# FATIGUE IN SYSTEMIC LUPUS ERYTHEMATOSUS: ITS RELATIONSHIP TO QUALITY OF LIFE, DEPRESSION, AND DISEASE ACTIVITY

by
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## ABSTRACT

The purpose of this descriptive, correlational study of 25 non-hospitalized adults was to examine relationships among fatigue, perceived quality of life (PQOL), disease activity, and depression for people who have systemic lupus erythematosus (SLE). The nature of fatigue in SLE and relationships among personal characteristics and the primary variables were also explored. Total fatigue correlated moderately strongly with PQOL. Physical, cognitive, emotional, and uncertainty dimensions of fatigue also correlated with PQOL, varying from weak to moderate. Total disease activity correlated moderately to moderately strongly with PQOL. Depression correlated moderately with PQOL, fatigue, and disease activity. Fatigue correlated moderately to strongly with disease activity. Path analysis supported the hypothesis that fatigue and depression mediate between disease activity and PQOL. Knowledge of the nature of fatigue in SLE, fatigue management strategies, the risk for depression, and client value systems will enable nurses to help clients achieve optimum PQOL.



Keywords: systemic lupus erythematosus, fatigue, quality of life, depression, disease activity

## DEDICATION

"Lupus is much like the elephant in the folktale. Having heard of the elephant but never having seen one, a curious monarch directed his wisest advisors to go forth, find and examine the exotic beast, and return and describe it. Unfortunately, all of the sages were sightless. Depending on whether each had encountered a leg, tusk, trunk or tail, the animal was likened to a tree trunk, a spear, a serpent, or a rope... The experience with lupus is often recognized only in retrospect- seen at the time as something else or, often, simply an enigma. Only when lupus is finally suspected and diagnosed may it be clear the events that took place months or even years earlier were actually- or, at least, possibly- signs and symptoms of lupus, or that seemingly unrelated incidents may actually have been connected" (Blau & Schultz, 1993, p. 9). This thesis is dedicated to all people who live with the 'disease of one-thousand faces'.

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TABLE OF CONTENTS

Page

## LIST OF TABLES

## LIST OF FIGURES

## LIST OF APPENDICES

# CHAPTER 1

# INTRODUCTION

Systemic lupus erythematosus (SLE) is one of over 100 forms of arthritis. Because of its variable course and multi-system involvement, it is also known as "the disease of 1000 faces". Most often, people with SLE have symptoms such as joint pain and skin problems, including rashes that may be exacerbated by exposure to sunlight. However, extensive involvement of other body systems, including the cardiovascular and renal systems, also occurs. Fatigue is a dominant symptom in people who have SLE (Hastings, Joyce, Yarboro, Berkebile, & Yokum, 1995; Krupp, LaRocca, Muir, & Steinberg, 1990; Krupp, LaRocca, Muir-Nash, & Steinberg, 1989; Robb-Nicholson et al., 1989; Wysenbeek, Leibovici, Weinberger, & Guedji, 1993). In fact, fatigue has been identified as one of the most disabling symptoms experienced (Krupp et al., 1990). Fatigue, therefore, may have great impact on perceived quality of life (PQOL) and be a source of depression for people who have SLE.

Although fatigue can be overwhelming in this population, little exploration has been made of its nature; that is, its unique qualities and properties. How fatigue is experienced by people with SLE, therefore, is not fully understood. As a result of incomplete understanding, development of effective interventions to reduce or manage fatigue in SLE has been limited. The aim of this study was to contribute to the current understanding of the nature of fatigue and its impact on PQOL for people who have SLE.

## Study Purpose

The purpose of this study was to determine the relationships among fatigue, perceived quality of life, depression, and disease activity in people who have SLE. The nature of fatigue in these people was also explored.

## Significance

Although fatigue may greatly affect peoples' lives, it remains a symptom that is generally under-diagnosed and incompletely understood by health care providers (Calin, Edmunds, & Kennedy, 1993; Robinson & Posner, 1992). Fatigue may be under-diagnosed because it may not be acknowledged as a

legitimate, physical symptom of some health conditions (Calin et al.). However, even when fatigue has been accepted as a legitimate symptom, the fatigue experience often remains misunderstood by health care providers (Robinson & Posner).

Fatigue has been acknowledged and generally accepted by researchers as a legitimate symptom in clients who have SLE (Krupp et al, 1989, 1990; Robb-Nicholson et al., 1989; Schwartz, Jandorf, & Krupp, 1993; Wysenbeek et al., 1993). However, the report by many people who have SLE that complaints of fatigue are not always met with adequate responses and are not explored fully by health care providers (personal communication, 1994), indicates that fatigue in SLE has not yet been completely legitimized. The significance of the current study lies in its potential to enlighten health care personnel about the nature and degree of fatigue experienced in people who have SLE, and the effect that fatigue has on their lives. As a result, client fatigue may be better understood by health care providers, and may be discussed more fully between clients and providers in the future.

Understanding of both the nature of fatigue and the relationship between fatigue and PQOL for people who have SLE will help health care providers gain a more complete understanding of the life experience of these people. Recognition and acceptance of the challenges that fatigue poses may be the initial step in understanding the choices people have made regarding the use of their limited energy. Health care providers may also be able to facilitate clients' choices of strategies to manage fatigue and use energy as a result of increased understanding of their life experience.

A more complete understanding of fatigue may also lead to changes in how nurses are educated about the fatigue experience. Nurses are involved in the care and management of many patients' symptoms. Student nurses, therefore, spend considerable time exploring many of these symptoms to understand both the experience of living with the symptom and there appropriate management. Pain and nausea, for example, are two concepts that receive much attention during undergraduate education. Fatigue, however, is not

studied to any great extent, even though it is a commonly experienced phenomenon. Education about pain management has changed dramatically as the understanding of the pain experience has increased. A similar increased understanding of fatigue will contribute to much needed changes in how nurses are educated about fatigue. In turn, this will contribute to increased patient insight and ability to cope with the challenges of fatigue and, thus, have a positive influence on their mood and PQOL.

The experience and outcome of fatigue in people who have SLE remains unclear because fatigue research in SLE is in its infancy. Results from this study will provide insight into the fatigue experience. In addition, while the relationship between fatigue and PQOL has been explored in this population (Burckhardt, Archenholz, & Bjelle, 1992, 1993; Hastings, et al., 1986; Liang et al., 1984) no correlational data have been reported. If significant correlations are found between fatigue and PQOL in the current study, the need for further exploration between the two concepts will be reinforced.

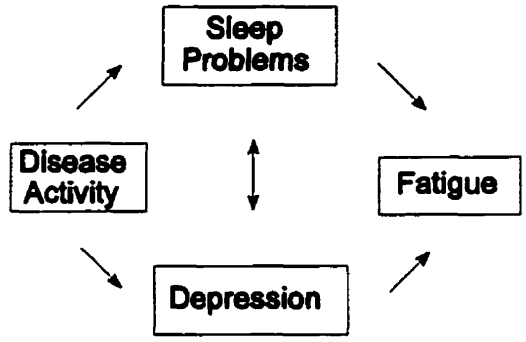
## Conceptual Framework

McKinley, Oullette, and Winkel (1995) proposed and tested a model of SLE fatigue that explored the mediating roles of sleep problems and depression between disease activity and fatigue (see Figure 1). The model was tested with 48 women who had SLE and 27 women from the general population. This model was revised to meet the needs of the current study. In this section, McKinley et al.'s model is outlined, including an overview of how the model was developed. The modified model is then described.

McKinley et al. (1995) perceived SLE disease activity to be the primary precipitating factor of fatigue. However, because fatigue persists in people who have SLE during periods when obvious disease activity is not detectable, they concluded that disease activity is an indirect contributor to fatigue. In McKinley et al.'s model, there are no direct lines linking the two variables. Instead, two interconnected variables, sleep problems and depression, were thought to mediate the relationship between disease activity and fatigue in people who have SLE. Thus, disease activity is directly linked to depression and sleep

problems in the model. These variables, in turn, are directly linked to fatigue.

Figure 1. McKinley et al.'s (1995) Proposed Model of Lupus Fatigue




From McKinley, P., Ouellette, S., & Winkel, G. (1995). The contributions of disease activity, sleep patterns, and depression to fatigue in systemic lupus erythematosus. Arthritis and Rheumatism, 38, p. 827.

## Development of Model by McKinley et al.

Disease activity and fatigue were the initial components of McKinley et al.'s (1995) model. Sleep problems and depression were incorporated into the model based on theoretical and experimental data. First, McKinley et al. justified their decision to include sleep problems as a mediator between disease activity and fatigue on the basis that sleep problems contribute to daytime fatigue, and elements related to disease activity that are present for many people who have SLE (such as pain, fever, medications, and depression) are implicated in sleep disturbance. Sleep problems were operationalized by the Spielman's (as cited in McKinley, et al.) Sleep Symptom Questionnaire, a 10-item, unstandardized self-report scale. Factor analysis yielded five factors, two of which were deemed relevant to the model: sleep disruption and sleep anxiety. The sleep disruption factor assessed the level of disturbed or lost sleep experienced by an individual, while sleep anxiety assessed the degree a person worried about the amount and quality of sleep s/he experienced. The model was tested using each of these factors as mediators between disease activity and fatigue.

Next, depression was incorporated into the model for two reasons. McKinley et al. (1995) felt that increased disease activity potentiates increased depression in SLE. They also made the decision to include depression based on the findings of Reynolds and Kupfer (as cited in McKinley et al.) and Van den Hoofdakker and Beersma (as cited in McKinley et al.), who found links between sleep pathology and depression. Depression was assessed by the Centre for Epidemiological Studies Depression Scale (CESD), a well established tool developed by Radloff (1977).

A bi-directional arrow was placed between sleep disturbance and depression because the nature of the relationship between these two variables remains unclear. This arrow allows consideration of the two possible pathways from disease activity to fatigue proposed in the model.

The two pathways to fatigue shown in the model were evaluated using 2-stage, least-squares regression analysis. When the model was tested using sleep disruption as a measure of sleep problems, three equations were evaluated and subsequently analyzed. The following conclusions were reached. First, sleep disruption was found to be a significant predictor of depression, while disease activity was not. Next, depression was found to be a significant predictor of sleep disruption, while disease activity was not. Finally, sleep disruption predicted fatigue, while both disease activity and depression were poor predictors. McKinley et al. (1995) concluded that a reciprocal relationship exists between sleep disruption and depression, and that the effect of disease activity on fatigue is mediated by sleep disruption and only marginally mediated by depression.

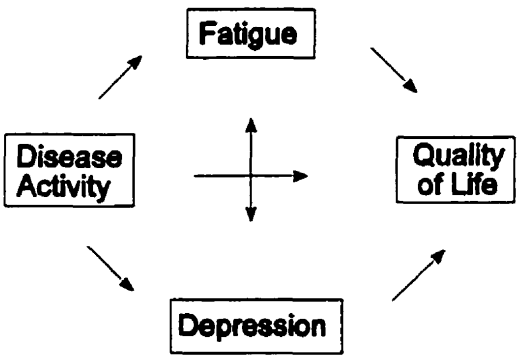
The model was similarly tested using sleep anxiety as a measure of sleep problems. First, depression was found to be significantly predicted by both disease activity and sleep anxiety. Depression was also found to mediate between disease activity and sleep anxiety. Finally, sleep anxiety was found to be a much greater predictor of fatigue than was depression. McKinley et al (1995) concluded that a reciprocal relationship exists between the sleep factors and depression, and the disease → depression → sleep → fatigue pathway was

a more probable path between disease activity and fatigue in SLE than the disease activity → sleep → depression → fatigue pathway.

Modification of Model for this Study

Disease activity is retained as the major precipitating factor to fatigue in SLE in the modified model, but the McKinley et al. (1995) model was revised in four ways for the current study: (a) the relationship between disease activity and fatigue was redefined, (b) sleep problems were deleted from the model, (c) the relationship between fatigue and depression was redefined and, (d) quality of life was added as the outcome variable (see Figure 2).

Figure 2: Modified McKinley et al. Model




In the original model, disease activity was considered to be an indirect contributor to fatigue. Disease activity, however, is now pictured as both a direct and an indirect contributor to fatigue in the modified model. This change was made for two reasons. First, moderate correlations between disease activity and fatigue in SLE have been found (Krupp et al., 1990; Wysenbeek et al., 1993), and second, people with SLE have stated that their fatigue is often worse during increased disease activity (personal communication).

The removal of sleep problems was a major change to the original model. Sleep problems occur in many rheumatic diseases where fatigue is a significant factor (Gudbjornsson, Broman, Hetta, & Hallgren, 1993; Hirsch et al., 1994; Mahowald, Mahowald, Bundlie, & Yetterberg, 1989) and also occur in

people who have SLE (McKinley, et al., 1995). Although the sleep problems variables were found to be strong predictors of fatigue in the original model, sleep problems were not included in the revised model for two reasons: (a) The number of questionnaires included in the current study was extensive and the addition of a sleep assessment questionnaire may have overwhelmed participants; and (b) sleep problems were assumed to contribute to fatigue.

McKinley et al. (1995) proposed two explanations for their finding that depression was not a contributor to fatigue in people who have SLE. First, instead of depression contributing to fatigue, they suggested that fatigue may contribute to depression. Second, they hypothesized that the relationship between fatigue and depression may be reciprocal rather than one-directional, therefore each variable may contribute to the other. As a result of consideration of these views, a bi-directional relationship between fatigue and depression was depicted in the revised model.

The final change to the model was the addition of perceived quality of life (PQOL) as the outcome variable in the modified model. PQOL is used as a global measure of the consequences of fatigue, disease activity, and depression. This addition was made based on the inverse relationships that seem to link fatigue and PQOL (Jeffrey, 1995; Krol, Sandermann, & Suurmeijer, 1993; Nelson et al., 1987; Tack, 1990a, 1990b), and depression and PQOL (Burckhardt, 1985; Burckhardt, Woods, Schultz, & Ziebarth, 1989; Burckhardt et al., 1992; Jeffrey; Liang, et al., 1984) in people with a variety of chronic illnesses.

In summary, McKinley et al. (1995) sought an explanation for the ongoing fatigue experienced between lupus flares. This study, however, seeks elaboration of the relationship between fatigue and depression, understanding of the mediational effects of fatigue and depression between disease activity and quality of life, and exploration of the consequences of fatigue in SLE.

## Research Questions

Four questions were investigated:

1. What are the relationships among perceived quality of life, fatigue,

depression, and disease activity for people who have SLE?

2. What are the relationships among demographic variables and the primary study variables of perceived quality of life, fatigue, depression, and disease activity in people who have SLE?

3. How do fatigue and depression mediate the relationship between disease activity and perceived quality of life?

4. What is the nature of fatigue in people who have SLE; that is, how is fatigue experienced?

## Definition of Terms

The following terms used in this study are defined: (a) PQOL, (b) fatigue, (c) depression, (d) disease activity, (e) person with SLE, and (f) demographics.

### Perceived Quality of Life

PQOL is defined as the subjective interpretation of the meaning attached to the many aspects of a person's life (Ferrans & Powers, 1988). Ferrans and Powers' Quality of Life Index-Arthritis Version was used to measure this concept (see Appendix A).

### Fatigue

Fatigue is the multi-dimensional, subjective feeling of extreme, constant or recurrent, lack of energy that involves the whole body (Graham, 1978, p. 13). It is resistant to rest and persists over time. The aspects of fatigue investigated in this study are: (a) physical fatigue, (b) cognitive fatigue, (c) emotional fatigue, (d) fatigue uncertainty, (e) overall fatigue, and (f) general fatigue.

#### Physical Fatigue

Physical fatigue is the dimension of fatigue that involves the sensation of bodily tiredness. It may be manifested by physical trembling, muscle weakness, decreased physical stamina, and the desire for rest or sleep. Physical fatigue was measured with the sensory subscale of the Piper Fatigue Scale (in press) (see Appendix B) and with the physical subscale of Wessley and Powell's (1989) 14-item Fatigue Scale (see Appendix C).

#### Cognitive Fatigue

Cognitive fatigue involves the changes that occur in thought processes

associated with fatigue. These may include difficult or slowed thinking, difficulty articulating thoughts, word finding problems, or difficulty concentrating. Cognitive fatigue was measured with the mental subscale of Wessley and Powell's (1989) 14-item Fatigue Scale.

Emotional Fatigue

Emotional fatigue involves the changes in mood that occur as part of the fatigue experience. Emotional lability, irritability (Graham, 1978, p. 79), anxiety, crying, anger, and impatience may be manifestations of emotional fatigue. This aspect of fatigue was measured with the Emotional Fatigue Scale, developed for the current study (see Appendix D).

Fatigue Uncertainty

Fatigue uncertainty is defined as the unpredictability and ambiguity (Mishel, 1981) surrounding fatigue, as well as the ability to foretell: (a) when fatigue will occur; (b) how long it will last; (c) how severe it will be; (d) whether it will be manifested primarily in a physical, cognitive, or emotional manner; or (e) how it may be alleviated. Clarity of the explanations received from health care workers and understood by the patient about fatigue influence the degree of ambiguity surrounding the concept (Mishel, 1981). Fatigue uncertainty was measured with a modified version of the Mishel Uncertainty in Illness-Community Scale (Mishel, 1989) (see Appendix E).

Overall Fatigue

Overall fatigue is defined as the total fatigue experienced by subjects and scores for overall fatigue were obtained by combining fatigue scores from the Piper Fatigue Scale (in press), the Fatigue Now subscale of the Emotional Fatigue Scale developed for the current study, and the fatigue related questions of the Mishel Uncertainty in Illness Community scale (Mishel, 1989).

General Fatigue

General fatigue is defined as the global perception of fatigue at its worst and at its best. This measure was developed for the current study. General fatigue was assessed with a 10-point rating scale that asked participants to describe the severity of their fatigue when it was at its worst and when it was at

its best, and with other fatigue related questions (see Appendix F). These other questions assessed patterns of sleep, such as duration of night-time sleep and day-time naps.

### Depression

Depression is defined as the sensation of negative mood, negative self-concept, and negative interpretation of life experiences (Radloff, 1977). The Centre for Epidemiological Studies Depression Scale (Radloff, 1977) was used to measure depressive symptoms (see Appendix G).

### Disease Activity

Disease activity is defined as the subjective interpretation of the nature and severity of SLE disease involvement. Disease activity was measured with Liang et al.'s (in press) Self-Administered Systemic Lupus Activity Measure (SA-SLAM) (see Appendix H).

### Person with SLE

A person with SLE is defined as someone who has received a definitive diagnosis of SLE from a rheumatologist, based on the criteria established by the American College of Rheumatology (1982).

### Demographics

Demographics of participants included age, sex, marital status, education, employment status, date of diagnosis, date of onset of symptoms, and past and current medications (see Appendix I).

### Assumptions

The following assumptions were made in conducting this study:

1. Fatigue is a multi-dimensional, subjective experience.
2. Fatigue is a valid experience in SLE, and it has a profound effect on those who experience it.
3. Quality of life is subjectively experienced.
4. The questionnaires were reliable and valid for the population.
5. Subjects answered questionnaires honestly.
6. Difficulty with sleep is related to fatigue.

# CHAPTER 2

# LITERATURE REVIEW

A summary of the research literature that describes SLE disease activity, fatigue, depression, and quality of life in general terms in chronic illnesses, and in specific terms in SLE are included in this chapter. The literature is used to both describe the current state of knowledge regarding the concepts and to describe the nature of the relationships among the variables proposed in the conceptual framework for the study.

## Systemic Lupus Erythematosus

Systemic lupus erythematosus (SLE) is an inflammatory, connective tissue disorder that may affect most of the major organ systems of the body. Approximately 90% of the people who have SLE are female, and the incidence in black women (1/245) is approximately three times the rate in white women (1/700) (Lockshin & Rothfield, 1988). The clinical course of SLE is usually unpredictable, punctuated by a series of exacerbations and remissions. Once thought of as a rare and fatal disease, improvements in diagnosis and treatment have contributed to the present view of lupus as a relatively common, chronic illness.

Diagnosis is often based on the classification criteria established by the American College of Rheumatology (ACR) (1982). At least four of the following criteria must be present for the diagnosis to be made:

1. Malar rash.
2. Discoid rash.
3. Photosensitivity.
4. Oral ulcers.
5. Arthritis.
6. Serositis (pleuritis or pericarditis).
7. Renal disorder (proteinuria or cellular casts).
8. Neurologic disorder (seizures or psychosis).
9. Hematologic disorder (hemolytic anemia, leukopenia, lymphopenia, or thrombocytopenia).

10. Immunologic abnormality (positive LE preparation, anti-double-stranded DNA, anti-SM antibodies, or false positive VDRL).

11. Antinuclear antibodies.

Most (90%) of people with SLE experience joint pain and swelling; approximately 85% have skin changes such as the classic butterfly facial rash, oral or nasal ulcers, photosensitive skin rashes, alopecia, or vasculitic lesions; 48% have muscle aches; about half have kidney damage; and one third experience pericarditis or pleural effusion (Tan & Rothfield, 1978). Other manifestations include, but are not limited to: visual loss, cardiovascular change, stroke, seizure, migraine, psychosis, hematological changes and pneumonia. Constitutional changes may include weight loss, fever, and fatigue.

Time lapse between onset of symptoms and diagnosis averages 4 to 6 years (Bauman, Barnes, Schreiber, Dunsmore, & Brooks, 1989; Haga & Cervera, 1994). Dealing with uncertainty is the inevitable result.

## Disease Activity in SLE

Although diagnosis can be based on the presence of four of the ACR criteria, Von Feldt (1995) has suggested that these criteria may be indicative of either very mild disease or a life threatening condition. Therefore, disease activity is ideally assessed by considering both the nature and the severity of SLE, both of which can be quite variable. The nature of disease activity is defined as the type of tissue involvement that has occurred. For example, the nature of activity might be joint inflammation, renal involvement, or central nervous system involvement. In contrast, severity is defined as the extent of tissue involvement. Using joint inflammation as an example, severity may be differentiated by the number of joints involved or by the degree of joint deformity. Organ involvement may be minimal or life threatening. Similarly, common constitutional symptoms such as fatigue may vary from mild to incapacitating.

Fatigue is reported by the majority of people who have SLE (Krupp et al., 1990). The proportion of people who have SLE and experience fatigue ranges from 80% to 100% (Wysenbeek et al., 1993). Approximately 41% to 76% of people who have SLE experience significant fatigue (Hastings et al. 1986;

Wysenbeek et al.), and about 53% have stated that fatigue is their most disabling symptom (Krupp et al.). Hastings et al. found that 56% of their SLE study subjects experienced limitations to their daily activities as a result of fatigue, and 62% of these people required day time rest. Sixteen percent of the respondents found fatigue to be the most difficult SLE symptom to accept. Clearly, fatigue is a major concern for this population.

## Fatigue

In the 1800s, fatigue was described as a pleasurable feeling that prevented one from dwelling on irritating thoughts and resulted in an uncaring sense of detachment from worldly trials and tribulations (Rabinbach, 1990, p. 39). As such, fatigue was a desirable sensation. During the Industrial Revolution, increased emphasis was placed on maximum production from the working class. Societal interpretation of the fatigue experience shifted. What was once deemed a pleasurable sensation became a potential source of social unrest and disorganization (Rabinbach, p. 38). Fatigue became a problem in need of solution. For people who experience fatigue as a chronic illness symptom, fatigue may always have been a problem in need of a solution. Literature related to fatigue is discussed from the perspectives of: (a) general dimensions of fatigue, (b) characteristics of fatigue in chronic illnesses, and (c) fatigue in SLE.

### General Dimensions of Fatigue

Fatigue is primarily a subjective sensation (Graham, 1978, p. 13; Hart, Freele, & Milde, 1990). As such, it has been defined as the whole body experience of overwhelming lack of energy encompassing physical, cognitive, and emotional dimensions (Graham, 1978, Part 1). These basic components of fatigue may be experienced as the subjective sensations of: (a) physical tiredness of the whole body; (b) mental changes, including difficulty in thinking, speaking, or concentrating; and (c) emotional changes such as anxiety, irritability, or general emotional lability. Although fatigue may be experienced primarily as one or the other of these dimensions, more than one dimension is usually experienced at a given time (Cameron, 1973; Graham, 1978, p. 22; Hart,

et al., 1990; Lewis & Wessley, 1992; Yoshitake, 1972).

## Fatigue in Chronic Illness

Basic differences exist between the fatigue experienced by healthy individuals and by those who have chronic illnesses (Belza, 1995; Krupp et al., 1989; Schwartz et al., 1993). Acute or normal fatigue has been described as the expected tiredness that results from over-exertion. Its symptoms are localized, rapid in onset, and short in duration. With rest, normal function returns quickly. Chronic fatigue associated with illness, on the other hand, has been described as unusual and extreme. It may be constant or recurrent in nature. Chronic fatigue tends to involve the whole body, is resistant to rest, and persists over time (Graham, 1978, p. 15; Hart et al., 1990). It is chronic fatigue that is explored in the current study.

Comparisons have been made between people with various chronic illnesses and healthy people regarding a number of dimensions of fatigue. The differences in severity, timing, and consequences of fatigue between people with chronic illnesses and healthy people are explored next.

### Severity

Fatigue is generally more severe in people with chronic illnesses than in healthy people (Belza, 1995; Krupp et al., 1989; Schwartz, et al., 1993). When people who have SLE have been compared to the healthy individuals, this pattern is typically upheld (Krupp, et al.; Schwartz, et al.). However, McKinley et al. (1995) found only a trend for greater fatigue severity in 48 women with SLE, when they compared them to 27 women from the general population. Fatigue was not severe for either group.

McKinley et al.'s (1995) unique finding may have occurred as a result of the method they used to measure severity. Fatigue severity was measured by scoring items related only to the consequences of fatigue. For example, one question asked people to rank the degree to which fatigue interfered with their ability to socialize. In other words, subjects were asked to evaluate the consequences fatigue had on their social life. It may be that fatigue severity is not accurately measured by assessing the consequences of fatigue alone.

Consequence-based severity subscales may actually measure peoples' ability to cope with fatigue, rather than severity of fatigue (McKinley, et al.). Timing of fatigue may be an essential element of assessing fatigue severity.

Timing

In general, compared to healthy people, people with chronic illnesses are more likely to state that they spend more time in the fatigued state (Belza, 1995; McKinley, et al., 1995), and that fatigue is continuous rather than intermittent, and chronic rather than acute in nature (McKinley, et al.).

Increased time in the fatigued state results in either a direct loss of usable time, because more time is spent in rest (Tack, 1990b; Robinson & Posner, 1992), or an indirect loss of time because time may be used less efficiently (Tack). People with chronic illnesses who experience severe fatigue, therefore, have fewer hours available to meet social, work, and recreation goals. The consequences of fatigue, therefore, may be great.

Consequences

Fatigue has a profound effect on many aspects of peoples' lives, including: (a) work life (Bartlett, 1943; Liang et al., 1984; Gulick, Yam, & Touw, 1989; McKinley et al., 1995; Myles & Romet, 1987; Nelson et al., 1987; Robinson & Posner, 1992; Tack 1990b); (b) social life (Calin et al., 1993; Hastings et al.,1995; Liang et al.; Nelson et al; Robinson & Posner; Tack, 1990b); (c) pain levels (Tack, 1990a), and (d) mood (Calin et al.; Hastings et al.; Liang et al.; Nelson, et al.; Tack, 1990a, 1990b). Comparison of the consequences of fatigue among people with chronic illnesses and healthy individuals is discussed in terms of physical consequences and then in terms of psychological consequences.

Physical consequences of fatigue are significantly greater in people who have chronic illnesses than in healthy individuals (Belza, 1995; Krupp et al., 1989; Schwartz et al., 1993). Specifically, Belza found that fatigue affected activities of daily living, such as ability to perform household chores, capacity for work, and ability to socialize, significantly more for people who had rheumatoid arthritis (RA) than in healthy controls. However, physical consequences of

fatigue may be difficult to differentiate from the combined effect of fatigue, pain, and other physical symptoms associated with many chronic illnesses.

Psychological consequences of fatigue may also be greater in people with chronic illnesses than in healthy individuals, although this point is debatable. For example, Belza (1995) found that distress that resulted from fatigue, as measured by a single item, was significantly greater in people who had RA compared to healthy controls. However, when levels of patience, motivation, and concentration were used as measures of the psychological consequences of fatigue, no significant differences were found between people with chronic illnesses and healthy individuals (Schwartz et al., 1993).

In summary, fatigue associated with chronic illnesses differs from fatigue experienced by healthy individuals in terms of its severity, timing, and consequences. Some support has been found for the idea that fatigue also varies from chronic illness to chronic illness (Schwartz et al., 1993). Little research has been conducted on the nature of fatigue in SLE.

## Fatigue in SLE

Understanding of the unique features of fatigue in SLE is limited by a paucity of research. Fatigue in people who have SLE is discussed in terms of possible causes, dimensions, and consequences.

### Possible Causes

The cause of fatigue in SLE remains unclear. Fatigue may occur as a result of: (a) physical aspects of SLE, (b) the psychological response to dealing with the disease, or (c) a combination of both these factors. Medications used in the treatment of SLE may also contribute to fatigue. An alternate cause may be decreased aerobic conditioning secondary to decreased activity (Robb-Nicholson et al., 1989). As with other people with chronic illnesses, many people who have SLE are less active than healthy individuals. Some people with SLE have been able to decrease the amount of fatigue they experience by improving their aerobic conditioning through prescribed exercise programs (Robb-Nicholson et al.). Finally, fatigue in people who have SLE may also occur secondary to fibromyalgia, which commonly occurs concurrently with SLE

(Middleton, McFarlin, & Lipsky, 1994; Morland, Miller, Whittingham, & Littlejohn, 1994).

Dimensions

As with other types of chronic illnesses, the physical, cognitive, and emotional dimensions of fatigue are considered important aspects of fatigue in SLE. Similarly, severity is also considered to be an important dimension of fatigue for this population (Krupp et al., 1990; Schwartz et al., 1993). Although people who have SLE have stated that their fatigue is unpredictable (Burckhardt et al., 1993), fatigue unpredictability is not assessed by most instruments.

Unpredictability and ambiguity are two related dimensions of uncertainty (Mishel, 1983). Unpredictability is the "perceived absence of stability of the course of the illness [symptom] and unpredictability of outcome" (Mishel, p. 359) and ambiguity is the sense of vagueness or lack of clarity people experience as a result of an illness (Mishel) or symptom.

Unpredictability may contribute to reduced capacity to plan ahead (Burckhardt, et al., 1993), emotional distress (Mishel, 1981), stress (Mishel), and depression (Krupp et al., 1990). Depression and perceived quality of life have been found to be negatively correlated for adults who have some rheumatic diseases (Jeffrey, 1995), but people who have SLE were not included in this study. Fatigue unpredictability may, therefore, both directly and indirectly (through depression) contribute to a poorer PQOL in people who have SLE.

People who have SLE have also stated that fatigue is not fully explored and discussed with them by health care providers (personal communication). Ambiguity, therefore, may also surround the fatigue experience for these people.

Consequences

Fatigue has been defined as the most disabling symptom experienced by 53% of people who have SLE (Krupp et al., 1990). It has also resulted in limitations to daily activities and the need for day time rest for more than 50% of these people (Hastings et al., 1986; Knippen, 1988). One might, therefore, presume that the physical consequences of fatigue in people who have SLE are great.

Exploration of the psychological consequences of fatigue in people who have SLE has been limited. One possible psychological consequence may be an altered perception of symptoms. McKinley et al. (1995) found that people with SLE tended to perceive fatigue as negative, abnormal, and destructive, whereas the controls tended to view fatigue as protective. It may be that this difference in perspective results from the type of fatigue endured. People who have SLE experience chronic fatigue, while healthy people usually experience acute fatigue. Living with fatigue day after day may cause people to attach a different meaning to their experience. This aspect of fatigue may also be a component of emotional fatigue.

Depression may also be a consequence of fatigue in SLE. Depression has been identified as contributing to fatigue in SLE in the past, however little support for this hypothesis has been obtained. In contrast, people who have SLE have stated that fatigue causes them to become "irritable and eventually depressed if it doesn't go away" (cited in Knippen, 1988, p. 59). The nature of the relationship between depression and fatigue in SLE has not been fully explored. Further research in this area is needed.

Physical and psychological consequences of fatigue may be multiple and profound for people who have SLE. Because of fatigue's potential to influence so many aspects of life, it may have a significant impact on PQOL in people with SLE.

### Summary

People who have chronic illnesses frequently experience chronic fatigue of a multi-dimensional nature. Fatigue may result in a number of physical and psychological consequences. Many people who have SLE find fatigue to be one of the most disabling symptoms they experience: Fatigue affects their ability to engage in normal, daily activities. Fatigue, therefore, may profoundly influence PQOL in people who have SLE.

## Quality of Life

Quality of life in chronic illness was originally conceptualized primarily from the standpoint of the objective impact of the particular disease or treatment,

rather than through subjective interpretation by the patient (Chambers, MacDonald, Tugwell, Buchanan, & Kraag, 1982; Sullivan, Karlsson, Furunes, Lapidus, & Lissner, 1993). Disease activity and functional abilities, for example, have been used as measures of quality of life (Stoll et al., 1997; Wolf, 1995). While disease activity may be related to quality of life, it is, at best, only a part of what is considered by people when they rate their quality of life. Low correlations found between disease activity and quality of life might actually be indicative of the ultimate uniqueness of the two concepts (Burckhardt et al., 1993). A person may have extensive disease involvement and still enjoy a good quality of life.

In attempting to assess quality of life, many life domains have been considered, including: (a) physical well-being; (b) material well-being; (c) occupation; (d) education; (e) emotional well-being; (f) stress; (g) relations with other people; (h) achievement of goals; (i) coping; (j) participation in social, community, and civic activities; (k) personal development and fulfillment; and (l) recreation (Campbell, 1976; Flanagan, 1982). Independence, or being able to do for one's self, has been considered to be an important aspect of quality of life for people with chronic illnesses (Burckhardt, et al.,1989).

Satisfaction with the domains of one's life and the degree of importance (value) attached to each component may both be essential factors of quality of life assessment: If personal values of life domains are not assessed, scores will not reflect the individual's perception of quality of life. For example, one may score poorly on satisfaction with one's education, but if education is viewed as unimportant by the individual, lack of satisfaction may not significantly affect perception of quality of life in that domain. Both satisfaction and importance are measured in the current study.

## Quality of Life in SLE

Measurement of PQOL for people who have SLE has been limited, but important inroads have been made (Burckhardt et al., 1992, 1993; Liang et al., 1989; Stoll et al., 1997). PQOL has been explored primarily using open ended

questions, but some quantitative measurement has also occurred.

Burckhardt et al. (1993) used questions such as "(1) What does quality of life mean to you?; (2) Which areas of your life are you most satisfied with?; and (3) Which areas of your life are you least satisfied with?" (p. 977) to compare quality of life between groups of women who had either SLE or RA. Liang et al. (1989) also explored perceived outcomes of the two diseases. Both groups concluded that SLE and RA had a profound impact on the psychological and social lives of their participants. People who had SLE, especially, noted significant changes in social activity (61%) and finances (45%) (Liang, et al.)

Burckhardt et al. (1993) also used a modified version of Flanagan's (1978) Quality of Life Scale (QOLS). This scale measures satisfaction related to material goods, health, interpersonal relationships, self, recreational activities, and independence. Importance attached to these areas, however, is not measured. There were no significant differences in quality of life ratings between the SLE and the RA groups ( SLE $\underline{M}$ = 86.1, $\underline{SD}$ = 13.6 and RA $\underline{M}$ = 83.4, $\underline{SD}$ = 9.6; possible range of 16 - 112, with higher scores indicating greater satisfaction). Each group was generally satisfied with most domains of life. Stoll et al. (1997) used functional health status questionnaires as measures of quality of life, with no attempt to obtain measures of satisfaction.

In addition to assessing satisfaction, Burckhardt et al. (1993) asked subjects to identify areas of life with which they were dissatisfied. Health and the ability to engage in recreational activities were areas of dissatisfaction for both groups, but dissatisfaction was expressed in different ways. Mobility was the primary area of dissatisfaction for people with RA. However, for the people with SLE, fatigue and inability to plan ahead because of the variability and unpredictability in how they felt on a day to day basis were major issues. Fatigue, uncertainty, and lack of control were major dissatisfaction themes.

## Summary

Quality of life is defined as the subjective interpretation of the meaning attached to the many aspects of a person's life. Ideally, therefore, measurement of quality of life is not limited to objective measures of achievement or functional

ability. Instead, it encompasses how people feel about or value what they have done or are doing in the many domains of their lives. Initial exploration of quality of life in people who have SLE has not considered the degree of importance attached to life domains, but has largely focused on satisfaction or dissatisfaction. Major areas of dissatisfaction have included uncertainty, lack of control, and fatigue.

## Fatigue and Quality of Life

Fatigue may directly affect PQOL by decreasing time available for life pursuits, and it may indirectly effect PQOL by contributing to frustration, stress, dissatisfaction, and depression. Both the degree of fatigue experienced and the manner in which one copes with it may also contribute to one's PQOL (Krol et al., 1993).

Although a number of researchers have explored the relationship between fatigue in chronic illnesses and individual aspects of life that may be important domains of quality of life assessment, little exploration of the relationship between fatigue and general PQOL has been done. The current state of knowledge with respect to fatigue and two domains of quality of life assessment, and fatigue and total PQOL follows.

### Fatigue and Two Domains of Quality of Life: Work and Social Relationships

Two aspects of life that have been explored in relation to fatigue are work and social relationships. First, work was an area of life affected by fatigue in three studies that assessed a variety of chronic illnesses. Nelson et al. (1987) noted that 24% of the 243 study subjects, who had a variety of medical conditions and whose chief complaint was fatigue, stated that fatigue caused difficulty with their work.

Gulick et al. (1989) looked specifically at factors which either impeded or enhanced work performance in 412 people who had multiple sclerosis (MS) using two open-ended questions and self-administered questionnaires. Participants were divided into four groups: (a) those employed outside the home, (b) homemakers, (c) those who were unemployed, and (d) individuals who were retired. One question asked subjects to identify things that made it

difficult to perform work or chores. Fatigue was the highest ranking work impediment for every group (25 to 51%).

Tack (1990b) explored the consequences of fatigue in 20 people who had RA. Subjects completed semi-structured interviews, in addition to the Profile of Moods Scale (POMS) and visual analogue scales pertaining to fatigue and pain. Again, fatigue was reported to have had profound effects on their ability to work.

Second, social and family relationships were identified as aspects of life that changed as a result of fatigue (Nelson, et al., 1987; Tack, 1990b). Less time and energy was available to invest in relationships. It may be, however, that people with chronic illnesses re-evaluate their priorities with regard to work and relationships. For example, many respondents in Tack's study stated that fatigue had caused them to place a higher value on relationships. A larger percentage of available energy was, therefore, invested in family and friends.

Other aspects of life have also been identified as being negatively affected by fatigue, including: (a) ability to complete tasks (Tack, 1990b); (b) overall enjoyment of life (Nelson et al., 1987); (c) sex life (Nelson et al.); and (d) sleep (Belza, Henke, Yelin, Epstein, & Gillis, 1993; Nelson et al.). Each of these aspects of life, including work and social relationships, are considered when PQOL is assessed. It may be that a lower overall PQOL is experienced by people who report great fatigue, however correlations have not been reported in these studies.

## Fatigue and Total Perceived Quality Of Life

Direct exploration of the relationship between fatigue and PQOL has been very limited. Using a linear analogue scale to measure fatigue severity and Ferrans and Powers' (1985) Quality of Life Index (QOLI) to assess quality of life, Jeffrey (1995) found that 290 subjects with RA and fibromyalgia who reported greater fatigue had lower overall quality of life ($r = -.43$, $p < .01$). The same relationship was found between fatigue and the Health and Function domain of PQOL ($r = -.47$, $p < .01$). Correlation between the single question "How much is fatigue a problem for you" and the total QOLI was also moderate ($r = -.48$, $p < .01$). This finding is expected to hold in the current study of people who have

SLE.

## Fatigue and Quality of Life in SLE

Exploration of the relationship between fatigue and quality of life in SLE has been extremely limited. As part of an exploratory study ($n$ = 50) about fatigue in SLE, Hastings et al. (1986) found that most subjects ($n$ = 41) felt that fatigue created problems in their lives. Physical functioning was affected by fatigue for 70% of the subjects, 38% stated that social functioning was changed, and 36% noted changes in emotional functioning attributed to fatigue. Daily activities were affected for 56% and 62% of the respondents stated that day time rest was required on a regular basis. Knippen (1988) asked people who had SLE to discuss the impact fatigue had on life. People stated that it was difficult to maintain full-time employment and it was difficult to perform their work to their satisfaction. Social lives were also limited, housekeeping chores were difficult, and family relations suffered.

Burckhardt et al. (1993) investigated predictors of quality of life in SLE and RA by asking subjects to explain what they felt contributed to dissatisfaction with areas of their life. Dissatisfaction revolved around areas of health for all. However, fatigue was identified as a major problem in people with SLE.

## Summary

Moderate correlations have been found between fatigue and quality of life in a number of chronic illness populations. Initial qualitative exploration of this relationship in people who have SLE indicates that the probability of finding a significant correlation between the two concepts is high. Fatigue may have a major impact on areas of life that are considered to be vital components of quality of life in SLE. Consequently, this relationship was also explored from a quantitative perspective in the current study.

Although Burckhardt et al. (1993) concluded that fatigue was a predictor of quality of life in SLE and RA, they found that psychological distress, was a better predictor. Global psychological distress was composed of two components: anxiety and depression. Depression, therefore, may also be a significant factor in the exploration of quality of life in chronic illnesses.

# Depression

## Depression in Chronic Illness

The incidence of depression in chronic illnesses is significantly higher than that found in the general population (Ahles, Khan, Yunus, Spiegel, & Masi, 1991; Belza et al., 1993; Gaudino, Masur, Kauffman, Sliwinski, & Krupp, 1995; Krupp et al., 1989; Krupp, Sliwinski, Masur, Friedberg, & Coyle, 1994). In these studies, the average incidence of depression in chronic illnesses was about 34% (range 5.5% to 54%). Some degree of depressive symptomology is also frequently present in many people who have SLE (Ganz, Gurland, Deming, & Fisher, 1972; Giang, 1991; Knippen, 1988; West, 1994; West, Emlen, Wener, & Kotzin, 1995).

## Depression in SLE

Estimates of the prevalence of general neuropsychiatric manifestations in SLE have ranged from 15% to 83% (Ganz, et al., 1972; Guze, 1967; Hall, Stickney, & Gardner, 1981; Omdal, Mellgren, & Husby, 1988). These manifestations fall into three broad categories: (a) diffuse, which includes organic brain syndromes and psychiatric disturbances such as depression or psychosis; (b) focal manifestations encompass any symptom that originates from a brain lesion; and (c) complex presentations have characteristics of both diffuse and focal manifestations (West, 1994; West et al., 1995). Depression, therefore, is one of many possible neuropsychiatric phenomena seen as part of the clinical picture in SLE. The nature of the relationship between depression and other neuropsychiatric manifestations associated with SLE has been difficult to define. As such, the general neuropsychiatric literature related to SLE, including possible causes, is reviewed as a preamble to the discussion of depression in SLE.

The occurrence of central nervous system (CNS) symptoms in SLE has been attributed to multiple causes. In some cases, actual brain tissue damage as a result of SLE activity has occurred, which initiates symptom onset (Futrell & Milliken, 1992; Levine & Welch, 1987; West et al., 1995). In other situations, symptoms may result from chemical imbalances (Kaell, Shetty, Lee, & Lockshin,

1986; Guze, 1967; Hall et al., 1981). Neuropsychiatric symptoms may also occur solely in response to the stress experienced by living and coping with the uncertainty, fatigue, and pain of this chronic illness. Whatever the cause, depressive symptoms are one of the most prevalent neuropsychiatric manifestations found in people who have SLE. Estimates of the incidence of depression in this group have ranged from 7% to 70% (Bauman et al., 1989; Ganz et al., 1972; Giang, 1991; Hall et al.; Knippen, 1988; Krupp et al., 1990; Liang et al., 1984; McKinley et al., 1995; Omdal et al., 1988; Robb-Nicholson et al., 1989).

As with other neuropsychiatric symptoms, the cause of depression in people with SLE is debatable. It is possible that a number of underlying factors are responsible and each play a role: (a) the stress of living with a chronic illness (Ganz et al., 1972; Liang et al., 1984; Mitchell & Thompson, 1991; Robb-Nicholson et al., 1989); (b) uremia (Kaell et al., 1986); (c) steroids (Guze, 1967); and (d) auto-antibodies (West et al., 1995). The debate between those who contend that depression occurs as a result of living with a chronic illness versus those who claim it results from a biological abnormality has been particularly lively. Research related to both perspectives is reviewed.

Two approaches have been used to explore depression that results from living with SLE. First, depressive symptomology in SLE has been compared to depressive symptomology in psychiatric outpatients (Mitchell & Thompson, 1991; Robb-Nicholson et al., 1989). Although different assessment tools were used in each of these studies, similar results were obtained: Depression in SLE was similar to depression found in the general medical population, and depression in SLE was milder than depression in the psychiatric population (Krupp et al., 1990, Mitchell & Thompson; Robb-Nicholson et al.). The conclusion reached was that depressive symptoms in SLE probably results from the stress of living with a chronic illness.

Secondly, depressive symptomology has been compared between people who have SLE and those who have RA (Ganz et al., 1972; Giang, 1991; Liang et al., 1984). Contradictory conclusions have been drawn. Ganz et al. and Liang et

al. found a similar incidence of depression for people who had SLE and those with RA (SLE = 51%; RA = 47%). They, therefore, rejected the hypothesis that depression resulted from pathology of the CNS in SLE, because CNS involvement does not occurs in RA. The similar results led them to also conclude that depression results from stress associated with living with chronic illnesses.

Conversely, Giang (1991) concluded that depression in SLE was at least partly the result of factors intrinsic to CNS disease. He also compared a group of people with SLE to a group with RA. Patients with SLE reported significantly higher depression scores than did those with RA. Because he concluded that SLE and RA were both "chronic, relapsing and remitting immunological illness[es] which cause disability and deformity and which is treated with similar medications" (p. 81), with the one significant difference being the lack of direct CNS involvement in RA, he made the assumption that the higher level of depression in SLE could not be accounted for by the stress of coping with a chronic illness or medication side effects alone, and that active CNS disease involvement must play a role in depression in SLE. West et al. (1995) found additional support for this perspective.

West et al. (1995) found that each of the 32 study patients who had diffuse neuropsychiatric manifestations also had elevated cerebrospinal fluid (CSF) antineural antibodies or serum antiribosomal-P antibodies. Five of these people presented with depression. He concluded that the presence of these auto-antibodies signified active CNS disease, and that the antibodies were involved in the development of the diffuse neuropsychiatric symptoms, including depression, that these people experienced.

## Summary

Depression frequently occurs in people who have chronic illnesses, including SLE. It seems likely that depressive symptomology in SLE results from multiple causes. Certainly, it is reasonable to conclude that the stresses associated with living with this chronic illness play a role. However, improved technology has also made it possible to begin to clarify the relationship between

biological disease activity and depression in SLE.

## Depression and Disease Activity in SLE

Direct exploration of the relationship between biological disease activity factors and depression in SLE has been limited. However, the relationship has been explored from two perspectives: (a) the type or nature of disease activity and depression and (b) the combined effect of the type and severity of disease involvement on depression.

The type or nature of disease activity can be measured by considering physical manifestations of disease or by considering laboratory analysis of blood. Either approach has obtained similar overall results. A relationship between disease activity and depression exists, albeit a moderate one (Adams, Dammers, Saia, Brantly, & Gaydos, 1994; Joyce et al., Berkebile, Hastings, Yarboro, & Yokum, 1989; West et al., 1995). Of particular interest was the finding that mucocutaneous manifestations of SLE, such as rash or alopecia, correlated most strongly with depression in both studies. It may be that these visible disfigurements provoke negative reactions from other people, which contributes to depression for people with these symptoms. Correlations have also been found between scores in the Clinical Activity Index measure of disease activity and depression ($r = .33$, $p < .05$) (Joyce et al.), and between joint problems and depression, and abdominal problems and depression (Adams et al.).

Although type of disease activity was measured in the previous studies, severity of activity was not. McKinley et al. (1995), however, used a modified version of Liang et al.'s (1989) Systemic Lupus Activity Measure (SLAM) to explore the relationship between disease activity and depression in 48 female SLE outpatients of a rheumatological and musculoskeletal clinic. This assessment instrument measures both the type or nature of disease activity and its severity. Depression was measured with the Centre for Epidemiological Studies Depression Scale (CES-D). Four items that have been shown to artificially inflate depression scores in people with RA were deleted from the scale. McKinley et al. stated that a significant correlation existed between

disease activity and depression, although values were not published. In addition, disease activity had a direct effect on depression as analyzed by regression equations, although the SLAM was only a weak predictor of depression.

Disease activity was measured by a variety of assessment tools in previous studies. Most of the instruments were based on the criteria established by the ARA. It is interesting to note that fatigue, although a common disease manifestation of SLE, is not included in the ARA criteria. Depression is also not specifically addressed, although the broad category of neuropsychiatric symptoms is included. Fatigue and depression are important symptoms which effect the experience of living with SLE. Exploration of the relationship between them may be vital to a complete understanding of the experience.

## Depression and Fatigue

People who are depressed usually experience some degree of fatigue, therefore, assessment of depression usually includes an appraisal of fatigue. Moderate correlations ($r$ = .31 to .47; $p$ < .05) between fatigue and depression have been found in studies of a number of chronic illness populations, even though a variety of assessment tools have been used (Belza, 1995; Jeffrey, 1995; Tack, 1990a, 1990b). Fatigue, however, may occur without depression. The nature of the relationship between fatigue and depression in chronic illnesses is not straight forward.

Similar results have been obtained by the few researchers who have explored the relationship between fatigue and depression in SLE. Robb-Nicholson et al. (1989) found that, in 23 people reporting fatigue who had stable SLE, 39% had mild depression. Hall et al. (1981) interviewed 19 people who had both SLE and a previous hospital admission which had included psychiatric symptoms. Severe lethargy was experienced by 10 of the 19 people, and was often related to periodic depression (correlations not published). Krupp et al. (1989) studied 29 outpatients with SLE. Scores on their self-developed Fatigue Severity Scale (FSS) and fatigue visual analogue scale scores correlated to CES-D scores ($r$ = .46, $p$ < .05). Knippen (1988) found a weaker but still positive

correlation between the CES-D and The Feeling Tone Checklist, a 10-item fatigue assessment tool ($r = .27$, $p < .01$).

From these data, one may conclude that there is a link between fatigue and depression in chronic illnesses, including SLE. Because correlations have been found between fatigue and depression, the possibility of a causal relationship also exists.

The causal relationship between fatigue and depression has been explored primarily from the perspective of depression as a contributor to fatigue, with unimpressive results. Belza et al. (1993) attempted to clarify the antecedents of fatigue in RA by using multiple regression analysis. The combination of depression, learned helplessness, and social support accounted for only 4% of the variance found in fatigue ($F[12, 114] = 6.35$, $p < .05$). Depression itself, therefore, explained very little about fatigue. Similarly, McKinley et al. (1995) analyzed the effect depression had on fatigue in women with SLE and concluded that "depression was a marginally significant predictor of fatigue, but... its effect was weak" (p. 831) and Knippen (1988) concluded that depression accounted for only 7% of the variance in fatigue in her study. Little support exists for the premise that depression is a cause of fatigue in chronic illnesses, given the rules of causality.

Walsh (1990) outlined criteria essential to the establishment of causality between two variables: (a) a correlation must exist between the variables, (b) temporal ordering must occur, (c) the relationship must be non-spurious, and (d) reasonable and sufficient cause may exist for the independent variable to affect the outcome variable. These criteria were used to illuminate the current state of exploration of the relationship between fatigue and depression in chronic illness, and were used to provide theoretical support for an alternative perspective of the relationship.

First, without doubt, a moderate correlation has been reported between fatigue and depression (Belza et al., 1993; Jeffrey, 1995; McKinley, et al., 1995). This criterion, therefore, has been met. Second, temporal ordering must be considered. Temporal ordering of depression and fatigue may be difficult to

determine if the relationship between fatigue and depression is a reciprocal one. Temporal ordering may also be difficult to assess with available assessment tools. For example, both Belza (1993) and McKinley et al. (1995) used instruments designed to assess depression over the past week. Unfortunately, the fatigue instrument used by Belza was also fashioned to assess fatigue over the prior week, and the instrument used by McKinley et al. included many items that required consideration of an extended time period, although participants were asked to complete the form based on the fatigue they experienced at the time of completion. People who have chronic fatigue, however, may have difficulty defining their fatigue at a fixed point in time: After all, as the word chronic implies, it is a phenomenon that occurs over an extended period. All things considered, the timing of depression as a predictor of fatigue was not clearly delineated in these studies.

Specific problems with timing momentarily set aside, remember that both Belza (1993) and McKinley et al. (1995) found depression to be only a weak predictor of fatigue. It may be that the fundamental theoretical ordering of the variables needs to be reconsidered; fatigue may predict depression, rather than depression predict fatigue, or there is no ordering and they are reciprocal variables, in people who have chronic illnesses.

Theoretical support for this perspective may exist. Fatigue may be considered a negative life event. Negative life events have certainly been shown to be causes of reactive depression. Research support for this hypothesis in SLE may also exist. Krupp et al. (1990) found that 56% of 59 subjects who had SLE stated that fatigue clearly predated depression. Krupp et al. hypothesized that depression may have occurred as a response to the unpredictable and inconsistent course of fatigue experienced in SLE. However, the temporal ordering of depression and fatigue remains unclear.

The third criterion suggested by Walsh as essential to the establishment of causality between variables has been partly explored as part of the previous discussion. This criterion specifies that the statistical relationship between variables not be spurious. As previously discussed, substantial theoretical

support exists for linking fatigue and depression in chronic illnesses, however, the relationship may be the result of other variables, for example, pain.

Finally, there must be necessary and sufficient cause in the predictor variable, for the outcome variable to occur. A necessary cause is defined as one which must be present for the outcome to occur, while sufficient cause is defined as a cause that is able to induce the effect on its own. It is this criterion that is most difficult, if not impossible to ascertain in the relationship between depression and fatigue. Neither fatigue nor depression must be present for the other to occur, and it is unlikely that fatigue alone causes depression or that depression alone causes fatigue.

### Summary

The nature of the relationship between fatigue and depression remains unclear. However, some support for the relatively novel notion that fatigue precipitates depression in people who have SLE, rather than the reverse, exists.

Exploration of the relationship between fatigue and depression might contribute to a broader understanding of the relationship these variables may have, in turn, with PQOL. As previously described, correlations between fatigue and PQOL exist. The relationship between depression and PQOL is described in the following section.

## Depression and Quality of Life

Depression has been used as a dimension in the assessment of quality of life (Sullivan et al., 1993), the assumption being that the greater the degree of depression one experiences, the poorer quality of life one has. Unfortunately, this view fails to take into account the individual's evaluation of depression as a contributor to quality of life. That being said, research findings have supported the idea that a relationship may exist between depression and PQOL in chronic illnesses. However, studies have sometimes grouped depression into broader psychological categories, making interpretation somewhat difficult.

Burckhardt (1985), for example, included depression as part of a negative attitudes category, when she attempted to find support for her model that explained variance in PQOL for people who had some form of arthritis or

rheumatic disease. In her study, negative attitudes were assessed using a self-developed tool which contained a depression measure. Negative attitudes such as depression, discouragement, anger, worry, and frustration each contributed to poorer quality of life scores. Fifteen percent of the variance in PQOL was attributed to these factors.

Similarly, depression was assessed under the umbrella category of psychological variables of the Arthritis Impact Measurement Scales (AIMS) in people who had either diabetes mellitus, an ostomy as a result of colon cancer or colitis, osteoarthritis, or RA (Burckhardt, et al., 1989). The AIMS psychological subscale measures depression and anxiety. Psychological aspects correlated with quality of life when measured at 3 and 6 week intervals ($r$ = -.39 to -.66). Separate correlations for depression and quality of life were not provided.

Jeffrey (1995) reported moderate correlations between scores on the Centre for Epidemiological Studies Depression scale (CES-D) and Ferrans and Powers' (1985) Quality of Life Index (QOLI) for people with RA ( $r$ = -.44, $p$ < .01). Support exists for the premise that a relationship exists between depression and PQOL in some chronic illnesses.

## Depression and Quality of Life in SLE

Exploration of the nature of the relationship between depression and quality of life in SLE has been limited. Liang et al. (1984) used a combination of structured questionnaires and open-ended questions to explore the broad, psychosocial impact of SLE and RA. They found a significant correlation between depression and loss of social activity which included relations with family and friends (value not published). Social function is an area often assessed in quality of life tools.

Burckhardt et al. (1992) correlated scores on the psychological subscale of the AIMS and a modified version of Flanagan's (1978) Quality of Life Scale (QOLS) ($r$ = -.56, $p$ < .001). For those who had SLE, the correlation was $r$ = -.63 ($p$ < .001), and for those who had RA, it was $r$ = -.46 ($p$ < .001). The AIMS measure of psychological distress was reported to be the best predictor of

quality of life for both groups. However, the AIMS psychological subscale was not designed to be a pure measure of depression because it also assesses anxiety.

## Summary

Some support exists for the supposition that depression and quality of life are related for persons who have chronic illnesses. Analysis of the initial research into the relationship between psychological factors and perceived quality of life in SLE lends credence to the hypothesis that depression and quality of life may also be related in persons with SLE. Additional research into this relationship is warranted. Although psychological factors, such as depression, may play important roles in perceived quality of life, physical factors, such as disease activity, must also be considered.

## Disease Activity and Quality of Life

Although correlations between disease activity and quality of life in chronic illnesses have been found, they are not generally as strong as those found between psychological factors and quality of life. For example, Jeffrey (1989) explored the relationship between disease activity and quality of life as part of a study designed to determine the predictors of quality of life in people who had RA. Correlations were found between a number of disease related measures and quality of life. Quality of life was greater for subjects who reported fewer problems with their RA ($r$ = -.18 to -.55), better functional ability ($r$ = .23 to .28), and less pain ($r$ = .25 to .31).

Burckhardt, et al. (1992) also correlated PQOL and disease activity in 50 women who had RA and 50 women who had SLE ($r$ = -.34, $p$ < .05). Disease activity was assessed, for the people who had SLE, by a modified version of Liang, Socher, Larson, & Schur's (1989) SLAM. The SLAM assesses both the nature and the severity of disease activity in SLE. This version differed from the original in that it did not contain laboratory measures, allowing subject, rather than physician, completion. In a subsequent study by Burckhardt et al. (1993), predictors of quality of life in SLE and RA were investigated. Perception of the global impact of SLE was second only to psychological distress in the 50 women

they interviewed. Global impact was defined as the summative measure of the AIMS, excluding the social activity and the psychological subscales. Given that the AIMS global impact has compared favorably to other health status instruments (Meenan, Gertman, & Mason, 1980), it may be considered to be a valid, patient perceived measure of the impact of disease activity. A correlation of $r = -.41$ ($p < .01$) was found between the global impact score and Flanagan's Quality of Life Scale. One may conclude that perceived disease activity in SLE influences perceived quality of life in this group. Psychological factors such as depression may affect perception and thus act as mediators between disease activity and perception of quality of life, as described in the conceptual framework model. Fatigue may also mediate the relationship between disease activity and quality of life. The relationship between disease activity and fatigue will be explored in the next section.

## Disease Activity and Fatigue in SLE

The relationship between disease activity and fatigue in SLE has been explored from two perspectives: correlation and prediction.

Wysenbeek et al. (1993) converted patient history and physical exams, conducted by physicians, to a scaled history and physical assessment tool that measured disease activity in SLE. Fatigue was rated by patients using a 1-item scale. The correlation between physician-rated general disease activity and patient-rated fatigue was moderate ($r = .49$, $p < .001$). Positive correlations were also found between fatigue and the following specific disease activity measures: (a) nervousness ($r = .34$, $p < .003$); (b) muscle pain ($r = .25$, $p < .02$); and (c) headache ($r = .25$, $p < .025$). Lymphocyte count had the strongest correlation to fatigue of all the laboratory measures assessed ($r = -.40$, $p < .016$). The relationship found between lymphocyte count and fatigue was explained as follows: Increased disease activity, as evidenced by lymphopenia, resulted in increased production of substances such as interleukin-1. Interleukin-1, a sleep promoter, contributed to an increased sensation of fatigue. Knippen (1988) found a similar correlation between fatigue, as measured by the Feeling Tone Checklist, and an earlier version of Liang et al's SLAM ($r = .36$, $p < .001$). When

these subjects were asked to rate their own disease activity, the correlation between fatigue and disease activity was even stronger ($r$ = .46, $p$ < .001).

In contrast to the previous studies, no correlation was found between fatigue and laboratory measures by Krupp et al. (1990). However, a correlation was found between fatigue and the physician-rated visual analogue scale for disease activity ($r$ = .30, $p$ < .05). Lymphocytes were not assessed in this study.

Finally disease activity, as experienced by either new manifestations of SLE or worsening of present symptoms, was significantly correlated to fatigue in a study by Zonana-Nacach et al. (1995) (values not published). Disease activity was assessed using Liang et al's (1989) SLAM.

In general, stronger correlations between disease activity and fatigue have been found with global disease assessment measures, rather than with specific disease measures, such as pain. The correlation found between lymphocyte count and fatigue was a noted exception.

Few researchers have attempted to explore the possibility of a predictive relationship between disease activity and fatigue in SLE, although this relationship has been examined in people with RA. Disease related variables, such as pain, sleep quality, activity level, co-morbidities, functional status, and disease duration, may account for approximately 42% of the variance in fatigue experienced by people with RA (Belza, et al., 1993).

As described previously, McKinley et al. (1995) examined the relationship between disease activity and fatigue in SLE. They reported that disease activity predicted fatigue, but that the effects of disease activity on fatigue were mediated by depression and sleep problems. Disease activity was measured by the SLAM based on activity experienced in the previous month, and fatigue scores were based on the fatigue experienced at the time of form completion. Knippen (1988) concluded that disease activity accounted for 13% of the variance in fatigue when disease activity was assessed by a health care professional. When disease activity was assessed by subjects, however, only 22% of the variance in fatigue was explained.

Hellmann et al. (1995) explored the relationship between dyspnea, a

specific measure of disease activity, and maximum exercise tolerance (MET) measured by $VO_{2max}$ in SLE ($r = .71$, $p < .001$). Since 60% of the people they assessed reported some degree of dyspnea, they concluded that pulmonary abnormalities may be the commonest cause of shortness of breath in SLE. The relationship between dyspnea and fatigue in SLE was not directly explored, but the suggestion was made that pulmonary disease activity may contribute to fatigue in SLE.

In contrast to the theoretical perspective of disease activity causing fatigue, people who have SLE have stated that they feel that increased fatigue predates other SLE symptoms (Hall et al., 1981). Increased disease activity may not only precipitate fatigue; fatigue may also precipitate disease activity.

It would be reprehensible to ignore the voices of the people who have SLE who have stated that fatigue can precipitate an SLE flare. A possible explanation for the mechanism by which fatigue contributes to disease activity in SLE may be derived from research done on stress and the immune system. Stress adversely affects the immune system. When people who have SLE push themselves beyond their capabilities, fatigue results. Fatigue may be a stressor, exerting negative effects on the immune system, thus resulting in increased disease activity.

While fatigue may contribute to disease activity, it is also logical to assume that if one did not have SLE, chronic fatigue would be less likely to be a problem; basic disease activity must, therefore, predate fatigue. Perhaps subclinical disease activity persists in seemingly quiescent periods, thus contributing to fatigue between SLE flares, but available disease activity measures lack the ability to detect subtle disease attributes. The fact that fatigue may persist between lupus flares adds to the difficulty experienced when attempting to determine the nature of the relationship between the two variables. However in the current study, disease activity was assessed for the 3-month period prior to form completion, and fatigue was assessed at the time of form completion, based on the assumption that disease activity contributes to fatigue in SLE.

Clearly, a relationship exists between disease activity and fatigue in SLE, albeit a small to moderate one. What remains obscure is the direction of the relationship. It may be that fatigue is an initiator of increased disease activity in SLE, but it is also possible that fatigue occurs in response to escalating illness.

## Chapter Summary

This chapter is summarized first in terms of limitations of previous SLE research and then in terms of the primary study variables in SLE.

Previous SLE research has been primarily cross-sectional and correlational in design. Sample sizes have been relatively small, thus generalizability of findings has been limited. Inconsistent fatigue, quality of life, and depression measurement techniques has also made interpretation and comparison of results difficult. Little control over relevant physiological factors related to fatigue has been done. There has also been limited exploration of fatigue and PQOL in people who have SLE. Many depression studies have acquired subjects from hospital inpatient lists, thus community dwelling individuals with less severe disease activity are under-represented. Further exploration of these variables for people who have SLE is warranted.

In people who have SLE, disease activity varies in nature, severity, and timing. Depression is a common neuropsychiatric symptom in people who have SLE. Whether depression results from bio-physical aspects of SLE, from the stress of living with a chronic illness, or from a combination of factors is unclear. It may be that chronic fatigue also contributes to depression in people who have SLE. The causes of fatigue in these people are also unclear, but it seems safe to assume SLE itself is an important precipitating factor. Depression may also contribute to fatigue. Chronic fatigue of a multi-dimensional nature is a dominant subjective symptom experienced by most people who have SLE. Fatigue has not been fully explored by health care professionals, however, exploration of the effect that fatigue may have people who have SLE has been initiated. Fatigue has been identified by many people with SLE as the most disabling symptom they experience (Krupp et al., 1990). It effects many domains of life that are considered when quality of life is being assessed, including work and social life.

Moderate correlations between depression and quality of life have been found in other chronic illness populations, but the relationships among disease activity, depression, fatigue, and quality of life in people who have SLE has been limited. This study was guided by a modified version of McKinley et al.'s (1995) model of lupus fatigue. The unique nature of fatigue in people who have SLE and the relationships among disease activity, fatigue, depression, and quality of life were explored.

# CHAPTER 3

# METHODOLOGY

In this chapter the research design, setting, sample, data collection procedures, and instrumentation are presented. Protection of human rights, and proposed data analysis conclude the chapter.

## Research Design

A descriptive correlational design was used to examine the relationships among fatigue, disease activity, depression, and quality of life. According to Burns and Grove (1993), a descriptive correlational design is appropriate when current situational relationships between clearly defined variables are to be examined (p. 302). A descriptive correlational design was an appropriate choice because this study involved examination of current variables.

## Setting

Some interviews and questionnaires were completed in the out-patient clinic of the rheumatologist, or at the April, 1997 meeting of a local branch of the Ontario Lupus Association, where those subjects were recruited. Most interviews were conducted in subject's homes.

## Sample Design

A convenience sample was used in this study. The following section contains information regarding sample size, sample criteria, and subject recruitment.

### Sample Size

According to Cohen (1988), an appropriate sample size may be estimated based on correlation as the primary test statistic (chap. 3). For the current study, effect size was estimated using correlation results from previous studies that explored relationships among fatigue, disease activity, depression, and quality of life.

Although the relationship between fatigue and quality of life has not been extensively explored, Jeffrey (1995) reported a correlation between fatigue and the total scores on the Quality of Life Index (QOLI) as $r = -.43$ ($p < .01$) in people with rheumatoid arthritis (RA). In addition, a correlation of $r = -.47$ ($p < .01$) was

found between the Health and Function subscale of the QOLI and fatigue, and a correlation was found between ratings for the question "How much is fatigue a problem for you?" and the total QOLI scores ($r$ = -.48, $p$ < .01). Jeffrey used the same instruments to assess these relationships in people who had fibromyalgia. Correlation of .40 ($p$ <.01) were found between the total QOLI and fatigue, and between the Health and Function subscale and fatigue.

Jeffrey (1995) also explored the relationship between depression and quality of life. She reported a correlation of $r$ = -.44 ($p$ < .01) between scores on the CES-D and the QOLI total. The strength of the correlation increased to $r$ = -.72 ($p$ < .01) between the Psychological/Spiritual subscale of the QOLI and the CES-D.

The absolute values of Jeffrey's (1995) correlation coefficients between fatigue and quality of life, and between depression and quality of life ranged from .43 to .72. According to Cohen (1988, p. 101) Table 3.4.1, a sample size of 30 allows detection of a moderate effect or correlation between .40 and .50, with an alpha set at .05 and a power of .80. Two of the instruments that Jeffrey used were also used in the current study: the CES-D and QOLI. Identical instruments are more likely to yield similar results, adding further weight to the choice of 30 as the proposed sample size.

## Sample Criteria

The target population included English speaking, literate adults between 18 and 70 years of age who had been diagnosed as having SLE by a rheumatologist. Exclusion criteria included: (a) concurrent rheumatological health problems, such as rheumatoid arthritis; (b) concurrent health problems that contribute to fatigue, such as multiple sclerosis; (c) known pregnancy; (d) in patients; and (e) living greater than a 2-hour drive from London. Subjects from the rheumatologist's practice were assumed to have a confirmed diagnosis of SLE. Subjects from the support group were asked what they had been told by their rheumatologist about their SLE. Only those who reported that the rheumatologist told them that they had SLE were included. Information about inclusion criteria was based entirely on self-report.

## Recruitment

The convenience sample was to be recruited from the practice of a rheumatologist at an urban teaching hospital in Southern Ontario. Potential subjects were told about the study during regularly scheduled office visits and were provided with a Letter of Information (see Appendix J) and Consent form (see Appendix K) at that time. They were given a phone number to contact if they wished to participate. Because few subjects contacted the researcher, two alternate recruitment methods were added sequentially. First, persons with SLE who had participated in other studies conducted by the rheumatologist were called by the researcher and asked if they wished to be involved in this study. Eleven of the 15 people contacted participated. These people were notified of the content of the Letter of Information during the telephone calls. On meeting with the researcher, the Letter of Information was reviewed prior to completing the consent. Second, members of a local chapter of the Ontario Lupus Association were notified of the study because sample size remained small. A description of the study, an invitation to participate in the study at the April support group meeting, and a contact number was published in their March and April (1997) newsletters. Letters of Information were distributed and discussed with all present at the April meeting.

On meeting with subjects at a mutually convenient time and place, the Letter of Information was reviewed, risks and benefits were discussed, and written consents were obtained prior to questionnaire completion.

## Data Collection Procedures

Questionnaires were completed either by subjects or by the researcher, if fatigue or joint pain limited the ability of the subjects to complete the forms themselves. Elements of the interviews that provoked discussion were audio recorded, if permission was granted by subjects. This occurred primarily when participants wished to explain their fatigue experience beyond the scope of the fatigue assessment tools.

Questionnaires took 1 1/2 hours to complete, on average. Demographic information was completed first by all subjects. Because the interview itself

could have contributed to fatigue, the order of completion of the remaining instruments was randomly selected from one of the following sequences to minimize extraneous effects on fatigue of the interview process:

1. Fatigue measures, Centre for Epidemiological Studies-Depression Scale (CESD), Self-Assessment Lupus Activity Measure (SA-SLAM), and Quality of Life Index (QOLI).

2. CES-D, SA-SLAM, QOLI, and fatigue measures.

3. SA-SLAM, QOLI, fatigue measures, and CES-D.

4. QOLI, fatigue measures, CES-D, and SA-SLAM.

Questions and concerns that arose during questionnaire completion were addressed by the researcher. These areas were primarily related to interpretation of items, but also included concerns about being heard and understood by health care professionals in relation to the nature of the fatigue experience.

## Instrumentation

### Demographic Information

Demographic data were collected to describe the subjects and to provide a basis for identifying factors which may have affected the findings. Items were also included to allow comparison of results to other studies and because items have been demonstrated to be related to the primary study variables. For example, age has been related to quality of life. Data collected for this section included age, sex, marital status, education, employment, date of diagnosis, date of onset of symptoms, and past and current medications. The questionnaire form was modified from one used by Jeffrey (1995).

### Fatigue

Given that fatigue is a multi-dimensional concept, current measures of fatigue were found to be inadequate in the assessment of the aspects of fatigue pertinent to this study. For this reason, a number of tools were used to assess fatigue and were administered in the order listed: (a) The Piper Fatigue Scale (in press), (b) 14-Item Fatigue Scale (Wessley & Powell, 1989), (c) Emotional Fatigue Scale, (d) Mishel's Uncertainty in Illness Community Form (Mishel,

1989) (e) a General Fatigue measure, and (f) an Overall Fatigue measure.

Piper Fatigue Scale

The two versions of the Piper Fatigue Scale were designed to measure fatigue from a number of dimensions. Piper's original fatigue tool (Piper, 1989) was used primarily with cancer patients, but has also been used in the assessment of fatigue in women who were pregnant and for women with SLE. Approximately 90% of the subjects involved in the testing of Piper's instrument have been women.

Piper's (in press) current fatigue scale (see Appendix B) was modified from her original fatigue assessment tool. The original tool was designed to measure fatigue from two perspectives: Usual patterns of fatigue were assessed separately from current fatigue. The tool was revised to its current format because the original tool involved considerable time to complete, and because inter-item correlations within subscales were high, (personal communication, 1996). The modified tool measures current fatigue only.

Description and scoring. The first section of Piper's original tool contained 42 items that assessed baseline fatigue; that is, fatigue patterns 6 months prior to diagnosis or treatment. The 40 items in the second part measured current fatigue. Responses in this version of the tool were recorded on visual analogue scales and summed into four scored subscales, which included scales that assessed temporal, intensity/severity, affective, and sensory aspects of fatigue. Open-ended questions solicited information about the evaluation of fatigue, factors that relieved fatigue, and associated symptoms of fatigue. These questions were not included in scoring. The revised version, used in the current study, measures four subscales of current fatigue that were derived through factor analysis: (a) behavioral/severity, (b) affective/meaning, (c) sensory, and (d) cognitive/mood. Anchored items are scored from 0 to 10 in this numerically-scaled version. Subscales are calculated by adding responses and dividing by the number of responses, so scores range from 0 to 10. Higher scores indicate greater fatigue. The total fatigue score is calculated similarly; the 22 items are summed then divided by 22. As a result, total scores also range from 0 to 10.

Reliability. According to Jacobson (1988), Cronbach alpha coefficients greater than .80 indicate acceptable internal consistency for established measures and greater than .70 indicate internal consistency for new measures. Internal consistency for the subscales of the original tool were generally acceptable, with Cronbach alpha ranging from .69 to .95. The current tool was based on items from the original tool, but no published psychometrics are available for the new form at this time. However, Piper did report improved internal consistency in the current tool (personal communication): alpha was greater than .89 for all subscales of the new version, and was .97 for the total tool.

Validity. In unpublished data, Piper stated that a literature review and a panel of 11 fatigue experts established face and content validity for the original scale (personal communication, 1996). Scores from the original tool were also moderately correlated with scores on the fatigue subscale of the Profile of Moods (POMS), the Fatigue Symptom Checklist and one other single-item measure of fatigue, thus establishing concurrent validity.

14-Item Fatigue Scale

The 14-item Fatigue Scale efficiently assesses two specific aspects of fatigue: physical symptoms and mental symptoms (see Appendix C). The 14-item Fatigue Scale was originally developed to determine differences in fatigue in people with post-viral fatigue ($n$ = 47), peripheral neuromuscular disorders ($n$ = 33), and affective disorders ($n$ = 26). Initial factor analysis yielded the two factors, with 8 items loading on the physical factor, and 5 items loading on the mental factor. One item (eye strain) was deleted from the tool, another item was added, and a third item was reworded as two separate items. Subsequent testing of the revised tool was conducted with new patients of a general practice centre ($n$ = 274) and consecutive attenders ($n$ = 100) at the same centre. (Chalder et al., 1993)

Description and scoring. Four-point, Likert-type scales grounded by better than usual (1) to much worse than usual (4) are used to rate the 14 items. Total fatigue scores are calculated by adding responses, so range from 14 to

56, with higher scores indicating greater fatigue. Similarly, scores can be obtained for the two subscales.

Reliability. Cronbach alpha ranged from .75 to .87 for the original tool and its sub-scales (Wessley & Powell, 1989). In subsequent testing, Chalder et al. (1993) reported alpha scores that ranged from .88 to.90 for the entire instrument, .85 for the physical sub-scale, and .82 for the mental subscale.

Validity. Items on the 14-item Fatigue Scale were developed by experts in fatigue, thus establishing face validity. No further validity testing has been reported.

Emotional Fatigue Scale

The Emotional Fatigue Scale (see Appendix D) is a 24-item questionnaire designed for this study to measure emotional aspects of fatigue. Although the cognitive/mood subscale of Piper's Fatigue Scale (in press) assesses the degree of impatience, tension, and depression experienced with fatigue, each of which are emotional aspects of fatigue, Piper's scale fails to assess many other manifestations of emotional fatigue. A tool was developed that would assess a wider range of emotional fatigue aspects because eliciting a broader understanding of the nature of fatigue was a goal in doing this study. In addition, separate scores for cognitive and emotional components of fatigue were not attainable using Piper's tool.

Development. This tool is in the initial stages of development. Because one goal of the study was to explore the nature of fatigue in SLE, and some evidence exists that leads one to conclude that fatigue varies over time in this population, the instrument was developed to assess emotional fatigue in two parts. The goal of the first section was to obtain a general sense of the possible range of emotional fatigue in people with SLE. The goal of the second section was to measure current emotional fatigue. The two subscales are, therefore, referred to as "general" and "current" emotional fatigue.

Description and scoring. The general subscale of the Emotional Fatigue consists of 12 items that rate emotional aspects of fatigue from "rarely or none of the time" (1) to "most of the time" (4), respectively. The remaining 12 items

contribute to the current emotional fatigue score. Possible responses to these items range from "strongly agree" (1) to "strongly disagree" (4). Scores are summed after reversing responses for items 7, 10, 11, and 12 in the general subscale, and for all items except items 10, 11, and 12 in the current emotional fatigue subscale. Final subscale scores may range from 12 to 48 for each subscale, with higher scores indicating greater emotional fatigue.

Reliability. No preliminary study was conducted to test this new questionnaire, however, internal consistency of the Emotional Fatigue Score was supported by Cronbach Alpha results found in the current study: .89 and .94 for the current subscales.

Validity. Content validity of the Emotional Fatigue Scale was established through a number of sources. First, an extensive literature review on the concept of fatigue yielded consistent information about the multi-dimensional, all-encompassing physical, emotional, and cognitive aspects of the fatigue experience (Tack, 1990b; Cameron, 1973; Graham, 1978, p. 22; Hart et al., 1990; Lewis & Wessley, 1992; Yoshitake, 1971): Emotional fatigue is a legitimate dimension of fatigue. Secondly, the emotional fatigue items were generated through personal experience with chronic fatigue, and discussion of the emotional aspects of fatigue with people who have SLE, RA, and fibromyalgia. Thirdly, the items were reviewed by two experts in rheumatic disease. Finally, the items were reviewed by a sample of people from the general population.

Burns and Grove (1993) recommended that a minimum of three experts be involved in the development and evaluation of new tools (p. 344). This was not done for the Emotional Fatigue Scale. Instead, the chief source of criticism of the tool came from people who have experienced emotional fatigue related to different forms of arthritis, including people who had SLE, RA, or fibromyalgia. Some specific items more accurately described their experience than others. These items varied from person to person. For example, some people stated that they tended to describe their emotional fatigue primarily as irritability. Others felt that tearfulness described their emotional fatigue experience most

accurately. It may be that different personalities experience emotional fatigue in different ways, therefore, a variety of items were retained to attempt to capture the full spectrum of the emotional fatigue experience in people who have SLE.

Mishel Uncertainty in Illness-Community Scale (1990)

Unpredictability of fatigue was measured with the Mishel (1990) Uncertainty in Illness-Community Scale (MUIS-C) (see Appendix E). This community version evolved from Mishel's original scale which focused on assessing uncertainty related to the illness experienced during hospitalization (Mishel, 1989). The community form assesses uncertainty related to illness when people are not hospitalized.

Development. After exploring the theoretical meaning of uncertainty and factors which precipitate it, Mishel elicited 62 statements from 45 inpatients about events that they viewed as uncertain. A 54-item scale was developed from these statements. This scale was further refined using a series of factor analyses of data obtained from a variety of patient populations, resulting in the current 32-item, 4-factor hospital version, and the 23-item, 1-factor community version (MUIS-C).

As directed by Mishel (1990) to customize the MUIS-C for the current study population, items were reworded to facilitate assessment of uncertainty related to fatigue, where appropriate. For example, item #2 "I have a lot of questions without answers" was changed to "I have a lot of questions about fatigue without answers". Respondents were encouraged to complete the questionnaire from the perspective of how it related to their fatigue. Items 1, 10, 14-16, 18, 19, 21, and 23 were not suitable for rewording. These questions were marked with "L", and participants were encouraged to respond to those items in terms of their SLE in general, rather than in terms of their fatigue.

Description and scoring. Items on the MUIS-C are answered on 5-point Likert scales, from strongly disagree (1) to strongly agree (5). Total scores are calculated by adding responses, after reversing scores for four items, so possible scores vary from 23 to 115, with greater uncertainty represented by higher scores. The fatigue uncertainty score is calculated in the same manner

using items 2-9, 11-13, 17, 20, and 22. Possible scores for this subscale range from 14 to 70.

Reliability. Mishel (1990) has reported alpha reliability coefficients from .75 to .92 for the MUIS-C. These numbers were derived from studies of a variety of illness populations in community settings, including samples of persons with RA and SLE. Alpha coefficients for both the RA and SLE populations were .86. A Cronbach alpha of .86 was obtained for the fatigue uncertainty subscale (items 2-9, 11-13, 17, 20, and 22) used in the current study.

Validity. Mishel (1981) established face and content validity by theoretical exploration of the concept and by using input from hospitalized people who experienced uncertainty in the formulation of scale items. Patterson (as cited in Mishel) found high correlations between the MUIS and the Comprehension of Illness Questionnaire in people who had cancer and were beginning radiotherapy, thus establishing convergent validity.

General Fatigue

To obtain a broad understanding of the individual fatigue experience, the general fatigue section was included. It assesses fatigue related issues that are not measured by the other tools. These included items related to variation in fatigue severity and sleep habits (see Appendix F).

Development. The general fatigue instrument was developed for this study. Variability of fatigue was deemed important to assess because people who have SLE have stated that they experience wide variations in fatigue (personal communication). Sleep related questions were included because correlations have been found between sleep and fatigue (McKinley, et al., 1995; Jeffrey, 1995).

Description and scoring. The general fatigue section contains a variety of response forms. Two items were included to obtain global measures of the variability in fatigue experienced by people with SLE. These items were formatted similar to items in the Piper Fatigue Scale to maintain response familiarity for respondents: Ten-point numerical rating scales are anchored at one end by "no fatigue" (0), and at the other end by "unable to move" (10).

Participants respond to the statements "When my fatigue is at its worst I have/am:" and "When my fatigue is at its best I have/am:". Potential scores for these two items range from 0 to 10. Sleep and rest items provide data about sleep quantity. Some are answered in units of time, and some are answered by yes, no, or sometimes responses.

Reliability. Reliability of numerical rating scales is influenced by the number of steps in the scale (Nunnally, 1978). Generally, providing numbers instead of having respondents write in numbers decreases response errors and facilitates data analysis, thus a pre-numbered scale was used. Arguments have been made for using an odd versus an even number of items in a scale. Nunnally has stated that probably neither is more reliable than the other, however, the total number of items in a scale does affect reliability: A scale containing at least 10 steps is generally more reliable than one containing less than 10. Reliability increases slowly between 11 and 20-step scales, peaking at 20 steps. The 11-step numerical rating scale format used in this study, therefore, contributes to reliability.

Validity. Face validity of the general fatigue questionnaire was established through consultation with colleagues, fatigue experts, and people who experience chronic fatigue. Psychometric testing of this instrument has not occurred.

Overall Fatigue

The Overall fatigue measure was developed to obtain a single fatigue score for use in path analysis which included all the fatigue subscales of interest. The Piper total score, the Current Emotional Fatigue score, and the fatigue subscale of the MUIS-C were used to reach the Overall measure. First, each score was converted to a score out of 10. Next, the converted Piper, Current Emotional Fatigue, and the MUIS-C fatigue scores were summed. Finally, the summed scores were divided by three to retain the 0 to 10 range of scores. Higher scores indicate greater fatigue.

Reliability. Because this tool was developed for this study, psychometric testing has been limited. However, internal consistency for the measure was

found to be .96 in the current study, indicating good internal consistency.

Validity. Content validity for the instrument was established through literature review in regards to the aspects of fatigue important to people who have SLE (see p 17).

## Perceived Quality of Life

Ferrans and Powers (1985) defined quality of life as the individuals' perception of well-being that resulted from the interaction of degree of satisfaction of life domains with the level of importance attached to those life areas. Quality of life was measured with the Quality of Life Index-Arthritis Version (QOLI) developed by Ferrans & Powers (1988) (see Appendix A). The Arthritis Version differs from the original version in that physical functioning in the original tool is divided into two items to assess upper and lower body functioning.

Development. The initial step in the development of the QOLI involved an extensive literature review and interviews (Ferrans & Powers, 1985). Relevant domains of quality of life and items by which they might be assessed were developed based on this information. The domains included: "health care, physical care and functioning, marriage, family, friends, stress, standard of living, occupation, education, leisure, future retirement, peace of mind, personal faith, life goals, personal appearance, self-acceptance, general happiness, and general satisfaction" (Ferrans & Powers, p. 17). Factor analysis of the tool yielded the following subscales: (a) health and functioning, (b) socioeconomic, (c) psychological/spiritual, and (d) family.

Description and scoring. The QOLI consists of 70 items divided into two major sections. Each item is in a 6-point Likert-type format. Response choices range from "very dissatisfied" (1) to "very satisfied" (6) in the satisfaction section, and from "very unimportant" (1) to "very important" (6) in the importance section. The first major section of the scale measures satisfaction related to each of 35 items and the second section measures the importance attached to each of the same 35 items. Ratings of importance are used to weight satisfaction responses. Thus, items that have both high satisfaction and high

importance obtain the highest PQOL scores, while items that indicate great dissatisfaction and high importance are given the lowest scores. Low importance items get middle range scores. Total and subscale scores are produced so all range from 0 to 30. Higher scores indicate a better perception of quality of life (Ferrans & Powers, 1985).

Reliability. Ferrans and Powers (1985) provided initial support for test-retest reliability of the QOLI using a total of 125 people from two sub-groups. A time lag of a minimum of 2 weeks from the initial test was used for the graduate students sub-group ($r$ = .87), and 1 month was used for patients receiving hemodialysis ($r$ = .81). These strong correlations support stability of the instrument. Internal consistency was also tested at this time using Cronbach alpha. Values of .93 (students) and .90 (patients) were obtained, thus supporting internal consistency of the instrument. Jeffrey (1989) tested the reliability of the QOLI in people who had arthritis. Cronbach alphas were greater than .80.

Validity. Content validity for the instrument was established through literature review and patient input. Validity and reliability testing was done initially with graduate students ($n$ = 88), then with hemodialysis patients ($n$ = 37). Convergent validity was established by comparing the QOLI with a single item question about overall level of life satisfaction. The correlation for the students was .75, and was .65 for the patients. Jacobson (1988) has stated that correlations between .60 and .70 are sufficient to predict validity of instruments, therefore the two instruments measured similar concepts. Jeffrey (1989) found a correlation of .55 ($p < .05$) between a single item global measure of quality of life and the QOLI.

## Depression

Depression was assessed by the Centre for Epidemiological Studies Depression Scale (CES-D) developed by Radloff (1977) (see Appendix G). The CES-D was designed to facilitate comparison of depressive symptoms to other variables within a study population. As such, it is not a diagnostic tool.

Description and scoring. Twenty items are rated on 4-point Likert-type scales to measure the presence of depressive symptoms during the week prior

to questionnaire completion. Response choices range from "rarely or none of the time - 0 to 1 day" (0) to "most of the time - 5 to 7 days" (3). Four items are reverse scored. Responses are added to obtain a single score with possible range from 0 to 60, with high scores indicating more depressive symptoms. An average group score greater than 16 indicates either a population at risk for depression, or a need for intervention with that population (Radloff, 1977). The developer has also suggested using caution in interpreting scores of individual.

Reliability. Internal consistency of the tool was originally assessed by Radloff (1977) using coefficient alpha and Spearman-Brown split-halves method in two groups, including a sample from the general population (Cronbach alpha = .85) and a sample of depressed psychiatric patients (Cronbach alpha = .90). Jeffrey (1995) rreported Cronbach alphas of .89 and .92 in people who had RA or fibromyalgia, respectively.

Validity. Convergent validity was established by comparing scores obtained from the CES-D to depression scores either assigned by interviewers ($r$ = .49 to .53), or obtained from other tools such as the Bradburn Negative Affect ($r$ = .55 to .63) or the Lubin scale ($r$ = .37 to .70). Blalock, DeVillis, Brown, and Wallston (1989) compared scores on the CES-D to the depression subscale score of the Arthritis Impact Measure ($r$ = .81).

### Self-Assessment of Disease Activity

The range of disease activity in SLE is broad, both in terms of its nature, and in terms of its severity. Liang et al's (in press) Self-Administered Systemic Lupus Activity Measure (SA-SLAM) was used to assess both the nature and the severity of SLE disease activity (see Appendix H). The SA-SLAM was selected over the original physician completed SLAM to be consistent with assessing subject's perceptions, as was done for all other measures.

Development. The SA-SLAM was revised from Liang et al.'s (1989) Systemic Lupus Activity Measure (SLAM). There are two major differences between the SLAM and the SA-SLAM. First, wording has been modified for the self-administered version, and second, the latter does not contain parameters for assessing blood work. Both tools assess constitutional symptoms such as

weight loss, fatigue, and fever. They also assess the following broad categories: (a) integument, (b) eye, (c) reticuloendothial status, (d) pulmonary function, (e) cardiovascular function, (f) gastrointestinal symptoms, and (g) neuromotor function.

Description and scoring. The SA-SLAM consists of 32 items divided into three major sections: (a) a general section composed of seven questions that require a "no" (0) or "yes" (1) response, with room for some elaboration; (b) a specific symptoms section consisting of 24 items that require the respondent to choose among "none" (0) to "severe" (3); and (c) a one item, global disease activity measure, assessed by a 10-point scale anchored by "no activity" on the left and "the most activity" on the right. Scores are calculated by summing all item responses with total scores ranging from -2 to 93, with higher scores indicating greater disease activity. A score of -2 was possible if a person was not experiencing any symptoms and responded to item 6, "...has your lupus been...", by choosing "much better".

Reliability. Liang et al.(1989) compared the reliability and validity of the SLAM to five other SLE assessment instruments. Twenty-five patients with SLE were assessed by a physician on two occasions separated by a 3 to 5 week interval. The six assessment tools, in addition to a patient completed visual analogue scale that rated disease activity, were completed at each visit. Inter-rater reliability for the SLAM was .86. The SA-SLAM has been tested by mail and by telephone. Psychometric evaluation of the tool by its developers is in progress, but not yet available. Acceptable internal consistency was found for the current study with Chronbach alpha of .89.

Validity. The SLAM had an average correlation of .90 with the other tools, thus confirming convergent validity (Liang et al., 1989). Of the 6 instruments compared, those that were more detailed were more sensitive to change in patient disease status. The SLAM was the second most sensitive tool assessed, with a treatment sensitivity index (TSI) of 266. Instruments ranged from a low TSI of 165, to a high of 375. Validity information is not yet available for the SA-SLAM.

## Data Analysis Plan

Data were entered into a computer and analyzed by the Statistical Package for the Social Sciences (SPSS/PC+). Descriptive and inferential statistical methods were used. First, demographic data were summarized using descriptive statistics to obtain a clear picture of the sample. Descriptive statistics were also used as the initial step in evaluating the data obtained from the fatigue, disease activity, depression, and quality of life assessment tools. Means, standard deviations, and ranges for each tool were reported in table format, as was reliability and normalcy of distribution. Following this initial summary of the data, each research question was analyzed.

### Research Question One

Pearson Product Moment Correlation coefficients were determined to ascertain the relationships among the total and sub-scale scores of all measures of fatigue, depression, disease activity, and quality of life that were normally distributed. Kendall's tau correlations were determined for questionnaires or subscales that were not normally distributed.

### Research Question 2

Correlation coefficients were calculated to ascertain the relationships among interval level demographic variables and the scores of all measures of fatigue, depression, disease activity, and quality of life. Independent t-tests and ANOVA were used to compare differences in the means for the primary study variables for categories of demographic variables.

### Research Question Three

Question three was answered using path analysis to determine whether fatigue and depression mediate the relationship between disease activity and PQOL. Path analysis was used to explore the direct and indirect causal relationships between variables by conducting multiple regression analyses (Pedhazur, 1982, chap. 15; Walsh, 1990, chap. 15).

Walsh proposed a series of steps for path analysis. The initial step was to develop a conceptual model that depicts the probable ordering of variables based on their theoretical timing. For the current study, the initial assumption

was that disease activity precedes fatigue and depression, which in turn influences PQOL. Fatigue and depression are depicted as mediators between disease activity and PQOL. Disease activity, therefore, was measured for the previous 3 months, depression was measured for the previous week, and PQOL was measured "now". Fatigue was assessed in a variety of ways, some of which methods assessed fatigue "now", while others assessed the nature of fatigue in general terms over a period of time. Measures that assessed fatigue now, specifically Overall Fatigue, were used in path analysis. The other variables used in path analysis were total scores on the CESD, the SA-SLAM, and the QOLI.

Walsh's (1990) next step is to determine effect coefficients for the direct and indirect paths between variables. Dependent variables were regressed on the independent variables to determine standard beta weights for the relationships depicted in Figure 3, as depicted by the small letters on the arrows between variables. Because the relationship between fatigue and depression was viewed as reciprocal, two indirect paths between disease activity and quality of life were possible; disease activity → fatigue → quality of life and disease activity → depression → quality of life. These paths were included in calculations of the total indirect effect.

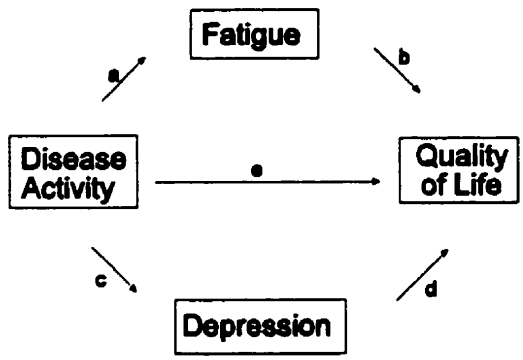
The beta weight obtained for e (see Figure 3) was the direct effect of disease activity on quality of life. The indirect effect of disease activity on quality of life was calculated by summing the product of the effect of c and d, with the product of a and b. Beta values > .05 for indirect effects are retained in the model (Pedhazur, 1982, p. 617). Additional support for mediation can be determined if the effect of the independent variable is significantly less when mediator variables are added to the equation (Walsh, 1990).

Research Question 4

The nature of fatigue in SLE was tentatively determined by identifying common responses to items on the fatigue questionnaires and by content analysis of: (a) answers obtained to open ended questions contained in the Piper Fatigue Scale, (b) discussion of fatigue that arose during completion of the

Mishel Uncertainty in Illness Community Form, and (c) discussion in regards to the difficulty people experienced in completing the 14-item Fatigue Scale. Variability of fatigue was assessed by comparing the differences in responses between the first two general fatigue items (paired t-test).

Figure 3: Model used in Path Analysis of the Direct and Indirect Effects of Disease Activity on Quality of Life




Note: Small letters on arrows indicate effect coefficients to be calculated.

## Protection of Human Rights

Prior to starting this study, approval was received from The University of Western Ontario Review Board for Health Sciences Research Involving Human Subjects, and from the hospital site used to recruit some subjects (see Appendix L).

The Letter of Information (see Appendix J) clearly stated the purpose of the study, and the time and type of involvement requested from subjects. They were informed that they could: (a) request a break, (b) end participation at any time, (c) refuse to answer any question, or (d) refuse to have any part of their interview audio recorded, if they wished. Subjects were also told that participation was voluntary and had no effect on the health care they received.

There were no known risks to participating in the study. Discomfort included two possibilities: The length of the questionnaire package might

contribute to fatigue in participants, and audio recording part of the interviews might raise concerns of confidentiality or general discomfort. The researcher was prepared to discuss and reach a mutually agreeable solution to any concerns that might arise from the questionnaires or interview process. There were no direct benefits anticipated for participants.

Consent was obtained in writing from all participants. All data collection forms and computerized data were identified by an assigned number to maintain confidentiality and anonymity. Data files and interview tape recordings were kept in a locked drawer in the researcher's home. Data were reported as group data. Identifiable information was shredded upon completion of analysis.

# CHAPTER 4

# RESULTS

The results of data analysis are presented in this chapter. Personal characteristics of the sample are described, followed by a summary of the descriptive statistics for the primary study variables. Finally, the results of the descriptive and inferential statistical analyses are summarized in relation to the research questions.

## Personal Characteristics

Although sample size was determined to be 30, slow accrual meant that after 9 months, only 25 subjects had been interviewed. The final sample, therefore, consisted of 25 people who have SLE, including 24 women (96%) and one man (4%). Most of the subjects were married or living in common-law relationships (84%, $n$ = 21), 8% were single ($n$ = 2), 4% were widowed ($n$ = 1), and 4% were separated ($n$ = 1). Age of participants ranged from 16 to 71 years, with a mean age of 39.9 years ($SD$ = 11.8). One minor was included because she was adamant about participating and to maximize the sample size. Parents of the minor were present during the interview process. Forty-four percent of the sample completed post-secondary education ($n$ = 11 ). An additional 44% ($n$ = 11 ) completed, but did not go beyond, high school. Most of the subjects were not working (80%, $n$ = 20). Of the five subjects who were working, two were working full time and three were working part time. Sixty-five percent of those not working were receiving disability income ($n$ = 13), 25% were unemployed ($n$ = 5), one was retired and one did not specify.

Mean time since the onset of symptoms was 16.6 years ($SD$ = 10.6), with a range of 1.5 to 40 years. In contrast, mean time since obtaining a definitive diagnosis was 5.6 years ($SD$ = 5.6), with a range of 0.1 to 23 years. There was a significant difference between the mean length of time since onset of symptoms and diagnosis (paired t-test).

## Summary of Descriptive Statistics for Major Study Variables

The major study variables included PQOL, fatigue, depression, and disease activity. Internal consistency was assessed for each questionnaire (see

Appendix M). Data were evaluated to determine normal distribution by calculating Pearson Skewness Coefficients (Munro & Page, 1993). The means, standard deviations, and ranges for scores were calculated (see Table 1) for: (a) the Quality of Life Index (QOLI) and its subscales; (b) the fatigue measures, including the Overall fatigue measure, the Piper Fatigue Scale and its subscales, the emotional fatigue measure, the fatigue uncertainty measure, and the cognitive fatigue measures; (c) the Centre for Epidemiology Scale-Depression (CESD); and (d) the Self-Assessment-Systemic Lupus Activity Measure (SA-SLAM). Parametric statistical tests (eg. Pearson Product Moment Correlation Coefficients) were used to analyze normally distributed data, and non-parametric tests (eg. Kendall's tau), were used to analyze data that were not normally distributed. Correlations are described in terms of being weak (< .35), moderate (.35 to .60), moderately strong (.60 to .70), or strong (> .70) (see Appendix N).

## Quality of Life

According to Frank-Stromberg (1988), a Cronbach alpha greater than .80 indicates internal consistency of an established instrument. Total and subscales of the Quality of Life Index (QOLI) had satisfactory alphas (.80 to .90), with the exception of the family subscale (see Appendix M). In addition, since data for the family subscale were not normally distributed, no further analysis was conducted for this subscale. Since other QOLI data were normally distributed, the means, standard deviations, and ranges for the QOLI total and its health, socioeconomic and psychological/spiritual subscales are reported in Table 1. Means for the total QOLI domains fell into the middle third of the possible range of scores.

## Fatigue

Internal consistency, normalcy of distribution, and the means, standard deviations, and ranges were calculated for the major fatigue instruments and their subscales. The 14-item fatigue scale was dropped from the study because of the difficulty people experienced completing it. No statistics, therefore, are included for the 14-item scale. Because the 14-item fatigue scale was not

usable, physical and cognitive measures were obtained from the Piper Fatigue Scale.

Overall Fatigue Score

The overall fatigue measure was developed from the Piper Fatigue Scale, the fatigue-related items of the Mishel Uncertainty in Illness Scale-Community, and the Emotional Fatigue Scale. Internal consistency for each of the components of the tool and their subscales were all acceptable, with Cronbach alpha's ranging from .86 to .97 (see Appendix M). The internal consistency of the overall fatigue scale was also assessed and was found to be acceptable (Cronbach alpha = .96). Data for the overall fatigue scale were normally distributed. Means for the Piper total score (M = 4.9) and for the overall fatigue score (M = 5.3) were very close to the middle of the possible range (see Table 1). Individual measures, however, ranged widely, with standard deviations over 1.7. Some people reported minimal overall fatigue (1.9 out of a possible 10), while others reported fatigue in the upper quarter of the possible range.

Physical Fatigue

Physical fatigue scores were obtained from a slightly modified version of the Sensory Subscale of the Piper Fatigue Scale. Current study data were subjected to confirmatory factor analysis. Two items factored into the Sensory scale. One item ("To what degree does the fatigue you are experiencing interfering with your ability to engage in sexual activity?") was deleted because subjects tended to leave it blank and because it did not conceptually fit. The other item was retained because it more closely fit the concept of physical fatigue ("To what degree would you describe the fatigue you are now experiencing as being pleasant/unpleasant?"). Internal consistency was found acceptable (Cronbach alpha = .93). Physical fatigue scores were normally distributed. The physical fatigue mean was in the middle of the possible range (see Table 1). Individual scores almost spanned the possible range.

Cognitive Fatigue

Because the 14-item Fatigue Scale was not usable, an alternate method of assessing cognitive fatigue was developed. Cognitive scores were derived from the Cognitive/Mood subscale of Piper's Fatigue Scale. Items 21, 22, and 23 were retained for the cognitive fatigue score because they fit conceptually

and because they held together during confirmatory factor analysis. Although the small number of subjects affects the accuracy of factor analysis, the analysis was done to provide support for using these three items as the Cognitive Subscale. Internal consistency was found acceptable (Cronbach alpha = .95). Cognitive fatigue scores were not normally distributed, therefore nonparametric statistical tests (eg. Kendall's tau) were used for all inferential statistical analyses. The mean for Cognitive Fatigue fell slightly below, but close to the middle of the possible range. Individual scores almost covered the range.

Emotional Fatigue

Cronbach alpha for the Emotional Fatigue Scale were acceptable for the General Emotional Fatigue and Current Emotional Fatigue subscales (see Appendix M). Scores for Current Emotional Fatigue were normally distributed, but scores for General Emotional Fatigue were not. Similar to the overall fatigue scale, means fell in the middle third of the possible range, but individual responses varied widely from a minimum of 12 to a maximum of 43 (see Table 1).

Fatigue Uncertainty

Cronbach alpha for the Fatigue Uncertainty Scale was acceptable (see Appendix M). Scores were also normally distributed. The mean for this fatigue measure was close to the middle of the possible range of scores (see Table 1).

Depression

Internal consistency was acceptable for this scale (Cronbach alpha = .89) but the scores were not normally distributed. The mean was mid-range (see Table 1).

Self-Assessment of Disease Activity

Two scores were derived from the SA-SLAM: a Total Disease Activity Score and a one-item Global Disease Activity Score. The SA-SLAM was assessed for internal consistency and was found to be acceptable (see Appendix M) and the scores were normally distributed. The Global Disease Activity Scores were not normally distributed. The mean for the Total Disease Activity Scale fell in the upper end of the lower third and the mean for the Global Disease Activity was mid-range (see Table 1).

Table 1: Mean, Standard Deviation, and Range of Scores for the Primary Study Variables: Quality of Life, Fatigue, Depression, and Disease Activity

| Variables | M | SD | Range of Scores | Possible Range |
|---|---|---|---|---|
| Quality of Life Index | | | | |
| QOLI Total | 19.0 | 5.2 | 8.8 - 26.2 | 0 - 30 |
| Subscales | | | | |
| Health/Functioning | 17.0 | 5.5 | 8.4 - 24.6 | 0 - 30 |
| Socioeconomic | 20.0 | 6.2 | 6.8 - 29.4 | 0 - 30 |
| Psychological | 19.2 | 6.0 | 6.8 - 27.5 | 0 - 30 |
| Fatigue Instruments | | | | |
| Overall | 5.3 | 1.7 | 1.9 - 8.0 | 0 - 10 |
| Piper Total | 4.9 | 2.4 | .18 - 9.1 | 0 - 10 |
| Piper Subscales | | | | |
| Behavioral/severity | 5.1 | 2.8 | 0 - 9.5 | 0 - 10 |
| Affective meaning | 5.2 | 2.7 | 0 - 9.0 | 0 - 10 |
| Sensory (Physical) | 5.2 | 2.7 | 0 - 9.4 | 0 - 10 |
| Cognitive/mood | 4.1 | 2.4 | .33-8.3 | 0 - 10 |
| Cognitive | 4.0 | 2.8 | 0 - 9 | 0 - 10 |
| Emotional Fatigue | | | | |
| General | 32.9 | 8.3 | 13 - 17 | 12 - 48 |
| Now | 25.6 | 8.4 | 12 - 43 | 12 - 48 |
| Fatigue Uncertainty | 44.0 | 10.2 | 17.5 - 56 | 14 - 70 |
| Fatigue at Best | 2.1 | 1.9 | 0 - 7 | 0 - 10 |
| Fatigue at Worst | 7.0 | 2.3 | 1 - 10 | 0 - 10 |
| Depression | 21.1 | 10.7 | 4 - 42 | 0 - 60 |
| Disease Activity Total | 28.5 | 13.0 | 5 - 55 | -2 - 93 |
| Global score | 5.4 | 2.8 | 0 - 10 | 0 - 10 |

## Research Question One

Research question one addressed the relationships among the major study variables of perceived quality of life (PQOL), fatigue, depression, and disease activity. The relationships among PQOL and fatigue, PQOL and

depression, PQOL and disease activity, fatigue and depression, fatigue and disease activity, and depression and disease activity are described.

## Quality of Life and Fatigue

Negative correlations were found among all quality of life and fatigue measures (see Table 2). Of the 20 correlations calculated, only three were not significant: (a) between the Total QOLI score and Emotional Fatigue ($r$ = -.41, $p$ = .053), (b) between the QOLI Health/Functioning Subscale and Emotional Fatigue ($r$ = -.32, $p$ = .14), and (c) between the QOLI Psychological/Spiritual Subscale and Fatigue Uncertainty ($r$ = -.22, $p$ = .053). In general, people who reported more fatigue reported a decreased PQOL.

Table 2: Correlations between Quality of Life and Fatigue

| QOLI[a] | Overall Fatigue | Emotional Fatigue | Fatigue Uncertainty | Cognitive Fatigue[b] | Physical Fatigue |
|---|---|---|---|---|---|
| Total[c] | -.77*** | -.41 | -.46* | -.50** | -.58** |
| Health[d] | -.68*** | -.32 | -.46* | -.46** | -.53** |
| SES[e] | -.71*** | -.45* | -.47* | -.51** | -.54** |
| Psych[f] | -.65** | -.42* | -.22 | -.52*** | -.59** |

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

[a] = Quality of Life Index

[b] = Kendall's tau used to calculate correlations

[c] = Total Quality of Life Score

[d] = Health/Functioning Subscale

[e] = Socioeconomic Subscale

[f] = Psychological/Spiritual Subscale

## Quality of Life and Depression

Negative correlations were found among all quality of life measures and depression (see Table 3). People who reported less depressive symptoms reported a higher PQOL.

Table 3: Correlations between Quality of Life and Depression

| Quality of Life | Depression[a] |
|---|---|
| Total | -.37* |
| Subscales | |
| Health/Functioning | -.35* |
| Socioeconomic | -.40** |
| Psychological/Spiritual | -.30* |

*p<.05 **p<.01

[a] Kendall's tau used to calculate correlations

## Quality of Life and Disease Activity

Negative correlations were significant for seven of the eight possible correlations among PQOL and disease activity measures (Table 4). People who reported less disease activity tended to report higher PQOL.

Table 4: Correlations between Quality of Life and Disease Activity

| Quality of Life | Total Disease Activity | Global Disease Activity[a] |
|---|---|---|
| Total | -.61** | -.39* |
| Subscales | | |
| Health/Functioning | -.63** | -.50** |
| Socioeconomic | -.58** | -.32* |
| Psychological | -.46* | -.25 |

*p<.05 **p<.01

[a] Kendall's tau used to calculate correlations

## Fatigue and Depression

Positive correlations were found among all fatigue and depression measures (Table 5). In general, people who reported more fatigue also tended to report more depression.

Table 5: Correlations between Fatigue and Depression

| Fatigue | Depression[a] |
|---|---|
| Overall | .48** |
| Subscales | |
| Emotional | .42** |
| Uncertainty | .34* |
| Cognitive[a] | .29 |
| Physical | .48** |

*p<.05 **p<.01

[a] Kendall's tau used to calculate correlations

## Fatigue and Disease Activity

Correlations among fatigue and disease activity measures varied (see Table 6). There were no significant correlations found between emotional fatigue and disease activity, while a strong, positive correlation was found between fatigue uncertainty and the total disease activity measure. With the exception of emotional fatigue, people who reported greater fatigue also tended to report greater disease activity.

Table 6: Correlations between Fatigue and Disease Activity

| Fatigue | Total Disease Activity | Global Disease Activity[a] |
|---|---|---|
| Overall | .45** | .43** |
| Subscales | | |
| Emotional | .33 | .24 |
| Uncertainty | .83*** | .32* |
| Cognitive[a] | .30* | .33* |
| Physical | .53** | .32** |

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

[a] Kendall's tau used to calculate correlations

### Depression and Disease Activity

Significant, moderate, positive correlations were found between CESD scores and Total Disease Activity ($r = .46$, $p < .01$) and CESD and Global Disease Activity ($r = .48$, $p < .01$). People who reported more depressive symptoms reported greater disease activity.

### Summary

People who reported a better quality of life also reported less fatigue, less depression and less disease activity. Subjects with greater fatigue reported more depressive symptoms and greater disease activity. Finally, those who reported more depressive symptoms reported greater disease activity.

## Research Question Two

Research question two addressed the relationships among demographic variables and the primary study variables (PQOL, fatigue, depression, and disease activity). The demographic variables assessed were years of formal education, age, time since onset of symptoms, time since diagnosis, work status, and marital status.

### Education and Primary Study Variables

Correlations between education and each primary study variable are summarized in Table 7. There were no statistically significant correlations between years of formal education and each quality of life measure, but a trend ($p < .10$) was found between all but the Psychological/Spiritual subscale. However, significant negative correlations were found between education and the overall, the emotional, and the fatigue uncertainty measures, depression, total disease activity, and the global disease activity measure. The correlation between education and cognitive fatigue, and education and physical fatigue were not statistically significant, but a trend ($p < .10$) was found. People who reported a higher education level experienced less fatigue, less depression, and less disease activity.

### Age and Time Since Onset of Symptoms and Primary Study Variables

There was no significant correlation between age and the primary study variables (Table 7). One weak but significant relationship was found between

time since onset of symptoms and the primary study variables. Cognitive fatigue correlated negatively with onset of symptoms ($r$ = -.31, $p$ < .05).

Time Since Diagnosis and Primary Study Variables

One statistically significant, negative correlation was found among the primary study variables and time since diagnosis, although it was weak (Table 7). The longer the elapsed time since a diagnosis was reached, the less cognitive fatigue reported.

Table 7: Correlations among Primary Study Variables and Education, Age, Time Since Onset of Symptoms, and Time Since Diagnosis

| Primary Study Variables | Education | Age | Time Since Symptoms | Time Since Diagnosis |
|---|---|---|---|---|
| Quality of Life | | | | |
| Total | .25 | .14 | .06 | .28 |
| Subscales | | | | |
| Health/Functioning | .30 | .08 | .25 | .25 |
| Socioeconomic | .29 | .17 | .23 | .24 |
| Psychological | .20 | .21 | .28 | .28 |
| Fatigue | | | | |
| Overall | -.39* | -.03 | -.04 | -.26 |
| Subscales | | | | |
| Emotional | -.34* | .01 | -.13 | -.23 |
| Uncertainty | -.40* | .003 | .16 | -.19 |
| Cognitive | -.29 | -.19 | -.31* | -.38** |
| Physical | -.26 | -.11 | -.03 | -.10 |
| Depression | -.33* | -.14 | -.05 | -.18 |
| Disease Activity | | | | |
| Total | -.38* | -.15 | .14 | -.21 |
| Global | -.43** | -.09 | .05 | -.03 |

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

## Work Status and Primary Study Variables

All PQOL measures except the Psychological/Spiritual measure were significantly related to work status (Table 8). People who were working reported better quality of life. Working subjects also reported significantly less fatigue uncertainty than those who were not working. This pattern was similar for the other fatigue measures, but they were not statistically significant. People who were working also reported less depression and less disease activity.

Table 8: Means, Standard Deviations and t-test for Primary Study Variables and Work Status

| Primary Study | Working[a] | | Not Working[b] | | t | p |
|---|---|---|---|---|---|---|
| Variables | Mean | SD | Mean | SD | | |
| Quality of Life | | | | | | |
| Total | 24.0 | 2.1 | 17.7 | 5.0 | -2.76 | .01 |
| Subscales | | | | | | |
| Health | 23.1 | 2.0 | 15.5 | 4.9 | -3.35 | .01 |
| Socioeconomic | 26.5 | 2.6 | 18.4 | 5.8 | -3.02 | .01 |
| Psychological | 22.2 | 2.5 | 18.4 | 6.4 | -1.29 | .21 |
| Fatigue | | | | | | |
| Overall | 4.1 | 1.4 | 5.6 | 1.6 | 2.0 | .058 |
| Subscales | | | | | | |
| Physical | 4.3 | 2.1 | 5.4 | 2.8 | .82 | .42 |
| Cognitive[c] | 2.6 | 2.6 | 4.4 | 2.8 | 36.5 | .36 |
| Emotional | 21.0 | 8.2 | 26.8 | 8.2 | 1.4 | .18 |
| Uncertainty | 34.9 | 12.8 | 46.2 | 8.5 | 2.4 | .03 |
| Depression[c] | 12.4 | 7.2 | 23.3 | 10.4 | 20.5 | .05 |
| Disease Activity | | | | | | |
| Total | 15.3 | 12.1 | 31.8 | 11.1 | 2.92 | .01 |
| Global[c] | 3.4 | 3.1 | 5.9 | 2.6 | 24.5 | .08 |

[a]n = 5 [b]n = 20 [c]Mann Whitney U

## Marital Status and Primary Study Variables

Marital status had six categories, but the small sample size and the number of subjects who were married justified collapsing marital status into two categories for analysis. The "not married" category included subjects who were divorced, single, separated or widowed. All other subjects, including those living common-law, were classified as married. There was no difference in PQOL, fatigue, depression, or disease activity for those who were married and not married (Table 9).

Table 9: Means, Standard Deviations and t-test for Primary Study Variables and Marital Status

| Primary Study Variables | Married[a] | | Not Married[b] | | t | p |
|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | | |
| Quality of Life | | | | | | |
| Total | 18.3 | 4.9 | 21.1 | 6.1 | 1.14 | .27 |
| Subscales | | | | | | |
| Health | 16.1 | 5.3 | 19.7 | 5.4 | 1.43 | .18 |
| Socioeconomic | 19.8 | 5.8 | 20.8 | 7.8 | .32 | .75 |
| Psychological | 18.1 | 5.7 | 22.5 | 6.1 | 1.63 | .12 |
| Fatigue | | | | | | |
| Overall | 5.6 | 1.5 | 4.5 | 1.9 | -1.38 | .18 |
| Subscales | | | | | | |
| Physical | 5.4 | 2.8 | 4.4 | 2.3 | -.76 | .46 |
| Cognitive[c] | 4.5 | 2.4 | 2.8 | 2.2 | 43.0 | .37 |
| Emotional | 26.9 | 8.1 | 21.7 | 8.7 | -1.34 | .19 |
| Uncertainty | 44.9 | 8.8 | 40.7 | 14.5 | -.88 | .39 |
| Depression[c] | 22.1 | 11.2 | 17.8 | 8.8 | 41.0 | .31 |
| Disease Activity | | | | | | |
| Total | 29.9 | 13.2 | 24.0 | 11.9 | -.98 | .34 |
| Global[c] | 5.7 | 2.8 | 4.3 | 2.9 | 41.5 | .32 |

[a] n = 19 [b] n = 6 [c] Mann Whitney U

## Research Question Three

Question three addressed whether fatigue and depression mediate the relationship between disease activity and quality of life. Scores used in path analysis included: the Overall Fatigue score, the total scores on the Self-Assessment Systemic Lupus Activity Measure, the Centre for Epidemiological Studies-Depression Scale, and the Quality of Life Index.

The following steps were taken to determine effect coefficients between disease activity and PQOL. First, PQOL (outcome variable) was regressed on disease activity, fatigue, and depression (predictor variables) using multiple linear regression. Next, fatigue was regressed on disease activity. Finally, depression was regressed on disease activity. Beta weights obtained from linear regression are pictured in Figure 4. All beta weights were greater than .05, therefore, they are considered to be significant. The total effect of disease activity on quality of life was calculated by adding the direct and indirect effects. The total effect of disease activity on quality of life is high. The direct and indirect effects of disease activity on quality of life are summarized in Table 10.

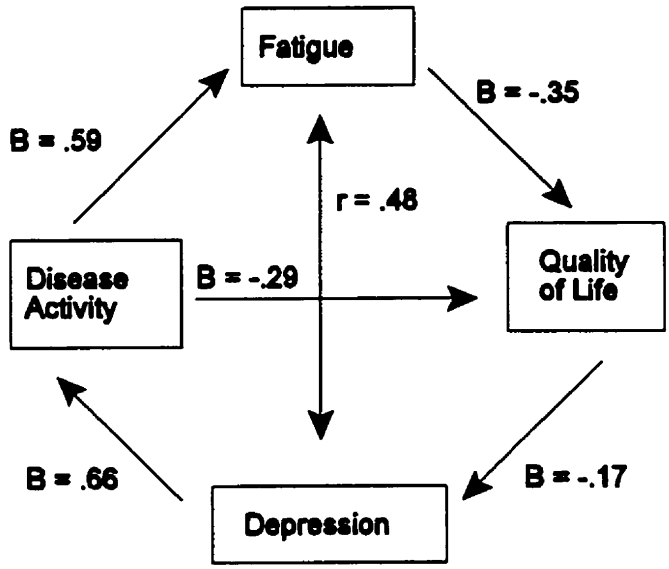
Table 10: Effect of Disease Activity on Quality of Life: Analysis of Direct and Indirect Effects

| Variable | Direct Effect | Indirect Effect | Total Effect |
|---|---|---|---|
| Disease Activity | -.29 | (.66)(-.17) + (.59)(-.35) = -.32 | = -.61 |
| Fatigue | -.35 | - | |
| Depression | -.17 | - | |

## Research Question Four

Research question four addressed the nature of fatigue in people who have SLE. Questionnaire items that evoked common responses are summarized, followed by other fatigue themes that arose during interview discussions.

Figure 4: Beta Coefficients from Linear Regression for the Pathways in the Mediation Model




Note: Correlation coefficient between between fatigue and depression is included in Figure 4. This value was not used in calculations of effect coefficients.

Physical Fatigue Items

Most subjects (about 60%) reported that their physical fatigue was more unpleasant than pleasant, more a sensation of weakness than of strength, more a sensation of tiredness than of feeling refreshed, and more a feeling of being unenergetic than of being energetic. Two physical fatigue items did not follow this pattern. When asked to choose between the anchors of awake and sleepy, people were roughly equally divided in reporting that they were more awake ($n$ = 11) than sleepy ($n$ = 10) (the midpoint of the scale was chosen with the most frequency), and more lively ($n$ = 12) than listless ($n$ = 10).

Cognitive Fatigue Items

The mid-point was chosen most frequently for all cognitive fatigue items ($n$ = 6 for each item). Those who did not choose the mid-point chose <5, or that

they were more able to concentrate (n = 11), remember (n = 12), and think clearly (n = 12), more than those who chose >5, or unable to concentrate (n = 8), unable to remember (n = 7), and unable to think clearly (n = 7).

Emotional Fatigue Items

The general emotional fatigue subscale was used to get an overall sense of the nature of emotional fatigue in people who have SLE. Impatience was identified by 76% (n = 19) of participants as being present some (24%) or most (52%) of the time that fatigue was experienced. Sixty-four percent (n = 16) rarely (36%) or occasionally (28%) felt content when fatigued. Sixty percent (n = 15) experienced mood swings some (20%) or most (40%) of the time when fatigued. Fifty-two percent (n = 13) were unhappy some (42%) or most (12%) of the time when fatigued, and 48% (n = 12) felt that their emotions were out of control some (32%) or most (16%) of the time when fatigued.

Fatigue Uncertainty

Most (92%, n = 23) subjects agreed (32%) or strongly agreed (60%) that the course of fatigue changes, resulting in good days and bad days, and 64% (n = 16) agreed (44%) or strongly agreed (20%) that fatigue changes unpredictably. Seventy-two percent (n = 18) agreed (60%) or strongly agreed (12%) that they were unclear how bad their fatigue would be in the future, and 32% (n = 12) agreed (12%) or strongly agreed (20%) that they had many questions about fatigue without answers.

Fatigue Uncertainty items 5 ("The explanations they give me about my fatigue seem hazy to me") and 8 ("I understand everything explained to me about my fatigue") provoked the most discussion, and had the highest number of undecided or missing responses. When it was recognized that difficulty with these items was a common occurrence, subsequent respondents who were interviewed in their homes (n = 9) were asked to explain their difficulty. Every person stated that they were not provided with explanations about fatigue, thus they felt incapable of answering the questions.

Other Fatigue Themes

A number of fatigue themes became apparent throughout the interviews.

Every subject was not asked about each theme because themes were not identified until a number of interviews had already been completed. The number of interviews varied with each theme. However, 21% (n = 5) women identified that fatigue changed somewhat predictably with their menstrual cycle. Sixteen percent (n = 4) felt that, at times, nothing relieved fatigue and that it simply had to run its course, and 12% (n = 3) felt that physical fatigue, when it persisted for an extended time period, contributed to emotional fatigue.

## Fatigue and Rest

Mean night time sleep was 7.5 hours (SD +/- 2.5 hours), and ranged from 4 to 13 hours per night. Eighty percent (n = 20) reported that they sometimes (n = 13) or daily (n = 7) had a day time nap. The mean nap length was 1.6 hours (SD +/- .87 hours), and naps ranged from .5 to 4 hours.

## Variability of Fatigue

A significant difference was found between subject fatigue "at its worst" (M = 7.02) and "at its best" (M = 2.12), indicating individuals experienced considerable variability in fatigue ($t = 11.39$, $p < .001$).

## Chapter Summary

Most subjects were married women who were on disability income. The majority of subjects experienced symptoms of SLE for many years before receiving a definitive diagnosis. Considerable support was found for the relationships depicted in the conceptual model: People who reported better quality of life reported less fatigue, less depression, and less disease activity. Subjects with greater fatigue reported more depressive symptoms and greater disease activity, and those who reported more depressive symptoms also reported greater disease activity.

People who reported a higher level of formal education reported less fatigue, depression, and disease activity. The shorter the time since onset of symptoms and time since diagnosis, the greater the cognitive fatigue reported. Cognitive fatigue was the only variable that was significantly related to these two factors. Working subjects reported better quality of life, less fatigue, fewer depressive symptoms, and less disease activity. Marital status and age were

unrelated to the primary study variables.

Physical fatigue was reported most often as unpleasant, weakness, tiredness, and lack of energy. A majority of subjects did not feel that sleepiness or listlessness described their physical fatigue. Most subjects chose the mid-point for cognitive fatigue items. Emotional fatigue was most often described as involving impatience, lack of contentment, mood swings, unhappiness, and out of control emotions. Fatigue uncertainty involved unpredictability and questions about fatigue that had no answers. Three new themes came out of discussion. First, some women reported that fatigue fluctuated with their menstrual cycle. Second, some subjects felt that, at times, fatigue simply had to run its course, and finally, a number of subjects stated that when physical fatigue was prolonged, emotional fatigue resulted.

# CHAPTER 5
# DISCUSSION

The purpose of the current study was to explore the relationships among perceived quality of life, fatigue, depression, and disease activity. Despite limitations of the study, a number of important relationships were clarified. First, prior to this study, the relationship between PQOL and fatigue in people who have SLE had not been explored from a quantitative perspective. Moderately strong to strong correlations were found between these two constructs in the current study, thus supporting the previous qualitative findings that the two were closely linked. Secondly, the importance of assessing fatigue uncertainty in people who have SLE was established. Finally, fatigue and depression have been more clearly defined as mediators between disease activity and PQOL, at least in some people who have SLE.

Results of the study are discussed in terms of characteristics of the sample, the primary study variables, and the research questions. Limitations and implications of the study conclude this chapter.

## Characteristics of the Sample

In the current study, the relationships among perceived quality of life, fatigue, depression, and disease activity were examined. These four variables have not been studied in combination in the past. Characteristics of the sample and variables, including the primary study variables are, therefore, compared to sample characteristics of studies of one or more of the variables.

### Characteristics of the Subjects

The current study sample was found to be similar to samples in other studies for age, gender, and education. Differences were found for marital status and work status. Discussion of difficulty making comparisons for disease duration concludes this section.

The average age for subjects in the current study was similar to the age of subjects in other SLE studies that have explored: (a) quality of life (Burckhardt et al., 1992); (b) fatigue (Knippen, 1988; Krupp et al., 1989, 1990; McKinley et al., 1995; Robb-Nicholson et al., 1989; Wysenbeek et al., 1993);

(c) depression (Knippen; Krupp et al., 1989, 1990; McKinley et al.; Robb-Nicholson et al.); and (d) disease activity (Burckhardt et al.; Knippen; Krupp et al., 1990; McKinley et al.; Robb-Nicholson et al.; Wysenbeek, et al.) The current study sample consisted predominantly of women, which is also similar to the other studies. The mean years of formal education for the current study sample was close to the mean of college education found in other studies that looked at similar variables (Burckhardt et al.; McKinley et al.; Liang et al. 1989), with the exception of Wysenbeek et al.'s study.

A higher proportion of subjects in the current study were married than subjects in the comparison studies that reported this statistic (Burckhardt et al. 1992; Knippen, 1988; McKinley et al, 1995; Robb-Nicholson et al., 1989).

The proportion of employed people was markedly less in the current study sample compared to other studies, and the number of subjects on long term disability was higher (Burckhardt et al., 1992; Knippen, 1988; McKinley et al., 1995; Robb-Nicholson et al., 1989). Subjects for each of these studies were recruited through rheumatology clinics affiliated with hospitals in the United States or in Sweden. In contrast, about one-half of the subjects in the current study were recruited from a rheumatologist and one-half were recruited from a lupus support group. It may be that people who seek peer support are experiencing more difficulty related to their SLE and are, therefore, less likely to be employed outside the home. Conversely, being involved in a support group may provide people with the necessary tools and knowledge to negotiate their way through the challenges of obtaining long term disability.

Comparison of disease duration was difficult because other researchers did not explain whether their figures were based on time since diagnosis or on time since onset of symptoms (Burckhardt et al., 1992; Knippen, 1988; Robb-Nicholson et al., 1989; Wysenbeek et al., 1993). However, the mean time since diagnosis for the current study was within the range of means reported in the previously mentioned investigations. In the current study, a significant difference was found between time since diagnosis and onset of symptoms, indicating that people experienced a lengthy period of symptoms without a definitive diagnosis.

## Primary Study Variables

Scores obtained from measures of the primary study variables are compared to other samples in the following section.

### Quality of Life

Although the Quality of Life Index (QOLI) has not been used to measure quality of life in people who have SLE, it has been used with people who have other forms of rheumatic diseases. Jeffrey (1995) reported slightly higher PQOL for people who had RA compared to the current study findings. However, the values found for people who had fibromyalgia were similar to scores found in the current study (Jeffrey). Ferrans (personal communication, 1995) also found similar values for people who had narcolepsy. Thus, people who have SLE are one of only three chronic illness populations who have lower PQOL than other chronic illness populations.

Using a different measure of PQOL, Burckhardt et al. (1992) reported that the mean for total quality of life fell in the upper third of the possible range, for people who had SLE. In contrast, the mean was in the middle third of the range for the QOLI in the current study. Perceived quality of life, therefore, may have been somewhat lower for people in the current study than for subjects in the study by Burckhardt et al. Two explanations may account for this:
(a) differences in the methods of measurement used in the two studies and/or
(b) differences in the work status of the two samples. Significantly fewer people were working in the current study than in the study by Burckhardt et al. The relationship between work and PQOL is explored more fully in a subsequent section of this chapter.

### Fatigue

Although a variety of fatigue assessment tools have been used by researchers to assess fatigue in people who have SLE, mean scores have generally hovered around the mid-point (Knippen, 1988; Krupp et al., 1989, 1990), as did all means for fatigue measures in the current study. The Piper Fatigue Scale, used in the current study, was also used by McKinley et al. (1995) with people who had SLE, although McKinley et al. used an earlier

version of the instrument. The mean Piper Fatigue Scale Total Score for the current study was slightly higher than that reported by McKinley et al., however, this difference may have resulted from the use of different versions of the Piper Fatigue Scale. Alternatively, the difference may be a reflection of the sample. People in the current study were much less likely to be employed, which may indicate that fatigue was more of a problem for this group than in the sample described by McKinley et al. Mean fatigue scores for people who were working in the current study were lower than mean fatigue for those who were not working, but the difference between means was not significant ($t = 1.35$, $p = .19$). The small sample size may have affected power of analysis. However, Total Piper mean in the current study was similar or slightly higher than scores obtained from people with a variety of other chronic health conditions (Piper, 1989).

Comparison of subscale means of the Piper Fatigue Scale is not possible for two reasons: (a) the subscales are not the same for the two versions, and (b) McKinley et al. (1995) did not publish their subscale results. However, all subscale means were near the mid-point in the current study. Subscale means differed more (the trend toward the mid-point was not observed) in other chronic illness studies which used the Piper scale (Piper, 1989).

Other fatigue instruments used in this study were either new (Emotional Fatigue Scale) or modified versions of established instruments (Fatigue Subscale of Mishel Uncertainty in Illness-Community). Means for both were also at about the mid-point, indicating that the severity of emotional fatigue and fatigue uncertainty is similar to the mid-range of the other dimensions of fatigue assessed with the Piper Fatigue Scale.

In summary, mean scores for the dimensions of fatigue assessed in the current study were all close to the mid-range of possible scores, unlike the more diverse dimension scores found in some other chronic illness populations.

## Depression

The mean score obtained from the Centre for Epidemiological Studies-Depression Scale (CESD) in the current study was higher than scores obtained

from some of the studies of people who had SLE (Krupp et al., 1989, 1990; McKinley et al., 1995), but very similar to that found by Knippen (1988). However, even in studies with lower means, means were at or just marginally below 16, the cutoff for identification of "at risk" populations (Radloff, 1977). Some people who have SLE are potentially at risk for depression.

The CESD has been used with people who have other forms of rheumatic diseases. Means are higher in SLE than those found for people who have RA, but similar to that found in people who have fibromyalgia (Jeffrey, 1995). Whether increased depression scores in people who have SLE result from the challenge of living with SLE or as a result of organic causes remains unclear.

It may be that the depressive symptoms seen in many people who have SLE are actually symptoms of "chronic sorrow". Chronic sorrow has been described as "the emotional pain associated with the losses and disappointments of long-term illness and disability...[and is a] recurring, periodic sadness that is permanent and progressive" (Lindgren, Burke, Hainsworth, & Eakes, 1992, p. 28). Frank et al. (1992) also concluded that dysphoria, what they stated was the core defining criterion for depression in people who have chronic illnesses, might represent the normal distress faced by people dealing with the challenge of living with a chronic illness. Dysphoria was characterized by negative self-evaluations, depressed affect, and suicidal ideation.

Disease Activity

No other Self-Assessment Systemic Lupus Activity Measure (SA-SLAM) data are available for comparison, however, other versions of SLAM have been used (Burckhardt et al., 1992; Knippen, 1988; McKinley et al., 1995; Liang et al., 1989). The SA-SLAM mean was greater than the disease activity mean found by Burckhardt et al., similar to that found by Knippen, and less than that found by McKinley et al. and Liang, et al.. Subject selection criteria may have affected these outcomes. For example, it seems reasonable for unhospitalized people to have lower disease activity. Selection criteria were not specified by Liang et al., beyond stating that subjects were being followed at a hospital. McKinley et al. also recruited from a hospital patient registry. Burckhardt et al. stated that their

recruits were either inpatients or outpatients, as were subjects in Knippen's study. All participants in the current study were outpatients. Lower SLAM scores were obtained from the three studies that clearly involved a portion of outpatients. Current study results were near the midpoint of all the outpatient studies.

Interestingly, some people who scored higher on the total disease activity measure in the current study reported low to moderate disease activity on the global score, while others who reported few symptoms reported higher disease activity. It may be that people's perception of disease activity changes over time, perhaps because of the length of time one has had to adjust to symptoms. This hypothesis was not, however, supported by current study data ($r$ = .05, $p$ = .72). Alternatively, perception of disease activity may be influenced by the course of SLE over time: People who have experienced more severe symptoms in the past may perceive current disease activity as low, in contrast to people who are experiencing relatively more disease activity at present compared to the past.

## Research Questions

Results are discussed by research question in the next section.

### Research Question One

Research question one focused on the relationships among the primary study variables. The relationships among perceived quality of life and fatigue, perceived quality of life and depression, perceived quality of life and disease activity, fatigue and depression, fatigue and disease activity, and depression and disease activity are discussed, in turn.

#### Perceived Quality of Life and Fatigue

The relationship between quality of life and fatigue described in the conceptual model was supported. In the current study, people who reported greater fatigue also reported poorer PQOL. Although this relationship has not been explored by other researchers interested in SLE, current study findings support the work of researchers interested in other forms of rheumatic diseases (Jeffrey, 1995). The relationship between PQOL and fatigue is discussed from two perspectives: (a) the general relationship between PQOL and overall

fatigue, and (b) the relationship among quality of life domains and the physical, cognitive, emotional, and uncertainty dimensions of fatigue. The relationships among dimensions of fatigue and quality of life have not been explored previously, therefore, current study findings cannot be directly compared to other findings.

Support for the General Relationship Between Perceived Quality of Life and Fatigue. Fatigue had the strongest correlation to PQOL in the current study. The general relationship between fatigue and quality of life supports the conceptual model. Belza (1995) used the word "impact" to describe how fatigue affected activities of daily living, including the ability to perform household chores, capacity for work, and ability to socialize, in people who had RA and in healthy controls. The primary means by which fatigue affects life may be through its effects on available time.

As previously stated, fatigue in chronic illnesses contributes to either a direct loss of usable time, because more time is spent in rest (Tack, 1990b; Robinson & Posner, 1992) or an indirect loss of time because time may be used less efficiently (Tack). People with chronic illnesses who experience fatigue, therefore, have fewer hours available to meet ordinary life pursuits. Reaching a satisfactory balance among the many dimensions of life poses a challenge to most people. People who experience chronic fatigue have fewer available hours and less energy to obtain this balance, therefore, choices must be made about how limited time and energy is to be spent. Whatever decision is reached, the choices involve an element of loss: (a) loss of income if work time is decreased, (b) loss of social relationships if time is no longer spent with friends or family, or (c) the loss of physical or mental outlets if recreational activities are curtailed. As one person said: "I no longer have the flexibility to both work and play at will. I have to make choices. I work as much as I need to but I am not able to go out socially" (as cited in Knippen, 1988, p. 55). It is reasonable to find that giving up valued activities reduces satisfaction for individuals who experience fatigue. Since satisfaction with life domains has been identified as an essential aspect of quality of life (Ferrans & Powers, 1985; Flanagan, 1978), it also is logical to

assume that fatigue affects perception of quality of life. The dimensions of fatigue explored in this study were related to the dimensions of quality of life to varying degrees, and will be discussed in turn.

Physical and Cognitive Fatigue and Perceived Quality of Life. Of all the fatigue dimensions, physical and cognitive fatigue related the strongest to peoples' total PQOL and to each domain of quality of life. If it takes a greater amount of time to complete a task because of fatigue (Tack, 1990b), less may be accomplished, satisfaction may be decreased, and poorer perception of quality of life may result. Krupp et al. (1989) and Schwartz et al. (1993) found that the effects of fatigue on peoples' lives were significantly greater for people with chronic illnesses than for healthy individuals. It would seem that people with chronic illnesses experience greater physical consequences or losses as a result of fatigue than do normal controls, perhaps because of increased fatigue severity in these individuals, or because of the combined effect of fatigue, pain, and other physical symptoms associated with many chronic illnesses. Physical energy and the ability to think clearly (part of cognitive fatigue) seem to be aspects of daily life that are essential to feeling good about peoples' accomplishments, abilities, and the future.

Emotional Fatigue and Perceived Quality of Life. People who reported greater emotional fatigue also reported poorer PQOL. The strongest relationships were found between emotional fatigue and the SES and psychological/spiritual domains of quality of life.

SES items assess perception of financial status and social relationships. Emotional fatigue and SES are explored from these two perspectives. The association found between emotional fatigue and SES in the current study may have resulted from the financial impact of being on long term disability. Many people in the current study were receiving long term disability. Disability payments are lower than wages. People on disability may feel less financial security and may have been required to adopt a lower standard of living. Increased stress and emotional fatigue may result. It seems reasonable to assume that the relationship between financial aspects of SES and emotional

fatigue would be stronger for people on disability, compared to people who are working. Some support was found for this hypothesis in the current study: The negative relationship was stronger between perception of financial status and emotional fatigue for people on long term disability ($r$ = .33) than for people who were working ($r$ = .01), although the difference was not significant between the two groups when correlations were compared using Fisher z transformations described by Cohen and Cohen (1983, p. 54).

People who are working may have less time and energy to nurture supportive relationships. The impact of lost relationships may, therefore, be greater for people who are working. Correlations between relationship aspects of SES and emotional fatigue might be expected to be stronger in people who are working compared to those on disability. This tendency was supported by current study findings. Negative correlations were stronger between perception of supportive relationships and emotional fatigue in those who were working ($r$ = -.41) compared to people who were on long term disability ($r$ = -.12). The difference between correlations was not significant when compared using Fisher z transformations.

The negative relationship between emotional fatigue and the psychological/spiritual domain may partly be explained by the similarity of items. Both scales assess perception of inner aspects of self and, in some cases, both scales assess the same concept. For example, happiness is addressed in each. If one experiences less happiness (greater emotional fatigue), it would seem reasonable that one might also be less satisfied by one's level of happiness, if happiness is deemed an important part of life.

Fatigue Uncertainty and Perceived Quality of Life. People who reported greater fatigue uncertainty also reported a lower PQOL, with the exception of their perception of the psychological/spiritual domain. Because the unpredictability aspect of uncertainty has been identified as a significant characteristic in SLE fatigue (Bertino & Lu, 1993; Burckhardt et al., 1993; McKinley et al., 1995), it was the primary focus of uncertainty assessment at the outset of the current study. However, through discussion of items in the MUIS-C,

it became obvious that fatigue ambiguity was also a major component of fatigue uncertainty for these subjects. The relationship among these two uncertainty concepts is discussed in terms of PQOL.

Although physical fatigue may compel one to rest, if one could predict when physical fatigue would strike, its effect on work, social life, and recreation might be somewhat mitigated. Careful planning and pacing of activities would be possible. However, when fatigue strikes unpredictability, advance preparation and planning is more difficult or impossible. For example, a person may get up and go to work with a reasonable amount of energy, only to be struck down with profound fatigue at any time during the day. Unpredictability of fatigue may, therefore, be a source of difficulty with co-workers and employers. It may contribute to reduced ability to maintain employment, poorer income, poorer perceived health and functional ability, and lower SES. It seems reasonable to find that people who experience more unpredictability in their fatigue also perceive their quality of life to be poorer.

Ambiguity surrounding fatigue was exemplified by the recurring theme: "no one explains anything about fatigue to me". Many people were unsure if the medications they were taking were supposed to effect fatigue or if their fatigue control strategies were effective. Some subjects reported that some strategies worked at some times, but at other times nothing alleviated fatigue and that it became a matter of simply "waiting it out". People described their experience with fatigue as fighting an "unpredictable", "invisible", and "unknown" entity. It seems reasonable that people who experience greater unpredictability and ambiguity about their fatigue also experience a poorer quality of life.

The relationship between fatigue uncertainty and the psychological/spiritual dimension of PQOL was weak. This was an unexpected finding in light of previous studies that linked uncertainty in illness with stress (Mishel, 1981), emotional distress (Mishel, 1991), and depression (Krupp et al., 1990), and "lack of information" (ambiguity) with depressed feelings (Bauman et al., 1989). A stronger relationship was expected because many items in the psychological/spiritual domain are similar to factors mentioned above. For

example, "peace of mind" roughly corresponds to the concept of uncertainty. Fatigue uncertainty was assessed with parts of a tool that was designed to measure uncertainty related to illness, rather than focusing on a specific symptom. The MUIS-C may not be a valid way of measuring fatigue uncertainty. Although the relationship between fatigue uncertainty and PQOL has not been previously explored, uncertainty related to chronic illness has been found to be inversely related to PQOL (Jeffrey, 1989; Lamb, 1996; Searle, 1992; Staples, 1993). This pattern was upheld in the current study of fatigue uncertainty.

Perceived Quality of Life and Depression

People who experienced more depressive symptoms reported lower PQOL. These findings were expected and support the conceptual model. They also support the relationship between depressive symptoms and PQOL found for people who had RA and fibromyalgia (Jeffrey, 1995).

The strongest relationship was found between depression and the SES domain of quality of life in the current study, however, although a negative relationship was found between the SES subscale and depression, it was not strong. This moderate relationship may have resulted from the different perspectives of subjects who were working and subjects who were on disability. In the current study, the negative relationship between SES and depression was considerably weaker for people who were on disability ($r$ = -.25, $p$ = .14) compared to people who were working ($r$ = -.80, $p$ = .05), although correlation coefficients were not significantly different using Fisher z transformations (Cohen & Cohen, 1983). This pattern is similar to that found between people who had RA who were either working or receiving disability (J. Jeffrey, personal communication). Interpretation of these findings is difficult, however, one possibility may be that people on disability modify their material expectations or values over time. This hypothesis supports previous findings that people who have chronic illnesses are able to re-prioritize what is important in their lives, with relationships becoming more important than material things (Liang et al., 1989; Tack, 1990b). However, links have been made between income and depression (Goldsmith, Darity, & Veum, 1996) and in the current study, the

strongest negative correlations were found between depression and items of the SES subscale that assessed economic status ($r$ = -.51 to -.60, $p$ < .01) rather than items that assessed social relationships ($r$ < -.17, $p$ nss). The ultimate effect of employment status on the relationship between depression and SES remains unclear.

Perceived Quality of Life and Disease Activity

The relationships found between disease activity and quality of life supported the conceptual model, however, stronger relationships were found than was expected. As envisioned, total disease activity was more strongly associated with PQOL than was the one item global measure, and the strongest relationship was found between disease activity and the health and functioning domain of quality of life. Burckhardt et al.'s (1992) weaker correlations may have been the result of using a different quality of life measure that did not take into account the importance of life domains.

On the other hand, researchers who have explored this relationship in other chronic illnesses have also tended to find weaker correlations than those found in the current study. Most assessments of disease activity have been completed by physicians, rather than by patients. Perception of disease activity may differ between patients and practitioners. The SA-SLAM assesses disease activity from the perspective of the person who has SLE, rather than from the health care provider's point of view. Stronger correlations between disease activity and PQOL may result when both disease activity and PQOL are self-assessed.

Fatigue and Depression

The relationship found between fatigue and depression supports the conceptual model. Significant, positive relationships were found between depression and fatigue, with the exception of the cognitive fatigue measure. Subjects who reported greater fatigue reported more depressive symptoms. Other researchers have also found a positive relationship between these two variables in people who have SLE, but the relationship was either not as strong as that found in the current study (Knippen, 1988) or not comparable because

values were not published (McKinley, et al., 1995). The Feeling Tone Checklist used by Knippen assessed physical and mental aspects of fatigue. It did not, therefore, measure the breadth of fatigue dimensions assessed in the current study. This may account for the weaker relationship. The current study findings support the results of research that explored the relationship between depression and fatigue in people who have other rheumatic diseases (Jeffrey, 1995; Tack, 1990a, 1990b).

One purpose of this study was to explore the possible reciprocal relationship between fatigue and depression. When asked to explain their perception of the relationship between the two, responses ranged from "fatigue has nothing to do with my mood" to the more common response of "when I can't do what I want to do because of fatigue, I get depressed". Fatigue may contribute to loss of valued activities, and thus potentiate depression. The latter response provides support for Katz & Yelin's (1995) finding that depressive symptoms resulted from loss of valued activities in people who have RA. Although fatigue may be a legitimate symptom of depression, prolonged fatigue may also contribute to depression in people who have SLE.

Fatigue and Disease Activity

People who reported greater total disease activity reported more fatigue. This finding was expected and supports those found in previous SLE studies, even when a variety of fatigue and disease activity measures were used (Knippen, 1988; Krupp, et al., 1990; Wysenbeek, et al., 1993; Zonana-Nacrach, et al., 1995). Unlike the current study, the previously mentioned studies did not attempt to determine the relationship between specific dimensions of fatigue and disease activity, therefore comparisons are not possible. The relationships between these dimensions and disease activity are discussed in the next sections.

Physical Fatigue and Disease Activity. The strong correlation found between physical fatigue and disease activity was expected. It has been speculated that increased physical fatigue results from increased production of Interleukin-1 during times of increased disease activity. Interleukin-1 is an

initiator of the generalized acute-phase response to infectious states, physical injury, inflammatory processes, and immunologic reactions (Dinarello, 1984; Greenberg, Gray, Mannix, Eisenthal, & Carey, 1993) and it may contribute to fatigue by inducing slow-wave sleep in these states, as a protective mechanism. The sensation of physical fatigue leads to an inclination to rest, allowing available energy to be devoted to the healing process (Krueger et al. as cited in Dinarello, 1984). The relationship found between physical fatigue and disease activity was expected. The strength of the correlation found between fatigue uncertainty and disease activity, however, was not.

Fatigue Uncertainty and Disease Activity. Not only was the hypothesis that fatigue uncertainty was a significant fatigue factor for people who have SLE, the relationship between fatigue uncertainty and disease activity was stronger than expected. It may be that the increased physical fatigue associated with increased disease activity becomes more of a day to day issue, so that more thought and self-questioning about fatigue is done. When disease activity increases, people may become less satisfied with the ambiguity and lack of information available to them about fatigue, and the variability of fatigue may become more apparent. The degree of contentment about their state of knowledge about fatigue in SLE may decrease. This may also negatively affect their perception of quality of life.

Emotional Fatigue and Disease Activity. No significant relationship was found between emotional fatigue and disease activity, however, people who experienced more emotional fatigue did tend to report greater disease activity. The effect of sample size aside, it may be that this finding provides evidence that emotional fatigue is less closely linked to physical symptoms than is physical fatigue.

Interestingly, significant relationships were found between emotional fatigue and depression, and between depression and disease activity. These findings provide support to the idea that emotional fatigue and depression are unique concepts. It might also be that these findings contribute support to the theory that depression in SLE results from pathological changes in CNS

functioning, as suggested by others (Giang, 1991; West, 1995).

Disease Activity and Depression

People who reported greater disease activity reported greater depression, as previously mentioned. Correlations found in the current study support findings of other researchers interested in SLE (Joyce et al., 1989). As previously mentioned, increased disease activity may result in increased loss of valued activities. Loss of valued activities was a significant risk factor in the development of depressive symptoms in people who have RA (Katz & Yelin, 1995). Depression may also result from CNS changes, but this was not explored in the current study.

Summary

The correlations found among all of these variables fulfill one of the criteria for model testing. The conceptual model was supported by current study data. Relationships exists among disease activity, fatigue, depression, and PQOL in people who have SLE.

## Research Question Two

Significant relationships were found among a number of demographic and primary study variables. Only the following significant findings are discussed: (a) perceived quality of life and education, and work; (b) fatigue and education, work, time since onset of symptoms, time since diagnosis; (c) depression and education, and work; and (d) disease activity and education, and work.

Perceived Quality of Life and Education, and Work

In the current study, people who had a higher education tended to perceive quality of life as better than those who had less education. The relationship between PQOL and work was also significant: People who were working reported greater PQOL than those who were not working. In contrast, Burckhardt et al. (1993) found no relationship between work status and quality of life for people who had either SLE or RA. They indicated surprise at this finding, stating that they expected that the work ethic would negatively influence perceived quality of life of their predominantly disabled subjects. As previously mentioned, the tool they used to measure quality of life assessed satisfaction

only. It may be that this tool does not provide the same measure as the one used in the current study that factors personal values into scoring.

Fatigue and Demographic Variables

People with more formal education reported less fatigue. Higher education may have been attainable because of less overall fatigue or higher education may promote increased understanding of the fatigue process, thus moderating the effects of fatigue uncertainty. In the current study, people who had undefined symptoms of SLE as children were less likely to engage in post-secondary education. Severity of fatigue during this time period is unknown, however, fatigue is a common symptom of SLE and it tends to increase with disease activity. It may be that people who had symptoms prior to completing high school also experienced more fatigue compared to those whose symptoms started at a later age. Fatigue may have been a factor in decreasing the likelihood of completing post-secondary education.

Higher education, fatigue, and work status may be related in that higher education may provide people with a wider range of employment options, and promote more flexibility in use of time, allowing people to maximize fatigue management techniques and to obtain better control over work and home-related activity levels. For example, more highly educated people may have increased access to less physically demanding work conditions. They may also have more flexibility in work hours, allowing them to work around fatigue unpredictability, and they may have more financial resources available to them through better disability packages, both when on partial disability and when no longer working. Allaire, Anderson, and Meenan (1996) found that people who had RA and were employed in professional fields or administrative positions, where physical demands were low, were more likely to remain employed. Higher education may place people in the position where these types of employment are possible.

If prolonged fatigue precipitates increased emotional fatigue, as stated by some of the current study participants, emotional fatigue may also be more controllable in people with higher education because increased education may

provide people with more control over work related activity levels: People with higher education may be more likely to be employed in less physically demanding jobs than less educated people. As a result, physical fatigue may be lessened and thus not precipitate emotional fatigue. People with higher education may also be able to purchase assistance in the home that less educated, lower income people could not buy. Higher education, through increased financial resources, may also act directly to reduce emotional fatigue by decreasing stress related to financial constraints and concerns.

Without doubt, a relationship between overall fatigue and education was found in the current study. A trend for people who experienced greater overall fatigue to be not working was also found, however, fatigue uncertainty was the only fatigue measure that was significantly related to work status. All mean fatigue scores were higher for those people who were not working. Fatigue uncertainty has not been measured in the past, although Knippen (1988) quoted one of her subjects as saying: "Irregular energy levels makes working outside the home impossible" (p. 56). It seems reasonable to find that people who experience less ambiguity and more predictability in relation to their fatigue are better able to maintain employment. Fatigue uncertainty is a legitimate component of fatigue in people who have SLE. In general, people in the current study who reported the most fatigue tended to be receiving long term disability.

Knippen (1988) explored the relationship between general fatigue and length of illness and concluded that no relationship existed. In the current study, cognitive fatigue was the only fatigue dimension that related to time since onset of symptoms and time since diagnosis. Subjects in the current study who experienced greater elapsed time since onset of symptoms and diagnosis experienced less cognitive fatigue. Although this relationship has not been explored in previous studies, so comparison to other research findings is not possible, it may be that stress related to dealing with an onslaught of vague and transient symptoms contributes to initial increased cognitive fatigue. With time, people may become more familiar with symptoms and are less overwhelmed and more able to concentrate.

Depression and Education, and Work Status

People who had more formal education reported fewer depressive symptoms. Higher education may contribute to better coping strategies, thus helping people feel in more control of their situation. Less depression may result from an increased sense of mastery or control over life in general. Alternatively, people who experience less depression may be more likely to complete more education. People in the current study who had undefined SLE symptoms as children were less likely to engage in post-secondary education, but there were no significant differences between current depression means of those who had early onset of symptoms and those whose symptoms started after completion of highschool.

People who were not working were significantly more depressed than those who were employed outside the home.

Disease Activity and Education, and Work Status

People who had more formal education reported less disease activity. It seems reasonable that people who have more disease activity will find it more difficult to complete higher education, and people in the current study who had undefined SLE symptoms as children were less likely to engage in post-secondary education. The finding that people who reported more disease activity were less likely to be working was also not surprising, and supports findings found with other chronic illness populations (Allaire et al., 1996; Gulick et al., 1989; Stenstrom, Lindell, Swanberg, Nordemar, & Harms-Ringdahl, 1992).

## Research Question Three

Research question three addressed whether fatigue and depression mediate the relationship between disease activity and quality of life. Although the sample was small, findings provide support for the conceptual model.

Disease activity has both direct and indirect effects on PQOL in people who have SLE. The value of the coefficient for the indirect path was similar to the coefficient for the direct path, indicating that fatigue and depression are important mediators between disease activity and quality of life in people who have SLE, as hypothesized in the conceptual model. In addition, the total effect

of disease activity on quality of life was higher when fatigue and depression were added to the equation, also supporting the theoretical model.

Fatigue and depression may mediate between disease activity and quality of life via the following sequence. First, increased disease activity contributes to increased fatigue. As severity of fatigue escalates, people are unable to maintain valued activities. Loss of valued activities, more than overall functional decline, has been found to be related to depressive symptoms (Eberhardt, Larsson, & Nived, 1993) or to contribute to depressive symptoms (Katz & Yelin, 1995) in people who have RA. As mentioned in chapter two, increased depressive symptoms have been linked to poorer PQOL. Because measurement of quality of life considers peoples' values, it seems reasonable to assume that disease activity effects PQOL via fatigue and depressive symptoms that result from loss of valued activities.

## Research Question Four

Research question four addressed the nature of fatigue in people who have SLE. Not surprisingly, people in the current study reported significant levels of fatigue for all dimensions. Because many of the fatigue measures have not been used in other studies, it is difficult to determine if these levels of fatigue are typical for other people who experience chronic fatigue.

### Characteristics of Physical Fatigue

Physical fatigue was experienced as unpleasant by the majority of the people in the current study. McKinley et al. (1995) also reported that people who had SLE tended to view fatigue as an unpleasant sensation. As expected, physical fatigue was also described by most subjects as feeling tired and unenergetic. The trend for people to not assess physical fatigue as sleepiness or listlessness was interesting. It may be that these items do not measure physical manifestations of fatigue, but rather represent cognitive or motivational aspects of fatigue. Some support for this premise exists in that patterns of responses were similar to those found with the three cognitive fatigue items. Responses tended to be around the mid-point for these items.

Characteristics of Cognitive Fatigue

Subjects chose the mid-point of the three cognitive items with the greatest frequency. The reason for this is not completely clear. However, when asked to explain their choices, one person stated that fatigue was unrelated to their ability to concentrate, remember, or think clearly. Other people, however, clearly stated that when their fatigue was at its worst, these aspects of cognition suffered. Most people who participated in the study were not experiencing their worst fatigue at the time of interview. It may be that cognitive fatigue occurs after physical and emotional fatigue have reached a critical level, similar to the idea voiced by some subjects that emotional fatigue occurs as a result of prolonged severe physical fatigue. Conversely, discussion of fatigue, an area of interest to most subjects, may have motivated them to focus and remain alert during the interview. Many subjects became noticeably excited about the chance to talk about their fatigue experiences.

Characteristics of Emotional Fatigue

Emotional fatigue was characterized by impatience, lack of contentment, uncontrollable mood swings, and unhappiness. Less conclusive, but significant support was found for irritability, anxiety, crying, and anger as manifestations of emotional fatigue in these people. Emotional fatigue has not been specifically assessed in the past, so comparisons to other findings is not possible. However, emotional fatigue was related to depression in the current study. Some participants stated that emotional fatigue resulted from extreme physical fatigue that lasted for an extended period of time. When people could not do what they wanted to do, they became emotionally drained. Many symptoms of emotional fatigue are similar to symptoms of depression. It may be that depression in people who have SLE occurs, in part, as a result of the frustrations of living with chronic fatigue.

Characteristics of Fatigue Uncertainty

As suspected, fatigue uncertainty was also a very important dimension of the fatigue experienced by study subjects. Unpredictability and ambiguity of fatigue were both legitimate aspects of fatigue uncertainty for many of these

people. Most subjects reported that their fatigue changed unpredictably, resulting in good days and bad days.

Fatigue ambiguity revolved primarily around lack of communication about fatigue between patients and health care providers. Communication road blocks may originate from patients or from health care professionals. In a report that explored fatigue in ankylosing spondylitis, clients were reluctant to disclose fatigue because they felt that their physician would either consider the complaint irrelevant, or would interpret fatigue as psychological, rather than physical, in origin (Calin et al., 1993). The social stigma associated with the psychological origin of a symptom may influence clients' decision to relate experiencing fatigue, or not. Health care workers' perception of symptoms may also influence the importance attached to a complaint, and the manner in which they respond to it. For example, Robinson and Posner (1992) found that nurse perception of fatigue duration and severity in clients who were undergoing biologic response modifier therapy did not correlate with what the clients stated they felt. The nurses in this study were also able to identify factors that clients felt worsened their fatigue with only 17% accuracy. These nurses did not understand the nature of the fatigue experienced by their patients, so were unable to respond appropriately.

Fatigue ambiguity may increase when complaints of fatigue by patients are ignored or explained solely as symptoms of depression, pain, or inadequate sleep. Depression, pain, and inadequate sleep may be legitimate fatigue related factors, however, these factors do not explain the whole experience of fatigue in many people. If fatigue is ignored or solely attributed to other causes, patients with SLE may begin either to doubt their ability to interpret their own body signals or experience growing frustration with lack of understanding by the health care community.

Other Fatigue Themes

An interesting theme voiced by some women in the current study was that fatigue fluctuated with their menstrual cycle. The reason for this is not clear, however, autoimmune diseases, including SLE, are more common in women

than in men. Prevalence of SLE is also higher post puberty. Decreased progesterone levels have been found in women who have SLE (Arnalich et al., 1992; Benito-Urbina, Huarte-Loza, Gijon-Banos, & Arnalich-Fernandez, 1995; Munoz, Gil, Lopez-Dupla, Vazquez, & Gonzalez-Gancedo, 1994) and elevated prolactin levels have also been correlated to increased SLE disease activity (Khamashata, Ruiz-Irastorza, & Hughs, 1997). All things considered, it seems reasonable to hypothesize that fatigue, in people who have SLE, is partly influenced by hormonal factors and further exploration of these relationships are warranted.

Another theme that came out of discussion of fatigue in the current study was the persistence and extremity of fatigue experienced by some people, at some times. People stated that, at times, nothing helped their fatigue and it simply had to run its course. As health care professionals, we need to keep this in mind when counseling clients on fatigue management. Pacing activities may be effective at some points, but not at others. Over-emphasis on this strategy may not be reasonable. Some people may choose to work through their fatigue, while others may choose to hibernate until the worst is over. We need to respect individual choices.

## Limitations of the Study

A number of limitations of the study need to be addressed, including the sample and study design. Measurement issues and limitations of the model are described as part of the design issues.

### Sample Limitations

The targeted sample size for the current study was 30, but the final sample consisted of 25 people, 24 of whom were women. The predominantly female sample was typical of other SLE studies. The sample was also similar to other studies for level of disease activity (mild to moderate), age, sex, and level of formal education. However, the number of subjects on long term disability was not typical. As previously mentioned, the method of recruitment may have restricted the variety of subjects in the sample. People who did not attend a community support group may have been under-represented. The average time

since diagnosis was also slightly different. It was lower than that found in other SLE studies. Finally, relying on self-report of health problems may have resulted in including subjects who had other conditions which could contribute to fatigue.

Although the sample size was smaller than anticipated, most correlations among the primary study variables were statistically significant. However, the small sample size limits generalizability of the findings to English speaking out-patients who have mild to moderate disease activity, and it affects the power of the path analysis results. These results must be considered to be exploratory.

## Study Design

Issues related to measurement and the model are addressed in the following sections.

### Measurement Issues

The 14-item fatigue scale was dropped from the study because of the degree of difficulty people experienced completing it. People experienced difficulty because responses to the tool were worded in such a way that subjects compared their current physical and mental fatigue to their normal state. These people had experienced years of chronic fatigue, so fatigue had become their normal state. The tool might be more appropriate for people who are experiencing acute fatigue or fatigue of shorter duration than what was experienced by subjects in this study.

The 14-Item scale had been specifically chosen because it was designed to measure physical and cognitive fatigue, two dimensions of fatigue that were of primary interest. Because the tool was dropped from the study, alternate ways of assessing these two dimensions were sought. As noted in chapter three, the sensory subscale of Piper's tool was used to assess physical fatigue because it contained items that were conceptually similar to the 14-Item physical fatigue measure. In addition, factor analysis of the data from the current study yielded a factor that contained all the items from Piper's sensory factor, plus 2 other items. One of these items, which asked participants to describe the effect fatigue had on sex, was deleted for two reasons. First, study participants frequently left it blank, and second, it did not conceptually fit the physical fatigue factor. Instead,

it could be viewed as a consequence of physical fatigue. The other item asked participants about the pleasantness or unpleasantness of fatigue. This item was retained in the final physical fatigue measure because it was conceptually close to other physical interpretations of fatigue.

Three items from Piper's Cognitive/Mood subscale were used to assess cognitive fatigue. These items were conceptually accurate measures of cognitive fatigue. In addition, they loaded as one factor in factor analysis of the current study data and they were internal consistency. However, three items may not assess the full breadth of cognitive fatigue experienced by the subjects.

The emotional fatigue and fatigue uncertainty subscales were used for the first time in the current study. Although both subscales were internally consistent, minimal psychometric testing of the scales limits assessment of their reliability and validity. In addition, subjects found it difficult to answer two items in the fatigue uncertainty subscale, so responses to these items may not have been accurate.

Limitations of the Model

The model used in the current study included three variables that affect PQOL in people who have SLE. Symptoms of SLE, such as pain, decreased mobility and sleep problems, may be other factors that impact on PQOL, but they were not measured. These variables were not measured because inclusion would have considerably extended an already lengthy interview. As a result, the model provides only a partial picture of the factors that may influence PQOL in people who have SLE.

Although the current study may have several limitations, it does provide a starting point for understanding the relationships among PQOL, fatigue, depression, and disease activity in people who have SLE.

## Implications of the Study

Implications of the current study are discussed in terms of implications for nursing practice, nursing education, nursing research, and implications for other health care personnel who work with people who have SLE.

## Nursing Practice

In the current study, people who experienced poorer PQOL experienced more fatigue, depression, and disease activity. While information about SLE disease activity and depression has been adequately addressed in the research literature, information about PQOL and its relationship to the experience of fatigue, depression and disease activity has not. However, if quality of life is a factor that is considered when health care and social policies are being developed (Ferrans & Powers, 1985), factors which affect it must be acknowledged, understood, and addressed. Fatigue is a factor that is closely related to PQOL in people who have SLE.

When people have limited energy and time, secondary to chronic fatigue, they must make choices about energy expenditure. Nurses need to understand that these choices are influenced by personal values and societal expectations. Nurses need to support clients in their choices. To support choices, nurses need to understand clients' priorities and perceptions about life. They can achieve understanding by encouraging clients to explore priorities and to discuss the level of satisfaction and the degree of importance they attach to aspects of their life. When nurses know what clients value and want, they are better able to help them to explore strategies that will assist them in achieving their goals. For example, if work is the client's priority, the nurse and client can explore ways to modify the work environment, work hours, or type of employment. If personal relationships are a priority for the client, spending limited energy on relationships is the client's goal. If the nurse's goal is to have the client return to work, they will be working against each other. Understanding the client's goals enables the nurse to work with, rather than against, the client. Understanding the experience of fatigue in people who have SLE will also facilitate the working relationship between nurses and people who have SLE.

Limited knowledge about fatigue contributes to the inability of nurses to facilitate successful fatigue coping strategies with their clients. Many nurses have only a limited understanding of how fatigue is experienced by people who have chronic illnesses. Fatigue in people who have SLE may occur during

periods of little obvious disease activity, so disease activity itself does not provide us with an accurate tool to anticipate levels of fatigue. By recognizing that fatigue may occur at any time and by listening to clients talk about their fatigue, health care professionals will acquire understanding of the fatigue experience. Listening to them talk about their fatigue helps health care providers to "walk in their clients' shoes". When we are able to see life as others see it, we are better able to help that individual achieve some sort of satisfactory balance among the many aspects of life. Talking also facilitates self-reflection for the client, which encourages self-discovery of patterns of fatigue and fatigue relief strategies, and can be the initial step toward some sense of control over fatigue.

In addition to discussion, routine assessment of fatigue and PQOL with reliable assessment tools would allow nurses to achieve a better understanding of fatigue, and enable them to help people make choices about where they want to put their time and energy. However, tools must be evaluated for accuracy in what they measure. Results of the current study provide support for the premise that fatigue in people who have SLE has physical, cognitive, emotional, and uncertainty dimensions. Nurses need to incorporate assessment of fatigue uncertainty into fatigue measurement in people who have SLE, which has not been included in tools in the past.

Answers to open ended questions from the current study suggests that fatigue management strategies used by participants do not provide consistent relief from fatigue. Instead, different strategies work better at different times. Sometimes nothing works but to "wait it out". Nurses need to keep in mind that there is no one right way to manage fatigue in people who have SLE. Sometimes fatigue is not controllable.

Health care providers need to spend more time talking about fatigue, increase our accuracy in assessing fatigue, and increase understanding of the nature, cause, and treatment of fatigue in chronic conditions in order to maximize the quality of life enjoyed by people with chronic illnesses. If fatigue is not discussed, it will remain under diagnosed and misunderstood.

Nurses need to be aware of the often lengthy time lapse between onset of symptoms and diagnosis of SLE, and they need to be sensitive to the manner in which they relate to people who are experiencing a variety of unexplained symptoms. Like the "pretenders disease" of the early 1900s, that was later recognized as multiple sclerosis, people who are dealing with unexplained symptoms of SLE can be very sensitive to subtle hints that their symptoms are "all in their head". A number of current study participants stated that the time between onset of symptoms and time of diagnosis was extremely stressful, not only because of the fear of the possibility of receiving a diagnosis of SLE, but also because of the non-supportive attitude of some health care providers that contributed to self-doubt and the feeling that they were "crazy". These attitudes may also contribute to depression in people who have SLE. Results from this study suggest that people who have SLE are potentially at risk for depression and that depression mediates the relationship between disease activity and PQOL. Depression may result from a variety of physical and stress related causes in these people. Nurses need to assess affect and be prepared to intervene when depression becomes an issue in order to maximize quality of life in people who have SLE.

## Nursing Administration

Subjects in the current study were not hospitalized. Most people who have SLE are treated primarily as outpatients and are admitted to hospital episodically when complications are severe. Increased disease activity was clearly related to increased fatigue in the current study. Nursing administrators need to be aware that fatigue may be extreme in acutely ill, hospitalized people who have SLE and inservices to staff about fatigue and its management need to be supported.

## Nursing Education

Fatigue is a life experience that is not discussed to any great degree during basic nursing education. Nurse educators need to spend more time discussing fatigue with students and staff to ensure a better understanding of how people experience fatigue. Educators need to discuss the multiple

dimensions of fatigue, including physical, cognitive, emotional, and uncertainty components, so students will understand the total experience of fatigue in various chronic and acute illness populations. Educators also need to develop skills in students that will enable them to help people determine how they want to use what energy and time they have. For example, values assessment skills may be included. Finally, educators need to discuss fatigue management strategies with students to improve students' competence in helping people cope with fatigue and achieve their aspirations.

## Nursing Research

The current, exploratory, cross-sectional study provides support for the hypothesis that relationships exist among disease activity, fatigue, depression and PQOL in people who have SLE, and it provides initial support for the hypothesis that fatigue and depression are mediators between disease activity and PQOL. Follow-up replication with a larger sample is warranted, and would provide a means for more accurate model testing and generalization to a larger population. In addition, a more accurate picture of the relationship among the variables over time would be obtained from a longitudinal study. Specifically, the possible changes in the relationship between fatigue and PQOL could be explored; it may be that as fatigue becomes more familiar and people adapt their life style to accommodate it, PQOL also changes. For example, PQOL may be quite different during the time period when major decisions in regards to employment and long-term disability are being made, versus five years later. A longitudinal study might also shed some light on the effect the energy expenditure decision making process has on PQOL.

The presence of fatigue and depression as mediators between disease activity and PQOL provides support for the premise that each are separate and unique concepts. Although measures of disease activity have been used to assess quality of life, they probably do not supply an accurate quality of life measure. This must be considered in future research.

## Implications for Other Health Care Personnel

SLE is a disease of variable, visible and invisible symptoms. Living with

potentially disabling, invisible symptoms, such as fatigue, is challenging to live with. Invisible symptoms cannot be described in concrete, measurable, objective terms. This may pose a problem to insurance companies when they are asked to provide long-term disability to an employee whose most disabling symptom is fatigue. Accurate measurement of fatigue, and knowledge of its relationship with PQOL may provide an insurance company with data from which a reasonable decision may be made about long-term disability. However, although there are a number of fatigue assessment tools available, most do not attempt to assess fatigue uncertainty. Fatigue unpredictability and ambiguity are major work related concerns in people who have SLE and should be considered when exploring fatigue in these people.

Uncertainty in SLE also results from the time lapse between onset of symptoms and a definitive diagnosis. Insurance companies need to bear in mind that considerable disability may occur prior to diagnosis. Braden (1990) found that people experienced less uncertainty once they were designated disabled.

## Summary

Although a small convenience sample was used in the current exploratory study, results indicate that relationships do exist among disease activity, fatigue, depression, and quality of life in people who have SLE. In fact, some of these relationships are very strong. Fatigue has a significant impact on peoples' lives. Initial support for the hypothesis that fatigue and depression are mediators between disease activity and quality of life was also found. All relationships of the conceptual framework were supported, however, directions of relationships were not fully explored. The current study results provide a strong base for future exploration of these variables in this population.

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Appendix A
The Quality of Life Index

Section A: Satisfaction

Directions: For each of the following please choose the answer that best describes how satisfied you are with that area of your life. Please circle the answer that is closest to your answer. There is no right or wrong answer.

1- Very dissatisfied
2- Moderately dissatisfied
3- Slightly dissatisfied
4- Slightly satisfied
5- Moderately satisfied
6- Very satisfied

How satisfied are you with:

| | | | | | | |
|---|---|---|---|---|---|---|
| 1. Your health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. The health care you receive? | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. The amount of pain you have? | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. The amount of energy you have for everyday activities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. Your ability to do things that use your hands and arms? | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. Your ability to get around? | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. The amount of control that you have over your life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Your potential to live a long time? | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. Your family's health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Your children? | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. Your family's happiness? | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. Your relationship with your spouse or significant other? | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. Your sex life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. Your friends? | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. The emotional support you get from others? | 1 | 2 | 3 | 4 | 5 | 6 |

1- Very dissatisfied
2- Moderately dissatisfied
3- Slightly dissatisfied
4- Slightly satisfied
5- Moderately satisfied
6- Very satisfied

| | | | | | | |
|---|---|---|---|---|---|---|
| 16. Your ability to meet family responsibilities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. Your usefulness to others? | 1 | 2 | 3 | 4 | 5 | 6 |
| 18.The amount of stress or worries in your life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 19. Your home? | 1 | 2 | 3 | 4 | 5 | 6 |
| 20. Your neighbourhood? | 1 | 2 | 3 | 4 | 5 | 6 |
| 21. Your standard of living? | 1 | 2 | 3 | 4 | 5 | 6 |
| 22. Your job (if employed)? | 1 | 2 | 3 | 4 | 5 | 6 |
| 23. Not having a job (if unemployed, retired or disabled)? | 1 | 2 | 3 | 4 | 5 | 6 |
| 24. Your education? | 1 | 2 | 3 | 4 | 5 | 6 |
| 25. Your financial independence? | 1 | 2 | 3 | 4 | 5 | 6 |
| 26. Your leisure time activities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 27. Your ability to travel on vacations? | 1 | 2 | 3 | 4 | 5 | 6 |
| 28. Your potential for a happy old age or retirement? | 1 | 2 | 3 | 4 | 5 | 6 |
| 29. Your peace of mind? | 1 | 2 | 3 | 4 | 5 | 6 |
| 30. Your personal faith in God? | 1 | 2 | 3 | 4 | 5 | 6 |
| 31. Your achievement of personal goals? | 1 | 2 | 3 | 4 | 5 | 6 |
| 32. Your happiness in general? | 1 | 2 | 3 | 4 | 5 | 6 |
| 33. Your life in general? | 1 | 2 | 3 | 4 | 5 | 6 |
| 34. Your personal appearance? | 1 | 2 | 3 | 4 | 5 | 6 |
| 35. Yourself in general? | 1 | 2 | 3 | 4 | 5 | 6 |

Section B: Importance

Directions: For each of the following please choose the answer that best describes how important that area of life is to you. Please circle the answer that is closest to your answer. There is no right or wrong answer.

1- Very unimportant
2- Moderately unimportant
3- Slightly unimportant
4- Slightly important
5- Moderately important
6- Very important

How important to you is:

| | | | | | | |
|---|---|---|---|---|---|---|
| 1. Your health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. The health care you receive? | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. The amount of pain you have? | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. The amount of energy you have for everyday activities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. Your physical independence? | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. Your ability to get around? | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. The amount of control that you have over your life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Your potential to live a long time? | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. Your family's health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Your children? | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. Your family's happiness? | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. Your relationship with your spouse or significant other? | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. Your sex life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. Your friends? | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. Emotional support? | 1 | 2 | 3 | 4 | 5 | 6 |
| 16. Meeting responsibilities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. Being useful to others? | 1 | 2 | 3 | 4 | 5 | 6 |

1- Very unimportant
2- Moderately unimportant
3- Slightly unimportant
4- Slightly important
5- Moderately important
6- Very important

| | | | | | | |
|---|---|---|---|---|---|---|
| 18. Having a reasonable amount of stress or worries? | 1 | 2 | 3 | 4 | 5 | 6 |
| 19. Your home? | 1 | 2 | 3 | 4 | 5 | 6 |
| 20. Your neighbourhood? | 1 | 2 | 3 | 4 | 5 | 6 |
| 21. Your standard of living? | 1 | 2 | 3 | 4 | 5 | 6 |
| 22. Your job (if employed)? | 1 | 2 | 3 | 4 | 5 | 6 |
| 23. Having a job? | 1 | 2 | 3 | 4 | 5 | 6 |
| 24. Your education? | 1 | 2 | 3 | 4 | 5 | 6 |
| 25. Your financial independence? | 1 | 2 | 3 | 4 | 5 | 6 |
| 26. Leisure time activities? | 1 | 2 | 3 | 4 | 5 | 6 |
| 27. The ability to travel on vacations? | 1 | 2 | 3 | 4 | 5 | 6 |
| 28. Having a happy old age or retirement? | 1 | 2 | 3 | 4 | 5 | 6 |
| 29. Peace of mind? | 1 | 2 | 3 | 4 | 5 | 6 |
| 30. Your personal faith in God? | 1 | 2 | 3 | 4 | 5 | 6 |
| 31. Achieving personal goals? | 1 | 2 | 3 | 4 | 5 | 6 |
| 32. Happiness? | 1 | 2 | 3 | 4 | 5 | 6 |
| 33. Being satisfied with life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 34. Your personal appearance? | 1 | 2 | 3 | 4 | 5 | 6 |
| 35. Are you to yourself? | 1 | 2 | 3 | 4 | 5 | 6 |

## Appendix B

### Piper Fatigue Scale

Directions: For each of the following questions, circle the number which best describes the fatigue you are experiencing now. Please make every effort to answer each question to the best of your ability. Thank you very much!

1. How long have you been fatigued? (*check one response only)*

a._____minutes
b._____hours
c._____days
d._____weeks
e._____months
f._____other (*please describe*):

2. To what degree is the fatigue you are feeling causing you distress?

No distress — A great deal of distress

0 1 2 3 4 5 6 7 8 9 10

3. To what degree is the fatigue you are feeling interfering with your ability to complete your work or school activities?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

4. To what degree is the fatigue you are feeling interfering with your ability to visit or socialize with your friends?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

5. To what degree is the fatigue you are feeling interfering with your ability to engage in sexual activity?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

6. Overall, how much is the fatigue you are experiencing now interfering with your ability to engage in the kind of activities you enjoy doing?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

7. How would you describe the degree of intensity or severity of the fatigue which you are experiencing now?

Mild — Severe

0 1 2 3 4 5 6 7 8 9 10

8. To what degree would you describe the fatigue which you are experiencing now as being:

Pleasant — Unpleasant

0 1 2 3 4 5 6 7 8 9 10

9. To what degree would you describe the fatigue which you are experiencing now as being:

Agreeable — Disagreeable

0 1 2 3 4 5 6 7 8 9 10

10. To what degree would you describe the fatigue which you are experiencing now as being:

Protective — Destructive

0 1 2 3 4 5 6 7 8 9 10

11. To what degree would you describe the fatigue which you are experiencing now as being:

Positive — Negative

0 1 2 3 4 5 6 7 8 9 10

12. To what degree would you describe the fatigue which you are experiencing now as being:

Normal — Abnormal

0 1 2 3 4 5 6 7 8 9 10

13. To what degree are you now feeling:

Strong — Weak

0 1 2 3 4 5 6 7 8 9 10

14. To what degree are you now feeling:

Awake — Sleepy

0 1 2 3 4 5 6 7 8 9 10

15. To what degree are you now feeling:

Lively — Listless

0 1 2 3 4 5 6 7 8 9 10

16. To what degree are you now feeling:

Refreshed — Tired

0 1 2 3 4 5 6 7 8 9 10

17. To what degree are you now feeling:

Energetic — Unenergetic

0 1 2 3 4 5 6 7 8 9 10

18. To what degree are you now feeling:

Patient — Impatient

0 1 2 3 4 5 6 7 8 9 10

19. To what degree are you now feeling:

Relaxed — Tense

0 1 2 3 4 5 6 7 8 9 10

20. To what degree are you now feeling:

Exhilarated — Depressed

0 1 2 3 4 5 6 7 8 9 10

21. To what degree are you now feeling:

Able to concentrate — Unable to concentrate

0 1 2 3 4 5 6 7 8 9 10

22. To what degree are you now feeling:

Able to remember — Unable to remember

0 1 2 3 4 5 6 7 8 9 10

23. To what degree are you now feeling:

Able to think clearly — Unable to think clearly

0 1 2 3 4 5 6 7 8 9 10

24. Overall, what do you believe is most directly contributing to or causing your fatigue?

25. Overall, the best thing you have found to relieve your fatigue is:

26. Is there anything else you would like to add that would describe your fatigue better to us?

27. Are you experiencing any other symptoms right now?

_____No _____Yes. Please describe:

Appendix C
14-Item Fatigue Scale

Directions: For each of the following please circle the answer that best describes your fatigue.

1- Better than usual
2- No more than usual
3- Worse than usual
4- Much worse usual

Physical symptoms

| | | | | |
|---|---|---|---|---|
| 1. Do you have problems with tiredness? | 1 | 2 | 3 | 4 |
| 2. Do you need to rest more? | 1 | 2 | 3 | 4 |
| 3. Do you feel sleepy or drowsy? | 1 | 2 | 3 | 4 |
| 4. Do you have problems starting things? | 1 | 2 | 3 | 4 |
| 5. Do you start things without difficulty but get weak as you go on? | 1 | 2 | 3 | 4 |
| 6. Are you lacking in energy? | 1 | 2 | 3 | 4 |
| 7. Do you have less strength in your muscles? | 1 | 2 | 3 | 4 |
| 8. Do you feel weak? | 1 | 2 | 3 | 4 |

Mental symptoms

| | | | | |
|---|---|---|---|---|
| 9. Do you have difficulty concentrating? | 1 | 2 | 3 | 4 |
| 10. Do you have problems thinking clearly? | 1 | 2 | 3 | 4 |
| 11. Do you make slips of the tongue when speaking? | 1 | 2 | 3 | 4 |
| 12. Do you find it more difficult to find the correct word? | 1 | 2 | 3 | 4 |
| 13. How is your memory? | 1 | 2 | 3 | 4 |
| 14. Have you lost interest in the things you used to do? | 1 | 2 | 3 | 4 |

## Appendix D
## Emotional Fatigue Scale

Part 1. General Emotional Fatigue

Directions: For each of the following please circle the answer that best describes your fatigue.

1- Rarely or none of the time
2- Occasionally or a little of the time
3- Some or a moderate amount of time
4- Most of the time

When I am fatigued...

| | | | | |
|---|---|---|---|---|
| 1. ...I am irritable. | 1 | 2 | 3 | 4 |
| 2. ...I am impatient. | 1 | 2 | 3 | 4 |
| 3. ...my mood swings. | 1 | 2 | 3 | 4 |
| 4. ...I am angry. | 1 | 2 | 3 | 4 |
| 5. ...I am frustrated. | 1 | 2 | 3 | 4 |
| 6. ...I am anxious. | 1 | 2 | 3 | 4 |
| 7. ...I am not confident. | 1 | 2 | 3 | 4 |
| 8. ...I am unhappy. | 1 | 2 | 3 | 4 |
| 9. ...I feel my emotions are out of control. | 1 | 2 | 3 | 4 |
| 10. ...I am calm. | 1 | 2 | 3 | 4 |
| 11. ...I am content. | 1 | 2 | 3 | 4 |
| 12. ...I am happy. | 1 | 2 | 3 | 4 |

Part 2. Emotional Fatigue Right now...

1- Strongly agree
2- Agree
3- Disagree
4- Strongly Disagree

| | | | | |
|---|---|---|---|---|
| 1. ...I am irritable. | 1 | 2 | 3 | 4 |
| 2. ...I am impatient. | 1 | 2 | 3 | 4 |
| 3. ...my mood swings. | 1 | 2 | 3 | 4 |
| 4. ...I am angry. | 1 | 2 | 3 | 4 |
| 5. ...I am frustrated. | 1 | 2 | 3 | 4 |
| 6. ...I am anxious. | 1 | 2 | 3 | 4 |
| 7. ...I am not confident. | 1 | 2 | 3 | 4 |
| 8. ...I am unhappy. | 1 | 2 | 3 | 4 |
| 9. ...I feel my emotions are out of control. | 1 | 2 | 3 | 4 |
| 10. ...I am calm. | 1 | 2 | 3 | 4 |
| 11. ...I am content. | 1 | 2 | 3 | 4 |
| 12. ...I am happy. | 1 | 2 | 3 | 4 |

## Appendix E
## Uncertainty in Illness-Community Form

Directions: For each of the following statements, circle the number which best describes your fatigue right now. If a statement can not be responded to in terms of fatigue, please answer it in terms of your lupus.

1- Strongly disagree
2- Disagree
3- Undecided
4- Agree
5- Strongly Agree

| | | | | | |
|---|---|---|---|---|---|
| 1. I don't know what is wrong with me. | 1 | 2 | 3 | 4 | 5 |
| 2. I have a lot of questions about fatigue without answers. | 1 | 2 | 3 | 4 | 5 |
| 3. I am unsure if my fatigue is getting better or worse. | 1 | 2 | 3 | 4 | 5 |
| 4. It is unclear how bad my fatigue will be. | 1 | 2 | 3 | 4 | 5 |
| 5. The explanations they give me about my fatigue seem hazy to me. | 1 | 2 | 3 | 4 | 5 |
| 6. The purpose of each treatment related to fatigue is clear to me. | 1 | 2 | 3 | 4 | 5 |
| 7. My fatigue continues to change unpredictably. | 1 | 2 | 3 | 4 | 5 |
| 8. I understand everything explained to me about my fatigue. | 1 | 2 | 3 | 4 | 5 |
| 9. The doctors say things to me about fatigue that could have many meanings. | 1 | 2 | 3 | 4 | 5 |
| 10. My treatment is too complex to figure out. | 1 | 2 | 3 | 4 | 5 |
| 11. It is difficult know if the treatments or medications I am getting are helping my fatigue. | 1 | 2 | 3 | 4 | 5 |
| 12. Because of the unpredictability of my fatigue, I cannot plan for the future. | 1 | 2 | 3 | 4 | 5 |
| 13. The course of my fatigue keeps changing. I have good days and bad days. | 1 | 2 | 3 | 4 | 5 |
| 14. I have been given many differing opinions about what is wrong with me. | 1 | 2 | 3 | 4 | 5 |
| 15. It is not clear what is going to happen to me. | 1 | 2 | 3 | 4 | 5 |

1- Strongly disagree
2- Disagree
3- Undecided
4- Agree
5- Strongly Agree

| | | | | | |
|---|---|---|---|---|---|
| 16. The results of my tests are inconsistent. | 1 | 2 | 3 | 4 | 5 |
| 17. The effectiveness of my fatigue treatment is undetermined. | 1 | 2 | 3 | 4 | 5 |
| 18. Because of the treatment, what I can do and cannot do keeps changing. | 1 | 2 | 3 | 4 | 5 |
| 19. I'm certain they will not find anything else wrong with me. | 1 | 2 | 3 | 4 | 5 |
| 20. The fatigue treatment I am receiving has a known probability of success. | 1 | 2 | 3 | 4 | 5 |
| 21. They have not given me a specific diagnosis. | 1 | 2 | 3 | 4 | 5 |
| 22. The seriousness of my fatigue has been determined. | 1 | 2 | 3 | 4 | 5 |
| 23. The doctors and nurses use every day language so I can understand what they are saying. | 1 | 2 | 3 | 4 | 5 |

## Appendix F
## General Fatigue Items

1. When my fatigue is the worst, I have (am):

| No fatigue | | | | | | | | | | Unable move |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

2. When my fatigue is the best, I have (am):

| No fatigue | | | | | | | | | | Unable to move |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

3. How many hours do you sleep each night?_____

4. Do you nap during the day?

_____yes
_____no
_____sometimes
If you nap, for how long?_____

5. Has your fatigue been constant?

_____yes
_____no

Please explain if your fatigue has not been constant:

## Appendix G
## Centre for Epidemiological Studies-Depression Scale

Directions: Below is a list of ways you might have felt or behaved. Please tell us how often you felt this way during the past week by circling the number which best describes how you have felt in the past week.

0- Rarely or none of the time
1- Occasionally or a little of the time (1 or 2 days)
2- Some or a moderate amount of the time (3 or 4 days)
3- Most of the time (5 or 7 days)

During the past week:

| | | | | |
|---|---|---|---|---|
| 1. I was bothered by things that don't usually bother me. | 0 | 1 | 2 | 3 |
| 2. I did not feel like eating; my appetite was poor. | 0 | 1 | 2 | 3 |
| 3. I felt that I could not shake off the blues, even with help from my family or friends. | 0 | 1 | 2 | 3 |
| 4. I felt that I was just as good as other people. | 0 | 1 | 2 | 3 |
| 5. I had trouble keeping my mind on what I was doing. | 0 | 1 | 2 | 3 |
| 6. I felt depressed. | 0 | 1 | 2 | 3 |
| 7. I felt that everything I did was an effort. | 0 | 1 | 2 | 3 |
| 8. I felt hopeful about the future. | 0 | 1 | 2 | 3 |
| 9. I thought my life had been a failure. | 0 | 1 | 2 | 3 |
| 10. I felt fearful. | 0 | 1 | 2 | 3 |
| 11. My sleep was restless. | 0 | 1 | 2 | 3 |
| 12. I was happy. | 0 | 1 | 2 | 3 |
| 13. I talked less than usual. | 0 | 1 | 2 | 3 |
| 14. I felt lonely. | 0 | 1 | 2 | 3 |
| 15. People were unfriendly. | 0 | 1 | 2 | 3 |
| 16. I enjoyed life. | 0 | 1 | 2 | 3 |
| 17. I had crying spells. | 0 | 1 | 2 | 3 |
| 18. I felt sad. | 0 | 1 | 2 | 3 |
| 19. I felt that people disliked me. | 0 | 1 | 2 | 3 |
| 20. I could not get "going". | 0 | 1 | 2 | 3 |

## Appendix H
## Self-Administered Systemic Lupus Activity Index

Directions: Please circle thee answer that best describes your lupus in the last 3 months.

Part 1: General

In the past 3 months....

1. ...have you had a lupus flare?
   No - 0 Mild - 1 Moderate - 2 Severe - 3

2. ...have you seen a doctor for your lupus?
   No - 0 Yes - 1 If yes, how many visits?_____

3. ...has your doctor mentioned any change in your kidney function?
   No - 0 Yes - 1 If yes, is it better - 1
   worse - 2

4. ...have you been hospitalized for your lupus?
   No - 0 Yes - 1 If yes, how many days?_____

5. ...did your doctor increase your prednisone?
   No - 0 Yes - 1 I am not taking prednisone - 8

6. ...has your lupus been...
   much better - -2 better - -1 same - 0 worse - 1 much worse - 2

7. ...have you had any other medical problems?
   No - 0 Yes - 1 If yes, describe_____

Part B: Symptoms

Directions: Please circle the answer that best describes your lupus during the past 3 months.

None- 0
Mild- 1
Moderate- 2
Severe- 3

In the past month, I have had.....

| | | | | |
|---|---|---|---|---|
| 1. ...weight loss, without trying | 0 | 1 | 2 | 3 |
| 2. ...fatigue | 0 | 1 | 2 | 3 |
| 3. ...fevers | 0 | 1 | 2 | 3 |
| 4. ...sores in mouth or nose | 0 | 1 | 2 | 3 |
| 5. ...rash on cheeks (butterfly) | 0 | 1 | 2 | 3 |
| 6. ...other rash | 0 | 1 | 2 | 3 |

None- 0
Mild- 1
Moderate- 2
Severe- 3

| | | | | |
|---|---|---|---|---|
| 7. ...dark blue or purple spots you could feel on your skin | 0 | 1 | 2 | 3 |
| 8. ...rash or feeling sick after going in the sun | 0 | 1 | 2 | 3 |
| 9. ...bald patches on scalp, or clumps of hair on pillow | 0 | 1 | 2 | 3 |
| 10. ...swollen glands | 0 | 1 | 2 | 3 |
| 11. ...shortness of breath | 0 | 1 | 2 | 3 |
| 12. ...chest pain with deep breath | 0 | 1 | 2 | 3 |
| 13. ...fingers or toes turning dead white | 0 | 1 | 2 | 3 |
| 14. ....stomach or belly pain | 0 | 1 | 2 | 3 |
| 15. ...numbness or tingling in your arms or legs | 0 | 1 | 2 | 3 |
| 16. ...seizures | 0 | 1 | 2 | 3 |
| 17. ...stroke | 0 | 1 | 2 | 3 |
| 18. ...forgetfulness | 0 | 1 | 2 | 3 |
| 19. ....feeling depressed | 0 | 1 | 2 | 3 |
| 20. ...unusual headaches | 0 | 1 | 2 | 3 |
| 21. ...muscle pain | 0 | 1 | 2 | 3 |
| 22. ...muscle weakness | 0 | 1 | 2 | 3 |
| 23. ...pain or stiffness in joints | 0 | 1 | 2 | 3 |
| 24. ...swelling in joints | 0 | 1 | 2 | 3 |

Part C: Overall Disease Activity

Directions: Please circle the number that best describes your disease activity during the past 3 months.

| No activity | | | | | | | | | | Most activity |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

## Appendix I
## Demographic Data

Directions: Please fill in the following information.

1. Your age on your last birthday____

2. Sex: _____Male
_____Female

3. Marital status: _____Single
_____Married
_____Divorced
_____Separated
_____Widowed
_____Other

4. How far did you go in school_____

5. Are you employed outside the home?

_____Yes. If yes, are you working _____full time
_____part time

_____No. If no, are you _____retired
_____unemployed

6. When were you first diagnosed with lupus?_____

7. When did you first have symptoms?_____

8. Please list the medications you are now taking:

9. When your fatigue has been bad in the past, what medications were you taking?

Appendix J
Information Letter
Living with fatigue in systemic lupus erythematosus

Investigators :Janet Jeffrey, RN, PhD
Mary Van Soeren, RN, PhD
Janet Pope, MD, Rheumatologist
Candice Bray, RN, MScN Student

Dear Patient,

The purpose of this study is to find out more about fatigue in lupus, and to find out how fatigue may affect people's satisfaction with their quality of life.

What you are being asked to do is to meet with me for about 1 and 1/2 hours to fill in a questionnaire and answer questions about fatigue. Parts of the interview will be audio (tape) recorded. You may ask that the recorder be turned off at any time, or if you do not wish your interview to be recorded. please let me know and I will not tape it.

There are five parts to the questionnaire. The first part asks for general information, such as your age. The following parts deal with fatigue, quality of life, depression and disease activity. They may not be in this order. Please complete them in the order you find them in your package.

Since a questionnaire cannot tell the whole story, I (Candice Bray) would like to be present when you complete the forms. This gives you an opportunity to tell me more about your fatigue. We can meet at your home, or a room will be available to use at Dr. Pope's office. Please let me know which you prefer.

What you say to me, or what you write on your questionnaire will be confidential and anonymous. Your name will not be on any form or transcriptions of audio tapes. Consent forms will be kept in a different place from questionnaires and will be available only to me. In addition, when discussing this research with my research committee, no names will be used. The results from this study will be reported in a thesis as a requirement of a Master of Science in Nursing degree.

Questionnaires and interviews take time and energy. If you choose to participate you may refuse to answer any of the questions, and you are free to end the interview at any time. Refusing to take part in the study or withdrawing from the study will not affect the health care you receive.

There are no direct benefits to you from this study. However, nurses and doctors may gain a better understanding of fatigue and how it affects your life. This may have positive affects on how they care for people with lupus in future. The only cost to you in participating in the study will be the time you spend.

If you would like more information, please give me a call. Or if you let Dr. Pope know of your interest, she will give me your name and I will phone you. I can be reached through my research advisor, Dr. Janet Jeffrey, at The University of Western Ontario at (519) 679-2111, Ext. 6602. Please leave a message and I will return your call.

Thank you for your interest and I look forward to meeting you!

Sincerely,
Candice Bray, BA, RN, BScN
Graduate Student
Faculty of Nursing
University of Western Ontario,
London, Ontario N6A 5B8

## Appendix K
## Consent

**Living with fatigue in systemic lupus erythematosus**

I have read the information letter attached to this form, which explains the research study. I understand what I am being asked to do. I agree to take part in this study. All questions have been answered to my satisfaction.

Signature:_____

Date:_____

# Appendix L

*The* UNIVERSITY *of* WESTERN ONTARIO

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THE REVIEW BOARD HAS EXAMINED THE RESEARCH PROJECT ENTITLED:
"Living with fatigue in systemic lupus erythematosus."

REVIEW NO: ES363R

AS SUBMITTED BY: Dr. J. Jeffrey (C.Bray), Nursing, Health Science Centre

AND CONSIDERS IT TO BE ACCEPTABLE ON ETHICAL GROUNDS FOR RESEARCH INVOLVING HUMAN SUBJECTS UNDER CONDITIONS OF THE UNIVERSITY'S POLICY ON RESEARCH INVOLVING HUMAN SUBJECTS.

APPROVAL DATE: 04 April 1997 (questionnaire added to the study)

AGENCY:

TITLE:

Bessie Borwein, Chairman

c.c. Hospital Administration

London, Ontario • Canada • N6A 5C1 • Telephone: (519) 661-3036

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THE REVIEW BOARD HAS EXAMINED THE RESEARCH PROJECT ENTITLED:
"Living with fatigue in systemic lupus erythematosus."

REVIEW NO: E5363

AS SUBMITTED BY: Dr. J. Jeffrey (C. Bray), Nursing, Health Science Centre

AND CONSIDERS IT TO BE ACCEPTABLE ON ETHICAL GROUNDS FOR RESEARCH INVOLVING HUMAN SUBJECTS UNDER CONDITIONS OF THE UNIVERSITY'S POLICY ON RESEARCH INVOLVING HUMAN SUBJECTS.

APPROVAL DATE: 19 June 1995 (UWO Protocol, Letter of Information & Consent)

AGENCY: IODE (Candice Bray)

TITLE: Same as above

Bessie Borwein

Bessie Borwein, Chairman

c.c. Hospital Administration

## Appendix M
## Internal Consistency of Study Instruments

| Variable and Instrument | Cronbach alpha |
|---|---|
| Quality of Life | |
| Quality of Life Index | |
| Total | .87 |
| Health /Functioning | .80 |
| Socioeconomic | .87 |
| Psychospiritual | .90 |
| Family | .62 |
| Fatigue | |
| Piper Fatigue Scale | |
| Total | .97 |
| Behavioral/Severity | .92 |
| Affective meaning | .86 |
| Sensory | .93 |
| Cognitive/mood | .92 |
| Physical Fatigue | .93 |
| Cognitive Fatigue | .95 |
| Emotional Fatigue Scale | |
| General Emotional | .89 |
| Emotional Fatigue Now | .94 |
| Fatigue Uncertainty | .86 |
| Depression | .89 |
| Disease Activity | |
| Total | .89 |

## Appendix N
## Interpretation of Correlation Coefficients

| | |
|---|---|
| **Weak** | $r < .35$ |
| **Moderate** | $r$ .35 to .6 |
| **Moderately strong** | $r$ .6 to .7 |
| **Strong** | $r > .7$ |

UIC The University of Illinois at Chicago

Department of Medical-Surgical Nursing (M C 802)
College of Nursing
845 South Damen Avenue, 7th Floor
Chicago, Illinois 60612-7350
(312) 996-7900

March 5, 1996

Ms. Candice Bray
23381 McEvoy Rd.
R.R. #2
Mount Brydges, Ontario
Canada N0L 1W0

Dear Ms. Bray:

Thank you for your interest in the Ferrans and Powers Quality of Life Index (QLI). I have enclosed the generic version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, social and economic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate the subscale scores and overall scores.

At the present time there is no charge for use of the QLI. You have my permission to use the QLI for your study. In return, I ask that you send me a photocopy of all publications of your findings using the QLI. I then will add your publication(s) to the list that I send out to persons who request permission to use the QLI.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
Assistant Professor

BARBARA F. PIPER, D.N.Sc., R.N., O.C.N., F.A.A.N.
190 PROFESSIONAL CENTER PARKWAY
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FAX: 415-472-1175
OFFICE: 415-472-1140

2/12/96

Candice

C - Keep me posted on your research -

Dear ~~Colleague~~:

Thank you for expressing interest in using the Piper Fatigue Scale (PFS) in your research. You have my permission to use the PFS in your study. In exchange for this permission however, I make only two requests.

The first request is that you furnish me with selected demographic data about your sample (i.e., age, gender, diagnosis) and PFS scoring information (i.e., mean subscale and total fatigue scores, standard deviations, reliability and validity estimates). This will enable me to continue to revise and collate information on the PFS across samples. Secondly, I would appreciate receiving from you a cashier's check or money order in the amount of $25.00 to cover PFS duplicating and mailing charges. (See enclosed agreement form). Of course, it goes without saying that I would be delighted to receive a copy or reprint of your published study, thesis or dissertation! If necessary, I will gladly reimburse you for expenses in duplicating and mailing your copy to me.

PFS CURRENT FORMAT AND SCORING INSTRUCTIONS: The PFS in its current form (7/10/95) is composed of 22 numerically-scaled, "0" to "10" items which measure four dimensions of subjective fatigue: behavioral/severity (6 items; #2-7); affective meaning (5 items: #8-12); sensory (5 items: #13-17); and cognitive/mood (6 items: #18-23). These 22 items are used to calculate the four subscale/dimensional scores and the total fatigue score. Four additional items (#1 and #24-27), are not used to calculate subscale or total fatigue scores, but are recommended to be kept on the scale as these items furnish rich, qualitative data. Item #1, in particular gives a categorical way in which to assess the duration of the respondant's fatigue.

To score the PFS, add the items contained on each specific subscale together and divide by the number of items on that subscale. This will give you a subscale score that remains on the same "0" to "10" numeric scale. Should you have missing item data, and the respondant has answered at least 75%-80% of the remaining items on that particular subscale, calculate the subscale mean score based on the number of items answered, and substitute that mean value for the missing item score (mean-item substitution). Recalculate the

subscale score. To calculate the total fatigue score, add the 22-item scores together and divide by 22 in order to keep the score on the same numeric "0" to "10" scale.

These dimensions have been confirmed statistically in a recently completed methodological study (Piper, et al, in press) that used a principal [redacted]s factor analysis with oblique [redacted] rotation on a mailed, cross-sectionally-designed study's data set of 715 Philadelphia women with breast cancer.[93] As the results of this analysis have not yet been published, I would appreciate it if you would treat this information as "priviledged personal communication."

In this methodologic study, the the numeric version of the PFS was used for the factor analysis. A five factor/subscale solution originally was identified. As the fifth factor had only two items, #9: "Ability to bathe/wash" and #11: "ability to dress", these items and factor were dropped from the final version of the PFS. Nine items did not load on any factor: 1-3, 4a, 4c, 5, 10, 26, & 29; thus, these items were dropped from the final version. The remaining four factors/subscales were then reviewed to insure that inter-item correlations were between .30-.70; the number of items in each subscale were five or more; the standardized alpha did not drop below .89; and all gender specific items were deleted.

Nine items originally loaded on Factor 1, the "Behavioral/Severity Subscale": 4b, 6-8, 12-16. Three of these items were dropped from the final subscale: 4b, 7 & 8. Thus, 6 items remain on the final version of this subscale: 6, 12-16. Five items loaded on Factor 2, the "Affective Meaning Subscale": 17a-17e. All five items were retained in the final version of this subscale. Eight items originally loaded on Factor 3: the "Sensory Subscale": 18-25. Items 18, 22, & 25 were deleted; leaving five items: 19-21, & 23, 24 in the final version of this subscale. Eight items originally loaded on Factor 4, the "Cognitive/Mood Subscale": 27- 28, & 30-35. Items 27 and 30 were dropped; leaving six items: 28, 31-35 in the final version of this subscale.

The standardized alpha did not drop below .89 for any of the subscales, and the standardized alpha for the entire scale (N=22 items) was .966, indicating some redundancy among the items is still present. Additional revisions however, will await further testing. For your information, a copy of the earlier PFS version, with retained items and their indicated subscale identifiers is enclosed.

**HISTORY AND BACKGROUND OF THE PFS:** The scale, when it originally was developed[75] was in two forms, a baseline form (PFS-B) designed to measure usual patterns of fatigue and any changes experienced six months prior to

diagnosis/treatment, and a current form (PFS-C), that determined fatigue patterns "now" or "for that day". Items were measured on "0"-"100" visual analogue scales (VASs). There were seven subscales or dimensions thought to be representative of subjective fatigue on these earlier versions of the PFS: temporal, intensity/severity, affective, sensory, evaluative, relief, and associated symptoms. Only items contained on the four subscales temporal, intensity/severity, affective, and sensory were used to calculate fatigue subscale and total fatigue scores. There were 42 items on the PFS-B; 40 on the PFS-C.

Internal consistency reliability estimates (Cronbach's alpha) for the PFS-B subscales ranged from .69 for the associated symptoms dimension to .95 for the sensory dimension in a sample of radiation therapy patients (35 breast and 15 lung cancer patients). Face and content validity of the items were determined by a review of the literature, pain and fatigue theories, and by an 11-member, national fatigue expert panel review. Concurrent validity estimates were determined by significant correlations between the subscale and mood disturbance scores of the Profile of Mood States (POMS), and the Fatigue Symptom Checklist subscale and total fatigue scores (FSCL). Moderate evidence for discriminant and convergent validity was found. Cluster analysis provided evidence for the PFS-B's initially proposed multidimensionality.[75]

As the PFS-C items were essentially identical to the items on the PFS-B with the exception of the two additional items and the "during the past six months" phrasing, it was decided to drop the PFS-B format and to proceed with the PFS-C only. Two versions were subsequently tested ("0"-"100" VAS and a "0"-"10" numeric format). As less missing data occurred on the numeric version and the supposed increase in measurement sensitivity from the VAS did not seem to be clinically significant, I chose to use the numeric version in my subsequent studies.

In a growing series of investigations that have used the VAS form of the PFS however, PFS reliability and validity estimates consistently are reported to be moderate to strong (see Tables 11-14). Please note that the subscale/dimension scores are based on the original dimensions and items contained on the PFS-C. Items on the original "temporal dimension subscale" with the exception of #3, the categorical duration question, were not retained in the final 22-item numeric version of the PFS. Items #6, 12-16, part of the original "Severity Subscale" were retained in the final "Behavioral/Severity Subscale." All items (#17a-17e) on the original "Affective Subscale" were retained in the "Affective Meaning Subscale." Items 19-21, 23-24, part of the original "Sensory Subscale" were retained in the final "Sensory Subscale." Items 28, 31-34, originally part

of the "Sensory Subscale" were retained and relabeled as part of the new "Cognitive/Mood Subscale." No data are yet available on the 22-item, subscale scores and total fatigue scores with the exception of my most recent study.

I hope that this material will be useful to you. Should you require any additional information or clarification, please do not hesitate to call or FAX me.

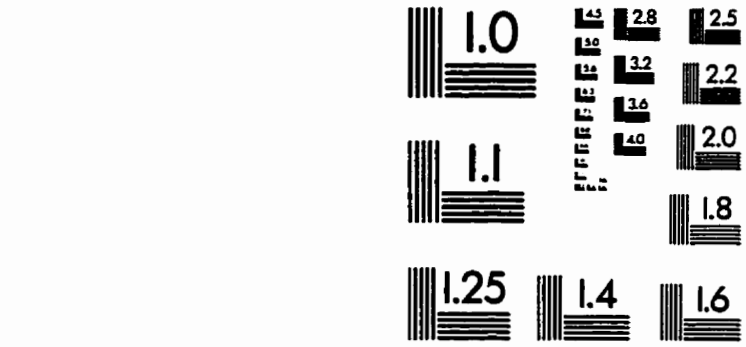
Sincerely,

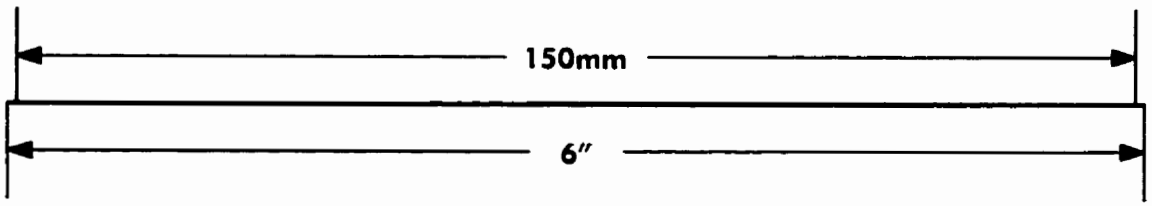
Barbara F. Piper

Dr. Barbara F. Piper, R.N.

Piper, B.F., Dibble, S.R., Dodd, M.J., Weiss, M., Slaughter, R., & Paul, S. (In Press). The revised Piper Fatigue Scale: Confirmation of its multidimensionality and reduction in the number of items in women with breast cancer [Abstract]. Oncology Nursing Forum Supplement.

TEST TARGET (QA-3)

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