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The Relationship of Perceived Social Support, Health Status, and Quality of Life in Female Systemic Lupus Erythematosus Patients

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THE RELATIONSHIP OF PERCEIVED SOCIAL SUPPORT, HEALTH STATUS, AND QUALITY OF LIFE IN FEMALE SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS

by

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Master of Arts, University of New Haven, 1993

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This dissertation, submitted by Seanne S. Tyson in partial fulfillment of the requirements for the degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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This dissertation meets the standards for appearance conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

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Date May 27, 1997

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In Loving Memory of my Mother

Linda Terry

and my "Grandmothers"

Doliska Tyson, Millie Carpenter, Billie-Ann Schwedes, & Cruz Gasporra

ABSTRACT

This study was designed to explore the relationship among perceived social support, health status, and quality of life in a sample of female Systemic Lupus Erythematosus (SLE) patients. A strong positive correlation was found between perceived social support and quality of life. Negative correlations were found between perceived health status and perceived social support, and perceived health status and quality of life. Last, a negative correlation was found between objective health status and quality of life. In multiple regression analyses, perceived social support explained a significant amount of variance in the quality of life variable in conjunction with both observed health status and perceived health status. This study has important implications for workers in the health care industry. It is important for health care providers to pay attention to not only the physical, but also to the psychosocial components of health care delivery in relation to SLE patients. Because there is no known cure for SLE, attention needs to be focused on helping the SLE patient improve her life quality. This study has shown that both perceived health status and quality of life are related to social support and suggests that when working with patients with chronic illness such as SLE, the introduction of social support information may prove to be a very important component to a holistic treatment of mind and body.

CHAPTER I

INTRODUCTION

Systemic Lupus Erythematosus (SLE) or lupus is a chronic autoimmune disease that can cause damaging inflammation of various body parts, especially the skin, joints, blood, and kidneys. Lupus patients may suffer symptoms ranging from cardiopulmonary complications to central nervous system disease, such as epileptic-type seizures, memory loss, confusion, and psychosis (Dibner & Colman, 1994; Steinman, 1993; Aladjem, 1982). About five hundred thousand Americans have lupus with about sixteen thousand new cases diagnosed each year. More than 90 percent of lupus patients are women, a statistic which corresponds to 1 in 500 women being diagnosed with this baffling disease (Dibner & Colman, 1994). Because lupus has no known cure (Dibner & Colman, 1994; Kelly, Harris, Ruddy, & Sledge, 1985; Aladjem, 1982), much research has focused on helping lupus patients to live well despite the disease (Dibner & Colman, 1994; Falk, 1994). One research emphasis has been to understand factors that will help those with chronic illness to improve their quality of life (Nunes, Raymond, Nicholas, Leurer, & Webster, 1995; Krol, Saunderman, & Suurmeijer, 1993; Kober, Kuchler, Broelsch, Kremer, & Henne-Bruns, 1990).

Quality of Life

The definition of quality of life is elusive, in spite of frequent references to the concept quality of life in health care research, professional literature and the public press (Ferrans & Powers, 1985; Shaw, 1977). Disagreement exists among researchers as to both the specific dimensions that should be included in the construct quality of life and how these dimensions should be measured (Nunes et al., 1995). Miller (1983) stated that quality of life is a concept that contains no consistent or universal meaning. He went on to define quality of life as being the ability to maximize satisfaction by learning to live life to its fullest and functioning to the optimum of one's capabilities in all stages of life. Lubkin (1990) stated that life quality may be influenced by four theoretical components of the total human condition: (a) the physical, (b) the psychosocial, (c) the spiritual, and (d) the cultural. She contends that all four variables are important, and require management and attention to maintain an intact functional system. Lubkin (1990) stated that the goal of quality of life research should be to help individuals with chronic illnesses obtain "optimal functioning at the highest level of independence" (Lubkin, 1990, p. 138). Ferrans and Powers (1992) defined quality of life as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (p. 29). The four quality of life dimensions recognized by Ferrans and Powers (1985) included (a) health and functioning, (b) socioeconomic aspects, (c) psychological/spiritual aspects, and (d) family (Nunes et al., 1995).

Social Support

One way in which health care providers and researchers have tried to improve quality of life for patients with chronic illness is through the use of social support (Nunes et al., 1995; Hanestad & Albreksten, 1993; Krol et al., 1993; Kober et al., 1990; Magilvy, 1985). It has been shown that individuals diagnosed with the same chronic condition of approximately the same severity, who are receiving the same treatments can have a considerable variation in disease progression, recovery, and adaptation to living with the condition (Lindsey, 1992). The construct of social support has been studied in relation to the variability of disease progression, recovery, and adaptation. Broadhead et al. (1983) found that social support may have a protective function and may be related to positive health outcomes. Conversely, loss of or lack of social support has been linked with illness and disease progression (White, Richter, & Fry, 1992; Cohen, 1979). White et al. (1992) assessed the impact of potential stressors, such as actual and perceived health status, coping strategies, and perceived social support, on the psychosocial adaptation of women with diabetes mellitus. They found that health status (actual and perceived) significantly influenced perceived social support ($\beta = .28$, $p < .05$). Additionally, White et al. (1992) found that stressful life events, health status, palliative coping, and perceived social support had a direct impact on psychosocial adjustment of the chronically ill patient, accounting for 56% of the variance in the regression equation.

Cobb (1976) defined social support as the individual's belief or perception that he or she is cared for and is a member of a network of mutual obligations. Cobb proposed that individuals under a great amount of stress who have access to supportive social ties do not or will not develop the adverse health consequences that their counterparts who felt isolated or unsupported do (Cobb, 1976). Lindsey, Norbeck, Carrieri, and Perry (1981) described the social support system as consisting of a group of persons whose interpersonal relationships satisfy specific social needs of the individual. The network may include family, friends, professional contacts, or self-help groups. Norbeck (1988) asserted that when a person's social network is sparse, surrogate support must be provided. She defined surrogate support as "the provision of support by a professional that is designed to replace the support that is inadequate or unavailable from the person's support network" (Norbeck, 1988, p. 102). This support can be temporary, as in a crisis situation, or may be provided on an ongoing, long-term basis for individuals with more chronic needs (Nunes et al., 1995).

Relationship of Social Support and Quality of Life

Over the last decade, researchers have begun to investigate the relationship between social support and quality of life in those with chronic and acute medical conditions (Nunes et al., 1995; Hanestad & Albreksten, 1993; Krol et al., 1993; Gilden et al, 1992; Magilvy, 1985). Nunes et al. (1995) investigated the relationship between social support and quality of life in 50 HIV-positive individuals. The patients were self-selected into one of three conditions: (a) participants in support groups at an outpatient behavioral medicine clinic, (b) inpatient or respite care patients with HIV, or (c) respondents to advertisements at AIDS service organizations. The study found that social support was significantly correlated with quality of life ($\underline{r} = .81$, $\underline{p} < .0001$). Additionally, HIV status (asymptomatic HIV, symptomatic HIV, AIDS) was significantly related to quality of life ($\underline{r} = .36$, $\underline{p} < .01$). HIV status, however, was not significantly related to social support (Nunes et al., 1995).

SLE, Social Support, and Quality of Life

Few studies have looked directly at the relationship between SLE and quality of life. Burckhardt, Archenholtz, and Bjelle (1993) assessed the quality of life and health status of 50 women with SLE and compared them with 50 age matched women with Rheumatoid Arthritis (RA) using open ended questions, the Quality of Life Scale (QOLS-S; Flanagan, 1978), Arthritis Impact Measurement Scales (AIMS; Meenan, Gertman, & Mason, 1980), Rheumatology Attitude Index (RAI; Nicassio et al., 1985), and two measures of disease activity. They found that the patients with SLE expressed more concerns about their disease and potential for managing it than the patients with RA. There were no differences found between the two groups on the QOLS-S. It was shown that both groups were highly satisfied with many aspects of their lives. The best predictor of life quality in both groups was psychological distress followed by social and physical functioning in the group with RA and perception of global impact of the disease in the SLE group. Burckhardt et al. (1993) stressed the importance of attending to and placing a great importance on the psychological well-being, as well as, the physical well-being of the patient in treating SLE and attempting to improve life quality.

There has apparently been no research on quality of life and social support or support groups that has focused on any type of lupus population. Studies have found a positive correlation between social support and quality of life in patients with AIDS (Nunes et al., 1995), insulin-dependent diabetes mellitus (Hanestad & Albreksten, 1993), rheumatoid arthritis (Krol et al., 1993) and in hearing impaired older women (Magilvy, 1985). An investigation into the relationship of quality of life , perceived social support, and health status in an SLE population was a timely and logical next step toward understanding social support, quality of life, and chronic illness.

Purpose of the Study

My primary purpose with this study was to examine the relationship among health status, perceived social support and quality of life in women diagnosed with systemic lupus erythematosus (SLE). I also examined the reasons why women with SLE choose not to attend support groups.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

Because it is fundamental to the understanding of SLE, I began this literature review with the concept of chronic illness and the adaptations that those with chronic illnesses must make when trying to cope with their illness. Next, I provide an overview of the medical and psychosocial aspects associated with the chronic, rheumatic disorder SLE. I then review, in turn, the primary constructs in this study; health status, quality of life, and perceived social support. Finally, I close this review with a discussion of the lack of research studies relating social support and quality of life in any type of SL population.

Chronic illness and the Rheumatic Disorders

Throughout history, humans have recognized the presence of illness and have attempted to repair or minimize the damages of disease. Health care providers deal with a great variety of health issues that range from the acute to the chronic. Many researchers have attempted to present an all-encompassing, clear definition of chronic illness. The characteristics of chronic diseases have been identified by the Commission on Chronic Illnesses to be all impairments or deviations from normal that include one or more of the following: permanency, residual disability, non pathological alteration, required rehabilitation, and a long period of supervision and care (Roberts, 1955). Feldman (1974) defined chronic illness as an ongoing medical condition with a spectrum of social, economic, and behavioral complications that require meaningful and continuous personal and professional involvement. Cluff (1981) defined chronic illness as a condition, not cured by medical intervention, requiring periodic monitoring and supportive care to reduce the degree of illness, and maximize the patient's ability for self-care.

It is difficult to precisely define chronic illness because it takes on so many forms. Lubkin (1990) offers the following: "Chronic illness is the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self care, maintenance of function, and prevention of further disability" (p.6). Chronic illness tends to affect many facets of one's life including social, psychological, physical, and economic aspects. Adapting successfully to chronic illness requires a recognition that the resulting improvements in quality of life are worth the struggle and hard work of adapting and changing to the new life circumstances.

In the past, much more attention was paid to the medical etiology and treatment of chronic illness than to the psychosocial aspects or ramifications of having a chronic illness. Recently more attention is being paid to the social and psychological aspect of chronic disease by psychiatrists, nurse scientists and behavioral scientists (Strauss et al., 1984). Gerson and Strauss (1975) provide a useful framework for the salient common features of chronic illness and the impact of the illness on the patient. The following characteristics of chronic illness are essential to keep in mind when reading this review and when thinking about the impact that SLE has on both the patient and the patient's family (Gertman & Strauss, 1975):

1. Chronic illnesses are long-term by nature.

2. Chronic illnesses are uncertain in a variety of ways. Often prognosis is uncertain, and only the evolving course of the disease provides enough information to make possible a reasonable estimate of what is going to happen-and when. Such uncertainties in prognosis can often cause considerable stress for patients with a chronic illness.

3. Chronic diseases are multiple diseases. For a variety of reasons, long-term illnesses tend to multiply themselves; a single chronic condition often leads to multiple

chronic conditions. Many chronic diseases are systemic and degenerative in effect, so that the long-term breakdown of one organ or physiological system leads in turn to involvement of others.

4. Chronic diseases are quite invasive on the lives of patients. The need to adjust to the demands of a regimen and the limitations on activity imposed by symptoms implies a reorganization-often radical-of the patient's life style, commitments, and activities.

Chronic illness often isolates patients from friends and community activities. The combination of social and medical factors involved in a chronic disease complex often result in significant withdrawal from community life, in the loss of friends, and in the abandonment of hobbies and recreational pursuits.

5. Patients with chronic diseases require a wide variety of ancillary services, if they are to be dealt with properly. Often, some form of psychological counseling or therapy is needed to help cope effectively with the disease-induced stress and its consequences.

6. Chronic illnesses are expensive.

In summary, chronic illnesses are long-term, uncertain, expensive, often multiple, intrusive, and require palliation, especially because they are "incurable" (Strauss et al., 1988).

One important category of chronic illness is that of the rheumatic disorders. There are 37 million people in the United States who have a diagnosed rheumatic disease (Robins, Allegrante, & Paget, 1993). Rheumatic diseases are characterized by destructive changes in joints, muscles, tendons, and ligaments. There may also be changes in blood vessels throughout the body from damage caused by the immune system (Dibner & Colman, 1994). Patients with rheumatological disease suffer from a chronic illness with many associated complications, ranging from the profound disability of rheumatoid arthritis to the often unpredictable and significant impairment of systemic lupus erythematosus (Darby & Schmidt, 1988).

Systemic Lupus Erythematosus

Scott's (1991) dissertation entitled A Study of Lifelong Transitions, Experimental Learnings, and Coping Responses of Six Female Systemic Lupus Erythematosus Patients Between the Ages of 20 and 51 Years provides a good introduction to SLE. Part of my literature review from pages nine to thirteen comes from Scott's (1991) study. Two decades ago, SLE was both a rare and a baffling disease. Only 40% of SLE patients were expected to live three years following their diagnosis (Scott, 1991). Today, more than 90% of those diagnosed with SLE will survive ten or more years (Philips, 1991). SLE is recognized to be more prevalent than muscular dystrophy, multiple sclerosis, cystic fibrosis, rheumatic fever, pernicious anemia, Hodgkin's disease, and leukemia (Dibner & Colman, 1994; Scott, 1991). As previously stated, about five hundred thousand Americans have lupus with about sixteen thousand new cases diagnosed each year. More than 90 percent of lupus patients are women, a statistic which equates to a chance of 1 in 500 women being diagnosed with this disease (Dibner & Colman, 1994). Lupus is often called a "woman's disease". Lupus affects adult females 10-15 times more than males (Dibner & Colman, 1994). People of African, American Indian, and Asian origin develop the disease more frequently than Caucasians (Dibner & Colman, 1994). Lupus is known to run within families, though there is no known gene or genes which are thought to cause the illness. Ten percent of SLE patients have a close relative who already has or may develop SLE (Dibner & Colman, 1994). Five percent of the children born to individuals with lupus will develop the disease.

SLE is a chronic autoimmune disease of unknown origin and no known cure (Dibner & Colman, 1994). Some environmental factors that may trigger the disease are: infections, antibiotics, ultraviolet light, extreme stress, and certain drugs. Diagnosis of SLE is difficult because its symptoms may mimic other illnesses, are sometimes vague, and are transitory (Dibner & Colman, 1994; Kelley et al., 1985). Many SLE patients experience transitory aches and pains and run a low grade fever. Many are afraid or feel embarrassed to present such vague symptomology to their physicians and subsequently suffer for long periods of time before being diagnosed (Aladjem, 1982). Because of the inconsistent nature of symptoms, it is often difficult for patients to communicate them to health-care providers (Dibner & Colman, 1994; Permut, 1989). To determine if a patient has lupus, a rheumatologist will refer to the Criteria for SLE (officially known as the Revised Criteria for the Classification of Lupus, developed in 1982 by the American College of Rheumatology; Dibner & Colman, 1994; Tan et al., 1982). To be diagnosed as having SLE, a patient has to have had four or more of the following symptoms either serially or simultaneously during any period of observation: malar rash, discoid rash, photosensitivity, oral ulcers, arthritis, serositis, renal disorder, neurologic abnormalities, immunologic abnormalities, hematologic abnormalities, and antinuclear antibodies (Dibner & Colman, 1994; Kelley et al., 1985).

The term "lupus" actually refers to three different autoimmune diseases: discoid lupus, systemic lupus erythematosus (SLE), and drug-induced lupus. Discoid lupus is a skin disease that is characterized by a rash that usually appears on the face, neck, and scalp and inside the ears. Discoid lupus does not usually cause other symptoms and does not affect any internal organs. Drug-induced lupus is usually triggered by certain drugs, notably hypralazine, which is used to treat hypertension, and procainamide, which is used to treat irregular heartbeat. Usually, once the drug is discontinued, the symptoms will disappear. Systemic lupus erythematosus (SLE) is the most serious form of the disease lupus. SLE may involve the skin, joints, and tendons as well as other body organs. Because of the involvement of connective tissue, SLE is often referred to as a connective tissue disease; however, lupus is also a collagen vascular disease because inflammation of the blood vessels, vasculitis, is a common complication (Dibner & Colman, 1994; Scott, 1991).

Having SLE can increase the odds of developing serious complications which must be treated properly. The most common complications associated with having SLE are kidney disease, cardiopulmonary complications, neuropsychiatric disorders Sjogren's Syndrome, eye disorders, and orthopedic complications. Cardiopulmonary complications may include pericarditis, myocarditis, coronary artery disease, valvular heart disease, and pulmonary disease. Neuropsychiatric disorders may include central nervous system disease, and depression (Dibner & Colman, 1994).

The kidneys are very vulnerable organs in SLE patients. About one-third of all SLE patients will develop lupus nephritis, which is a serious kidney disease that can lead to kidney failure. The kidneys' job is to purify the blood of bodily waste products and to help maintain fluid and chemical balances in the body (Dibner & Colman, 1994). Kidney disease is treated through diet, corticosteroids, immunosuppressive drugs, and sometimes kidney dialysis or transplant.

Nearly one-third of all SLE patients will develop some type of heart or lung complication. Pericarditis is the inflammation of the sac that surrounds the heart. Myocarditis is a serious condition that is caused by inflammation of the heart muscle. Five to 10 percent of all SLE patients will develop myocarditis. Coronary artery disease can also be found in women with SLE. It may be caused by many factors such as the medications that SLE patients take or due to a complication of kidney disease. Other complications associated with SLE are valvular heart disease and pulmonary disease (Dibner & Colman, 1994).

Neuropsychiatric symptoms are caused by medical or psychiatric disorders that may indicate SLE involvement of the nervous system. Neurologic problems are one of the first signs of SLE in some patients. Nearly one-half of all SLE patients will suffer from some type of neuropsychiatric disorder. The most common forms of neuropsychiatric disorders are central nervous system disease and clinical depression. Central nervous system disease encompasses a group of problems ranging from epileptic-type seizures, memory loss, headaches, muscle weakness, confusion, clinical depression, and psychosis. It is estimated that about one in five of all female SLE patients may suffer from clinical depression. Depression is a illness that is often characterized by feelings of hopelessness and helplessness (Dibner & Colman, 1994).

Other common complications found in SLE patients are Sjogren's syndrome, eye disorders, and orthopedic complications. Sjogren's syndrome is a chronic autoimmune, inflammatory disease in which the body's glands do not produce enough protective lubricant, which can result in dry mouth, dry eye, and often vaginal dryness (Dibner & Colman, 1994). Sjogren's syndrome can cause inflammation and dryness in the eye that can lead to infection or damage of the cornea. A common orthopedic complication associated with SLE is avascular necrosis. Avascular necrosis usually is caused by the blockage of small blood vessels that supply blood into the hip. The cartilage in the hip eventually dies and over time, the loss of cartilage can lead to degenerative arthritis (Dibner & Colman, 1994).

Because of all the complications associated with SLE, it is a disease that is likened to an endless roller coaster ride with many ups and downs (Scott, 1991). Flare-ups vary in intensity and in length across occasions and patients. A flare-up may consist of mild joint pain and fatigue that may last a few days, or it may involve severe joint and muscle pain with many or all of the other symptoms mentioned previously (Scott, 1991). Flare-ups may force a person to take great amounts of medications and be hospitalized for a month or more. Flare-ups can result in death (Aladjem, 1982).

Many of the issues related to lupus are very similar to those of other chronic illnesses (Dibner & Colman, 1994). SLE is clearly a chronic illness whose prevalence seems to be on the increase. Contributing to this increase may be the improved ability of the medical community to accurately diagnose those with SLE. Chronic factors that those with SLE often face are as follows (as cited in Scott, 1991):

1. <u>Chronic fatigue</u>. Fatigue from chronic illness can actually cause "fatigue of chronic illness." Inactivity inhibits the functioning of the autonomic nervous system (Aladjem, 1972; Nguyen, 1984).

2. Loss. The losses from chronic illness are endless and too numerous to count. Those with SLE must learn to live with the threat of a flare-up every day while trying to live, work, and play with a semblance of a normal lifestyle.

3. Changes in relationships. Any relationship that meets important needs, or through which lasting patterns of behavior are developed, can be lost when changes occur, especially when those which are related to chronic illness (Falk, 1994). The stress of chronic illness can create a tremendous amount of uncertainty in a relationship. Coping with a serious illness is a hardship for the patient, family, and close friends. Chronic illness creates a situation in which there is little certainty (Strauss et al., 1984).

4. Diagnostic difficulty. It is very difficult to diagnose lupus (Dibner & Colman, 1994). Often patients go to two or three different physicians before the accurate diagnosis of lupus is made. Diagnosis is so difficult because lupus often mimics other diseases.

5. Lifestyle issues. The chronically ill recognize times that they may have to limit or curtail their activities due to the illness (Strauss et al., 1984).

Adapting to SLE

Being diagnosed with a chronic, potentially life threatening disease can be a very frightening experience. Physical and psychological survival can be emotionally draining. One usually grieves the loss of one's previous life prior to diagnosis. Falk (1994) describes the process of living well with lupus. He gives four suggestions that may help one live well despite the losses associated with having a chronic illness.

1. Accept the reality of loss. The losses associated with having lupus can be numerous and initially overwhelming. It takes time to get over the disbelief that follows shocking news and to acknowledge the losses and changed needs that accompany chronic disease. This is accomplished primarily through talking, or by "telling the story" of the loss, articulating what has happened, and how and when it occurred. Support groups and counseling are often a safe, helpful atmosphere to talk about the chronic illness in one's life.

2. Expression of feelings. The expression of the feelings that accompany a major loss can be a great challenge, as many are taught from an early age to hide their feelings. Many have had few role models to show them how to safely and fully ventilate painful emotions such as anger, guilt, anxiety, and deep sadness. Everyone has a unique way of ineffectively coping with emotions---e.g., drinking too much to dull the pain, not taking good care of oneself so as to feel punished, or becoming demanding or rigid to feel in control. The person who lives well with lupus works to find or create a therapeutic environment where the emotions that accompany loss may be fully felt and safely expressed on an ongoing basis.

3. Adaptation to a new environment in which the lost entity is missing. Simply put, the challenge is to figure out how to live joyfully and productively with the changes and challenges that accompany a chronic illness like lupus. "We usually embrace change which we sought but resist change thrust upon us" (Falk, 1994, p.2). So, the new learning which follows loss often occurs slowly. It takes time and diligence to identify the inner resources and external supports which will undergird the new structure of life.

4. Moving forward and becoming emotionally invested in life again. When a major life change such as the emergence of chronic disease happens, one has to say good-bye to a way of life that can no longer be. When such loss first occurs, there is little else about which one can think or feel; it absorbs attention and emotions completely. Being a person with lupus is the only way in which one sees oneself and one sees little else but the losses that this entails. But over time, and with work on the three tasks mentioned previously, one can focus on and become absorbed by other things. One comes to believe that having lupus is only one of many aspects of one's identity; that it has a place in life but it does not define life. When the losses of lupus become real, feelings are experienced around those losses and one begins to learn to adapt to the changes they have created. With a major life change, such as a chronic illness diagnosis, one must mourn the losses of the old and recognize that one can live well beyond the diagnosis.

Education, Health Status, and SLE

Many researchers in the last decade have investigated ways to help lupus patients not only adapt to, but to thrive within the restrictions of their illness. One way this has been done is to educate the lupus patient about the disease. It is generally believed that with a chronic illness such as SLE it is beneficial for a patient to obtain as much scientifically valid information about the disease as possible. Several coping mechanisms are often used in response to chronic illness. The main coping strategies used in trying to cope with a chronic illness like SLE are obtaining information, direct action, inhibition, and seeking out social support (Dibner & Colman 1994). Konttinen et al. (1991) investigated whether an SLE information guide could influence patient knowledge about the disease. They wrote a 45 page comprehensive guidebook on SLE for Finnish SLE patients. No guidebooks were available to Finish SLE patients prior to 1988. Sixty-six patients participated in the study. The patients' knowledge of SLE was measured prior to and eight-to-ten weeks after reading the SLE patient guide. The study found that the knowledge of SLE can be significantly improved with such a handbook or information guide.

Patients with chronic conditions account for the majority of health care expenditures in the U.S. (Stewart et al., 1989). Besides educating lupus patients about their disease, researchers have focused on the varying effects of health status and its impact on the lupus patient (Corwell & Schmitt, 1990; Joyce et al.,1989; Pfeiffer & Wetstone, 1988). Joyce et al. (1989) looked at the physical manifestations of disease activity and the health status of patients with SLE. Forty-nine patients completed the Arthritis Impact Measurement Scale (AIMS; Meenan, Gertman, & Mason, 1980) and an examination of physical features of SLE documented by the Clinical Activity Inventory (CAI; Liang, Socher, Roberts, & Esdaile, 1988). The authors found a significant correlation of .55 ($\underline{p} < .001$) between the total scores for the CAI and the AIMS, indicating that disease manifestations of SLE are significantly related to overall health status. They concluded that health status is likely to change as SLE disease activity decreases. Conversely, as the symptoms of SLE increase, the patient is likely to experience an increase in limitations in physical activity, an increase in pain, and perhaps the onset of depression.

<u>Measuring Functional Health Status in SLE</u>

There are two ways of measuring health status with the lupus patient; one can look at objective, clinical measures administered by a medical specialist and one can look at subjective measures based on the patient's perception of health status or disease impact. Clinical measures for evaluating health status with the lupus patient that have been shown to have sound psychometric properties include the British Isles Lupus Assessment Group (BILAG), the University of Toronto SLE Disease Activity Index (SLE-DAI), and the Systemic Lupus Activity Measure (SLAM; Liang, Socher, Larson, & Schur, 1989). The judgment of whether a patient with systemic lupus erythematosus is better or worse or has more or less active disease is a central question in patient management and care. Yet even with the above instruments and the other sixty plus systems available for defining and measuring SLE, there is still no consensus on what disease activity means or how it should be measured (Liang, Socher, Roberts, & Esdaile, 1988; Liang, Stern, & Esdaile, 1988; Albert, Hadler, & Rothfield, 1978).

Another way of looking at functional health status is through the patient's perception. There are three broad types of subjective instruments available to assess functional health status with the SLE patient: generic health profiles, utility measures, and arthritis specific health profiles or instruments (Bell, Bombardier, & Tugwell, 1990).

Generic instruments have been developed to reflect the impact of ill health on the lives of people in a wide variety of populations. They cover function, disability, and distress. Subcategories of generic instruments include health profiles and utility measures. Health profiles are single instruments that measure different aspects of quality of life in a wide variety of conditions. A scoring system permits aggregation of the collected information into a score or index. Such instruments allow the assessment of the effects of an intervention on many aspects of quality of life through the use of only one instrument. Commonly used health profiles include the Rand Health Insurance Study (HIS; Brock et al, 1979) and the Sickness Impact profile (SIP; Bergner, Babbitt, & Pollard, 1976).

Utility measures of health-related quality of life were derived from economic and decision theories (Bell, Bombardier, & Tugwell, 1990). They provide a quantitative measure of the value or preference patients attach to their overall health status relative to perfect health and death. Accordingly, changes in utility as a result of a specific intervention reflect changes in the value of an individual's health status. Commonly used utility measures include the Quality of Well Being (QWB) and the Health Status Index (HSI; Torrance, 1986).

Arthritis-specific instruments provide more specialized information in a concise way. Arthritis-specific measures focus on aspects of health targeted toward arthritis and arthritis symptom complexes, such as SLE (Bell, Bombardier, & Tugwell, 1990). Frequently used arthritis-specific measures of health status include the Arthritis Rheumatism Association Functional Class (Steinbrocker, Traeger, & Batterman, 1949), the Functional Status Index (FSI; Jette, 1980), the Health Assessment Questionnaire (Fries, Spitz, & Young, 1982) and the Arthritis Impact Measurement Scales (AIMS; Meenan, Gertman, & Mason, 1980).

Quality of Life

In spite of frequent references to quality of life in relation to health care issues in the professional literature and public press, the definition of the concept remains elusive (Ferrans & Powers, 1985; Shaw, 1977). A great amount of variation exists among researchers as to both the specific dimensions included in quality of life and how these dimensions should be measured (Nunes et al., 1995). Miller (1983) stated that quality of life is a concept that contains no consistent or universal meaning. He goes on to explain quality of life as being the ability to maximize satisfaction by learning to live life to its fullest and functioning to the optimum of one's capabilities in all stages of life.

Specific psychological and physical manifestations of SLE that can affect quality of life are decreased self esteem, poor body image, depression, and sexual dysfunction. Bauman et al. (1989) conducted a needs assessment of 386 SLE patients in New South Wales and found that the most commonly reported problems were depressed feelings, reduced activity, stress, and change in body image. Corwell and Schmitt (1990) in a study of 26 women with rheumatoid arthritis (RA) (23 women with SLE, and 28 healthy women), examined the relationship between perceived health status, self esteem, and body image, the relationship of perceived health status, body image, and self esteem to age and duration of diagnosis, and the problems, needs, and fears of women with RA and SLE. They found that higher perceived health status scores were related to higher self esteem in all three groups. Significant correlations were not found in any group between perceived health status and body image, though the authors noted that the SLE patients experienced a more generalized body image disturbance than did the RA patients. Last, there were no significant correlations found for body image, self esteem, and perceived health status with age or duration of illness.

Curry, Levine, Jones, and Kurit (1993) looked at the influence of medical and psychosocial variables on sexual outcome or sexual adjustment with 100 women diagnosed with SLE. Sexual adjustment was assessed by a standardized structured interview schedule called the Sexual Adjustment Interview for Women (SAIW; Curry et al., 1993). The SAIW is based on Kaplan and Kohl's (1972) conceptualization of sexual response phases and the Diagnostic and Statistical Manual, Third Edition Revised (DSM III-R; American Psychiatric Association, 1987) classification of sexual dysfunctions. "The SAIW elicits information about several areas of current and premorbid psychological functioning, including level of sexual desire (drive and motivation), vaginal lubrication, subjective arousal, orgasmic attainment, and sexual satisfaction"

(Curry et al., 1993, p.34). The central issue in the study was the identification of factors that influence the impact of SLE on women's sexual adjustment. The authors found that a combination of medical, psychosocial, and demographic variables predicted sexual adjustment in SLE patients better than any single variable. Depression and body image were not found to contribute significantly to sexual adjustment. The authors urge that SLE patients be considered by medical professionals in a holistic manner. With the improved survival rate of SLE patients, quality of life issues are becoming increasingly germane, and sexual outcome or adjustment is an important variable to consider when looking at health related quality of life.

Measuring Quality of Life

Quality of life has been defined in purely objective terms by measuring such items as housing, income, physical function, and purity of air (House, Livingston, & Swinburn, 1975). Campbell, Converse, and Rogers (1976) attempted to measure both the objective and subjective dimensions that bear on the quality of life. Hornquist (1982) wrote that quality of life should include measures of both individual needs and the available resources. Research has clearly indicated the importance of health in determining life satisfaction (Nunes et al., 1995). As a result of these findings, health indices have been developed that attempt to define quality of life as it applies to the state of wellness of the individual (Frank-Stromborg, 1988). Most health indices have tended to concentrate on the physical functions without assessing the interactions or contributions of the mind or spirit. What has emerged from a review of the literature about health indices for determining quality of life is a general consensus that attributes of mind, body, and spirit all need to be included in any comprehensive approach (Frank-Stromborg, 1988).

Because quality of life is still an evolving area of clinical research, there are multiple issues and choices that must be considered in instrument selection. The first issue is whether the concept can be measured by a single instrument or dimension or requires multiple instruments and the measurement of multiple dimensions. Fletcher and

Bulpitt (1985) have shown that there are serious restrictions on the use of multiple instruments to measure life quality which include feasibility, design, and costs. The second issue is whether to use an instrument that results in descriptive, qualitative data or one that provides quantitative data. Many of the qualitative instruments identify the specific areas that have been affected by the disease and thus have changed the person's overall quality of life (Frank-Stromborg, 1988). In contrast, the quantitative instruments yield an overall quality of life assessment score. The third issue is whether to use an objective instrument, that allows a health professional to evaluate the patient's quality of life, or a subjective instrument that allows the patient to evaluate and report on his or her own perceived quality of life. A criticism of past quality of life research is that most studies have tended to reflect the health professional's perception of the patient's quality of life rather than the patient's own evaluation (Penckofer & Holm, 1984).

Given the restrictions or limitations in using multiple instruments in assessing quality of life and the criticism of objective instruments being the health professional's subjective view of the patient's quality of life, I will focus on single measure, subjective quantitative instruments. Two such instruments are the Quality of Life Index by Padilla et al. (1983) and Ferran and Powers' (1985) Quality of Life Index (QLI). The Padilla et al. (1983) Quality of Life Index views quality of life as a broad concept, and its items address three general areas: psychological well-being, physical well-being, and symptom control. One is able to compute a total quality of life score, as well as, scores on the three separate dimensions. The Quality of Life Index was tested with four subject groups; oncology outpatients receiving chemotherapy, or radiation therapy, oncology inpatients receiving chemotherapy, and non patient volunteers. Both test-retest reliability ($\underline{r} > .60$) and internal consistency reliability estimates ($\underline{\alpha} = .88$) were high.

Ferrans and Powers' Quality of Life Index (QLI) was developed to measure the quality of life of both healthy people and those who are experiencing an illness (Ferrans & Powers, 1985). The 35 items on this instrument assess 18 areas, including life goals, general satisfaction, stress, and physical health. The instrument consists of two sections. One section measures satisfaction with four domains of life, and the other measures the importance of each domain to the subject. The four domains are health and functioning, socioeconomic status, psychological/spiritual functioning, and family. The psychometric properties of the QLI are strong and will be discussed in the method section.

Social Support: An Overview

One way in which researchers have tried to improve quality of life for patients with chronic illness is through the use of social support (Nunes et al., 1995; Hanestad & Albreksten, 1993; Krol et al., 1993; Kober et al., 1990; Magilvy, 1985). Social support is a construct that has been defined in as many different ways, much as the quality of life construct has. It has been shown that individuals diagnosed with the same chronic condition of approximately the same severity, who are receiving the same treatments can have a considerable variation in disease progression, recovery, and adaptation to living with the condition (Lindsey, 1992). Broadhead et al. (1983) found that social support may have a protective function and may also be related to positive health outcomes. Conversely, loss of or lack of social support has been linked with illness and disease progression (Cohen, 1979).

In examining social support, it seems prudent to first look to Cassel and his seminal work, which linked together stress and susceptibility to organic disease and psychological distress. Cassel (1974) stated his principal hypothesis as follows: "The circumstances in which increased susceptibility to disease would occur would be those in which, for a variety of reasons, individuals are not receiving any evidence that their actions are leading to desirable and/or anticipated consequences" (p.405). It is important to note Cassel's assertion that people can become physically, mentally, or socially debilitated if they do not receive or perceive signs from significant others that make them feel safe and valued. One aspect of health is people's capacity to know what other people expect of them and how they are generally evaluated by others (Wasserman & Danforth, 1988). When individuals experience a failing sense of coherence or well being in their world, then their susceptibility to disease increases. People's sense of coherence depends in part on their confidence in the positive outcomes of their actions.

Cassel (1974) further contends that the nature and strengths of available group supports is protective of health. This health protection hypothesis has prompted various definitions of social support, all of which tend to feature the same elements (Wasserman & Danforth, 1988). Caplan (1974) suggested:

> Support system implies an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time. The various elements of the support system may be spontaneous, that is, not organized in a planned way by someone who is interested in promoting the health of the individual or the population, but emerging from the needs of the individual and the natural biosocial responses of the people in his community or from the values and traditions of his culture and society (p.7).

Barrera (1981) has formulated the components of social support to include material aid, physical assistance, intimate interaction, guidance, feedback, and social participation. On inspection, Barrera's view of social support in very similar to Caplan's, but Barrera's new or novel feature is that of social participation for fun, relaxation, and diversion from demanding conditions.

Cobb (1976) formulates the concept of social support as "information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations" (p. 300). Support means an affirmation that a person is loved and valued, regardless of achievement. Cobb (1976) and Caplan (1974) also emphasize the reciprocity inherent in support systems. Those who are helped may someday become helpers and vice versa. Support of others is characterized by mutuality and mutual aid.

Bloom's (1982) conceptualization of social support is more extensive and elaborate than those of the other theorists, and involves, five dimensions (Wasserman & Danforth, 1988). Bloom's first dimension is the maintenance of the social identity. Bloom has in mind both the macro and micro aspects of social identity. The macro aspect refers to the "degree to which an individual is integrated into larger society" (Bloom, 1982, p. 136). The micro perspective refers to the "interaction between the target individual and the support system revealing the process by which an individual's social ties provide social identity feedback" (p. 137). Feedback helps the focal person understand that there are often people who face the same circumstances and that some of the focal person's behavior is appropriate given the experienced strain and tension.

Bloom's (1982) second dimension is emotional support, behavior that assures the individual that he is loved and valued as a person regardless of achievement. The third dimension is tangible support and the fourth dimension is environmental support and information. Tangible support includes financial support and environmental support and information includes support one receives from the environment or community. The fifth dimension Bloom calls "social affiliation" which incorporates the concept of peoples' interdependence in both social and psychological terms. Bloom's categories replicate Cobb's (1976) and Cassel's (1974), capturing conceptually the human need for affiliation and social identity-the need for attachment, connection, and bonding (Wasserman & Danforth, 1988).

Social support should have two types of effect or functions: (a) a health facilitating function: e.g. satisfaction of affiliative needs, self esteem maintenance (direct effect); and (b) a stress reducing function: facilitation of cognitive, emotional and practical/instrumental adjustment e.g. giving information about the treatment of the disease, practical and financial aid (buffer effect) (Krol et al., 1993). The diagnosis of having an incurable, chronic disease is regarded as an adverse life event. According to Krol et al. (1993), people receiving satisfactory amounts of social support from their social network cope more easily with the consequences of a chronic disease than people who do not have these resources. One dimension of social support that researchers have begun to investigate in relation to chronic illness is that of social support group participation.

Support Groups

Support groups serve a useful function in helping people with various stresses related to crises, life transitions, and chronic conditions. Schopler and Galinsky (1993) looked at support groups and attempted to make a distinction among self-help groups, support groups and treatment groups for clarity of definition and to provide a conceptual framework that would help to guide subsequent practice and research. They found that there is no consensus on the definition of support groups and only a limited evaluation of their impact. According to Schopler and Galinsky (1993), the major distinctions that can be made among groups relate to sponsorship, conceptions of participant roles, the basis of leadership, and the focus of the group.

Self-help groups are usually initiated by professionals and frequently are affiliated with a national or regional sponsoring organization. The sanction and control of group activities lies with members, and leader and member roles may be somewhat synonymous. The emphasis in self-help groups is on self-help, mutual aid, and peer support. Examples of self-help groups are Alcoholics Anonymous and other structured twelve-step programs.

Treatment groups are more leader centered than self-help groups, with clear distinctions between the roles of leaders and members. Persons are selected for group membership because they share common concerns. Whatever the therapeutic orientation, complex treatment technologies involving assumptions about the cause and cure of problems and specialized therapeutic techniques are invoked. An example of a treatment group would be an in-patient alcohol treatment program.

Support groups lie between self-help groups and treatment groups. Sponsors may be national organizations, local associations and organizations, or private practitioners. Support groups are member-centered, but there are some distinctions among participant roles. Leadership may be provided by professionals, volunteers, or at times by members. Leaders share authority and often share similar experiences with members. Members are usually expected to take active roles in sharing their experiences, providing information, giving advice, and drawing out other members. Leader interpretations of psychological factors are not likely to be a focus of these groups. In the support group, the group is likely to become both a supportive environment and a potential means for developing the coping abilities of the members. (Schopler & Galinsky, 1993). An example of a support group would be the lupus support groups sponsored by the Lupus Foundation of America or the Arthritis Foundation (Dibner & Colman, 1994).

Even with the aid of the above definitions, it can be seen that there are still blurred boundaries or divisions among the three groups. Only limited attention has been given to the systematic evaluation of support group processes and outcomes. Subramenian (1986) found that patients in a support group for chronic pain improved on measures of physiological and psychological functioning, whereas controls exhibited no change or a decline. Spiegal et al. (1989), in a ten-year follow up to a cancer support group, found that women support group members lived longer than those in the control condition. Krupnick et al. (1993) evaluated the clinical and research literature on professionally-led support groups for cancer patients. They found that recent research from <u>Medline</u> and <u>Psychlit</u> searches show that professionally-led support groups are increasing in number, and suggest, that participation in such groups enhances patients' quality of life.

Research findings on support groups and their impact on quality of life are limited and mixed. Hanestad and Albrektsen (1993) examined the effect of participating in a support group on self-assessed quality of life. Twenty-five subjects participated in groups of four to six members for six months. Group processes were aimed at alleviating distress and improving satisfaction with life. The processes included installation of hope, imparting information and improving group cohesion. Participants and thirty-six control subjects completed Hornquist's quality of life measure (Hornquist, 1989) during a pre test and at the end of the six-month treatment period. No significant differences were found between the treatment and control group on differences in pre and post-test scores, indicating that support group participation did not affect self-assessed quality of life. They stated that the findings may be due to methodological problems, i.e., selection, sample size, the sensitivity of the instrument used, the potency of the intervention, and the construct of quality of life as an outcome variable. The authors concluded that if the quality of life experience is a relatively enduring phenomenon that depends on multiple personal and environmental factors, it may be unrealistic to think that the quality of life experience can be improved over such a limited period of time no matter how intensive the intervention. A six month intervention may not be enough to produce a significant change.

Gilden et al. (1992) found that support groups improved the health care and quality of life of older diabetic patients. The authors wanted to assess whether knowledge or psychosocial and glycemic benefits of a diabetes education program are enhanced by a support group for older participants. Group A consisted of 11 patients who received the diabetes education program and 18 months of subsequent support group participation. Group B comprised 13 patients who received only the education program. In group C there were eight individuals on a "waiting list" for group A or B, who served as a control. Quality of life was addressed by two sub-scales, QLa and QLb. QLa reflected more demanding and intensive life-style changes due to diet, exercise, and other general factors. QLb reflected less demanding behaviors including medication, compliance and self-testing. It was found that patients who participated in the education and support group intervention (Group A) scored significantly higher ($p < .05$) on knowledge, quality of life, stress, and family involvement in diabetes care than patients in the control group. Group A also demonstrated greater knowledge and greater quality of life than group B which did not receive the support group intervention. Gilden et al. (1992) concluded that diabetes education programs can have long term benefits for knowledge, psychosocial functioning, and glycemic control among older diabetic patients. The addition of support groups enhanced diabetes knowledge and psychosocial functioning. Coupling social support groups with psychoeducational information about diabetes appeared to help elderly diabetic patients improve their quality of life.

Measuring Social Support

Social support can be divided into two main types: social emotional support and instrumental support (Krol, Sanderman, & Suurmeijer, 1993). Social emotional support is support that meets the social or emotional needs of the person such as the need for affiliation or a sense of community. Instrumental support is tangible support that helps the person acquire what she needs such as money for medical care or assistance in grocery shopping etc. The need for and the provision of social emotional support and instrumental support is largely determined by the situation in which the individual is involved. Because of the subjective nature of social support, various social support instruments have focused on the patient's perceived level of social support. Two general social support measures that have well-established reliability and validity are the Norbeck Social Support Questionnaire (NSSQ; Norbeck, Lindsey, & Carrieri, 1981) and the Personal Resources Questionnaire (PRQ) developed by Brandt and Weinert (1981; cited in Norbeck, 1988).

The Norbeck Social Support Questionnaire (NSSQ; Norbeck, Lindsey, & Carrieri, 1981) was based on the earlier work of Kahn (1979). Respondents list their social support network members and then rate them on a series of questions related to functional properties of social support and to structural network properties. Content validity and data to support internal consistency reliability, test-retest reliability, concurrent validity, predictive validity, construct validity, predictive validity, construct validity, freedom from social desirability response bias, and normative data from employed adults have been reported (Norbeck, 1988).

The Personal Resources Questionnaire (PRQ) (Brandt & Weinert, 1981) is based on Weiss' (1974) traditional five categories of relational functions. The PRQ measures a number of social support resources, satisfaction with assistance received, and perceived social support. Continued work with the instrument has resulted in careful revisions and additional testing of its psychometric properties with various populations (Weinert & Brandt, 1987). Norbeck (1988) stated that the authors have provided evidence for the PRQ's content validity, internal consistency reliability, test-retest reliability, predictive validity, and freedom from social desirability response bias.

Social Support, Quality of Life, and Chronic Illness

Weinberger, Hiner, and Tierney (1986) investigated how social support acted as a buffer against negative health-related consequences evoked by stress in 193 patients with osteoarthritis. Weinberger et al. (1986) found that bi-weekly phone calls over a six month period significantly ($p = .0002$) increased the patients overall perceived level of social support from baseline measurement. Social support measurements went from a baseline mean of 28.24 (SD = 10.50) to 31.52 (SD = 12.77). Further, it was found that the patients had significantly ($p < .01$) decreased physical disability and pain (functional status) following the 6 month treatment period. The authors attributed the improvement in functional status to the telephone interviewers being perceived as a source of social support to persons who may have support deficits. Although this was an interesting study, the absence of a control group leaves regression to the mean as a viable alternative explanation for the improvement observed.

White, Richter, and Fry (1992) assessed the impact of potential stressors (such as actual and perceived health status), coping strategies, and perceived social support on the psychosocial adaptation of women with diabetes mellitus. Using regression analysis, they also found that health status significantly influenced perceived social support ($\beta = .28$, $p < .05$), and that stressful life events, health status, palliative coping, and perceived social support had a direct impact on psychosocial adjustment, accounting for 56% of its variance.

More recently, Tell et al (1995) studied a sample of 256 black and white dialysis patients to identify factors associated with health-related quality of life. The authors found that the greater the perceived social support, the better the reported and observed functional level. Social support was associated with fewer limitations in leisure time activities ($r = .14$, $p = .028$), with greater feelings about life ($r = .23$, $p = .0003$) and with better life satisfaction ($r = .34$, $p < .0001$). Tell et al., 1995 also found that in each regression equation, social support and black race were the strongest predictors of health-related quality of life.

Nunes et al. (1995) investigated the relationship between social support and quality of life in 50 HIV-positive individuals. The patients had self-selected into one of three conditions: (a) participants in support groups at a behavioral medicine unit, (b) inpatient or respite care patients with HIV, or (C) respondents to advertisements at AIDS service organizations. Social support was significantly correlated with quality of life ($r = .81$, $p < .001$). Further, HIV status (asymptomatic HIV, symptomatic HIV, & AIDS) was significantly related to quality of life ($p < .01$). However, HIV status was not significantly related to social support (Nunes et al., 1995).

SLE and Quality of Life

Few studies have directly looked at the relationship of SLE and quality of life. One reason for this may be due to the ambiguity of the construct "quality of life". Burckhardt et al. (1993) assessed the quality of life and health status of 50 women with SLE and compared them with 50 age-matched women with Rheumatoid Arthritis (RA) using open ended questions, the Quality of Life Scale (QOLS-S; Flanagan, 1978), the Arthritis Impact Measurement Scales (AIMS; Meenan et al., 1980), the Rheumatology Attitude Index (RAI; Nicassio et al., 1985), and two measures of disease activity. There was no significant correlation in either group between disease duration and quality of life. The patients with SLE expressed more concerns about their disease and potential for managing it than did the patients with RA. There were no differences found between the two groups on the QOLS-S. Both groups were highly satisfied with many aspects of their lives. The best predictor of life quality in both groups was psychological distress followed by social and physical functioning in the group with RA and perception of global impact of disease in the SLE group. The authors stress the importance of paying more attention to the psychological well-being (along with, the physical well-being) of the patient in treating SLE in attempting to improve life quality.

It appears that no research studies have been conducted on quality of life and social support or support groups that have focused on any type of lupus population. There are about 442 lupus support groups in the United States that are being run out of the local chapters of the Lupus Foundation of America (B. Kauffman, personal communication, January 23, 1996) as well as numerous lupus support groups coordinated through the Arthritis Foundation of America. Recent research findings have found a significant correlation between health status, social support and quality of life in patients with AIDS (Nunes et al., 1995), insulin-dependent diabetes mellitus (Hanestad & Albreksten, 1993), rheumatoid arthritis (Krol et al., 1993) and in hearing impaired older women (Magilvy, 1985). Additionally, Lubkin (1990) in Chronic Illness Impact and Intervention states that, "research studies to determine how various environmental, psychosocial, and behavioral factors influence specific chronic illnesses and disease progression are especially important" (p. 322). Because of these recent research findings and the need for continued quality of life research, a research study investigating the relationship of quality of life and social support in an SLE population seems a timely and logical next step. In this study, I looked at the relationship among health status, perceived social support, and quality of life in a population of women diagnosed with SLE.

CHAPTER III

METHOD

Statement of the Problem

The primary purpose of the present study was to examine the relationship among perceived social support, health status, and quality of life in women diagnosed with systemic lupus erythematosus (SLE). In addition, I attempted to assess the reasons why women with SLE choose not to attend support groups.

Procedures

Three self-report measures (Appendices A, B, and C) and a support group attendance-demographic questionnaire (Appendix D) were used in this study. On July 5, 1996, 125 patients were mailed a questionnaire packet which included a personalized letter from Dr. Lessard (a rheumatologist in Grand Forks, North Dakota), consent forms, the four questionnaires and a stamped pre-addressed return envelope. The participants were instructed to mail the uncoded consent forms back to this researcher, where they will be kept in a locked cabinet for seven years. The participants were also asked to mail the questionnaires back to the author after completing them. Dr. Lessard filled out an objective health status measure (Appendix E) during the patients' office visit. Out of 125 mailed questionnaire packets, forty-five were returned. In November of 1996 a second mailing was conducted and sixteen additional packets were received, yielding a total of sixty-one completed questionnaire packets. From August 1996 to February 1997 Dr.

Lessard filled out the objective health measure on patients when they had an office visit, or he obtained the information from the patient's file from her most recent office visit.

Participants

The participants were patients of Dr. James Lessard, MD, a rheumatologist in Grand Forks, North Dakota, a medium-sized, rural midwestern community. Criteria for selection included (a) female sex; (b) age between 18 to 90 years; (c) duration of disease longer than one year; and (d) diagnostic criteria for SLE fulfilled (Tan et al., 1982). A convenience sample of 61 women diagnosed with SLE was obtained from Dr. Lessard's rheumatology practice. Of 125 questionnaire packets distributed to patients with criteria, 20 were returned with wrong addresses, and another 15 of the patients were deceased. Of the 90 remaining possible participants, 61 survey packets were returned resulting in a 68% response rate.

Demographic characteristics of the respondents are reported in Table 1. The 61 female SLE patients ranged in age from 22 to 85 years. The mean age was 51.02 years (SD = 16.67). A majority of the respondents were Caucasian (93.4%). SLE disease duration since diagnosis ranged from one year to 50 years. The mean duration was 11.86 years (SD = 9.34). Analysis indicated that 47 participants were married (77.0%), four were divorced (6.6%), five were widowed (8.2%). The education level ranged from grade school education to completion of post graduate education. Income ranged from an annual income of less than $10,000 dollars to more than $70,000; with the modal income of the participants falling into the $30,000 - $39,999 category (19.7%).

Table 1

Characteristics of the Sample

	Frequency	Percent
Age (years)		
20-29	5	8.2
30-39	10	16.4
40-49	15	24.6
50-59	12	19.7
60-69	5	8.2
70-79	10	16.4
80-89	2	3.3
No Response	2	3.3
Ethnicity		
Caucasian	57	93.4
Asian-Pacific. Island.	1	1.6
Indian/Alaskan	1	1.6
No response	2	3.3
Marital Status		
Married	47	77.0
Widowed	5	8.2
Divorced	4	6.6
Other	3	4.9
No response	2	3.3
Income Status		
Less than $10,000	8	13.1
$10,000 - $19,999	8	13.1
$20,000 - $29,999	9	14.8
$30,000 - $39,999	12	19.7
$40,000 - $49,999	8	13.1
$50,000 - $59,999	4	6.6
$60,000 - $69,999	4	6.6
$70,000 - $79,999	3	4.9
No Response	5	8.2

Table 1 Cont.

	Frequency	Percent
Time Since Diagnosis (Years)		
1-9	25	41.0
10-19	16	26.2
20-29	7	11.5
30-39	2	3.3
40-50	1	1.6
No Response	10	16.4
Education		
Grades 7 thru 9	3	4.9
Grades 10 thru 11	5	8.2
High School Graduate	14	23.0
1-4 Years College	23	37.7
College Graduate	10	16.4
Professional or Graduate	7	6.6
No Response	2	3.3

Instruments and Variables

Measuring Health Status

There are two ways of measuring health status: through a clinical, objective measure, or with a subjective measure based on the patient's self-report of health status or disease impact. The Arthritis Impact Measurement Scales 2 (AIMS2), a 78 item self-report questionnaire, was chosen as a subjective health measure for this study, because the AIMS2 has been shown to be a reliable and valid measure of health status in SLE patients (Meenan et al., 1992). The Systemic Lupus Activity Measure (SLAM; Liang, Socher, Larson, & Schur, 1989) was chosen as a physician rated objective measure of disease activity for this study, because it has been shown to be a reliable and valid measure of SLE (Gladman, 1994; Liang, Fortin, Isenberg, & Snaith, 1991; Liang et al., 1989), and because Dr. Lessard liked the SLAM and agreed to incorporate it into use with his patients for the duration of the study.

Arthritis Impact Measurement Scales 2 (AIMS 2; Meenan, Mason, Anderson, Guccione, & Kazis, 1992). The second version of the Arthritis Impact Measurement Scales (AIMS2) is an improvement on an evaluation instrument, the Arthritis Impact Measurement Scales (AIMS; Meenan, Mason, & Gertman, 1980), that was developed to measure patient outcome in the rheumatic diseases. The AIMS2 is designed to measure the health status component of outcome in a multidimensional fashion using specific scales, summary components, and overall impact measures.

The AIMS2 used in this study has 78 items. The first 57 items are responded to on 5 point rating scales and are broken down into the 12 subscales: mobility level, walking and bending, hand and finger function, arm function, self-care tasks, household tasks, social activity, support from family and friends, arthritis pain, work, level of tension, and mood. Items 58 to 78 ask about respondent satisfaction with each of the 12 subscale domains, health status, health perceptions, arthritis impact, and demographic information, through use of 6 point rating scales or yes-no items.

Previous factor analyses have shown that the 9 original subscales of the AIMS could be combined into 3 or 5 component models of health status. The three component model involves facets of physical function, psychological status, and pain, whereas the 5 component model combines the nine subscales of the AIMS into measures of lower extremity function, upper extremity function, affect, symptom, and social interaction (Mason, Anderson, & Meenan, 1988). The 5 component model for the AIMS2 would group the 12 subscales into physical, affect, symptom, social interaction, and role components. The 3 component model would group the 12 subscales of the AIMS2 into the physical, affect, and symptom components.

Internal consistency reliability coefficients for the AIMS2 for the 12 subscales, as reported by Meenan et al. (1992), ranged from .72 to .91. Test-retest reliability coefficients at a two week interval ranged from .78 to .94. Validity analyses showed that patient designation of an area as a problem or as a priority for improvement was significantly ($p < .001$) associated with a poorer AIMS2 scale score in that area (Meenan et al., 1992). Because no other instrument more specific than the AIMS for measuring the health status of the SLE patient has been found in the literature (Joyce et al., 1989), the newer version, AIMS2, was a logical choice for measuring health status with the SLE patients in this study.

Regrouping of AIMS2 Subscales

There was content overlap and high subscale intercorrelations (see Appendix G) among some of the 12 subscales of the AIMS2 (mobility, walk and bend, hand and finger functioning, arm functioning, pain, social activity, support from friends and family, work, household activity, level of tension, and mood). Therefore, the 12 subscales were regrouped, based on content, to create four new variables. The subscales were regrouped as follows: (a) Mobility, walk and bend, hand and finger, arm, and pain were combined into a new variable entitled "AIMS PHYSICAL" which stands for the physical components of the AIMS2; (b) social activity and support from friends and family were combined into a new variable entitled "AIMS SUPPORT" which stands for AIMS2 social support; (c) work and household activity were combined into a new variable entitled “AIMS WORK”; and (d) level of tension and mood were combined into a variable entitled “AIMS MOOD”.

Systemic Lupus Activity Measure (SLAM; Liang, Socher, Larson, & Schur, 1989). The SLAM, a physician rating scale, uses clinical disease symptoms and laboratory results to measure disease activity. Parameters for the measure were derived from the literature and was refined in 1983 by members of the American Rheumatological Association (ARA) Council on SLE and by clinical judgment (Liang et al., 1989). The items chosen for the scale represent those manifestations that occur more frequently, those that can be graded, and those that can be operationally defined and reliably rated. Definitions and rules for ascertainment of manifestations are based on the ARA Dictionary of the Rheumatic Diseases (1982). To improve reliability, clinical examples are given as anchors for each scale; detailed instructions are also provided.

The SLAM covers symptoms that occurred in the previous month, and include 24 clinical manifestations and 8 laboratory parameters to evaluate organs which cannot be assessed otherwise. Parameters of immune function are not included. Because disease activity is always considered with disease severity, both dimensions are incorporated in the scales (Liang et al., 1989). A manifestation or symptom is determined to be either active or inactive. "Severity is then used to expand a scale's gradations and is judged by the need to treat with immunosuppressive agents, the need to follow the patient more closely, or the functional or prognostic consequences of the manifestation" (Liang et al., 1989, p. 1109). Possible scores on the SLAM range from zero to 85. Lower scores idicate less disease activity, with higher scores representing a more active disease state.

The convergent validity of the SLAM with other SLE diagnostic systems was high, with correlations of .97 with both the Ropes system (Ropes, 1976) and the New York Hospital for Special Surgery (NYHSS) system (Lockshin et al., 1984) and .92 with the British Isles Lupus Assessment Group (BILAG) scale (Bacon et al., 1986). The inter-rater reliability of the SLAM was found to be .86 (Liang et al., 1989).

Measuring Quality of Life

Quality of life can be measured using either a single or multiple instruments, qualitative or quantitative measure(s), and objective or subjective measure(s). Because of design and cost issues, a single, subjective quantitative measure, the Quality of Life Index (QLI; Ferrans & Powers, 1985), was used in this study.

The Quality of Life Index (QLI; Ferrans & Powers, 1985). The QLI is a self-administered questionnaire consisting of two parts: Part one measures satisfaction with various domains of life, and part two measures the importance of the same domains to each subject. Specific life factors assessed by the tool include health care, physical health and functioning, marriage, family, friends, stress, standard of living, occupation, education, leisure, future retirement, sex, peace of mind, personal faith, life goals. personal appearance, self-acceptance, general happiness, and general satisfaction (Ferrans & Powers, 1985). These factors are grouped into four subscales: (a) health and functioning, (b) socioeconomic, (c) psychological/spiritual, and (d) family.

Satisfaction is measured through responses to 34 items on a 6-point Likert-type scale, ranging from "very satisfied" to "very dissatisfied." The importance of each of these 34 items to the individual is rated on a 6-point Likert-type scale ranging from "very important" to "very unimportant." The scores are calculated by weighting each satisfaction response with its corresponding importance response. Individual item scores belonging to a given domain are added for a domain score. The domain scores are then summed for an overall quality of life score ranging from 0 to 30. The highest scores are produced by high satisfaction/high importance responses, and the lowest are produced by high dissatisfaction/high importance responses. A higher QLI score indicates a high satisfaction and a high importance in various life domains. A lower QLI score indicates high dissatisfaction with various life domains, yet a high importance with those same domains.

Criterion-related (concurrent) validity was supported in two different samples, with correlations of .76 and .65 between scores on the QLI and a question concerning overall satisfaction with life (Ferrans & Powers, 1985). Cronbach's alphas of .93 and .90 provided support for internal consistency reliability (Ferrans & Powers, 1985). Test-retest correlations of .87 in one sample with a 2-week interval and .81 in another sample with a 1-month interval supported stability reliability (Ferrans & Powers, 1985).

Measuring Social Support

The social support measure used in this study was chosen, because it focuses on both the patient's support resources and her satisfaction with help received from those resources. The measure also focuses on the patient's perceived level of overall social support. Krol, Sanderman, and Suurmeijer (1993) found both social emotional support and instrumental support to be important components to the overall construct of social support. Through focusing on both situational and social support, the Personal Resource Questionnaire 85 (PRQ85; Weinert, 1987) comes close to tapping into both the social emotional and the instrumental components of social support. Higher PRQ85 scores indicate more perceived social support than lower scores.

The Personal Resource Questionnaire 85 (PRQ85; Weinert, 1987). The PRQ85 is a self-administered, two-part instrument developed by Brandt and Weinert (1981) to measure situational and perceived social support. After its initial use, a modified version, the PRQ82, was developed. After extensive use and testing of the PRQ82, the current version, the PRQ85 (Weinert, 1987), was developed.

Part one of the PRQ85 addresses situational support in 10 life situations in which the individual might be expected to need support or assistance. It obtains information concerning the person's resources and satisfaction with the help received from these resources. Part two of the instrument consists of 25 items presented on a 7-point rating scale, which measure the respondent's perceived level of social support. Because it specifically evaluates the subjective aspect of social support, Part 2 of the PRQ85 was used in this study. Scores on this scale can range from 25 to 175, with higher scores indicating higher levels of perceived social support.

Psychometric testing of the PRQ85 in four samples indicated that the measure has strong internal consistency reliability, with coefficients ranging from .87 to .90 (Weinert, 1987). Factor analysis of the PRQ85 indicated that the underlying structure did not contain five factors, as originally hypothesized. It was determined that three factors accounted for 43.4% of the variance. These were identified as intimacy/assistance, integration/affirmation, and reciprocity (Weinert & Tilden, 1990). Overall, the authors have provided evidence for content validity, internal consistency reliability, test-retest reliability, predictive validity, and freedom from social desirability response bias (Norbeck, 1988).

A social support group attendance-demographic questionnaire was used to assess support group participation. The questionnaire further acted as a needs assessment tool for the possible formation of future SLE support groups in the greater Grand Forks region. Demographic data for this study was obtained from questions 67-78 in the AIMS2.

Creating New Composite Measures

The total scores of the QLI and AIMS2 were highly correlated in preliminary data analysis ($\underline{r} = -.41$, $\underline{p} < .01$). Conclusions drawn from the analysis of the data may, therefore, be suspect due to the extent that the QLI and the AIMS2 measure similar global constructs, such as an overall feeling of wellness or life satisfaction. Because of this high correlation, the four regrouped AIMS2 variables, the QLI subscales, the SLAM total score, the SLAM 10-point visual analogue scale and the demographic questionnaire were combined to form three new measures, reflecting (1) composite perceived health, (2) composite objective health, and (3) composite quality of life. The composite objective health measure consists of the SLAM total score and the SLAM 10-point visual analogue scale. The composite perceived health measure consists of the regrouped AIMS2 physical variable (AIMS Physical), the quality of life health subscale, and the 10-point demographic visual analogue scale. Finally, the composite quality of life measure consists of the QLI subscales of family, socioeconomic status, and psychology/spirituality, and the regrouped AIMS2 variables of work (AIMS Work), support (AIMS Support), and mood (AIMS Mood). Composite scores were computed through first changing data to Z-scores and then combining scores. Intercorrelations of the composite measures are presented in Table 4 in Chapter 4.

Hypotheses

The following hypotheses were examined.

Hypothesis 1

The total score on the composite perceived health status measure will be significantly positively correlated with the total score on the composite objective health status measure.

Hypothesis 2

The total score for the PRQ85 part 2 (perceived social support) will be significantly negatively correlated with the total score of the composite perceived health status measure. (The correlation is negative due to how the composite perceived health status measure is scored).

Hypothesis 3

The total score for the PRQ85 part 2 (perceived social support) will not be significantly correlated with the total score of the composite objective health status measure. In other words, there will be no relationship between perceived social support and objective health status.

Hypothesis 4

Total score for the PRQ85 part 2 (perceived social support) will be significantly positively correlated with the total score of the composite quality of life measure.

Hypothesis 5

The total score of the composite perceived health status measure will be significantly negatively correlated with the composite quality of life measure. (The correlation is negative due to how the composite perceived health status measure is scored).

Hypothesis 6

The total score of the composite objective health status measure will be significantly negatively correlated with the total score of the composite quality of life measure. (The correlation is negative due to how the composite objective health status measure is scored).

Hypothesis 7

Scores on PRQ85 part 2 (perceived social support) will significantly improve prediction of quality of life beyond that from objective and perceived health status.

Hypothesis 8

Disease duration, as measured by question 68 in the AIMS2 and controlled for by age and marital status, will not be correlated with the total score composite quality of life measure

Analyses of Data

All data analysis was conducted on an IBM compatible computer with the software package SPSS for Windows version 6.1. Descriptive statistics with frequencies, percentages, and mean scores, when appropriate, were computed for demographic data obtained from 68-78 of the Arthritis Impact Measurement Scales 2, including age, race, education level, household income, relationship status, and length of time since diagnosis with SLE. Additional descriptive statistics are reported in Table 6 in Appendix F.

Descriptive analyses of the data was conducted with the standard deviations and means of the total scores for the composite objective health status measure, composite perceived health status measure, composite quality of life measure, and the PRQ-85 part 2 (perceived social support) are presented in Table 2 in Chapter 4. Descriptive analyses of the data was also conducted with the standard deviations and means of the total scores for the SLAM, AIMS2, QLI, and the PRQ85 part 2 are also presented in Table 2 in Chapter 4.

A correlation matrix for the total scores and subscales for the composite objective health status measure, composite perceived health status measure, composite quality of life measure and the PRQ85 part 2 (perceived social support) are presented in Table 4 in Chapter 4. A multiple regression analysis was used with the total score PRQ85 part 2 (perceived social support) and total score composite perceived health status, and total score composite objective health status being used to predict the total score composite quality of life.

A correlation matrix of the total scores for the SLAM, AIMS2, QLI, and the PRQ85 part 2 are presented in Table 3 in Chapter 4. The correlation matrix including the 12 subscales of Mobility Level, Walking and Bending, Hand and Finger Function, Self-Care Tasks, Household Tasks, Social Activity, Support from Family and Friends, Arthritis Pain, Work, Level of Tension, and Mood of the AIMS2 and the four subscales Health and Functioning, Socioeconomic, Psychological/Spiritual, and Family of the QLI is presented in Table 7 in Appendix G.

CHAPTER IV

RESULTS

Data were derived from the analysis of the 61 completed survey packets (which contained the AIMS2, QLI, PRQ-85), a demographic-social support questionnaire, and from analysis of the SLAM. Creation and analysis of the composite quality of life measure, composite perceived health status measure, and composite objective health status measure were also derived from the 61 completed survey packets. Analysis of these data was accomplished consistent with the eight hypotheses presented in Chapter 3. Each hypothesis was assessed according to an established .01 or .05 level of significance.

Data Analysis

The scores on perceived social support measured by the PRQ85-part 2 ranged from 85 to 169 (M = 139.75, SD = 21.19). Scores on the composite quality of life measure ranged from -12.88 to 84.00 (M = 52.44, SD 21.43). The scores on the composite perceived health status measure ranged from -29.00 to 43.29 (M = -9.23, SD 15.54). Scores on the composite objective health measure ranged from zero to 16.50 (M = 4.66, SD = 3.38). Scores on quality of life measured by the QLI ranged from 3.16 to 30.0 (M = 21.5, SD = 6.03). The scores on perceived health status measured by the AIMS-2 ranged from 5.50 to 73.75 (M = 25.95, SD = 14.77). Finally, scores on objective health status as measured by the SLAM ranged from zero to 12.00 (M = 3.48, SD=2.53).

Table 2 displays the means, standard deviations, and range of scores for the intact and composite study variables. The intercorrelations of the intact study variables and composite variables are displayed in Table 3. Subscale intercorrelations of the intact study variables are presented in Appendix G. The intercorrelations of the composite variables are displayed in Table 4.

Table 2

Means, Standard Deviations, and Ranges of Scores for Intact and Composite Variables

	M	SD	Range
Composite Perceived Health	-9.23	15.54	-29.99 - 43.29
Composite Objective Health	4.66	3.38	00.00 - 16.50
Composite Quality of Life	52.44	21.43	-12.88 - 84.00
AIMS2	25.95	14.77	5.50 - 73.75
SLAM	3.48	2.53	0.00 - 12.00
QLI	21.50	6.03	3.16 - 30.00
PRQ85 Part 2	139.75	21.19	85.00 - 169.00

Table 3

Intercorrelations of Intact Variables

	2.	3.	4.	5.	6.
1. AIMS2 Total	.55*	-.78*	-.41*	.23**	.12
2. Dem VAS		-.48*	-.17	.30**	.07
3. QLI Total			.49*	-.26**	-.15
4. PRQ-85 Part 2 Total				-.02	-.03
5. SLAM Total					.56*
6. SLAM VAS					

* p < .01
** p < .05

Table 4

Intercorrelations of Intact Variables with Composite Variables

	Objective Health	Perceived Health	Quality of Life
AIMS2			
1. Mood	-.02	.50*	-.65[a]
2. Physical	.23	.93[a]	-.63*
3. Support	.01	.41*	-.58[a]
4. Work	.05	.31**	-.40[a]
5. VAS	.29	.66[a]	-.48*
Objective Health			
6. SLAM	.95[a]	.28**	-.24
7. SLAM VAS	.78[a]	.22	-.17
Quality of Life			
8. Family	.35*	-.63	.73[a]
9. Health	-.24	-.89[a]	.86*
10. SES	-.19	-.73*	.87[a]
11. Spiritual	-.23	-.68*	.87[a]
Social Support			
12. PRQ85	-.03	-.44*	.61*
Composite Variables			
13. Objective Health	1.00	.28**	-.23**
14. Perceived Health		1.00	-.79*
15. Quality of Life			1.00

* $p < .01$

** $p < .05$

[a] Scale is an element of composite score.

Hypotheses

Hypothesis 1

The total score for the composite perceived health status measure will be significantly positively correlated with the total score of the composite objective health status measure.

The total score of the composite perceived health status measure was found to be significantly positively correlated with the composite objective health status measure ($r = .28$, $p < .05$) which is consistent with the original hypothesis.

Hypothesis 2

The total score for the PRQ85 part 2 (perceived social support) will be significantly negativley correlated with the total score of the composite perceived health status measure. (The correlation is negative due to how the composite perceived health status measure is scored).

The total score for the PRQ-85 part 2 (perceived social support) was significantly negatively correlated with the total score of the composite perceived health status measure ($r = -.44$, $p < .01$) as hypothesized.

Hypothesis 3

The total score for the PRQ85 part 2 (perceived social support) will not be significantly correlated with the total score of the composite objective health status measure. There will be no relationship between perceived social support and objective health status.

The total score for the PRQ-85 part 2 (perceived social support) was not significantly correlated with the total score of the composite objective health status measure ($r = -.03$, $p > .05$) as hypothesized.

Hypothesis 4

Total score for the PRQ85 part 2 (perceived social support) will be significantly positively correlated with the total score of the composite quality of life measure.

Total score for the PRQ85 part 2 (perceived social support) was significantly positively correlated with the total score on the composite quality of life measure ($r = .61$, $p < .01$) as hypothesized.

Hypothesis 5

The total score of the composite perceived health status measure will be significantly negatively correlated with the composite quality of life measure. (The correlation is negative due to how the composite perceived health status measure is scored).

The total score of the composite perceived health status measure was significantly negatively correlated with the composite quality of life measure ($r = -.79$, $p < .01$) as hypothesized.

Hypothesis 6

The total score of the composite objective health status measure will be significantly negatively correlated with the total score of the composite quality of life measure. (The correlation is negative due to how the composite objective health status measure is scored).

The total score of the composite objective health status measure was significantly negatively correlated with the total score of the composite quality of life measure ($r = -.23$, $p > .05$) which is consistent with the original hypothesis.

Hypothesis 7

Scores on the PRQ85 part 2 (perceived social support) will significantly improve prediction of quality of life beyond that from objective and perceived health status.

I found that the composite perceived health status measure and the composite objective health status measure explained 63 % of the variance in the composite quality of life measure ($R^2 = .63$, $p < .01$). The addition of the PRQ85 part 2 (perceived social support) to the regression equation explained an additional 9% of the variance in the composite quality of life measure ($R^2 = .72$, $p < .01$).

Hypothesis 8

Disease duration, as measured by question 68 in the AIMS2, and controlled for by age and marital status, will not be significantly correlated with total score composite quality of life measure.

The partial correlation between disease duration and composite quality of life, and controlled for by age and marital status, was not found to be significantly different from zero ($r = .11$, $p > .05$), which is consistent with the original hypothesis.

Support Group Participation

Only six participants attended a social support group for SLE regularly (9.8%), leaving 55 respondents who did not attend any type of support group (90.2%) (Table 6). The number one reason that people did not attend was because they were unaware of meetings in their area (45.9%) or it was too far to travel to get to a meeting (13.1%).

Table 5

Support Group Attendance

	Frequency	Percent
Support Group Attendance		
Yes	6	9.8
No	55	90.2
Interest in Joining Support Group		
Yes	35	64.0
No	20	36.0
Reasons for Not Attending Support Group		
Flares	2	3.3
Lack of Interest	5	8.2
Too Busy	6	9.8
Too Far to Travel	8	13.1
Inclement Weather	4	6.6
Unaware of Meetings	28	45.9
Other	8	13.1
Interest in Leading Support Group		
Yes	7	11.5
No	54	88.5
Receiving Phone Support		
Yes	18	29.5
No	43	70.5
Giving Phone Support		
Yes	20	32.8
No	41	67.2

Analysis indicated that thrity-five respondents would be interested in joining a support group (64.0%) with 20 stating that they would not be interested in joining a support group (36.0%). Further, seven stated that they would be interested in leading a support group

(11.5%) and 18 stated that they would be interested in receiving some type of phone support for SLE (29.5%). Last, twenty stated that they would be interested in giving phone support (32.8%). Patients were also asked to give their zip code as a needs assessment for the development of future SLE support group. Grand Forks had the highest number of zip codes reported with 12 (20%).

CHAPTER V

DISCUSSION AND SUMMARY

The primary purpose of this study was to examine the relationship among perceived social support, health status, and quality of life in a sample of women diagnosed with Systemic Lupus Erythematosus (SLE). Reasons why women chose to not attend social support groups for SLE were also assessed.

Hypothesis 1

There was a significant but very modest relationship between the composite objective health status measure and the composite perceived health status measure, which is consistent with the original hypothesis. Although there is some convergence in how the SLE patient and Dr. Lessard are assessing and perceiving the degree of SLE activity and health status, there remains substantial differences in these two measurements. One explanation may be that the perceived health status measure may be measuring the day to day, episodic nature of the disease, while the objective health status measure is assessing a cross section of disease activity at one point in time.

Hypothesis 2

There was a significant relationship between perceived social support and the composite perceived health status measure in the female SLE patients sampled. This may indicate that the more the SLE patient feels that she is supported, the better she may perceive her health status to be or the better she may feel. This is consistent with the findings of Nunes et al. (1995) who looked at perceived social support in relation to HIV/AIDS and Tell et al. (1995) who found that the higher the perceived social support, the better the reported observed functional level in black and white dialysis patients.

Hypothesis 3

There was no relationship between perceived social support and the composite objective health status measure, as is consistent with the original hypothesis. This finding makes intuitive sense, because objective SLE physical symptoms such as malar rash, alopecia, and lymphocyte count would not be expected to have a causal relationship or cause the feelings of perceived social support. Nunes et al. (1995) also found no significant relationship between perceived social support and CD4 lymphocyte count.

Hypothesis 4

A strong significant relationship (r =.61, p < .01) was found between the PRQ85 part 2 (perceived social support) and the composite quality of life measure in this sample of SLE patients. This indicates that if the SLE patient were to improve her level of perceived social support, she may perceive her quality of life as improving. One way to gain social support is through support group attendance. This is consistent with Nunes et al. (1995) who found a significant positive relationship between perceived social support and quality of life in a sample of HIV/AIDS patients.

Hypothesis 5

There was a significant relationship between the composite perceived health status measure and the composite quality of life measure. This further indicates that perception of health status in SLE patients is related to how they perceive or view their quality of life. If the SLE patient perceives her health status as being good, she may also perceive her quality of life as being good. This is also related to Hypothesis 4 where perceived social support was found to be related to quality of life. Improving the SLE patient's perceived social support may help to improve the patient's perceived health status which may, in turn, improve the patient's quality of life. This finding is consistent with Burckhardt et al. (1993) who found that life quality in Rheumatoid Arthritis patients could best be predicted through psychological distress and physical functioning.

Hypothesis 6

A significant relationship was found between the composite objective health status measure and the composite quality of life measure which is consistent with the original hypothesis. Nunes et al. (1995) also found a relationship between CD4 lymphocyte count and quality of life. This finding makes intuitive sense. If the SLE patient was not presenting with many clinical manifestations or symptoms, she may feel better and have a better perceived quality of life, than someone who is experiencing more acute symptomology.

Hypothesis 7

It was found that quality of life in this sample of female SLE patients could better be predicted when perceived social support was looked at in conjunction with objective health status and perceived health status, rather than by only looking at health status (objective and perceived) alone. This finding has important implications for health care providers. It may be wise for health care workers to provide support group and other types of social support information to their SLE patients. In this way, the SLE patient is treated in a more thorough or holistic manner, with both her physical and psychosocial needs being addressed or taken into account.

Hypothesis 8

As is consistent with Burkhardt et al. (1993), there was no relationship found between disease duration and quality of life when age and marital status were controlled for in this sample of SLE patients. This indicates that disease duration has no strong or significant relationship with quality of life or that quality of life has the potential for being enhanced or improved in the SLE patient regardless of the length of time that she has had or has been diagnosed with SLE.

Qualitative Information

Though this study was quantitative in nature, about 20 respondents included notes or letters when they returned the surveys. Approximately 15 of the respondents were very excited about the study and felt that there could never be enough SLE research. These respondents wanted to help in any way that they could and some even included their phone numbers. Some of the respondents wrote notes about God or Jesus and talked about how He was their help during times of trouble and that they knew that God wouldn't ever give them more than they could handle. Some of the respondents felt that God would always be their comfort even when conventional medicine may not be helping with their SLE.

About five of the respondents expressed a great deal of anger about having SLE. They wrote about the pain and uncertainty associated with their disease. While they were happy that I was researching or studying more about SLE, they also felt that it was impossible to have a thorough understanding of the disease without actually having it.

Summary

The study looked at eight hypotheses and found that perceived social support is significantly positively related to quality of life in this sample of women with SLE. Perceived health status was significantly negatively correlated with both perceived social support and quality of life; objective health status was significantly negatively correlated with quality of life. The results of this study further indicate that perceived social support is positively correlated with quality of life and that quality of life is negatively correlated with perceived health status and objective health status.

It was found that the two major reasons that women did not attend SLE support groups were that they were unaware of meetings in their area or it was too far to travel to reach a support group meeting. Results further indicated that SLE patients sampled are interested in joining support groups and that a substantial interest in the formation of a support group in the Grand Forks region exists.

Although this was a quantitative study, notes or letters were included from some of the respondents. Most of the notes expressed praise for this study and were happy to be included. Some expressed anger at the unpredictability of their disease and didn't think that any type of research would help them.

Limitations

This study is limited to the 61 female SLE patients who filled out the survey packets from Dr. Lessard's rheumatology practice in Grand Forks, North Dakota. Limitations further include the self-report nature of four out of the five instruments and the self-selection of the participants in the study. The design of this study examined the nature of the relationships between selected demographic variables, perceived social support, quality of life, perceived health status, and objective health status, however, no conclusions regarding the direction of the relationships or causality may be determined from this study. A final limitation of this study is the underrepresentation of minorities in the sample.

Conclusions and Recommendations

The results of this study have helped to contribute to a better understanding of the relationships among perceived social support, quality of life, perceived health status and objective health status in a sample of women with SLE. Because SLE is not an automatic death sentence, with more than 90% of newly diagnosed cases surviving ten years or more, and because about sixteen thousand new cases of SLE are diagnosed each year, it is important to look at improving the quality of life of people with this chronic illness (Dibner & Colman, 1994). One way quality of life may be improved is through increased or enhanced social support (Nunes et al., 1995). It is important for health care providers to treat the SLE patient in a holistic manner, and an important component of this holistic treatment is the inclusion of the assessment of perceived social support. The study also found that women are interested in joining a support group for SLE, but do not attend because they do not know where SLE support groups are held or the support groups are too far away to travel to. Grand Forks, North Dakota does not currently have an SLE support group and results of this study indicate that there is an interest in starting a support group for SLE in Grand Forks.

Because the Lupus Foundation of America has over 442 lupus support groups, I recommend a study that uses an experimental design in placing one group of SLE patients in a support group and one in a control group and then looks at the resulting relationship of social support to quality of life. In this way, a stronger conclusion regarding the causal relationship between social support and quality of life may be made than was permitted by the present correlational study.

APPENDICES

APPENDIX A

ARTHRITIS IMPACT MEASUREMENT SCALES 2

ID ________1-4/
Adm# ________5-6/
Card #1 7/*

ARTHRITIS IMPACT MEASUREMENT SCALES 2

(AIMS2)

Instructions: Please answer the following questions about your health. Most questions ask about your health during the past month. There are no right or wrong answers to the questions and most can be answered with a simple check (X). Please answer every question.

AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to MOBILITY LEVEL

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
1. How often were you physically able to drive a car or use public transportation?						8/
2. How often were you out of the house for at least part of the day?						9/
3. How often were you able to do errands in the neighborhood?						10/
4. How often did someone have to assist you to get around outside your home?						11/
5. How often were you in a bed or chair for most or all of the day?						12/

……

AIMS

These questions refer to WALKING AND BENDING.

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
6. Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports?						13/
7. Did you have trouble either walking several blocks or climbing a few flights of stairs?						14/
8. Did you have trouble bending, lifting or stooping?						15/
9. Did you have trouble either walking one block or climbing one flight of stairs?						16/
10. Were you unable to walk unless assisted by another person or by a cane, crutches, or walker?						17/

AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to **HAND AND FINGER FUNCTION**.

DURING THE PAST MONTH...	**All Days (1)**	**Most Days (2)**	**Some Days (3)**	**Few Days (4)**	**No Days (5)**	
11. Could you easily write with a pen or pencil?	___	___	___	___	___	18/
12. Could you easily button a shirt or blouse?	___	___	___	___	___	19/
13. Could you easily turn a key in a lock?	___	___	___	___	___	20/
14. Could you easily tie a knot or a bow?	___	___	___	___	___	21/
15. Could you easily open a new jar of food?	___	___	___	___	___	22/

……

AIMS

These questions refer to **ARM FUNCTION**

DURING THE PAST MONTH...	**All Days (1)**	**Most Days (2)**	**Some Days (3)**	**Few Days (4)**	**No Days (5)**	
16. Could you easily wipe your mouth with a napkin?	___	___	___	___	___	23/
17. Could you easily put on a pullover sweater?	___	___	___	___	___	24/
18. Could you easily comb or brush your hair?	___	___	___	___	___	25/
19. Could you easily scratch your low back with your hand?	___	___	___	___	___	26/
20. Could you easily reach shelves that were above your head?	___	___	___	___	___	27/

AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to SELF-CARE TASKS.

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
21. Did you need help to take a bath or shower?	____	____	____	____	____	28/
22. Did you need help to get dressed?	____	____	____	____	____	29/
23. Did you need help to use the toilet?	____	____	____	____	____	30/
24. Did you need help to get in or out of bed?	____	____	____	____	____	31/

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AIMS

These questions refer to HOUSEHOLD TASKS.

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
25. If you had the necessary transportation, could you go shopping for groceries without help?	____	____	____	____	____	32/
26. If you had kitchen facilities, could prepare your own meals without help?	____	____	____	____	____	33/
27. If you had household tools and appliances, could you do your own housework without help?	____	____	____	____	____	34/
28. If you had laundry facilities, could you do your own laundry without help?	____	____	____	____	____	35/

AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to SOCIAL ACTIVITY

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
29. How often did you get together with friends or relatives?	___	___	___	___	___	36/
30. How often did you have friends or relatives over to your home?	___	___	___	___	___	37/
31. How often did you visit friends or relatives at their homes?	___	___	___	___	___	38/
32. How often were you on the telephone with close friends or relatives?	___	___	___	___	___	39/
33. How often did you go to a meeting of a church, club, team or other group?	___	___	___	___	___	40/

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AIMS

These questions refer to **SUPPORT FROM FAMILY AND FRIENDS**

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
34. Did you feel that your family or friends would be around if you needed assistance?	___	___	___	___	___	41/
35. Did you feel that your family or friends were sensitive to your personal needs?	___	___	___	___	___	42/
36. Did you feel that your family or friends were interested in helping you solve problems?	___	___	___	___	___	43/
37. Did you feel that your family or friends understood the effects of your arthritis?	___	___	___	___	___	44/

AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to ARTHRITIS PAIN.

DURING THE PAST MONTH...	Severe (1)	Moderate (2)	Mild (3)	Very Mild (4)	None (5)	
38. How would you describe the arthritis pain you usually had?	___	___	___	___	___	45/

	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
39. How often did you have severe pain from your arthritis?	___	___	___	___	___	46/
40. How often did you have pain in two or more joints at the same time?	___	___	___	___	___	47/
41. How often did your morning stiffness last more than one hour from the time you woke up?	___	___	___	___	___	48/
42. How often did your pain make it difficult for you to sleep?	___	___	___	___	___	49/

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AIMS

These questions refer to WORK.

DURING THE PAST MONTH...	Paid work (1)	House work (2)	School work (3)	Unemployed (4)	Disabled (5)	Retired (6)	
43. What has been your main form of work?	___	___	___	___	___	___	50/

If you answered unemployed, disabled or retired, please skip the next four questions and go to the next page.

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
44. How often were you unable to do any paid work, house work or school work?	___	___	___	___	___	51/
45. On the days that you did work, how often did you have to work a shorter day?	___	___	___	___	___	52/
46. On the days that you did work, how often were you unable to do your work as carefully and accurately as you would like?	___	___	___	___	___	53/
47. On the days that you did work, how often did you have to change the way your paid work, house work or school work is usually done?	___	___	___	___	___	54/

AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to LEVEL OF TENSION.

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
48. How often have you felt tense or high strung?	___	___	___	___	___	55/
49. How often have you been bothered by nervousness or your nerves?	___	___	___	___	___	56/
50. How often were you able to relax without difficulty?	___	___	___	___	___	57/
51. How often have you felt relaxed and free of tension?	___	___	___	___	___	58/
52. How often have you felt calm and peaceful?	___	___	___	___	___	59/

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AIMS

These questions refer to MOOD

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
53. How often have you enjoyed the things you do?	___	___	___	___	___	60/
54. How often have you been in low or very low spirits?	___	___	___	___	___	61/
55. How often did you feel that nothing turned out the way you wanted it to?	___	___	___	___	___	62/
56. How often did you feel that others would be better off if you were dead?	___	___	___	___	___	63/
57. How often did you feel so down in the dumps that nothing would cheer you up?	___	___	___	___	___	64/

Please check (X) the most appropriate answer for each question.

These questions refer to satisfaction with each health area.

DURING THE PAST MONTH...	Very Satisfied (1)	Somewhat Satisfied (2)	Neither Satisfied Nor Dissatisfied (3)	Somewhat Dissatisfied (4)	Very Dissatisfied (5)	
58. How satisfied have you been with each of these areas of your health?						
MOBILITY LEVEL (example: do errands)	___	___	___	___	___	65/
WALKING AND BENDING (example: climb stairs)	___	___	___	___	___	66/
HAND AND FINGER FUNCTION (example: tie a bow)	___	___	___	___	___	67/
ARM FUNCTION (example: comb hair)	___	___	___	___	___	68/
SELF-CARE (example: take bath)	___	___	___	___	___	69/
HOUSEHOLD TASKS (example: housework)	___	___	___	___	___	70/
SOCIAL ACTIVITY (example: visit friends)	___	___	___	___	___	71/
SUPPORT FROM FAMILY (example: help with problems)	___	___	___	___	___	72/
ARTHRITIS PAIN (example: joint pain)	___	___	___	___	___	73/
WORK (example: reduce hours)	___	___	___	___	___	74/
LEVEL OF TENSION (example: felt tense)	___	___	___	___	___	75/
MOOD (example: down in dumps)	___	___	___	___	___	76/

ID 1-4/
ADM# 5-6/
CARD #2 7/
AIMS

Please check (X) the most appropriate answer for each question.

These questions refer to arthritis impact on each area of health.

DURING THE PAST MONTH...	Not a Problem For Me (0)	Due Entirely To Other Causes (1)	Due Largely To Other Causes (2)	Due Partly to Arthritis and Partly To Other Causes (3)	Due Largely To My Arthritis (4)	Due Entirely To My Arthritis (5)	
59. How much of your problem in each area of health was due to your arthritis?							
MOBILITY LEVEL (example: do errands)	___	___	___	___	___	___	8/
WALKING AND BENDING (example: climb stairs)	___	___	___	___	___	___	9/
HAND AND FINGER FUNCTION (example: tie a bow)	___	___	___	___	___	___	10/
ARM FUNCTION (example: comb hair)	___	___	___	___	___	___	11/
SELF-CARE (example: take bath)	___	___	___	___	___	___	12/
HOUSEHOLD TASKS (example: housework)	___	___	___	___	___	___	13/
SOCIAL ACTIVITY (example: visit friends)	___	___	___	___	___	___	14/
SUPPORT FROM FAMILY (example: help with problems)	___	___	___	___	___	___	15/
ARTHRITIS PAIN (example: joint pain)	___	___	___	___	___	___	16/
WORK (example: reduce hours)	___	___	___	___	___	___	17/
LEVEL OF TENSION (example: felt tense)	___	___	___	___	___	___	18/
MOOD (example: down in dumps)	___	___	___	___	___	___	19/

AIMS

You have now answered questions about different **AREAS OF YOUR HEALTH**. These areas are listed below. Please check (x) up to **THREE AREAS** in which you would **MOST LIKE TO SEE IMPROVEMENT**. Please read all 12 areas of health choices before making your decision:

check = 1
blank = 0

60. **AREAS OF HEALTH**	**THREE AREAS FOR IMPROVEMENT**	
MOBILITY LEVEL (example: do errands)	________	20/
WALKING AND BENDING (example: climb stairs)	________	21/
HAND AND FINGER FUNCTION (example: tie a bow)	________	22/
ARM FUNCTION (example: comb hair)	________	23/
SELF-CARE (example: take bath)	________	24/
HOUSEHOLD TASKS (example: housework)	________	25/
SOCIAL ACTIVITY (example: visit friends)	________	26/
SUPPORT FROM FAMILY (example: help with problems)	________	27/
ARTHRITIS PAIN (example: joint pain)	________	28/
WORK (example: reduce hours)	________	29/
LEVEL OF TENSION (example: felt tense)	________	30/
MOOD (example: down in dumps)	________	31/

Please make sure that you have checked no more than **THREE AREAS** for improvement.

Please check (X) the most appropriate answer for each question.

These questions refer to your **CURRENT** and **FUTURE HEALTH**.

	Excellent (1)	Good (2)	Fair (3)	Poor (4)	
61. In general would you say that your **HEALTH NOW** is excellent, good, fair or poor?	___	___	___	___	32/

....

	Very Satisfied (1)	Somewhat Satisfied (2)	Neither Satisfied Nor Dis-satisfied (3)	Somewhat Dissatisfied (4)	Very Dis-satisfied (5)	
62. How satisfied are you with your **HEALTH NOW**?	___	___	___	___	___	33/

	Not a Problem For Me (0)	Due Entirely To Other Causes (1)	Due Largely To Other Causes (2)	Due Partly to Arthritis and Partly To Other Causes (3)	Due Largely To My Arthritis (4)	Due Entirely To My Arthritis (5)	
63. How much of your problem with your **HEALTH NOW** is due to your arthritis?	___	___	___	___	___	___	34/

....

	Excellent (1)	Good (2)	Fair (3)	Poor (4)	
64. In general do you expect that your **HEALTH 10 YEARS FROM NOW** will be excellent, good, fair or poor?	___	___	___	___	35/

	No Problem At All (1)	Minor Problem (2)	Moderate Problem (3)	Major Problem (4)	
65. How big a problem do you expect your arthritis to be **10 YEARS FROM NOW**?	___	___	___	___	36/

AIMS

Please check (X) the most appropriate answer for each question.

This question refers to OVERALL ARTHRITIS IMPACT.

	Very Well (1)	Well (2)	Fair (3)	Poor (4)	Very Poorly (5)	
66. CONSIDERING ALL THE WAYS THAT YOUR ARTHRITIS AFFECTS YOU, how well are you doing compared to other people your age?	___	___	___	___	___	37/

…………………………………………………………………………………………

AIMS

67. What is the main kind of arthritis that you have?		check = 1 blank = 0
Rheumatoid Arthritis	___	38/
Osteoarthritis/Degenerative Arthritis	___	39/
Systemic Lupus Erythematosis	___	40/
Fibromyalgia	___	41/
Scleroderma	___	42/
Psoriatic Arthritis	___	43/
Reiter's Syndrome	___	44/
Gout	___	45/
Low Back Pain	___	46/
Tendonitis/Bursitis	___	47/
Osteoporosis	___	48/
Other	___	49/

68. How many years have you had arthritis? ___ 50-51/

…………………………………………………………………………………………

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
69. How often have you had to take MEDICATION for your arthritis?	___	___	___	___	___	52/

Please check (X) yes or no for each question.

70. Is your health currently affected by any of the following medical problems?

	Yes (1)	No (2)	
High blood pressure____________	____	____	53/
Heart disease____________	____	____	54/
Mental illness____________	____	____	55/
Diabetes____________	____	____	56/
Cancer____________	____	____	57/
Alcohol or drug use____________	____	____	58/
Lung disease____________	____	____	59/
Kidney disease____________	____	____	60/
Liver disease____________	____	____	61/
Ulcer or other stomach disease____________	____	____	62/
Anemia or other blood disease____________	____	____	63/

	Yes (1)	No (2)	
71. Do you take medicine every day for any problem other than your arthritis?	____	____	64/

	Yes (1)	No (2)	
72. Did you see a doctor more than three times last year for any problem other than arthritis?	____	____	65/

AIMS

Please provide the following information about yourself:

73. What is your age at this time? ______ 66-67/

74. What is your sex?

Male (1) ______ 68/
Female (2) ______

75. What is your racial background?

White (1) ______ 69/
Black (2) ______
Hispanic (3) ______
Asian or Pacific Islander (4) ______
American Indian or Alaskan Native (5) ______
Other (6) ______

76. What is your current marital status?

Married (1) ______ 70/
Separate (2) ______
Divorced (3) ______
Widowed (4) ______
Never married (5) ______

77. What is the highest level of education you received. 71/

Less than seven years of school (1) ______
Grades seven through nine (2) ______
Grades ten through eleven (3) ______
High school graduate (4) ______
One to four years of college (5) ______
College graduate (6) ______
Professional or graduate school (7) ______

78. What is your approximate family income including wages, disability payment, retirement income and welfare? 72/

Less than $10,000 (1) ______
$10,000 - $19,999 (2) ______
$20,000 - $29,999 (3) ______
$30,000 - $39,999 (4) ______
$40,000 - $49,999 (5) ______
$50,000 - $59,999 (6) ______
$60,000 - $69,999 (7) ______
More than $70,000 (8) ______

Thank you for completing this questionnaire.

APPENDIX B

PERSONAL RESOURCE QUESTIONNAIRE 85

PERSONAL RESOURCE QUESTIONNAIRE (PRQ-85)

® Brandt and Weinert

In our everyday lives there are personal and family situations or problems that we must deal with. Some of these are listed below. Please consider each statement in light of your own situation. **CIRCLE** the number before the person(s) that you <u>could count</u> on in each situation that is described. You may circle more than one number if there is more than one source of help that you <u>count on.</u> In addition, we would like to know if you have had this situation or a similar one in the past <u>SIX MONTHS</u>, and how satisfied you are with the help you received.

==

Q-1a. If you were to experience urgent needs (crisis), who would you turn to for help? (Please **CIRCLE** all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ______________________________

b. Have you had urgent needs (crisis) in the past <u>SIX MONTHS</u>?

1 YES
2 NO (If NO, skip to Q-2a.)

c. If you have experienced urgent needs (crisis) in the past <u>SIX MONTHS</u>, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-2a. If you needed help for an extended period of time in caring for a family member who is sick or handicapped, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ______________________________

b. Have you needed help in caring for a sick or handicapped family member in the past <u>SIX MONTHS</u>?

1 YES
2 NO (If NO, skip to Q-3a.)

c. If you have needed help in caring for a sick or handicapped family member in the past <u>SIX MONTHS</u>, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-3a. If you were concerned about your relationship with your spouse, partner, or intimate other, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ______________________________

b. Have you had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-4a.)

c. If you have had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-4a. If you needed help or advice for a problem with a family member or friend who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ____________________

b. Have you needed help or advice regarding a problem with a family member or friend in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-5a.)

c. If you have needed help or advice in the past SIX MONTHS regarding a problem with a member or friend, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED

Q-5a. If you were having financial problems, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ____________________

b. Have you had financial problems in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-6a.)

c. If you have had financial problems in the past SIX MONTHS to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-6a. If you felt lonely, who would you turn to? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ____________________

b. Have you felt lonely in the past <u>SIX MONTHS</u>?

1 YES
2 NO (If NO, skip to Q-7a.)

c. If you have felt lonely, in the past <u>SIX MONTHS</u>, to what extent do you feel satisfied with the help you have received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-7a. If you were sick and not able to carry out your usual activities for a week or so, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ____________________

b. During the past <u>SIX MONTHS</u>, have you been sick for a week and not able to carry out your usual activities?

1 YES
2 NO (If NO, skip to Q-8a.)

c. If you have been sick for a week during the past <u>SIX MONTHS</u> to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-8a. If you were upset and frustrated with the conditions of your life, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ______________________________

b. Have you been upset and frustrated with the conditions of your life in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-9a.)

c. If you have been upset and frustrated with the conditions of your life in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-9a. If you were having problems with your work at home or at your place of employment, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ______________________________

b. Have you had problems related to your work in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-10a.)

c. If you have had problems with your work situation in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-10a. If you needed someone to talk to about your day-to-day personal concerns, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) ______________________________

b. Have you needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-11)

c. If you have needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-11. Below are some statements with which some people agree and others disagree. Please read each statement and CIRCLE the response most appropriate for you. There is no right or wrong answer.

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SOMEWHAT DISAGREE
4 = NEUTRAL
5 = SOMEWHAT AGREE
6 = AGREE
7 = STRONGLY AGREE

STATEMENTS

---

a. There is someone I feel close to who makes me feel secure 1 2 3 4 5 6 7

b. I belong to a group in which I feel important 1 2 3 4 5 6 7

c. People let me know that I do well at my work (job, homemaking) 1 2 3 4 5 6 7

d. I can't count on my relatives and friends to help me with problems 1 2 3 4 5 6 7

e. I have enough contact with the person who makes me feel special 1 2 3 4 5 6 7

f. I spend time with others who have the same interests that I do 1 2 3 4 5 6 7

g. There is little opportunity in my life to be giving and caring to another person 1 2 3 4 5 6 7

h. Others let me know that they enjoy working with me (job, committees, projects) 1 2 3 4 5 6 7

i. There are people who are available if I needed help over an extended period of time 1 2 3 4 5 6 7

j. There is no one to talk to about how I am feeling 1 2 3 4 5 6 7

k. Among my group of friends we do favors for each other 1 2 3 4 5 6 7

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SOMEWHAT DISAGREE
4 = NEUTRAL
5 = SOMEWHAT AGREE
6 = AGREE
7 = STRONGLY AGREE

STATEMENTS							
l. I have the opportunity to encourage others to develop their interests and skills	1	2	3	4	5	6	7
m. My family lets me know that I am important for keeping the family running	1	2	3	4	5	6	7
n. I have relatives or friends that will help me out even if I can't pay them back	1	2	3	4	5	6	7
o. When I am upset there is someone I can be with who lets me be myself	1	2	3	4	5	6	7
p. I feel no one has the same problems as I	1	2	3	4	5	6	7
q. I enjoy doing little "extra" things that make another person's life more pleasant	1	2	3	4	5	6	7
r. I know that others appreciate me as a person	1	2	3	4	5	6	7
s. There is someone who loves and cares about me	1	2	3	4	5	6	7
t. I have people to share social events and fun activities with	1	2	3	4	5	6	7
u. I am responsible for helping provide for another person's needs	1	2	3	4	5	6	7
v. If I need advice there is someone who would assist me to work out a plan for dealing with the situation	1	2	3	4	5	6	7
w. I have a sense of being needed by another person	1	2	3	4	5	6	7
x. People think that I'm not as good a friend as I should be	1	2	3	4	5	6	7
y. If I got sick, there is someone to give me advice about caring for myself	1	2	3	4	5	6	7

APPENDIX C

QUALITY OF LIFE INDEX

Ferrans and Powers
QUALITY OF LIFE INDEX

Part I. For each of the following, please choose the answer that best describes how **satisfied** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. The health care you are receiving?	1	2	3	4	5	6
3. The amount of pain that 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. The amount of control you have over your life?	1	2	3	4	5	6
7. Your potential to live a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6

(Please Go To Next Page)

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	4	5	6
21. Your job?	1	2	3	4	5	6
22. Not having a job?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your personal faith in God?	1	2	3	4	5	6
30. Your achievment of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

(Please Go To Next Page)

Part II. For each of the following, please choose the answer that best describes **how important** that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Health care?	1	2	3	4	5	6
3. Being completely free of pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Your physical independence?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6
15. Meeting family responsibilities?	1	2	3	4	5	6
16. Being useful to others?	1	2	3	4	5	6
17. Having a reasonable amount of stress or worries?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6

(Please Go To Next Page)

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
19. Your neighborhood?	1	2	3	4	5	6
20. A good standard of living?	1	2	3	4	5	6
21. Your job?	1	2	3	4	5	6
22. To have a job?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Leisure time activities?	1	2	3	4	5	6
26. The ability to travel on vacations?	1	2	3	4	5	6
27. Having a happy old age/retirement?	1	2	3	4	5	6
28. Peace of mind?	1	2	3	4	5	6
29. Your personal faith in God?	1	2	3	4	5	6
30. Achieving your personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Being satisfied with life?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Are you to yourself?	1	2	3	4	5	6

APPENDIX D

DEMOGRAPHIC-SOCIAL SUPPORT QUESTIONNAIRE

SYSTEMIC LUPUS ERYTHEMATOSUS, QUALITY OF LIFE, AND SUPPORT AMONG PATIENTS STUDY: DEMOGRAPHIC AND SUPPORT HISTORY QUESTIONS

1. You have been diagnosed by Dr. Lessard as having: (Please check all that apply)
_____ SLE
_____ Anticardiolipin
_____ Both SLE and Anticardiolipin

(Here Forward SLE will refer to both SLE and Anticardiolipin)

2. Do you know any other people with SLE?
______ yes If Yes:
(a) How often do you interact with them?
______________________.
(b) Do you gain social support from them?
______________________.
(c) Do you give social support to them?
______________________.
______no

3. In the past 12 months, have you attended an Arthritis, Lupus or other "medical-oriented" support group to obtain social support for SLE?
_____ yes
_____ no

4. How often do you attend the support group meetings?
______ one time a month
______ once every other month
______ four to five times in the past year
______ one to three times in the past year
______ never

5. If you don't go to meetings or can't make it to a meeting, it is usually due to (Please check all that apply; if more than one, please number them in order of which reason happens most often from "1" most often, "2", next most often. etc.):
______ flares or other SLE related medical reasons
______ lack of interest in the topic or the speaker
______ too busy to attend
______too far to ride to get to the meeting
______lack of transportation
______inclimate weather conditions
______unaware of any meetings in the area
______other (Please describe) ______________________________

6. If you do not attend an SLE support group, would you be interested in joining one?
______Yes (If yes), What would hope to gain from being in the support group?

____.

______No

7. Would you be interested in leading an SLE support group?
______Yes (If yes) What would you hope to gain by leading a SLE support group?

____.

______No

8. Would you be interested in receiving social support for SLE through the phone?
______Yes (If yes) What would hope to gain from such telephone support?

____.

______No

9. Would you be interested in giving social support to others with SLE over the phone?
______Yes (If yes), What would you hope to learn or gain from participating in a support system?
____.

______No

10. Could you please indicate either your zip code or the town you live in to enable us to determine areas where there may be enough people with SLE for some sort of support group or support network in the future? ______________________________.

11. Has SLE or any medication that you have taken for SLE affected or changed your physical appearance?

_______No _______Yes

If yes, how satisfied are you with your appearance?

______	______	______	______	______
very satisfied	satisfied	neither satisfied nor dissatisfied	dissatisfied	very dissatisfied

12. Have you experienced any sexual difficulty since your diagnosis of SLE?

______No ______Yes

If yes, how satisfied are you with your sex life?

_____	_____	_____	_____	_____
very satisfied	satisfied	neither satisfied nor dissatisfied	dissatisfied	very dissatisfied

13. Since your diagnosis with SLE, have you had any fertility difficulties or problems?

______Yes

______No

If yes, please briefly explain.____

____.

14. Do you smoke cigarettes?

______Yes If yes, how much do you smoke per day?

______ No

______ Less than one-half of a pack per day.
______ One pack per day.
______ One and one-half packs per day.
______ Two packs per day.

15. Are you affected by any of the following health problems?

	Yes	No
malar rash	____	____
discoid rash	____	____
photosensitivity	____	____
oral ulcers	____	____
hair loss	____	____
Sjogren's Syndrome	____	____

16. **Please Mark the Following Global Rating Scale in Relation to SLE Disease Activity in the Past Month.**

APPENDIX E

SYSTEMIC LUPUS ACTIVITY MEASURE

SLE ACTIVITY MEASURE
(OVER LAST MONTH)

NAME

DATE

RATER

CONSTITUTIONAL

	ABSENT or NORMAL	MILD - MODERATE	SEVERE	NOT RECORDED
1. Weight loss	0	1 <10% body weight	3 >10%	☐
2. Fatigue	0	1 No limits on activity	3 Functional limitation	☐
3. Fever	0	1 37.5-38.5°C	3 >38.5°C	☐

INTEGUMENT

		MILD	MODERATE	SEVERE	NOT RECORDED
4. Oral/nasal ulcers, or periungal erythema, or malar rash, or photosensitive rash or nail fold infarct	0	1 Present			☐
5. Alopecia	0	1 Hair loss with trauma	2 Spontaneous hair loss		☐
6. Erythematous, maculopapular rash, or discoid lupus, or lupus profundus, or bullous lesions	0	1 <20% Total Body Surface (TBA)	2 20-50% TBA	3 >50% TBA	☐
7. Vasculitis (leucocytoclastic vasculitis, urticaria, palpable purpura, livedo reticularis, ulcer or panniculitis)	0	1 <20% TBA	2 20-50% TBA	3 >50% TBA or necrosis	☐

EYE

8. Cytoid bodies	0	1 Present		3 visual acuity < 20/200	☐
9. Hemorrhages (retinal or choroidal) or episcleritis	0	1 Present		3 visual acuity < 20/200	☐
10. Papillitis or pseudotumor cerebri	0	1 Present		3 visual acuity < 20/200 or field cut	☐

RETICULOENDOTHELIAL

	ABSENT or NORMAL	MILD	MODERATE	SEVERE	NOT RECORDED
11. Diffuse lymphadenopathy (cervical, axillary, epitrochlear)	0	1 Shotty	2 >1cm x 1.5cm		☐
12. Hepato- or splenomegaly	0	1 Palpable only with inspiration	2 Palpable without inspiration		☐

PULMONARY

	ABSENT or NORMAL	MILD	MODERATE	SEVERE	NOT RECORDED
13. Pleural effusion/pleurisy	0	1 Shortness of breath or pain only with prompting. Exam normal or near normal.	2 Shortness of breath or pain with exercise, decreased breath sounds and dull lower lobe(s).	3 Shortness of breath or pain at rest, decreased breath sounds and dull middle and lower lobes.	☐
14. Pneumonitis	0	1 X-ray infiltrates only	2 Shortness of breath with exercise	3 Shortness of breath at rest	☐

CARDIOVASCULAR

15. Raynaud's	0	1 Present			☐
16. Hypertension	0	1 Diast. 90-105	2 Diast. 105-115	3 Diast. >115	☐
17. Carditis	0	1 Pericarditis by EKG &/or RUB &/or effusion by echo; no sx	2 Chest pain or arrhythmia	3 Myocarditis with hemodynamic compromise &/or arrhythmia	☐

GASTROINTESTINAL

18. Abdominal pain (Serositis, pancreatitis, ischemic bowel, etc.)	0	1 Complaint	2 Limiting Pain	3 Peritoneal signs/ ascites	☐

NEUROMOTOR

19. Stroke syndrome (includes mononeuritis multiplex, transient ischemic attack(TIA), reversible ischemic neurologic deficit (RIND), cerebrovascular accident (CVA), retinal vascular thrombosis)	0	1 Single TIA	2 Multiple TIA/RIND, or mononeuritis multiplex or cranial neuropathy or chorea	3 CVA/myelitis, retinal vascular occlusion	☐
20. Seizure	0	1 1-2/month	2 > 2/month	3 Status epilepticus	☐
21. Cortical dysfunction	0	1 Mild depression/ personality disorder or cognitive deficit	2 Δ in sensorium or severe depression or limiting cognitive impairment	3 Psychosis or dementia or coma	☐
22. Headache (including migraine equivalents)	0	1 Symptoms or transient neuro deficit	2 Interferes somewhat with normal activities	3 Incapacitating/ aseptic meningitis	☐
23. Myalgia/myositis	0	1 Complaint	2 Limits some activity	3 Incapacitating	☐

JOINTS

	ABSENT or NORMAL	MILD	MODERATE	SEVERE	NOT RECORDED
24. Joint pain from synovitis and/or tenosynovitis	0	1 Arthralgia only	2 Objective inflammation	3 Limited function	☐

OTHER

25. (Write rules for ascertainment and ad hoc scale)	0	☐	☐	☐	☐

LABORATORY

	NORMAL	MILD	MODERATE	SEVERE	UNKNOWN, NOT RECORDED
26. Hematocrit	0 >35	1 30-35	2 25-29.9	3 <25	☐
27. WBC	0 >3500	1 3500-2000	2 2000-1000	3 <1000	☐
28. Lymphocyte count	0 1500-4000	1 1499-1000	2 999-500	3 <499	☐
29. Platelet count	0 >150T	1 100-150T	2 99-50T	3 <50T	☐
30. ESR (Westergren)	0 <25	1 25-50	2 51-75	3 >75	☐
31. Serum creatinine or creatinine clearance	0 0.5-1.3mg/dl or 80-100%CrCl	1 1.4-2mg/dl or 79-60%CrCl	2 2.1-4mg/dl or 30-60%CrCl	3 >4mg/dl or <30%CrCl	☐
32. Urine sediment	0	1 >5 RBC &/or WBC/hpf &/or 0 to 1-3 granular &/or cellular casts/hpf &/or 1-2+ proteinuria &/or <500 mg/L 24° urine protein	2 > 10 RBC &/or WBC/hpf or >3 granular &/or cellular casts/hpf &/or 3 or 4+ &/or 500 mg/L-3.5 g/L 24° urine protein	3 >25 RBC or WBC/hpf &/or Red cell cast &/or >4+ proteinuria &/or >3.5 g/L > 3.5 g/L 24° urine protein	☐

MD GLOBAL RATING OF SLE ACTIVITY *

0 NONE — 10 MOST

APPENDIX F

DEMOGRAPHIC INFORMATION

Table 2
Demographic Information

	Frequency	Percentage
Medication Usage for SLE		
All Days	35	57.4
Most Days	8	13.1
Some Days	4	6.6
Few Days	5	8.2
No Days	8	13.1
No Response	1	1.6
Alcohol or Drug Use		
Yes	2	3.3
No	59	96.7
Cigarette Use		
Yes	12	19.7
No	49	80.3
Medical Complications or Comorbidity		
Anemia	8	8.0
High Blood Pressure	22	36.1
Cancer	1	1.6
Diabetes	2	3.3
Discoid Rash	9	9.0
Hair Loss	17	27.9
Kidney Disease	6	9.8
Liver Disease	3	4.9
Lung Disease	5	8.2
Mental Illness	3	4.9
Malar Rash	12	19.7
Oral Ulcer	11	18.0
Photosensitivity	22	36.1
Sjogren's Syndrome	7	11.5
Ulcer or Stomach Distress	6	9.8
Fertility		
Yes	6	9.8
No	54	88.5
No Response	1	1.6

Table 2 Cont.

	Frequency	Percentage
SLE Induced Physical Appearance Change		
Yes	25	41.0
No	35	56.4
No Response	1	1.6
Satisfaction with SLE Induced Physical Appearance Change		
Very Dissatisfied	1	4.0
Dissatisfied	18	72.0
Neither Satisfied Nor Dissatisfied	3	12.0
Satisfied	3	12.0
SLE Induced Sexual Difficulty		
Yes	9	14.8
No	52	85.2
Satisfaction with Sex Life in Relation to SLE Difficulty		
Very Dissatisfied	1	11.0
Dissatisfied	3	33.3
Neither Satisfied Nor Dissatisfied	3	33.3
Satisfied	1	11.0
Very Satisfied	1	11.0

APPENDIX G

INTERCORRELATION OF AIMS 2 SUBSCALES

INTERCORRELATION OF QLI SUBSCALES

CORRELATION OF AIMS 2 SUBSCALES WITH INTACT VARIABLES

CORRELATION OF AIMS 2 SUBSCALES WITH QLI SUBSCALES

Table 7

Intercorrelation of AIMS2 Subscales

	Arm	Family	Hand	House	Mobility	Mood	Pain	Social	Self Care	Tension	Walk	Work
1	1.00	.14	.82*	.49*	.66*	.22	.62*	.17	.75*	.36*	.54*	.55*
2		1.00	.26**	.18	.12	.37*	.36*	.32**	.09	.32**	.20	.19
3			1.00	.33*	.61*	.27**	.65*	.11	.60*	.30**	.46*	.55*
4				1.00	.57*	.97	.48*	.31**	.38*	.23	.56*	.42*
5					1.00	.13	.52*	.35*	.64*	.34**	.48*	.46*
6						1.00	.28**	.16	.21	.46*	.15	.08
7							1.00	.27**	.48*	.43*	.66*	.64*
8								1.00	.16	.16	.19	.30
9									1.00	.25	.36**	47*
10										1.00	.47*	.28
11											1.00	60*
12												1.00

* $p < .01$

** $p < .05$

Table 8
Intercorrelation of QLI Subscales

	Family	Health	SES	Spiritiual
Family	1.00	.70*	.52*	.52*
Health		1.00	.79*	.74*
SES			1.00	.77*
Spiritual				1.00

Table 9
Correlation of AIMS2 Subscales with Intact Variables

	AIMS2	PRQ-85	QLI	SLAM
AIMS2				
Arm	.76*	-.26**	-.57*	.06
Family	.47*	-.44*	-.34**	.15
Hand	.73*	-.23	-.52*	.08
House	.60*	-.22	-.37*	.24
Mobility	.73*	-.16	-.56*	.17
Mood	.37*	-.26**	-.37*	.02
Pain	.84*	-.31**	-.65*	.26**
Social	.45*	-.35**	-.38*	-.13
Self-Care	.64*	-.18	-.45*	.19
Tension	.56*	-.36**	-.51*	-.01
Walk	.76*	-.26**	-.59*	.29**
Work	.73*	-.21	-.58*	.22

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

Table 10

Correlation of AIMS2 Subscales with QLI Subscales

	Quality of Life			
	Family	Health	SES	Spiritual
AIMS2				
Arm	-.40*	-.56*	-.52*	-.39*
Family	-.25	-.36**	-.44*	-.23
Hand	-.44*	-.58*	-.49*	-.27**
House	-.21	-.33**	-.33**	-.27**
Mobility	-.45*	-.47*	-.51*	-.42*
Mood	-.22	-.41*	-.41*	-.34**
Pain	-.30**	-.63*	-.59*	-.50*
Social	-.20	-.34**	-.41*	-.34**
Self-Care	-.56*	-.49*	-.44*	-.38*
Tension	-.19	-.52*	-.50*	-.60*
Walk	-.35**	-.60*	-.37*	-.48*
Work	-.40**	-.51*	-.48*	-.50*
AIMS2 Total	-.53*	-.76*	-.72*	-.65*
Dem VAS	-.35**	-.48*	-.37*	-.44*
PRQ-85 Total	.38*	.48*	.59*	.54*
QLI Total	.63*	.87*	.81*	.88*
SLAM Total	-.30	-.21	-.19	-.25
SLAM VAS	-.36**	-.23	-.13	-.12

* p < .01
** p < .05

APPENDIX H

LETTER FROM DR. LESSARD

Grand Forks Clinic, Ltd.
Our Specialty is You

November 1, 1996

Dear Patient:

A few months ago a psychology doctoral candidate, Ms. Seanne Tyson, and I sent you a letter along with a packet of questionnaires asking you to consider participating in a study she is performing on patients with Lupus. Hopefully the results of this study will benefit Lupus patients in our area with the specific intention that maybe a support group will be formed to help patients deal with this all too often devastating disease.

Over the past months we have received responses from a great many of you and the information is very useful. We, however, have not yet heard from you. I know that may patients have told me that they had intended to respond but just didn't get around to it. I know that all of our lives are very busy and filled with priorities much higher than Ms. Tyson's doctoral thesis. However, I would appreciate very much if you would take a few minutes to complete the questionnaires as best you can.

Although I hope, very much, that you will be willing to participate in this study, I promise that the information will be kept confidential. I also pledge that, should you decide not to participate, your relationship with me and your health care will not be prejudiced in any way.

Thank you very much for your time. I hope that this letter finds you well.

Sincerely yours,

James A. Lessard, MD
Rheumatology

1000 S. Columbia Rd. P.O. Box 6003 Grand Forks, ND 58206-6003 (701) 780-6000 Admin. FAX (701) 780-6641

APPENDIX I

LETTER FROM SEANNE TYSON

Dear Patient, October 15, 1996

Enclosed are four questionnaires that I am asking you to fill out as a part of my dissertation study. My dissertation will look at the relationship of social support and health status to quality of life in women with systemic lupus erythematosus (SLE). I want to thank you in advance for filling out the surveys. The following is a short explanation of each survey and the approximate time that it will take you to complete each one.

1. The Arthritis Impact Measurement Scales-2 (AIMS 2). The AIMS-2 will look at health status in relation to SLE. It is a 78 item questionnaire and will take approximately 30 minutes to complete.

2. The Quality of Life Index (QLI). The Quality of Life Index looks at your satisfaction with different aspects of your life, such as general happiness, friends, and family. It is a 68 item questionnaire and will take approximately 30 minutes to complete.

3. The Personal Resource Questionnaire 85 (PRQ-85). The Personal Resource Questionnaire 85 looks at the amount or availability of social support you have or you receive. It is a 35 item questionnaire and will take approximately 15 minutes to complete.

4. The Demographic and Social Support Questionnaire. The Demographic and Social Support Questionnaire is something that I wrote and it looks at general demographic information, support group attendance history, and a few general, medical type questions that the other surveys did not ask. It is a 16 item questionnaire and will take approximately 15 minutes to complete.

You need not complete all surveys in one day, you may want to complete them over two days.

After the surveys are completed please mail them, along with the signed consent form, in the provided envelope. **Postage has already been paid**, so please just drop the envelope into a mail box.

I thank you in advance for participating in my study.

Sincerely,

Seanne S. Tyson, M.A.

APPENDIX J

CONSENT FORM

Information About and Consent to Participate in the Research Study
Systemic Lupus Erythematosus, Quality of Life, and Support Among Patients:
Investigators: Seanne Tyson, MA & James Lessard, M.D.

You are invited to participate in the Systemic Lupus Erythematosus (SLE), Quality of Life, and Support Among Patients study. The goal of this study is to look at the relationship of social support to quality of life in SLE patients. This study also serves as a needs assessment for the future formation of SLE support groups in your area. You were selected to participate in this study because you are (a) one of Dr. Lessard's patients; (b) female; (c) age 20 or older; (d) and have a prior diagnosis of SLE, Anticardiolipin, or both, and (e) are able to understand and read English.

The study consists of you filling out and returning the four enclosed questionnaires in the envelope provided. Additional SLE status or health information will be obtained by Dr. Lessard from your patient file. You may also be asked to fill out one additional survey on your SLE disease activity at your next scheduled appointment with Dr. Lessard. **This study includes no medications, injections, or blood draws.**

There are no foreseeable discomforts or threats to you by participating in this study. By participating in this study you may be helping to improve the quality of life of SLE patients by providing valuable and important information regarding your attendance or non-attendance in SLE support groups and quality of life information.

All information in this study will be kept confidential, through the use of coded questionnaires and envelopes. Your name will never be released in relation to this study. Dr. Lessard's office will have both the codes and the names kept separately in locked file cabinets. **Participation or non-participation in this study will in no way effect care or treatment to you from Dr. Lessard.** If you decide to participate in this study, you are free to discontinue participation at any time without prejudice.

Any questions during or after this study can be directed to Seanne Tyson at (701) 777-9372, Dr. Lessard at the Grand Forks Clinic at (701) 780-6379, or Eleanor Tveit at the Medical Park Institutional Review Board at (701) 780-6161. Results of this study will be available through Dr. Lessard's office in approximately 12 months.

Enclosed are two copies of this consent form, one to be mailed in the pre-addressed envelope with the completed surveys and one for you to keep.

All of my questions have been answered and I am encouraged to ask any questions that I may have concerning this study in the future. I have read all of the above and willingly agree to participate in this study as explained to me by Dr. Lessard's letter and information in this consent form.

Name ______________________

Signature ______________________

Date ______________________

APPENDIX K

PERMISSION LETTERS

MONTANA
STATE UNIVERSITY
BOZEMAN

College of Nursing

Main Campus
Sherrick Hall
MSU • Bozeman
Bozeman, MT 59717
Phone (406) 994-3783
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Billings Campus
Campus Box 574
MSU • Billings
Billings, MT 59101
Phone (406) 657-2912
Fax (406) 657-1715

Great Falls Campus
2800 11th Ave. South
Suite 4
Great Falls, MT 59405
Phone (406) 455-5610
Fax (406) 454-2526

Missoula Campus
UM North Corbin Hall
Missoula, MT 59812
Phone (406) 243-6515
Fax (406) 243-5745

January 24, 1996

Seanne Tyson
209 State Street Apt# 310
Grand Forks ND 58203

Dear Ms. Tyson:

Thank you for requesting the PRQ-85. This letter will serve as permission to use the tool. Enclosed you will find a copy of the tool which you may reproduce in whatever quantity necessary for your study. However, the exact format of the PRQ-85 must be maintained. Any changes to question stems or answer sets must be approved in advance. Translations to other than English must be submitted to this office with a certification that the translation is accurate prior to use of any translated version of the PRQ-85.

Also enclosed are instructions for coding and a bibliography. We strongly encourage you to use this bibliography to familiarize yourself with the published literature on the PRQ-85.

If you have not already done so, please send us a brief abstract of your proposed study and the population that you plan to sample in your research. We will include this information in a database. We also ask that you send a check payable to Clarann Weinert in the amount of $ 4.00 to cover the costs of postage and xeroxing. If you do, in fact, use the PRQ-85 for data collection in your study, we ask that you send us an abstract of your findings and conclusions whenever they are available. If you are a student, please include the name of your advisor and the university you are attending.

Should you have any questions or need clarification, kindly write or e-mail UNUCW@MSU.OSCS.MONTANA.EDU. We will try to respond in a timely manner by e-mail if you include your address or in writing.

Thank you for your interest in the PRQ-85. We hope that this tool will help you in your work.

Sincerely,

Clarann Weinert

Clarann Weinert, SC,PhD,RN,FAAN

Mountains and Minds • The Second Century

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

January 25, 1996

Ms. Seanne Tyson
209 State Street
Apt. 310
Grand Forks, ND 58203

Dear Ms. Tyson:

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 subscale scores and overall scores.

At the present time there is no charge for use of the QLI. You have me 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 Esting Ferrans, PhD, RN, FAAN
Assistant Professor

Chicago Peoria Quad-Cities Urbana-Champaign
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in the School of Medicine

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January 1995

Dear Colleague:

Thank you for your request for information on the second version of the Arthritis Impact Measurement Scales (AIMS2). A copy of the new instrument is enclosed along with a brief User's Guide that describes scoring.

To summarize, three types of changes have been made in this new version of AIMS. First, modifications have been made in the original nine scales. Some items with low reliability and/or sensitivity were eliminated so that all scales now have four or five items. Three items were removed from the household physical activities scale because they dealt with cognitive functions rather than physical functions. The number of response options per item was also standardized, eliminating all yes/no responses.

Second, we have included three new scales: arm function, work and social support. These three scales were added to assess aspects of health status that were not covered in the original AIMS. Work information can be used as a categorical variable (employed, student, disabled, etc.) or as a four item scale. Finally, three new pages were added to AIMS2 to assess satisfaction, problem attribution, and problem prioritization.

The measurement properties of AIMS2 have proven to be very similar to those of the original instrument. We therefore do not feel that AIMS2 needs to be re-tested for reliability or validity in all those groups or settings where the original AIMS has already been tested.

The AIMS2 is a copyrighted instrument. Investigators who plan to use it in commercially sponsored research should contact me for permission and to discuss a possible user's fee. Academic users have authorization to employ the AIMS2 without restriction.

Best of luck with your research.

Sincerely,

Robert F. Meenan, MD, MPH, MBA
Professor of Medicine

RFM:der

REFERENCES

REFERENCES

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