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SYMPTOMATOLOGY,
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by

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To my loving family and friends:

you know who are, you know what this took to accomplish,

you kept on believing, and never stopped giving.

No gift bestowed upon one person by another is more precious.

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ABSTRACT

The purpose of this study was to examine the effects of perceived symptom transition and problematic symptoms on uncertainty, hope, and state anxiety in Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). Also of interest was the possible mediating effects of uncertainty and hope on state anxiety in this chronically ill population. Further psychometric evaluation of two new symptom-related measures was also performed.

The sample consisted of 124 patients with CFIDS who were recruited from physicians' practices in three western states. The mean age of this predominantly white, female sample of married college graduates was 40. Ninety-two percent worked before becoming ill, with 82% working 40 or more hours a week. Subjects reported a significant decrease in the number of hours they have been able to work since becoming ill.

Symptom-related measures used in this cross-sectional mail survey included the De Groot Perceived Symptom Transition Scale, a new 12-item scale designed to assess the degree to which illness symptoms are perceived to be in a state of change, and the De Groot Chronic Fatigue Syndrome Symptom Scale, a 56-item symptom inventory that also serves as a measure of how problematic CFIDS-specific symptoms are perceived to be. Initial support for the reliability and construct validity of these two scales was demonstrated in this study. Other measures included the Mishel Uncertainty in Illness Scale, the Beck Hopelessness Scale, and the State-Trait Anxiety Inventory. Correlation, multiple regression, and path analytic procedures were used to analyze the study data.

Perceived symptom transition was found to explain significant variance in state anxiety, uncertainty, and hopelessness in this sample. Problematic symptoms were significantly associated with uncertainty and hopelessness, while uncertainty and hopelessness explained significant variance in state anxiety. No differential effect of hopelessness and uncertainty on anxiety was found.

Path analysis demonstrated significant direct and indirect effects of perceived symptom transition on state anxiety, as well as direct effects on uncertainty and hopelessness. Problematic symptoms exerted direct effects only on uncertainty and hopelessness. Perceived symptom transition and hopelessness emerged as the only significant predictors of state anxiety in the path model.

Study findings suggest the importance of symptom-related perceptions and appraisal in determining stress-associated responses to the illness situation. Further study is required to determine if the proposed theoretical model obtains across illness types, among samples, and over time.

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CHAPTER 1

THE STUDY PROBLEM

Chronic illness is the number one health problem in the United States today. It is estimated that 50% of the population has one or more chronic conditions, with 23 million of these individuals experiencing major activity limitations (Bracht, 1979). One fourth of those with limited activity are so severely affected by their condition that they are unable to work, go to school, keep house, cook, or perform other customary activities associated with their particular age group (National Center for Health Statistics, 1978). The victory over the scourge of infectious diseases in the first half of this century has rightfully shifted attention to the staggering physical, psychological, social, spiritual, and economic toll of chronic illness. By their intrusive and generally unremitting nature, chronic illnesses can threaten one's very existence, well-being, belief structure, emotional state, socio-economic status, and primary relationships.

Coping With Chronic Illness

Coping with chronic illness has been viewed by many as a set of adaptive tasks, problem potentials, or crises to be managed on an on-going basis (Cohen & Lazarus, 1979; Hamburg, 1974; Moos & Tsu, 1977; Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczec, & Wiener, 1984). These adaptive tasks reflect the various bio-psycho-social demands of chronic illness, and include managing symptom distress (Hamburg, 1974; Strauss et al., 1984), preserving emotional balance (Cohen & Lazarus, 1979; Moos & Tsu, 1977) and preparing for an uncertain future (Mages & Mendelsohn, 1979; Moos & Tsu, 1979; Nerenz & Leventhal, 1983; Sanders & Kardinal, 1984; Strauss et al., 1984; Wiener, 1977). As such, these adaptive tasks, problems, or crises constitute major sources of stress for the chronically ill who must manage these demands on a daily basis. Stress in chronic illness has been associated with undesirable effects or outcomes such as poor psycho-social adjustment (Foxall, Ekberg & Griffith, 1985; Mishel, Hostetter, King, & Graham, 1984), anxiety, depression, and helplessness (Bukberg, Penman & Holland, 1984; Feldman, 1974; Westbrook & Viney, 1982), mood disturbance (McCorkle & Benoliel, 1983) and hopelessness (Mishel, Hostetter, King & Graham, 1984). Since stress in healthy individuals has been implicated in physical illness (Rabkin & Streuning, 1976; Suls & Mullen, 1981) as well as lowered immune system functioning (Locke, 1984; Miller, 1986), the added impact of stress on those with already compromised health may be considerable.

Cognitive Appraisal

The central mediating role of cognitive appraisal in determining the stressfulness of a particular situation and what a person's response will be has been well explicated (Lazarus, 1966; Lazarus & Folkman, 1984; Lazarus & Launier, 1978). Cognitive appraisal is an on-going evaluative process focused on the meaning or significance of a given situation. Not all chronic illness situations are uniformly appraised as stressful across or within individuals. Cognitive appraisal is a situation- and context-bound process affected by various person and situation factors. In their review of major person variables relevant to stressful appraisals, Lazarus and Folkman (1984) include commitments and beliefs. Commitments reflect an individual's choices, values and goals in life, and serve to motivate behavior. Beliefs frame an individual's perceptual set, shaping his/her views of reality. Examples include beliefs about personal control and existential beliefs, such as faith in God, which foster the maintenance of hope. Situational variables relevant to stressful appraisals include novelty, predictability, event uncertainty, and such temporally related factors as imminence, duration, and temporal uncertainty (Lazarus & Folkman, 1984). Situational ambiguity and the timing of the stressful event or situation in relation to other life span development issues also affect whether that situation or event is appraised as stressful.

Growing awareness of the unceasing and often unpredictable demands of chronic illness has spawned scientific and theoretical interest in the antecedent, mediating, and consequential correlates of stress and coping in chronic illness situations. The majority of these studies have focused on major intrapersonal coping-related variables such as age, personality, intelligence, self-care skills, values, beliefs, emotional states, and cognitive capacity (Lipowski, 1970). However, important stress-related situational variables have remained unstudied or have just begun to be explored.

Uncertainty

Uncertainty has long been considered a major stressor in chronic illness (Davis, 1960; Fox, 1957; Mages & Mendelsohn, 1979), yet systematic research into this phenomenon is relatively recent (Christman, McConnell, Pfeiffer, Webster, Schmitt, & Ries, 1988; Mishel, 1981; Viney & Westbrook, 1981; Yarcheski, 1988). Little is known about the antecedents of uncertainty, potential mediating relationships with close conceptual companions such as hope, and the stress-related outcomes of uncertainty, such as anxiety. Although an individual's appraisal of symptom pattern and the changing nature of illness symptoms have been repeatedly cited as sources of both uncertainty and stress in chronic illness (Cohen & Lazarus, 1979; Mishel & Braden, 1988; Moos & Tsu, 1977; Strauss et al., 1984), the effects of these important illness-related variables remain obscure. This is due, in part, to the lack of valid and reliable measures which are sensitive to illness-specific symptoms, yet generalizable across illness types. The identification of situation characteristics that predict stress appraisals and the variables which may moderate their effect is an important step in understanding stress and coping-related chronic illness phenomena.

This study is designed to bridge existing knowledge gaps by addressing two new illness-related conceptualizations and scales involving symptom transition, or the degree to which illness symptoms are perceived to be fluctuating or changing, and problematic symptoms, or how troublesome or difficult illness-specific symptoms are appraised for the individual. The influence of these variables on the stress-related dependent variable of anxiety will be examined, and their effects on hope and uncertainty will be explored. The population selected for study are adult patients with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS; also known as Chronic Fatigue Syndrome). This rather elusive syndrome has been known by various names over the past fifty years, including such monikers as: Icelandic Disease, Benign Myalgic Encephalomyelitis, Chronic Epstein Barr Virus, Chronic Mononucleosis, and the "Yuppie Flu".

Chronic Fatigue Immune Dysfunction Syndrome

This syndrome is characterized by the sudden onset of persistent yet variable mononucleosis-like symptoms, including dramatic, debilitating fatigue that worsens with exercise and does not resolve with rest, mild fever, sore throat, lymph enlargement and pain, joint and muscle pain, gastrointestinal symptoms, cardiovascular disturbances, sleep disorders, mood disturbances, and a variety of cognitive impairments. Unlike mononucleosis, these symptoms never appear to resolve, wreaking havoc with an individual's ability to function. Half of those afflicted with CFIDS become periodically bedridden (Buchwald, Sullivan, & Komaroff, 1987). Although various viral mechanisms and immunological dysfunctions have been implicated in CFIDS (Behan, Behan, & Bell, 1985; Berris, 1986; Jones et al., 1984; Strauss et al., 1985; Tobi, 1982), no definitive cause, cure, or treatment has been identified. Because a working case definition has been only recently adopted by the Centers for Disease Control (Holmes et al., 1988), the actual prevalence of Chronic Fatigue Immune Dysfunction Syndrome is unknown. However, some studies have suggested prevalence rates as high as 21% in general patient populations (Buchwald, Sullivan, & Komaroff, 1987).

The natural history and long-term implications of CFIDS are also unknown, although there is evidence of periodic, temporary remissions in some patients, and symptom persistence or worsening in others (DuBois, Seeley, & Brus, 1984). Since CFIDS may have predilection for female 25-45 year olds who are at a highly active and productive stage of life, the potential physical, emotional, social, and economic toll of this syndrome is enormous. Uncertainty surrounds every aspect of this puzzling syndrome, from its cause, treatment, cure, and long-term effects, to what its proper name should be. What does appear certain however, is that the syndrome is very real (DuBois et al., 1984; Komaroff, 1987), and that it poses an often sudden, dramatic, and enduring threat to the health and well-being of its victims.

This study will examine the effects of problematic symptoms and symptom transition on uncertainty, hope, and anxiety in patients with Chronic Fatigue Immune Dysfunction Syndrome. Of particular interest are the possible mediating effects of uncertainty and hope on anxiety in this chronically ill population. In addition, further psychometric evaluation of the De Groot Perceived Symptom Transition Scale (DPSTS) and the De Groot Chronic Fatigue Syndrome Symptom (DCFSS) Scale will be performed. The specific aims of this study are:

1. To examine the relationships among uncertainty, hope, and anxiety in patients with CFIDS.
2. To examine the influence of perceived symptom transition and perceived problematic symptoms on uncertainty and hope in patients with CFIDS.
3. To examine the effects of perceived symptom transition as well as perceived problematic symptoms on anxiety in patients with CFIDS.
4. To assess further the validity and reliability of the De Groot Perceived Symptom Transition Scale and the De Groot Chronic Fatigue Syndrome Symptom Scale.

The ultimate significance of this study rests in its potential contribution to: 1) an understanding of the role of symptom transition and perceptions of problematic symptoms as they affect stress-related outcomes in a chronic illness situation; 2) knowledge about the stress-buffering effects of hope and uncertainty in a chronic illness situation; 3) systematic description of illness-related variables in a chronic illness which is poorly understood and not systematically studied; and 4) the refinement of valid and reliable instruments for future study of CFIDS in particular, and chronic illness in general.

CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

This chapter begins by advancing a theoretical framework for viewing stress and coping in general. This perspective provides the foundation for the subsequent discussion of stress and coping in chronic illness. Once the question of "coping with what" is answered for chronic illness situations, attention is directed to a discussion of major study concepts.

Uncertainty in chronic illness is the major organizing concept for this study. A discussion of characteristics of uncertainty will be followed by a presentation of various definitions of uncertainty. A definition of uncertainty in chronic illness will then be examined. Sources of uncertainty in chronic illness will be reviewed, and five dimensions of uncertainty in chronic illness will be proposed. A synthesis of specific source content for uncertainty in chronic illness will be presented as the rationale for the selection of other study variables.

The sections that follow will discuss other important uncertainty-related concepts relevant to this study, including hope and symptomatology. In addition, proposed theoretical mechanisms related to the etiology of Chronic Fatigue Immune Dysfunction Syndrome will be examined, CFIDS symptomatology will be explored, and symptom measurement in CFIDS will be addressed. Each section will be summarized, relating the discussion to the overall aims and purposes of this study. Relevant literature related to these concepts or the population under study will be included.

Stress and Coping

Certain relevant assumptions guide the adoption of the transactional view of stress and coping as espoused by Lazarus and his colleagues (Lazarus, 1966, 1977; Lazarus & Folkman, 1984; Lazarus & Launier, 1978). Among these are the belief that human beings are unique bio-psycho-social-spiritual beings who are in constant, mutual interaction (transaction) with their environment. In addition, the way a person thinks, feels, or acts is a product of these person/situation transactions. It is also assumed that some level of cognition (whether conscious, unconscious, or pre-conscious) is involved in guiding and interpreting every person/environment interchange, and that emotions are a product of cognitive activity. Although some person/environment transactions are perceived as stressful, stress and responses to it are not always pathological or inherently negative. Psychological stress is viewed as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (Lazarus & Folkman, 1984, p. 21). Psychological stress gives rise to responses which individuals attempt to manage in various ways, although "successful" management in one domain (i.e., psychological) may result in consequences in another domain (i.e., physiological). Thus, coping efforts aimed at managing these stressful situations are not, in themselves, inherently good or bad. The success of particular coping efforts can be evaluated only by their relative effects on bio-psycho-social functioning or somatic health.

Fundamental to Lazarus' transactional perspective is the central mediating role that cognitive appraisal plays in determining whether or not a situation will be perceived as stressful and what the individual's response will be. The ongoing process of cognitive appraisal is evaluative in nature, focusing on the meaning or significance of a situation or event.

Lazarus and his colleagues distinguish between two major types of appraisal, each relating to a major evaluative issue. Primary appraisal judges the significance of a transaction for a person's well-being, asking "what's at stake here -- am I in trouble or being benefitted, now or in the future, and in what way?" A situation can be appraised as: 1) irrelevant; 2) benign-positive; and/or 3) stressful. If a transaction carries no personal investment or implication for well-being, it will be appraised as irrelevant. A benign-positive appraisal is made when the outcome, significance, or meaning of the encounter is construed as positive. As mentioned earlier, stressful appraisals occur in situations that are felt to tax or exceed one's resources and endanger well-being.

Three types of stressful appraisals are possible. Harm-loss is appraised when some injury or damage has already occurred, while threat implies anticipated or potential harm. Challenge appraisals focus on the potential for growth or gain in an encounter, and are characterized by excitement, eagerness, and other related emotions. These categories of stressful appraisals are not mutually exclusive and may occur simultaneously during a given transaction.

Secondary appraisal seeks to evaluate appropriate resources and actions by asking what can be done about a situation. Like primary appraisal, secondary appraisals may be conscious, unconscious, or on the fringe of consciousness (Cohen & Lazarus, 1979). Bemoaning the unfortunate and inaccurate use of the terms "primary" and "secondary" in relation to appraisals, Lazarus and Folkman (1984) point out that primary appraisal is not inherently more important than secondary appraisal and that primary appraisal does not necessarily precede secondary appraisal in time. Primary and secondary appraisals can occur simultaneously, and together they shape the degree of psychological stress perceived and the quality and strength of the resulting emotional reaction.

The appraisal process is continuous, involving on-going reappraisals based on new or revised information. For example, if the coping strategy employed is successful, an appraisal initially judged as stressful might well be reappraised as irrelevant or benign/positive. Appraisals are influenced by such person factors as commitments and beliefs as well as situation factors such as novelty, predictability, event uncertainty, ambiguity, and temporal factors (Lazarus & Folkman, 1984).

The transactional theoretical model advanced by Lazarus and Folkman (1984) considers coping as "constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person" (p. 14).

This process-oriented definition of coping is distinguished from routinized automatic adaptive behavior such as wearing seat belts, and includes any efforts that a person undertakes in a stressful situation, no matter how successful the efforts are. This perspective does not insist that a person entirely overcome a situation as in the case of hierarchical coping definitions that equate adequate coping with mastery. Examples of such hierarchical, mastery related conceptions include Haan's (1977) ego process taxonomy, Shapiro's (1965) neurotic coping styles, or White's (1974) notions of coping, defense, and mastery.

Five major coping modes have been described: 1) information seeking; 2) direct action; 3) inhibition of action; 4) intrapsychic coping; and 5) turning to others for support (Lazarus & Folkman, 1984). These coping modes are non-hierarchical in nature, with none assuming superiority over the others. Lazarus and Folkman further identify two functions of coping. *Problem-focused* coping is directed at managing the stressful problem or situation, while *emotion-focused* coping is aimed altering or regulating the emotional response associated with it. Each of the five coping modes can serve problem-focused or emotion-focused functions.

In addition to these coping modes and functions, Lazarus and Folkman identify major categories of coping resources which influence the types of strategies chosen. Personal coping resources include health and energy, positive beliefs, problem solving ability and social skills, social support, and material resources. Extrapersonal or environmental resources are considered to be both social and material in nature. Actual coping strategies and the resources they draw upon in an encounter are variable, depending upon the individual situation. In this way, coping is viewed as a context-bound process consisting of what a person actually does in a given situation and how those actions change over time.

The actual choice of coping strategy depends on such factors as the degree of uncertainty, presence of conflict, and degree of helplessness (Lazarus & Launier, 1978). Coping processes are viewed as having an overall effect on morale, social functioning, and somatic health, the bio-psycho-social indices of adaptation. Because of the non-hierarchical nature of specific coping efforts, judging the adaptation of coping becomes a question of values, temporal considerations, and situational context. For example, some coping strategies such as denial may be adaptive for short-term use, but may appear maladaptive over time if it prevents an individual from seeking care for a serious health problem.

Lazarus' model of stress and coping emphasizes the central mediating role of cognition in the appraisal process and underscores the context-bound nature of stress appraisals. This suggests that an individual's appraisal of a particular situation is the most important determinant of how stressful the situation is perceived to be and what action might be taken to manage the situation. This theoretical perspective also asserts that if an individual's perception of a situation changes, the individual may reappraise the situation and respond in a different way. This changed perception may be the result of earlier coping efforts or due to some altered aspect of the situation. Although the appraisal process may seem inherently circular, it has been asserted that the remedy is to specify from theory the predicted antecedents, mediators, and consequences of the process, and demonstrate their effects through research (Lazarus & Folkman, 1984).

The transactional stress/coping perspective also posits that certain features of a given situation may influence appraisal more than others, and that these may change from situation to situation. For example, the situational factor of novelty may be appraised as positive by an individual who is attending her first cheese tasting party at a friend's house. However, if this same individual, who also has CFIDS, suddenly cannot remember how to get home and has never experienced such a memory lapse before, the novelty of the situation is likely to be appraised as highly stressful and anxiety-producing. Lazarus and Folkman (1984) observe that specifying the antecedent person and environment factors and their effect on emotional consequences is a necessary step toward the development of predictive theory.

Stress and Coping in Chronic Illness

Psychological stress in chronic illness can arise from the very nature of the chronicity of the illness and the consequent demands placed on the individual. Not surprisingly, the potential "stuff" of stress is readily seen in the formal definition of chronic illness as "the irreversible presence, accumulation or latency of disease states or impairments that involve the total environment for supportive care and self-care, maintenance of function, and prevention of further disability" (Curtin & Lubkin, 1986, p. 6). Specifically, chronic diseases are often of gradual or insidious onset, of long duration, without a single causative agent and incurable in nature (Burish & Bradley, 1983).

Kassenbaum and Bauman (1965) cite the temporary or permanent incapacity for role performance that chronic illness may involve, and its nonrandom distribution in the population by age, gender, ethnicity, occupation, etc. Others have noted the general stigmatizing effects of chronic illness for those who become its victims (Saylor, 1986), especially if the condition is in any way visible (Goffman, 1963). Sontag (1977) points out that unclear etiology of illness or ineffective treatment is considered suspect in our society, contributing to the stigma and stress of chronic illness. It also has been observed that chronic illnesses are characterized by uncertainty in prognosis, course, treatment, and a variety of related dimensions. Chronic conditions also require proportionately greater efforts at palliation, and have a tendency to result in multiple related conditions. They are disproportionately intrusive in the lives of patients, they require a wide variety of supportive ancillary services and they are expensive (Strauss et al., 1984).

The reach of chronic illness is long and wide, touching every aspect of a person's life. The chronic illness experience has been viewed as a three-phase biographical disruption involving changes in assumptions and behaviors that have been taken for granted, a rethinking of an individual's biography and self-concept and a mobilization of resources to face one's altered circumstances (Bury, 1982). The major life changes and disruption accompanying chronic illness carry an enormous potential for stress appraisals. For those suffering from Chronic Fatigue Immune Dysfunction Syndrome, these effects may be magnified due to the unusually uncertain nature of the syndrome and the controversy surrounding it. Not surprisingly, emotional distress has been universally associated with CFIDS in descriptive accounts (Jones, Ray, Minnich, Hicks, Kubler, & Lucas, 1985; Komaroff, 1987; Ross & Monro, 1989).

The various situation factors associated with stress appraisals in chronic illness have been conceptualized as adaptive tasks or problems that form the focus of coping efforts. Cohen and Lazarus (1979) synthesize various perspectives as they identify five major adaptive tasks of illness: 1) reducing harmful environmental conditions and enhancing prospects of recovery; 2) tolerating or adjusting to negative events and realities; 3) maintaining a positive self image; 4) maintaining of emotional equilibrium; and 5) continuing satisfying relationships with others (p. 232). They also make the important point that not all individuals view illness as a threatening experience. Some may appraise an illness or certain aspects of the experience as a challenge or something to be conquered or mastered. As mentioned earlier, the valence associated with an appraisal is dependent upon person/environment factors which are situation-bound.

Moos and Tsu (1977) adopt a crisis framework to explain coping with chronic illness, and proffer two general categories for their set of seven adaptive tasks. Illness-related tasks are comprised of dealing with pain and incapacitation, dealing with the hospital (health care) environment and special treatments or procedures, and developing adequate relations with professional staff. Preserving a reasonable emotional balance, self-image, relationships with family and friends, and preparing for an uncertain future are all general adaptive tasks. While similar to the Cohen and Lazarus (1979) view, Moos and Tsu (1977) add preparation for an uncertain future, a notion acknowledged by many (Nerentz & Leventhal, 1983; Sanders & Kardinal, 1984; Strauss et al., 1984; Wiener, 1977).

Strauss and his colleagues (1984) conceive of coping with chronic illness as problem potentials posed for daily living. These potential problems are social and psychological in nature, and arise from the multiple and competing demands of the chronic illness experience. Some of the major areas for potential problems in chronic illness are: 1) The prevention of medical crises and their management once they occur; 2) The control of symptoms; 3) The carrying out of prescribed regimens and the management of problems attendant on carrying out the regimens; 4) The prevention of, or living with, social isolation caused by lessened contact with others; 5) The adjustment to changes in the course of the disease, whether it moves downward or has remissions; 6) The attempts at normalizing both interaction with others and style of life; 7) Funding, or finding the necessary money to pay for treatments or to survive despite partial or complete loss of employment; and 8) Confronting attendant psychological, marital, and familial problems (p. 16).

Adding an interesting situational perspective, Forsyth, Delaney, and Gresham (1984) assert that in addition to the many adaptive tasks inherent in chronic illness, certain periods are inherently more stressful and intrusive than others. These "critical junctures" can be considered crises in the illness course, often demanding the mobilization of all possible resources. Critical junctures occur when there is an increase in symptoms, spreading symptoms to other areas of the body, diminished treatment effectiveness, or the appearance of complications. The authors point out that the occurrence of these critical junctures signals the need for major changes and increased control since the usual strategies appear to be ineffective.

The notion of "critical junctures" in chronic illness course may first appear contrary to the traditional view that chronic, unremitting stress results in psychological and physical exhaustion, which makes responding to exceptionally stressful times virtually impossible (Selye, 1956). However, two points must be made. The first is that despite its unremitting nature, chronic illness is still characterized by variability in course. Illness symptoms wax and wane whether or not the general illness trajectory is generally considered stable or downhill. This variability allows for some days, hours, or moments to be perceived as worse than others and some types of symptom changes to be appraised as more threatening than others. As such, variability in symptomatology is a major source of uncertainty and stress in chronic illness (Strauss et al., 1984; Jessop & Stein, 1985; Mason, 1985; Wiener, 1975).

The second point is that emotional habituation can result from continued efforts to cope with a chronic stressor. Having day-to-day experience with a persistent source of stress allows for the development of new coping skills, readjustments of priorities and the general opportunity to meet the many illness demands over time (Altman & Wohlwill, 1977; Lazarus & Folkman, 1984; and Schönpflug, 1983). Thus, the damaging effects of stress over time can be mitigated by how long the individual has experience to deal with it. This experience and the relative efficacy of coping efforts will in turn affect subsequent reappraisals.

Cohen and her colleagues (1982) have categorized stressors according to their duration. They distinguish chronic persistent situations, chronic intermittent stressors and acute time-limited events. They also describe a pattern which they label a stress-event sequence in which a stressful event (e.g. illness diagnosis) leads to a series of stressful events which occur over time. In this last case, the stressful series can be appraised as individual or separate events, each with its own set of threats and implications, or as one protracted event. The point is that no matter how the chronic illness situation is initially perceived, cognitive reappraisal may alter the perception of durational pattern and associated threat at any time. Thus, emotional habituation may cause what appears to outsiders as a chronic, persistent stressor to be appraised by the individual as a less stressful chronic intermittent event, or an acute time-limited event whose stressfulness will end shortly. The decrease in psychological stress associated with chronic intermittent stressors is felt to be related to the rest and recovery that can occur between each stressful episode.

The mechanisms described in the preceding section may explain the many time-honored descriptive accounts in the literature of critical junctures that occur in illness course, the specific illness-related factors which prompted their occurrence, and their associated emotional consequences. These include:

1. The widely acknowledged and predicted effect of variability in illness symptomatology on uncertainty and stress in chronic illness (Benner & Wrubel, 1989; Forsyth, Delaney, & Gresham, 1984; Mason, 1985; Strauss et al., 1984; Wiener, 1975; Viney & Westbrook, 1982a).
2. The importance of cognitive appraisal in determining the meaning and consequent stressfulness of illness symptoms (Cohen & Lazarus, 1979; Lazarus & Folkman, 1984).
3. The relationship of uncertainty to hope (Bury, 1982; Dufault & Martocchio, 1985; Mishel, Hostetter, King, & Graham, 1984; Viney & Westbrook, 1981).
4. The relationship of variability of illness symptoms, uncertainty, and hopelessness to anxiety (Averill, 1973; Miller, 1979; Viney & Westbrook, 1976).

Unfortunately, the majority of these important variables and relationships have either not been examined at all, have not been examined in relation to one another, or remain unexplored in many chronic illnesses such as CFIDS. The stress, coping, and chronic illness framework described earlier provides a general perspective for viewing the relationships among these important variables, and identifies several areas for study. These include whether or not symptom variability or change actually affects uncertainty and stress-related outcomes, the identification of illness-related variables which affect appraisal, the relationship of uncertainty to hope, and the extent to which variability of illness symptoms affect uncertainty, hope, and anxiety.

Uncertainty

Uncertainty is widely recognized as an operant variable in the chronic illness experience (Bury, 1982; Jessop & Stein, 1985; Curtin & Lubkin, 1986; Mishel, 1984; Viney & Westbrook, 1981). Considered to be a major adaptive task and focus of coping efforts in chronic illness (Moos & Tsu, 1977; Mages & Mendelsohn, 1979), uncertainty has been viewed as a major source of stress for the chronically ill (Cohen & Lazarus, 1979; Strauss, et al., 1984). As such, uncertainty is the central organizing construct for this study. This section will focus first on general characteristics of uncertainty, followed by an examination of various definitions of the construct. Uncertainty in chronic illness will then be defined, and sources of illness-related uncertainty identified.

Characteristics of Uncertainty

The ancient Aristotlean tradition of assuming the inherent superiority of certainty, when combined with present-day Cartesian ideals, has directly influenced current conceptions of uncertainty. For example, there exists the predominant and implicit assumption that uncertainty is necessarily negative (Parsons, 1980) and that action must be taken to reverse or modify its presence. Dewey (1960, p. 223) observes that "The intrinsic, troublesome and uncertain quality of situations lie in the fact they hold outcomes in suspense; they move to evil or good fortune. The natural tendency of man is to do something at once, there is impatience with suspense, and lust for immediate action."

Nowhere is this tradition of viewing uncertainty as an inherently negative state more apparent that in a review of the uncertainty-related variables selected for study in current research efforts. Uncertainty has been associated with psychological disturbance (Jessop & Stein, 1985), lower levels of psychological adjustment to illness (Mishel, Hostetter, King, & Graham, 1984), as well as stress, fear, and anxiety (Averill, 1973; Mason, 1985; Miller, 1979b; Monat, 1976; Viney & Westbrook, 1976). Haan (1979, p. 123) points out that a patient's "greatest fear may not be knowing but instead, not knowing." Hopelessness, depression, and decreased self-esteem have all been linked to uncertainty (Charmaz, 1983; Dufault & Martocchio, 1985; Mason, 1985; Mishel, 1984) as have an increase in physical symptoms (Forsyth, Delaney, & Gresham, 1984) and physical illness (Suls & Mullen, 1981). Additionally, overall coping effectiveness has been found to be negatively related to situational uncertainty and ambiguity (Shalit, 1977).

Unfortunately, the negative view of uncertainty persists despite the illuminating assertions of the quantum revolution in physics which spawned what is called the "probabilistic paradigm" (Bursztajn, Feinbloom, Hamm & Brodsky, 1981). This new view accepts uncertainty as an inherent part of reality, acknowledging the potential for positive effects from uncertainty. This represents a sharp departure from the "mechanistic paradigm" which traditionally disavows recognition of that which is uncertain. Interestingly, this expanded view is supported by some empirical and anecdotal evidence related to uncertainty in illness situations. For example, Mishel (1984) found evidence of a curvilinear relationship between threat of severe illness and uncertainty in a sample of 100 medical patients. As the threat of severe illness increased, uncertainty in illness increased, but only to a point. At the highest levels of illness threat, the level of uncertainty began to decrease. Mishel concluded that this relationship may illustrate that at times, uncertainty may actually support optimism or hope, resulting in lower uncertainty (or more certain) scores at the highest threat level. Similarly, in a study of adolescents with cystic fibrosis, Yarcheski (1988) found higher levels of uncertainty to be associated with a longer future time perspective. In addition, Mishel (1983b) noted that lack of information (one type of uncertainty) was associated with a more positive parental assessment of the seriousness of their child's illness. Davis (1960, p. 45) similarly observed that "Uncertainty can be grounds for hope as well as despair."

Other findings also support the notion that uncertainty can have beneficial effects. Results from a qualitative study of patients with rheumatoid arthritis (Wiener, 1975, p. 98) demonstrated that: "The very uncertainty that makes the disease so intolerable, also mitigates against the acceptance of this invalid status, for there is always hope of another remission." Even in the most extreme circumstances, uncertainty has been described as less stressful than relative certainty. For example, in a study of cancer patients, Hinton (1977, p. 66) observed that: "Uncertainty was rife...and could be troublesome, although for some it was a preferable alternative to finality."

Unfortunately, the lack of sensitive, reliable, and valid measures of related variables has hampered the objective illustration of the possible stress-buffering relationship between uncertainty and hope. In addition, in many of these studies, uncertainty emerged as a result of qualitative analysis rather than serving as a pre-operationalized concept measured by a valid and reliable instrument. While qualitative description is undeniably rich, exclusive reliance on these methods restricts the generalizability of research findings and the development of prescriptive theory in general.

Other authors have proposed characteristics of uncertainty that should be considered. For example, the subjective nature of uncertainty implied by the transactional stress-coping framework advanced earlier has been recognized by those with rationalist/ positivistic leanings as well (Cohen, 1965; Downey, Hellriegel, & Slocum, 1977). In their interesting work related to subjective probability estimates, Tversky and Kahneman (1973, 1974, 1981) propose how individuals assess the probability of an uncertain event or the value of an uncertain quantity. The authors demonstrate that people rely on a limited repertoire of heuristic principles which result in judgments based on information that appears less complex. As such, these heuristics also serve as a basis for rather severe and systematic error.

The representative heuristic postulates that probabilities are determined according to the degree to which A resembles B, or how representative A is of B. The availability heuristic relies on a ease with which instances of a particular event or occurrence are brought to mind. The adjustment and anchoring heuristic involves a formulation of estimates by starting from an initial estimated value that is subsequently adapted or adjusted to allow for the final estimate.

These heuristics are likely to be used in various chronic illness situations. For example, in assessing how problematic a particular symptom is and whether or not some action should be taken, the adjustment and anchoring principle might be used to compare the current state with the usual state. Similarly, the representative heuristic might be used to compare one's current symptom pattern with the symptom pattern usually experienced. Due to their evaluative nature, these heuristics are inherently appraisal-related.

The authors point out that the presence of these heuristics are but one part of uncertainty-related judgments and that other variables such as knowledge and the basis of one's entire belief structure enter into the overall judgment process. Nonetheless, this work lends strong evidence for the necessarily subjective nature of individual judgments, even in the face of contrary information. Tversky's and Kahneman's work thus supports the notion that there is no "objective truth," just subjective perceptions which are uniquely true. Montagna (1980) seconds this conclusion, asserting that subjective probability determinations are distinct, but significant ways of knowing. Bury (1982) acknowledges the incomplete nature of knowledge in general, agreeing that knowledge must be "supplanted by, and set against a body of knowledge and meaning drawn from the individual's own biography" (p. 179). In this way, uncertainty becomes an intensely personal experience.

Some writers have observed the paradoxical nature of uncertainty. Moos and Schaefer (1984) remind us that at times "patients must prepare for permanent loss of function while preserving the belief that restoration of function may be possible" (p. 13). Another paradoxical source of illness-related uncertainty arises when a person has no symptoms of an illness, but significant pathology is uncovered by means of "high tech" screening and detection devices, requiring complex, time-consuming or life-altering changes to treat the condition. It is no wonder that anxiety often appears as a close conceptual companion of uncertainty. Other authors have observed that uncertainty and the responses to it are culturally defined. For example, Wright and Phillips (1980) found that individuals from "fate oriented" cultures (i.e., Asian cultures) engage in probabilistic thinking which is less defined and more extreme than their western counterparts.

These general characteristics of uncertainty have affected related research in several ways. First, the notion that uncertainty is inherently negative may have contributed to a general aversiveness to uncertainty-related research in the past. This may be related to the notion that to be uncertain is to be "lacking" in some way. Additional support for this contention will be found in the following section which will discuss various definitions of uncertainty. A second result of viewing uncertainty as necessarily negative has likely been the lack of studies with research questions related specifically to the possible beneficial effects of uncertainty. Finally, the general complexity, subjectivity, and culture-bound nature of uncertainty may have contributed to the lack of research interest in chronic illness situations in particular.

Conceptualization and Definitions of Uncertainty

The vast majority of existing definitions of uncertainty generally reflect their deductive, rational, and positivistic roots by considering the phenomena to be explicitly related to a lack of knowledge, predictability or probability (see Table 1). Some authors consider uncertainty to be

TABLE 1

Definitions Of Uncertainty

Disciplinary Focus	**Definition**
Economics/Management	
Downs (1957)	A lack of sure knowledge about the past, present, future or hypothetical events.
Duncan (1972)	Arises from: 1) A lack of information regarding the environment; 2) Lack of knowledge regarding consequences of a decision; and/or 3) The inability to assign probabilities.
Downey, Hellriegel & Slocum (1977)	An attribute of an individual's behavioral environment arising from the relationship between person and environment.
Connolly (1980)	The case in which all consequences of all alternative actions are unknown.
Lorenzi (1980)	A general lack of predictability or precision in estimation; the inability to forecast.
Houghland & Shepard (1980)	It may reflect unpredictable relationships between environmental elements, inadequate perceptions of existing relationships or a combination of both.
Psychology	
Frenkel-Brunswik (1949)	Intolerance of cognitive ambiguity is the tendency to resort to black and white solutions, to arrive at premature closure as to valuative aspects, often at the neglect of reality, and to seek for unqualified and unambiguous general acceptance and rejection of other people.

TABLE 1

Definitions of Uncertainty (continued)

Disciplinary Focus	**Definition**
Psychology (continued)	
Budner (1962)	Ambiguous situations cannot be adequately structured or categorized by the individual because of the lack of sufficient cues. Three situations give rise to ambiguity: novelty, complexity, and insolubility. Intolerance of ambiguity is the tendency to perceive ambiguous situations as sources of threat.
Monat, Averill & Lazarus (1972)	Temporal uncertainty is not knowing when an event will occur, but the probability is known. Event uncertainty exists when the probability of occurrence is unknown.
McIntosh (1974)	Uncertainty occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to predict outcomes accurately.
Norton (1975)	Intolerance of ambiguity is a tendency to perceive or interpret information marked by vague, incomplete, fragmented, multiple, probable, unstructured, uncertain, inconsistent, contrary, contradictory, or unclear meanings as actual or potential sources of psychological discomfort or threat. Ambiguity is the consequence of a situation, interaction or event, while uncertainty is a state of mind brought about by ambiguity.
Milburn & Billings (1976)	Certainty exists if the decision-maker has complete and accurate knowledge of the consequences. Uncertainty exists when the decision-maker cannot assign definite probabilities.
Viney & Westbrook (1976)	A state of cognitive anxiety brought about by response unavailability.

TABLE 1

Definitions of Uncertainty (continued)

Disciplinary Focus	**Definition**
Medical Sociology	
Fox (1957)	There are three types of uncertainty: 1) Incomplete or imperfect mastery of available knowledge; 2) Limits of knowledge itself; and 3) Difficulty in distinguishing between 1) and 2).
Davis (1960)	Two types of uncertainty exist: "real" or clinical uncertainty which is a scientific and clinical phenomenon, and functional uncertainty which is purposefully created by the practitioner to achieve some end which is deemed as beneficial. Functional uncertainty is thus used as a patient/situation management strategy (e.g., to foster hope).
Nursing	
Mishel & Braden (1988)	The cognitive state of a person when an event cannot be adequately structured or categorized because sufficient cues are lacking. It also occurs in a situation where the decision-maker is unable to assign definite value to objects or events, or is unable to predict outcomes accurately. When a person cannot structure meaning for illness events, a cognitive state of uncertainty exists.

solely related to a lack of information (Connolly, 1980; Downs, 1957; Fox, 1957) or predictability (Lorenzi, 1980), while others incorporate combinations of all three concepts in their definitions (Duncan, 1972; Houghland & Shepard, 1980). These definitions are drawn primarily from information theory (Shannon & Weaver, 1949) which views uncertainty as a lack of information, and from the classic model of rational decision-making (Knight, 1921). Decision theory asserts that individuals make optimal choices through rational stages of identification of the problem, alternatives, consequences, and outcomes. Values are assigned to each possible outcome in advance so that an a priori evaluation of each consequence can occur. The subjective expected utility model (Savage, 1970) further takes into account individual beliefs about the subjective probability in uncertain situations, multiplying these probabilities by their assigned utility value in order to identify the alternative with the highest expected score. Both theoretical perspectives have been criticized for their simplistic and overly-rational perspective (Milburn & Billings, 1976).

Definitions which consider uncertainty from a cognitive or perceptual perspective (Mishel, 1984; Viney & Westbrook, 1976) are clearly in the minority. However different these definitions might initially seem, it is readily apparent that they continue to reflect the strong influences of their positivistic predecessors. For example, although Mishel considers uncertainty to be a perceptual variable (1983a) and a cognitive state (1984), her definition includes specific reference to a lack of cues, information or knowledge, predictability and/or evaluative difficulty.

Viney and Westbrook's (1976) notion of uncertainty appears equally grounded in a stimulus-response view of perception and information processing. They define cognitive anxiety as "occurring when the individual is unable to anticipate and integrate experience meaningfully" (1976, p. 141). This awareness can occur under the following conditions: a) when there are extremely novel stimuli previously unexperienced by the construct system; b) when additional constructs are needed but are not available; c) when incongruous and/or conflicting stimuli are present; d) when uncertainty is generated by response unavailability; and e) when there is any problem that interferes with cognitive processing such as an increase in the rate of stimulus presentation.

Some of the definitions of uncertainty found on Table 1 were initially developed with a decision-theory focus (Connolly, 1980; Downey, Hellriegel, & Slocum, 1979; Downs, 1957; Lorenzi, 1980), intended for use in the fields of management and economics. Other conceptions belie their psychological perspectives (Milburn & Billings, 1976; Monat, Averill, & Lazarus, 1972; Viney & Westbrook, 1976). Three of the works in psychology (Budner, 1962; Frenkel-Brunswik, 1949; Norton, 1975) equate ambiguity with uncertainty, viewing intolerance of ambiguity as a personality trait or disposition related to the tendency to perceive ambiguous situations as threatening.

Frenkel-Brunswik's (1949) classic work provides the fundamental framework for viewing intolerance of ambiguity. As a personality variable, intolerance of ambiguity is related to rigidity and ultimately to authoritarianism. Frenkel-Brunswik also relates the construct to the unwillingness to deal in probabilities and a preference for that which is safe and definite. At the other end of this bipolar scheme are individuals who can see positives and negatives while accepting ambivalent emotions. Those who are tolerant of ambiguity tend to reduce ambiguous cognitive patterns to certainty either by the use of the familiar or the stereotypic. Intolerance of ambiguity has also been related to rigidity and dogmatism in other work (Norton, 1975).

The work on intolerance of ambiguity raises an obvious issue related to the conceptual distinction between uncertainty and ambiguity. Although many authors appear to use the terms interchangeably (Cherlin, 1980, Comaroff & McGuire, 1981; Fisher, 1984), others consider ambiguity as a character or consequence of the context or situation and view uncertainty as a person-related variable (Lerner, 1980; Norton, 1975). Lazarus and Folkman (1984) consider <u>ambiguity</u> as a lack of clarity in a given situation and <u>uncertainty</u> as "confusion about the meaning of the environmental configuration" (p. 105). They note that a person can experience uncertainty in an unambiguous situation and relative certainty or confidence in an ambiguous situation, depending upon subjective interpretation and various other person factors. They also point out that with increased ambiguity there is a concomitant increase in the influence of person factors in interpreting a situation.

Although the conceptual distinction between uncertainty and ambiguity is theoretically useful, its practical significance may become obscured by the difficulty in identifying situation characteristics independent of person characteristics. Because of the often interdependent nature of these two concepts and the ultimate reliance on the individual's interpretation and experience, the term "uncertainty" will be used throughout this work.

Monat (1976) and his colleagues (Monat, Averill, & Lazarus, 1972) further distinguish between two types of uncertainty. Temporal uncertainty relates to the unknown timing of an occurrence of known probability, whereas event uncertainty refers to an unknown probability of the event's occurrence. Implied in this definition is the notion of predictability, which asserts that there are "predictable environmental characteristics that can be discerned, discovered or learned" (Lazarus & Folkman, 1984, p. 85). There is a considerable body of literature which supports the general preference for predictable aversive stimuli in animals (Badia, Harsh, & Abbott, 1979). The preference for predictable events is hypothesized to be due either to the ability to engage in anticipatory coping to reduce the aversiveness of the stressor (Lazarus & Folkman, 1984) or to be the relaxation that is allowed by having "safety signal" warning of impending stress (Seligman, 1968). The evidence for predictability in human studies is somewhat harder to interpret. This may be due in part to the assertion that predictability and controllability are interrelated and often confounded in research (Miller, 1979a). Thompson (1981) defines control as "The belief that one has at one's disposal a response that can influence the aversiveness of event" (p. 89). To have control means that one can do something about the situation. Thus, it would appear that, as Miller (1979a) asserts, predictability has nothing at all to do with controllability. Lazarus and Folkman (1984) further observe that "One cannot control a situation that is not predictable; however, there may be predictability without control" (p. 86).

The various conceptualizations and definitions of uncertainty reviewed provide a theoretical perspective for the conception of uncertainty in chronic illness to be discussed in the following section. In addition, they demonstrate the long and enduring tradition of viewing uncertainty primarily as a lack of knowledge, predictability or probability. This view is restrictive when applied to the complex, multidimensional nature of uncertainty in chronic illness. The implication of this assertion will be discussed in the two sections that follow.

Definition of Uncertainty in Illness

Interestingly, the only set of explicit definitions of uncertainty that are illness-related and patient-focused are those offered by Mishel (1981; 1983a; 1983b; 1984) and Mishel and Braden (1988). Her conceptualization involves four classes of illness events and eight dimensions of uncertainty. The illness events include: 1) discomfort, incapacitation, and other illness-related symptoms; 2) treatment management; 3) unfamiliar technical environments and personnel; and 4) assessment of the future. These illness events relate closely to the four forms of uncertainty described by Mishel. These involve: a) ambiguity about the illness state; b) complexity regarding the treatment and system of care; c) lack of information about the diagnosis and seriousness; and d) unpredictability of the disease course and prognosis (Mishel, 1988, p. 225). The eight uncertainty dimensions or characteristics considered by Mishel are: vagueness, lack of clarity, ambiguity, unpredictability, inconsistency, probability, multiple meanings, and lack of information. According to Mishel (1984):

> When such stimuli as symptoms, diagnosis and treatments are perceived as uncertain, the perceptual tasks of recognition and classification are hampered and a cognitive structure of events is not formed. When a cognitive structure is not formed, the patient's ability to adequately appraise the situation and choose appropriate actions is limited. (p. 164)

Mishel (1988) views the "stimuli frame" as the primary antecedent to uncertainty and illness. The stimuli frame as proposed is comprised of three components: symptom pattern, event familiarity and event congruence. Symptom pattern relates to perceived pattern consistency or configuration. Event familiarity involves how repetitive, habitual, or recognizable the illness situation is perceived to be. Event congruence involves the degree of consistency between the expected and actual illness experience. Mishel asserts that these three variables allow for meaning of the illness to be interpreted, understood, and/or determined. She also notes that these three variables are inversely related to uncertainty. Thus, any disruption in perceived symptom pattern, the occurrence of unfamiliar symptoms, or the occurrence of unexpectedly problematic symptoms would all increase uncertainty in illness.

According to Mishel, the three components comprising the stimuli frame are directly influenced by cognitive capacity and structure providers. Cognitive capacity involves the individual's information processing capability. When these capabilities are limited by various person- and illness-related factors, the ability to perceive symptom patterns, event familiarity and event congruence will be diminished and uncertainty will increase. She also notes that attentional capacity is particularly susceptible to illness-related effects such as pain, medication, poor nutrition, and the like.

Structure providers involve the various resources available to assist an individual in interpreting the stimuli frame. These include education, social support, and credible authority. Education is proposed to have both direct and indirect effects on uncertainty. By providing a larger context for the interpretation of meaning and allowing for more rapid modification of uncertainty, those with higher education are proposed to experience less uncertainty and/or uncertainty for a shorter period of time. Social support has been shown to reduce uncertainty through feedback related to the meaning of events. Credible authority relates to the amount of confidence and trust an individual has in health care providers. When confidence is high, uncertainty will be lessened.

Although Mishel (1988) views uncertainty as a state of incomplete recognition and classification of an event, she asserts that uncertainty is essentially a neutral experience until it is appraised as a danger or opportunity. Inference and illusion are two major processes posited in uncertainty appraisal. Inferences about the meaning of a situation or event are influenced by various personality dispositions, while illusions involve generally positive beliefs which are maintained in order to manage stressful appraisals. She points out that "uncertainty provides the foundation upon which illusionary meaning can be constructed" (1988, p. 299), and notes that the maintenance of hope may actually rely on the existence of uncertainty.

Mishel's conceptualization of uncertainty has spawned the only systematic and growing body of work directly related to uncertainty in illness situations. The Mishel Uncertainty and Illness Scale (MUIS), developed as measure of the four dimensions or forms of uncertainty (to be discussed in Chapter 3) has contributed to theory development in this area. Three versions of this MUIS currently exist. One scale is for adult in-patients, while the community form is for use in out-patient settings. A version for parents of ill children has also been developed. However, many questions related to the antecedents, mediators and consequences of uncertainty remain unresolved. These involve the proposed influence of symptom patterns, problems and transition on uncertainty, the relationship of uncertainty to hope and the possible stress-buffering effects of both of these variables, as well as the identification of other stress-related outcomes of uncertainty.

Although Mishel's conception of uncertainty in illness has unquestionably encouraged uncertainty-related theory development, it is nonetheless constrained by its positivistic information-processing perspective. For example, Mishel (1988) asserts that when uncertainty exists, one of three conditions is possible: a) the event is not recognized; b) the event is recognized but not classified; and c) the event is recognized but classified incorrectly. The latter condition is implicitly pejorative and does not recognize the possibility that an uncertain event or situation may be both recognized and correctly classified. In fact, the very notion that there is a correct way to classify an event or situation appears contrary to Mishel's assertion that uncertainty is affectively neutral and determined by person and situation factors.

Additionally revealing is Mishel's (1988) consideration of illusion as one of the two major appraisal processes. Likened to such defenses as avoidance and denial, Mishel observes that uncertainty may be used to construct favorable, self-enhancing beliefs that are otherwise impossible with certainty. Her unfortunate choice of words for this process relegates important person variables such as various beliefs as well as hope to the rather trivial status of an illusion.

Although Mishel's conception (and hence, the MUIS) involves some sources of illness-related uncertainty such as ambiguity about aspects of illness state, complexity of treatment and system of care, lack of information about illness, diagnosis and seriousness, and unpredictability of illness course and prognosis, other sources of uncertainty in chronic illness are left unaddressed. In fact, the MUIS purports to measure uncertainty in general illness situations rather than chronic illness situations. A review and synthesis of sources of uncertainty in chronic illness will provide the final rationale for the selection of variables.

It should also be noted that the conceptualizations of uncertainty previously discussed highlight several additional relevant issues. First, uncertainty-related research and theory development has been hampered by the underutilization of explicit coping frameworks to guide individual research efforts. This has likely contributed to the fragmented and non-continuous nature of uncertainty-related research that has been observed (Fiddle, 1980) as well as various problems related to the generalizability of findings. Utilization of such frameworks can assist in the selection of relevant variables for study as well as approaches to measurement of related phenomena.

The lack of an explicit definition of uncertainty in chronic illness situations also limits research problem identification and the range of possible variables considered for study. For example, despite repeated acknowledgements of the subjective nature of uncertainty (Bury, 1982; Cohen, 1964; Downey, Hellriegel, & Slocum, 1977) and the long-standing awareness that subjective meaning affects emotional and behavioral responses (Lazarus & Folkman, 1984), none of the existing uncertainty-related measures (including the Mishel Uncertainty in Illness Scale) attempts to assess the meaning of uncertainty for the individual. In addition, the assumption that uncertainty is inherently negative has likely restricted insight into the complex relationships that undoubtedly exist among related antecedent, mediating, and consequent variables. If existing measures such as the MUIS are to be used in future research, they should be applied in conjunction with a subjective, appraisal-related measure. In this way, proposed theoretical mechanisms such as the beneficial effects of uncertainty may be detected.

Sources of Uncertainty in Chronic Illness

In this study, the identification of specific *sources of uncertainty* in chronic illness served as an additional template or "blueprint" guide for the selection of relevant study variables. This template or blueprint of sources of uncertainty in chronic illness was developed by summarizing and synthesizing the answer to the question, "uncertainty about what?" As pointed out earlier, rich descriptions and conceptual formulations exist which either directly address the types of uncertainty in chronic illness situations or imply potential sources of illness-related uncertainty that must be managed on an on-going basis (see Table 2). As illustrated in Table 2, several

TABLE 2

Sources of Uncertainty and Illness

Author(s)	**Sources of Illness-Related Uncertainty**
Hamburg (1974)	Coping tasks related to: 1) keeping stress within manageable limits; 2) maintaining a sense of personal worth; 3) maintaining or restoring relations with significant others; 4) enhancing prospects for recovery of bodily functions; and 5) increasing the likelihood of working out a personally valued and socially acceptable situation after maximum physical recovery is attained.
Wiener (1975)	1) intermittent resource reduction in mobility skill or energy; 2) disease progression, severity and areas afflicted; 3) whether or not pain will be present; 4) the intensity of disability; 5) Whether or not the onset was gradual or sudden; and 6) the duration and frequency of flare-ups.
Moos & Tsu (1977)	Illness-related adaptive tasks: 1) dealing with pain and incapacitation; 2) dealing with the hospital (health care) environment and special treatments/procedures; 3) developing adequate relations with professional staff.
	General adaptive tasks: 4) preserving a reasonable emotional balance; 5) preserving self-image and maintaining a sense of competence and mastery; 6) sustaining relationships with family and friends; and 7) preparing for an uncertain future.
Weisman & Worden (1977)	Areas of concern: 1) health; 2) self-appraisal; 3) work and order finances; 4) family; 5) religion; 6) friends; 7) existential concerns.

TABLE 2 (continued)

Sources of Uncertainty and Illness

Author(s)	**Sources of Illness-Related Uncertainty**
Cohen & Lazarus (1979)	Adaptive tasks of illness: 1) reducing harmful environmental conditions and enhancing prospects of recovery; 2) tolerating or adjusting to negative events and realities; 3) maintaining a positive self-image; 4) maintaining emotional equilibrium; 5) continuing satisfying relations with others.
Haan (1979)	Illness-related concerns: 1) How life-threatening is it?; 2) Is it reversible? 3) How imminent is its full onslaught? 4) What was the fate of others with the same diagnosis or forecast? and 5) Did their impairment, illness course or cure conform to the physician's current description? 6) Is the physician competent? 7) What are the probabilities of actualizing the outcome described by the physician? 8) How much pleasure and usual lifestyle must be changed or given up? 9) Will members of one's social network support the course one chooses to adopt (i.e., following or ignoring physician's recommendations)?
Jones, Weise, Moore & Haley (1981)	1) The degree to which a symptom is perceived as threatening and disruptive; 2) Symptom familiarity and requirement for medical treatment; and 3) how embarrassing the symptom is.
Bury (1982)	1) whether and how to disclose the illness to others; 2) illness impact; 3) illness course; 4) appropriate behavior; and 5) incorporation of illness into one's self-concept.

TABLE 2 (continued)

<u>**Sources of Uncertainty and Illness**</u>

Author(s)	Sources of Illness-Related Uncertainty
Miller (1983)	The work of chronic illness: 1) modifying routines and life styles; 2) maintaining a positive self-concept; 3) dealing with role change; 4) grieving losses associated with chronic illness; 5) handling physical discomfort; 6) maintaining feelings of control; 7) maintaining hope despite an uncertain or downward course; and 8) dealing with social stigma.
Forsyth, Delaney & Gresham (1984)	Critical junctures in illness course: 1) increase in symptom severity or frequency; 2) symptoms spreading to other areas of the body; 3) decreased treatment effectiveness; and 4) illness complications.
Strauss et al. (1984)	Problem potentials: 1) prevention of medical crises and their management once they occur; 2) symptom control; 3) carrying out and managing prescribed regimens; 4) prevention of or living with social isolation; 5) adjusting to change in illness course; 6) attempts at normalizing interactions and life styles; 7) finding the necessary money to pay for treatment and/or living costs; 8) confronting attendant psychological, marital and familial problems.
Weisman (1984)	Preoccupations with: 1) existence (survival); 2) health care (treatment effectiveness); 3) delivery of services (confidence and trust in providers); 4) work and finances (financial support and fulfillment of role expectations); 5) symptom control (amount of suffering); 6) family; 7) friends; 8) religion; 9) personal well-being; 10) self-regard.
Mason (1985)	Lack of knowledge related to: 1) illness severity; 2) medication requirement; 3) cure; 4) causation of illness; 5) self-management.

authors describe the work of chronic illness as dealing with coping/adaptive tasks required by illness situations (Cohen & Lazarus, 1979; Hamburg, 1974; Miller, 1983; Moos & Tsu, 1977) while others identified sources of uncertainty directly (Bury, 1982; Mason, 1985; Wiener, 1977). Uncertainty in chronic illness situations has also been implicitly related to specific illness concerns (Forsyth, Delaney, & Gresham, 1984; Haan, 1979; Jones, Weise, Moore, & Haley, 1981; Weisman & Worden, 1977), problem potentials (Strauss et al., 1974), and preoccupation with several illness-related consequences (Weisman, 1984).

Analysis of these sources of chronic illness uncertainty identified on Table 2 reveal at least five domains of uncertainty related to various aspects of: the self, health care personnel, significant others, existential concerns, and illness-related concerns. As such, they provide a partial answer to the question, "uncertainty about what?" However, it is also possible to identify specific sources of uncertainty within each domain. These sources of uncertainty form the content objects or foci of uncertainty appraisals in chronic illness (See Table 3). As such, they comprise the specific "stuff" of chronic illness uncertainty and thus represent a more complete answer to the questions "uncertainty about what?"

The content of uncertainty appraisals involving the domain of self generally relate to feelings of personal competence, ability, or mastery and include the degree to which one can manage the symptoms and various other physical manifestations of their illness. Strauss and his colleagues (1984) have written extensively about the work related to chronic illness management, especially in relation to palliative efforts. They have also observed that chronic illnesses tend to lead to a multiplicity of conditions, increasing the potential workload exponentially. One's ability to manage the complexities of the health care environment is another source of uncertainty related to the self. This may relate to such specific outcomes as how well one can negotiate the appointment process at one's clinic or physician's office, or involve a more general sense of relative competence related to the health care system in general.

TABLE 3

Uncertainty and Chronic Illness

Domain	**Source of Uncertainty**
Self	· Managing the symptoms and other physical manifestations of illness · Managing the complexities of the health care environment · Managing the treatments procedures and their related side effects · Maintaining adequate relationships with physicians and other health care personnel · Sustaining relationships with family and friends. · Maintaining emotional stability · Preserving a sense of self
Health Care Personnel	· Practicing knowledgeable and skillfully · Recommending care and treatment that is reasonable and/or necessary . Using available and/or appropriate technology
Significant Others	· Providing love, emotional support, physical assistance, and material resources
Existential	· Discerning meaning and purpose in the illness experience. · Maintaining belief in an external force that is wise, merciful, and just
Illness-Related	· Diagnosis · Causation · Predictability of illness course · Controllability of illness course · Survivability · Symptom predictability · Symptom severity · Symptom frequency · Symptom number · Symptom pattern · Symptom visibility · Symptom interference · Symptom complexity · Symptom novelty · Symptom duration · Symptom controllability · Life impact

An individual's perceived ability or inability to manage illness-related treatments, procedures and their side effects constitutes another potential source of uncertainty related to the domain of self. At times, the side effects of treatments may be more distressing than the treatment itself, as in the case of hair loss after radiation treatment, or nausea, vomiting, and weight loss from chemotherapy. At other times, the treatments and/or procedures themselves can be sources of uncertainty, especially when their outcome is unknown. Three types of uncertainty appraisals are possible in these situations. A treatment or procedure may be seen as positive or beneficial and thus not stressful if it is perceived as a way of improving one's condition or prospects. A good example of such an appraisal is the situation in which a diabetic, about to undergo a below-the-knee amputation for a chronic, debilitating, and recently life-threatening infection assesses the situation as positive. In contrast, the same situation can evoke a stressful appraisal if the individual believes his or her condition or prospects will be worsened by loss of the limb. A third individual might also appraise the situation as stressful, but perceive the situation as challenging. Lazarus and Folkman (1984) observe that stressful appraisals which are threatening can co-exist with challenge appraisals and although often related, the two concepts are separate and distinct.

Another source of uncertainty in chronic illness is the relative ability of the individual to maintain adequate relationships with physicians and other health care providers. Because of the ongoing nature of chronic illness and the reliance on palliative treatment, the importance of these relationships should not be underestimated. As with other sources of uncertainty, their relative importance or significance may wax and wane throughout the illness course according to situational requirements or characteristics. Uncertainty related to the ability to sustain relationships with family and friends also may vary throughout an illness course, depending on the degree of incapacity that exists at a given time. Unfortunately, social isolation has been recognized as a common consequence of chronic illness (Davis, 1975; Strauss et al., 1984). As such, it portends some change in relationships and the need to adjust to these new arrangements.

The importance of maintaining emotional stability and preserving a sense of self are universally recognized in chronic illness. Chronically ill individuals struggle with altered self-concepts and new definitions of self throughout the illness course (Bury, 1982; Charmaz, 1983). Adjusting to changing illness demands can give rise to uncertainty related to one's self-definition and whether one has the personal ability, resources, and/or will to prevail. One's sense of self is also related to the ability to contribute to personal, familial, and/or social welfare in a meaningful way. This ability to contribute is usually associated with the degree to which one can fulfill role obligations and expectations.

The domain of uncertainty related to <u>health care personnel</u> arises from various sources as well. The degree to which one believes that the physician and the other health care providers are practicing knowledgeably and skillfully is one such source of uncertainty. Additional sources include whether or not health care personnel are recommending care and treatment that is reasonable and/or necessary and whether or not available and/or appropriate technology is being employed. Mishel (1988) refers to this source of uncertainty as "Credible Authority," observing that it relates to trust and confidence in health providers. It should be noted that these areas relate to confidence in the <u>ability of others</u> to act appropriately and can be distinguished from the source of uncertainty related to the <u>contribution of the self</u> in maintaining adequate relationships with others. Interestingly, Mason, Clark, Reeves, and Wagner (1969) observe that faith in the healer and the methods of healing employed as well as the belief that the methods relate to the illness cause are associated with rapid healing.

Relevant sources of chronic illness uncertainty related to <u>significant others</u> involve beliefs about the ability of others to provide long-term emotional support, physical assistance, and material resources. Although the physical, emotional, and material needs of the chronically ill may be undeniably great throughout the illness course, these increased demands may take their toll on their loved ones. For example, Sexton and Munro (1985) found that wives of chronically ill men reported higher stress levels and lower life satisfaction scores than comparison wives. These wives of the chronically ill took on more new roles and responsibility, gave up more social activities, had lower health ratings and less frequent sexual relations than their counterparts. It is likely that the effects of increased illness demands on significant others in turn affects their subsequent ability to provide additional support, thus contributing to uncertainty appraisals in this domain.

Sources for the existential domain of uncertainty in chronic illness involve one's ability to discern meaning and purpose in the illness experience and to maintain belief in an external force that is wise, merciful, and just. Lazarus and Folkman (1984) acknowledge the meaning-seeking and meaning-constructing nature of human existence, pointing out the continuous nature of our evaluative appraisals. Frankl (1959) asserts that the failure to find meaning in existence results in psychopathology, while Allport (1959) reminds us of Nietzsche's apt observation: "He who has a why to live can bear with almost any how" (p. xi). The fundamental relationship among meaning, hope, and uncertainty has been observed by many (Fromm, 1986; Green, 1977, Korner, 1970; Mishel, Hostetter, King, & Graham, 1984). Others assert the relationship of uncertainty to beliefs (Beyth-Maron & Dekel, 1985; Montagna, 1980) which bridge the gap to hope (Dufault & Martocchio, 1985). This posits a dialectic relationship between hope and uncertainty with each variable facilitating and influencing the other.

The illness-related domain of uncertainty contains various general and symptom-related sources of uncertainty, such as the diagnosis and presumed illness causation. As discussed earlier, diagnostic certainty can be related to either increased or decreased psychological stress, depending on the individual's appraisal. Even in the absence of a specific diagnosis, it has been asserted that individuals construct causal explanations for life events which are predictors of their emotional and behavioral response (Weiner, 1974). It has also been predicted that important situations involving stress or unexpected outcomes are more likely to result in causal searches than other more benign situations (Weiner, 1979).

Interestingly, recent studies in chronically ill populations have called the assumption of causal attribution into question in naturalistic settings. For example, Lowery, Jacobsen, and Murphy (1983) found that fifteen percent of their sample of 55 male patients with rheumatoid arthritis did not construct causes, and that those subjects not ascribing causes were significantly more depressed, anxious, and hostile. In another study of 296 diabetics and 83 newly-diagnosed patients with a myocardial infarction, Lowery, Jacobsen, and McCauley (1987) found that only about half of the predominately female samples reported a causal search related to their condition. In addition, both affect and expectations for recovery scores were higher in the group who had not engaged in a causal search. These findings appear to underscore the importance of both person and situation factors in cognitive appraisal by demonstrating the difficulty of prediction based on the presence of illness alone.

Predictability, controllability, and survivability of illness course are three additional illness-related sources of uncertainty in chronic illness. The relative ability or inability to plan for the future is related to illness course predictability (Strauss et al., 1984). Other factors such as perceptions of treatment effectiveness and an individual's general beliefs about his or her health relate to illness course controllability. Survivability refers to how life-threatening an illness is perceived to be. A cognitive-phenomenological perspective asserts that whether or not a person believes s/he will survive a particular illness has little to do with objective "reality." Mason (1985) demonstrated that diabetic patients perceived their illness to be more severe than their physicians' rating of illness severity. The majority of a patient sample afflicted with Chronic Fatigue Immune Dysfunction Syndrome report believing that the illness may cause their death, even though no known deaths have been attributed to the syndrome (Cheney, P., personal communication, November 7, 1987).

Several symptom-related sources of chronic illness uncertainty are proposed. These include symptom predictability, severity, frequency, complexity, novelty, duration, and controllability. Additional sources of uncertainty are symptom number, pattern, visibility, and interference. Jessop and Stein (1985) point out that the greater the visibility of the condition the greater the uncertainty related to illness prognosis and the reaction of others. Wiener (1975) cites the contribution of symptom variability to uncertainty, noting that disease progression, severity and areas of affliction have particular relevance in chronic illness. She also describes other symptom-related sources of uncertainty as: 1) whether there will be any pain; 2) the area of the body involved; 3) the intensity of the disabilities; 4) whether the onset will be gradual or sudden; 5) the duration of the flare up; and 6) the frequency of the flare ups. Jones, Weise, Moore, and Haley (1981) have demonstrated three properties which affect the perceived interpretation of illness symptoms. The first and strongest property relates to the degree to which a symptom is perceived as threatening and disruptive, while the second involves symptom familiarity and the requirement for professional treatment. The third relates to how embarrassing the symptom is. These properties affect the individual's emotional response as well as what action will be taken to manage the symptoms.

Overall life impact is the final illness-related source of uncertainty in chronic illness proposed by this alternative conceptualization. As Strauss and his colleagues (1984) suggest, chronic illness experiences are inordinately intrusive in general, with some carrying rather drastic actual or potential life implications and/or changes. The nature, likelihood, and degree of perceived transition related to these chronic illness consequences form the basis for this source of uncertainty.

Although some sources of uncertainty, such as symptom transition or variability, may be considered more common or important than others, uncertainty in chronic illness arises from a number of sources. Additional factors contributing to uncertainty may include, as Fox (1957) suggests, the lack of personal knowledge, the limits of medical knowledge itself, or the inability to distinguish between the two. The lack of personal knowledge may be due to such diverse causes as a lack of interest or motivation, or the inability to comprehend. Uncertainty might also arise from deliberate attempts to withhold information by physicians or staff (Davis, 1960; Eddy, 1984; Katz, 1984), from situational or environmental ambiguity (Lazarus & Folkman, 1984; Lerner, 1980; Norton, 1975), or as noted earlier, from successful coping efforts. In the final analysis and irrespective of cause, an uncertainty appraisal in chronic illness arises from the individual's perception of his/her unique illness situation. Any one or all of the five domains of uncertainty in chronic illness may be involved in the appraisal of uncertainty, and any number or combination of specific sources could be implicated.

The template or blueprint of uncertainty in chronic illness summarized in Table 3 further supports and clarifies the particular antecedent, mediating, and consequent variables that were selected for inclusion in this study. The focus of this study involves the antecedent effects of perceived symptom transition and how problematic symptoms are appraised (from the illness-related domain), the mediating effect of hope (from the existential domain), and the outcome of anxiety as a stress-related variable. This template also hypothesizes relationships among an individual's perception of seriousness of illness, prognosis and illness course, activity level and perceived symptom transition, problematic symptoms, hope, uncertainty, and anxiety. This blueprint of domains and sources of uncertainty in chronic illness also influenced the development of measures for this study. For example, the Mishel Uncertainty in Illness Scale does not tap many of the symptom specific sources of uncertainty in chronic illness such as pattern, visibility, interference, novelty, frequency, etc. Since these symptom-related characteristics are proposed to be important antecedents of uncertainty in chronic illness, a measure of perceived symptom transition and specific item content was suggested by this framework. Further, the MUIS does not attempt to elicit an individual's appraisal of illness symptoms. Since symptom appraisal is proposed to exert an important influence on uncertainty and anxiety in chronic illness, further development of the De Groot Chronic Fatigue Syndrome Symptom Scale was warranted.

Hope in Chronic Illness

As suggested by the template presented in the previous section, hope is an important variable associated with the existential domain of uncertainty in chronic illness. The assertion that hope serves an essential sustaining function in life, is an important determinant of human behavior, and is ultimately related to health is universally acknowledged (Engel, 1968; Fromm, 1968; Green, 1977; Korner, 1970). Hope has been depicted both as a predictor of adaptation and as a mediator of stress (Engel, 1968; Schmale, 1971; Hinton, 1974). Although various state and dispositional definitions of hope exist, Dufault and Martocchio (1985) offer a broader, more complex process perspective on hope based on their research. They assert that hope is "a multi-dimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future goal, which, to the hoping person, is realistically possible and personally significant" (p. 380).

Dufault and Martocchio distinguished between generalized hope, which involves an overall sense of some undefined future good, and particularized hope, which involves an important or valued outcome or hope object. These hope objects can be concrete, abstract, explicit, or implicit. The authors identify six dimensions of hope: affective, cognitive, behavioral, affiliative, temporal, and contextual. Each dimension is comprised of various components which shape an individual's experience of hope. As the emphasis changes among and between dimensions of hope, the process of hoping is actualized. The authors observed that the lack of knowledge about outcome is the basis for uncertainty and that anxiety, doubtfulness, uneasiness, vulnerability, and sadness are some of the related affective responses resulting from uncertainty. Korner (1970) acknowledges the feeling of "assumed certainty" that is fostered by hope, which serves as a level of assurance that what is feared will not occur. Others assert the relationship of uncertainty to beliefs (Beyth-Maron & Dekel, 1985; Montagna, 1980) which bridge the gap to hope (Dufault & Martocchio, 1985). It would appear that hope is a more general and/or encompassing concept than uncertainty in chronic illness, although uncertainty appears to maintain a dialectic relationship with hope.

Smith's (1983) conception of hope includes the notion of personal action and involvement in the hoping process. Korner (1970) points out that while hope is energizing, it is not a source of energy: "powerful psychological changes can be observed within the shortest time period; individuals will be galvanized into action" (p. 136). This action does not necessarily translate into personal control, despite the claim that "hope is real when it contains elements that one can control and personally affect" (Dubree & Vogelpohl, 1980, p. 2048). Vaillot (1970) argues that "any situation justifying hope is, by definition, not amenable to strictly ordinary means, and hope sets its goals beyond mere human provisions. It follows that no techniques, no man-made remedies, can supply what is hoped for" (p. 272).

Obayowana's (1980) view of hope incorporates this latter point: "hope is the feeling that what is desired is also possible, or that events may turn out for the best" (p. 67). Thus, things may turn out well whether or not one personally has control over the outcome. Lynch (1965) summarizes this position well by stating that "hope is truly on the inside of us, but hope is an interior sense that there is help on the outside of us" (pp. 31-32).

The "interior sense" described by Lynch to characterize hope has been differentiated from optimism by several authors. Some writers suggest that optimism is more superficial and self-centered than hope (Marcel, 1962; Vaillot, 1970). Bruhn (1984) observes that "hope is more than optimism; it is an expression of values that are reinforced or altered by the way other people behave towards us" (p. 219). Thus, hope is viewed as a more variable, episodic or state-related phenomena. Menninger (1959) asserts that optimism is more distant from reality, implying a more generalized and enduring dispositional nature.

Despite general emphasis on the positive aspects of hope, Korner (1970) has observed that hope is viewed as a mixed blessing in our culture. She states that "there is some recognition of the power of hope to make life under stress tolerable, but there is a confusion and conflict about its efficacy and the wisdom of relying on it" (p. 134). However, Travelbee (1966) questions our ability to make interventions based on our judgments about an individual's level of hope. She asks:

> Which is the better way? To attempt to help an individual to accept that which is inevitable, but in the helping to emphasize the possibility (even if highly improbable) of a cure, or to make no attempt to assist a patient in accepting his illness and instead encourage him to search for a cure which does not exist? When hope is killed (even if it is revived and killed again) what is the individual left with but an anxious desperation akin to despair? Yet who among us is really wise enough to answer these questions with any degree of certainty? (1966, p. 58)

An additional conceptual issue relating to hope is whether or not it is a purely conscious or cognitive phenomena. Most authors explicitly or implicitly infer cognitive and affective dimensions of hope, while some add ethico-religious dimensions (Schrag, 1977; Sevensky, 1981; Vanderpool, 1977). A minority consider unconscious or pre-conscious hope, but fail to address the practical assessment or utility of these distinctions (Fromm, 1968; Korner, 1970).

Research on hope has demonstrated an association with long-term survival in dialysis patients (Ziarnick, Freeman, Sherrard, & Calsyn, 1977), while hopelessness has been associated with depression (Beck, Kovacs, & Weisman, 1975; Moore & Paolillo, 1984), suicide attempts (Pokorney, Kaplan, & Tasai, 1975) and increased psychological adjustment problems (Mishel, Hostetter, King, & Graham, 1984). In an interesting study of cancer patients, Stoner and Kaempfer (1985) found that the degree of hope held by patients was inversely related to their recall of being given information about their probable life expectation. Thus, subjects who were more uncertain about their prognosis were more hopeful. This finding posits the potentially beneficial effects of uncertainty when the relative "certainty" is appraised as negative, and thus stressful.

In a related study of 54 women with gynecological cancer, Mishel, Hostetter, King, and Graham (1984) found that increased levels of uncertainty explained 25% of the variance in hopelessness, and that there was a significant relationship between psychosocial adjustment to illness and hope. Although this study suggests that uncertainty may exert an important influence on an individual's level of hope/hopelessness, the precise mechanism for this finding is not clear, nor are the situational factors which might influence this relationship. There is strong theoretical support for illness related variables such as symptom transition and problematic symptoms to exert a significant influence on this relationship. However, until the DPSTS and DCFSS were developed, no valid and reliable measures of these related variables existed, hampering efforts to fully and precisely explore these relationships. It is also not evident whether Mishel, Hostetter, King, and Graham's findings are generalizable to other illness situations or samples. With a highly uncertain illness such as Chronic Fatigue Immune Dysfunction Syndrome, different relationships may be found.

Issues in Illness Symptomatology

Existing approaches to the study of illness symptomatology have highlighted several issues and limitations which will be addressed by the strategy used in this study. For example, despite the assertion that symptom management is a major adaptive task of chronic illness (Lazarus & Folkman, 1984; Moos & Tsu, 1977; Strauss et al., 1984) and that illness symptoms shape an individual's definition of an illness (Mechanic, 1979), studies investigating symptom management have been rare. Research on symptomatology has primarily focused on symptom reporting as it relates to illness behavior in well populations (Costa & McCrae, 1980; Mechanic, 1979; Pennebaker, 1982; Smith, Pope, Rhodewalt, & Poulton, 1989). Although Mechanic (1980) suggests that symptom reporting is an illness behavior dependent upon developmental experience, actual illness, psychological state, and a sense of well-being, and that the major determinants of physical and psychological symptom reporting are actual illness and symptom experience as well as cultural influences, these important illness-related variables have been largely unstudied.

Few studies have examined actual illness-related antecedents of symptom reporting. Instead, among psychologists there appears to be greater research interest in personality traits such as neuroticism or negative affectivity as predictors of symptom/health reporting (Blazer & Houpt, 1979; Costa & McCrae, 1985; Watson & Pennebaker, 1989). Neuroticism has been defined as "a broad dimension of individual differences in the tendency to experience negative, distressing emotions and to possess associated behavioral and cognitive traits" (Costa & McCrae, 1987, p. 30). It has been asserted that neuroticism, or "negative affectivity" (Watson & Clark, 1984) is virtually indistinguishable from other psychological constructs such as psychological distress, poor morale, depression, maladjustment, and trait anxiety (Allred & Smith, 1989; Costa & McCrae, 1985). The focus on symptom reporting as an <u>outcome</u> of negative personality traits may have contributed to a general reluctance to assess symptoms in more depth and to study their role as predictors or antecedents of negative emotional states.

As with the assumption of the inherently negative nature of uncertainty discussed earlier, the notion of symptom reporting in general appears to suffer from a similar positivist/post-positivist "tug-of-war." Nowhere is this more apparent than in relation to the "objective" vs. "subjective" nature of symptom reporting scales. Watson and Pennebaker (1989) note the dual nature of self-report health- or symptom-related scales, observing that these scales have both a subjective, psychological component and one that is objective and health-related. They assert that the inherent subjectivity in self-report scales may or may not allow an accurate assessment of the "true" health state. The notion of subjective vs. objective health/symptom reporting has remained an issue even though self-ratings of health and symptom status have been used routinely as proxy measures of objective ratings and significant correlations between self-rated and physician-rated health have been reported (LaRue, Bank, Jarvik, & Hetland, 1979; Linn & Linn, 1980; Maddox & Douglas, 1973).

Costa and McCrae (1985) proposed three models to explain how the relationship between subjective and objective health, or "appearance and reality" (p. 19) has been interpreted. Naive Realism, or Model I, posits the assumption that an individual's symptom reports are true and should be taken at face value. The Psychiatric Categorical Model, or Model II, suggests that self-reports of symptoms are either accurate or unfounded. This dichotomous view necessitates a judgment that the report reflects actual physical illness or psychopathology, usually in the form of Hypochondriasis. The third model, or Dimension of Somatic Concern, purports that congruence of symptoms with health state varies from individual to individual, and there are "consistent and enduring differences in the perception, interpretation, and reporting of bodily symptoms; and that there is a continuum from persistent under-reporting to frank

Hypochondriasis" (p. 20). This model suggests that the relationship between symptoms and health state is dependent upon an individual's symptom reporting style.

The pejorative feel of the Model I is apparent even in the very name the authors have affixed to the model. It is this author's view that the second model or Psychiatric Categorical Model has heavily influenced research on illness symptomatology and is the predominant model underlying most personality-oriented research examining symptom reports. Costa and McCrae (1985) point out the pejorative nature of this model as well. They make the important point that mental and physical illness can coexist, and that categorizing a patient as hypochondriacal is, in itself, a subjective, unvalidated judgment made by physicians or others. The third model, proposed by the authors to rectify the shortcomings of the first two, is equally trait-based, and "makes it clear that veridicality of symptom reports is always in question" (p. 20). The authors emphasize the importance of obtaining both objective and subjective symptom and health assessments.

Unfortunately, the authors do not propose the next logical extension or possibility of a fourth model. This can be termed a "Situational Context Model" which acknowledges both person and environment factors in symptom reporting. In this model, equal attention would be paid to features of the illness situation in addition to personality traits.

That a "true" objective measure of health status exists at all can be called into question, given the transactional/ phenomenological theoretical framework advanced here. That two individuals may hold differing perceptions of one person's symptom experience <u>is</u> supported by the framework. In this case, it is only necessary to distinguish whether the perception in question belongs to the individual who is ill, or whether the rater is a health professional or an individual other than the identified patient. Only then can the findings be interpreted appropriately. In this study, where the emphasis is on an individual's perception of his/her own illness experience, and how that perception influences other person variables, the question of objective symptom verification becomes mute.

Interestingly it has been pointed out that so-called "objective" ratings by physicians or other providers rely heavily on subjective patient histories and reports of symptoms (Costa & McCrae, 1987). These authors also observe that "well-controlled studies with objective indicators of health status are relatively rare" (p. 307). In some cases this may be a function of the state of technology as well as the type of illness confronting American health care providers. As pointed out earlier, chronic illnesses are, by definition, incurable and without proven treatment. In many cases, establishing a diagnosis is a matter of assessing subjective reports along with objective evidence, if definitive diagnostic tests are not available. Thus, uncertainty is an inherent feature of the probabilistic process of chronic illness diagnosis and/or treatment.

Chronic Illness Symptomatology

There are few non-personality-related studies involving symptomatology in the chronically ill. Those that exist typically focus on symptomatology as independent variables which predict other health outcomes. In McCorkle and Benoliel's (1983) study of patients with myocardial infarction and lung cancer, symptom distress emerged as the most influential explanatory variable for mood disturbance and current concerns. The Symptom Distress Scale (McCorkle & Young, 1978) was modified for the clinical population used in their study, and no evidence of reliability or validity is provided. Other studies focus on individual symptoms common to a particular disorder, such as pain and severity of impairment in arthritis (Burckhardt, 1985) or severity of disability (Viney & Westbrook, 1981) as they relate to outcomes such as quality of life, anger, depression, anxiety, and the like. Little attention has been given to the construction of valid and reliable measures intended for use across chronic illness populations.

Benner and Wrubel (1989) observe that in illness situations, symptoms are context-bound lived human responses to those situations. Unfortunately, there is a dearth of studies which attempt to elicit an individual's appraisal of the meaning of a particular symptom, or how problematic it may be in his/her life. Given the acknowledged relationship of cognitive appraisal to coping efforts and outcomes related to morale, social functioning and somatic health (Cohen & Lazarus, 1979), knowledge of how a symptom is appraised is fundamental to an understanding of stress-related illness effects.

In addition, there is agreement in the literature that any new or reappearing symptoms can be perceived as a treatment or management failure, or as a sign that the disease is progressing (Benner & Wrubel, 1989; Forsyth, Delaney, & Gresham, 1984). The stressful nature of symptom change has been explained in relation to perceived inconsistency or discontinuity in an established symptom pattern (Mishel & Braden, 1988). When symptoms form a particular pattern related to their number, frequency, location, intensity, and/or duration; and are perceived to be predictable, salient, and distinguishable; any remission, exacerbation, inconsistency, or unpredictability results in greater uncertainty and ambiguity about the illness condition.

The potential stressfulness of illness symptoms which change in quality or character has been acknowledged by many, and can be considered as one of the major situation factors affecting stress appraisals in chronic illness situations. Unfortunately, this important variable has been given scant attention by researchers. In one study, symptom pattern was operationalized as a one-item measure involving subject's ratings about the controllability of physical function (Mishel & Braden, 1988). The validity of this item as a measure of symptom pattern is seriously questioned. Not surprisingly, this variable did not contribute significant variance to the patient's perception of uncertainty.

It seems clear from the framework advanced that at least two types of symptom-related measures are required for research on chronic illness. The first is a method to assess the type, number, and appraised impact of illness-specific symptoms, while the second relates to a more general measure of symptom transition that assesses the degree of symptom change occurring, regardless of the particular symptom constellation.

Chronic Fatigue Immune Dysfunction Syndrome

Proposed Theoretical Mechanisms

Although the etiology and specific mechanism for the production of symptoms in CFIDS is unknown, several theoretical possibilities exist. In his review of current theories of CFIDS, Bell (1989) summarizes the current competing conceptualizations.

Simple depression was considered as an early, causative candidate for this disorder. Bell notes the propensity of physicians to use this diagnosis as a catch-all when confronted with a patient with complex, poorly understood symptoms. As research evidence of immunologic abnormalities (Behan, Behan, & Bell, 1985; Cheney, 1988; Tosato, Strauss, Henle, Pike, & Blaese, 1985; Kris, Roord, & Zegers, 1985; Komaroff, 1989), muscle metabolism and muscle biopsy irregularities were identified (Behan, Behan, & Bell, 1985), the case for primary depression as a cause of CFIDS fell into disfavor among informed clinicians and researchers. That the clinical and immunological picture and symptom pattern of CFIDS is distinct from depression and other psychiatric disorders has been generally acknowledged. In addition, the epidemic outbreaks of CFIDS-like illness which have been reported lend additional support to the non-psychiatric pathogenesis of this disorder (Kreusi, Dale, & Strauss, 1989).

The "Camel's Back Theory" (Bell, 1989) of the etiology of CFIDS presumes a fundamental immune system breakdown caused by continual system stress. This stress may be caused by a variety of person and environmental factors including viral infection, life stress, pollution, general lifestyle, etc. After reaching its limit, the immune system begins to falter, allowing chronic viral infections to assume an unusually superordinate role. In this case, the viral agent is like the straw that broke the proverbial camel's back, expressing the illness consequences as CFIDS.

The "Common End Pathway Theory" posits that there are a variety of possible etiologic factors which may result in a common symptom complex known as CFIDS. This may explain the frequent implication of various viruses, such as Epstein-Barr Virus (EBV) and Human Herpes Virus-6 (HHV-6) in the etiology of CFIDS (Berris, 1986; Jones et al., 1985; Dubois et al., 1984; Strauss et al, 1985) as well as the possible role of candidiasis (Renfro, Feder, Lane, Manu, & Matthews, 1989). Bell (1989) points out that if this theoretical mechanism is true, the search for a single causative agent is fruitless. Attention should be more appropriately directed to the particular immune mechanisms which trigger a variety of infectious agents into producing this coherent constellation of symptoms. Interestingly, significantly high levels of Interleukin-2 have been found in two CFIDS samples (Cheney, Dorman, & Bell, 1989). The lymphokine Interleukin-2 is known to produce many of the symptoms of CFIDS, including myalgias, confusion, depression, and fatigue.

The "Simple Agent Theory" of CFIDS etiology assumes that a single agent, yet undiscovered, causes the syndrome. Although predisposing factors might be implicated, including other viral conditions, CFIDS would not occur without the added presence of this "Agent X." This proposed mechanism can be contrasted with a more complex etiology that Bell calls "Agent X and a Trigger Infection." This view posits either a single agent or some "trigger infection" that can cause an outbreak. Specifically, "Agent X" causes an underlying immune dysfunction which by itself is not problematic. However, if exposed to the "trigger infection," CFIDS is fully expressed. Bell observes that different "trigger infections" could be implicated in each outbreak situation. Epstein-Barr Virus, HHV-6, Cytomegalic Virus (CMV) and other such trigger agents are considered prime agents for this etiological theory.

"Agent X and Viral Reactivation" is another possibility that Bell describes. In this scenario, reactivation of a previously dormant virus occurs. Herpes group viruses (EBV, HHV-6, CMV, and Herpes Group I & II) are considered especially good candidates for this theory, since their tendency for latency and reactivation is well established.

Bell also considers the two prevalent views for symptom production in CFIDS. These perspectives do not consider the specific etiologic agent. Instead, the focus is on the mechanism of symptom production, regardless of cause. The "Lymphokine Theory" posits that elevated lymphokines such as Interleukin 1 and 2 and alpha interferon are responsible for CFIDS symptomatology. Lymphokines are hormone-like substances which allow communication between immune system cells. As mentioned earlier, significant increases in Interleukin-2 have been documented in CFIDS samples (Cheney, Dorman, & Bell, 1989).

The "Mast Cell Theory" also attempts to explain the particular symptom constellation of CFIDS. Mast cells normally mediate allergic symptoms. The majority of CFIDS patients report allergies, and they respond poorly to allergy shots. Bell reports that the majority of these non-responding allergic patients have a deficiency in Immunoglobulin E (IgE) which is involved in mast cell degranulation. He suggests that in this case, mast cell proliferation would permit allergic symptoms without IgE mediation. He cites the clinical success of treating CFIDS patients with antihistamines or trycyclic antidepressants, which are also potent antihistamines.

Symptomatology in CFIDS

The synthesis of current theories of the etiology and symptom production in CFIDS provides a useful background for a discussion of research in CFIDS symptomatology. Despite apparent symptom consistency across subjects and inherent symptom variability, little systematic research into CFIDS symptomatology has been done. This is due, in part, to the lack of a working case definition until recently (see Holmes et al., 1988). Symptom-related reports in the literature are primarily descriptive accounts of symptom frequency drawn from small samples (Dubois et al., 1984; Jones et al., 1985; Komaroff, 1987; Strauss et al., 1985). These classic works offer no account of the symptom rating methods used or any estimate of their psychometric properties. It is clear that some standardized CFIDS symptom scale is required to improve the generalizability of findings and communications about symptom specific concerns.

Early research studies of CFIDS patients were focused primarily on the relationship of psychological factors to symptom reports. Due to the recency of the working definition for CFIDS, some studies involved samples of patients who complained of ordinary fatigue, rather than the symptom constellation diagnostic of CFIDS (see Manu, Matthews & Lane, 1988). This approach has been severely criticized for contributing to negative impressions of CFIDS sufferers, since the results indicated that chronic fatigue was associated with psychiatric disorders in a majority of subjects (Komaroff, Strauss, Gantz, & Jones, 1989). The authors critical of such studies pointed out the important distinction between chronic fatigue and CFIDS. They also note that it is possible that some patients with CFIDS might have concurrent psychiatric disorders, and that these conditions are not mutually exclusive. They also note that concurrent psychiatric conditions may actually increase the patient's vulnerability to CFIDS.

To date, only one study has explored the relationship of lifetime psychiatric morbidity with patients meeting the CFIDS diagnostic criteria. These subjects were further selected on the basis of a EBV titer (Krues, Dale, & Strauss, 1989). The twenty-eight subjects were referred from all over the U.S. to take part in a placebo-controlled study of acyclovir, an antiviral agent. As part of the protocol, subjects were interviewed using the Diagnostic Interview Schedule (DIS; Robins et al, 1981). The interview format requires subjects to indicate whether or not they have experienced certain "criterion" symptoms of psychiatric disorders. Physical symptoms always associated with CFIDS were excluded from determination of prevalence of psychiatric disorder.

Age at onset of CFIDS was compared with age of onset of psychiatric problems by retrospective self-report.

Psychiatric diagnoses were identified in 75% of the predominantly female sample. These diagnosis included simple phobia, somatization disorder, major depressive episode, dysthymia, panic/agoraphobia, alcohol abuse/dependence, and antisocial personality. Ten percent of the twenty women and 62% of the eight men did not qualify for a DSM-III diagnosis. Depressive disorders were found to occur concurrently with or subsequently to the onset of CFIDS. It should also be noted that depression accounted for the largest percent of disorders for women (55%) and men (25%).

This retrospective account suggested that CFIDS followed onset of psychiatric problems in 10 of 21 cases. Although these findings may suggest vulnerability to CFIDS that is coexistent with high EBV titers, the study suffers from several weaknesses. These include the small sample size, possible selection bias of patients willing to participate in NIH studies, as well as selection bias due to the requirement for a high EBV titer. Since Epstein-Barr Virus is known for its lifelong dormancy, it could be that the illness expression known as CFIDS, did in fact precede the onset of perceptible CFIDS symptoms. This explanation is consistent with Bell's (1989) "Agent X and Viral Reactivation Theory."

Measurement of Symptomatology in CFIDS

To date, no studies of CFIDS have involved systematic assessment of illness-related perceptions using standardized measures. Unfortunately, many of the existing general symptom measures assess symptom frequency rather than perceived symptom transition or how problematic symptoms are perceived to be (Belloc, Breslow, & Hockstim, 1971; Broadman, Erdmann, Lorge, & Wolff, 1949; Mechanic, 1980; Pennebaker, 1982). Other symptom scales are too brief and thus not inclusive of the CFIDS symptom constellation (Belloc, Breslow, &

Hockstim, 1971; Cohen & Hoberman, 1983; Mechanic, 1980). Some, like the Cornell Medical Index (Brodman, Erdmann, Lorge, & Wolff, 1949) are frequency-based, not inclusive of CFIDS symptoms, and too long for use in this population. Besides its considerable length, the Health Status Questionnaire (Belloc, Breslow, & Hockstim, 1971) combines physical symptoms with other actual and chronic health conditions. Like the scales previously mentioned, this scale was developed for use in general populations. The psychometric properties of other scales developed for use in a particular study are not reported (Mechanic, 1980; Watson & Pennebaker, 1989).

It is clear from the preceding discussion that at least two additional types of research are required in CFIDS. The first is methodological and involves the development and testing of an appraisal-based CFIDS-specific symptom-related scale, as well as a general measure of perceived symptom transition. The second is research that utilizes these measures of symptom-related antecedents of illness appraisals and stress-related outcomes. This latter type of research requires the acceptance of the paradigm implicit in the theoretical framework advanced in this chapter. Specifically, psychological stress, anxiety, and other emotional distress related variables can legitimately be viewed as consequent to the illness situation, and symptom-related variables may be rightfully studied as antecedents to these outcomes.

The only known attempt to develop a valid and reliable symptom-related measure is the De Groot Perceived Symptom Transition Scale (DPSTS). This self-report measure was designed to assess the degree to which illness symptoms are perceived to be in a state of change or transition. Symptom transition is assessed on a 5-point Likert scale according to various symptom characteristics or qualities, including overall symptom change, as well as any change in the number, type, frequency, severity, duration, location, novelty, visibility, intrusiveness, or interference with life activities. Initial psychometric evaluation of the DPSTS was performed on a convenience sample of 66 patients with Chronic Fatigue Immune Dysfunction Syndrome recruited from the practices of two San Francisco Bay Area physicians who were known to treat a large number of patients with CFIDS. The mean age of this predominantly white, female sample of college-graduates was 40 (SD=9.3, range=25-65 years). Fifty-four percent were single, separated, divorced, or widowed. Ninety-two percent worked before becoming ill, with 81% working 40 hours a week or more. Subjects reported a significant decrease in the number of hours they have been able to work since becoming ill (t=-6.41, df=39, p<.001)). Fifty-four percent had an income above $30,000.

Psychometric evaluation on a revised 9-item version of the DPSTS resulted in a standardized coefficient alpha of .81, with an average inter-item correlation of .32. Item-scale correlations ranged from .37 to .61. A principal components factor analysis with Varimax rotation yielded a two-factor solution. Items loading on Factor 1 relate to specific aspects of symptom change such as novelty, visibility, and type or kind. Items loading on Factor 2 appear to be related to a more global assessment of symptom transition, including general severity, overall change and how bothersome the symptoms are perceived.

Initial validity estimates for the DPSTS include significant correlations (alpha=<.05) in the predicted directions with subject's ratings of current health status (r=.42), perception of illness course (r=.32), current level of daily activity (r=-.26), and perception of illness prognosis (r=.24). These correlations indicate initial support for convergent validity of the DPSTS. Unexpectedly, the DPSTS was not significantly correlated with the De Groot Chronic Fatigue Syndrome Symptom Scale in this pilot study. Given the findings discussed in the next section, as well as Chapters 4 and 5, it is not clear if these findings represent evidence of divergence or are related to other unknown sample differences.

Satisfactory levels of reliability and initial support for validity were demonstrated for the DPSTS. Additional evidence of reliability and construct validity is required so that the usefulness of this measure as it relates to stress-associated outcomes can be established. Results of additional psychometric evaluation are reported in Chapter 4.

The De Groot Chronic Fatigue Syndrome Symptom Scale was also subjected to initial testing during this pilot phase. This 56-item scale was developed to serve as a CFIDS symptom inventory as well as a measure of how problematic specific-related symptoms are in daily life. Specific symptom domains include those which are general or constitutional, gastrointestinal, or related to sleep disturbance, fatigue, cognitive impairment, mood changes, central nervous system dysfunction, musculoskeletal, cardiorespiratory, integumentary involvement, and allergies. For each symptom experienced since becoming ill, subjects are asked to indicate how serious a problem that symptom is now, using a 5-point Likert Scale. The pilot evaluation focused on subjects' ability to correctly interpret scale directions and complete the scale without difficulty. Initial pilot testing resulted in some minor wording changes in the instructions to subjects. Surprisingly, the DCFSS was not significantly associated with the subjects' rating of current health status, illness course, prognosis, or level of daily activity in this pilot sample. As indicated earlier, it is not clear if this pattern of correlations represents divergence or is related to other unknown sample differences. That the DCFSS was not significantly associated with the DPSTS lends support to the latter explanation, since it is reasonable to assume a significant, but moderate, correlation between these two measures. Results of further testing for this scale is also reported in Chapters 4 and 5.

Summary

This chapter has presented a transactional view of stress and coping which emphasizes cognitive appraisal as the major determinant of how stressful a situation is perceived to be. The importance of illness-situation factors such as symptomatology was illustrated and the general lack of illness-situation and symptom-related research in chronic illness was demonstrated. The central organizing construct of uncertainty was described, and its contribution as a major source of stress in chronic illness was supported. Five domains of uncertainty in chronic illness were proposed and specific source content for uncertainty and stress appraisals in chronic illness was identified. Support for the constructs of perceived symptom transition and problematic symptoms was provided, and content for related measures was delineated.

The important study concept of hope was also discussed, as well as its proposed relationship to symptom transition, problematic symptoms, uncertainty, and anxiety. Issues related to illness symptomatology were raised and chronic illness symptomatology was further explored. The proposed theoretical mechanisms for illness etiology and symptom production in CFIDS were examined, and the general lack of symptom-related research in CFIDS was illustrated. The need for two types of valid and reliable measures were identified as well. The first relates to the construct of perceived symptom transition as it pertains to chronic illness situations in general. Only then can the effect of symptom transition be systematically illustrated. The second relates to the need for a CFIDS-specific symptom inventory which also incorporates a measure of an individual's symptom appraisal. This will increase generalization of findings related to CFIDS symptomatology, and allow assessment of the importance of symptom appraisal in this syndrome.

Assumptions and Definitions

Assumptions relevant to this study include:

1. Human beings are unique bio-psycho-social-spiritual beings who are in constant, mutual, interaction (transaction) with their environment.
2. The way a person thinks, feels, or acts is a product of person/situation transactions.
3. Some level of cognition is involved in guiding and interpreting every person/environment interchange, and that emotions are a product of cognitive activity.

4. Although some person/environment transactions are perceived as stressful, psychological stress and responses to it are not always pathological or inherently negative.
5. Psychological stress gives rise to responses which individuals attempt to manage in various ways, although "successful" management in one domain (i.e., psychological) may result in consequences in another domain (i.e., physiological). Thus, coping efforts aimed at managing the stressful situations can not be viewed as positive or negative and no a priori judgment of the efficacy of coping based upon a particular coping behavior employed can be made.
6. Chronic Fatigue Immune Dysfunction Syndrome and the symptoms associated with it are stressors for those afflicted with the condition.
7. State anxiety is a stress-related response.
8. Chronically ill individuals can perceive coherent patterns in existing illness symptoms, and thus can detect symptom changes when they occur.
9. An individual's appraisal of a particular illness situation is more predictive of emotion and state outcomes than the objective features of the situation.

Definition of Terms

The following are definitions of important study concepts:

Chronic Fatigue Immune Dysfunction Syndrome: A chronic, debilitating condition often appearing after a viral illness, which is characterized by the sudden, unexplained onset of persistent mononucleosis-like symptoms. These symptoms include debilitating fatigue that worsens with exercise and does not resolve with rest, mild fever, sore throat, lymph enlargement and/or pain, joint and muscle pain or weakness, headaches, sleep disturbance, and various neuropsychological complaints including visual disturbance, cognitive impairment, and mood disorders (Holmes et al, 1988).

Symptom Transition: The degree to which a particular illness symptom pattern or constellation is perceived to be in state of change.

Problematic Symptom Pattern: How problematic, troublesome, or difficult specific illness-related symptoms are perceived to be in an individual's daily life.

Uncertainty: A cognitive state involving the inability to interpret or assign meaning to illness-related events. It occurs when an individual has difficulty structuring or categorizing an event, assigning values or predicting outcomes (Mishel, 1988).

Hope: A dynamic life force characterized by a confident yet uncertain expectation of achieving a future goal, which, to the hoping person, is realistically possible and personally significant (Dufault & Martocchio, 1985).

Psychological Stress: A particular relationship between the person and situation that is appraised as taxing or exceeding his/her resources and endangering his/her well-being (Lazarus & Folkman, 1984)

Anxiety: A state characterized by subjective feelings of tension, apprehension, nervousness and worry, and by activation or arousal of the autonomic nervous system. This subjective state depends on the degree to which an individual perceives a specific situation to be psychologically dangerous or threatening (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983).

Research Questions

The purpose of this study is to examine the extent to which illness symptomatology affects the stress-related response of anxiety in chronic illness, and the degree to which levels of uncertainty and hope/hopelessness may mediate these effects. More specifically, this study seeks to answer the following questions:

1. Is there a relationship among symptom transition, problematic symptoms, uncertainty, hopelessness and state anxiety in CFIDS?
2. What is the influence of uncertainty and hopelessness on state anxiety in CFIDS?
3. Do levels of hopelessness affect the relationship between uncertainty and state anxiety in CFIDS?
4. What are the effects of symptom transition and problematic symptoms on state anxiety in CFIDS?
5. What are the effects of symptom transition and problematic symptoms on uncertainty and hopelessness in CFIDS?
6. Of symptom transition, problematic symptoms, hopelessness, uncertainty, which variable(s) exert the most influence on state anxiety in CFIDS?
7. Do either symptom transition or problematic symptoms have indirect effects on state anxiety in CFIDS?

An additional purpose of this investigation is to assess further the reliability and construct validity of the De Groot Perceived Symptom Transition Scale (DPSTS) and the De Groot Chronic Fatigue Syndrome Symptom (DCFSS) scale. The following additional questions make this second purpose more explicit:

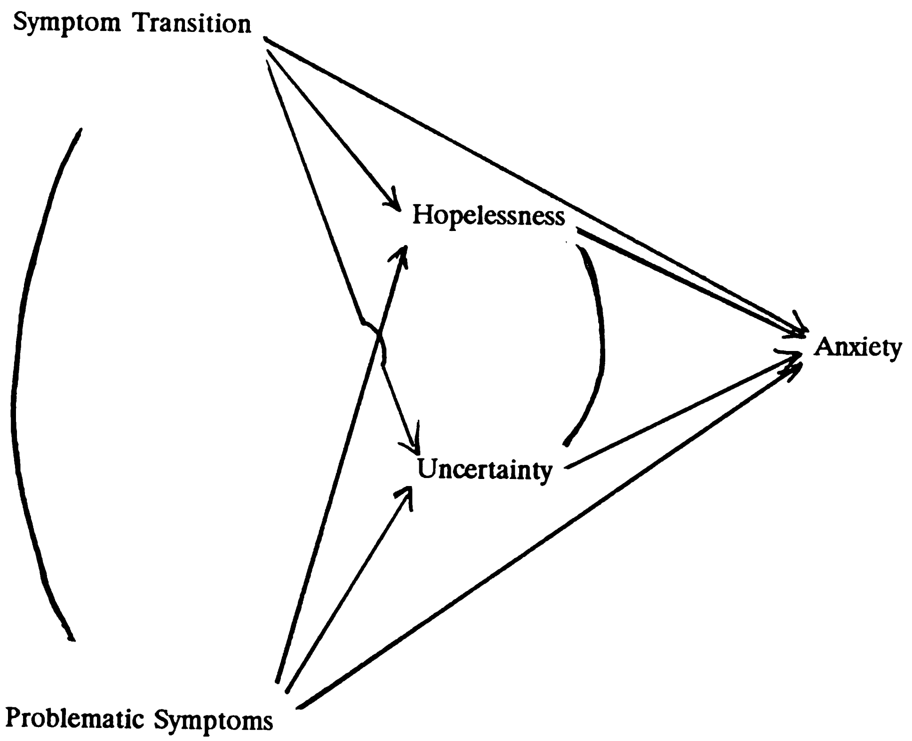
8. What is the internal consistency of the DPSTS in this CFIDS sample as measured by the coefficient alpha?

9. What is the factor structure for the DPSTS?
10. Do DPSTS and DCFSS scores correlate as predicted with subject's rating of problematic symptoms, how they feel now, perception of illness severity, course, prognosis, levels of daily activity, uncertainty, hopelessness, and state anxiety?

The model in Figure 1 presents a conceptual illustration of the proposed relationships among the major variables under study.

FIGURE 1

PROPOSED MODEL



CHAPTER 3

METHODOLOGY

Research Design

This cross-sectional descriptive survey involved a one-time mail administration of a pencil-and-paper self-report questionnaire packet to a convenience sample of 227 non-refusing subjects from California, Nevada, and Oregon. One hundred and twenty-four subjects returned completed questionnaires, representing a 55% response rate.

The rights of human subjects were protected and assured through the use of an approved consent form and research protocol (see Appendix A). Each participating physician compiled a list of patients who met the inclusion criteria. Initial contact with potential subjects was made by a letter from the prospective subject's physician. Prospective subjects were appraised of the study purpose, invited to participate and asked to return a pre-stamped refusal card if they chose not to participate in the study. A list of these prospective subjects who did not return a refusal card was made available to the investigator so that a follow-up letter and study packet could be sent. Returned study packets and all study information was coded so that no individual names were used. Records were kept in locked files and access to these files was restricted to the investigator.

Sample

The study sample consisted of 124 subjects recruited from three physicians' practices, one from the San Francisco Bay Area, one from the Incline, Nevada area and one from the Portland, Oregon metropolitan area. Selection criteria for this study included consenting adult subjects between the ages of 18 and 65 who were diagnosed with Chronic Fatigue Immune Dysfunction Syndrome, and who were able to read and write English. Subjects with concurrent chronic health conditions such as auto-immune disorders, HIV disease, cancer, and major psychiatric or neuromuscular diseases were excluded. Participating physicians developed the list of potential subjects from their active patient files. The three participating physicians were selected because of their well-known and respected expertise with CFIDS, and their general interest in research related to the disorder. Two physicians are affiliated with major university medical centers, while the other was involved in pioneering work with the initial definition of CFIDS.

A diagnosis of Chronic Fatigue Immune Dysfunction Syndrome is made when a patient fulfills certain major and minor criteria set forth in the Centers for Disease Control's case definition (Holmes et al., 1988). Major criteria include new onset of persistent or relapsing and debilitating fatigue that does not resolve with bed rest and impairs daily activity 50% or more for a period of six months or more. Other conditions such as cancer, multiple sclerosis, HIV disease, and autoimmune diseases which could cause these symptoms must be ruled out as appropriate. It should also be noted that there currently are no definitive laboratory tests for diagnosing CFIDS. Minor criteria include both objective and subjective symptoms and clinical findings, including mild fever (oral temperature between 37.5°C and 38.6°C) or chills, non-exudative pharyngitis, enlarged or painful axillary or cervical lymph nodes, unexplained generalized muscle weakness, myalgia, prolonged fatigue after exercise, unusual headaches, migratory arthralgia without joint swelling or erythema, and various neuropsychological complaints such as photophobia, transient visual scotomata, forgetfulness, excessive irritability, confusion, difficulty thinking, inability to concentrate, and depression. Other characteristic features of Chronic Fatigue Immune Dysfunction Syndrome include sleep disturbances (either hypersomnia or insomnia) as well as illness onset over a few hours to a few days. A diagnosis of CFIDS is made when both major criteria are fulfilled in addition to at least six of the symptom criteria <u>and</u> two of the physical criteria, <u>or</u> at least eight of the symptom criteria.

In order to attain an estimate of how consistently the diagnostic criteria were being applied by the diagnosing physician, approximately 50 patient charts of one participating physician were reviewed by a research assistant in the pilot phase and 150 charts were reviewed for concurrence by the investigator for this study. The concurrence was estimated to be 93%. This consistency is not surprising since all three physicians participating in the Study Phase are known to treat a large number of CFIDS patients and have been involved in other studies.

Data Collection Methods

Data collection techniques involved administration of a mailed, pencil-and-paper, self-report questionnaire packet as well as chart review. In addition to informed consent forms and the Experimental Subjects Bill of Rights, the CFS study packet (see Appendix B) contained a general CFS Questionnaire, the De Groot Perceived Symptom Transition Scale, the De Groot Chronic Fatigue Syndrome Symptom Scale, the Mishel Uncertainty in Illness Scale (Mishel, 1981), the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974), and the STAI-Form Y (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1988).

The CFS Questionnaire was developed for this study and contains items related to general demographic information, health history, perceptions of current health status, and prognosis.

The De Groot Perceived Symptom Transition Scale (DPSTS). The version of the DPSTS tested in this study was a 13-item 5-point Likert scale designed to assess the degree to which particular illness symptoms are perceived to be in a state of change or transition (see Appendix C). Symptom transition is assessed according to various symptom characteristics or qualities, and includes overall symptom change, as well as any change in the number, type, frequency, severity, duration, pattern location, novelty, visibility, intrusiveness, or interference with life activities.

Despite adequate initial estimates of reliability and validity as presented in Chapter 2, three additional items were added to the current version of the DPSTS. These items are intended to add content domains not specified in the first version, such as frequency and number of symptoms (items 8 and 13) as well as general symptom interference (item 6). One item was reworded to clarify the intent of an initial item which did not perform well (see item 13). Results of additional reliability and validity assessment are discussed in Chapter 4.

The De Groot Chronic Fatigue Syndrome Symptom (DCFSS) Scale. This 56-item scale was developed to serve as a symptom inventory as well as a measure of how problematic specific illness-related symptoms are in daily life (see Appendix D). Specific symptom domains include those which are general or constitutional, gastrointestinal, or related to sleep disturbance, fatigue, cognitive impairment, mood changes, central nervous system dysfunction, musculoskeletal, cardiorespiratory, integumentary involvement, and allergies. For each symptom experienced since becoming ill, subjects are asked to indicate how serious a problem that symptom is now, using a 5-point Likert Scale. Initial pilot testing resulted in some minor wording changes in the instructions to subjects. Interestingly, age was found to be inversely associated with the total number of reported symptoms (r=-.39, p<.001) in the pilot sample. The mean age for this predominately female pilot sample (n = 66) was 40 years old (SD=9.3, range=25-65 years). Gender was not correlated with the number of symptoms and neither age nor gender were associated with the mean scale score. However, the mean scores for musculoskeletal problems were significantly associated with current levels of daily activity (r=.26, p<.001). Results of further validity testing of this new scale is discussed in Chapter 4.

The Mishel Uncertainty in Illness Scale (MUIS). This 34-item scale (Mishel, 1981) is designed to measure adult patient's perceptions of uncertainty as it relates to symptomatology, diagnosis, treatment, relationship with care givers, and prognosis (see Appendix E). The coefficient alpha is .91 for the total scale and item-to-total correlations range from .44 to .71. Results of factor analysis demonstrate a 4-Factor structure comprised of Ambiguity (Factor 1), Complexity (Factor 2), Deficient Information (Factor 3), and Unpredictability (Factor 4). The MUIS discriminated between diagnostic work-up patients and those with a confirmed diagnosis, with work-up patients having higher scores. Uncertainty was also highly correlated with hospital stress. The 28-item Community form of the MUIS was used in this study. The Community form of the MUIS differs from the original version in that items related to the inpatient experience were deleted. For example, items such as "I do not know when to expect things will be done to me" and "It's vague to me how I will manage my case after I leave the hospital" were dropped from the scale. Normative data on patients with lupus, post-myocardial infarction (MI), irritable bowel disease, arthritis, and other diagnoses (Table 4) demonstrate coefficient alphas ranging from .86 to .93, with a mean score of 65 for the combined sample of lupus and post-MI patients (n=187).

The Beck Hopelessness Scale (BHS). This 20-item, true-false scale was designed to measure the extent of negative attitudes or expectancy about the future (see Appendix F). Kuder-Richardson-20 reliabilities for seven clinical samples ranged from .87 to .93. Test-retest reliability at one week was reported to be .69 ($p<.001$) and .66 ($p<.001$) at six weeks for a different sample. Point-biserial item-total correlations for seven samples were significant beyond the .01 level, with the majority of correlations greater than .50 for each sample. Results of a principal components factor analysis reveal three factors. Factor 1 relates to Feelings about the Future, while Factor 2 refers to the Loss of Motivation. Factor 3 involves Future Expectations. Numerous studies have established the concurrent and predictive validity of the BHS. For example, BHS scores correlated with the Stewart Future test as well as clinical ratings of hopelessness in various samples. Several studies showed the BHS sensitive to changes in levels

TABLE 4

Normative Data

Community Form - Uncertainty Scale

Data Set	$\bar{X}$	SD	Coefficient Alpha
Lupus N = 84	78.3	14.0	.86
Post MI N = 103	54.4	12.9	.89
All Cases N = 187	65.0	17.9	.93

of depression as predicted over treatment course, as well as predictive of the seriousness of suicidal intent and patient's reaction to a successful experience. As predicted, BHS scores were inversely related to morale and social functioning in chronic heart failure patients. Interestingly, no difference in BHS mean score was found between chronically ill and acutely ill patients or between the entire physically ill samples and adults in general (see Table 5). The maximum score on the BHS is 20. Mean scores of 0-3 are considered normal, 4-8 is considered mild hopelessness, 9-14 is moderate and greater than 14 indicates severe hopelessness.

The State-Trait Anxiety Inventory (STAI) Form-Y. The well-known STAI was designed to measure both State anxiety (S-anxiety), or the situation-related subjective feeling of tension, apprehension, nervousness and worry, as well as Trait anxiety (T-anxiety), the more stable and enduring propensity for anxiety-proneness. A person with a high score on T-anxiety exhibits the tendency to respond to threatening events with more anxiety than those with a lower score. Form-Y of the STAI represents a major revision over Form-X that has resulted in a "purer" measure of anxiety which is more independent of depression (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Form-Y has been tested on over 5,000 subjects. (See Appendix G). Alpha coefficients for S-anxiety range from .90 to .94 for working adults in three age groups. T-anxiety alpha coefficients range from .89 to .92 in these same groups. Median item-total correlations range from .53 to .64 for the various groups. Various test-retest reliability estimates demonstrate high stability of T-anxiety and low stability for S-anxiety. The median correlation between S- and T-anxiety is .65. Factor analysis of all items of the STAI yielded a 2-factor solution in one group and a 4-factor solution in another. In both groups, the factors discriminated between S-anxiety and T-anxiety. In addition, there were significant differences between psychiatric and non-psychiatric patients, and convergent validity was demonstrated by significant correlations with various other anxiety measures. S-anxiety scores were found to be

TABLE 5

Selected Normative Results for the Beck Hopelessness Scale

Author/Year	Sample	N	$\bar{X}$	SD
Beck, Kovacs & Weissman (1975)	Suicide Attempters	384	9.0	5.5
	Schizophrenics	98	7.6	NR
	Depressives	193	9.3	NR
Taylor (1978)	College Students			
	Males	60	2.3	2.2
	Females	74	2.4	1.8
Greene (1981)	Irish Adults (Random Selection)	396	4.4	3.1
Greene, O'Mahoney & Runlasamy (1982)	Hospitalized Patients	60	3.7	2.7
	Chronically Ill	30	4.2	3.2
	Acutely Ill	30	3.2	2.1
Durham (1982)	Forensic Patients	99	6.6	4.9
	Psychiatric Patients	118	6.0	4.7
	College Students	197	2.3	2.2
Mendonca, Holden, Mazmanian & Dolan (1983)	Psychiatric Patients	27	7.1	4.5
	Suicide Ideators	41	11.3	5.6
	Suicide Attemptors	10	10.2	6.3

Note: NR = not reported.

substantially higher for two samples of students under various forms of stress. Selected normative data for the STAI is illustrated on Table 6.

Procedure

Prospective subjects who did not return a refusal card were sent a follow-up letter, study packet and a stamped addressed return envelope. Subjects were asked to return completed study packets and a signed copy of the consent form. The study packets contained pencil-and-paper self-report measures arranged in the following order: general CFS Questionnaire, the De Groot Chronic Fatigue Syndrome Symptom Scale, the De Groot Perceived Symptom Transition Scale, the Mishel Uncertainty in Illness Scale, the Beck Hopelessness Scale and the STAI-Form Y (See Appendix B).

Data Analysis

All data analysis procedures for this study were carried out using the microcomputer-based CRUNCH Software• Statistical Package (CRUNCH Software, Inc., 1987). Single-order correlational analysis relied on the use of pairwise deletion for missing data. Mean substitution was used to calculate the total scale and/or subscale scores for the MUIS, the DPSTS, the STAI, and the DCFSS when missing data were encountered.

The general analytic strategies employed in this study included the use of direct, single-order correlations among the variables for research question #1. Research questions #2 through #7 involved a series of multiple regressions using different variables in the model as dependent variables.

Specifically, research question #2 involved a one-step regression of uncertainty and hopelessness on state anxiety in which uncertainty and hopelessness were forced in as a set at

TABLE 6

Normative Data for the STAI

Sample	N	S-Anxiety X̄	S-Anxiety SD	T-Anxiety X̄	T-Anxiety SD
Working Adults					
Male	1387	35.7	10.4	34.9	9.2
Female	451	35.2	10.6	34.8	9.2
College Students					
Male	324	36.5	10.0	38.3	9.2
Female	531	38.8	11.9	40.4	10.1
Military Recruits					
Male	1893	44.0	12.2	37.6	9.5
Female	71	47.0	14.4	40.0	9.9
Neuropsychiatric Patients	461	47.7	13.2	46.6	12.4
Medical-Surgical Patients	161	42.4	13.8	41.9	12.7
With Psychiatric Complaints	34	42.3	15.7	41.3	12.5
Without Psychiatric Complaints	110	42.7	13.8	44.6	10.5

the first step. These results allow for an assessment of the unique contribution of these variables to state anxiety at this step of the proposed model.

Research question #3 involved a two-step hierarchical regression on anxiety, with uncertainty and hopelessness forced in at step one. An interaction term involving hopelessness and uncertainty was forced in at step two to determine the possible differential effects of hope.

Research question #4 involved a one-step regression of symptom transition and problematic symptoms on state anxiety. These two variables were forced in at step one, allowing for an assessment of their unique contribution to variance in state anxiety.

Research question #5 involved a series of two regressions, with uncertainty as the dependent variable in one regression and hopelessness as the dependent variable in the other. In both regressions, symptom transition and problematic symptoms were forced in at step one, in order to determine their individual effects on uncertainty and hope.

Research question #6 involved a two-step hierarchical regression on state anxiety. In the first step, symptom transition and problematic symptoms were forced in, while the second step involved forcing in hopelessness and uncertainty as a set. This regression allows for overall assessment of the relative strength of the proposed model. Those variables with the largest significant Beta weights are considered to be the strongest predictors in this model.

Research question #7 involved using the Beta weights from three regressions as path coefficients for the proposed model and examining the results for direct and indirect effects. Specifically, the Beta weights from the regression results for research questions #5 and #6 were used. In addition, the Beta weights from the last step of the regression performed for research question #6 were also included.

Several assumptions underlie the use of multiple regression procedures (Asher, 1976; Kerlinger & Pedhazur, 1973). Among these are the assumption of a zero mean of the residuals, homogeneity of error variance, normality of residuals, and independence of error terms.

Although regression procedures are generally considered to be robust to assumption violations (Asher, 1976; Bohrnsted & Carter, 1971; Kerlinger & Pedhazur, 1973), others have noted the serious problem in parameter estimation which may occur if several violations occur in combination (Belsley, Kuh, & Welsch, 1980; Hey, 1974). Verran and Ferketich (1984) advocate assessing the nature and extent of the violations and basing any acceptance of violation upon: 1) its magnitude; 2) whether it occurs alone or in combination with others; 3) amenability to correction; 4) other violations which occur as a result of the correction.

In this study, the regression assumptions of linearity were initially examined by inspection of scatter plots of the various dependent variables against the independent variables. The assumption of zero mean of the error term was assessed by inspection of the mean of the unstandardized residuals for each regression equation (Lewis-Beck, 1980; Verran & Ferketich, 1987). Plotting standardized residuals against the predicted dependent variable for each regression equation allowed for the assumption of homoscedasticity, or equality of variance, to be assessed (Cohen & Cohen, 1983; Verran & Ferketich, 1984). Normality was assessed by graphic analysis of residual distributions with a histogram overlay (Verran & Ferketich, 1984). Careful inspection of the results of these tests revealed no major violations requiring correction. It should also be noted that a power analysis (Cohen & Cohen, 1983) revealed that with a sample size of 124, a moderate effect size of .30 had a 92% probability of detection at a .05 alpha level. Specific detail on the regression procedure used for each research question follows.

Research question #8 involved the assessment of the coefficient alpha as a test of the internal consistency of the De Groot Perceived Symptom Transition Scale. Research questions #9 through #11 relate to additional validity assessment that was performed for the DPSTS and DCFSS. Research question #9 was addressed through the use of a principal components factor analysis and Varimax rotation, to determine the general factor structure for the DPSTS. In addition, research questions #10 and #11 were addressed by assessment of single-order correlations among the two scales and various measures identified in the research questions. It should be noted that, in addition to the scales measuring uncertainty, hope and state anxiety discussed earlier, the subjects' rating of how they feel now, perception of illness severity, course, prognosis, and levels of daily activity were measured by items on the CFS Questionnaire. The predicted directions of validity coefficients for the DPSTS and the DCFSS are illustrated in Figure 2.

FIGURE 2

PREDICTED DIRECTIONS OF VALIDITY COEFFICIENTS FOR THE DPSTS AND DCFSS

	SERIOUS	FEELNOW	COURSE	PROGNOSIS	ACTIVITY	MUIS	BHS	S-ANXIETY	DSTS	DCFSS
DPSTS	+	+	+	+	-	+	+	+		+
DCFSS	+	+	+	+	-	+	+	+	+	
Subscales										
gastrointestinal										
constitutional	+	+	+	+		+		+		
sleep disturbance	+	+	+	+		+	+	+		
fatigue	+	+	+	+	-	+	+	+		
cognitive	+	+	+	+		+	+	+		
mood	+	+	+	+		+	+	+		
neurological	+	+	+	+		+				
musculoskeletal	+	+	+	+	-	+				
integumentary										
allergy										
cardiorespiratory	+	+	+	+	-					

CHAPTER 4

RESULTS

Preliminary Analysis

Sample Demographic Characteristics

Descriptive statistics for this study were used to assess general characteristics of the sample. The mean age of study subjects was 40 years old (SD=9.4, range=18 to 65 years), with females comprising 78% of the sample. Thirty-eight percent of the sample reported attending but not graduating from college, while a full 51% reported obtaining a college or graduate degree. Seven percent of the sample reported graduating from high school, while only 3% reported completing grades 1-11. Ninety-three percent of the subjects were white and 59% reported that they were married. Of those who reported being single, separated, divorced, or widowed, one-third reported having a steady partner. Well over one-half (57%) reported that no children lived with them in the household, while another 30% reported that no more than two children lived with them. Ninety-three percent reported that they considered themselves to be heterosexual, while the remaining 7% indicated they were homosexual.

Although the majority of subjects reported earning $30,000 or less per year (53%), 47% reported earning $31,000 or more per year, while a full 23% reported earning more than $51,000. Ninety-two percent of the subjects reported working before becoming ill, with 43% working 40 hours per week and 39% working 45 or more hours per week. Over half of the subjects (52%) reported employment in technical, professional, or executive/administrative occupations, while 25% reported employment in secretarial/clerical, unskilled labor or service occupations. The remaining subjects (23%) reported that they were students, homemakers, or employed in other positions. Fifty-eight percent of the subjects reported that they currently work, with the average subject working 32 hours per week. This represents a significant decrease in the number of hours they reported being able to work since becoming ill (t=-11.53; df=105, p<.05).

Subjects reported having been ill an average of 66 months, or 5.5 years (SD=55.5, range=18 to 408 months). They also reported having seen a physician an average of seven times over the past six months, and 33 times over the past two years. Study participants reported a mean time of nine months from when they first became ill to when they first went to see a physician about their illness. Twenty-seven months was the average length of time reported from the first doctor visit to the actual diagnosis, suggesting that these subjects dealt with diagnostic uncertainty for a long time. Subjects reported having been ill on an average of almost 2 1/2 years since their diagnosis.

The majority (65%) of subjects perceived the cause of their illness to be a combination of life stress, work stress, a virus and/or toxic chemical exposure. However, a full 24% report that the cause of their illness is unknown. Eighteen percent of this sample attribute their illness solely to a viral cause.

The majority (63%) of study participants identified a relatively rapid onset of their illness, consistent with the CDC's major diagnostic criteria. Those reporting the more gradual onset of five weeks to one year (37%) frequently cited difficulty in determining the precise onset, since it seems like a bad flu that never went away.

Feeling unusually tired, fatigued, or lack of energy was cited as one of the top three symptoms presently causing the most difficulty, problem, or concern by 67% of the subjects. This unusual fatigue was cited as the number one problem by 39% of the respondents, considered to be the number two problem by another 17%, and identified as the number three problem by 13% of the sample. Other symptom candidates for the number one problematic symptom were headaches (10%), followed by difficulty thinking, following directions, or making calculations (3%).

Symptoms considered to be the second most problematic were muscle aches and pains (8%) and difficulty concentrating (7%). The third-ranked symptoms, aside from fatigue, include headaches (9%) and joint pain (9%). These findings are consistent with the existing literature as well as subscale scores on the DCFSS. The fatigue subscale scores were the highest among the nine DCFSS subscales ($\bar{X}$ = 4.1), followed by cognitive impairment ($\bar{X}$ = 3.3), musculoskeletal ($\bar{X}$ = 3.05), mood ($\bar{X}$ = 3.05), and sleep disturbance ($\bar{X}$ = 2.96).

The majority of subjects perceived their illness to be fairly serious (Serious), with 75% rating it moderately serious, very serious, or extremely serious. Only 9% of respondents considered their illness as not serious. Interestingly, when subjects were asked to rate how they felt <u>today</u> (Feel Now), the modal response was "no better or worse than usual" (33%), while 25% reported that they felt worse than usual. Forty-two percent of the subjects reported feeling better than usual. Many subjects wrote unsolicited remarks next to the scale indicating that how they felt fluctuated from day to day and week to week.

Subjects' perceptions of illness course (Course) are equally revealing. Thirty-eight percent of subjects perceived they were improving, and 4.8% believed they have totally recovered from their condition. However, 26% reported that their illness fluctuates too much for them to tell whether they are improving or not. Another 15% believed their illness has not changed for better or worse, while 16% believed their condition is getting worse over time.

Subjects' mean rating of current level of daily activity (Activity) on a scale of 1 to 10 was 5.2, consistent with one of the CDC's major diagnostic criteria for CFIDS. Only 21% rated their current level of activity at 7 or more, while 55% rated their activity at 5 or less. Once again, many subjects wrote unsolicited comments about the variability of activity with this illness.

When asked to describe their belief about their illness/condition in the future (Prognosis), it is interesting to note that 36% believed it would improve, and another 30% believed it would go away completely, indicating a hopeful prognosis. Another 18% believed that their illness would remain unchanged, while a full 16% believed it would worsen or lead to their death. Not surprisingly, subjects rating of poorer illness prognosis correlated highly with hopelessness ($\underline{r}$=.52, p<.0001).

The overall profile of this sample is that of well-educated, well-paid, career-oriented, middle-aged females who have been chronically ill for some time. Although it reportedly took a relatively long time, on the average, to establish their diagnosis, subjects are well into a post-diagnosis period. They report the fluctuating nature of their illness course and the problematic nature of their symptoms, but remain generally hopeful that their condition will improve.

Instrument Reliability and Validity

One of the stated aims of this study was to assess further the reliability and construct validity of the De Groot Perceived Symptom Transition Scale and the De Groot Chronic Fatigue Syndrome Symptom Scale. These aims are specifically reflected in research questions #8 through #11. Results of the psychometric evaluation of the reliability of these scales as well as other instruments used in the study will be presented in this section.

DPSTS Reliability

Initial assessment of the internal consistency of the 13-item DPSTS resulted in a standardized coefficient alpha of .92. Nunnally (1978) proposes that .80 is the minimum acceptable level for a new scale, and that .90 is the preferred minimum for applied settings if decisions are to be made based on the scores. The average inter-item correlation was .47, closely approximating the $\geq$ .5 criteria set by Nunnally.

Item-scale correlations ranged from .39 to .77, with one item falling below the $\geq$ .5 criterion. This item (#9 on the initial version of the DPSTS) also performed poorly on the initial pilot study. Item content involved symptom transition related to symptoms spreading to new areas of the body. Since this general content domain was covered by other DPSTS items (e.g. #2 & #10) and the item performance was poor, it was dropped from the scale.

The reliability of the revised 12-item version of the DPSTS (Figure 3) was then re-evaluated. Standardized alpha was found to be .93, indicating a high degree of internal consistency. The average inter-item correlation was .51, representing a slight improvement over the initial version. Item-scale correlations clearly met Nunnally's $\geq$ .5 criterion for all items on the revised scale (See Table 7).

Reliability of Other Instruments

It should be noted that reliability was assessed for the other standardized measures used in this study. In this sample of 124 subjects with Chronic Fatigue Immune Dysfunction Syndrome, the standardized alpha was .93 for the Beck Hopelessness Scale, .88 for the Mishel Uncertainty and Illness Scale, .96 for State Anxiety, and .93 for the Trait Anxiety measure. These high levels of internal consistency serve to reduce the possibility of unreliability as a major source of error in this study.

DPSTS Validity

Establishing the validity of the DPSTS involved two stages: initial assessment of content validity and empirical assessment of construct validity. Both phases will be addressed in the section that follows.

FIGURE 3

DE GROOT PERCEIVED SYMPTOM TRANSITION SCALE

Think about the symptoms of your illness or condition over the **PAST WEEK.** Compare your **present** symptoms to the symptoms you had **before** this week. Then, indicate how much you agree or disagree with the following statements by using the five point scale which follows each statement: 1 = **Strongly Disagree**; 2 = **Disagree**; 3 = **Undecided or Unsure**; 4 = **Agree**; 5 = **Strongly Agree**. Circle the **one** number which most closely fits your experience over the **PAST WEEK.**

		SD	D	U	A	SA
1.	Overall, my symptoms are getting better.	1	2	3	4	5
2.	I have more types/kinds of symptoms than I did before.	1	2	3	4	5
3.	I am free of symptoms more often now.	1	2	3	4	5
4.	I notice my symptoms more often now.	1	2	3	4	5
5.	My symptoms are not as bad/severe as they have been.	1	2	3	4	5
6.	My symptoms interfere with my life more now.	1	2	3	4	5
7.	My symptoms seem to last for a longer time now.	1	2	3	4	5
8.	I have a greater number of symptoms now.	1	2	3	4	5
9.	I have new symptoms that I have not felt before.	1	2	3	4	5
10.	My symptoms are more visible to others than they have been.	1	2	3	4	5
11.	My symptoms don't bother me any more than they usually do.	1	2	3	4	5
12.	I experience my symptoms less often now.	1	2	3	4	5

TABLE 7

Reliability of the DPSTS

Alpha: 0.9249 Standardized Alpha: 0.9251

Minimum Interitem Correlation:	0.297
Maximum Interitem Correlation:	0.833
Average Interitem Correlation:	0.507

Item	Label	Item - Scale Correlation
1	General symptom status	0.777
2	Symptom diversity	0.720
3	Symptom pattern	0.726
4	Symptom awareness	0.573
5	Symptom severity	0.714
6	Symptom interference	0.760
7	Symptom duration	0.709
8	Symptom number	0.761
9	Symptom novelty	0.658
10	Symptom visibility	0.601
11	Symptom intrusiveness	0.515
12	Symptom frequency	0.690

Content Validity

According to Nunnally (1978), content validity is concerned with sampling adequacy and the degree to which a measure reflects the content of the specified domain. He identifies two standards for assuring content validity: 1) a representative collection of items, and 2) "sensible" methods of test construction (p. 92). To ensure a representative collection of items, initial construction of the DPSTS involved extensive literature review, consultation with clinical experts and input from patients who were chronically ill.

As discussed in Chapter 2, the literature is replete with examples of the general and specific types of symptom transition that are problematic for the chronically ill. Once a general outline of the content domain was formulated, it was subjected to review by a doctorally prepared nurse expert in chronic illness research as well as a master's prepared clinical specialist. Item content was added or revised based upon their analysis and remarks. Additional input was obtained from several chronically ill individuals who had CFIDS, arthritis, and other auto-immune disorders. Input was also sought from three physicians with internal medicine practices. Two physicians are affiliated with major university medical centers on the West Coast, and one has a private practice in Nevada.

In order to capture the variability of symptom transition in a way that could be easily quantified, a scale format was necessary. Due to the generally fatiguing nature of chronic illness in general and CFIDS in particular, a simple scale format which was brief and easy to use was sought. For this reason, a five-point Likert (1932) scale was selected. Although some disagreement may exist as to whether these scales constitute ordinal or interval level measures, Nunnally (1978) acknowledges the practicality and appropriateness of considering them to be interval scales. This assertion allows the averaging of scores and the application of more powerful parametric analytic strategies (Polit & Hungler, 1983; Wonnacott & Wonnacott, 1984).

The DPSTS items were designed to tap both general and specific domains of symptom transition. These included general symptom status, diversity, pattern (continuous vs. intermittent), severity, interference, duration, number, novelty, location, visibility, intrusiveness, and frequency. Once the DPSTS items were transformed into a Likert format, care was taken to have an approximately equal number of positively and negatively worded items to avoid response bias (Nunnally, 1978). The scale and instructions for completion were again subjected to review by clinical and research experts for clarity prior to pilot testing. During the initial pilot test and study phase, a space for written comments was provided on the instrument so that subjects could comment on any aspect of the scale that they desired. None of the 66 respondents in pilot phase or the 124 subjects in the study phase included any comments related to their lack of understanding about the completion of the scale or its meaning.

Adequate levels of internal consistency have also been cited as circumstantial evidence of content validity (Nunnally, 1978). However, Nunnally reminds us that content validity inevitably "rests mainly on appeals to reason regarding the adequacy with which important content has been sampled and on the adequacy with which the content has been cast in the form of test items" (p. 93).

Construct Validity

Empirical validation testing of the DPSTS involved two primary strategies. First, exploratory factor analysis (Kim & Mueller, 1978a) was undertaken to ascertain the minimum number of underlying factors or dimensions that might account for the covariation observed. Second, evidence of convergence was sought in an effort to establish the evidence of construct validity.

Factor Analysis

Although factor analysis and the resultant "factorial composition" is related to each type of validity, it is considered fundamental to construct validity (Nunnally, 1978). As such, factor analysis is used to determine the underlying structure of a construct through psychometric statistical methods. In the words of Cattell (1965), factor analysis involves making "invisible influences visible" (p. 191).

Two assumptions are fundamental to the use of factor analysis (Kim & Mueller, 1978a), the first called the *Postulate of Factorial Causation*, assumes that an underlying causal variable is related to the observed variables, and that these observed variables are linear combinations of that underlying cause. Adopting the second assumption, or *Postulate of Parsimony* requires the acceptance of the most parsimonious factor model that is meaningful or interpretable. Three basic steps are involved in factor analysis (Kim & Mueller, 1978b, p. 11): 1) preparing the relevant correlation/covariance matrix, 2) extracting initial factors, and 3) rotating to a terminal solution.

In this study, a Principal Components factor analysis with Varimax rotation (Kaiser, 1958) was applied to the twelve-item DPSTS in order to determine the number of factors underlying the construct of perceived symptom transition. The Principal Components factor extraction method maximizes the sum of squared loadings of each factor extracted (Nunnally, 1978). Nunnally asserts that the component factors obtained by this method will explain as much as or more total variance than any other method. Additionally, this approach summarizes the data without hypothesizing the shared variance assumed by the common factor analysis approach.

The Principal Components analysis of the DPSTS yielded a two-factor solution, indicating that two factors met the Kaiser criterion with an eigenvalue ≥ 1 (See Table 8). These two factors were then subjected to a Varimax rotation in order to achieve the most

TABLE 8

Principal Components Analysis

	Eigenvalue	Percent	Cumulative Percent
1	6.6435	55.36	55.36
2	1.3170	10.98	66.34
3	0.7668	6.39	72.73
4	0.7196	6.00	78.72
5	0.5796	4.83	83.55
6	0.4601	3.83	87.39
7	0.3719	3.10	90.49
8	0.3445	2.87	93.36
9	0.2776	2.31	95.67
10	0.2221	1.85	97.52
11	0.1623	1.35	98.88
12	0.1350	1.12	100.00

simplified orthogonal solution that was interpretable. This rotation method achieves what is referred to as "simple structure" (Cattell, 1965) by tending to result in items or variables with higher loadings on some factors and very low loadings on others. Factor loadings are correlations between individual variables/items and factors, and as such are estimates of the contribution of each variable/item to the factor. Eigenvalues are the sum of the squared loadings.

Table 9 illustrates the Varimax rotated loadings for each factor as well as the commonalities (h^2), or contribution of each item to the total explained variance. A loading criterion of ≥ .40 then was used to determine factor composition.

The seven items loading on Factor One appeared to be related to specific aspects and impact related to symptom transition or change, such as diversity, awareness, interference, duration, number, novelty, and visibility. The five items on Factor Two appeared to be related to a more global assessment of symptom transition, including general symptom status, overall pattern, severity, intrusiveness, and frequency pattern.

It should be noted that detailed inspection of the results of the factor analysis revealed that two variables (Item #6 & #11) did not load "cleanly" on a single factor. This was indicated by less than a .2 spread separating the individual factor loadings. While Kaiser (1958) asserts that the Varimax rotation will provide the best orthogonal simple structure, it is not guaranteed that the structure will in fact be simple. The Varimax rotation improves the likelihood of attaining a simple structure, however. In this case, these findings suggest that the two variables are factorially complex (Kim & Mueller, 1978b). Given the complex, evaluative nature of the construct of perceived symptom transition, this finding is not unexpected.

TABLE 9

Principal Components With Varimax Rotation for DPSTS

Variable	Label	Factor 1	Factor 2	h^2
1	Symptom status		.79	.78
2	Symptom diversity	.83		.76
3	Symptom pattern		.89	.85
4	Symptom awareness	.53		.41
5	Symptom severity		.76	.69
6	Symptom interference	.61		.65
7	Symptom duration	.73		.66
8	Symptom number	.86		.82
9	Symptom novelty	.82		.70
10	Symptom visibility	.65		.50
11	Symptom intrusiveness		.47	.34
12	Symptom frequency		.87	.79
	Eigenvalue	6.64	1.32	
	% of Variance	55.36	10.98	
	Cumulative % of Variance	55.36	66.34	

Convergence

Nunnally (1978) has synthesized the prevailing view of construct validation approaches, noting three major aspects. The first involves specifying a domain of observables, while the second involves testing relations among observables. The third aspect of construct validation involves testing relations among constructs. Nunnally points out that, assuming internal consistency of different measures in a domain, sufficient evidence for construct validity requires that a measure *behaves as expected*. He also observes that:

> In one lifetime each scientist can perform only a relatively small number of major studies, and consequently there is no time to do all that is required to specify the domain of a construct, develop measures of the construct, and relate those measures to other variables of interest (p. 100).

Major aims of this study have been to initiate specification of a new construct related to perceived symptom transition, to test the structural properties of a newly-developed measure of this construct, and to examine its relationship to other constructs. Recognizing the fundamental truth of Nunnally's latter observation, initial construct validation efforts were specifically focused on the relationship of perceived symptom transition to other constructs and variables. Due to the acknowledged difficulty of finding adequate measures to demonstrate divergence (Nunnally, 1978) efforts were specifically directed towards evidence of convergence.

As conceived, the perception of symptom transition has no inherent valence. However, perceived symptom transition is likely to be associated with "negative" outcomes if the transition is appraised as stressful or problematic. In this case, the expected pattern of correlations would necessarily involve the significant positive association of perceived symptom transition and problematic symptoms when the associations among symptom transition, uncertainty, hopelessness, and state anxiety were also positive and significant. Since symptom variability has been identified as a particularly potent stressor in CFIDS, this pattern of correlations among major study variables appeared most likely. According to the theoretical framework advanced in Chapter 2, this pattern of correlations may not hold for other populations who are likely to view symptom transition in a more positive light, such as those who are going into remission.

In addition to the predicted associations noted above, if perceived symptom transition is appraised as a critical juncture in illness course, it should correlate with a measure of perceived illness course, seriousness of illness, and a rating of how the individual feels now. Similarly, if perceived symptom transition portends a negative change in illness course, it is also reasonable to expect it to be associated with a poorer perception of illness prognosis and a lower level of daily activity in an illness in which fatigue is such a prominent feature.

It should be noted that problematic symptoms were measured by the DCFSS scale (to be discussed further in the following section), while seriousness of illness was measured by an item on the CFS Questionnaire. Hopelessness was measured by the Beck Hopelessness Scale, and the Mishel Uncertainty in Illness Scale was used as a measure of uncertainty. State anxiety was measured by the S-anxiety scale of the STAI-Form Y. An individual's rating of how he/she currently feels, as well as the variables of illness course, activity, and prognosis are measured by items #22, #23, #24, and #25 on the CFS Questionnaire. A Type I error rate of .05/9 or .005, was used to evaluate the significance of each validity coefficient.

As Table 10 reveals, the DPSTS was significantly correlated in the predicted directions with problematic symptoms, perception of illness course, perception of seriousness of illness, as well as the subject's ratings of how he or she currently feels. In addition, the DPSTS was significantly associated with poorer perceptions of illness prognosis as well as decreased daily activity level ($\underline{r}$=-.66, p<.0001). As expected, increased symptom transition was associated with increased uncertainty and hopelessness ($\underline{r}$=.44 and $\underline{r}$=.34, p<.0001). Higher DPSTS scores were also correlated with higher state anxiety scores ($\underline{r}$=.51, p<.0001). The magnitude of the DPSTS

TABLE 10

Validity Coefficients for the DPSTS

	PROBLEMATIC SYMPTOMS	COURSE	SERIOUS	FEEL NOW	PROGNOSIS	ACTIVITY¤	UNCERTAINTY	HOPE-LESSNESS	STATE ANXIETY
DPSTS									
r	.63	.73	.53	.66	.55	-.66	.44	.34	.51
r^2	.40	.53	.28	.44	.30	.44	.19	.12	.26

Note: $p < .0001$ for all correlations
¤ - Lower score = poorer rating

correlations, although relatively high for most of the variables, does not suggest redundancy of measures. Table 10 appears to demonstrate initial evidence for the convergent validity of the DPSTS. Other issues related to the demonstration of construct validity through divergence will be addressed in Chapter 5.

DCFSS Validity

The De Groot Chronic Fatigue Syndrome Symptom Scale is a 56-item scale developed to serve as a CFIDS symptom inventory as well as a measure of how problematic CFIDS-related symptoms are perceived to be in daily life. The theoretical framework advanced in Chapter 2 posits the importance of an individual's appraisal and perception in determining the stressfulness of illness-related symptoms. Specifically, illness symptoms which are currently perceived as problematic in daily life are likely to be related to stress appraisals and stress-related outcomes. In addition, problematic symptoms may express an appraisal of "negative certainty." The extent to which symptom transition is perceived as negative, threatening or harmful should also be reflected by an association with problematic symptoms. Problematic symptoms can also be viewed as sources of uncertainty and hopelessness in the chronically ill.

Unfortunately, no systematically developed and tested instrument existed to measure these domains in CFIDS. The existence of such a measure could be used to identify symptom patterns in CFIDS, to illustrate the effects of symptom-related characteristics other than severity, and to provide additional support for the construct validity of the symptom transition scale. The DCFSS was developed with these objectives in mind. Psychometric assessment of this instrument focused on content and construct validation. Due to the nature of the instrument and the construct, traditional approaches to reliability assessment such as tests of internal consistency and stability were deemed inappropriate and unnecessary.

Content Validity

The content domain of the DCFSS was initially specified by a thorough literature review of symptomatology in CFIDS. Four physicians who were known to have a large number of CFIDS in their internal medicine practices were consulted for content concurrence. The content was then formulated into scale items fitting a five-point Likert scale format. This format was selected according to the rationale cited earlier for the DPSTS. Items were grouped according to similar symptom content domain. These domains included those which are general or constitutional, gastrointestinal, or related to sleep disturbance, fatigue, cognitive impairment, mood changes, central nervous system dysfunction, musculoskeletal, cardiorespiratory, integumentary, and allergies.

Once the scale and instructions were devised, a panel of experts comprised of two epidemiologists and two patients with CFIDS reviewed the scale for concurrence and clarity. Analysis of the completion pattern and comments on 66 responses in the pilot phase and 124 responses in the study phase revealed no consistent problems in understanding or completing the scale.

Construct Validity

As discussed earlier in this section, several relationships with DCFSS were proposed based upon theoretical and empirical rationale. Correlations of the DCFSS with several other measures were performed in an effort to determine whether or not the scale performed as expected.

The DCFSS was tested with measures of symptom transition (DPSTS), hopelessness (BHS), uncertainty (MUIS), and state anxiety (S-Anxiety). Because perceived problematic symptoms were also likely to be associated with an individual's appraisal of the seriousness of his/her illness, illness course, a subject's rating of current health status, and perception of illness prognosis, these variables were also included. It also appeared reasonable that the number of symptoms subjects reported and the number of M.D. visits reported for six months and two years would also exhibit positive association with how problematic symptoms are perceived. Increased levels of problematic symptoms in patients with CFIDS were also likely to be associated with lowered levels of daily activity. This relationship was postulated since fatigue and various musculoskeletal problems are such prominent features of this illness. Similarly, high DCFSS scores were likely to be negatively associated with the number of hours per week an individual is able to work. The results of these construct validation tests are illustrated in Table 11.

The findings displayed in Table 11 demonstrate significant correlations in the predicted directions for all of the major study variables. A Type I error rate of .20/13, or .01, was used to evaluate the significance of DCFSS correlations with major study variables. The significant correlations range from .29 for the number of MD visits reported over the last six months to -.63 for activity and .63 for symptom transition. The magnitude of these correlations does not suggest redundancy of measures. The highest DCFSS correlations are between symptom transition and level of daily activity, with 40% of the variance explained by this relationship. More moderate associations are noted for hopelessness, anxiety, course, prognosis, physician visits over the last six months and two years, as well as a subject's rating of current health status. The lowest correlations with the DCFSS, although not significant at the $p<.01$ level, were with the number of symptoms reported and the hours worked per week.

Table 11 also demonstrates interesting findings related to the DCFSS subscale scores. A Type I error rate of .20/11, or .02, was used to evaluate subscale correlations with other study variables. Higher perceived problematic symptoms in all subscales except integumentary were strongly associated with perceptions of greater illness seriousness. Poorer ratings of current health status were found to be associated with higher scores on all subscales except integumentary, allergy, and sleep disturbance. Higher scores on all subscales except allergy,

TABLE 11

Validity Coefficients for the DCFSS

	SERIOUS	COURSE	FEELNOW	PROGNOSIS	ACTIVITY¤	SYMPTOM NUMBER	SYMPTOM TRANSITION	HOURS WORK NOW	MD 6 MOS	MD 2 YRS	HOPE-LESSNESS	UNCER-TAINTY	STATE ANXIETY
DCFSS	.60***	.46***	.48***	.37***	-.63***	.19*	.63***	-.22*	.29**	.36**	.40***	.50***	.47**
Subscales													
gastrointestinal	.43***	.33***	.41***	.27**	-.41***	.32*	.54***	-.16			.33***	.38***	.36***
constitutional	.46***	.44***	.46***	.32***	-.45***	.19*	.59***	-.23*			.21*	.30***	.37***
sleep disturb.	.43***	.21*	.27**	.21*	-.38***	.20*	.40***	-.04			.32***	.29**	.36***
fatigue	.57***	.45***	.44***	.34***	-.63***	.37***	.58***	-.23*			.32***	.54***	.33***
cognitive	.53***	.30***	.28**	.29**	-.50***	.41***	.49***	-.21*			.34***	.44***	.40***
mood	.54***	.34***	.36***	.36**	-.48***	.43***	.53***	-.15			.52***	.50***	.54***
neurological	.52***	.43***	.41***	.42***	-.53***	.12	.55***	-.16			.37***	.38***	.34***
musculoskeletal	.59***	.43***	.45***	.23*	-.62***	.36***	.62***	-.30**			.35***	.48***	.32***
integumentary	.28**	.21*	.28**	.21*	-.32***	.40***	.41***	-.14			.16	.22*	.21*
allergy	.34***	.09	.22*	.09	-.35***	.29**	.31***	-.10			.16	.25*	.18*
cardioresp.	.37***	.34***	.34***	.29**	-.45***	.45***	.50***	-.20*			.27**	.40***	.34***

* $p < .05$
** $p < .01$
*** $p < .001$

¤ - Lower score = poorer rating

musculoskeletal, integumentary, and sleep disturbance were also associated with poorer illness prognosis. Interestingly, perception of illness course exhibited a similar pattern of correlations, except that musculoskeletal problems were associated with poorer perceptions of illness course. In addition, for all subscales, the more problematic symptoms were perceived, the lower the associated level of reported daily activity. More problematic symptoms were significantly associated with an increased number of symptoms on all subscales except gastrointestinal, constitutional, sleep disturbance, and neurological. Not surprisingly, for all DCFSS subscales, higher problematic symptom scores were significantly correlated with higher perceived symptom transition scores. Of all DCFSS subscales, only problematic musculoskeletal symptoms were found to be associated with fewer hours worked per week. Higher mean scores on all subscales except constitutional, allergy, and integumentary were significantly associated with increased hopelessness. Finally, more problematic symptoms in all subscales except integumentary and allergy were significantly associated with increased uncertainty and state anxiety. Table 11 appears to provide initial evidence for the construct validity of the DCFSS.

Summary

Assessment of the psychometric properties of the De Groot Perceived Symptom Transition Scale and the De Groot Chronic Fatigue Syndrome Symptom Scale were described and results presented. Findings indicate initial support for the reliability, content, and construct validity of these measures. Standardized alphas for other measures used in this study were also presented.

Analysis of Research Questions

This section will present the findings related to research questions #1 through #7, in the order presented in Chapter 2.

Research Question 1: Is there a relationship among symptom transition, problematic symptoms, uncertainty, hopelessness, and state anxiety in CFIDS?

The single-order correlations among perceived symptom transition, problematic symptoms, hopelessness, and state anxiety in this sample of 124 CFIDS patients are presented in Table 12. A Type I error rate of .05/10, or .005, was used to evaluate each of these relationships. The correlations reveal that all of the variables are significantly related, however the magnitude of these relations is not so high as to suggest inordinate redundancy. As predicted in the proposed model, greater symptom transition is positively related to more problematic symptoms, as well as greater uncertainty, hopelessness, and state anxiety.

An increase in problematic symptoms is additionally associated with higher levels of uncertainty, hopelessness, and state anxiety, while increased uncertainty is similarly related to greater hopelessness and state anxiety. That hopelessness and state anxiety were strongly related is evident as well. The magnitude of the correlations is the largest for both symptom transition with problematic symptoms, and hope with state anxiety (r=.63, p<.0001). In addition, hopelessness is more strongly associated with anxiety (r=.63) than uncertainty (r=.45) and symptom transition is slightly more highly correlated with anxiety (r=.51) than is problematic symptoms (r=.47). Similarly, problematic symptoms is more strongly associated with uncertainty (r=.50) than is symptom transition (r=.44). A slightly lower magnitude is associated with symptom transition and hope (r=.39). It is apparent that Table 12 provides supporting evidence of the significant relationships among the study variables.

TABLE 12

Correlations Between Symptom Transition, Problematic Symptoms, Uncertainty, Hopelessness, and State Anxiety (N = 124)

	SYMPTOM TRANSITION	PROBLEMATIC SYMPTOMS	UNCERTAINTY	HOPE- LESSNESS	STATE ANXIETY
SYMPTOM TRANSITION	1.00	.63	.44	.39	.51
PROBLEMATIC SYMPTOMS		1.00	.50	.40	.47
UNCERTAINTY			1.00	.45	.45
HOPELESSNESS				1.00	.63
STATE ANXIETY					1.00

Note: $p < .0001$ for all correlations

Although the single-order correlations are useful to demonstrate association and explained variance among pairs of variables, the relative influence of two or more independent variables is more appropriately demonstrated by multiple regression procedures. This analytic strategy was used in research questions #2 through #6 to illustrate the more complex influences of each variable in the model. The Type I error rate was set at .10 for each of these research questions, and the Bonferroni procedure (Cohen & Cohen, 1983) was used to partition this error for the variables in each regression. The particular error rate used to evaluate each regression will be described in the following sections.

Research Questions 2: What is the influence of uncertainty and hopelessness on state anxiety in CFIDS?

The first regression was performed to demonstrate the relative influence of uncertainty and hopelessness on the dependent variable of state anxiety. Both independent variables were evaluated using a Type I error rate of .10/2, or .05. The results presented in Table 13 demonstrate that when uncertainty and hopelessness are forced into the regression at the same step, they account for significant variance in state anxiety. Although these two variables together account for 42% of the variance in state anxiety, examination of the Beta weights reveals that hopelessness is the stronger predictor of anxiety ($\underline{B}$=.54 versus $\underline{B}$=.19).

Research Question 3: Do levels of hopelessness affect the relationship between uncertainty and state anxiety in CFIDS?

In order to determine if levels of hopelessness affect the relationship between uncertainty and state anxiety in CFIDS, a hierarchical regression was performed. After entering uncertainty and hopelessness together at the first step, an interaction term was entered to test for the differential effects of these variables. The independent variables were evaluated using a

TABLE 13

Regression of Uncertainty and Hopelessness on State Anxiety

	MULTIPLE R	R^2	BETA	F	P
STEP 1					
Uncertainty			.19*	43.42	0.0000
Hopelessness	.65	.42	.54***		

TABLE 14

Differential Effect of Hopelessness and Uncertainty on State Anxiety

	MULTIPLE R	R^2	R^2 CHANGE	F	P
STEP 1					
Uncertainty Hopelessness	.65	.42	.42	43.10	0.0000
STEP 2					
Uncertainty x Hopelessness	.65	.42	.00	0.108	0.7432

TABLE 15

Regression of Symptom Transition and Problematic Symptoms on State Anxiety

	MULTIPLE R	R^2	BETA	F	P
STEP 1					
Symptom Transition			.39***		
Problematic Symptoms	.54	.29	.19	23.807	0.0000

---

*	$p < .05$
**	$p < .01$
***	$p < .001$

Type I error rate of .10/3, or .03. The results of this regression (See Table 14) indicate that, in this sample, there is no significant differential effect of hopelessness or uncertainty on anxiety. Put another way, the relationship between uncertainty and anxiety is not dependent upon the level of hope/hopelessness.

Research Question 4: What are the effects of symptom transition and problematic symptoms on state anxiety in CFIDS?

Another regression was performed to determine the effects of symptom transition and problematic symptoms on state anxiety. Both independent variables were evaluated using a Type I error rate of .10/2, or .05. As demonstrated in Table 15, the results indicate that symptom transition and problematic symptoms together account for 29% of the variance in state anxiety. However, inspection of the Beta weights demonstrates that, in this equation, symptom transition is the only significant predictor of state anxiety ($\underline{B}$=.39).

Research Questions 5: What are the effects of symptom transition and problematic symptoms on uncertainty and hopelessness in CFIDS?

To examine the effects of symptom transition and problematic symptoms on uncertainty and on hopelessness, two regressions were performed. Uncertainty served as the dependent variable in the first regression, while hopelessness was the dependent variable in the second. In both regressions, the contribution of the independent variables to explained variance was evaluated using a Type I error rate of .10/2, or .05. The results of these regressions are found in Tables 16 and 17. Table 16 demonstrates that symptom transition and problematic symptoms are both significant predictors of uncertainty, together accounting for 27% of the variance in uncertainty. In this equation, problematic symptoms is a slightly stronger predictor of uncertainty ($\underline{B}$=.30, $p<.01$) than symptom transition ($\underline{B}$=.27, $p<.05$). The effect of these two

TABLE 16

Regression of Symptom Transition and Problematic Symptoms on Uncertainty

	MULTIPLE R	R'	BETA	F	P
STEP 1					
Symptom Transition			.27*		
Problematic Symptoms	.52	.27	.30**	22.018	0.0000

TABLE 17

Regression of Symptom Transition and Problematic Symptoms on Hopelessness

	MULTIPLE R	R'	BETA	F	P
STEP 1					
Symptom Transition			.25*		
Problematic Symptoms	.44	.19	.24*	14.200	0.0000

* $p < .05$

** $p < .01$

*** $p < .001$

variables on hopelessness is displayed in Table 17. Together, symptom transition and problematic symptoms were found to be significant predictors of hopelessness, accounting for 19% of the explained variance. The variance in hopelessness explained by these two variables is somewhat less than the variance they explain in uncertainty. Since the Beta weights for each variable are virtually identical, their predictive strength is equal in this equation.

Research Question 6: Of symptom transition, problematic symptoms, hopelessness, and uncertainty, which variables exert the most influence on state anxiety in CFIDS?

In order to assess the relative explanatory strength of each independent variable in the model, and to test the model itself, a regression was performed with symptom transition and problematic symptoms forced in at Step 1. Hopelessness and uncertainty were forced in at Step 2, in accordance with the proposed temporal sequencing of these variables. The contribution of each independent variable was evaluated at Step 2, using a Type I error rate of .10/4, or .025. As demonstrated by Table 18, the entire model explains 48% of the variance in state anxiety. Inspection of the Beta weights, or standardized regression coefficients, at Step 2 reveal that, when all the variables are in the model, perceived symptom transition and hopelessness emerge as the only significant predictors of state anxiety, with hopelessness as the strongest predictor.

Research Question 7: Do either symptom transition or problematic symptoms have indirect effects on state anxiety in CFIDS?

In order to determine if symptom transition and/or problematic symptoms exert indirect as well as direct effects, the Beta weights from these regression equations (research questions #5 and #6) were used as path coefficients and placed on the appropriate path in the proposed model (see Figure 4). A Type I error rate of .20/4, or .05, was used to evaluate the independent variables in the model.

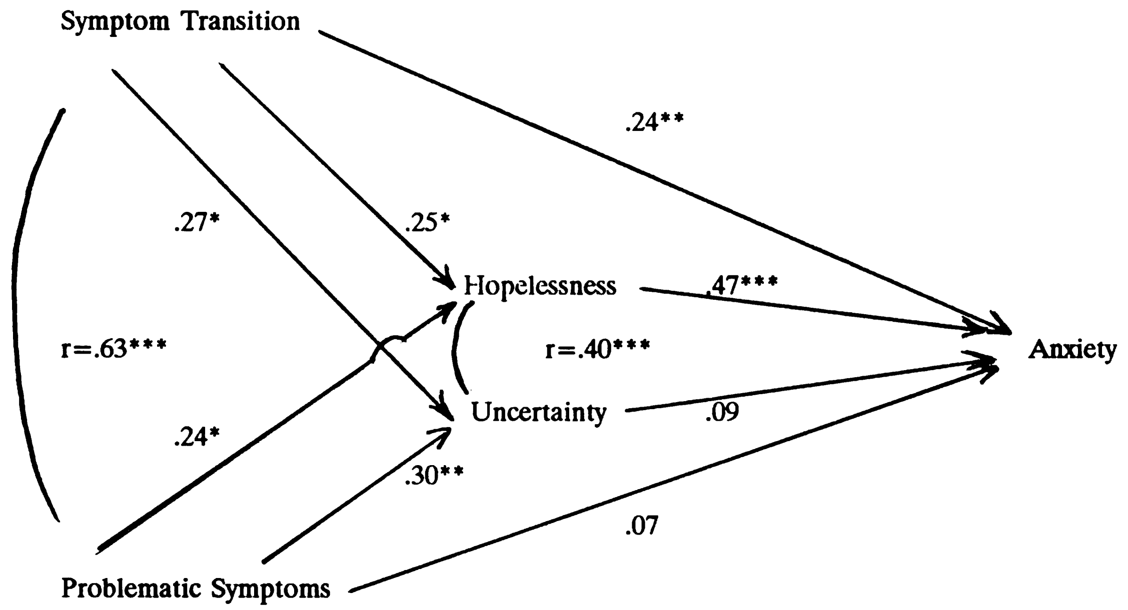
TABLE 18

Regression of Symptom Transition, Problematic Symptoms, Hopelessness, and Uncertainty on Anxiety

	MULTIPLE R	R^2	BETA	F	P
STEP 1	.53	.28		23.19	0.0000
Symptom Transition			.37	14.00	0.0003
Problematic Symptoms			.21	4.30	0.0402
STEP 2	.69	.48		26.91	0.0000
Hopelessness			.47		
Uncertainty			.09		
Variables in the Model					
Symptom Transition			.24	7.18	0.0084
Problematic Symptoms			.07	0.53	0.4668
Hopelessness			.47	36.52	0.0000
Uncertainty			.09	1.16	0.2831

FIGURE 4

PATH MODEL



*	$p < .05$
**	$p < .01$
***	$p < .001$

The path model illustrates that symptom transition exerts significant direct and indirect effects on state anxiety. The indirect effects are exerted almost equally through hopelessness and uncertainty. Interestingly, the effect of problematic symptoms on anxiety is all indirect, via hopelessness and uncertainty. The total effect, or sum of direct and indirect effects, can be calculated (see Asher, 1976; Cohen & Cohen, 1983). Using this method, the total estimated effect of perceived symptom transition on anxiety is .38.

Other Findings

The following discussion will focus on findings related to the results of additional correlational and regression analyses.

In order to determine the influence that treating physicians might have on major study variables, one-way ANOVA's were performed on state anxiety, hopelessness, uncertainty, symptom transition, and problematic symptoms. Table 19 reveals that no significant mean differences were found for any of the dependent variables. Recalling that treating physicians in this study were from three distinct geographic regions of the western United States, it seemed additionally useful to assess possible mean differences in perceptions of seriousness of illness, prognosis, illness course, and level of daily activity. No significant physician effect was found for any of these additional dependent variables.

The relationship of illness length and gender to symptom transition, problematic symptoms, uncertainty, hopelessness, and state anxiety is illustrated in Table 20. Inspection of this table reveals that longer illness length is associated with higher levels of perceived symptom transition ($\underline{r}=.21$, $p<.05$) and more problematic symptoms ($\underline{r}=.21$, $p<.05$). However, gender was found to be unrelated to symptom transition, problematic symptoms, uncertainty, hopelessness, or state anxiety in this sample.

TABLE 19

Analysis of Variance Summaries for Treating Physicians

DV	df	SS	MS	F	P
Problematic Symptoms					
Between Ss	2	1.21	.60	1.03	0.36
Within Ss	120	70.23	.58		
Symptom Transition					
Between Ss	2	79.75	39.88	0.92	0.41
Within Ss	120	5212.43	43.44		
Uncertainty					
Between Ss	2	1177.47	588.73	2.14	0.12
Within Ss	120	32931.38	274.43		
Hopelessness					
Between Ss	2	1.02	0.51	0.09	0.92
Within Ss	120	709.73	5.91		
State Anxiety					
Between Ss	2	187.18	93.59	2.28	0.11
Within Ss	120	4934.61	41.12		

TABLE 20

Correlations of Demographic and Illness Factors With Other Study Variables

	AGE	GENDER	EDUCATION	INCOME	SEXUAL IDENTITY	ILLNESS LENGTH	SYMPTOM NUMBER	HOURS WORKING
Symptom Transition	-.06	.08	-.18*	-.21*	-.11	.21*	.35***	-.28**
Problematic Symptoms	-.07	.15	-.16	-.08	-.19*	.21*	.19*	-.22*
Uncertainty	-.17*	.13	.04	.05	-.12	.05	.29**	-.14
Hopelessness	-.05	.05	-.06	-.04	-.10	.16	.22*	-.23*
State Anxiety	-.14	.12	-.13	-.09	-.07	.06	.26**	-.23*
Trait Anxiety	-.18*	.19*	-.16	-.20*	-.11	.07	.28**	-.24**

* $p < .05$
** $p < .01$
*** $p < .001$

Several other findings are apparent in Table 20. For example, higher levels of perceived symptom transition are associated with lower educational levels and income ($p<.05$). Symptom transition and problematic symptoms are both significantly associated with illness length ($p<.05$) and the absolute number of symptoms ($p<.0001$ and $p<.05$ respectively). Not surprisingly, higher levels of perceived symptom transition and problematic symptoms are both significantly associated with working fewer hours per week. Interestingly, higher problematic symptom scores were found to be associated with heterosexuality ($p<.05$). Independent groups t-tests confirmed this finding ($\underline{t}=2.23$; $\underline{df}=122$; $p<.05$).

Uncertainty was found to be inversely associated with age ($p<.05$) and positively correlated with the absolute number of symptoms ($p<.01$). Hopelessness was also found to be associated with a higher number of reported symptoms ($p<.05$) and working fewer hours per week ($p<.05$). Similarly, increased state anxiety was associated with a greater number of symptoms ($p<.01$) and working fewer hours per week ($p<.05$).

Although the primary focus of this study was on situation/illness state variables related to uncertainty appraisals, data were collected on a trait anxiety measure as well. As evident in Table 20, those with higher trait anxiety tended to be younger ($\underline{r}=-.18$, $p<.05$) female ($\underline{r}=.19$, $p<.05$) and at a lower income level ($\underline{r}=-.20$, $p<.05$). Trait anxiety was also associated with a greater number of symptoms ($\underline{r}=.28$, $p<.01$) and working fewer hours per week ($\underline{r}=-.24$, $p<.01$). It should also be noted that in this sample, trait anxiety had the highest correlation with state anxiety of any variable studied ($\underline{r}=.81$, $\underline{p}<.0001$). Nunnally (1978) observed that correlations as high as .7 are rare. Correlations of the magnitude found between these two measures suggests conceptual overlap and redundance. The implications of this finding will be discussed in Chapter 5.

In order to further assess the explanatory power of the DPSTS, two additional regressions on state anxiety were performed. Of particular interest is the finding that, in the face of such high correlations of state and trait anxiety, perceived symptom transition explains a small but significant ($p<.01$) percent of variance in state anxiety, even when trait anxiety is controlled (see Table 21). Table 22 demonstrates that symptom transition continues to explain a small but significant ($p<.01$) percent of variance in state anxiety when trait anxiety, hopelessness, and uncertainty are all entered into the regression first. For this latter equation, examination of the Beta weights reveal that T-anxiety ($B=.63$, $p<.0001$) and symptom transition ($B=.18$, $p<.01$) are the strongest predictors of state anxiety, followed by hopelessness ($B=.15$, $p<.05$).

Examination of correlations between various illness-related variables reveals several interesting findings as well. In an effort to control for Type I error, a significance level of .01 was used to evaluate these associations. As Table 23 demonstrates, longer illness length is significantly associated with poorer perceptions of illness course ($r=.27$), seriousness of illness ($r=.25$), and perception of illness prognosis ($r=.24$). Illness length was also related to the reported number of physician office visits over two years ($r=.29$).

Subjects who worked fewer hours per week had lower daily activity overall ($r=.39$). In addition, a higher number of reported symptoms was significantly associated with lower levels of daily activity ($r=-.29$) and perceptions of greater seriousness of illness ($r=.27$). Lower levels of daily activity were also significantly associated with the number of prescription medications taken ($r=-.35$), poorer ratings of how subjects feel now ($r=-.51$) and poorer perceptions of illness course ($r=-.61$).

A higher number of prescription medications currently taken was found to be associated with perceptions of increased seriousness of illness ($r=.21$) and a higher number of reported physician office visits at six months ($r=.19$) and two years ($r=.22$). In addition, an increase in perceived seriousness of illness was significantly associated with how subjects feel now

TABLE 21

Regression of Trait Anxiety and Symptom Transition on State Anxiety

	MULTIPLE R	R^2	R^2CHANGE	F	P
STEP 1					
Trait Anxiety	.80	.64	.64	231.62	0.0000
STEP 2					
Symptom Transition	.82	.67	.03	11.14	0.0011

TABLE 22

Regression of Trait Anxiety, Hopelessness, Uncertainty, and Symptom Transition on State Anxiety

	MULTIPLE R	R^2	R^2 CHANGE	F	P
STEP 1					
Trait Anxiety	.80	.64	.64	236.29	0.0000
STEP 2					
Hopelessness Uncertainty	.81	.66	.02	3.43	0.0355
STEP 3					
Symptom Transition	.83	.68	.02	8.88	0.0035

TABLE 23

Correlations Between Illness-Related Variables

	ILLNESS LENGTH	HOURS WORKING	SYMPTOM NUMBER	MED NUMBER	FEEL NOW	COURSE	ACTIVITY¤	SERIOUS	PROGNOSIS	MD 6 MOS	MD 2 YRS
Illness Length	1.00	-.21	.21*	.16	.06	.27**	-.22*	.25**	.24**	.20*	.29**
Hours Working		1.00	-.39*	-.39*	-.30*	-.15	.39**	-.10	-.09	-.28*	-.32*
Symptom Number			1.00	.16	.21*	.19*	-.29***	.27**	.18*	.19*	.22*
Medication Number				1.00	.19	.15	-.35***	.21*	.04	.40***	.34**
FeelNow					1.00	.56***	-.51***	.44***	.48***	.21*	.15
Course						1.00	-.61***	.46***	.53***	.19*	.14
Activity							1.00	-.66***	-.46***	.10	.06
Serious								1.00	.41***	.40***	.28**
Prognosis									1.00	.10	.07
MD 6 MOS										1.00	.79***
MD 2 YRS											1.00

* $p < .05$
** $p < .01$
*** $p < .001$

¤ - Lower score = poorer rating

(r=.44),poorer perceptions of illness course (r=.46) and lower levels of daily activity (r=-.66). Not surprisingly, perceptions of seriousness of illness were also associated with physician visits over six months and two years, while the number of physician visits at six months was positively correlated with the number of reported visits over two years. Similarly, poorer perceptions of illness prognosis were also significantly associated with how subjects feel now (r=.48), poorer perceptions of illness course (r=.53), lower levels of daily activity (r=-.46) and greater perceptions of illness seriousness (r=.41).

Summary

This chapter has reviewed study findings related to sample characteristics, psychometric evaluation of the De Groot Perceived Symptom Transition Scale, the De Groot Chronic Fatigue Syndrome Symptom Scale, and other standardized measures used in this research. In addition, results related to major research questions were presented. Finally, findings involving subsidiary research questions and additional analyses were reviewed.

CHAPTER 5

DISCUSSION

This chapter will discuss the meaning and significance of study findings in relationship to the proposed model for symptomatology and uncertainty in chronic illness. Issues related to instrument validity and reliability will be addressed. Additional study findings will be examined in light of their contribution to the theoretical framework in general and CFIDS in particular. Limitations and/or alternative explanations will appear throughout this discussion. The implications of study findings for nursing and future research will also be addressed.

The Proposed Model

Uncertainty and stress in chronic illness can arise from many person- and situation-related sources. The findings from this study support the proposed model and the strong relationship among two new illness-related constructs--symptom transition and problematic symptoms--and uncertainty, hopelessness, and anxiety. That higher levels of symptom transition are associated with perceptions of more problematic symptoms may relate to the inextricable link between perceptions of the illness situation and appraisal processes (Lazarus & Folkman, 1984; Lazarus & Launier, 1978). In this study, symptom transition may be viewed as the individual's perception of changes in the illness or symptom situation, and its valence may be reflected, in part, by how problematic the symptoms are perceived to be. Thus, higher levels of perceived symptom transition in the face of more problematic symptoms would indicate a stressful appraisal. The significant association of these two variables with state anxiety tends to support this view. However, it would be important to determine if these relationships with state anxiety would still be maintained in the situation where there were high levels of perceived symptom transition and <u>low</u> levels of problematic symptoms. In this scenario, the transactional stress and coping perspective would posit lower levels of state anxiety since less problematic symptoms should reflect non-stress related appraisals.

The strong direct effect of symptom transition on state anxiety evidenced by the path model supports the proposed theoretical importance of this variable. That perceived symptom transition also exerted an indirect effect on state anxiety through its influence on hopelessness and uncertainty provides added evidence of the complex relationships among these variables. In addition, it suggests a moderate total effect of symptom transition on state anxiety in this model.

As demonstrated by the path model, the influence of problematic symptoms on anxiety did not remain significant when considered along with the effects of perceived symptom transition. This finding is consistent with the view that, in this model, problematic symptoms may be appraisal related, exerting its influence on anxiety indirectly. This possibility is further supported by the significant relationship of problematic symptoms with perception of seriousness of illness, rating of current health status, illness prognosis, number of symptoms, lower levels of daily activity, and decreased hours worked per week.

Interestingly, both symptom transition and problematic symptoms were found to explain significant variance in hopelessness as well as uncertainty. These findings indicate that perceived symptom transition and problematic symptoms exert a strong direct effect on hopelessness and uncertainty. These findings also illustrate that the influence of problematic symptoms on anxiety is indirect, through its effect on uncertainty and hopelessness. This additionally supports the notion that problematic symptoms may be related to the valence aspect of appraisal, influencing uncertainty and hopelessness directly.

The direct effect of both symptom transition and problematic symptoms is somewhat greater on uncertainty than hopelessness. Given that hopelessness was found to exert a much larger effect on anxiety than uncertainty, and that hopelessness and uncertainty are significantly related, it may be that uncertainty exerts the majority of influence on anxiety through its relationship with hopelessness. This mechanism has been postulated by many, but has not been demonstrated elsewhere (Christman et al, 1988; Dufault & Martocchio, 1985; Fromm, 1968; Korner, 1970; Stoner & Kaempfer, 1985). Although it has long been observed that uncertainty may actually facilitate hope in some circumstances (Christman et al, 1988; Davis, 1960; Mishel, 1984; Wiener, 1977), this effect has not been easy to detect. That no differential effect of hopelessness or uncertainty was found leaves this question unresolved. However, the study findings suggest an important dialectic relationship between these two variables. Since the degree of life threat has been identified as a source of uncertainty in illness (Haan, 1979), it is possible that studies of conditions which are more life-threatening will illustrate these effects more clearly.

This study suggests the importance of perceived symptom transition as a strong predictor of uncertainty, hopelessness, and anxiety in CFIDS. In addition, problematic symptoms were found to exert a significant direct effect on hopelessness and uncertainty. When the full model was tested as proposed, hopelessness, and perceived symptom transition emerged as the only significant predictors of anxiety in this CFIDS sample. In this study, perceived symptom transition is considered a situation-related variable, in that it reflects an individual's perception of his/her illness situation. Hopelessness is seen as a person variable, underscoring the importance of both factors in the chronic illness experience.

Instrument Reliability and Validity

The study findings indicate initial support for the reliability and construct validity of both the DPSTS and the DCFSS. Although the primary focus of validation effects were aimed at content and convergent validity, some evidence of divergence for both scales exists. Since both scales are significantly correlated with each other, and involve different but related aspects of symptom-related perceptions, it is not surprising to find similar correlation patterns with other instruments or variables. However similar these patterns might be, the magnitude of association for these correlations is somewhat different. For example, although both scales are significantly associated with perception of current health status, the DPSTS exhibits a stronger association than the DCFSS (*r*=.67 vs. *r*=.48). Similarly, the DPSTS is more strongly associated with perception of illness course (*r*=.74 vs. *r*=.45) and perception of illness prognosis (*r*=.56 vs. *r*=.37). The magnitude of these correlations supports the expectation that perceived symptom transition constitutes a crisis in illness course in this population, and as such, should have stronger associations with measures relating to health status, illness course, and prognosis.

Despite the evidence of convergence in this study, it should be noted that the DPSTS and DCFSS were not significantly associated in an earlier pilot study of 66 CFIDS patients. It is not clear whether these findings were due to the smaller sample size or whether these patients simply viewed their symptoms as less problematic overall. If the latter explanation is true, lower levels of uncertainty, hopelessness, and state anxiety should also result. Unfortunately, the related measures were not administered in the pilot phase, making evaluation of this alternative impossible.

Additional evidence of divergence may be demonstrated by consideration of the significant inverse association of the DPSTS with education. Symptom transition involves the ability to perceive changes in symptom patterns. Mishel (1988) points out that symptom perception involves perceptual and cognitive biases. She additionally notes that education can provide a general knowledge base for interpreting the illness/symptom experience. It has also been suggested that less education results in more time required for an individual to construct meaning or interpret a situation, and that these individuals remain uncertain for longer periods of time (Mishel, 1988). It is thus reasonable to assume that those with less education may find it difficult to interpret the transition experience to begin with. This could result in higher levels of perceived symptom transition but would not necessarily affect their perception of how problematic symptoms are. This would explain the significant inverse correlation of the DPSTS with education as well as the lack of such a finding for the DCFSS.

Additional evidence of convergent and discriminant validity for the DCFSS is demonstrated by various subscale correlations with study variables. For example, it is not unexpected that all subscales <u>except</u> allergy, integumentary, sleep disturbance, and musculoskeletal were associated with poorer perceptions of illness prognosis. These symptoms, although bothersome, do not carry the same prognostic importance as cardiorespiratory, cognitive, or fatigue-related symptoms in CFIDS. Similarly, all subscales except allergy, integumentary, and sleep disturbance were associated with poorer perceptions of illness course. It is interesting to note that problematic musculoskeletal symptoms were significantly associated with perceptions of illness course, but not prognosis. Since problematic musculoskeletal symptoms were also associated with reports of lower levels of daily activity and how subjects feel now, the implications of these symptoms may be more present-oriented than future-oriented.

The finding that higher mean DCFSS subscale scores were also associated with perceptions of greater seriousness of illness and poorer ratings of current health status is reasonable, given the diverse and complex constellation of symptoms associated with CFIDS. In addition, more problematic symptoms were significantly associated with greater perceived symptom transition for all subscales. This supports the theoretical assertion that perceived symptom transition constitutes an illness crisis when the change is perceived as problematic. This finding also supports the expected convergence of these two variables in that perceived symptom transition is primarily viewed as problematic in this population. The finding that higher mean scores for the constitutional, fatigue, cognitive impairment, musculoskeletal, and cardiorespiratory subscales were significantly associated with fewer hours worked per week is consistent with the general severity of these particular symptoms in CFIDS. Given that all subscales were significantly associated with reports of lower daily activity, the symptom subscales associated with fewer hours worked appear to have particular relevance for CFIDS-associated disability.

Finally, the path model itself provides additional evidence of the divergence of the DPSTS and the DCFSS. As indicated earlier, DPSTS scores demonstrated both direct and indirect influences on state anxiety. In contrast, DCFSS scores did not demonstrate significant direct influence on state anxiety. Instead, DCFSS scores exerted their effect indirectly, via direct influence on hopelessness and uncertainty.

An additional construct validity issue raised earlier in this chapter resurfaces when examining the pattern of correlations for the DPSTS. Although the construct of perceived symptom transition has no implicit valence, the theoretical framework advanced in Chapter 2 posits "negative" effects when symptom transition is appraised as "negative" or problematic. In addition, perceived symptom transition is viewed to be particularly problematic in the CFIDS population under study. Both assertions are supported by the study findings. However, the converse expectation that perceived symptom transition would result in lower levels of uncertainty, hopelessness, and state anxiety if the symptoms were perceived as less problematic is also possible. Although this interesting possibility was not tested in this study, it is important to consider for future study. Testing the veracity of these assumptions will further illustrate the nature of the construct of perceived symptom transition.

Other Findings

Other study findings are equally illuminating. For example, although age has been found to be unrelated to uncertainty (Mishel, 1984), a significant inverse association was found in this sample. Although the effect size is low (r=-.17), the finding that younger patients tend to be more uncertain may reflect the realities of chronic illness onset at a time when illness is unexpected. Neugarten (1979) observes that when an event occurs "off time," a crisis can result.

Young to middle-aged individuals do not expect to be stricken suddenly with a chronic, debilitating illness such as CFIDS. Chronic conditions are often viewed in our society as something that happens to old or otherwise stigmatized individuals (Goffman, 1963). The meaning and impact of CFIDS for a younger individual's life, or even for the foreseeable future, is simply uncertain.

The finding that lower education and income were associated with higher levels of perceived symptom transition but not other major study variables is somewhat ambiguous. Although the size of these effects is low ($\underline{r}$=-.18 and $\underline{r}$=-.21, respectively), it could be that lower education and income imply that an individual has less ability or resources to seek regular health care, and thus is not able to control his/her symptoms as well. Positive correlations with illness length, the number of symptoms, and fewer hours worked per week support this contention. An alternative explanation is that these individuals are simply sicker due to some other unidentified risk factor.

The finding that heterosexuality is significantly associated with reports of more problematic symptoms in this sample is interesting but somewhat puzzling. Whether this finding is an artifact or represents some adaptive tendency for homosexuals to view difficult life circumstances as less problematic overall is unclear. This latter explanation may involve a natural "habituation" which may occur when individuals are continually confronted with a stigmatized existence (Goffman, 1963).

The interpretation of the association of illness length with symptom transition and problematic symptoms may be more straightforward. These relationships may reflect perceptions of illness reality, in that those who have been sick longer may also be more ill. This explanation is supported by positive correlations with reports of the number of symptoms, number of physicians visits in the last six months and two years, and perception of illness seriousness. These variables were also associated with lower reported daily activity in this sample.

An alternative explanation for these findings relates to the significant associations among an increased number of symptoms, fewer hours worked per week, and other major study variables with trait anxiety. This interpretation posits that these findings can be explained by the concept of "negative affectivity," or the general tendency to interpret and respond to situations in an anxiety-prone way. Thus, the report of higher levels of perceived symptom transition, problematic symptoms, uncertainty, hopelessness, state anxiety, number of symptoms, lower levels of daily activity, number of physicians, etc., are seen as a function of negative affectivity, not actual illness state. Although the influence of various personality traits thought to be related to uncertainty should undoubtedly be studied, in this study the alternative trait-based explanation cannot be supported. This is due to the unusually high correlation between the Trait and State anxiety measures. This high correlation suggests conceptual overlap and redundance of measures. After careful review of the psychometric evaluations of the STAI Form-Y (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983), this author asserts that more empirical support currently exists for the construct validity of the Form-Y S-Anxiety measure than the T-Anxiety scale. If the State Anxiety scale is used in future uncertainty-related research, dispositional measures other than the Trait Anxiety Form-Y scale should be used in order to avoid the interpretive difficulties posed by this apparent redundancy.

An additional point relating to the preceding discussion can be made. In this study, numerous self-report variables were included to serve as more than a purely descriptive or psychometric function. These items were used as a consistency check for possible reporting or response bias. The pattern of significant correlations does not appear consistent with such a response bias. For example, individuals who worked fewer hours per week reported more prescription medications (by name), a poorer rating of health status, lower levels of daily activity, and more physician visits over the past six months and two years. However, hours worked per week were <u>not</u> significantly associated with perceptions of illness course, seriousness of illness or illness prognosis, which is inconsistent with a significant response bias (Table 23).

CFIDS-Related Findings

Several additional study findings related to CFIDS are important to note. The finding that gender was not significantly associated with any major study variables is particularly relevant in CFIDS. Since this syndrome appears to affect women more than men, there has been some speculation among less informed individuals that CFIDS is a disease of "neurotic women." One epidemiologist personally shared his view that CFIDS was caused by "working too hard at home with the children." Although this perception was dispelled by the sample characteristics reviewed in Chapter 4, it is of added interest that the number of children living at home had no significant relationship with any variable in this study.

Equally interesting are the sample mean scores on the standardized measures used in this study. Despite the severe activity restriction and general illness impact reported by subjects, they reported lower levels of hopelessness ($\bar{X}=2.14$) than other samples of hospitalized ($\bar{X}=3.17$), chronically ill ($\bar{X}=4.2$) or acutely ill ($\bar{X}=3.2$) patients (Greene, O'Mahoney & Runlasamy, 1982). Further, subjects reported higher mean uncertainty scores ($\bar{X}=87.1$) than post-myocardial infarction patients ($\bar{X}=54.4$) or those with lupus ($\bar{X}=78.3$). Although those mean differences were not tested for statistical significance, they may have "practical" significance. For example, this latter finding is not unexpected in a group diagnosed with an illness with no known cause, cure, treatment, diagnostic test, or knowledge of long-term implications. However, when considering the combination of higher uncertainty and lower hopelessness in this sample as compared with other patient groups, two interesting possibilities arise. The first is that despite their uncertainty, this CFIDS sample is more hopeful because their illness is not known to be life-threatening. The alternative explanation is that the relative hopefulness in the face of such high levels of uncertainty in this sample may represent the hope-fostering function of uncertainty which has been proposed by many (for example: Korner, 1970; Mishel, 1988; Wiener, 1977) and described in Chapter 2.

The finding that there were no significant differences in symptom transition, problematic symptoms, hopelessness, uncertainty, or state anxiety according to treating physician is also encouraging. The three physicians involved in this study practice in three distinct geographic regions of the western United States. The possibility that geographic, treatment, and/or regional selection differences were operative appeared not to be the case in this sample.

Study findings related to specific illness symptomatology indicate general concurrence with existing CFIDS literature, although the DCFSS scale allows for a greater level of symptom specificity than generally reported. The use of the DCFSS can provide greater knowledge about the range and type of symptoms associated with CFIDS, as well as the particular types of symptoms considered to be most stressful. For example, in this study, high rating of problematic symptoms for all subscales except "allergies" were significantly associated with uncertainty and state anxiety. In addition, all subscales except "integumentary" were significantly associated with ratings of hopelessness. These findings suggest that subjects consider allergy-related symptoms, and those integumentary symptoms such as rashes, mouth sores, and lip blisters as less problematic overall.

Although several significant findings were reported in this study, several limitations, or threats to internal and external validity (Cook & Campbell, 1979), should be kept in mind. The primary threat to internal validity is posed by possible selection bias associated with this convenience sample. Because the sample was drawn from physicians' practices with known expertise in CFIDS, it could be that this sample is unusually well-informed, persistent, or different in some other way from the majority of those with CFIDS. The use of a sample drawn from three geographic areas represented an attempt to deal with this issue. Since the investigator was not physically present when the patient lists were compiled, it could also be that some patients were omitted from the list based on some unknown criteria. In addition, those subjects who actually completed and returned the questionnaire packet may be less ill than the 45% who did not respond, or they may be different with regard to some other characteristics or set of attributes.

The major threats to external validity in this study relate to possible "Hawthorne effect" or measurement effects. The former might be operative simply because the subject is participating in a research study. This may result in some response bias, or the tendency to respond to questionnaire items in a given way. Measurement effects might also be involved to some degree in this study, due to the preset order of instruments in the questionnaire packet. However, these effects may be minimal since questionnaires were filled out anonymously.

Cook and Campbell (1979) also assert the problem of mono-operation bias that can occur when only one measure of a possible "cause" is used. They point out that the use of a single measure may underrepresent the construct of interest and may contain "irrelevancies," resulting in diminished construct validity of the research in general (p. 65). Because no other measures of symptom transition were available, problematic symptoms were also measured in order to minimize the effect of this threat.

Although some validity threats exist in this study, instrument reliability, sample size, and the use of powerful and robust statistical methods assist in mitigating possible threats to statistical conclusion validity. The findings that symptom transition emerged as a significant predictor of hopelessness, uncertainty, and state anxiety, and that problematic symptoms exerted significant direct effects on both uncertainty and hopelessness have several implications for future research efforts.

Implications for Future Research

Additional construct and criterion-related validation testing is required for both the DPSTS and DCFSS. Construct validation efforts should focus on divergence and convergence for both measures. For example, it is necessary to address empirically whether the DPSTS is always associated with problematic symptoms and "negative" or undesirable outcomes, or if there are situations in which perceived symptom transition is viewed as less threatening or stressful. Studies involving "known groups," such as those whose symptoms are actually improving, those whose symptoms are relatively unchanged, and those who are steadily getting worse, would assist in this determination. The testing of the DPSTS should also involve the use of a variety of chronic illness diagnoses with more diverse age and gender representation to determine the generalizability of the construct and its effects. In addition, the intra-individual study of perceived symptom transition over time would allow for assessment of the degree of symptom variability according to diagnostic, demographic or other illness-related dimensions.

The DCFSS should be tested in other geographically diverse random samples drawn from a variety of settings. This would allow for more unbiased assessment/verification of the CFIDS symptom constellation and prevalence of problematic symptoms. Both the DPSTS and the DCFSS should be tested with other trait and state measures of stress-associated antecedents and outcomes in order to provide further evidence of construct validity. In addition, both objective and subjective non-stress-related measures should be used to assess the impact of these constructs. For example, measures which assess physical function could be studied in relation to the DCFSS. Other person variables such as psychosocial adjustment to illness or life satisfaction should be examined as they relate to the DPSTS.

Uncertainty-related research involving the constructs of perceived symptom transition and problematic symptoms should focus on at least three areas. First, other samples of those with highly life-threatening conditions should be studied so that the proposed, yet undemonstrated, beneficial effects of uncertainty may be illustrated. Based upon the strong relationship of hopelessness to other variables in this study, hope/hopelessness should continue to be included in other studies in order to detect these proposed beneficial effects, as well as other possible modes of action. Second, the proposed model of symptomatology and uncertainty should be tested in other populations over time. This would assist in confirming or establishing the theoretical antecedents of uncertainty, hope/hopelessness, and anxiety with those diagnosed with life-threatening and non life-threatening illness. Finally, this model should be tested across a variety of illness, age, and gender groups in order to determine if the relationships demonstrated in this study are generalizable. Of particular interest is the consistency with which symptom transition exerts direct and indirect effects on hopelessness, uncertainty, and other relevant variables. In addition, the degree to which the indirect effects of problematic symptoms on hopelessness and uncertainty are affected by chronic illness type, age, and gender should be examined.

It should also be noted that the domains and sources of uncertainty introduced in Chapter 2 and depicted in Table 3 can be used as a template or guide for the identification and selection of variables for inclusion in future uncertainty theory-related research. For example, variables related to the domain of uncertainty involving the self, such as self-esteem or self-efficacy, are likely to be associated with uncertainty in illness. Existential domain variables such as belief in a just world (Rubin & Peplau, 1975) or illness-related domain beliefs pertaining to illness causation are also proposed to affect uncertainty. Identification, explication and/or verification of the relationships proposed in this template will assist in the further development and refinement of theory in uncertainty and illness.

Implications for Nursing

This study illustrated the importance of perceived symptom transition and problematic symptoms as antecedents of uncertainty, hopelessness, and anxiety in CFIDS. That uncertainty exerted an indirect effect on anxiety through hopelessness was also demonstrated. As such, the study findings have at least three implications for nursing. The first is the recognition of the legitimacy of the patient's symptom experience as a proper focus of study and concern. A primary goal of nursing intervention is symptom alleviation. When symptoms persist, as in most chronic illnesses, frustration and feelings of inadequacy in the nurse may occur. These unpleasant feelings can ultimately result in a tendency to "blame the victim" for symptom continuation. The nurse may also avoid the patient, or discussions involving how the patient is actually feeling. This generalized reluctance to acknowledge a patient's symptom experience has undoubtedly contributed to the lack of nursing and health-related research in illness symptomatology in the past. Legitimizing the study of the patient's perception of the symptom experience will likely result in increased research attention to this important area.

The second nursing implication of this study involves the recognition that symptom variability is an inherent characteristic of CFIDS and other chronic illnesses as well. As such, the perception of symptom transition appears likely to result in increased uncertainty, hopelessness, and anxiety. Nurses are in a unique position to characterize for patients the variability inherent in various chronic illness situations. Sharing this information may allow patients to anticipate their illness course more accurately. This may reduce the stressfulness of the illness situation by reducing the symptom-related uncertainty associated with it.

Equally important is the need to educate patients as to the specific symptom changes or problematic symptoms which may signal the need for assessment by a clinician. This would assist patients in appraising symptoms and interpreting possible health consequences in a more informed, discriminating manner. In this way, patients could more easily differentiate between symptoms which signal deteriorating conditions versus those which have impact on their daily life, but are not as serious. The ability to discriminate between these situations may reduce the stressfulness of symptom transition situations and prevent health complications through more appropriate and timely interventions. For example, most patients with CFIDS are plagued by muscle aches and pains, while some may develop potentially severe cardiac conditions or serious balance disturbances. It is important for the patient to be able to distinguish among symptoms as well as within symptoms. Thus, the patient should be made aware of the bothersome, but non-threatening, nature of muscle aches and pains, as well as the need to seek treatment if chest pain or heart beat irregularities occur. Similarly, if a patient already has a balance disorder, some parameters for gauging the need for treatment or the need to refrain from dangerous activities, such as driving, should be offered. In this way, knowledge about perceived symptom transition and the variables which are related to it may directly or indirectly contribute to the health and quality of life of those who are chronically ill.

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APPENDIX A

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

A. PURPOSE AND BACKGROUND

Holly A. De Groot, MS, RN, and PhD candidate from the Department of Mental Health, Community and Administrative Nursing, is conducting a study about the effects of Chronic Fatigue Syndrome (also known as Chronic Fatigue Immune Dysfunction Syndrome) on daily life. Because I have Chronic Fatigue Syndrome, I am being asked to participate in this study.

B. PROCEDURES

If I agree to be in this study, the following will occur:

1. I will be asked to respond to questionnaires about various physical and emotional effects of my illness/condition.
2. The investigator may check my medical records to gather information about my symptoms and past medical history.

The questionnaires will take about an hour to complete, and will be mailed to me so that I may respond to them wherever I choose.

C. RISKS/DISCOMFORTS

1. Some of the questions may make me uncomfortable or upset, but I am free to decline to answer any questions that I do not wish to.
2. Confidentiality: Study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. Study information will be coded and kept in locked files at all times. Only study personnel will have access to the files.

D. BENEFITS

There will be no direct benefit to me from participating in this study. The anticipated benefit of these procedures is a better understanding of how Chronic Fatigue Syndrome affects human lives.

E. ALTERNATIVES

I am free to choose not to participate in this study.

F. COSTS

There will be no costs to me as a result of taking part in this study.

G. REIMBURSEMENT

I will not be reimbursed for my participation in this study.

H. QUESTIONS

If I have any questions or comments about participation in this study, I should first contact the investigator, Holly De Groot, MS,RN. She may be reached at (415) 383-3240. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the Committee office between 8:00 AM and 5:00 PM, Monday to Friday, by calling (415) 476-1814, or by writing to the Committee on Human Research, Suite 11, Laurel Heights Campus, Box 0616, University of California, San Francisco, CA 94143.

I. CONSENT

I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in the study will have no influence on my present or future health care.

________________ ________________________________

Date Subject's Signature

April 17, 1989

Dear patient:

This letter is to advise you of an opportunity to participate in a research study related to Chronic Fatigue Syndrome (also known as Chronic Immune Dysfunction Syndrome). This study is being conducted by Holly De Groot, RN, who is a PhD candidate at the University of California, San Francisco. Ms. De Groot is interested in the effect of Chronic Fatigue Syndrome (CFS) on your daily life. Participating in this study will involve completing a set of questionnaires that Ms. DeGroot will send to you by mail.

If you do not want to participate in this study, please return the enclosed stamped card by April 26, 1989. If you return the card, Ms. De Groot will know that you do not wish to participate, and no further contact with you will be made. Remember to include your name and address on the card so that your name will be sure to be deleted from the list of potential participants.

If you want to participate in this study, do not return the card. If Ms. De Groot does not hear from you by April 26, 1989, she will know that you are interested in participating in the study, and she will contact you by mail, further explaining the study and how you can participate.
Whether or not you choose to participate in this study will not affect your medical care or treatment in any way.

I appreciate your consideration of this study.

Sincerely,

Jane Doe, MD

May 5, 1989

Dear patient:

A short time ago, you received a letter from your physician advising you of an opportunity to participate in a research study. This study is being conducted as a part of my doctoral studies at the University of California, San Francisco.

Since you have indicated interest in participating in this study by not returning the card enclosed with your physician's letter, I am sending you the study questionnaire packet. Included in this packet are two copies of a form entitled "Consent to Participate in a Research Project" which you must read and sign if you choose to participate in this study. You should keep one copy of this consent for your records and return the other signed copy to me along with your completed questionnaire packet in the pre-stamped envelope provided. Also included is a copy of the "Experimental Subjects Bill of Rights" which you should also read and keep for your reference.

Completion of the questionnaire packet will take about one hour of your time. Completed questionnaires and a signed copy of the "Consent to Participate in a Research Project" should be returned to me no later than May 22, 1989.

If you have any questions about this study, please do not hesitate to call me at (415) 383-3240. You may also refer to the consent form for additional contacts should you prefer to speak with someone else about this study.

Thank you for your consideration to participate in this study,

Sincerely,

Holly A. De Groot, MS, RN

APPENDIX B

CFS STUDY

Thank you for consenting to participate in this study. Your contribution is an important one and will allow us to understand more about Chronic Fatigue Syndrome (CFS).

This questionnaire packet will take about 45-60 minutes to complete and you may use either pen or pencil to record your responses. There are no right or wrong answers to the questions. You may answer each item in the way that best reflects your situation or experience with Chronic Fatigue Syndrome.

When you have finished the questionnaire packet, please return it right away using the stamped envelope provided, remembering to include a signed copy of the "Consent to Participate in a Research Study".

Thank you once again for your valuable contribution!

CFS QUESTIONNAIRE

Age: __________

2. Sex: ____ Male ____ Female

Racial/Ethnic Background:

- ___ American Indian
- ___ Asian
- ___ Black
- ___ Hispanic
- ___ White
- ___ Other

4. Are you:

- ___ Married
- ___ Single, separated, divorced or widowed

5. If not married, are you (select one):

- ___ With a steady partner?
- ___ With an occasional partner?
- ___ With no partner?

Usual Occupation: ____________________

Before you became ill, did you work?
___ yes ___ no

If yes, how many hours per week? ___

8. How many children do you have living with you in your household? ________

Do you currently work? ___ yes ___ no

If yes, how many hours per week? ___

Education completed:

- ___ Grades 1-11
- ___ High school graduate
- ___ College training, but not college graduate
- ___ College graduate
- ___ Graduate degree

11. Annual income before taxes:

- ___ $10,000 or less
- ___ $11,000 to $20,000
- ___ $21,000 to $30,000
- ___ $31,000 to $40,000
- ___ $41,000 to $50,000
- ___ $51,000 or more

Month/year you first became ill with CFS: ____________________

Month/year you first went to see a doctor about your illness: __________

Month/year you were first diagnosed with CFS: ____________________

What do you think caused your illness? ______________________________

____

How did your illness begin? (please check one):

- ____ It developed rapidly over one or two days.
- ____ It developed gradually over a week or a month.
- ____ It developed slowly over a number of months.
- ____ Other (please explain). ______________________________

____

Do you have any other health problem(s)? ___ yes ___ no
If yes, please describe.

____

____

Do you currently take any medications prescribed by a doctor? ___ yes ___ no
If yes, please name them.

____

____

Do you currently take any over-the-counter or unprescribed medications? ___ yes ___ no
If yes, please list them.

____

____

Please turn to the next page

Below is a list of symptoms which some people with your illness/condition may ex-
ence. For each symptom that you have experienced, SINCE YOU BECAME ILL please indi-
how much of a problem it is for you NOW in your daily life by using the following
e: 1 = not a problem at all; 2 a slight problem; 3 = a moderate problem; 4 = a
ous problem; 5 = a very serious problem. If you have NOT experienced a particular
tom since you became ill, please circle N/A, for Not Applicable.

SYMPTOM	**HOW MUCH OF A PROBLEM FOR YOU?**					
	Not a Problem 1	2	Moderate Problem 3	4	Very Serious Problem 5	Not Applicable N/A
poor appetite	1	2	3	4	5	N/A
stomach pain	1	2	3	4	5	N/A
nausea	1	2	3	4	5	N/A
vomiting	1	2	3	4	5	N/A
diarrhea	1	2	3	4	5	N/A
weight gain	1	2	3	4	5	N/A
weight loss	1	2	3	4	5	N/A
night sweats	1	2	3	4	5	N/A
sore on scratchy throat	1	2	3	4	5	N/A
swollen lymph glands in neck, armpit or groin	1	2	3	4	5	N/A
gland pain in neck, armpits or groin	1	2	3	4	5	N/A
unpleasant reaction after drinking alcohol	1	2	3	4	5	N/A
fever measured by thermometer	1	2	3	4	5	N/A
chills	1	2	3	4	5	N/A
difficulty falling asleep	1	2	3	4	5	N/A
difficulty staying asleep	1	2	3	4	5	N/A
difficulty staying awake	1	2	3	4	5	N/A
not feeling rested when awakening in the morning	1	2	3	4	5	N/A
unusual tiredness or fatigue after exercise	1	2	3	4	5	N/A
feeling unusually tired, fatigued or lack of energy	1	2	3	4	5	N/A

SYMPTOM	HOW MUCH OF A PROBLEM FOR YOU?					
	Not a Problem 1	2	Moderate Problem 3	4	Very Serious Problem 5	Not Applicable N/A
difficulty concentrating/ easily distracted	1	2	3	4	5	N/A
forgetfulness	1	2	3	4	5	N/A
difficulty thinking, following directions or making calculations	1	2	3	4	5	N/A
feeling confused at times	1	2	3	4	5	N/A
difficulty finding the right word	1	2	3	4	5	N/A
feeling down or "blue"	1	2	3	4	5	N/A
frequent mood changes	1	2	3	4	5	N/A
feeling tense or anxious	1	2	3	4	5	N/A
bothered by bright lights	1	2	3	4	5	N/A
blurred or fuzzy vision	1	2	3	4	5	N/A
other visual problem	1	2	3	4	5	N/A
muscle twitches/jerking	1	2	3	4	5	N/A
seizures or "fits"	1	2	3	4	5	N/A
trouble keeping balance	1	2	3	4	5	N/A
dizziness	1	2	3	4	5	N/A
headaches	1	2	3	4	5	N/A
skin tingling or numbness	1	2	3	4	5	N/A
other odd skin sensations	1	2	3	4	5	N/A
stiffness after sitting/sleeping	1	2	3	4	5	N/A
muscle aches or pains	1	2	3	4	5	N/A
muscle weakness	1	2	3	4	5	N/A
joint pain	1	2	3	4	5	N/A
jaw ache	1	2	3	4	5	N/A

SYMPTOM	HOW MUCH OF A PROBLEM FOR YOU?					
	Not a Problem		Moderate Problem		Very Serious Problem	Not Applicable
	1	2	3	4	5	N/A
puffy face in the morning	1	2	3	4	5	N/A
swollen fingers	1	2	3	4	5	N/A
skin rash	1	2	3	4	5	N/A
red or flushed face	1	2	3	4	5	N/A
sores/ulcers in mouth or on tongue	1	2	3	4	5	N/A
lip blisters	1	2	3	4	5	N/A
hay fever	1	2	3	4	5	N/A
sinus conditions	1	2	3	4	5	N/A
other allergies	1	2	3	4	5	N/A
rapid, irregular or abnormal heartbeat	1	2	3	4	5	N/A
chest pain/pressure	1	2	3	4	5	N/A
shortness of breath	1	2	3	4	5	N/A
cough	1	2	3	4	5	N/A

other (explain) ____

____

____

Of the symptoms you identified above, list the three symptoms below that presently cause you the most difficulty, problems or concern:

1.____________________
2.____________________
3.____________________

How serious do you consider your illness/condition to be?
(circle only one answer)

Not Serious	Somewhat Serious	Moderately Serious	Very Serious	Extremely Serious

1. Think about the symptoms of your illness or condition over the **PAST WEEK**. Compare our **present** symptoms to the symptoms you had before this week. Then, indicate how much you gree or disagree with the following statements by using the five point scale which follows ach statement: 1 = **Strongly Disagree**; 2 = **Disagree**; 3 = **Undecided or Unsure**; 4 = **Agree**; = **Strongly Agree**. Circle the one number which most closely fits your experience over the **AST WEEK**.

		SD	**D**	**U**	**A**	**SA**
.	Overall, my symptoms are getting better.	1	2	3	4	5
.	I have more types/kinds of symptoms than I did before.	1	2	3	4	5
.	I am free of symptoms more often now.	1	2	3	4	5
.	I notice my symptoms more often now.	1	2	3	4	5
.	My symptoms are not as bad/severe as they have been.	1	2	3	4	5
.	My symptoms interfere with my life more now.	1	2	3	4	5
.	My symptoms seem to last for a longer time now.	1	2	3	4	5
.	I have a greater number of symptoms now.	1	2	3	4	5
.	My symptoms have not spread to other areas of my body.	1	2	3	4	5
0.	I have new symptoms that I have not felt before.	1	2	3	4	5
..	My symptoms are more visible to others than they have been.	1	2	3	4	5
..	My symptoms don't bother me any more than they usually do.	1	2	3	4	5
.	I experience my symptoms less often now.	1	2	3	4	5

Comments:

Which of the following statements best describes how you feel today? (circle only one number)

1. I have never felt better.
2. I feel a lot better than I have in a long time.
3. I feel a little better than usual.
4. I feel no better or worse than usual.
5. I feel a little worse than usual.
6. I feel much worse than I have in a long time.
7. I have never felt worse.

From the statements that follow, select the one which most closely fits your experience and circle the number next to it.

1. I have totally recovered from my illness/condition.
2. My illness/condition is improving over time.
3. My illness/condition fluctuates/changes too much for me to tell whether I'm getting better or worse.
4. My illness/condition has not really changed for better or worse.
5. My illness/condition is getting worse over time.

Please rate your current level of daily activity by circling a number from "0" to "10" on the scale that follows. Assume that a "0" applies when you are bedridden and/or can do none of the things you could before you became ill. A rating of "5" would indicate that you can do about half of what you could before you became ill, while a "10" would indicate that you can do everything you could before you became ill. Circle only one number.

0 1 2 3 4 5 6 7 8 9 10

Choose the one statement below which best describes your belief about your illness/condition in the future.

1. It is likely to go away completely.
2. It will probably improve somewhat over time.
3. It will probably be similar to how it is now.
4. It is likely to be somewhat worse over time.
5. It may lead to my death.

Please identify up to five important ways this illness has affected you (For example: "I can't concentrate well enough to read anymore" or "I used to work full-time, but now can only work 10 hours a week").

1. ____

2. ____

3. ____

4. ____

5. ____

Has a physician ever diagnosed you with (or treated you for) any of the following conditions? If "Yes", give the date it began next to the name of the condition.

Month/Year

____/____ Diabetes mellitus

____/____ High blood pressure

____/____ Thyroid disease

____/____ Addison's disease

____/____ Cushing's disease

____/____ Myasthenia gravis

____/____ Multiple sclerosis

____/____ Epilepsy

____/____ Emphysema

____/____ Sarcoidosis or Wegener's granulomatosis

____/____ A viral influenza

____/____ Measles, mumps, or chicken pox

____/____ Intestinal worms or "traveler's diarrhea"

____/____ Blood disease

____/____ Digestive tract disease

Month/Year

____/____ Hepatitis

____/____ Mononucleosis

____/____ Psoriasis

____/____ Arthritis

____/____ Lymphoma or leukemia

____/____ AIDS or ARC

____/____ Tuberculosis

____/____ Asthma

____/____ Endocarditis

Month/Year

___/___ Cancer. What kind? ____________________

___/___ Psychiatric condition. What kind? ____________________

___/___ Fungal infection (such as Candida, Valley Fever, histoplasmosis, blastomycosis). What kind? ____________________

___/___ Autoimmune disease (such as systemic lupus, scleroderma, rheumatoid arthritis). What kind?

____

___/___ Exposure to toxic chemicals. What kind? ____________________

___/___ Severe allergies. What kind? ____________________

___/___ Heart disease. What kind? ____________________

___/___ Lung disease. What kind? ____________________

___/___ Liver disease. What kind? ____________________

___/___ Kidney disease. What kind? ____________________

___/___ Hormone imbalance. What kind? ____________________

___/___ Sexually transmitted disease (such as gonorrhea, syphilis, chlamydia).

What kind? ____________________

___/___ Neurological condition. What kind? ____________________

Do you consider yourself to be:

____ heterosexual
____ bisexual
____ homosexual

How many visits to a physician have you made:

in the last six months? ________
in the past two years? ________

What is your primary means of paying for your medical care? (check only one)

____ Private insurance or health plan
____ Medicare
____ MediCal
____ Self payment

Is there anything else you would like to add? ________________________________

____

____

Would you like to be contacted in the future regarding participation in other studies related to Chronic Fatigue Syndrome?

_____ Yes
_____ No

Please turn to the next page

nstructions: Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement.

. I don't know what is wrong with me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

. I am unsure if my illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

It is unclear how bad my symptoms will be.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

The explanations they give about my condition seem hazy to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

. The purpose of my care is clear to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

. When I have symptoms, I know what this means about my condition.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

. My symptoms continue to change unpredictably.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

. I understand everything explained to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

.0. The doctors say things to me that could have many meanings.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

.1. The care I receive is too complex to figure out.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

.2. It is difficult to know if the care or medications I am getting are helping.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

.3. Because of the unpredictability of my condition, I cannot plan for the future.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

14. **The course of my condition keeps changing. I have good and bad days.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

15. **I have been given many differing opinions about what is wrong with me.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

16. **It is not clear what is going to happen to me.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

17. **I usually know if I am going to have a good or bad day.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

18. **The results of my tests are inconsistent.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

19. **The effectiveness of my care is undetermined.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

20. **I can generally predict the course of my condition.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

21. **Because of my condition, what I can do and cannot do keeps changing.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

22. I'm certain they will not find anything else wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

23. The care I am receiving has a known probability of success.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

24. They have not given me a specific diagnosis.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

25. My physical distress is predictable; I know when it is going to get better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

26. My diagnosis is definite and will not change.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

27. The seriousness of my condition has been determined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

28. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

his questionnaire consists of 20 statements. Please read the statements carefully one by one. If the statement scribes your attitude for the **past week including today**, darken the circle with a 'T' indicating TRUE in the lumn next to the statement. If the statement does not describe your attitude, darken the circle with an 'F' dicating FALSE in the column next to this statement. **Please be sure to read each statement carefully.**

1. I look forward to the future with hope and enthusiasm. Ⓣ Ⓕ
2. I might as well give up because there is nothing I can do about making things better for myself. Ⓣ Ⓕ
3. When things are going badly, I am helped by knowing that they cannot stay that way forever. Ⓣ Ⓕ
4. I can't imagine what my life would be like in ten years. Ⓣ Ⓕ
5. I have enough time to accomplish the things I want to do. Ⓣ Ⓕ
6. In the future, I expect to succeed in what concerns me most. Ⓣ Ⓕ
7. My future seems dark to me. Ⓣ Ⓕ
8. I happen to be particularly lucky, and I expect to get more of the good things in life than the average person. Ⓣ Ⓕ
9. I just can't get the breaks, and there's no reason I will in the future. Ⓣ Ⓕ
10. My past experiences have prepared me well for the future. Ⓣ Ⓕ
11. All I can see ahead of me is unpleasantness rather than pleasantness. Ⓣ Ⓕ
12. I don't expect to get what I really want. Ⓣ Ⓕ
13. When I look ahead to the future, I expect that I will be happier than I am now. Ⓣ Ⓕ
14. Things just don't work out the way I want them to. Ⓣ Ⓕ
15. I have great faith in the future. Ⓣ Ⓕ
16. I never get what I want, so it's foolish to want anything. Ⓣ Ⓕ
17. It's very unlikely that I will get any real satisfaction in the future. Ⓣ Ⓕ
18. The future seems vague and uncertain to me. Ⓣ Ⓕ
19. I can look forward to more good times than bad times. Ⓣ Ⓕ
20. There's no use in really trying to get anything I want because I probably won't get it. Ⓣ Ⓕ

THE PSYCHOLOGICAL CORPORATION
HARCOURT BRACE JOVANOVICH, INC.

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

Consulting Psychologists Press

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

APPENDIX C

. Think about the symptoms of your illness or condition over the **PAST WEEK**. Compare r **present** symptoms to the symptoms you had **before** this week. Then, indicate how much you ee or disagree with the following statements by using the five point scale which follows h statement: 1 = **Strongly Disagree**; 2 = **Disagree**; 3 = **Undecided or Unsure**; 4 = **Agree**; **Strongly Agree**. Circle the **one** number which most closely fits your experience over the **T WEEK**.

	SD	**D**	**U**	**A**	**SA**
Overall, my symptoms are getting better.	1	2	3	4	5
I have more types/kinds of symptoms than I did before.	1	2	3	4	5
I am free of symptoms more often now.	1	2	3	4	5
I notice my symptoms more often now.	1	2	3	4	5
My symptoms are not as bad/severe as they have been.	1	2	3	4	5
My symptoms interfere with my life more now.	1	2	3	4	5
My symptoms seem to last for a longer time now.	1	2	3	4	5
I have a greater number of symptoms now.	1	2	3	4	5
My symptoms have not spread to other areas of my body.	1	2	3	4	5
I have new symptoms that I have not felt before.	1	2	3	4	5
My symptoms are more visible to others than they have been.	1	2	3	4	5
My symptoms don't bother me any more than they usually do.	1	2	3	4	5
I experience my symptoms less often now.	1	2	3	4	5

Comments:

APPENDIX D

19. Below is a list of symptoms which some people with your illness/condition may experience. For each symptom that you have experienced, **SINCE YOU BECAME ILL** please indicate how much of a problem it is for you **NOW** in your daily life by using the following scale: 1 = not a problem at all; 2 a slight problem; 3 = a moderate problem; 4 = a serious problem; 5 = a very serious problem. If you have **NOT** experienced a particular symptom since you became ill, please circle **N/A**, for Not Applicable.

	SYMPTOM	**HOW MUCH OF A PROBLEM FOR YOU?**					
		Not a Problem 1	2	Moderate Problem 3	4	Very Serious Problem 5	Not Applicable N/A
1.	poor appetite	1	2	3	4	5	N/A
2.	stomach pain	1	2	3	4	5	N/A
3.	nausea	1	2	3	4	5	N/A
4.	vomiting	1	2	3	4	5	N/A
5.	diarrhea	1	2	3	4	5	N/A
6.	weight gain	1	2	3	4	5	N/A
7.	weight loss	1	2	3	4	5	N/A
8.	night sweats	1	2	3	4	5	N/A
9.	sore on scratchy throat	1	2	3	4	5	N/A
0.	swollen lymph glands in neck, armpit or groin	1	2	3	4	5	N/A
1.	gland pain in neck, armpits or groin	1	2	3	4	5	N/A
2.	unpleasant reaction after drinking alcohol	1	2	3	4	5	N/A
3.	fever measured by thermometer	1	2	3	4	5	N/A
4.	chills	1	2	3	4	5	N/A
5.	difficulty falling asleep	1	2	3	4	5	N/A
6.	difficulty staying asleep	1	2	3	4	5	N/A
7.	difficulty staying awake	1	2	3	4	5	N/A
8.	not feeling rested when awakening in the morning	1	2	3	4	5	N/A
9.	unusual tiredness or fatigue after exercise	1	2	3	4	5	N/A
0.	feeling unusually tired, fatigued or lack of energy	1	2	3	4	5	N/A

	SYMPTOM	HOW MUCH OF A PROBLEM FOR YOU?					
		Not a Problem 1	2	Moderate Problem 3	4	Very Serious Problem 5	Not Applicable N/A
1.	difficulty concentrating/ easily distracted	1	2	3	4	5	N/A
2.	forgetfulness	1	2	3	4	5	N/A
3.	difficulty thinking, following directions or making calculations	1	2	3	4	5	N/A
4.	feeling confused at times	1	2	3	4	5	N/A
5.	difficulty finding the right word	1	2	3	4	5	N/A
6.	feeling down or "blue"	1	2	3	4	5	N/A
7.	frequent mood changes	1	2	3	4	5	N/A
8.	feeling tense or anxious	1	2	3	4	5	N/A
9.	bothered by bright lights	1	2	3	4	5	N/A
0.	blurred or fuzzy vision	1	2	3	4	5	N/A
1.	other visual problem	1	2	3	4	5	N/A
2.	muscle twitches/jerking	1	2	3	4	5	N/A
3.	seizures or "fits"	1	2	3	4	5	N/A
4.	trouble keeping balance	1	2	3	4	5	N/A
5.	dizziness	1	2	3	4	5	N/A
6.	headaches	1	2	3	4	5	N/A
7.	skin tingling or numbness	1	2	3	4	5	N/A
8.	other odd skin sensations	1	2	3	4	5	N/A
9.	stiffness after sitting/sleeping	1	2	3	4	5	N/A
0.	muscle aches or pains	1	2	3	4	5	N/A
1.	muscle weakness	1	2	3	4	5	N/A
2.	joint pain	1	2	3	4	5	N/A
3.	jaw ache	1	2	3	4	5	N/A

HOW MUCH OF A PROBLEM FOR YOU?

	SYMPTOM	Not a Problem 1	2	Moderate Problem 3	4	Very Serious Problem 5	Not Applicable N/A
44.	puffy face in the morning	1	2	3	4	5	N/A
45.	swollen fingers	1	2	3	4	5	N/A
46.	skin rash	1	2	3	4	5	N/A
47.	red or flushed face	1	2	3	4	5	N/A
48.	sores/ulcers in mouth or on tongue	1	2	3	4	5	N/A
49.	lip blisters	1	2	3	4	5	N/A
50.	hay fever	1	2	3	4	5	N/A
51.	sinus conditions	1	2	3	4	5	N/A
52.	other allergies	1	2	3	4	5	N/A
53.	rapid, irregular or abnormal heartbeat	1	2	3	4	5	N/A
4.	chest pain/pressure	1	2	3	4	5	N/A
5.	shortness of breath	1	2	3	4	5	N/A
6.	cough	1	2	3	4	5	N/A

7. other (explain) ____

____

____

8. Of the symptoms you identified above, list the three symptoms below that presently cause you the **most** difficulty, problems or concern:

1.____________________

2.____________________

3.____________________

APPENDIX E

No. ______________

MISHEL UNCERTAINTY IN ILLNESS SCALE
COMMUNITY FORM

Instructions: Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

2. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

3. I am unsure if my illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

4. It is unclear how bad my symptoms will be.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

5. The explanations they give about my condition seem hazy to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

6. The purpose of my care is clear to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

7. When I have symptoms, I know what this means about my condition.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

8. My symptoms continue to change unpredictably.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

9. I understand everything explained to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

10. The doctors say things to me that could have many meanings.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

11. The care I receive is too complex to figure out.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

12. It is difficult to know if the care or medications I am getting are helping.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

3. Because of the unpredictability of my condition, I cannot plan for the future.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

14. The course of my condition keeps changing. I have good and bad days.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

15. I have been given many differing opinions about what is wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

16. It is not clear what is going to happen to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

17. I usually know if I am going to have a good or bad day.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

18. The results of my tests are inconsistent.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

9. The effectiveness of my care is undetermined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

20. I can generally predict the course of my condition.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(1)	(2)	(3)	(4)	(5)
______	______	______	______	______

21. Because of my condition, what I can do and cannot do keeps changing.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
______	______	______	______	______

22. I'm certain they will not find anything else wrong with me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
______	______	______	______	______

23. The care I am receiving has a known probability of success.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
______	______	______	______	______

24. They have not given me a specific diagnosis.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
______	______	______	______	______

25. My physical distress is predictable; I know when it is going to get better or worse.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
______	______	______	______	______

26. My diagnosis is definite and will not change.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
______	______	______	______	______

27. The seriousness of my condition has been determined.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
______	______	______	______	______

28. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
______	______	______	______	______

APPENDIX F

BHS

Date: ____________________

Name: ______________________________ Marital Status: __________ Age: ________ Sex: ______

Occupation: ______________________________ Education: ______________________________

This questionnaire consists of 20 statements. Please read the statements carefully one by one. If the statement describes your attitude for the **past week including today**, darken the circle with a 'T' indicating TRUE in the column next to the statement. If the statement does not describe your attitude, darken the circle with an 'F' indicating FALSE in the column next to this statement. **Please be sure to read each statement carefully.**

1. I look forward to the future with hope and enthusiasm. Ⓣ Ⓕ
2. I might as well give up because there is nothing I can do about making things better for myself. Ⓣ Ⓕ
3. When things are going badly, I am helped by knowing that they cannot stay that way forever. Ⓣ Ⓕ
4. I can't imagine what my life would be like in ten years. Ⓣ Ⓕ
5. I have enough time to accomplish the things I want to do. Ⓣ Ⓕ
6. In the future, I expect to succeed in what concerns me most. Ⓣ Ⓕ
7. My future seems dark to me. Ⓣ Ⓕ
8. I happen to be particularly lucky, and I expect to get more of the good things in life than the average person. Ⓣ Ⓕ
9. I just can't get the breaks, and there's no reason I will in the future. Ⓣ Ⓕ
10. My past experiences have prepared me well for the future. Ⓣ Ⓕ
11. All I can see ahead of me is unpleasantness rather than pleasantness. Ⓣ Ⓕ
12. I don't expect to get what I really want. Ⓣ Ⓕ
13. When I look ahead to the future, I expect that I will be happier than I am now. Ⓣ Ⓕ
14. Things just don't work out the way I want them to. Ⓣ Ⓕ
15. I have great faith in the future. Ⓣ Ⓕ
16. I never get what I want, so it's foolish to want anything. Ⓣ Ⓕ
17. It's very unlikely that I will get any real satisfaction in the future. Ⓣ Ⓕ
18. The future seems vague and uncertain to me. Ⓣ Ⓕ
19. I can look forward to more good times than bad times. Ⓣ Ⓕ
20. There's no use in really trying to get anything I want because I probably won't get it. Ⓣ Ⓕ

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APPENDIX G

SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
R. L. Gorsuch, R. Lushene, P. R. Vagg, and G. A. Jacobs

STAI Form Y-1

Name ______________________________ Date ____________ S ____

Age ____________ Sex: M ____ F ____ T ____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

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SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name ______________________________ Date ______________

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④