has been referred to as having a sense of coherence (Antonovsky, 1979). This would include being able in find meaning in life events, being able to put things in long-term perspective, or interpreting life events into an ongoing life plan (Averill, 1973; Frankl, 1963; Kobasa, 1979; Moos, 1979). A sense of coherence may derive from viewing events as being under one's personal control, under the control of powerful (legitimate) others (e.g., of society), under the control of fate or God (i.e., predetermined), or from a philosophical outlook on life. Viewing events as due to chance (i.e., as unpredictable, arbitrary) is the opposite of a sense of coherence.

This brings us back to Averill's (1973) concept of cognitive control, i.e., the way in which an event is interpreted, appraised, or incorporated into a cognitive plan. Actually, Averill considers such interpretation as "control" only when it reduces the net long-term stress. Thus, his concept of cognitive control includes the outcome.

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More simply, a sense of coherence is the extent to which a person perceives events as part of a meaningful scheme, and is thus independent of the outcomes.

With respect to illness, having a strong sense of coherence would be expected to facilitate coping to the extent that the person could fit the illness into the coherent scheme (e.g., the illness is the will of God, the illness is because the person smoked). Kobasa (1979) found that having the ability to find meaning in stressful life events was associated with less illness in a group of highly stressed executives. Conversely, believing recovery is up to chance may hinder coping. For example, if a person strongly believes that something will heal him or her (e.g., believes in the efficacy of self-care <u>or</u> the efficacy of medical care) as opposed to believing that healing is beyond anyone's control, that person may become better (Jourard, 1971, pp. 85-90).

<u>Sense of Purpose</u>. Having a sense of purpose refers to having an immediate purpose in one's life, a reason to live, e.g., feeling important and needed by friends and family, or having a mission or goal to fulfill (Visotsky, Hamburg, Goss, et al, 1961; Hutschnecker, 1951; Moos, 1979). In a group of patients with severe polio, those who felt a strong sense of being important and needed (e.g., mothers of small children) made more favorable adjustments than those who did not (Visotsky, Hamburg, Goss, et al, 1961).

<u>Sense of Meaning</u>. Whether life holds any meaning or satisfaction for a person is closely related to having a sense of coherence and a sense of purpose, but may nevertheless be somewhat different from these concepts. Meaning in life may derive from religion or spiritual

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beliefs, love, work, family, or interesting experiences, i.e., what the person likes about living. Satisfaction with life and enjoyment in living probably indicate that life has meaning for a person. In one study, sudden death among coronary patients was predicted on the basis of an inability to find meaningful satisfaction in social and leisure activities and frustration in the person's job and family (Wolf, 1967; see Engel, 1971).

<u>Self-Sufficiency or Autonomy</u>. Self-sufficiency refers to a sense that one does not need to depend on others for help. It has been conceptualized as a tendency toward self-determination, or a tendency to resist external influences (Angyal, 1941; see Moos, 1976).

This concept can be considered as a continuum, the other end of which would be a tendency towards dependency on others for help in coping.

The concept of self-sufficiency may be quite useful in understanding the role of social supports. That is, a self-sufficient person may cope well with no social support, whereas a dependent person may need a large amount of social support.

<u>Self-Image</u>. Self-image (or self-esteem) refers to one's attitudes about oneself, i.e., the extent to which one is satisfied with and has respect for oneself (Pearlin and Schooler, 1978; Rosenberg, 1965).

Four separate but interactive components of self-image have been defined as: 1) body image, 2) the achieving self, 3) the interpersonal self; and 4) the identification self (Gates, 1974; see Taylor and Levin, 1976).

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Self-denigration, or the tendency to hold negative attitudes towards oneself or to feel inferior or inadequate in comparison to other people may be the opposite end of a continuum or may be an independent factor (Derogatis and Cleary, 1977; Pearlin and Schooler, 1978; Rosenberg, 1965).

Closely related to this concept is one termed self-commitment. Self-commitment has been defined as having the ability to recognize one's distinctive values, goals, and priorities, and as having an appreciation of one's capacities to have purpose and to make decisions (Kobasa, 1979). Having such a commitment to oneself has been associated with lower illness in a group of highly stressed executives (Kobasa, 1979). Self-esteem was negatively related to the number of psychosomatic symptoms (e.g., insomnia, headache, dizziness) in a sample of soldiers (see Rosenberg, 1965).

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Sense of Challenge. Having a basic sense of challenge with respect to life has been defined as feeling positively about changes in the environment, valuing a life filled with interesting and new experiences, being actively involved with one's environment, and having a sense of responsibility towards life's demands (Kobasa, 1979). Having a sense of challenge in terms of being actively involved with one's environment and in terms of having a sense of responsibility was associated with less illness in a study of highly stressed executives (Kobasa, 1979).

If people have a sense of challenge with respect to life, they may respond to illness as a challenge, e.g., see the illness as a creative opportunity to learn more about themselves (Lipowski, 1970; Pelletier, 1977).

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<u>Sense of Humor</u>. A sense of humor is not easily defined, as it has a number of meanings. It may be defined most conventionally as laughing fairly easily at the same kinds of things that other people find amusing and laughable. Another broader meaning refers to an ability to see oneself and others in a somewhat distant way; life is viewed from a perspective in which one can laugh at people and events, yet remain in contact with these same people and events (Moody, 1978).

Having a sense of humor can be contrasted to being resistant to humor and laughter. That is, for some people laughter evokes feelings of guilt.

<u>Intelligence</u>. A person's intelligence may be a resource when faced with a serious illness.

In a study of people with malignant melanoma, those who survived the longest had larger verbal intelligence scores than those who survived the shortest time (Krasnoff, 1959).

Sociocultural

Social Support. A great bulk of literature has been concerned with the role of social supports as a mediator of stress. (See for example Cassell, 1976; Kaplan, Cassel, Gore, 1977; Lin, Simeone, Ensel, et al, 1979; Porritt, 1979; and Wortman and Dunkel-Schetter, 1979). Basically, the theory suggests that given a stressful situation, people with adequate social supports will experience less distress. Social supports can be described in terms of their quantity (e.g., number of friends), quality (e.g., having people one can trust), availability (e.g., likelihood of having someone there when needed), use (e.g., actually spending time with people), meaning (e.g., importance of friends), and satisfaction with these supports.

One important issue in considering the role of social supports in coping is that of individual <u>needs</u> for social supports. Some people are more self-sufficient and thus need a relatively small amount of support, whereas others may need greater amounts (Kaplan, 1977).

It has been noted that a person with a serious illness will have an unusually high need for affectionate regard by love objects and other persons on whom he/she is emotionally dependent (Janis, 1958, p. 200). Similarly, Visotsky, Hamburg, Goss, et al (1961) noted that polio patients have a high need for frequent contact with others, even if that contact is brief. He suggests that a sense of isolation is very threatening while hospitalized and ordinary loneliness can become more frightening than usual. It has also been suggested that seriously ill people have a particular need for support from other seriously ill patients, i.e., from others who have experienced the same problems and feelings (Kushner, 1977; Meyerowitz, 1980; Ryan and Ryan, 1979; Visotsky, Hamburg, Goss, et al, 1961). Hamburg and Adams (1967) point out that people cope more effectively with disability when they have a firm sense of belonging in a highly valued group such as family or community.

This generally high need of ill people for increased social support comes at a time when these supports are often diminished. For example, people with serious illness (especially cancer) are often faced with isolation from friends because these friends fear contagion, fear the expression of intense emotions or don't wish to be reminded of their own

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vulnerability (Videka, 1979). In addition, the person's family may become more distant because of all the disruptions.

There is much literature on the association between social support and health. In a correlational study, patients with rheumatoid arthritis who were isolated and alienated from others had more functional incapacity (Moos and Solomon, 1965). Cancer patients who withdrew socially were more emotionally distressed than those who talked with others (Weisman and Worden, 1976). In men hospitalized with road injuries, the quality of social supports was more important than the quantity in determining a good outcome, where outcome was measured in terms of health, emotional distress, work adjustment, and life enjoyment. Being accompanied by someone to the emergency room was positively associated with relief from chest pain in a sample of people who sought emergency room care for chest pain (Linn, Ware, and Greenfield, 1980). Polio patients in the acute phase who were visited frequently by warm, respectful relatives and friends were the best adjusted (as determined by a variety of subjective measures) (Visotsky, Hamburg, Goss, et al, 1961). People who lacked social and community ties were more likely to die in a nine-year follow-up study of 6,928 adults (Berkman and Syme, 1979).

It has been suggested that the crucial distinction is between having no friends and having one or more (Langner and Michael, 1960; see Kaplan, 1977).

One mechanism that has been proposed whereby social supports are viewed as facilitative is that social supports provide a sense of being important and needed, or of belonging (Visotsky, Hamburg, Goss, et al,

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1961). In this sense, having social supports is closely related to having a sense of meaning or purpose. Another mechanism suggested is that having social supports allows the expression of affiliative tendencies (i.e., provides a person with an outlet for emotional expression) which serve to reduce anxiety (Schacter, 1959, see Kaplan, 1977). Jourard (1971) eloquently described the benefits of social support: "being heard and touched by another who cares seems to reinforce identity, mobilize the spirit, and promote self-healing."

<u>Social Opportunities for Control</u>. The extent to which family, friends, or employers provide the ill person with opportunities for control will affect that person's coping responses. For example, a wife may consult her hospitalized husband regarding family decisions or ask when he would like her to visit, thus offering him an opportunity for control, or she could deny him these opportunities. Similarly, an employer may offer a person a choice of alternatives (e.g., work at home, work part-time), or instead fire that person.

Medical

Physicians and medical personnel can influence how a person copes in several ways. These include: 1) humaneness and facilitation of expression of feelings and concerns, 2) providing information, choices, and opportunities for participation, 3) competence, and 4) allowing hope and optimism.

<u>Humaneness</u> and <u>Facilitation</u> of <u>Expression</u>. The emotional quality of the physician-patient relationship has been suggested as affecting the physiological condition of heart patients (Lynch, Thomas, Mills, et

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al, 1974, see DiMatteo, 1979), their survival (Jarvinen, 1955; see DiMatteo, 1979), and their adjustment to having mastectomies (Jamison, Wellisch, Pasnau, et al, 1978; see Meyerowitz, 1980).

<u>Providing Information, Choices, and Opportunities for</u> <u>Participation</u>. Medical personnel may provide information, choices, and opportunities for the patient to participate; whether these are beneficial depends on the patient and the particular circumstances.

Information can be provided on the nature of the illness, possible treatments, and probable effects and risks of each treatment, treatment procedures, and the amount of discomfort to be expected. Having such information has been termed informational control (Averill, 1973; Krantz and Schulz, 1979). There is some controversy over whether having such information is beneficial or harmful to the patients. Some suggest that patients who have information about the amount of discomfort to be expected from a noxious procedure are able to tolerate the discomfort more easily (Taylor, 1979). Johnson (1975) found that having information about the physical sensations to expect during a stressful medical procedure reduced the distress. Krantz and Schulz (1979) found that providing patients with information about what symptoms to expect reduced complications following heart attack. Surgical patients who were told about postoperative pain and what could be done for it required only half as much postoperative narcotics in a controlled study (Egbert, Battit, Welch, et al, 1964). Uncertainty seems to be an important source of stress. People apparently prefer the predictable to the unpredictable, and having information allows this predictability (Yager and Robinson, p. 76). Terminally ill patients were found to

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resent not being kept fully informed and being excluded from decisions regarding their own treatment (Yalom and Greaves, 1977).

Whether information about what to expect during noxious medical procedures is beneficial or not may depend on whether the patient is a sensitizer (typically seeks information to prepare for things) or a repressor (prefers not to know). Shipley, Butt, and Horwitz (1979) found that having such information was beneficial for sensitizers but increased anxiety for repressors.

Adverse effects of providing information on possible treatment complications are that patients may be deterred from lifesaving treatments because of knowing the risks (Ravitch, 1974, see Cohen and Lazarus, 1979, p. 231), and that more of these complications may occur through the power of suggestion (as in the placebo effect) (Cohen and Lazarus, 1979). Similarly, telling a person a poor prognosis may lead to helpless, giving-up behavior, thus fulfilling that prognosis.

There is some evidence that most patients remain inadequately informed (i.e., forget substantial amounts of the information) regardless of the amount of information, the manner in which it is presented, and the type of medical procedure involved (Cassileth, Zupkis, Sutton-Smith et al, 1980; Horwitz, 1976).

Choices and participation can be with respect to daily events (e.g., timing of baths in hospital), treatments (e.g., surgery or chemotherapy), or responsibility for self-treatment (e.g., take responsibility for injections). The hospital environment usually provides little opportunity for choices and participation. That is, scheduling of treatment, meals, visitors, baths, is nearly always done

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for the convenience of hospital staff.

It has been argued that allowing the patient more choices may improve that patient's physical and psychological health (Janis, 1958; Taylor, 1979). Langer and Rodin (1976) found that allowing patients to make choices about daily matters resulted in better health, a heightened sense of well-being, and longer survival. Mills and Krantz (1979) found that patients who were both provided with information about a blood test procedure and allowed to choose which arm to use experienced less anxiety and distress over the procedure.

Whether such opportunities for choices and participation are beneficial to the patient may depend on the patient's desire to be a participant. Some people prefer to place themselves in the hands of the medical system and would consider it a burden to become a participant in the decisions.

Providing information, choices, and opportunities for participation may or may not give the patient a sense of control; this probably depends on the person's usual sense of control.

<u>Competent</u>, <u>Inspire Confidence</u>. If medical personnel appear inexperienced, or incompetent, patients way lose confidence.

<u>Allowing Hope and Optimism</u>. A strong influence on the patient's coping responses will be the extent to which medical personnel, especially the physician, allow for hope and optimism regarding recovery.

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Sociodemographic

Sociodemographic factors, such as socioeconomic status, clearly will have an effect on the coping responses of an individual (Antonovsky, 1979). For example, amount of income will affect whether a person will be able to seek expert advice, get second opinions, search out relevant information, or get household help or professional counseling.

Socioeconomic status was a consistent predictor of returning to work after a heart attack (Croog, 1968; Higgins and Pooler, 1968). Heart attack patients with higher socioeconomic status were more likely to receive counseling and education on their rehabilitation (Aday and Eichhorn, 1972).

COPING RESPONSES

Coping responses can be classified into behaviors and cognitions (thoughts). Although this usually represents a useful distinction, a response can often be considered as both. For example, refusal to accept the prognosis may manifest itself in both thoughts and behaviors. Thus, for purposes of this paper, responses will not be classified.

Sense of Control

As a coping response, a sense of control can refer to: 1) one's sense of control over life in general now (i.e., in the presence of the illness); and 2) as one's sense of control over the outcomes of this illness.

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The first way of describing control as a response (having a sense of control over one's daily life now) is the same as discussed earlier with respect to control as a psychological context variable. The distinction between one's usual (pre-illness) sense of control and one's current (in the presence of the illness) sense of control is important because the conditions of illness often reduce this sense of control, e.g., the person may be unable to work or be confined to bed. A person's perceptions of control given the illness will depend on that person's usual sense of control. That is, for some people (e.g., those accustomed to a large amount of control), the reduction in control is severe, whereas for others it may not change much.

It would be interesting to test whether it is the <u>absolute level</u> of control or the <u>degree of loss</u> of control that is important in predicting outcomes.

The extent to which the person feels a sense of control over the outcomes of this particular illness is distinct from that person's sense of control over his/her health in general (as was discussed earlier as a context variable). Although there is undoubtedly some relationship, the first represents a more generalized attitude whereas the second pertains to a very salient current illness. A sense of control over the outcomes of this illness may derive from beliefs that one can <u>personally</u> control the outcomes (e.g., that one's behaviors, thoughts, or emotions willaffect the outcomes) or from beliefs that one is in the hands of powerful others (e.g., that one's doctor is providing an effective treatment).

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Denial/Avoidance

As a coping response, denial and avoidance are complex and somewhat difficult to conceptualize. Denial has been defined as the effort to negate a problem or situation; avoidance refers to acceptance of the reality of the threat, but there is deliberate effort not to think or talk about it (Cohen and Lazarus, 1979, p. 226).

In speaking of denial as a response to serious illness, one must first ask "denial of what"? There are three basic forms of denial: 1) of facts; 2) of the meaning of the facts; and 3) of one's emotional state (Lipowski, 1970).

To deny the facts is to deny the existence of the illness. However, one must be careful in defining "facts." Whereas a lump in the breast might be considered as a "fact," a first diagnosis of cancer may not be. In the latter case, the seeking of a second opinion may not properly be labeled as denial of the facts. This of course becomes more complicated as information accrues (i.e., do two opinions represent "fact"?). Denial of the facts may indicate a lack of or misunderstanding of information. For example, if a person has no pain and has not been informed of a poor prognosis, that person may not believe he/she is ill.

To deny the meaning of the facts is to minimize the personal significance or implications of having the illness (Hackett and Cassem, 1974; Janis, 1958; Lipowski, 1970; Moos, 1979; Visotsky, Hamburg, Goss, et al, 1961). This -ay take the form of denying that one may be dependent (Chodoff, 1962), minimizing the seriousness of the illness (Janis, 1958; Visotsky, Hamburg, Goss, et al, 1961); maximizing one's

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ability to cope (Janis, 1958); or maximizing one's chance of receiving help (Janis, 1958). This form of denial is akin to maintaining hope, and may not necessarily be unrealistic. Given the shortcomings of medicine in predicting outcomes with certainty, denial of the meaning of the "facts" may represent adaptive coping behavior.

Finally, one may deny one's emotional state, as for example refusing to acknowledge that one is fearful, angry or hostile. Denying negative affect may take the form of displacing it (e.g., focusing on the family's negative affect, Katz, 1970), attributing it to other things (Janis, 1958, p. 198; Moos, 1979) or displaying a hearty, jovial manner (Hackett and Cassem, 1974).

All of these types of denial need to be distinguished from avoidance. A person can avoid thinking about or talking about the illness (facts, meaning, or affect) yet not be denying it (Goldstein, 1973; Hackett and Cassem, 1974; Lazarus, 1979; Krantz and Schulz, 1979). Such avoidance may indicate a conscious unwillingness to discuss such an emotionally laden issue, (e.g., so as not to burden one's family), or may indicate an inability to do so (Krantz and Schulz, 1979).

The use of denial as a response varies both among people, and in the same person at different stages in the illness (Lipowski, 1970). It is especially likely to occur in the early phases of the illness (Visotsky, Hamburg, Goss, et al, 1961) or when the threat of damage is great (Janis, 1958).

The extent of denial may vary from severe (e.g., delusional denial of the illness) to mild (e.g., selective misinterpretation of facts) (Lipowski, 1970). Hackett and Cassem classified people into three

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categories of the extent of denial based on the amount of fear expressed: 1) major deniers (felt no fear); 2) partial deniers (eventually admitted fear); and 3) minimal deniers (complained of anxiety or readily admitted fright). This classification confounds denial with willingness to express negative affect.

Depending on the form and extent of denial, it may be adaptive (e.g., reduce fear to a point that allows the person to function; allow hope and optimism) or maladaptive (e.g., person does not seek treatment). The effectiveness of a particular denial response varies depending on the person, the situation, and the stage in the process of coping.

Denial and avoidance are sometimes related to positive outcomes and sometimes to negative outcomes. Denial and avoidance were positively associated with survival in patients in a coronary care unit (Hackett and Cassem, 1974). Breast cancer patients who initially used denial were more likely to survive than those who responded with stoic acceptance (Greer, Morris, and Pettingale, 1979). More postsurgical complications were observed in patients who used denial strongly (Janis, 1958; see Beisser, 1979).

In an experimental study in which subjects were threatened by possible electric shock, those who used avoidant thinking showed more stress (indicated by pulse rate and skin resistance) than those who did not (Houston and Holmes, 1974). These authors concluded that subjects who did not use avoidant thinking used the time to reappraise the threat as less serious, thus reducing their level of stress.

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Acceptance

The opposite of denial is the acceptance of the illness. As in denial, one can distinguish the acceptance of facts, of the meaning of the facts, and of one's emotional state. Additional questions that need to be addressed regarding acceptance are whether it represents a positive acceptance in which the person continues to live as fully as possible, or a resignation and giving up. The term "insightful" acceptance has been used to refer to being able to accept dependency without bitterness or hostility, or to accept any loss without feelings of personal devaluation (Chodoff, 1962).

Breast cancer patients who responded with stoic acceptance did not survive as long as those who responded with a fighting spirit or denial (Greer, Morris, and Pettingale, 1979). In a sample of women with metastatic breast cancer, those who were better adjusted to their illness (in terms of overall psychological adjustment) did not survive as long as those less well adjusted (Derogatis, Abeloff, and Melisaratos, 1979).

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Hope

Maintaining hope or optimism refers to having a sense that there is a high probability that things will work out as reasonably as can be expected (Antonovsky, 1979; Simonton, Simonton, and Creighton, 1978). It has been suggested that maintaining hope has beneficial effects on other outcomes, i.e., that if one expects to get well and behaves as if one will get well, this expectation may increase one's chances of getting well (i.e., the self-fulfilling prophecy) (Cousins, 1979;

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Hutschnecker, 1951; Simonton, Simonton, and Creighton, 1978; Visotsky, 1961). Hope is strongly influenced by those in the patient's environment such as physicians and family (Visotsky, 1961).

The placebo effect is closely related to hope. It has been well documented that if the physician and the patient believe that a particular treatment or medication will work, it does work more often than would be expected by chance (see, for example Beecher, 1955; Benson and Epstein, 1975; or Rosenthal, 1966).

Hope may be difficult to measure because people may verbalize a positive expectancy but behave in ways that express negative expectancies (Simonton, Simonton, and Creighton, 1978).

Breast cancer patients who had a highly optimistic attitude (accompanied by a search for greater information) survived longer than those who responded with stoic acceptance or feelings of helplessness or hopelessness (Greer, Morris, and Pettingale, 1979).

Giving Up

A complex of responses has been identified and labeled as "giving up" (Engel, 1968; Sweeney, Tinling, and Schmale, 1970). Giving up refers to a sense of psychological impotence, a feeling of being unable to cope (Engel, 1968), or a loss of motivation (Schmale, 1972). Two affects of giving up have been labeled as helplessness and hopelessness (Engel, 1968). Each refers to the same unpleasant feeling, but they are distinguished on the basis of the attribution the person makes as to the cause of the impotence. Helplessness refers to feelings of being powerless to cope because of environmental constraints (Engel, 1968; Seligman, 1975; Schmale, 1972). The person feels forced to wait for something in the environment to change (Sweeney, Tinling, Schmale, 1970). Although this results in behavioral passivity (Taylor, 1979), the person nevertheless remains alert to environmental changes (Sweeney, Tinling, and Schmale, 1970).

Hopelessness occurs when the person assumes personal responsibility for the inability to cope, i.e., believes that there is nothing he/she or anyone can do (Sweeney, Tinling, and Schmale, 1970; Schmale, 1972; Engel, 1968). Hopelessness is thus more unpleasant than helplessness, because there is not even the hope that something external may change; i.e., hopelessness has a permanent, irreversible quality (Sweeney, Tinling, and Schmale, 1970). Hopelessness is associated with low selfesteem (Schmale and Iker, 1971). Both hopelessness and helplessness lead to feelings of depression (Schmale, 1972).

Breast cancer patients who responded with feelings of helplessness or hopelessness did not survive as long as those who responded with denial or a fighting spirit (Greer, Morris, and Pettingale, 1979).

Use of Mental Imagery

The mental images that a person uses with respect to the illness is a relatively new aspect of coping being discussed. For example, people can visualize themselves being well, visualize their white blood cells as being nonexistent, or the cancer can be visualized as a powerful thing against a weak treatment (Simonton and Simonton, 1975).

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One way mental imagery has been suggested to be effective is in its effect on physiological responses. When a person thinks about stressful events, some of the physiological activity associated with those events occur; the more specific the image, the more specific the response (Jacobson, 1938). The use of mental imagery in healing is based on this finding, i.e., if a person envisions pleasurable events (either by recalling them or anticipating them), the physiological responses associated with pleasurable events will be evoked.

Another mechanism that has been suggested is that by repeatedly creating mental images of desired events, the person comes to expect that these events will happen. Such a positive expectation influences the way the person behaves and feels, creating a self-fulfilling prophecy (Simonton, Simonton, and Creighton, 1978).

To the extent that feelings influence the healing processes, such mental imagery may affect illness outcomes. This idea is the subject of much controversy, both on ethical and methodological grounds (Kolata, 1980; Scarf, 1980). For example, if a person tries it and yet the illness progresses, a sense of failure or guilt may result (Holland, 1979, p. 17).

Nevertheless, it may be a valuable coping mechanism and should be subjected to a controlled study.

Setting Goals

One approach to the overwhelming number of tasks that must be dealt with in response to the illness is to set limited or intermediate goals, i.e., break the problems down into manageable bits and work on them one

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at a time (Caplan, 1964; see Moos, 1976; Moos, 1979, p. 14). Even when an intermediate goal is not directly related to recovery, such a response (if reinforced) may encourage future effort and provide a sense of accomplishment (Visotsky, Hamburg, Goss, et al, 1961).

Setting goals can be viewed as a means for examining one's life and making desired changes. A suggestion has been made to set three threemonth goals, three six-month goals and three one-year goals, where the latter are broken down into manageable parts (Simonton, Simonton, and Creighton, 1978). The process of setting goals that address a variety of needs (e.g. recreation, personal growth, exercise, time alone) may allow a look at whether one's needs in these areas are being met. Simonton, Simonton, and Creighton suggest that many people spend so much time meeting the expectations of others (e.g., employer, spouse, children) that they are not sure what they want for themselves. Goalsetting is thus viewed as a way of taking control and working to fill one's own needs.

Goal setting may also be viewed as a way of creating a future, as a statement that there are things to be accomplished, reasons for living, and a belief that one will live to accomplish them (Simonton, Simonton, and Creighton, 1978).

Activity Versus Passivity

Coping responses can be considered solely in terms of an active/passive dimension, i.e., doing something as opposed to not doing something, regardless of what is done. It has been suggested that relief and encouragement are provided when patients have a sense of

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being able to do something rather than waiting passively for whatever is to come (Visotsky, Hamburg, Goss, et al, 1961).

It may be that the <u>number</u> of coping responses is important in effective coping, i.e., that diversity is more effective than excessive reliance on a small number of coping responses (Yager and Robinson, p. 97).

Taking Control/Participating in Recovery

The terms instrumental control (Schulz, 1976), behavioral control (Krantz and Schulz, 1979; Averill, 1973) and decisional control (Averill, 1973) all refer to acting on the environment to change the situation. In the context of coping with a serious illness, however, the situation (i.e., the illness) can rarely be changed directly. Thus, taking direct action takes on a slightly different meaning, that of becoming a participant in the process of recovery.

Becoming a participant in the healing process is increasingly being advocated (see, for example, Fiore, 1979 and Jaffe, 1980). Such participation may entail learning skills to cope with stress, maintaining a positive attitude, seeking the help and support of others, seeking information, sing the self-healing power of the mind, or participating in decisions regarding types of treatment. Participating in medical decisions must be exercised with common sense, i.e., the person should not be making medical decisions that are beyond his/her realm of competence. The term <u>informed participation</u> has been used to characterize this; the patient is "neither a passive recipient of services nor fully in charge of medical decisions, but is rather an

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informed, active member of a team responsible for his/her health" (Taylor and Levin, 1976). Making such choices often leads to an increase in perceived control (Mills and Krantz, 1979).

Taking control through action is closely related to the concept of activity versus passivity. Simply "doing something" may provide the person with a sense of control (Visotsky, Hamburg, Goss, et al, 1961). With respect to serious illness, the term "tackling" has been used, referring to a tendency to adopt an active attitude toward the challenges and tasks posed by the illness (Lipowski, 1970).

Information Seeking

One response to a serious illness is to seek information regarding the illness. This can be considered as one aspect of taking control or becoming a participant. Such information may pertain to the nature of the illness, its etiology, the diagnostic and therapeutic procedures used, its natural progression, and its implications or prognosis. Several purposes of information seeking have been suggested, for example, to reduce the uncertainty or ambiguity about the illness (Lipowski, 1969; McIntosh, 1974; Taylor, 1979); to restore a sense of control (Moos, 1979, p. 13; Lazarus, 1979; Mills and Krantz, 1979), to give the person something to do (Moos, 1979, p. 13; Yager and Robinson, p. 76) and to question the facts and continue searching for more acceptable answers (Weisman and Worden, 1976). Depending on the purpose, different outcomes may be observed.

There is apparently considerable variation in people's inclination to obtain information. Lazarus (1979) classified surgery patients into

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two types: 1) avoiders (those who were not interested in listening to anything related to their illness or surgery) and 2) vigilant types (those who tried to get as much information as they could).

Based on a review of the literature, McIntosh (1974) concluded that most patients would rather have information, and reacted well to having it.

Failure to seek information may be due to not wanting to appear a nuisance, not wanting to expose one's ignorance, diffidence, or a reluctance of medical personnel to convey information (McIntosh, 1974).

Laughing

The idea that laughter can be therapeutic has been suggested as a well-known, but little discussed, fact (Cousins, 1979; McDougall, 1922; Moody, 1978). Its benefits have been noted as bringing about euphoria or general well-being (McDougall, 1922; Moody, 1978), reduction of pain (Cousins, 1979); relaxation (Walsh, 1928); stimulation of the internal organs (Moody, 1978), and reduction of muscular tension (Moody, 1978). It has been suggested that laughter provides a way of establishing communication between people (Moody, 1978).

Adopting or Avoiding the Sick Role

The sick role includes behaviors such as staying in bed, not performing one's usual activities, and other behaviors that are not sanctioned if one is healthy. The adoption of the sick role in response to the illness can be viewed negatively (i.e., as giving in, becoming dependent), or positively (i.e., as surrendering to the care of

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competent persons, complying with the physician's orders) (Kasl and Cobb, 1966; Lipowski, 1969). Thus, adopting the sick role must be carefully distinguished from other concepts such as compliance and giving up.

Parsons (1951) viewed the sick role as one in which the person was exempt from his or her normal social obligations but in exchange for this privilege was obliged to cooperate to the fullest to get well. He viewed the sick role as socially disruptive, one that should be controlled to prevent its abuse (see Bloom and Wilson, 1979).

The sick role concept must be considered within the context of the nature and severity of the illness (Parsons, 1951) which determines the appropriateness of adopting or avoiding the sick role. Given an "appropriate" situation (e.g., following surgery) the ability to accept the sick role may represent "insightful acceptance" of the situation (Chodoff, 1962), and the inability to adopt the sick role (due to inability to be dependent, desire to maintain control) may be extremely detrimental. On the other hand, if the situation is inappropriate, adopting the sick role may indicate an attempt to escape an unpleasant situation, a clamoring for help, giving in to dependency needs, or a demand to be cared for (Chodoff, 1962).

One way to evaluate sick role behavior may be to determine what (if any) benefits the person derives from being ill. These might include increased attention and caring from other people, avoiding a troublesome situation such as work or family, an opportunity to think and perhaps gain a new perspective on life, a relief from having to meet the expectations of others, or making it acceptable to ask for love or

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express one's unhappiness (Hutschnecker, 1951; Lipowski, 1969; and Simonton, Simonton, and Creighton, 1978). If a person is deriving a number of benefits from being ill, it may be necessary to focus on ways of deriving these benefits in ways other than through the illness.

It may be difficult to assess many of these benefits of illness, because such benefits are probably recognized by patients as not socially acceptable. For example, people may like having the extra attention but would never admit that they like it.

Making Positive Life Changes

Some seriously ill people respond by making positive life changes. That is, on becoming ill, they take stock of what they want from life and make changes to come closer to their goals. It is as if on being faced with a shortened life span, they realize they should use that time well. Such changes might include becoming emotionally closer to family or friends, quitting a high-pressure job, leaving an unsatisfying relationship or situation, becoming more religious or spiritual, doing things they always wanted to do, or becoming more sensitive to their own needs and feelings.

Requesting Support/Seeking Reassurance

People who are ill are socially and psychologically vulnerable, i.e., need special reassurance that they are worthy (Bloom and Wilson, 1979). Ways of requesting support from others may be to join special groups such as self-help groups (Jaffe, 1980; Yalom and Greaves, 1977; Moos, 1979, p. 13), or request reassurance or emotional support from

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family, friends, or medical staff (Moos, 1979, p. 13; Visotsky, Hamburg, Goss, et al, 1961; Caplan, 1964; see Moos 1976). For some people this may be difficult, as many of us have a culturally induced reluctance to seek help for emotional problems (Simonton, Simonton, and Creighton, 1978).

Pleasurable_Behaviors

Behaviors may be adopted (or continued) that provide satisfaction or pleasure in and of themselves. For example, hobbies, meditation, exercise, or listening to music may be considered as responses that are designed to create pleasure (Lipowski, 1969; Pelletier, 1977).

As a coping response, the important point here is that the person spends time doing things that are enjoyable. Not at issue here is the nature of the activity (i.e., different activities are enjoyable for different people).

To the extent that positive emotions have a beneficial effect on the body, time spent doing pleasurable activities may affect outcomes of the illness.

Stress Reduction Behaviors

Many behaviors that are enjoyable to a person may also be considered as stress reducing. However, this may not always be the case (e.g., the person may run to reduce stress but not enjoy it). Thus, stress-reduction behaviors should be considered separately from pleasurable behaviors.

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Some investigators suggest that only certain activities will adequately discharge the physical effects of stess (for example exercise, meditation, or progressive relaxation) whereas other activities that people commonly think of as "relaxing" (e.g. watching TV, drinking) will not discharge stress effects (Simonton, Simonton, and Creighton, 1978).

Behaviors that are designed to reduce stress include progressive relaxation (Benson, 1975; Jacobson, 1938), meditation (Bloomfield, Cain, and Jaffe, 1975; LeShan, 1976), autogenic training (Schultz and Luthe, 1969, see Jaffe, 1980), biofeedback (Brown, 1977), exercise (Selye, 1956), hypnosis or self-hypnosis (Kroger, 1977), mental imagery (Simonton, Simonton, and Creighton, 1978), and relaxation exercises (Jaffe, 1980).

Escape/Distraction

Behaviors that are engaged in as a means of escaping or distracting oneself from the illness may comprise a category distinct from pleasurable behaviors or stress reduction behaviors. For example, some people may engage in "keeping busy" simply to distract themselves, not particularly enjoying the activities (e.g., housecleaning, working extra hours, going to social gatherings). Sleeping, watching TV, drinking, using drugs, or daydreaming might fall into this category of distracting behaviors.

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Expression of Feelings

Expression to others of positive and negative feelings is probably an important coping response. Such expression is viewed as an outlet for discharging feelings (Monat and Lazarus, 1977, p. 151; Schmale and Iker, 1977), and as a way of resolving some of the problems (Weisman and Worden, 1976). However, such expression can alienate other people if it is excessive or tends towards "crying 'why me?'" (Weisman and Worden, 1976).

The nonexpression of emotion is believed to lead to increased physiological arousal (Tourangeau and Ellsworth, 1979) and to changes in patterns of cellular organizations (Schmale and Iker, 1971). People who were better at facially expressing emotion in response to emotionally loaded slides were found to have a lower skin conductance and heart rate (Buck, Miller, and Caul, 1974) and were less physiologically reactive to electric shock (Notarius and Levenson, 1976). Progression of cancer was faster in those lacking self-expression (e.g, those who were serious, over-cooperative, over-nice, passive, apologetic) (Blumberg, West, and Ellis, 1954). Women with metastatic breast cancer who were communicative about their distress survived longer than those who were not (Derogatis, Abeloff, and Melisaratos, 1979). Lung cancer patients had fewer outlets for emotional discharge than a group of controls (Kissen, Brown, and Kissen, 1969).

The expression of emotion must be distinguished from the feelings of emotion. Many people choose not to express their feelings, but this does not indicate the extent of their feelings.

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The Will to Live

Although the will to live is not a specific coping response, it nevertheless merits attention as a higher order construct that may explain patterns of coping responses. It has been described as a powerful drive to stay alive (i.e., the creative instinct) (Hutschnecker, 1951), as the belief that one is not going to die even though the prognosis is poor (Moody, 1978), and as having a reason to live or a feeling of being responsible to life for something (Frankl, 1963). Visotsky, Hamburg, Goss, et al (1961) describe a similar concept, the "determination to improve," as a powerful attitude in which the person is eager to make progress, determined to do everything possible toward improving. Visotsky suggests that although this attitude seems to be a personality characteristic, it nevertheless can be significantly influenced by the behavior of friends, family, hospital staff, and community.

OUTCOMES

Whether the various coping responses described above are effective or not can be determined by looking at a variety of outcomes of these responses. These include medical outcomes (e.g., reduction of tumor), quality of life outcomes (reduction of pain, positive well-being), and length of life. These outcomes have been categorized here as follows: length of survival, physiological, physical, social, positive mental states, negative mental states, and self-concept.

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Length of Survival

Length of survival is the most final outcome that can be used to evaluate the effectiveness of coping.

Physiological

Physiological outcomes refer to bodily processes and signs of illness that may or may not be symptomatic. These may be indicative of the course of the disease without the person's awareness. For example, tumor size, metastasis of cancer, blood counts, heart rate, and blood pressure may all be related to how a person copes. Physiological indicators of the immune response (e.g. amount of steroids in the blood) may be especially important to evaluate as a function of coping responses, as these may clarify the mechanisms involved in the effect of coping on the course of illness.

Physical

Physical outcomes are those that pertain to the body and include symptoms, pain, and functional status (e.g., ability to walk or climb stairs).

Functional status refers to the performance of, or ability to perform, a variety of daily activities (Stewart, Ware, Brook, et al, 1978). These-include major role activities (job, school, or housework), physical activities (walking, climbing stairs), self-care activities (bathing, eating), and mobility (getting around the community, being able to drive). The advantage of functional status measures of health is that they are useful across a variety of illnesses, i.e., they are not illness-specific.

Sexual functioning has not traditionally been included in measures of functional status, but may be particularly relevant to people with serious illnesses. People who are ill may be especially likely to have sexual problems because of surgery, medications, or low energy. Role functioning may also be especially relevant to ill people. For many people, their work is not only a way to earn a living but is closely tied to their identity and self-concept. Problems in working may occur as a direct result of the illness (e.g., due to hospitalization or recuperation) or indirectly through discrimination by employers (e.g., people with cancer are often stigmatized).

Social

A person's ability to continue fulfilling social roles and to relate to other people are important in evaluating the effectiveness of various coping responses, to the extent that these outcomes are valued by the person. As an outcome, the focus should be on the person's satisfaction with his or her ability to function socially, rather than on the extent of social supports.

Negative Mental States

Both negative and positive feelings are important outcomes in terms of evaluating the effectiveness of coping. Negative feelings that are especially relevant to coping effectiveness are depression, anxiety, anger, and guilt. These may be used as outcomes to assess the effectiveness of various coping responses (e.g., does participating in

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the healing process reduce depression) or as mediators of other illness outcomes (e.g., does the reduction of depression result in longer survival).

Depression generally refers to affective states such as feeling blue, downhearted, sad, or discouraged. Although there are also somatic symptoms of depression (e.g., insomnia, low energy, anorexia), these may reflect disease states in addition to depression. Thus, it is preferable to refer specifically to the affect (see Plumb and Holland, 1977; Silberfarb, Maurer, and Crouthamel, 1980; and Ware, Johnston, Davies-Avery, et al, 1979).

Anxiety has also blen defined in terms of affect as well as somatic complaints. As in depression, it is preferable to assess anxiety in terms of affect so as not to confound it with symptoms of illness. Affective components of anxiety include nervousness, restlessness, tension, and jumpiness. Serious illness offers many possibilities for experiencing anxiety, such as medical treatments and procedures, threat of recurrence, not knowing what to expect, unfamiliar hospital surroundings, and financial concerns.

Anger and resentment may be felt by seriously ill people towards the doctor, family, and towards the world in general. Such anger may be generalized (i.e., over being ill and others being healthy) or specific to a variety of situations (e.g., being angry because surgical reconstruction did not fulfill their expectations).

Seriously ill people experience considerable guilt about being ill and needing help, being unable to perform usual roles, for somehow bringing the illness on themselves (e.g., by smoking, not exercising),

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and for being a burden to their family and friends.

Positive Mental States

Positive mental states generally include satisfaction with life, being happy, cheerful, pleased, excited, interested in something, or on top of the world (Bradburn, 1969; Ware, Johnston, Davies-Avery, et al, 1979).

Self-Concept

The maintenance of self-respect, self-esteem, a sense of worth, and self-expression are basic psychological needs that may be threatened by a serious illness. Thus, they provide valuable outcomes for assessing the effectiveness of coping responses.

In addition, a person's body image may be an important aspect of self-concept to evaluate, because many serious illnesses or treatments result in disfigurement (see Schwab and Hameling, 1968).

IV. HYPOTHESES

A number of hypotheses suggest themselves, as one thinks about these concepts of coping. One broad category of hypotheses has received a great deal of attention recently--whether coping responses that create positive emotions and mental states may enhance other outcomes (e.g., physical, physiological, survival). This idea is based on the premise that there is a mind-body link, that one's emotions and thoughts affect the physiological workings of the body. There is considerable evidence that this is true with respect to negative emotions and thoughts. For example, the perception of stress has been shown to increase the secretion of corticosteroids, which in turn inhibit the immune response (Totman, 1979). Feelings of helplessness and depression have been linked to adrenalin depletion (Seligman, 1975). Depressed patients are at greater risk of operative death (Kimball, 1968; see Krantz and Schulz, 1979). Sad emotions are believed to predispose a person to malignancies (Simonton and Simonton, 1975; LeShan, 1959). Anxiety and tension are related to shorter survival time in cancer patients (West, Blumberg, and Ellis, 1952; see LeShan, 1959). Depression has been shown to retard recovery from influenza (Imboden, Canter, and Cluff, 1961).

The idea that positive thoughts and emotions can be beneficial is more recent, and evidence of such effects is more anecdotal than empirical (Cousins, 1979; Frank, 1975; Jaffe, 1980; Moody, 1978; Pelletier, 1979; Simonton, Simonton, and Creighton, 1978). For example, Frank (1975), Jaffe (1980), and Cousins (1979) have suggested that

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positive mental states such as hope, faith, and laughter can enhance a person's recuperative powers, and as such are an integral part of the healing process.

This is an important hypothesis, because it may be a clue to the mechanism of how coping responses can influence illness outcomes. The following mechanism might be hypothesized: effective coping responses are those which enhance a person's positive emotions and outlook; these positive feelings enhance the person's immune system, which leads to reduced pain and symptoms or remission, allowing the person to function and survive.

An alternate and equally plausible hypothesis, however, is that the physiological, biological, and physical outcomes of the disease process influence one's emotions and outlook (i.e., that if one is feeling good, it is because the disease process has reversed itself). If this hypothesis is true, intervention to achieve positive emotions with the purpose of altering the course of illness would serve no purpose.

Another hypothesis might focus on feelings of control rather than on positive emotions. For example, it has been suggested that patients who take an active role in the healing process, i.e., share the responsibility for their recovery by mobilizing their own resources, may not only attain a higher quality of life but may even prolong their life (Simonton, Simonton, and Creighton, 1978; Jaffe, 1980; Pelletier, 1977).

The mechanism that might be hypothesized to explain this is that becoming an active participant in the healing process increases the patient's feelings of being in control, which may in turn positively affect the immune system.

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Virtually no longitudinal research has been conducted regarding these hypotheses. Although there are increasing numbers of self-help clinics and programs designed to involve the patient as an active participant in the healing process (see Jaffe, 1980; Fiore, 1979; Simonton, Simonton, and Creighton, 1978), none have been adequately evaluated. Such evaluation will not be an easy task, as these interventions are complex. For example, Simonton, Simonton, and Creighton (1978) simultaneously provide their patients with professional counseling, choices, encouragement to think about what they want out of life, visual imagery, relaxation, and a host of other interventions. Neverthless, sound research is possible if it is carefully designed. Some of the more obvious difficulties in evaluating the effects of coping are that one must be able to account for the effects of the nature of the illness, the type of treatment, and constitutional factors such as age and genetic makeup, all of which will have powerful effects on the outcomes studied above. Essentially, one would like to test an immense model that includes all of the context variables, coping responses, and outcomes, in addition to the nature of the illness, treatment, and constitutional factors. Clearly, this is impractical and methods must be devised to control for many of these while testing for others.

Because many of today's illnesses are ineffectively treated by medical care, it is important to consider the possibility that psychological interventions may have an effect on some of these illnesses.

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I. REFERENCES

- Aday, L. and Eichhorn, R. "The Utilization of Health Services: Indices and Correlates," DHEW Publication No. (HSM) 73-3003, U. S. Department of Health, Education, and Welfare, 1972.
- Angyal, A. <u>Foundations</u> for a <u>Science</u> of <u>Personality</u>, New York: The Commonwealth Fund, 1941.
- Antonovsky, A. <u>Health</u>, <u>Stress</u>, <u>and</u> <u>Coping</u>, San Francisco: Jossey-Bass, 1979.
- Averill, J. R. "Personal Control Over Aversive Stimuli and its Relationship to Stress," <u>Psychological Bulletin</u> 80:286-303, 1973.
- Brecher, H. K. "The Powerful Placebo," Journal of American Medical Association 159:1602-1606, 1955.
- Beisser, A. R. "Denial and Affirmation in Illness and Health," <u>American</u> <u>Journal of Psychiatry</u> 136:1026-1030, 1979.
- Benson, H. and Epstein, H. D. "The Placebo Effect: A Neglected Assec in the Care of Patients," <u>Journal of the American Medical Association</u>, 232, 1975.
- Benson, H. <u>The Relaxation Response</u>, New York: William Morrow and Company, 1975.
- Berkman, L. F. and Syme, L. "Social Networks, Host Resistance, and Mortality: A Nine-year Follow-up Study of Alameda County Residents," <u>American Journal of Epidemiology</u> 109:186-204, 1979.
- Bloom, S. W. and Wilson, R. N. "Patient-Practitioner Relationships," in H. E. Freeman, S. Levine and L. G. Reeder (Eds.) <u>Handbook of Medical</u> <u>Sociology</u>: <u>Third Edition</u>, Englewood Cliffs: Prentice Hall, Inc., 1979.
- Bloomfield, H. H., Cain, M. P. and Jaffe, D. T. <u>TM Discovering Inner</u> <u>Energy and Overcoming Stress</u>, New York: Delacorte Press, 1975.
- Blumberg, E. M., West, P. M., and Ellis, F. W. "A Possible Relationship between Psychological Factors and Human Cancer," <u>Psychosomatic</u> <u>Medicine</u> 16:277-286, 1954.
- Bradburn, N. M. <u>The Structure of Psychological Well-Being</u>, Chicago: Aldine Publishing Co., 1969.
- Brown, B. <u>Stress</u> and the <u>Art of Biofeedback</u>, New York: Harper & Row, 1977.

Brown, B. New Mind, New Body, New York: Harper & Row, 1975.

- Buck, R. W., Miller, R. E., and Caul, W. F. "Sex, Personality, and Physiological Variables in the Communication of Affect Via Facial Expression," Journal of Personality and Social Psychology 30:587-596, 1974.
- Caplan, G. <u>Principles of Preventive Psychiatry</u>, New York: Basic Books, 1964.
- Cassel, J. "The Contribution of the Social Environment to Host Resistance," <u>American Journal of Epidemiology</u>, 104:107-123, 1976.

Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K. et al. "Informed Consent--Why Are Its Goals Imperfectly Realized?" <u>The New England</u> Journal of Medicine, 302:896-900, 1980.

- Challes, D. "A New Voice for Medicine: The American Holistic Medical Association," <u>Holistic Health Review 3:111-120</u>, 1979.
- Chodoff, P. "Understanding and Management of the Chronically Ill Patient," <u>American Practicioner</u> 13:136-144, 1962.
- Cohen, F. and Lazarus, R. S. "Coping with the Stresses of Illness," in G. C. Stone, F. Cohen, N. Adler, & Associates (Eds.), <u>Health</u> Psychology, San Francisco: Jossey-Bass, 1979.
- Cousins, N. <u>Anatomy of an Illness</u>, New York: W. W. Norton & Company, 1979.
- Croog, S. H., Levine, S. and Lurie, Z. "The Heart Attack Patient and the Recovery Process," <u>Soc. Sci & Med</u>. 2:111-164, 1968.
- Derogatis, L. R., Abeloff, M. D., and Melisaratos, N. "Psychological Coping Mechanisms and Survival Time in Metastatic Breast Cancer," Journal of the American Medical Association 242:1504-1508, 1979.
- Derogatis, L. R. and Cleary, P. A. "Confirmation of the Dimensional Structure of the SCL-90: A Study in Construct Validation," <u>Journal of</u> Clinical Psychology 33:981-989, 1977.
- DiMatteo, M. R. "A Social Psychological Analysis of Physician-Patient Rapport: Toward a Science of the Art of Medicine," <u>The Journal of</u> Social Issues 35:12-33, 1979.
- Dohrenwind, B. S. and Dohrenwind, B. P. (Eds.) <u>Stressful Life Events</u>: <u>Their Nature and Effects</u>, New York: Wiley, 1974.
- Egbert, L. D., Battit, G. E., Welch, C. E., et al. "Reduction of Postoperative Pain by Encouragement and Instruction of Patients," <u>New</u> <u>England Journal of Medicine</u> 270:825-827, 1964.

- Engel, G. L. "A Life Setting Conducive to Illness: The Giving-Up Given-Up Complex," <u>Bulletin Menninger Clinic</u> 32:355-365, 1968.
- Engel, G. L. "Sudden and Rapid Death During Psychological Stress," <u>Annals of Internal Medicine</u> 74:771-782, 1971.
- Engel, G. L. "The Biopsychosocial Model and the Education of Health Professionals," <u>General Hospital Psychiatry</u>, 1979.
- Fiore, N. "Fighting Cancer-One Patient's Perspective," <u>The New England</u> Journal of <u>Medicine</u> 300:284-289, 1979.
- Fox, B. H. "Premorbid Psychological Factors as Related to Cancer Incidence," Journal of Behavioral Medicine 1:45-133, 1978.
- Frank, J. D. "The Faith That Heals," Johns Hopkins Medical Journal 137:127-131, 1975.
- Frankl, V. E. <u>Man's Search for Meaning: An Introduction to Logotherapy</u>, New York: Washington Square Press, 1963.
- Gates, C. C. "The Emotional Impact of Mastectomy--the Self-Esteem Process," Confidential working paper, Peter Bent Brigham Hospital, September 1974.

t

- Goldstein, M. "Individual Differences in Response to Stress," <u>American</u> Journal of Community Psychology 2:113-137, 1973.
- Greer, S., Morris, T., and Pettingale, K. W. "Psychological Response to Breast Cancer: Effect on Outcome," The Lancet, October 13, 1979.
- Hackett, T. P. and Cassem, N. H. "Development of a Quantitative Rating Scale to Assess Denial," <u>Journal of Psychosomatic Research</u> 18:93-100, 1974.
- Hamburg, D. A., and Adams, J. E. "A Perspective on Coping Behavior," <u>Archives General Psychiatry</u>, 17:277-284, 1967.
- Higgins, A. and Pooler, W. "MI and Subsequent Reemployment in Syracuse New York," <u>Amer J. Pub. Health</u> 58:312, 1968.
- Holden, C. "Behavioral Medicine: An Emergent Field," <u>Science</u>, 209:479-481, 1980.
- Horwitz, N. "Post-Op Patients Forget, Fabricate, Even Deny Having Consent Talks," <u>Hospital Tribune</u>, March 22, 1976, pp. 1, 17,
- Howard, J. and Strauss, A. (Eds.) <u>Humanizing Health Care</u>, New York: John Wiley and Sons, 1975.
- Hutschnecker, A. A. The <u>Will to Live</u>, Englewood Cliffs: Prentice-Hall, Inc., 1951.

Imboden, J. B., Canter, A., and Cluff, L. E. "Convalescence from Influenza," Archives of Internal Medicine 108:115-121, 1961.

Jacobson, E. Progressive Relaxation, University of Chicago Press, 1938.

Jaffe, D. T. Healing from Within, New York: Alfred A. Knopf, 1980.

Jamison, K. R., Wellisch, D. K., and Pasnau, R. O. "Psychosocial Aspects of Mastectomy: 1. The Woman's Perspective," <u>American Journal</u> of <u>Psychiatry</u> 135:432-436, 1978.

Janis, I. <u>Psychological Stress</u>: <u>Psychoanalytic and Behavioral Studies</u> of Surgical Patients, New York: John Wiley and Sons Inc., 1958.

Jarvinen, K. A. J. "Can Ward Rounds be a Danger to Patients with Myocardial Infarction?," British Medical Journal 1:318-320, 1955.

Johnson, J. E. "Stress Reduction Through Sensation Information," in Sarason, I. G. and Spielberger, C. D. (Eds.) <u>Stress</u> and <u>Anxiety</u>, Vol. 2, Washington, D.C.: Hemisphere, 1975.

- Jourard, S. M. <u>The Transparent Self</u>, New York: D. Van Nostrand Co., 1971.
- Kaplan, B. H., Cassel, J. C., and Gore, S. "Social Support and Health," Medical Care 15 (Supplement):47-68, 1977.

Kasl, S. V. and Cobb, S. "Health Behavior, Illness Behavior, and Sick Role Behavior," <u>Arch. Environ. Health</u> 12:246-266, 1966.

Katz, J. L. et al. "Psychoendocrine Aspects of Cancer in the Breast," <u>Psychosomatic Medicine</u> 32:1-18, 1970.

Kimball, C. P. "The Experience of Open-Heart Surgery: Psychological Responses to Surgery," <u>Psychosomatic Medicine</u>, 30:552, 1968.

Kissen, D. M., Brown, R. I. F., and Kissen, M. "A Further Report on Personality and Psychosocial Factors in Lung Cancer," <u>Annals of N.Y.</u> <u>Academy of Sciences</u> 164:534-545, 1969.

Kobasa, S. C. "Stressful Life Events, Personality, and Health: An Inquiry Into Hardiness," Journal of Personality and Social Psychology 37:1-11, 1979.

Kolata, G. "Texas Counselors Use Psychology in Cancer Therapy," Smithsonian 11:49-56, 1980.

Krantz, D. S., and Schulz, R. "Life Crisis, Control, and Health Outcomes: A Model Applied to Cardiac Rehabilitation and Relocation of the Elderly," in A. Baum and J. E. Singer (Eds.), <u>Advances in</u> <u>Environmental Psychology</u>, <u>Vol. 2</u>, Hillsdale, New Jersey: L. Erlbaum Associates, 1979. Krasnoff, A. "Psychological Variables and Human Cancer: A Crossvalidation Study," <u>Psychosomatic Medicine</u> 21:291-295, 1959.

ļ

Kroger, W. S. <u>Clinical and Experimental Hypnosis</u>, <u>Second Edition</u>, Philadelphia: J. B. Lippincott Co., 1977.

Kushner, R. Why Me?, New York: Harcourt, Brace Jovanovich, 1977.

- Langer, E. and Rodin, J. "The Effects of Choice and Enhanced Personal Responsibility for the Aged: A Field Experiment in an Institutional Setting," <u>Journal of Personality and Social Psychology</u> 34:191-198, 1976.
- Langner, T. and Michael, S. <u>Life Stress and Mental Health</u>, New York: Free Press, 1960.
- Lau, R. R. "The Origins of Health Locus of Control Beliefs," <u>Journal of</u> <u>Personality and Social Psychology</u>, in press.
- Lau, R. R. and Ware, J. E. "Refinements in the Measurement of Health-Specific Locus of Control Dimensions," <u>Medical Care</u> (in press).
- Lazarus, R. S. "Cognitive and Coping Processes in Emotion," in B. Weiner (Ed.) <u>Cognitive Views of Human Motivation</u>, New York: Academic Press, 1974.
- Lazarus, R. S. "Positive Denial: The Case for Not Facing Reality," <u>Psychology Today</u>, pp. 44-60, November 1979.
- Lazarus, R. S. <u>Psychological Stress</u> and the <u>Coping Process</u>, New York: McGraw-Hill, 1966.
- Lazarus, R. S. and Launier, R. "Stress-Related Transactions Between Person and Environment," in L. A. Pervin and M. Lewis (Eds.) <u>Perspectives in Interactional Psychology</u>, New York: Plenum Press, 1978.
- Lefcourt, H. M. Locus of Control, Current Trends in Theory and Research, New York: John Wiley & Sons, 1976.
- LeShan, L. "Psychological States as Factors in the Development of Malignant Disease: A Critical Review," <u>Journal of the National Cancer</u> <u>Institute</u> 22:1-18, 1959.

LeShan, L. How to Meditate, New York: Bantam Books, 1976.

Lin, N., Simeone, R. S., Ensel, W. M., et al. "Social Support, Stressful Life Events, and Illness: A Model and an Empirical Test," <u>Journal</u> of <u>Health and Social Behavior</u> 20:108-119, 1979.

Linn, L. S., Ware, J. E. Jr., and Greenfield, S. "Factors Associated with Relief from Chest Pain Following Emergency Care," <u>Medical Care</u> 18:624-634, 1980.

- Lipowski, Z. J. "Physical Illness, the Individual and the Coping Process," <u>Psychiatry in Medicine</u> 1:91-102, 1970.
- Lipowski, Z. J. "Psychosocial Aspects of Disease," <u>Annals of Internal</u> <u>Medicine</u>, 71:1197-1206, 1969.

Lynch, J. J., Thomas, S. A., Mills, M. E., et al. "The Effects of Human Contact on Cardiac Arrhythmia in Coronary Care Patients," <u>Journal of</u> <u>Nervous and Mental Disease</u> 158:88-99, 1974.

McDougall, W. "A New Theory of Laughter," Psyche 2:298-300, 1922.

McIntosh, J. "Processes of Communication, Information Seeking, and Control Associated with Cancer: A Selective Review of the Literature," <u>Social Science and Medicine</u> 8:167-187, 1974.

Mechanic, D. Medical Sociology, New York: Free Press, 1968.

Mechanic, D. "The Stability of Health and Illness Behavior: Results From a 16-year Follow-up," <u>American Journal of Public Health</u> 69:1142-1145, 1979.

t

Meyerowitz, B. E. "Psychosocial Correlates of Breast Cancer and Its Treatments," <u>Psychological Bulletin</u> 87:108-131, 1980.

- Mills, R. T. and Krantz, D. S. "Information, Choice, and Reactions to Stress: A Field Experiment in a Blood Bank with Laboratory Analogue," Journal of Personality and Social Psychology 37:608-620, 1979.
- Monat, A. and Lazarus, R. S. (Eds.) <u>Stress</u> and <u>Coping</u>: <u>An Anthology</u>, New York: Columbia University Press, 1977.
- Moody, R. A. Laugh After Laugh: The Healing Power of Humor, Jacksonville, Florida: Headwaters Press, 1978.
- Moos, R. H. and Solomon, G. F. "Personality Correlates of the Degree of Functional Incapacity of Patients with Physical Disease," <u>Journal of</u> <u>Chron. Disease</u> 18:1019-1038, 1965.

Moos, R. H. and Tsu, V. D. "The Crisis of Physical Illness: An Overview," in R. H. Moos (Ed.), <u>Coping with Physical Illness</u>, New York: Plenum Medical Book Co., 1979.

Moos, R. H. (Ed.) <u>Coping with Physical Illness</u>, New York: Plenum Medical Book Co., 1979.

Moos, R. H. (Ed.) Human Adaptation: Coping with Life Crises, 1976.

Notarius, C. I. and Levenson, R. W. "Expressive Tendencies and Physiological Response to Stress," Journal of Personality and Social

-64-

Psychology 37:1204-1210, 1979.

- Nunnally, J. C. <u>Psychometric Theory: Second Edition</u>, New York: McGraw-Hill, 1978.
- O'Regan, B. and Carlson, R. J. "Defining Health: The State of the Art," <u>Holistic Health Review</u>, 3:86-102, 1979.

Parsons, T. The Social System, New York: Free Press, 1951.

- Pearlin, L. I., and Schooler, C. "The Structure of Coping," <u>Journal of</u> <u>Health and Social Behavior</u> 19:2-21, 1978.
- Pelletier, K. R. Holistic Medicine, New York: Delacorte Press, 1979.
- Pelletier, K. <u>Mind as Healer</u>, <u>Mind as Slayer</u>, New York: Delacorte Press, 1977.
- Porritt, D. "Social Support in Crisis: Quantity or Quality?" Soc. Sci. & Med. 13A:715-721, 1979.
- Ravitch, M. M. "Informed Consent--Descent to Absurdity," <u>Resident and</u> <u>Staff Physician</u>, 1974, 20:10s-20s.
- Rosenberg, M. <u>Society</u> and the <u>Adolescent</u> <u>Self-Image</u>, Princeton: Princeton University Press, 1965.
- Rosenthal, R. <u>Experimenter Effects in Behavioral Research</u>, New York Appleton-Century-Crofts, 1966.
- Rotter, J. B., Seeman, M., and Liverant, S. "Internal vs. External Locus of Control of Reinforcement: A Major Variable in Behavior Theory," in N. F. Washburne (Ed.), <u>Decisions</u>, <u>Values</u>, and <u>Groups</u>, London: Pergamon, 1962.
- Ryan, C. and Ryan, K. M. <u>A Private Battle</u>, New York: Simon and Schuster, 1979.
- Scarf, M. "Images that Heal: A Doubtful Idea Whose Time Has Come," Psychology Today, 14:33-46, 1980.
- Schacter, S. <u>Psychology of Affiliation</u>, Palo Alto: Stanford University Press, 1959.
- Schmale, A. H. "Giving Up as a Final Common Pathway to Changes in Health," <u>Advances in Psychosomatic Medicine</u> 8:20-40, 1972.
- Schmale, A. H., and Iker, H. P. "Hopelessness as a Predictor of Cervical Cancer," <u>Social Science</u> and <u>Medicine</u>, 5:95-100, 1971.
- Schultz, J. H. and Luthe, W. <u>Autogenic Therapy</u>, 6 vols. New York: Grune and Stratton, 1969.

- Schulz, R. "Effects of Control and Predictability on the Physical and Psychological Well-Being of the Institutionalized Aged," <u>Journal of</u> <u>Personality and Social Psychology</u> 33:563-573, 1976.
- Schwab, J. J. and Hameling, J. "Body Image and Medical Illness," <u>Psychosomatic Medicine</u>, 30:51-71, 1968.
- Seligman, M. E. P. <u>Helplessness: On Depression</u>, <u>Development</u>, <u>and Death</u>, San Francisco: W. H. Freeman and Co., 1975.

Selye, H. The Stress of Life, New York: McGraw-Hill, 1956.

- Shipley, R. H., Butt, J. H., and Horwitz, E. A. "Preparation to Reexperience a Stressful Medical Examination: Effect of Repetitious Videotape Exposure and Coping Style," <u>Journal of Consulting and</u> <u>Clinical Psychology</u> 47:485-492, 1979.
- Simonton, O. C. Matthews-Simonton, S., and Creighton, J. <u>Getting Well</u> Again, Los Angeles: J. P. Tarcher, Inc., 1978.
- Simonton, O. C. and Simonton, S. S. "Belief Systems and Management of the Emotional Aspects of Malignancy," <u>Journal of Transpersonal</u> <u>Psychology</u> 7:29-47, 1975.
- Stavraky, K. M. et al. "Psychological Factors in the Outcome of Human Cancer," Journal of Psychosomatic Research 12:251-259, 1968.
- Stewart, A. L., Ware, J. E., and Brook, R. H. "The Conceptualization and Measurement of Health for Adults in the Health Insurance Study, Vol. II: Physical Health," The Rand Corporation, R-1987/2-HEW, July 1978.
- Straus, A. L. and Glaser, B. G. <u>Chronic Illness and the Quality of Life</u>, St. Louis: The C. V. Mosby Company, 1975.
- Sweeney, D. R., Tinling, D. C., and Schmale, A. H. "Differentiation of the Giving-up Affects--Helplessness and Hopelessness," <u>Archives of General Psychiatry</u> 23:378-382, 1970.
- Taylor, S. E. "Hospital Patient Behavior: Reactance, Helplessness, or Control?" Journal of Social Issues 35:156-184, 1979.
- Taylor, S. E. and Levin, S. "The Psychological Impact of Breast Cancer: A Review of Theory and Research," San Francisco: West Coast Cancer Foundation, 1976.

Totman, R. Social Causes of Illness, New York: Pantheum, 1979.

Tourangeau, R. and Ellsworth, P. C. "The Role of Facial Response in the Experience of Emotion," Journal of Personality and Social Psychology 37:1519-1531, 1979.

- U.S.D.H.H.S. <u>Coping with Cancer</u>: <u>A Resource for the Health</u> <u>Professional</u>, NIH Publication No. 80-2080, Bethesda, Maryland, 1980.
- Videka, L. M. "Psychosocial Adaptations in a Medical Self-Help Group," in M. L. Lieberman, L. D. Borman and Associates (Eds.), <u>Self-Help</u> <u>Groups for Coping with Crisis</u>, San Francisco: Jossey-Bass, 1979.
- Visotsky, H. M., Hamburg, D. A., Goss, M. E., et al. "Coping Behavior Under Extreme Stress," <u>Archives of General Psychiatry</u> 5:423-448, 1961.
- Wallston, B. S., Wallston, K. A., Kaplan, G. D., et al. "Development and Validation of the Health Locus of Control (HLC) Scale," <u>Journal of</u> <u>Consulting and Clinical Psychology</u> 44:580-585, 1976.
- Walsh, J. J. Laughter and Health, New York: D. Appleton and Co., 1928.
- Ware, J. E., Johnston, S. and Davies-Avery, A. "The Conceptualization and Measurement of Health for Adults in the Health Insurance Study, Vol. III: Mental Health," The Rand Corporation, R-1987/3-HEW, December 1979.
- <u>Webster's New Collegiate</u> <u>Dictionary</u>, Springfield, Massachusetts: G&C Merriam Co., 1975.
- Weisman, A. D., and Worden, J. W. "The Existential Plight in Cancer: Significance of the First 100 Days," <u>International</u> <u>Journal</u> of <u>Psychiatry in Medicine</u>, 7:1-15, 1976.

Weisman, A. Coping with Cancer, New York: McGraw-Hill, 1979.

- West, P. M., Blumberg, E. M., and Ellis, F. W. "An Observed Correlation between Psychological Factors and Growth Rate of Cancer in Man," Cancer Research, 12:306-307, 1952.
- White, R. W. "Strategies of Adaptation: An Attempt at Systematic Description," in Coelho, G. V., Hamburg, D. A. and Adams, J. E. (Eds.), <u>Coping and Adaptation</u>, New York: Basic Books, Inc., 1974.
- Wolf, S. "The End of the Rope: The Role of the Brain in Cardiac Death," <u>Canad</u>. <u>Med</u>. <u>Ass</u>. J. 97:1022-1025, 1967.
- Wolff, C. T., Friedman, W. B., Hofer, M. A., et al. "Relationships Between Psychological Defenses and Mean Urinary 17-Hydroxycorticosteroid Excretion Rates," <u>Psychosomatic Medicine</u> 26:576-591, 1964.
- Wortman, C. B. and Dunkel-Schetter, C. "Interpersonal Relationships and Cancer: A Theoretical Analysis," <u>Journal of Social Issues</u>, 35:120-155, 1979.
- Yager, J. and Robinson, J. "Stress and Coping in Illness," unpublished draft.

Yahn, G. "The Impact of Holistic Medicine, Medical Groups, and Health Concepts," <u>Journal of the American Medical Association</u>, 242:2202-2205, 1979.

Yalom, I. D. and Greaves, C. "Group Therapy with the Terminally Ill," Am. J. <u>Psychiatry</u> 134:396-400, 1977.

