THE PSYCHOLOGICAL IMPACT OF SYSTEMIC LUPUS ERYTHEMATOSUS ON THE PRIMARY CARE-GIVER

by

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This thesis is dedicated in memory of my father, Peter E. King, for his undaunted spirit -- both past and present.
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ABSTRACT

Variables that impact on the psychological and physical well-being of the primary care-giver of a family member with systemic lupus erythematosus (S.L.E.) were studied. The purpose of this descriptive study was to explore if social support and perceived uncertainty towards the illness state of S.L.E. were associated with the development of psychological stress and physical symptoms in the primary care-giver.

Thirty primary care-givers of a family member with S.L.E. comprised the sample. Data were collected using measurement tools that tapped social support, uncertainty, psychological stress and physical symptom development. Pearson product moment correlations and regression analysis were the methods of statistical analysis utilized.

Findings indicated a significant relationship between uncertainty and psychological stress. Social support was found to be inversely related to the lack of information factor of uncertainty. There were no significant relationships between the degree of uncertainty, stress, social support and physical symptom development.
CHAPTER 1

INTRODUCTION

Chronic illness is an aversive insult to the equilibrium of the "ill" individual and also to the family of the "ill" individual (Kretzer and Morgon, 1979). Kretzer and Morgon (1979) cite that chronic illness is devastating to families because the illness creates an environment that is shadowed with various stressors and everlasting uncertainties. Bonner (1974) cites that a family whose member is afflicted with a chronic illness often feels ignorant because of the uncertainty and stress that exist regarding the chronic illness state.

Systemic lupus erythematosus (S.L.E.) is a chronic autoimmune disease that has effected as many as 500,000 individuals and their families in the United States. In light of the uncertain nature of the disease, medical science to date experiences tremendous difficulty in initially diagnosing, treating and defining a predictable path that the disease will follow. There is no defined "patient" profile of an individual that is afflicted with S.L.E. because medical researchers are presently ignorant of a definite physiological cause (Dubois, 1981).

A family where one of its members is afflicted with S.L.E., like other families with chronic illness, experiences a state of uncertainty and stress towards the disease process (Mailick, 1979; Mishel, 1982). Within the family unit it is the primary care-giver who is especially confronted with uncertainty concerning their family member's
diagnosis, prognosis, treatment regimen and the information relayed by professional care-givers regarding the disease state (Crayton, 1979; Farkas, 1980). The primary care-giver of the American family is often the member to absorb a large degree of the stress experienced in the family dynamics (Bell and Vogel, 1960). Bell and Vogel (1960) conclude that when one member of a family is ill, the support available for the primary care-giver is minimal. Thus, the primary care-giver of an individual with S.L.E. must absorb a large percentage of the uncertainty and probable stress resulting from the illness.

This resulting stress that the primary care-giver experiences is noted to elicit physical symptoms and various disease states (Klein, 1967). More specifically, Bartrap (1977) reports that spouses and primary care-givers had decreased immunological competence after experiencing uncertainty and stress stemming from their significant other's illness state.

The literature provides further support that the primary care-giver of a chronically ill person is a significant variable in health care and that health professionals should attempt to understand the impact that the illness has on the afflicted family members (Glaser, 1970; Kaplan and Cassel, 1975; Farkas, 1980). The impact that chronic illness has upon the family unit and the primary care-givers is not found in one homogeneous formula. A combination of psychological stressors disrupt the family milieu when a chronic illness is present (Cassel, 1975).

In light of the disruptive force that chronic illness creates in a family environment, health professionals must redirect their
intense focus from the "ill" individual to the primary care-giver and other family members. Investigations of the impact that chronic illness has on the primary care-giver are necessary in order to identify the sources of the psychological stress and their consequences.

Statement of the Problem

A body of literature presently exists regarding the relationship of chronic illness and the resulting psychological stress and illness onset that ensues in the family members of the chronically ill (Klein, 1967; Bartrap, 1977; Farkas, 1980). However, few have investigated the specific variables in the chronic illness process that are responsible for the primary care-givers developing psychological stress with resulting physiological symptoms (Klein, 1967; Strauss, 1975).

In order to develop a more scientific sphere of nursing knowledge to assist the primary care-givers and families of individuals afflicted with S.L.E., relationships between specific variables conceptualized as impacting on the primary care-giver's health need to be studied. The intent of this study was to investigate the following:

1) Uncertainty perceived by the primary care-givers about their family member's S.L.E. increases the primary care-giver's psychological stress response and physical symptom development.
2) Social support decreases the psychological stress response of the primary care-giver towards the chronic illness event by decreasing the uncertainty and therefore resulting in less physical symptom development in the primary care-giver.

**Purpose of the Study**

The purpose of this study was threefold:

1) Explore the impact that the variable of social support has upon the uncertainty that is experienced by the primary care-givers when their family member is afflicted with S.L.E.

2) Explore if the experience of uncertainty is associated with a primary care-giver's psychological stress response.

3) Explore if the experiences of uncertainty and subsequent psychological stress are associated with the development of various physiological symptoms in the primary care-giver.

**Significance of the Problem**

Chronic illness is noted in the literature to impact stressful on the family members, especially the primary care-giver of the afflicted individual (Bonner, 1974; Farkas, 1980). The primary care-giver, as a result of living continually with a chronic illness situation, is constantly exposed to multiple stressors that are generated from the chronic illness state. These stressors have been noted to
predispose the primary care-giver to various physiological symptom manifestations with resulting illness and breakdown (Klein, 1967). Although the literature discusses the relationship between chronic illness and stress in family members, little has been done, especially in the area of S.L.E., to investigate the specific stressors and buffering agents that act upon the primary care-giver of a person with chronic illness. A dearth of literature exists on the agents which act to elicit or moderate the stressful experience and the possible physical symptom onset.

Health care professionals attempt to assess and implement interventions in family situations where a chronic illness such as S.L.E. is found in order to alleviate stressors. This is done in hopes of maintaining an equilibrium within the family unit. The maintenance of a family equilibrium and the wellness of other family members, especially the primary care-giver, is imperative when chronic illness is present in a family. As Strauss (1975) pointed out, chronic illness is virtually impossible to manage unless the family unit is intact. The family members perform as agents who protect, assist and rescue the chronically ill person. The ability of the primary care-giver to perform in these roles has a significant influence on the trajectory of the afflicted individual's illness state (Strauss, 1975). Therefore, an investigation of the stressors and buffering agents that impact on the primary care-giver's psychological and physical states is a necessity if the care-givers are to assist their family member with S.L.E. to maintain a relatively optimal state of well-being.
Conceptual Framework

The conceptual framework for this study is based on a review of literature concerning the following variables.

1. Social Support
2. Uncertainty
3. Psychological Stress Response
4. Physical Symptomatic State

![Conceptual Framework Diagram]

Figure 1
Conceptual Framework of the Psychological Impact of S.L.E. on Primary Care-Givers

The conceptual framework (as noted in Figure 1) states that social support is an intervening variable between the cognitive variable of uncertainty and psychological stress. A deficient social support network augments the experience of uncertainty and stress. In this conceptual framework, uncertainty is positively related to a psychological stress response. The framework contends that if uncertainty is experienced, a psychological stress response ensues. The final conceptual linkage in the framework is the positive relationship between a psychological stress response and the development of a physical symptomatic state.
Conceptual Links

Social Support, Uncertainty and Stress

The variable of social support has received much attention over the years as a buffering agent in psychological stress and/or emotional distress (Cobb, 1976; Gore, 1978; Lin, 1979). Gore (1978) has found that unemployed men who were unsupported by their marital relationships had elevated cholesterol levels when compared to unemployed men who were supported. Other empirical evidence discussed the inverse relationship of social support and psychological maladjustment. These studies found that low social support was a predictor of psychological distress (Andrews, 1978; Henderson, 1979). Cobb (1976), an experienced investigator of social support, has supported the relationship with his claim that social support protects people from various life crises and assists people in recovery from illness.

Although social support has undergone much investigation over the years as a buffering agent in psychological stress, some question exists as to how it acts as a buffering agent (Wortman, and Dunkel-Schetter, 1979; Holohan and Moss, 1981). Some researchers have proposed that social support acts to reduce uncertainty in various life crises, i.e., illness events (Wortman and Dunkel-Schetter, 1979; Lin, 1979), but none have quantified the relationship. Lin (1979) contended that social support networks provide information about various events that are perceived as stressful. If social support is an information source, then the presence of social support when an uncertain event is experienced, can act to decrease the uncertainty by providing information
about the causes and consequences of the event. This reduction of uncertainty is accomplished because social support acts as a provider of information, thus alleviating some of the existing uncertainty and subsequent stress.

Social support serves a coping function (Gore, 1978). Pearlin and Schooler (1978) pointed out that protective functions of a coping behavior are to act as a controlling force in an experience, a neutralizer of the perceived problem and to act to maintain the problem within a controllable sphere. It can be inferred, if social support serves as a coping function and if it is present when uncertainty is experienced, it can act as a means of controlling, managing and reducing the perceived uncertainty generated from ambiguous events.

Wortman and Dunkel-Schetter (1979) have discussed the concept of social support and its ability to reduce perceived uncertainty. They contended that cancer patients experience tremendous degrees of uncertainty regarding their diagnosis, prognosis and various treatment regimens. This uncertainty was reduced by the actions of an intact social support network. They explained that social interactions provide feedback. This feedback acts to provide meaning for the events thus reducing the uncertainty and the confusion that is experience by these cancer patients. In a pilot study that explored uncertainty levels in women diagnosed with gynecological cancer Mishel (1982) has found through anecdotal notes that uncertainty levels were heightened in subjects whose social support networks were lacking or chaotic.
Gordon, Erwin and Moss (1973) reported that social communication networks are viewed as a means to reduce and control uncertainty. They claimed this is accomplished by establishing a network where each member depends on another member's expertise to handle various threatening events and situations. They contended that social support decreases uncertainty, but they noted that further research is needed to substantiate the stated relationship.

Uncertainty and a Psychological Stress Response

The variable of uncertainty is conceptualized as directly impacting on one's psychological stress response. Mishel (1981a, p. 258) defined uncertainty as "the cognitive state of the person created when an event could not be adequately structured or categorized because sufficient cues were lacking." This inability to structure or categorize occurred because the events were shadowed with unpredictability, a lack of information regarding causes and outcomes, ambiguity and vagueness (Mishel, 1981a). The variable of a psychological stress response is presented in this conceptual framework as the experience of emotional distress.

The linkage between uncertainty and a psychological stress response is supported by evidence from laboratory and clinical investigations. The laboratory findings indicated that when individuals were confronted with an uncertain event represented by unpredictability, the event was noted to elicit an emotional distress reaction (Berlyne, 1979).
Other investigations noted that subjects exposed to an uncertain environment created by the delivery of unpredictable shocks developed signs of emotional distress (Pervin, 1963; Weiss, 1970).

Clinical observations, found in the literature, support the view that uncertainty is directly related to a psychological stress response as indicated by emotional distress. Marks (1967) discussed various psycho-social factors that predisposed individuals to chronic emotional distress. He claimed that when individuals were exposed to incongruities, conflicts and discontinuities in their milieu, emotional distress resulted. Gordon, Ervin and Moss (1973), further expanding on Mark's idea, claimed that a state of incongruities or subjective uncertainty produced a psychological response illustrated by the occurrence of anxiety, anger, and depression. Davis (1972) provided further clinical support for the positive relationship of uncertainty and a psychological stress response. She found that hospitalized coronary care unit patients experienced emotional distress as a result of the uncertainty of not knowing their diagnoses and their inability to anticipate discomforts that resulted from various treatment regimens. Other clinical researchers claimed that the emotional distress that patients experienced stemmed largely from the uncertainty that was generated from various diagnoses, prognoses, and an overall inability to comprehend the consequences of a disease state (Gerle, 1960; Quint, 1960; Davis, 1972; McIntosh, 1974).
Psychological Stress Response and the Development of Physical Symptoms

A psychological stress response, as represented by emotional distress, is proposed to influence the development of physical symptoms or illness. Multiple researchers have postulated a positive relationship between these two variables (Rahe, 1964; Dodge and Martin, 1970; Rahe, 1972; Dohrenwend and Dohrenwend, 1974; Pakel, 1974; Gunderson and Rahe, 1978). The literature addressed this stated relationship in two ways. The life-event researchers claimed that various stressful life events have predisposed individuals to an increased number of physical symptoms of illness (Rahe, 1970; Dohrenwend and Dohrenwend, 1974; Gunderson and Rahe, 1978). This research, however, has undergone serious criticism regarding the measurement instrument itself and the overall validity of the studies (Rabkin, 1976; Andrews, 1978).

Other researchers claimed that psychological stress illustrated by emotional distress, resulted in illness. The illness state occurred after a prolonged arousal state ensued which stemmed from the individual perceiving an event as threatening (Bartrap, 1977; Frankenhauser, 1980; Henry, 1982).

Furst (1970) found that surgical patients who had high anxiety and overall emotional distress prior to surgery developed more post-operative complications. The post-operative complications consisted of a re-surfacing of latent psychosomatic conditions and an increased potential for gastric ulceration. Haft (1976) also found that emotional distress induced marked changes in platelet aggregation. Katz (1963) also supported this relationship with his findings that women who
expressed the most emotional distress (fear, worry, and despair) were noted to have the highest risk factors concerning their prognosis. More recent research supports the stated relationship by describing the physiological mechanisms that malfunction under emotional distress and result in a physiological symptomatic state (Katz, 1970; Vernikos-Danellis and Heybach, 1980; Frankenhauser, 1981).

Henry (1982) claimed that a psycho-social experience, i.e., emotional distress, can alter and override various neuroendocrine feedback controls that act to maintain and restore homeostasis. This overriding of the various neuroendocrine homeostatic mechanisms can lead to the gradual and/or sudden onset of pathophysiological symptoms such as cardiac arrhythmias.

The ability of emotional arousal and distress to override various neuroendocrine homeostatic feedback mechanisms with resultant physiological symptoms has further been investigated by Smith. Smith and associates (1968) claimed that emotional distress could override the powerful baroreceptor feedback mechanism, which controls systemic blood pressure. Emotional distress in response to environmentally stressful situations, he concluded, can induce the pathophysiological state of hypertension. Frankenhauser (1980) discussed the relationship between cortisol levels and external stressors. Cortisol, a hormone secreted by the pituitary adrenal cortex mechanisms was shown to rise in individuals who were confronted with the emotionally distressful situation of a loss of control of their environment.

The findings from current investigations and clinical observations provide support for the proposed relationships between social
support, uncertainty, emotional distress and development of physical symptoms or illness. The following conceptual and operational definitions are presented for each variable in the study.

**Conceptual Definitions**

**Social Support** -- Interpersonal transactions that include one or more of the following: the expression of positive affect of one person towards another, the affirmation or endorsement of a person's behaviors, perceptions or expressed views, the giving of symbolic or material aid to another (Norbeck, 1981). The above is noted by Norbeck (1981) to represent functional support.

**Uncertainty** -- The cognitive state of the person created when an event cannot be adequately structured or categorized because sufficient cues are lacking (Mishel, 1981a).

**Psychological Stress Response** -- A psychological state that is characterized by emotional distress and fluctuating affective states.

**Symptomatic State** -- A state that is characterized by the reporting of physical distress or various medical illnesses.

**Operational Definitions**

**Social Support** -- Total score on the Norbeck Social Support Questionnaire (N.S.S.Q.). The N.S.S.Q. measures three aspects of social support. These are the total functional, total network and total loss. Only the total functional score will be used in this study.
Uncertainty -- Total scale score on the 31-item Parent's Perception of Uncertainty Scale (P.P.U.S.). The P.P.U.S. will be modified to measure the uncertainty a primary care-giver experiences about a significant other's illness state.

Psychological Stress Response -- Total scale score on the 65-item Profile of Mood States (P.O.M.S.). The P.O.M.S. is a measure of emotional distress and fluctuating affective states, which quantifies the existence of Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment.

Symptomatic State -- Total scores on the Seriousness of Illness Rating Scale (S.I.S.). The S.I.S. consists of 126 medical diagnoses and various physical symptoms ranked according to grand mean by seriousness of illness. The S.I.S. will be modified in order to measure the physical symptoms a primary care-giver experiences.

Chapter Summary

This chapter has addressed the impact that a chronic illness such as S.L.E. has on family members, especially the primary care-giver. The purpose of the study, the significance of the study and conceptual framework were also addressed.

Social support was presented as an intervening agent in the uncertainty and stress experienced by primary care-givers of the chronically ill. Uncertainty was conceptualized as directly influencing a psychological stress response. Uncertainty and psychological stress were presented as influencing the development of physical symptoms or illness in the primary care-giver of one who has S.L.E.
CHAPTER 2

REVIEW OF LITERATURE

The literature pertinent to the variables of the study is discussed in this chapter. The following discussion will focus on the experience of living with chronic illness, followed by a brief discussion of systemic lupus erythematosus (S.L.E.). Next, the variables of social support, uncertainty, psychological stress and symptom development are presented. The problem in measuring social support is also reviewed.

Living with Chronic Illness

Chronic illness creates an environment that is characterized by a high emotional arousal for the patient and family (Abram, 1969; Westbrook and Viney, 1982). The family, as well as the chronically ill patient experience varying degrees of uncertainty, depression and anxiety (Maluick, 1981; Westbrook and Viney, 1982). A family unit is severely altered after chronic illness has impacted upon them. Sex and intimacy, personal interactions, friends, leisure time activities, and financial concerns stemming from unemployment due to the illness state are all affected by the occurrence of a chronic disease (Strauss, 1975). The uncertainty of the prognosis in chronic illness proves to be disruptive to families and their social relationships. Camaroff and Maguire (1981) have pointed out that others react to the illness with
embarrassment or with overt emotion. The family often misinterprets these reactions and is resentful of being patronized and of being given sympathy. Comaroff and Maguire (1981) stated that chronic illness radically changes the affected family's goals and values, the subjective meaning of their lives and future oriented expectations. They concluded that chronic illness permanently impacts on familial relations, quality of life and the family begins to question the meaning and definition of survival.

Matson and Brooks (1977) have investigated the psychological adjustment made by individuals who are afflicted with multiple sclerosis and found that the uncertainty of symptom exacerbation sometimes caused a regression in adjustment to the disease. Individuals with such a disease sometimes have a fuller appreciation of life, an appreciation gained by living intimately with an uncertain and threatening future (Matson and Brooks, 1977). One of Matson's findings was that the individuals who adjusted the best to living with multiple sclerosis were those who had intact family units.

Strauss (1975), along these same lines, has discussed the experience of the family and the affected individual when arthritis has impacted. He claimed that family members govern and salvage the "ill" family member during exacerbations and various crisis points in the disease. Strauss (1975) claimed that because the disease was so filled with uncertainty an intact family unit is necessary to assist the afflicted individual cope with the chronic illness state.
Although S.L.E. is a chronic disease that has afflicted a significant number of persons, few studies have investigated the experience of living with this chronic illness. It can only be surmised that the experience is similar to living with other uncertain chronic disorders. This research will be the first empirical study investigating the psychological impact that S.L.E. has on the primary care-giver.

Systemic Lupus Erthymatosus

S.L.E. is a chronic autoimmune disease characterized by a long and frustrating diagnostic phase, an unknown cause, unpredictable symptoms, non-specific treatments and a nebulous prognosis. The diagnosis of S.L.E., as the literature noted (Dubois, 1981), is not an easy one to confirm. An official diagnosis may take an unknown amount of months of observation, a barrage of laboratory tests and at times a variety of drugs in order to make a specific diagnosis (Hartley, 1978). Often the diagnosis of S.L.E. is confused with other chronic disorders, such as arthritis. In order to diagnose S.L.E. multiple blood tests, urine analyses, kidney function tests, skin tests, X-rays and E.K.G.'s are done, but none of these tests are specific for S.L.E. (Dubois, 1981). As Dubois (1981) pointed out, the diagnosis of the disease is tremendously difficult because there is no specific set of symptoms or pattern to the disease. The disease, S.L.E., is able to mimic other diseases. An example is that one out of six S.L.E. patients have a "false-positive" blood test for syphilis. The false-positive blood test for syphilis is often the first symptom of S.L.E. This does not mean the patient has such a venereal disease and to date no scientific relationship exists
between the two diseases. Some patients after receiving an official diagnosis of S.L.E. are relieved because the uncertainty of the diagnostic phase is over (Hartley, 1978).

The etiology of S.L.E. to date is unknown (Decker, 1982). Current researchers have described the cause to be related to a dysfunction of the immune system (Dubois, 1981). The body fails to recognize various antigens as its own and thus produces autoantibodies. These antibodies combine with the nuclear material in the cell and this material is then released into the systemic circulation. These antibodies, with the nucleus and other cellular parts, create a deleterious reaction in the small blood vessels. The effect on the various bodily systems depends on the type and amount of these antibodies (Hartley, 1978).

The symptoms of S.L.E. are totally unpredictable (Hartley, 1978; Dubois, 1981; Decker, 1982). Exacerbations and remissions of symptoms are a common occurrence in S.L.E. The patient can present as severely ill one week with various symptoms and in a few weeks present as totally asymptomatic. No two patients with S.L.E. are alike (Decker, 1982). The most common symptoms are joint swelling and pain, skin changes, swollen glands, lack of appetite and muscle aching. All of these symptoms can and are attributed to other disease states. No unique set of symptoms or pattern of events can describe S.L.E. (Dubois, 1981).

Following along with the uncertain nature of the disease there is no specific treatment for S.L.E. (Hartley, 1978). The medications that are prescribed to treat S.L.E. possess potential dangers. Antimalarial drugs are employed, due to the findings that patients have
shown improvements with these drugs. However, there is no scientific linkage between malaria and S.L.E. The side-effects of these drugs affect the digestive tract and one's vision. Aspirin is also used as a treatment measure to help control fever, pleurisy and joint pains. Due to the large doses necessary for symptom control, stomach ulcers and at times internal bleeding can occur. Cortisone-related drugs are also used for treatment purposes. They are used to treat the internal changes and assist the healing of the skin. These drugs, however, are notoriously known for their side-effects (Decker, 1982). Rest is often prescribed during an exacerbation of S.L.E. The afflicted person's activity of daily living revolves around the symptom occurrence. This, however, does not alleviate the chances for an exacerbation. Patients are told to avoid sunlight reflected from water, sand and/or snow; even shade has been noted to increase symptom development. The patient's lifestyle is continuously at the mercy of the disease (Dubois, 1981).

The prognosis for S.L.E. is nebulous. Presently, survival rates are improving for unknown reasons. As Decker (1982, p. 894) states "we must be doing something right." The literature asserted that with recent research regarding S.L.E., improved symptom control and treatment measures are becoming more of a reality. However, prevention and cure of the disease is not yet within the grasp of medical science (Dubois, 1981; Decker, 1982).

Social Support

First, the variable social support and its relationship to psychological stress and uncertainty will be presented. Its function and
role in illness will also be presented along with the problem in measuring the variable.

Social Support and Psychological Stress

In recent years social support has gained significant importance as a mediating agent in life stress (Cassel, 1976; Cobb, 1976; Gore, 1978; Lin et al., 1979; Fleming, 1982). Researchers have developed two general hypotheses regarding the effects of social support. One perspective is that possessing minimal or no social support is in itself stressful, and having greater levels of support is beneficial, regardless of the presence of stress. The lack or loss of a friend or family member has been noted to impact negatively on one's health status (Holmes, 1974; Bartrap, 1977). Another view of social support, namely the "stress buffering" perspective contends that high levels of social support assist people to better cope with stress. If stress is absent or minimal, social support acts as a rather benign agent—it neither helps nor harms (Fleming, 1982). The following is a review of recent studies displaying the various functions that social support has on stress and subsequent illness.

Gore (1978) investigated the effects of social support on unemployed men. She found that those men who were not reemployed and felt unsupported experienced higher serum cholesterol levels and various symptoms of depression than supported men. Andrews (1978) concluded that assistance given from family and friends to those in crisis had a positive impact on the effected psychological functioning. Berkman and Syme (1979) explored the impact that social support had on life
expectancy. They found that socially isolated persons had a significantly shorter life span than persons with a moderate to higher number of social contacts. Halahon and Moss (1981) further supported the previous finding regarding the beneficial aspects of social support. They concluded that when social support was present, symptoms of psychological maladjustment from unemployment were very low. Flemming et al. (1982) investigated the influences of social support on those who had undergone the tragedy of Three Mile Island (T.M.I.). The findings of the study concluded that those residents of T.M.I. who had experienced higher stress and/or emotional distress reported having little or no social support networks. Social support appeared to reduce the psychological and behavioral consequences of living with stress. A lack of social supportive interactions was found to be a predictor of psychological maladjustment (Ilfeld, 1976). Other researchers have suggested that social support functions to buffer life stress and illness (Nuckolls, 1972; Medalie, 1976; Gore, 1977). Gore (1977) pointed that intact social support networks were directly related to good health status. Medalie (1976) found that social networks acted to buffer and decrease illness reoccurrence in cardiac patients. Nuckolls (1972) contended that supported pregnant women displayed far fewer complications in delivering their children, than did unsupported women.

Cobb (1976) examined the role of social support in various life crises. Cobb discussed Jessner's (1952) findings that parents of hospitalized children, who were well informed and supportive of their children had a significant impact in preventing post-operative
complications. Cobb then noted the studies which explored the care of a myocardial infarction patient at home. The results indicated that treatment at home held no greater and even less risk than treating these patients in a highly technical and modern intensive care unit. Cobb deduced that the lesser risks associated with non-hospitalization were due to the supportive atmosphere found at home.

Cobb continued in his discussion of social support and pointed out its role in recovery from illness. Cobb claimed that social support assists the patient in the understanding of and compliance with various treatment regimens. To support this claim, Cobb cited Aruijo's (1973) work with adult asthmatics. Subjects with asthma who possessed much life stress and low social support required four times as many steroids in order to control their asthmatic conditions. Cobb concluded enough evidence is available which confirms the fact that social support can protect people from crisis and a wide variety of pathological states.

Social Support and Uncertainty

The inverse relationship between social support and stress or illness development has supporting evidence. However, the way social support functions to perform as this stress-illness reducing activity has not been fully supported in the literature. Flemming, (1982, p. 70) when describing how social support functions merely stated "it somehow makes people more resistant to the effects of stress."

Wortman and Dunkel-Schetter (1979) discussed the role of social support and its interaction with uncertainty. They propose that the more uncertain the ill person is, the more he/she needs social support
to clarify illness related events. Wortman and Dunkel-Schetter claimed that social support can reduce the uncertainty patients experience about their illness by reassuring them that their responses to the illness are normal. They also pointed out that uncertainty can be reduced by social comparison. The social comparison acts as a normalizer of various illness-related feelings and responses. Social support allows the chronically ill to ventilate, receive comparison information and in general provides feedback that clarifies the uncertainty and confusion about the illness experience.

Lin (1979) discussed social support as an information-provider about various life events. If uncertainty is a state where information is vague or lacking (Mishel, 1981), social support as an information-provider can assist in alleviating the uncertainty. Weissman and Worden (1975) anecdotally discussed that social support is beneficial to cancer patients because it provides information about the disease state and helps to reduce the uncertainty. Wortman and Dunkel-Schetter (1979) have presented support that cancer patients like to discuss their fears and uncertainties and an intact social support network allows for this uncertainty reduction to occur.

Problems in Measuring Social Support

Although social support has gained significance as a buffering agent in life stress and disease, there is a lack of conceptual agreement regarding what social support is and how it functions to protect people from stress and disease (Norbeck, 1981; Schaeffer, Coyne and Lazarus, 1981). Some researchers viewed social support as merely the
presence of another during a stressful experience while others viewed social support in a more complex nature and suggested various properties of a social network as important variables to study (Norbeck et al., 1981).

Norbeck et al., (1981) and Schaeffer (1981) have attempted to point out and clarify the various conceptual misconceptions that presently exist about social support. Schaeffer (1981) discussed the validity of the previous assumption that beneficial effects were positively associated with the size and range of a social support network. She explained that the assumption ignored the demands, constraints and conflicts that can occur with social relationships. She concluded that in order to assume that beneficial effects are associated with social support, the quality of the relationships within the social support network must be explored. Norbeck et al., (1981) also considered social support as a multi-dimensional concept where both functional and network properties deserve equal attention.

Schaeffer (1981) developed a scale which measured the varying aspects of social support. These were the tangible, emotional, and informational aspects. One of the surprising results was when social support was measured in this fashion it did not display the buffering effect on health and illness. She concluded that perhaps when social support is measured specifically rather than globally its effects are different than previously reported. She stated that in future research social support needs to be measured more scientifically and specifically in order to better understand its function in health and disease.
The variable of social support as an intervening variable and buffer on stress and uncertainty were presented. The literature review provided support for the conceptualization that supported primary care-givers will experience less uncertainty and stress than unsupported primary care-givers. Measurement problems concerning social support were also addressed.

**Uncertainty**

The cognitive variable, uncertainty, has been shown to impact stressfully on one's psychological and physiological functioning. Its presence in illness situations predisposes the "ill" individual and family members of the "ill" individual to psychological and physiological malfunction.

Berlyne (1979) discussed uncertainty in concert with the concepts of "drive," "arousal" and "stress." Berlyne claimed that drive, arousal, and stress, conceptually overlap, and intensify when an organism's equilibrium is disrupted. The presence of much environmental variability, Berlyne pointed out, also causes the same increase in drive, arousal and stress. The variable uncertainty, introduced by information theorists, provided assistance in quantifying the relationship between environmental variability and stress.

Berlyne (1960, 1967) over the past decades has done extensive laboratory experimentation with the concept of subjective uncertainty and its relationships to drive, arousal and stress. He hypothesized that subjective uncertainty acts to induce a drive and arousal in those who experience it. He further postulated that since drive, arousal and
stress overlap each conceptually, uncertainty should then be an influential variable in the occurrence of stress, including pathogenic stress. The following is a discussion of Berlyne's findings which support the above relationship.

Berlyne (1961) conducted a study to determine if a conflictual or uncertain event resulted in an increase in arousal. The findings indicated that those who underwent a highly conflictual event experienced an increased orientation reaction and arousal, measured by the Galvanic Skin Response. Another experiment by Berlyne and Borsa (1967) had similar results. The subjects who experienced the greatest subjective uncertainty also experienced an increased orientation reaction and subsequent arousal. This experiment was repeated and similar results occurred. Therefore, Berlyne and associates concluded that an increased orientation reaction and arousal occurred when subjective uncertainty was induced.

The term "drive" possesses various connotations (Berlyne, 1960). Berlyne stated that some of these connotations were similar with those of arousal. Therefore, the experiments previously mentioned indicated that subjective uncertainty increased a drive state. However, Berlyne pointed out that drive can also be seen as an aversive state and the alleviation of such a state is rewarding and can induce learning. This relationship was confirmed in an experiment performed by Nicki (1968). Nicki concluded that one felt more rewarded by exposure to the uncertainty-reducing information than exposure to unrelated information.
From the conceptual overlap of arousal, drive and stress, previously discussed, Berlyne contended that uncertainty can be a factor influencing stress. He stated that, although uncertainty is an influencing factor in the development of stress, it should not necessarily be shunned. A lack of uncertainty can lead to a lack of stimulation and a state of sensory or perceptual deprivation that has proven to be detrimental to psychological function (Berlyne, 1979). However, he stated that larger degrees of subjective uncertainty can also be severely detrimental. Unpredictable and ambiguous occurrences can be terrifying to those experiencing them. This type of occurrence, he claimed, was found in various illness states. Berlyne concluded that those who experienced large unwanted amounts of uncertainty were more inclined to experience breakdown and illness.

Lanzetta (1971, p. 122) discussed uncertainty similarly to that of Berlyne. He viewed uncertainty as a drive stimulus in information seeking. He hypothesized that "uncertainty is an important determiner of the search for and receptivity to information." He supported this hypothesis with various laboratory findings. In a laboratory experiment, subjects had to choose a "correct" answer from a set of responses. Before guessing they could have obtained information which increased the chance of guessing the right answer. Uncertainty was created by the large number of choices from which they were allowed to choose. The results indicated that as uncertainty increased the search for information also increased. Lanzetta (1971) conducted a similar experiment to support his previously stated hypothesis. His results again
supported his previous findings that uncertainty created a drive for information that was proportional with the amount of existing uncertainty. He viewed this drive for information as an attempt to reduce the uncertainty. This reduction of uncertainty was viewed as a reward or reinforcement for eliciting the search behavior.

Lanzetta theorized that uncertainty in varying degrees can be manipulated to cause the occurrence of beneficial results. Uncertainty at a less than moderate degree can be beneficial, however, Lanzetta also stated that at a moderate or greater degree, uncertainty creates an aversive state.

Monat, Averill, and Lazarus (1972) reported on the effects that temporal uncertainty and event uncertainty have on patterns of stress and anticipatory coping reactions. They claimed that uncertainty is an important antecedent to various anxiety reactions. Monat et al., (1972) cited uncertainty as an ambiguous concept in itself and that researchers in the field had not discriminated between the various types of uncertainty. Monat et al., (1972) distinguished between temporal and event uncertainty in hopes of ascertaining the various patterns of stress and coping reactions that occurred when the two types of uncertainty were present.

Temporal uncertainty was defined as not knowing when an inevitable threat (event) would occur. Event uncertainty was the experience of knowing when an event would occur, but the probability of the occurrence varied.
Monat's general findings after extensive laboratory experimentation indicated that temporal uncertainty was appraised as more threatening than time known conditions, but less threatening than event uncertainty. In a condition of temporal uncertainty a pattern of coping (attention deployment) which lowered arousal and a probable stress response occurred. Under conditions of event uncertainty, vigilance occurred and was accompanied by an increase in arousal. Monat noted that these results were not generalizable. The way in which people cope with threat and the relationship between threat, coping and stress is individual and attention must be given to the environment under which a person attempts to master the uncertain or threatening event.

Pervin (1963) discussed uncertainty in the realm of one's ability to predict and control events. He hypothesized that under threat conditions correct prediction of the stimulus would be preferred and less anxiety would be experienced than when a threat could not be predicted. He also postulated that if a subject was allowed to control a stimulus this would result in less anxiety than if the experimenter had control of the application of the stimulus. The findings illustrated that when one experienced threat, predictability was preferred to unpredictability.

In summary, Pervin has found that predictability was a desired phenomenon in threatening situations. Unpredictability was only desired in dull and mundane or less threatening situations. Therefore, Parvin concluded the degree of uncertainty and the type of conditions under
which uncertainty was experienced had an interactive effect on each other.

Suls and Mullen (1981) along the same lines as Pervin, explored the role that uncertainty played in the perceived control one had over life events and the impact this had on illness development. The results of their study indicated that life change had to be perceived as both undesirable and out of one's control in order to influence the development of various illnesses. This study provided further support that the amount of uncertainty and control one perceives about an aversive event impacts on one's health.

In summary, the experience of high level uncertainty can be viewed as one which impacts deleteriously on one's psychological and physiological function. At low levels, uncertainty has been discussed as enhancing intellectual curiosity, but at higher levels it can cause the development of stress. The review of literature will now discuss uncertainty and its occurrence in illness related events.

Uncertainty in Illness

From the above review of literature concerning the variable of uncertainty, it can be derived that the existence of uncertainty can influence the development of beneficial effects, such as intellectual curiosity (Lanzetta, 1971) and deleterious effects such as stress, illness and breakdown (Berlyne, 1979). The range of effects depend upon the degree of uncertainty that is experienced and the environment in which it occurred (Pervin, 1963).
The perception of uncertainty regarding an illness state has been noted by many researchers to be stressful and distressing (Davis, 1966; Comaroff and McGuire, 1981; Mishel, 1983d). Existing in an uncertain state causes, as Berlyne (1960) pointed out, an increase in arousal leading the individual to search for information to resolve the uncertainty. However, the search for information in a chronic illness state is a difficult one. The information needed to resolve uncertainty regarding the chronic illness is vague, ambiguous or at times not available (Abrams, 1972; Comaroff and McGuire, 1981). Thus, the persons living with a chronic illness state especially the primary care-giver, continues in a physiologically aroused state, to search for a resolution to the uncertainty. This continuous and long-term arousal has been noted to predispose primary care-givers to illness and breakdown (Berlyne, 1979).

The uncertain illness events found in a chronic illness state have been noted to lack a cognitive structure (Mishel, 1983d). An event that lacks a cognitive structure hampers one's ability to recognize, classify and adequately appraise a situation (Mishel, 1981a). A primary care-giver is not able to classify or adequately appraise various illness-related events because of their uncertain nature (Comaroff and McGuire, 1982). Mishel (1983d) noted that the literature cited vigilance and avoidance as the coping mechanisms utilized when uncertainty exists, although there is a lack of information regarding the effectiveness of these methods when illness is present. Lazarus (1977) stated that if various coping modes do not decrease the existing uncertainty, stress
has been shown to ensue. Stress has been noted by Selye (1956) to
hamper one's recovery or stabilization after an illness event.

Mishel (1983d) conducted one of the few empirical studies con­
cerning the relationship between uncertainty and stress in illness. The
purpose of her study was to examine the relationship between perceived
uncertainty and hospital stress. Her subjects consisted of 100 medical
patients, a majority of whom had a chronic illness as the primary diag­
nosis. The subjects were issued two questionnaires to measure the two
primary variables of uncertainty and stress. The Mishel Uncertainty in
Illness Scale (M.U.I.S.) was used to measure uncertainty. Stress was
measured by the Hospital Stress Rating Scale (H.S.R.S.). The H.S.R.S.
measured psychological stress that stemmed from the experience of
hospitalization.

The results revealed that those individuals who perceived their
multiple aspects of illness as uncertain also viewed the hospitalization
experience as stressful. It was not the specific hospital event that
evoked the stressful response, but it was the vagueness, the lack of
clarity, and the lack of information about the chronic illness events
that precipitated the stress (Mishel, 1983).

Comaroff and McGuire (1981) investigated the uncertainty and
ambiguity that existed in the parents of children diagnosed with the
chronic illness of leukemia. They pointed out the irony that exists in
the medical model regarding a chronic illness such as leukemia. The
"clinical gains" that medical science has achieved in conquering
leukemia have only heightened the uncertainties that exist toward the
chronic illness state. This piece-meal fashion by which medical science treats chronic illness, such as chemotherapies, has enhanced the unpredictable state of the afflicted's prognosis. The parent of the chronically-ill child, as the authors discussed, was faced with daily uncertainties about the cause of the disease, the effects of treatment regimens, and the eventual prognosis of the child. The parents were unable to place meaning on these events or develop a cognitive structure of the child's illness. The highest point of the stress experienced by these parents was shown to occur when their child's remission shattered and a relapse occurred. Urinary steroid levels were found to be elevated when this devastating event occurred.

Comaroff and McGuire (1981) suggested that perhaps medical science, with all its tremendous technology and "advances," only has exacerbated the crisis that occurs in a chronic illness state. They stated that medicine can be viewed as ambiguous in a double sense. Comaroff and McGuire (1981) summarized with this statement: "The more it appears to control the more threatening is the domain where knowledge is still lacking; and the more it controls, the more alienated the laymen is from control over its effects" (p. 121).

Other investigations have explored the uncertainty experienced by individuals diagnosed with cancer. Cassileth (1980) discussed the degree that cancer patients wish to be informed about and to participate in the various treatment and medical decisions regarding their chronic illness. The results of his study revealed that chronically-ill patients no longer played the role of the passive recipient of medical
care. He found that most patients wanted information and expressed a need to participate in their care. The uncertainty associated with cancer was described anecdotally to be "worse than knowing the facts." The reduction of the uncertainty by information-seeking maintained hope and decreased the existing fear and anxiety in these chronically ill individuals.

Waitzkin and Stueckle (1970) further commented on the uncertainty that is grounded in chronic illness. They claimed that the physicians maintain patients' uncertainty because this allows the physician to have total control and power over the medical regimen. If a physician was to alleviate existing chronic illness uncertainty, the patient then would be allowed various options or choices. This allotment of choice then decreases the physician's power over the various therapeutic decisions. When a physician controls and maintains uncertainty, choice of the various treatment measures is left solely to the doctor. Davis (1966) found that doctors withheld telling parents about their child's prognosis who were afflicted with the chronic illness, polio, long after they had known of definitive prognosis. He termed this "functional uncertainty." Roth (1963) found similar occurrences with chronically ill tuberculosis patients. Physicians were reluctant to disclose to these patients their discharge day, thus maintaining their power and control over them.

An irony in medicine exists. Patients and family members claim to want their illness-related uncertainty reduced. Yet, physicians are most comfortable with uncertainty at its zenith. In light of this
medical dilemma there is a need to further investigate this variable and its effect on the patient and the families where chronic illness has impacted.

A dearth of literature exists on the agents which act to elicit or moderate the uncertainty experienced by family members of individuals with S.L.E. as well as the individuals diagnosed with S.L.E. Mishel (1983c) has conducted one of the few studies concerning the uncertainty perceived by individuals afflicted with S.L.E. and also the family members of individuals with S.L.E. Their uncertainty clustered in three specific areas. These were: the ambiguity concerning the state of the illness; lack of information concerning the diagnosis; and unpredictability concerning the course of the illness. Some specific areas of the disease that these patients cited as uncertain were:

"The symptoms continuing to change unpredictably."

"The effectiveness of the treatment being undetermined."

"Having been given many differing opinions about what is wrong with them."

"The results of their tests being inconsistent."

Mishel (1983b) also found through anecdotal interactions that family members of individuals with S.L.E. experience uncertainty about the illness state. One family member stated, "The only thing you can be certain about is the uncertainty of the disease." Another stated, "You never know what to expect, one day he's fine, the next day he can't get out of bed. The worst thing about it is there's no real reason for the sudden change." From Mishel's study concerning the S.L.E.
population uncertainty seems to be intertwined with multiple aspects of the disease as it is with all chronic illness states.

**Psychological Stress and Physical Symptom Development**

The last conceptual linkage of a psychological stress response and physical symptom development will be reviewed. The literature will review briefly psychological stress as a life event and more extensively as a response to an environmental stressor, the focus of this study.

The literature over the past twenty years has devoted much attention to the relationship between episodes of psychological stress and the onset of physical symptoms (Rahe, 1970; Rahe, 1971; Chosey, 1972; Rahe, 1972; Araiyo, 1973; Rahe, 1974; Andrews, 1978; Caplan, 1981; Henry, 1981; Cox and MacKay, 1982; Flemming, 1982). Selye (1956) has suggested that stress is the "common denominator" of adaptation. Although, this is most likely not true (Baum, 1982) it still functions as a "catch all" term for general anxiety, discomfort and some unexplained nebulous disease conditions.

Life event research has been given much attention over the past 25 years. Life event researchers have demonstrated a temporal relationship between stressful social events in one's life that required change and adaptation and the number of reported symptoms or illnesses. The major assumption that has been made by life event researchers is that such stressful life events precipitated the onset of various illnesses (Adler and Engle, 1971; Nuckollis, 1972; Rahe, 1972; Marx, 1975). The same assumption is made regarding the impact that chronic illness has
on a family. The occurrence of chronic illness has been viewed as a stressful event that has lead to the development of illness and breakdown within the family unit (Dodge, 1972). This rather simplistic hypothesis has recently undergone critical analysis. Andrews (1978) suggested that there is no scientifically grounded evidence that psychological stress leads directly to physical illness. Their criticism was focused on the life change event literature that Rahe and associates have investigated over the years.

Andrews (1978) concluded that the question researchers should be more readily addressing is the effect episodic events and/or environmental stressors have on physical illness, as first proposed by Selye (1956). Andrews (1978) claimed that when an event is perceived as severely threatening, arousal is prolonged; this in turn causes chronic changes in autoimmune function, blood chemistry, hormonal levels and immune competence. This occurrence, Andrews (1978) claimed, leads to the development of physical symptoms and illness.

Bartrap (1977) conducted a study which supported this relationship. The study consisted of 26 spouses. These spouses had either just lost their partner or their partner had been injured and was given an uncertain prognosis. The intent of the study was to investigate if these spouses, when matched with a control group for age, sex, and race, displayed any endocrinological or immunological consequences. Blood chemistries were drawn at two different times, one at three weeks after the event (sample 1) and another six weeks after the event (sample 2). Sample 2 indicated the T-cell function was depressed although T-cell
number remained constant. They concluded that the emotional distress that ensued from the death or the illness of their spouse caused a decrease in immunological competence.

Pettingale (1977) investigated the relationship between the emotional response of anger suppression and serum IgA levels in women with breast tumors. He found that suppression of anger was correlated with increased IgA level in women with benign and malignant breast tumors. The author concluded that the elevated IgA levels acted as a blocking agent in cellular tumor control. Katz (1963) also investigated women with breast cancer. He found high levels of corticosteroids relative to androgen levels (which was noted to be a high risk factor in prognosis) in women who expressed psychological responses such as apprehension, fear, worry and despair.

Critselis (1976) discovered a rather interesting finding concerning lung cancer. A relationship has been suggested between bronchial carcinoma and low vitamin A levels. An oversecretion of A.C.T.H. in response to various environmental stressors was noted to increase glucocorticoid production causing the excretion of vitamin A and the onset of lung cancer.

Environmentally induced stressors have been shown to increase platelet aggregation. Haft (1976) studied the effects of an emotionally stressful situation on platelet function, and found that emotional stress induced marked changes in platelet aggregation. They observed a decrease in platelet function after the stressful event; caused by the increase in catecholamines. Platelet aggregation was decreased due
to the stimulation to aggregate during the actual stressful period. It is possible, he suggested, that if one is continually exposed to emotional stress increased platelet aggregation will lead to an intravascular platelet cluster forming in the arterial system, travel and possibly occlude an already artherosclerotic artery, leading to the development of a myocardial infarction.

Chapter Summary

The above literature review attempted to provide support for the conceptualization that the experience of psychological stress if influential in the development of physical symptoms or illness. The review was presented to display how a primary care-giver who is living with psychological stress generated from the uncertainty of the illness event is predisposed to disease development.
CHAPTER 3

METHODOLOGY

In this chapter research questions will be presented followed by a description of the measurement tools that were used to operationalize each concept. The study design including the setting, sample, data collection procedure, data analysis and limitations will also be discussed.

Research Questions

This study addressed the relationships among uncertainty, stress, social support and physical symptoms in the family member (primary care-giver) who assumes the primary care-taking responsibilities of a family member afflicted with systemic lupus erythematosus (S.L.E.). The research questions were:

1) Does the uncertainty perceived by the primary care-giver about the family member's S.L.E. correlate with the primary care-giver's psychological stress response?

2) Will the primary care-giver's experience of perceived uncertainty and psychological stress be related to the development of physical symptoms in the primary care-giver?

3) What is the effect of social support upon perceived uncertainty, stress and the development of physical symptoms in the primary care-giver?
Measurement Tools

Social Support

The variable of social support was measured by the Norbeck Social Support Questionnaire (N.S.S.Q.) (See Appendix A). The instrument has three main variables—Total Functional, Total Network, and Total Loss—each with three subscales. The N.S.S.Q. is a self-report questionnaire composed of nine questions, eight of which are Likert format and the remaining are Yes/No-type questions (Norbeck et al., 1982). Only the total functional subscales were used in this study.

The functional subscales of the N.S.S.Q. tap three components of supportive transaction, these are affect, affirmation and aid. The affect subscales explore the expression of positive affect of one person towards another. The affirmation subscale addresses the endorsement of another person's behavior. The aid subscales investigate the amount of material or symbolic aid given to another.

Reliability

The scale has high levels of test re-test reliability, tested using a Kendall Tau B correlation. Each of the functional items (affect, affirmation and aid) and network properties items had a test-retest reliability range of .85-.92. Kendall-Tau B correlation coefficients for test-retest scores were .83 and .71 for number of categories of persons lost and amount of support lost, respectively. Internal consistency was in a satisfactory range of .54 - .98 (Norbeck et al., 1981).
Validity

Construct validity of the instrument was investigated by comparing convergent and discriminant constructs to the N.S.S.Q. Low positive correlations (.05-.27) were found between the N.S.S.Q. and the similar constructs of the need for inclusion and affection. A lower association was found (.02-.11) between the N.S.S.Q. and need for control. Concurrent validity was established with another social support questionnaire, the Personal Resource Questionnaire. Medium levels of association (.24-.41) between the two scales were found.

Predictive validity was tested through investigating the buffering effect that social support had on life stress. Norbeck found that the N.S.S.Q. represented social support, as predicted in theory as a stress-buffering agent. A multiple regression analysis revealed that the three functional subscales accounted for 19-20 percent of the variance when entered into an equation with life stress as the outcome variable (Norbeck et al., 1983). Overall, the N.S.S.Q. has moderate validity, but findings do lend support to continued use of the scale. (Norbeck et al., 1983).

Uncertainty

The variable of uncertainty was measured by the Parents' Perception of Uncertainty Scale (P.P.U.S.) (See Appendix B). P.P.U.S. is a modified version of the Mishel Uncertainty in Illness Scale (M.U.I.S.). The M.U.I.S. was developed to measure the uncertainty adults perceive about their own illness, and the P.P.U.S. was developed to measure the uncertainty one experiences concerning another's illness state.
(Mishel, 1983c). The scale presently addresses the uncertainty a parent experiences about his/her child's illness. For this study the scale was modified by addressing the primary care-giver's experience of uncertainty about his/her significant other's illness state. The uncertainty scale is a 31-item Likert scale, constructed with a 1-5 point format, ranging from strongly agree to strongly disagree. The P.P.U.S. was modified to 26 items for this study. Items were deleted because they were not applicable to this population. Items that dealt with hospitalization were not viewed as appropriate areas to tap in this population and therefore were eliminated.

The scale is composed of four subscales. The ambiguity subscale is a seven item scale and explores the primary care-givers evaluation of the illness state as vague or unclear. The complexity subscale, a seven item scale refers to the multiple cues the primary care-giver perceives about treatment and system of care. The deficient information subscale, a five item scale deals with the absence of information concerning a significant other's diagnosis. The unpredictability subscale, a four item scale refers to the primary care-giver's perceived absence of stability regarding the course of the illness. The items which were deleted were extracted from the ambiguity and the complexity factors.

Reliability

The total scale has a standardized alpha of .91. The multi-ambiguity subscale, possessing 13 items, has an alpha of .87 with all item subscale correlations being substantial in the .40-.70 range. The lack of clarity subscale, a nine item subscale, has a standardized
alpha of .81 and item subscale correlations in the .46-.65 range. The lack of information subscale, having five items, has a standardized alpha of .73 and subscale correlations in the .41-.56 range. The unpredictability subscale, with four items has a standardized alpha of .72 and item subscale correlations in the .42-.62 range.

Coefficient theta was estimated for the overall scale and all subscales. A comparison of theta and alpha displayed no difference among the reliability estimates. This implies that the correlations are homogenous and the two estimates were highly similar (Mishel, 1983c). Overall reliability findings indicate that the subscales are internally consistent as evidenced by the above findings.

Validity

The P.P.U.S. underwent several measures to establish validity. The first was a factor analysis. Four factors emerged from the data, as predicted each factor measuring a characteristic of the construct of uncertainty (Mishel, 1983c).

Further support for validity was established by investigating if the scale (P.P.U.S.) distinguished between groups as predicted in theory. Mishel (1981a) theorized that medical groups, surgical groups, and diagnostic groups contain varying degrees of uncertainty. The diagnostic (rule-out) group was predicted to display the most uncertainty.

The results of a one-way analysis of variance revealed that the scale did not perform as predicted in theory. The diagnostic group did not display any greater amount of uncertainty than the medical group. The inability of the scale to perform as predicted was explained as a
conceptual problem rather than the fault of the scale. The conceptual problem being that childhood illnesses treated medically are often filled with vague symptomatology making the two very similar.

A third validity testing involved finding support for the theoretical prediction that parents' uncertainty will positively correlate with parents' judgments of the seriousness of the illness. Significant correlations were found between the total scale and judged seriousness of illness. Significant relationships were also displayed between seriousness of illness and the multi-ambiguity factor, lack of information factor and the unpredictability factor.

Mishel (1983e) concluded that further testing was necessary in the area of construct validity. Further investigation is also necessary using different dyads such as spouse-spouse, child-parent. This will be the first testing of the scale using primary care-givers as subjects.

Psychological Stress

The Profile of Mood States (P.O.M.S.) was used to measure psychological stress (See Appendix C). The P.O.M.S. is a measure of emotional distress, and fluctuating affective states. Baum (1982) states that the variable of psychological stress can be measured by evaluating one's emotional distress. The scale then can be viewed as an appropriate measure.

The P.O.M.S. is a 65 five point adjective rating scale. The P.O.M.S. has been developed to measure six affective mood states. There
are six subscales; these are: Tension-Anxiety, Depression-Depression, Anger-Hostility, Vigor-Activity, Fatigue-Inertia and Confusion-Bewilderment.

The Tension-Anxiety subscale is a nine item scale which is descriptive of heightened musculoskeletal tension and somatic tension which may not be overtly observable. The Depression-Depression subscale is a 15 item scale which represents a mood of depression, a sense of personal inadequacy, worthlessness and emotional isolation. The Anger-Hostility scale is a 12 item scale representing a mood of anger and antipathy toward others. The Vigor-Activity scale is an eight item scale which is descriptive of ebullience and high energy. It is negatively related to the other P.O.M.S. factors. The Fatigue-Inertia scale is a seven item scale which represents a mood of weariness and low energy levels. The Confusion-Bewilderment scale is a seven item scale that characterizes the mood of bewilderment, muddleheadness and forgetfulness.

Reliability

Internal consistency was performed using Kuder-Richardson 20 and all reliabilities were highly satisfactory (.84-.95). Test-retest coefficients were also satisfactory with scores from the six factors ranging from .61-.69 (McNair, Lorr, and Droppleman, 1981).

Validity

Predictive and construct validity were established through brief psychotherapy studies, controlled outpatient drug trials, studies of
response to emotion-inducing conditions, studies of concurrent validity coefficients and other P.O.M.S. correlates. Concurrent validity was established through significant correlations with three clinically derived scores from the Hopkins Symptom Distress Scale (McNair, Lorr, and Droppleman, 1981).

Physical Symptoms and Illness

Physical symptoms and illness was measured by the Seriousness of Illness Rating Scale (S.I.S.) (See Appendix D). The S.I.S. consists of 126 diagnoses ranked from least serious-dandruff (1) to the most serious-leukemia (126). Wyler et al., (1968) developed the scale by having physicians and lay persons score 126 disease items according to the respondent's concept of relative seriousness. A grand rank order and mean of the disease items were formed by combining the two groups (Wyler et al., 1968). Wyler et al., reported a highly significant degree of mean rank order correlation between the samples (Spearman, rho = 0.947) (Mishel, 1982). The scale was modified with 18 items discarded. The 18 physical symptoms or illnesses were eliminated because their etiology was of a congenital or hereditary nature and did not meet the criteria for a stress-induced illness.

Demographic Data

Demographic data were gathered from all subjects on the following areas: 1) the relationship of the subject to family member with S.L.E.; 2) the length of time the family member has had S.L.E.; 3) length of time since last flare-up occurred; 4) duration of last flare-up;
5) physical disability or bodily changes as a result of the disease or treatment; 6) the specific physical changes from the disease or treatments; 7) age; 8) sex; 9) marital status and; 10) educational status. These data were used in compiling descriptive statistics for the sample group (See Appendix E).

Methodology

The methodology includes the setting, sample, data collection procedure, data analysis and limitations of the study. Each of these aspects is discussed below in relation to this research project.

Setting

The setting for this descriptive design was the subject's home or at a convenient location for the subject. Subjects were informed verbally and in writing of the purpose of the study and requirements for participating in this study. The research project was approved by the Human Subjects Committee of The University of Arizona College of Nursing prior to any data collection procedures (See Appendix F). The subjects were read a disclaimer prior to answering the questionnaires and thus agreed to participate in the study (See Appendix G).

Sample

The sample was a convenience sample of 30 subjects obtained from the members of the American Lupus Society. The criteria for eligibility for this study were:
1) The member of the family that is afflicted with S.L.E. has been diagnosed for at least six months with S.L.E.
2) The diagnosis of S.L.E. was the primary diagnosis of the ill family member.
3) The subject (primary care-giver) was not diagnosed with a major chronic disease prior to the ill family member receiving a diagnosis of S.L.E.
4) The subject was at least 18 years old.
5) The subject was able to read and write English.

Data Collection Procedure

The subject was contacted by phone from list of family names made available by the American Lupus Society. The purpose of the study, the approximate amount of time that the subject had to give and the right to confidentiality was explained at this time. Next, a convenient time, place and date was arranged in order to issue the four questionnaires to the subject. The scales were assigned in a random order to each subject. Each scale was fully explained to the subject. The approximate amount of time it took to complete these four scales was a maximum of 40 minutes.

Data Analysis

Descriptive statistics were used to analyze the demographic characteristics of the sample size. The product moment correlation coefficient (Pearson r) was used and a correlation matrix was generated to determine the relationships among the stated variables. A series of
simple and multiple regression analyses were performed to respond to the research questions and to determine the direction of the relationship.

For research question 1: Does the uncertainty perceived by the primary care-giver about the family member's S.L.E. correlate with the primary care-giver's psychological stress response? Inspection of the relationships between the variables in the correlational matrix provided data for part of the first question. Question one was addressed further by regressing stress scores on uncertainty scores. Results of this analysis indicated the strength of uncertainty as a predictor of emotional distress.

Research Question 2: Will the primary care-giver's experience of perceived uncertainty and psychological stress be related to the development of physical symptoms in the primary care-giver? Inspection of the relationships between the variables in the correlational matrix provided data for part of the second question. Question two was addressed further by regressing symptom scores on stress and uncertainty scores to provide information for research question two. Results of this analysis indicated whether stress and uncertainty together were major predictors of symptom development and which psychological variable had the strongest impact on the development of a symptomatic state.

Research Question 3: What is the effect of social support upon perceived uncertainty, stress and the development of physical symptoms in the primary care-givers? Inspection of the relationships between the variables in the correlational matrix provided data for part of the
third question. Question three was further addressed by regressing symptom scores on social support, uncertainty and stress scores. Results of this analysis indicated whether social support, uncertainty and stress were predictors of physical symptom development.

Limitations

The time required to manifest physical symptoms after exposure to a stressor is unknown, therefore the requirement that the ill member of the family must be diagnosed with S.L.E. for at least six months is an arbitrary number and its relation to the variables is not known.

Summary

In this chapter, the methodology of this study has been discussed. The research questions addressed in this study were presented followed by an explanation of the measurement tools that were utilized. The study design, including setting, sample, data collection procedure, analyses and limitations were also presented.
CHAPTER 4

PRESENTATION AND ANALYSES OF DATA

This chapter includes: 1) the characteristics of the sample, 2) correlation matrixes displaying the relationships among the variables and 3) data analyses related to the research questions. Characteristics of the sample will be presented first.

Description of the Sample

Descriptive statistics were utilized to analyze and organize the characteristics of the sample (n=30). Information gathered on the 30 subjects includes demographic data of age, sex, educational status, marital status, relationship of the subject to the family member with systemic lupus erythematosus (S.L.E.), the length of time the family member has had S.L.E., the length of time since the family member's last flare-up occurred, the duration of the most recent flare-up and the specific bodily or physical changes that occurred in the family member as a result of the disease or various treatments.

Age and education of the sample are shown in Table 1. The mean age of the sample is 45.6 years. The mean years of education obtained is 14 or the equivalent of two years of a college education.

The demographic characteristics of sex, marital status and the relationship of the subject to the family member with S.L.E. are shown in Table 2. Sixty percent of the primary care-givers are males, fitting the profile of the disease which is female dominated. The majority of
Table 1  Demographic Characteristics of the Sample: 
Age, Years of Education (n = 30).

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>CATEGORY</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>18 - 30 years</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>32 - 40 years</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>41 - 50 years</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>51 - 60 years</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>63 - 70 years</td>
<td>5</td>
</tr>
<tr>
<td>Number of years of education obtained</td>
<td>6th - 12th grade</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>College</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Graduate School</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 2  Demographic Characteristics of the Sample: Sex, Marital Status, Relationship of the subject to Family Member with S.L.E. (n = 30).

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>CATEGORY</th>
<th>NUMBER</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male</td>
<td>18</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married</td>
<td>21</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Relationship of Subject to Family Member with S.L.E.</td>
<td>Spouse</td>
<td>14</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Child</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Friend</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Sibling</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Grandchild</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
the subjects are married (70 percent). Forty-seven percent of the sub-
jects are related as spouses and 27 percent describe themselves as
parents of a child with S.L.E.

Table 3 presents the data regarding the length of time the
family member has been diagnosed with S.L.E., the length of time since
the family member experienced a flare-up and the duration of the last
flare-up. The length of time the family member has been diagnosed with
S.L.E. ranged from six months to 50 years. The majority (46 percent)
of the family members with S.L.E. experienced a flare-up one month to
one year ago. Eighty percent of the afflicted family members experi-
enced a flare-up of less than a one month duration.

Table 4 presents the afflicted family members who have
experienced bodily or physical changes as a result of the disease of
treatment. Table 4 also displays specific bodily changes that were
experienced by the family member with S.L.E. Eight-three percent of
the afflicted family members experienced bodily changes resulting from
the disease of the treatment. The majority (23 percent) of the family
members experienced mobility changes. Only ten percent of the family
members experienced a combination of appearances, mobility and bodily
system changes.

Data Analysis Related to the
Research Questions

The research questions based on the conceptual framework were:
1) Does the uncertainty perceived by the "primary care-giver"
Table 3  Descriptive Characteristics of the Family Members with S.L.E.  
(n = 30)

<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>CATEGORY</th>
<th>NUMBER</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of time family member has been diagnosed with S.L.E.</td>
<td>6 mos - 2 years</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td>3 - 5 years</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>6 - 10 years</td>
<td>10</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>12 - 50 years</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>Length of time since last flare-up occurred</td>
<td>less than one month</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td>1 month - 1 year</td>
<td>14</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>1.5 - 6 years</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Duration of last flare-up</td>
<td>less than one month</td>
<td>24</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>3 - 6 months</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>10 mos - 2 years</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>
Table 4 Descriptive characteristics Regarding Bodily or Physical Changes in Afflicted Family Members (n = 30).

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>CATEGORY</th>
<th>NUMBER</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bodily or physical changes - as a result of the disease or treatment</td>
<td>YES</td>
<td>25</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td>NO</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Specific bodily changes that occurred</td>
<td>Appearance</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Mobility</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Bodily system</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Appearance and Mobility</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Appearance and Bodily system</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Mobility and Bodily system</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Appearance, Mobility and Bodily system</td>
<td>3</td>
<td>10</td>
</tr>
</tbody>
</table>
about the family member's S.L.E. correlate with the primary care-giver's psychological stress response?

2) Will the primary care-giver's experience of perceived uncertainty and psychological stress by related to the development of physical symptoms in the primary care-giver?

3) What is the effect of social support, perceived uncertainty, and stress on the development of physical symptoms in the primary care-giver?

Pearson correlation coefficients were computed to determine the relationships between the variables in order to address the research questions. A series of simple and multiple regressions were also performed to determine the direction and predictive strength of the specific relationships.

The data displayed in Table 5 addresses the first research question. It presents the relationship between uncertainty, the four uncertainty scale factors and psychological stress, as measured by emotional distress and the six factors of the emotional distress scale.

A statistically significant positive relationship is displayed between the Mishel Uncertainty In Illness Scale (M.U.I.S.) and the Profile of Moods Scale (P.O.M.S.). This correlation provides support that uncertainty perceived by the primary care-giver is related to emotional distress.

The total M.U.I.S. correlates at a statistically significant level with four subscales of the P.O.M.S. As noted in Table 5, the
Table 5 Correlations between Uncertainty (M.U.I.S.) and Emotional Distress (P.O.M.S.) Among Primary Care-Givers (n = 30)

<table>
<thead>
<tr>
<th></th>
<th>EMOTIONAL DISTRESS</th>
<th>TENSION</th>
<th>DEPRESSION</th>
<th>ANGER</th>
<th>HOSTILITY</th>
<th>VIGOR</th>
<th>FATIGUE</th>
<th>CONFUSION</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNCERTAINTY</td>
<td>.48**</td>
<td>.36*</td>
<td>.24</td>
<td>.46*</td>
<td>.41*</td>
<td>.10</td>
<td>.44*</td>
<td></td>
</tr>
<tr>
<td>AMBIGUITY</td>
<td>.21</td>
<td>.21</td>
<td>.07</td>
<td>.21</td>
<td>.32</td>
<td>.44*</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>COMPLEXITY</td>
<td>.54**</td>
<td>.33</td>
<td>.28</td>
<td>.55**</td>
<td>.49**</td>
<td>.24</td>
<td>.35</td>
<td></td>
</tr>
<tr>
<td>DEFICIENT INFORMATION</td>
<td>.48**</td>
<td>.26</td>
<td>.33</td>
<td>.52**</td>
<td>.20</td>
<td>.21</td>
<td>.39*</td>
<td></td>
</tr>
<tr>
<td>UNPREDICTABILITY</td>
<td>.24</td>
<td>.29</td>
<td>.11</td>
<td>.06</td>
<td>.06</td>
<td>.33</td>
<td>.14</td>
<td></td>
</tr>
</tbody>
</table>

* p ≤ .05
** p ≤ .01
*** p ≤ .001
M.U.I.S. has a statistically significant relationship with the tension-anxiety, anger-hostility, vigor and confusion subscales of the P.O.M.S. No statistical significant relationships are revealed between the M.U.I.S. and the depression-dejection subscale or the fatigue subscale of the P.O.M.S.

The P.O.M.S. displays a statistically significant relationship with two subscales of the M.U.I.S. The P.O.M.S. and the complexity and deficient-information subscales of the M.U.I.S. correlate at significant levels. There are no significant relationships displayed between the P.O.M.S. and the ambiguity and unpredictability subscales of the M.U.I.S.

Table 5 also displays the relationships among the various subscales of both the M.U.I.S. and the P.O.M.S. The ambiguity subscale of the M.U.I.S. correlates at a statistically significant level with the fatigue subscale of the P.O.M.S., while the complexity subscale of the M.U.I.S. significantly correlates with the anger-hostility and vigor subscales of the P.O.M.S. The deficient information subscale of the M.U.I.S. correlates with both the anger-hostility and confusion subscales of the P.O.M.S. at statistically significant levels. There are no statistical significant relationships displayed between the unpredictability subscale of the M.U.I.S. and the subscales of the P.O.M.S. Nor are there any significant relationships between the M.U.I.S. subscales and the tension-anxiety and the depression subscales of the P.O.M.S.
To further address question one, simple regression analysis was computed on emotional distress with uncertainty entered as the independent variable (See Table 6). The first regression analysis was performed with the total score of the P.O.M.S., the measure of emotional distress as the dependent variable. The M.U.I.S., the measure of uncertainty, was entered to ascertain the strength of uncertainty as a predictor of emotional distress. The results reveal (Table 6) that uncertainty accounted for 23 percent of the variance ($R^2 = 23$) with a significant level of .007. The results indicate that uncertainty is a significant predictor of emotional distress.

Tables 7 and 8 display the data that addresses the second research question. The correlations in Table 7 suggest no statistically significant relationships between the uncertainty experienced by the primary care-givers and the development of physical symptoms in the primary care-giver, although the correlations are in the expected directions. A relationship that could be considered substantively meaningful due to the strength of the correlation, is between the complexity subscale of the M.U.I.S. and physical symptom development. However, the ambiguity, the deficient information and the unpredictability subscales display no statistical or substantive relationship with the variable of physical symptoms development.

As seen in Table 8, there is no statistically significant relationship displayed between the total P.O.M.S. score and the total score of the Seriousness of Illness Rating Scale (S.I.R.S.), the measure
Table 6 Prediction of Emotional Distress by Uncertainty.

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>r</th>
<th>R^2</th>
<th>SIGNIFICANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertainty</td>
<td>.48</td>
<td>.23</td>
<td>.007</td>
</tr>
</tbody>
</table>

* p ≤ .05
** p ≤ .01
*** p ≤ .001

Table 7 Correlations Between Uncertainty and Symptom Development in the Primary Care-Giver (n = 30)

<table>
<thead>
<tr>
<th>UNCERTAINTY AMBIGUITY</th>
<th>COMPLEXITY</th>
<th>DEFICIENT INFORMATION</th>
<th>UNPREDICT-ABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Symptom</td>
<td>.28</td>
<td>.17</td>
<td>.31</td>
</tr>
</tbody>
</table>

* p ≤ .05
** p ≤ .01
*** p ≤ .001
Table 8  Correlations between Emotional Distress (P.O.M.S.) and Physical Symptom Development (S.I.R.S.) in the Primary Care-Givers

<table>
<thead>
<tr>
<th>Emotional Distress</th>
<th>Tension</th>
<th>Depression</th>
<th>Anger</th>
<th>Vigor</th>
<th>Fatigue</th>
<th>Confusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Symptom</td>
<td>.22</td>
<td>.21</td>
<td>.09</td>
<td>.09</td>
<td>-.24</td>
<td>.36*</td>
</tr>
<tr>
<td>Development</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*  p ≤ .05
** p ≤ .01
*** p ≤ .001
of physical symptoms development. The only statistically significant relationship is between the fatigue subscale of the P.O.M.S. and physical symptom development. An inverse relationship of .24 is displayed between the vigor subscale of the P.O.M.S. and physical symptom development, but his correlation did not reach statistical significance. The confusion subscale of the P.O.M.S. has a relationship of substantive magnitude with physical symptom development. The other subscales of the P.O.M.S. displayed no meaningful relationships with physical symptom development in the primary care-giver. Table 9 presents the second regression analysis intended to further explore the relationship of uncertainty and emotional distress to physical symptom development.

The second regression was performed with physical symptom development as the dependent variable. The M.U.I.S. was entered first followed by the total P.O.M.S. score to ascertain if uncertainty and emotional distress together were predictors of physical symptom development in primary care-givers. The results indicate that none of the variables accounted for a significant increase in $R^2$. Neither uncertainty nor emotional distress account for a significant amount of variance in physical symptom development in the primary care-givers.

Tables 10-13 display the data that address research question three. Table 10 reveals the correlations between social support and uncertainty. The only statistically significant relationships revealed are between the social support and the deficient information subscale of the M.U.I.S. The Norbeck Social Support Questionnaire (N.S.S.Q.) has
Table 9  Prediction of Physical Symptom Development by Uncertainty and Emotional Distress (n = 30)

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>SIMPLE r</th>
<th>MULTIPLE r</th>
<th>$R^2$</th>
<th>SIGNIFICANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertainty</td>
<td>.28</td>
<td>.28</td>
<td>.08</td>
<td>.121</td>
</tr>
<tr>
<td>Stress</td>
<td>.22</td>
<td>.30</td>
<td>.09</td>
<td>.614</td>
</tr>
</tbody>
</table>

* $p \leq .05$
** $p \leq .01$
*** $p \leq .001$

Table 10  Correlations Between Social Support and Uncertainty in Primary Care-Givers (n = 30).

| UNCERTAINTY AMBIGUITY COMPLEXITY DEFICIENT INFO. UNPREDICTABILITY |
|------------------------|--------------------------|-----------------|-----------------|-----------------|
| Social Support         | -.06                     | .09             | -.07            | -.38*           | .10             |
| Affect                 | -.05                     | .11             | -.05            | -.45**          | .12             |
| Affirmation            | .07                      | .10             | -.10            | -.40*           | .09             |
| Aid                    | .04                      | .04             | -.06            | -.25            | .09             |

* $p \leq .05$
** $p \leq .01$
*** $p \leq .001$
a statistically significant inverse relationship with the deficient information subscale of the M.U.I.S. Two subscales of the N.S.S.Q., affect and affirmation, also display statistically significant inverse relationships to the deficient information subscale of the M.U.I.S. The results of the data analysis reveal no other substantively meaningful or statistically significant relationships between social support and uncertainty.

Table 11 reveals the correlations between social support and emotional distress that occurred in the primary care-givers. There are no statistically significant relationship or substantively meaningful relationships displayed between social support and emotional distress. Neither the various subscales of the P.O.M.S. nor the subscales of the N.S.S.Q. show statistically significant relationships. All correlations are low except for depression which shows moderate correlations for a population of this size and correlations are in the expected direction.

Table 12 reveals the correlations between social support and physical symptom development in the primary care-givers. The correlations reveal no substantively meaningful or statistically significant relationships between social support and physical symptom development in the primary care-givers. All of the subscales of the N.S.S.Q. correlated at low levels with the variable of physical symptom development.
Table 11 Correlations Between Social Support (N.S.S.Q.) and Emotional Distress (P.O.M.S.) in the Primary Care-Givers (n = 30)

<table>
<thead>
<tr>
<th></th>
<th>Emotional Distress</th>
<th>Tension</th>
<th>Anxiety</th>
<th>Depression</th>
<th>Anger</th>
<th>Hostility</th>
<th>Vigor</th>
<th>Fatigue</th>
<th>Confusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>.15</td>
<td>-.05</td>
<td>-.25</td>
<td>-.14</td>
<td>.06</td>
<td>.05</td>
<td>-.19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affect</td>
<td>-.17</td>
<td>-.07</td>
<td>-.26</td>
<td>-.19</td>
<td>.07</td>
<td>.04</td>
<td>-.19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affirmation</td>
<td>-.16</td>
<td>-.04</td>
<td>-.27</td>
<td>-.15</td>
<td>.03</td>
<td>.04</td>
<td>-.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aid</td>
<td>.09</td>
<td>-.04</td>
<td>-.20</td>
<td>-.06</td>
<td>.07</td>
<td>.06</td>
<td>-.13</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 12 Correlations Between Social Support (N.S.S.Q.) and Physical Symptom Development (S.I.R.S.) in the Primary Care-Givers (n = 30)

<table>
<thead>
<tr>
<th></th>
<th>Social Support</th>
<th>Affect</th>
<th>Affirmation</th>
<th>Aid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Symptom Development</td>
<td>.16</td>
<td>.13</td>
<td>.18</td>
<td>.17</td>
</tr>
</tbody>
</table>
Table 13 presents the third regression analyses intended to further address the third research question. The third regression was performed with physical symptom development as the dependent variable. The total score of the N.S.S.Q., the measure of social support, was entered first, followed by the total scores of the M.U.I.S. and the P.O.M.S. The regression was performed to ascertain the effect that social support, uncertainty, emotional distress have on symptom development. The results, which were intended to respond to the third research question, indicate that none of the variables accounted for a significant increase in $R^2$. Social support, uncertainty and emotional distress did not account for any significant amount of variance in physical symptom development in the primary care-giver.

**Chapter Summary**

This chapter has presented characteristics of the sample population, the results of the Pearson product moment correlations among the variables and the results of the multiple regression analyses as these statistical analyses related to the research questions of this study.
Table 13  Prediction of Physical Symptom (S.I.R.S.) Development by Social Support (N.S.S.Q.), Emotional Distress (P.O.M.S.) and Uncertainty (M.U.I.S.).

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>SIMPLE r</th>
<th>MULTIPLE r</th>
<th>$r^2$</th>
<th>SIGNIFICANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>.04</td>
<td>.04</td>
<td>.00</td>
<td>.803</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>.28</td>
<td>.29</td>
<td>.08</td>
<td>.289</td>
</tr>
<tr>
<td>Stress</td>
<td>.22</td>
<td>.31</td>
<td>.09</td>
<td>.432</td>
</tr>
</tbody>
</table>

* *p ≤ .05
** *p ≤ .01
*** *p ≤ .001
CHAPTER 5
DISCUSSION, CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS

The relationship between the conceptual framework and the findings of this study, the conclusions based on these findings, recommendations for further research, and implications for nursing practice are included in this chapter. The findings as they relate to the conceptual framework will be presented first.

Findings Related to the Conceptual Framework

The conceptual framework will be briefly summarized to help clarify the following discussion. The proposed framework included uncertainty as the independent variable impacting directly on the psychological stress experienced by primary care-givers of one with systemic lupus erythematosus (S.L.E.). Psychological stress operationalized as emotional distress was proposed as directly impacting on the dependent variable of physical symptom development in primary care-givers. Social support was viewed as an intervening variable between uncertainty and stress. Social support was discussed to act as a buffer of psychological stress by reducing the uncertainty that was perceived by the primary care-givers about their family member's S.L.E.

Research question one addressed the conceptual linkage between perceived uncertainty and emotional distress. Correlational analysis indicated a strong relationship between uncertainty and emotional
distress ($r = .48$). On closer examination of the data it was determined that primary care-givers who experienced uncertainty about their family member's S.L.E. also experienced tension and anxiety, anger and hostility, confusion and lack of vigor. An explanation for this finding lies in the conceptualization that uncertainty is an antecedent of psychological stress. Researchers have discussed that if one is forced to live in an environment that is shadowed with unpredictable, ambiguous and vague events (characteristic of S.L.E.), stress in the form of anger, hostility, and generalized fatigue has been shown to ensue (Marks, 1975; Berlyne, 1979). The finding supported the conceptualization of uncertainty and stress.

Further inspection of the correlational matrix revealed that if various illness events were perceived as ambiguous, fatigue occurred in the primary care-giver ($r = .44$). A possible explanation for this finding was found in Berlyne's work (1979) on uncertainty. He explained, uncertainty is a state that induces physiological arousal. This arousal is maintained until the uncertainty is reduced. The arousal state is characterized by the activation of various physiological mechanisms, similar to those activated in a stress response, such as the flight-fight mechanism. The arousal state is only reduced when the uncertainty is alleviated. The uncertainty perceived by the primary care-giver about S.L.E. cannot be reduced via information seeking, but is reduced during a remission and activated again during a flare. Therefore, the primary care-giver
experiences fluctuating states between arousal and quiesence or continual arousal because of the illness's unpredictable and uncertain nature. Living in this constant state of physiological fluctuation may explain the primary care-giver's fatigued state.

The ambiguity subscale also correlated with the confusion subscale of the stress measurement ($r = .32$). This was explained by the vagueness associated with S.L.E. It acts to produce a state of bewilderment in the primary care-giver regarding the illness state. The ambiguity subscale displayed no other significant relationships with the emotional distress subscales.

The complexity subscale of the uncertainty scale displayed high correlations with the emotional distress scale ($r = .54$). The complexity subscale addressed the various multiple cues the primary care-giver perceived about the treatments and system of care. A possible explanation for this strong relationship is that the primary care-givers of a family member with S.L.E. have experienced multiple cues stemming from the various treatments. The "treatments" for S.L.E. are utilized purely for symptom control. These "treatment" regimens cause the occurrence of severe side-effects, precipitating further physiological breakdown, often worse than the disease. The multiple meanings associated with the "treatment" regimen used in S.L.E. offers a possible explanation as to why the complexity subscale is highly correlated with feelings of anger, hostility and confusion and a lack of vigor in the primary care-giver.

The unpredictability factor of the uncertainty scale had a low relationship to emotional distress ($r = .24$). The lack of information factor had
significant relationships with overall emotional distress ($r=.48$), specifically with anger, hostility ($r=.52$) and confusion ($r=.39$). A primary care-giver cannot resolve the uncertainty of S.L.E. through information seeking because there is minimal information regarding the illness state. Living in this constant state of uncertainty without the ability to resolve it through information-gathering may explain the occurrence of the anger, hostility and the confusion experienced by the primary care-givers.

The regression analyses indicated that uncertainty was a significant predictor of emotional distress ($R^2=.23$). This finding supported the laboratory investigations done by Berlyne (1979), the clinical investigation by Mishel (1982) and the clinical observations reported by Davis (1979) concerning the positive association between uncertainty and stress. These researchers have found that when an environment was shadowed with uncertainties, such as unpredictable and ambiguous events, emotional distress ensued.

Research question two addressed the conceptual linkage between perceived uncertainty, emotional distress and physical symptom development in the primary care-giver. The correlational analysis revealed low correlations between uncertainty and physical symptom development ($r=.28$), although all correlations were in a positive direction. The complexity factor of the uncertainty scale, displayed the highest correlation with physical symptom development ($r=.31$) This correlation appeared to be substantively meaningful. This was an interesting finding considering that the complexity factor and the emotional distress scale also correlated. It may be that the multiple and vague cues associated with the treatment
utilized in S.L.E. influenced the level of psychological distress and that this related to the development of physical symptoms. When primary care-givers are presented with multiple cues associated with treatment regimens, an arousal state occurs in an attempt to resolve the uncertainty. The resolution of the uncertainty is extremely difficult, thus the arousal is maintained accompanied by emotional distress. Continual emotional distress has been related to physical symptom development (Frankenhauser, 1980; Henry, 1983). Overall, uncertainty and physical symptom development had a low correlation (r=.28) but this could be influenced by the small number of the sample (n=30).

The correlational analyses between stress and physical symptom development revealed low correlations(r=.22). The confusion factor of the stress measurement, displayed the most substantively meaningful relationship (r = .34). The confusion experienced can be related back to the multiple cues that are associated with the various illness events found in S.L.E. The confusion creates a milieu in which resolution of the uncertainty is difficult. Therefore, if the confusion precludes the resolution of the uncertainty, a physiological arousal is maintained leading to physiological disruption with ensuing physical symptoms (Berlyne, 1979).

One of the more unusual findings was between the vigor and fatigue factors of the stress measurements and physical symptom development. The vigor factor, which was defined as high energy was reverse scored, thus the higher the score the greater the lack of vigor or low
energy levels. A lack of vigor (low energy) was inversely related to physical symptom development ($r = -.24$), indicating that more vigor was associated with symptom development. However, the fatigue factor was positively related to physical symptom development in the primary care-giver ($r = .36$).

Conceptually, this relationship was obviously unsupported. Therefore, one must examine the conceptual problems with the inclusion of both these factors in a measurement of emotional distress. McNair, Lorr and Droppleman (1979) claimed that the two factors were independent and not opposite poles of a single bipolar factor. Yet, vigor was defined by the authors as a mood of high-energy and fatigue as a mood of low-energy. The inclusion of factors that could be viewed as opposite poles of a single bipolar factor could possibly explain the unusual correlation found between vigor, fatigue and physical symptom development.

The third research question addressed the conceptual linkages between social support, uncertainty, stress and physical symptom development in primary care-givers. The correlational analyses between social support and uncertainty revealed a low relationship ($r = -.06$). A closer inspection of the matrix revealed that the uncertainty factor, deficient information correlated inversely with all of the social support factors. When social support was not operative, the primary care-giver lacked a resource for information. When a primary care-giver possessed an intact social support network that functioned as an information resource, uncertainty towards various illness events was reduced. This finding was the first empirical support for the proposed relationship between social support and uncertainty. Prior association between these two variables
had been based upon conceptual and clinical work.

The correlational analysis between social support and stress displayed low correlations ($r = .15$) except for the moderate correlations displayed between the depression factor of the stress scale and social support ($r = -.25$). This relationship was supported in the literature. Previous studies have found that low support was a predictor of depression and overall psychological distress (Andrews, 1978; Henderson, 1979).

The correlational analysis between social support and physical symptom development revealed low correlations in the expected direction. One explanation for the low correlation presented in this relationship is a small number in the sample size ($n = 30$). Another explanation for this finding is the newness of the Norbeck Social Support Questionnaire (N.S.S.Q.). The tool, as stated by Norbeck (1983) still requires further validity and reliability testing. Testing with a more refined social support measure may show a stronger association.

**Conclusions From the Findings**

Six conclusions were drawn after inspection of the data analyses: 1) the uncertainty experienced by primary care-givers was related to the development of emotional distress; 2) the experience of uncertainty was related to the development of tension, anxiety, anger, hostility, lack of vigor and confusion in this sample population; 3) an intact social support network may act as an information provider about various illness events and when present less uncertainty in the area of lack of information is experienced by the primary care-giver. The multiple regression analysis resulted in three conclusions: 1) uncertainty was
a major predictor of emotional distress and accounted for 23 percent of
the variance; 2) uncertainty and emotional distress did not account for
a substantial amount of variance in symptom development and did not
appear as predictors of physical symptom development; 3) social support,
uncertainty and emotional distress did not account for any significant
amount of the variance in symptom development and were not predictors
of physical symptom development.

Recommendations for Further Investigations

This study has raised questions which could be further investiga
gated by future studies. Recommendations for such studies include
replication of this study with the following modifications. 1) Increase
the sample size in order to determine whether established relationships
remain and to determine if the correlations that were in the expected
direction can be raised to a statistically significant level; 2) Use
another sample population such as primary care-givers of one who has
multiple sclerosis or another chronic illness to ascertain if the stated
relationships are maintained.

The following recommendation for further research is suggested
below. The Seriousness of Illness Rating Scale (S.I.R.S.), the measure
of physical symptom development, would not be used in future projects.
The S.I.R.S. was viewed as an inappropriate measure of actual physical
symptoms. It dealt mostly with catastrophic illness events mean ranked
by the seriousness of the illness. Therefore, the actual physical
symptoms that were experienced were masked in the scoring. Thus, the
low correlation displayed between physical symptoms and stress was actually a correlation between major illness and stress, a relationship not well supported in the literature.

**Implications for Nursing Practice**

Any implications for nursing practice presented based on this research must be prefaced with the precaution that these findings are preliminary and tentative at this point. These findings are not generalizable to other populations except for primary care-givers of one with S.L.E. Generalizing these results to other primary care-givers of one with S.L.E. involves the untested assumption that the populations are the same.

However, this study has derived some promising implications. The presence of uncertainty among primary care-givers may be a helpful predictor of emotional distress. Although, not found in this study, the literature has strongly supported that the presence of emotional distress is a strong predictor of physical symptom development. Although, specific psycho-social interventions are not available regarding how to reduce uncertainty, this study has strengthened the conceptual relationship of uncertainty and stress.

The finding that an intact social support network was a positive force in reducing an aspect of uncertainty implies that nurses can more readily attempt to mobilize support systems in a direction that provides the primary care-giver with information and feedback regarding various illness-events. In the final analysis, the study has addressed the stressors and buffering agents that impact on a primary care-giver's well
being. It provides nursing with preliminary material for developing clinical techniques that can be used to strengthen the family unit, thus enhancing the support network and the psychological well-being of a person with S.L.E.

Chapter Summary

This chapter has presented the findings of this study, the conclusions based on these findings, recommendations for future research, and implication for nursing practice.
APPENDIX A

Norbeck Social Support Questionnaire
SOCIAL SUPPORT QUESTIONNAIRE

PLEASE READ ALL DIRECTIONS ON THIS PAGE BEFORE STARTING.

Please list each significant person in your life on the right. Consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate the relationship, as in the following example:

Example:

<table>
<thead>
<tr>
<th>First Name or Initials</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>MARY T.</td>
<td>FRIEND</td>
</tr>
<tr>
<td>BOB</td>
<td>BROTHER</td>
</tr>
<tr>
<td>M. T.</td>
<td>MOTHER</td>
</tr>
<tr>
<td>SAM</td>
<td>FRIEND</td>
</tr>
<tr>
<td>MRS. R.</td>
<td>NEIGHBOR</td>
</tr>
</tbody>
</table>

etc.

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

— spouse or partner
— family members or relatives
— friends
— work or school associates
— neighbors
— health care providers
— counselor or therapist
— minister/priest/rabbi
— other

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life.

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

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University of California, San Francisco
Revised 1982
For each person you listed, please answer the following questions by writing in the number that applies.

1 = not at all
2 = a little
3 = moderately
4 = quite a bit
5 = a great deal

Question 1:
How much does this person make you feel liked or loved?

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________
11. ____________________
12. ____________________
13. ____________________
14. ____________________
15. ____________________
16. ____________________
17. ____________________
18. ____________________
19. ____________________
20. ____________________
21. ____________________
22. ____________________
23. ____________________
24. ____________________

Question 2:
How much does this person make you feel respected or admired?

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________
11. ____________________
12. ____________________
13. ____________________
14. ____________________
15. ____________________
16. ____________________
17. ____________________
18. ____________________
19. ____________________
20. ____________________
21. ____________________
22. ____________________
23. ____________________
24. ____________________
Question 3:
How much can you confide in this person?

1. ____________________________
2. ____________________________
3. ____________________________
4. ____________________________
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22. ____________________________
23. ____________________________
24. ____________________________

1 = not at all  
2 = a little  
3 = moderately  
4 = quite a bit  
5 = a great deal

Question 4:
How much does this person agree with or support your actions or thoughts?

1. ____________________________
2. ____________________________
3. ____________________________
4. ____________________________
5. ____________________________
6. ____________________________
7. ____________________________
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24. ____________________________

(13-15) [16-18]

GO ON TO NEXT PAGE
### Question 5:
If you needed to borrow $10, a ride to the doctor, or some other immediate help, how much could this person usually help?

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 |   |

### Question 6:
If you were confined to bed for several weeks, how much could this person help you?

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 |   |

1 = not at all  
2 = a little  
3 = moderately  
4 = quite a bit  
5 = a great deal
**Question 7:** How long have you known this person?

1 = less than 6 months  
2 = 6 to 12 months  
3 = 1 to 2 years  
4 = 2 to 5 years  
5 = more than 5 years

**Question 8:** How frequently do you usually have contact with this person? (Phone calls, visits, or letters)

5 = daily  
4 = weekly  
3 = monthly  
2 = a few times a year  
1 = once a year or less

<table>
<thead>
<tr>
<th>Number</th>
<th>Date</th>
<th>PERSONAL NETWORK</th>
<th>First Name or Initials</th>
<th>Relationship</th>
</tr>
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<tbody>
<tr>
<td>1.</td>
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</table>

**PLEASE BE SURE YOU HAVE RATED EACH PERSON ON EVERY QUESTION. GO ON TO THE LAST PAGE.**
9. During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?

_______ 0. No
_______ 1. Yes

IF YES:

9a. Please indicate the number of persons from each category who are no longer available to you.

_______ spouse or partner
_______ family members or relatives
_______ friends
_______ work or school associates
_______ neighbors
_______ health care providers
_______ counselor or therapist
_______ minister/priest/rabbi
_______ other (specify) ____________________________

9b. Overall, how much of your support was provided by these people who are no longer available to you?

_______ 0. none at all
_______ 1. a little
_______ 2. a moderate amount
_______ 3. quite a bit
_______ 4. a great deal
APPENDIX A

Request Form

I request permission to copy the Norbeck Social Support Questionnaire (NSSQ) for use in research in a study entitled: The Psychological Impact of Systemic Lupus Erythematosus on Primary Care Issues.

In exchange for this permission, I agree to submit to Dr. Norbeck a copy of the one-page scoring sheet for each subject tested. These data will be used to establish a broad normative database for the instrument for clinical and non-clinical populations. Aside from use in the pooled data bank, no other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses.

Barbara King, R.N.  
4/16/83  
(Signature)  
(Date)  
Position and Full Address of Investigator:  
Graduate Student University of Arizona  
1333 N. Turnbull #103  
Tucson, Az  85719

Permission is hereby granted to copy the NSSQ for use in the research described above.

Jane S. Norbeck  
April 22, 1983  
(Date)

Please send two signed copies of this form to:  
Jane S. Norbeck, D.N.Sc.  
Department of Mental Health and Community Nursing  
University of California, San Francisco  
N505-Y  
San Francisco, California 94143
APPENDIX B

Mishel Uncertainty in Illness Scale
MISHEL UNCERTAINTY IN ILLNESS SCALE

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 about your family member 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 about your family member, then mark under "Undecided" for that statement. Please respond to every statement.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I don't know what is wrong with him/her.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I have a lot of questions without answers.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. I am unsure if his/her illness is getting better or worse.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. It is unclear how bad his/her pain will be.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. The explanations they give about him/her seem hazy to me.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6. The purpose of each treatment for him/her is clear to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. His/her symptoms continue to change unpredictable.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8. I understand everything explained to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. The doctors say things to me that could have many meanings.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>10. I can predict how long his/her illness will last</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. His/her treatment is too complex to figure out.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12. It is difficult to know if the treatments or medications he/she is getting are helping</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Undecided</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>-------</td>
<td>-----------</td>
<td>----------</td>
<td>------------------</td>
</tr>
<tr>
<td>13. Because of the unpredictability of his/her illness, I cannot plan for the future.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>14. The course of her/his illness keeps changing. He/she has good and bad days.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>15. It is not clear what is going to happen to him/her.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>16. I usually know if he/she is going to have a good or bad day.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. The results of his/her tests are inconsistent.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>18. The effectiveness of the treatment is undetermined.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>19. I can generally predict the course of his/her illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Because of the treatment, what he/she can do and cannot do keeps changing.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>21. I'm certain they will not find anything else wrong with him/her.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. They have not given his/her a specific diagnosis.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>23. His/her physical distress is predictable, I know when it is going to get better or worse.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. His/her diagnosis is definite and will not change.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. The seriousness of his/her illness has been determined</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. The doctors and nurses use everyday language so I can understand what they are saying.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
APPENDIX C

Profile of Mood States
Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in ONE space under the answer to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Not at All</th>
<th>A Little</th>
<th>Moderately</th>
<th>Quite a Bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>21</td>
<td>Hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22</td>
<td>Relaxed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23</td>
<td>Unworthy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24</td>
<td>Spiteful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25</td>
<td>Sympathetic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26</td>
<td>Uneasy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27</td>
<td>Restless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28</td>
<td>Unable to concentrate</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29</td>
<td>Fatigued</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30</td>
<td>Helpful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31</td>
<td>Annoyed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32</td>
<td>Discouraged</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33</td>
<td>Resentful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34</td>
<td>Nervous</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35</td>
<td>Lonely</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36</td>
<td>Miserable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37</td>
<td>Muddled</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38</td>
<td>Cheerful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39</td>
<td>Bitter</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40</td>
<td>Exhausted</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41</td>
<td>Anxious</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42</td>
<td>Ready to fight</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43</td>
<td>Good natured</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44</td>
<td>Gloomy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

The numbers refer to these phrases:
0 = Not at all
1 = A little
2 = Moderately
3 = Quite a bit
4 = Extremely

MAKE SURE YOU HAVE ANSWERED EVERY ITEM
APPENDIX D

Serious of Illness Rating Scale
Serious of Illness Rating Scale

If you have experienced any of the following illnesses or physical symptoms since your family member has been diagnosed with S.L.E., please place a check next to the appropriate symptom or illness that you have experienced.

1. Dandruff
2. Warts
3. Cold sore, canker sore
4. Hiccups
5. Bad breath
6. Sty
7. Common Cold
8. Nosebleed
9. Sore Throat
10. Constipation
11. Laryngitis
12. Headache
13. Scabies
14. Boils
15. Heartburn
16. Acne
17. Bascessed Tooth
18. Tonsillitis
19. Diarrhea
20. Carbuncle
21. Chickenpox
22. Mumps
23. Dizziness
24. Sinus Infection
25. Increased Menstrual Flow
26. Fainting
27. Measles
28. Painful Menstruation
29. Infection of the middle-ear
30. Varicose Veins
31. Psoriasis
32. No Menstrual Periods
33. Hemorrhoids
34. Hay Fever
35. Low Blood Pressure
36. Eczema
37. Drug Allergy
38. Bronchitis
39. Hyperventilation
40. Shingles
41. Mononucleosis
42. Infected Eye
43. Bursitis 222
44. Whooping Cough 230
45. Lumbago 231
46. Fibroids of the Uterus 234
47. Migraine 242
48. Hernia 244
49. Goiter 283
50. Miscarriage 284
51. Ovarian Cyst 288
52. Irregular Heart Beats 302
53. Overweight 309
54. Anemia 312
55. Anxiety Reaction 315
56. Gout 322
57. Appendicitis 337
58. Pneumonia 338
59. Depression 344
60. Frigidity 347
61. Burns 348
62. Kidney Infection 374
63. Inability for Sexual Intercourse 382
64. Hyperthyroid 393
65. Asthma 413
66. Glaucoma 426
67. Sexual Deviation 446
68. Gallstones 454
69. Arthritis 468
70. Starvation 473
71. Accidental Poisoning 480
72. Slipped Disk 487
73. Hepatitis 488
74. Kidney Stones 499
75. Peptic Ulcers 500
76. Pancreatitis 514
77. High Blood Pressure 520
78. Small Pox 530
79. Deafness 533
80. Collapsed Lung 536
81. Epilepsy 582
82. Chest Pain 609
83. Nervous Breakdown 610
84. Diabetes 621
85. Blood Clot in Blood Vessels 631
86. Hardening of the Arteries 635
87. Emphysema 636
88. Tuberculosis 645
89. Alcoholism 688
90. Drug Addiction 722
91. Coma 725
92. Cirrhosis of the Liver 733
<table>
<thead>
<tr>
<th></th>
<th>Disease</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>93</td>
<td>Parkinson's Disease</td>
<td>734</td>
</tr>
<tr>
<td>94</td>
<td>Blindness</td>
<td>737</td>
</tr>
<tr>
<td>95</td>
<td>Blood Clot in the Lungs</td>
<td>753</td>
</tr>
<tr>
<td>96</td>
<td>Manic Depressive Psychosis</td>
<td>766</td>
</tr>
<tr>
<td>97</td>
<td>Stroke</td>
<td>774</td>
</tr>
<tr>
<td>98</td>
<td>Schizophrenia</td>
<td>776</td>
</tr>
<tr>
<td>99</td>
<td>Muscular Dystrophy</td>
<td>785</td>
</tr>
<tr>
<td>100</td>
<td>Tumor in the Spinal Cord</td>
<td>800</td>
</tr>
<tr>
<td>101</td>
<td>Heart Failure</td>
<td>824</td>
</tr>
<tr>
<td>102</td>
<td>Heart Attack</td>
<td>855</td>
</tr>
<tr>
<td>103</td>
<td>Brain Infection</td>
<td>872</td>
</tr>
<tr>
<td>104</td>
<td>Multiple Sclerosis</td>
<td>875</td>
</tr>
<tr>
<td>105</td>
<td>Bleeding in the Brain</td>
<td>913</td>
</tr>
<tr>
<td>106</td>
<td>Uremia</td>
<td>963</td>
</tr>
<tr>
<td>107</td>
<td>Cancer</td>
<td>1020</td>
</tr>
<tr>
<td>108</td>
<td>Leukemia</td>
<td>1080</td>
</tr>
</tbody>
</table>
Barbara King
1333 North Tyndall, #303
Tucson, Arizona 85719

Dear Ms. King:

Thank you for your interest in our research. I am pleased to give you permission to use the Seriousness of Illness Rating Scale in your proposed research.

I am enclosing the three reprints which we have on this topic. We have an Illness History questionnaire which may be of interest to you.

If we can be of further assistance please let us know.

Sincerely yours,

Thomas H. Holmes, M.D.
Professor of Psychiatry and Behavioral Sciences

THH:ma
Encl.
Dear Ms. King:

Thank you for your letter of April 4, 1983 requesting permission to use the Seriousness of Illness Rating Scale. Simply by obtaining permission from me, you are free to use the Scale. However, a condition for the use of the Scale is that you send me a copy of any publications that arise from the use of this measure. This is because I am interested in any work you generate using the Scale.

Very best of luck on your master's thesis and good luck also with your career.

Sincerely yours,

Allen R. Wylèr, M.D.
Associate Professor
APPENDIX E

Demographic Data
Demographic Data

Age: ________________

Sex: ________________

Educational Status:

1 2 3
Grades 6-12 College Graduate School

Marital Status:

M S Sep W D

Relationship of subject to family member with S.L.E.: ________________

How long has your family member had S.L.E.: ________________

How long ago was your family member's last flare up: ________________

How long did it last: ________________

Has there been any physical disability or bodily changes in your family member as a result of the disease and/or the treatment?

YES NO

List Changes:
APPENDIX F

Human Subjects Form
THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING

MEMORANDUM

TO: Barbara King
1333 N. Tyndall #103
Tucson, Arizona 85719

FROM: Ada Sue Hinshaw, R.N., Ph.D. Jan R. Atwood, R.N., Ph.D.
Director of Research Chairman, Research Committee

DATE: March 28, 1983


Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Sub-committee of the Research Committee, and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research, if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH:des
8/82
APPENDIX G

Disclaimer
Subject Disclaimer Form
"The Psychological Impact of S.L.E. on the Primary Care-Giver."

You are being asked to participate in a study exploring the psychological impact of being a primary care-giver of a family member with lupus.

The purpose of this study is to identify the relationship between your social support system, the uncertainty you experience about your family member's illness and the effect these have on psychological stress and illness development. You are asked to complete four questionnaires about these four area. This will take approximately one hour.

There are no hazards or costs to you as a result of participating in this study. Please feel free to ask questions regarding the study, and know that you are able to withdraw from the study at any time without incurring ill will.

You are asked to voluntarily participate in this study by answering the statements in these questionnaires. By responding to these questionnaires, you will be consenting to participate in the study, the results of which may be published at a later date. All questionnaires will be treated with anonymity and confidentiality. You may choose not to answer some or all of the questions if you so desire. Whatever your decision, there is no risk involved.

SIGNED:

Barbara King, R.N.
Master's Student
LIST OF REFERENCES


Mishel, Merle. Adjusting the Fitt--Developing uncertainty scales for different clinical populations. (Manuscript submitted for publication) 1983c.


Suls, Jerry and Mullen, Brian. Life events, perceived control and illness: The role of uncertainty. Journal of Human Stress, 6:30-34, 1981.

Waitzken, H. and Stoeckle, J. D. The communication of information about illness. Advances in Psychosomatic Medicine, 32:397-408, 1970.


