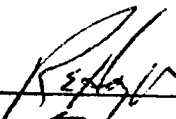


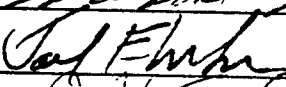
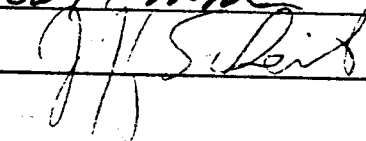
To the Graduate Council:

I am submitting a dissertation written by Luis Fernandez entitled "The World of the Lupus Patient. Psychological and Phenomenological Perspectives in Lupus Erythematosus." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.


Howard R. Pollio, Major Professor

We have read this dissertation
and recommend its acceptance:



Accepted for the Council:


Associate Vice Chancellor
and Dean of The Graduate School

THE WORLD OF THE LUPUS PATIENT
PHENOMENOLOGICAL AND PSYCHOLOGICAL PERSPECTIVES
IN LUPUS ERYTHEMATOSUS

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Luis Fernandez
August, 1992

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DEDICATION

This dissertation is dedicated to my maternal grandfather, Jose Lopez, my personal hero and model of what a man should be. From him I learned the first lessons of my life; self-respect, courage, determination and unwavering commitment to one's ideas. In loving memory and eternal gratitude.

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ABSTRACT

Illness, as a description of the human experience of being sick, involves more than the physiological or pathological dysfunction of the body. The prevailing view of illness, with its emphasis in biological understanding, precludes investigation of other aspects of illness and disease; with potentially detrimental consequences for the patient. Acknowledging the need to expand the current view of illness, this study investigated and described the patient's experience of being ill with Lupus Erythematosus. In addition, the present work sought to investigate the psychological phenomena present in this disease and its relationship to social, medical and phenomenological variables.

The method used in this study included phenomenological interviews and written descriptions of the patients experience of being ill with Lupus. Psychological testing (MMPI-2 and 16PF), and medical and behavioral self-reports also were incorporated in this study.

The participants were 39 Lupus patients ages 25 to 76, who were solicited through the East Tennessee Lupus Foundation. Results of the interviews revealed five major existential themes: Isolation/Invisibility, Constricted Existence, Vulnerability, Transformation and Resoluteness. The first theme, Isolation/Invisibility, pertained to the experience of isolation and estrangement from other people and an awareness that others "don't understand". Constricted Existence referred to the losses and limitations experienced by Lupus patients. Vulnerability was the most

frequently mentioned theme; it described the awareness of physical and mental symptoms and the feeling of helplessness and loss of control. Transformation was the experience of changes in moods, personality and life-style. Finally, Resoluteness referred to the attitude of fighting and struggling with the disease.

Other findings indicate a high prevalence of psychopathology among Lupus patients, with neurotic symptoms present in 74% of participants, and as many as 33% also reporting psychotic symptoms. Awareness of isolation, the number of symptoms reported, limited physical activity and lack of employment had significant effect on levels of neuroticism. The results of the study argued for a need to expand current views of illness and suggested possible avenues of intervention.

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CHAPTER 1

INTRODUCTION

"It is like being in an invisible glass box of pain which only I can see and feel. No one understands the ups and downs of this disease"

A Lupus Patient

The present work is a study in the phenomenological and psychological aspects of Lupus Erythematosus, a chronic inflammatory disease of the connective tissue. This disease may affect different organs of the body, ranging in severity from mild cutaneous lesions to serious multisystem involvement and even death. There is no known cause nor any cure to this point (Lahita, 1987; Dubois & Wallace, 1987). The person suffering from Lupus often presents with vague symptomatology making this disease difficult to diagnose. It is not uncommon for patients to be misdiagnosed or to be labeled "hysterics" or "neurotics" when a medical cause can not be found to account for the symptoms (Aladjem, 1982). Usually it takes an alert physician, a severe "flare up" or a lucky referral to a rheumatologist before Lupus is diagnosed and the patient can be reassured they are in fact "sick" and their illness is not "in their heads."

A common occurrence in Lupus is the presence of psychological disorder. Depression and anxiety are most common, but periods of brief psychosis are also frequently seen (Grade & Zegans, 1986). Patients may begin to experience not only the physical limitations imposed by the disease, but a deeper sense of alienation and a loss of

control, as they see their lives changed and transformed by this illness. As one lupus patient said: "Lupus turned my world upside down . . . friends become fewer and fewer. Very few go the distance, and allow you to be "sick." You then start to withdraw yourself. You have a lot of depression and sometimes not a good support system from family and friends . . . You are reduced to a non-person, your body is kaput, turned against you." This experience was well expressed by Henrietta Aladjem when she wrote: "In Lupus, the body and the soul are enmesh in a web of pain and desperation, and through it all many patients say no one understands, no one is willing to listen" (1982).

A review of the published literature, reveals an abundance of studies dealing with the medical and biological aspects of Lupus. There is also some literature reporting on the psychological problems present in Lupus, although most of it consists of retrospective studies of patient's charts or psychiatric evaluations, and not until very recently, researchers began to use some sort of standardized psychological instruments. In addition, the population studied have invariably been hospitalized patients. What is clearly absent from the professional literature however, is an interest in the personal experience of being ill with Lupus and in the meanings this disease has for the patient.

Holding to the view that illness is more than the biological elements that define it, and that it includes the totality of the person's range of experience, this study attempts to describe the experience of Lupus as is lived by the patient. Dr Arthur Kleinman

(1989), himself a physician, has written in the need to address this issue:

Social reality is so organized that we do not routinely inquire into the meaning of illness anymore that we regularly analyze the structure of our social world. Indeed, the everyday priority structure of medical training and of health care delivery, with its radically materialist pursuit of the biological mechanism of disease, precludes such inquiry. It turns the gaze of the clinician, along with the attention of patients and families, away from decoding the salient meaning of illness for them, which interferes with recognition of disturbing but potentially treatable problems in their life world . . . There is evidence to indicate that through examining the particular significance of a person's illness it is possible to break the vicious cycle that amplify distress. The interpretation of illness meanings can also contribute to the provision of more effective care. Through those interpretations the frustrating consequences of disability can be reduced (Arthur Kleinman, 1988).

Medical science, accounts for the experience of illness in terms of a deviance from the biological norm of health (Cockerman, 1988). In its simplest form, the medical model holds that the best explanation for a set of symptoms is to be found in disease entities. The cause is placed in the organism and is assumed to be biological in nature. Diagnosis consist of identifying this entity, and treatment in its elimination and/or control. When treatment is successful, the symptoms disappear (Norton, 1982). Patient complaints, physician observation and objective test data are all correlated with known clinical patterns and a diagnoses is made on these bases. The whole process is deterministic and logical.

The birth of modern medical thinking was characterized by two major developments. The first was the "localization" of illness in the tissues of the body which made illness a matter of discovering specific pathology. The second, after the dramatic work of Pasteur

and Koch, was the association of illness with environmental pathogens. Both developments occurred in a time when all of the sciences were striving to emulate the "hard" or "pure" sciences and knowledge was identified with some sort of sense data and verifiability was the standard of scientific thinking (Phillipis, 1987; Green, 1968; Sigerist, 1970; Rhodes, 1985). While this model is indeed quite useful, as evidenced by the incredible progress we have made conquering illness that once were the scourge of humanity, it has its limitations. By viewing illness as only a biological problem, this approach may overlook important non-biological factors in the experience of being ill.

For instance, the number one cause of death in the U.S. is heart disease (National Center for Health Statistics, 1986). We can point out to specific pathology and say that the cause of Coronary Artery Disease is the deposit of fatty or fibrous plaques in the coronary arteries of the heart which narrows the lumen of the arteries, decreasing the blood flow, etc., leading to a heart attack. Evidence strongly suggests, however, that smoking, stress level, obesity, personality, and sedentary life-style are important factors in the development of C.A.D. (Robbins, Cotran & Kumar, 1984; Lipowski et al 1977). All of these so called "psychosocial" factors may very well be understood as "causes" of C.A.D. The reason why we do not usually think of them in this light, has to do with current philosophical and cultural views; in other words, our scientific thinking is influenced by the prevailing cultural and philosophical assumptions which determine what sorts of elements we consider important in describing

or solving a "problem" (Kuhn, 1962). In addition, how we think about illness will determine not only the sort of research we do, but the sorts of interventions we make. Thus, we may opt for bypass surgery or angioplasty to treat C.A.D. rather than engage in an effort to modify the behaviors involved in the development of such disorder. Therefore, in determining what constitutes illness, as well as what constitutes appropriate treatment, philosophical, psychological, and cultural values and attitudes play a very important role, since they form the contextual ground from which the scientific enterprise is made possible.

Criticisms To The Traditional Medical Model

Philosophical Perspectives

Kuhn in his well known book The Structure of scientific Revolutions (1962), pointed out the importance of what he termed "paradigms." Paradigms are the contextual philosophical and theoretical views under which science and scientists do their work. His analysis maintained that scientists working under certain paradigms will work and perform experiments in accordance with their own theoretical perspectives and will not be able to "see" other realities except their own. From time to time when new information or findings are encountered which contradicts their framework, is usually discarded or explained away. Eventually, someone will point to these anomalies and a revolution will ensue, thereby replacing the old paradigm with a new one. There has been a great controversy over Kuhn's ideas, and they are far from being accepted by many (Seigel,

1980; Scheffler, 1967; Toulmin, 1971). Despite this, his contention that scientific work is dependent on paradigms, is useful in understanding the philosophical criticisms raised against the medical model.

The history of medicine, as traditionally viewed, presents a picture of steady progress and the accumulation of knowledge. Sigerist in his book Civilization and Disease (1970), presents this attitude. He writes:

When we look at the development of the medical sciences, we must admit that the progress achieved in the last hundred years has been stupendous. It was in line with the development of others sciences, taking advantage of every discovery made in physics, chemistry or biology. The progress has been an steady one, and if we want to realize what has been achieved in the last few decades, all we have to do is to read the first edition of Osler's textbook published in 1892 and compare it to our present knowledge. We must not forget however, that the advances of the last hundred years would have been impossible without the work of centuries that preceded them. They represent the culminating point of a long and arduous development (Sigerist, 1970 p. 177).

Although most people adhere to the proposition of the advancement of knowledge in the medical sciences, such progress has been achieved in a unique theoretical and philosophical context. Medical knowledge reflects and is influenced by the current views of the world, nature and man. This is the main argument of the philosophical criticism of the current medical model (Kidel & Rowe-Leete, 1988; Helman, 1985).

Current views in contrast to the views held by ancient and even other contemporary societies, emphasizes the materialistic and objective nature of illness and disease (Kidel & Rowe-Leete, 1988). This view was a product of new thinking and discoveries in the field

of medicine and was influenced by Cartesian philosophy. A significant contribution of Descartes for medicine was his view of the body as a machine (Rhodes, 1985). This allowed scientists for the first time to apply the laws of biology, chemistry and physics to the functioning of the human body independent of the patient's consciousness, i.e., disease was seen as a problem with the "machine." This attitude, although admittedly useful in the understanding of many illness, has become problematic when trying to explain the "psycho-somatic" disorders, the effects of psychological factors in illness, the concept of stress and many other phenomena, especially the significance and meaning of illness (Lipowski, Lipsitt & Whybrow, 1977; Kidel & Rowe-Leete, 1988). Kidel and Rowe-Leete express this best in their book The meaning of Illness:

Our understanding of psyche and soma is so deeply rooted in a Cartesian dualism which rigorously distinguishes and dissociates pure consciousness (res cogitans) from pure extension (res extensa), that any other alternative view of spirit and matter is very difficult for us to conceive. We are trapped inside a model which absolutely separates "physical" from "emotional" or "mental" events, and we have befuddle ourselves into futile attempts at understanding the causal link between them . . . While scientific medicine, which arises out of a detached objective viewpoint, endorses a dissociation between bodily symptoms and other factors in a person's life, perspectives that involve less than a schism between psyche and soma naturally encompass a psychological dimension and necessitates an experience of illness at a more personal level. If we understand illness more than a mechanical malfunction for which we may not be responsible it assumes a different kind of significance: we can experience it as part of our story as an event or process which has, in terms of life history, a meaningful place (Kidel and Rowe-Leete, 1988, p. 15-16).

Another important factor in the conceptualization of illness and the role of the physician had to do with the so called "localization"

of pathology. This radical shift in perspective was brought about by the work of Bichat (1771-1802) (Sullivan, 1986). His emphasis in the study of tissues as the site of pathology made illness a matter of finding a "lesion":

The lesion becomes the necessary and sufficient condition for the presence of disease. By revealing the lesion at autopsy, it becomes possible for the physician to identify disease in a way totally independent of the patient experience of it. Disease then begins to be autonomous from patients' experience sense of disability (Sullivan, 1986, p. 335).

Bichat's work had a tremendous influence in medical thinking and paved the way to Broussais, Corvisart, Laennec, and especially to the cellular theories of Virchow (Green, 1968).

In general, it is claimed by those who oppose the traditional medical model, that a "paradigm shift" is necessary. The direction of change is indicated towards a more holistic view of illness, which current views do not provide. Illness does not have to be seen as a "thing" and to be sick is more than just the presence of a lesion or pathogen. The patients' experience, his or her "phenomenology," the cultural and interpersonal dynamics and the individual meaning of the illness are important factors to be considered (Black Nick et al, 1984; Helman, 1985; Kidel & Rowe-Leete, 1988).

Cultural Perspectives

Payer (1989) in a recent book entitle Medicine and Culture provides a cultural criticism of the medical model. This criticism is based on her belief that medicine is a science that is not practiced consistently across western nations despite their commitment to the

scientific method. Although others have shown how different cultures have different beliefs about illness and their treatment (Kidel & Rowe-Leete, 1988), what makes her approach illuminating is that her analysis of cultural influences in medicine focus on nations which share a common intellectual background. She argues that cultural attitudes and beliefs influence the type of illness that are mostly treated, the sorts of treatments used and even the conceptualization of illness.

In her analysis Payer uses four western nations: France, England, Germany and United States as her examples. French medicine is characterized by being rationalist and based in the methodology of their greatest thinker Rene Descartes. While "Cartesian thinking" is sometimes used pejoratively outside France, the French teach their children to "think like Descartes." What this translates into is a treatment based in rational analysis with little concern with the empirical research exemplified by English medicine. For instance, when the Pasteur Institute introduced the Flu vaccine, they did so without running any clinical trials. In more recent times, they announced the use of Cyclosporine to treat AIDS based in the treatment of six patients over a period of a week. Another characteristic of French medicine is its view of illness as a failure of the internal defenses rather than an invasion from without. For the French the "*terrain*," which roughly translated means the constitution, is the object of special attention and consequently, attempts are made to make the internal defenses stronger by means of tonics, spas, vitamins etc.

German medicine is characterized by an emphasis on the heart. Payer mentions an study in which German and American doctors were shown the same ECGs; the Germans found 40% of the patients had abnormal ECGs while the Americans found only 5% abnormal. The Germans diagnosed heart diseases more frequently and prescribe more heart drugs than the English, Americans or French. Payer theorizes some of the reason for this attitude of German medicine has to do with their Romantic tradition and their view of the heart as the seat of emotions. Although she does not mention this, as early as the 19th century many German doctors were still writing and supporting a vitalistic, even mystical view of illness (Sigerist, 1970).

Unlike the Germans and the French, English physicians are less concerned with the internal environment or "*terrain*"; their emphasis is on external attacks from "*without*." Prescriptions for spas, tonics etc. are almost non-existent, while they tend to overprescribe antibiotics. Of the top 20 most prescribed drugs, the English list 3 antibiotics while the Germans none. The English are more parsimonious and practical in their approach to treatment; the French call them the "the accountants of the medical world." The English prescribe fewer drugs, take fewer x-rays and do half as many operations. Their thresholds for what laboratories values are "normal" are much more higher than in the other Western Countries considered.

Finally, Payer writes, "American medicine could be summed up in one word: 'aggressive.'" Americans perform more surgery, prescribe more drugs and usually follow treatments which are oriented towards some kind of action upon the organism. Like the English the mentality

is that illness is produced by external factors, which need to be eradicated and destroyed. In the words of a French physician: "The only thing that Americans fear is germs and communists."

In short, Payer's analysis of the current views of illness and medical treatment in the four most industrialized western nations, point to the fact that cultures, with their views, tradition and national philosophies, play a very important part in the conceptualization and practice of medicine. This, she believes, goes beyond superficial dissimilarities in theory and practice, but reflects a very fundamentally different perspective which casts doubts in the idea of an objective, culture-free science of medicine.

Psychological Perspectives

Psychological criticisms of the medical model, rest on the assumption that the nature of illness goes beyond narrow definitions of the "pathological paradigm." Although this view is not essentially different from the philosophical and cultural perspectives already mentioned, emphasis is placed on the psychological, behavioral and social aspects of illness (Lipowski, Lipsit & Whybrow, 1977). Out of this concern for the psychological aspects of disease, a new field of study and research was born, the study of psycho-somatic disorders (Wittkower, 1977).

The problem in working with the psychosomatic disorders is the implication of the existence of two different sorts of phenomena: the somatic and the psychic, with each requiring different research paradigms, and each sharing a distinct language and units of study

(Helman, 1985; Bakal, 1979; Lipowski, 1968). The major difficulty encountered has been the failure to develop a theoretical framework capable of incorporating both perspectives (Helman, 1985; Engel, 1967). For the biological oriented researcher, psychological phenomena becomes a significant obstacle due to difficulties conceptualizing and measuring this phenomena. Even within the psychological research paradigm, doubts remain in regards to the appropriate area of study. Psychoanalytically oriented theorists for example, emphasize intrapsychic dynamics while social learning theorists, emphasize the role of cognitions and behaviors in health and disease (Dunbar, 1948; Alexander et al, 1968; Kleinman, 1980; Beck, 1972). Faced with these difficulties, some theorists have tried to incorporate the physical, psychological and social aspects of illness into a holistic perspective of illness (Lipowski, 1968; Engel, 1977). Others have viewed psychosomatic disorders from three different etiological perspectives: psyche, soma and society (Helman, 1985).

The early formulation of psychosomatic disorders stressed the idea that certain psychological dynamics, generally outside the field of awareness, "caused" the illness. More specifically, the expression of the unconscious conflict took the form of a somatic symptom, the psyche element is "converted" into a somatic one (Helman, 1985; Beck, 1972). This was Freud and Breuer's (1966) early formulation of hysteria. Dunbar (1948), a pioneer in the field of psychosomatic medicine, studied a large number of patients, and came to the conclusion that certain psychosomatic illness were associated with a particular personality type. She described several personalities such

as the peptic ulcer personality, the arthritic personality, the coronary personality and others. Recent research, however, has not found strong support for her theories (Lipowski, 1968). More recent psychoanalytic writers have made emphasis in the "object relations" of psychosomatic patients and have pointed out to the poverty of fantasies and mental representations (Wittkower, 1977). These patients have often been described as lacking words for feelings (Nemiah & Sifneos, 1970).

A slightly different approach to psychosomatic disorders deals with the concept of "vulnerability" (Shuval, 1981; Helman, 1985). Alexander (1969), rejected both the conversion and specific personality theories of psychosomatic disorders in favor of a more complex multi-causal model (Helman, 1985; Beck, 1977). This model includes three factors:

- 1) the individual's psychological conflict and defense pattern,
- 2) the effects of an onset situation that brings out this conflict,
- 3) a physical or physiological vulnerability or weakness (Helman, 1985; Wittkower, 1977).

In this model, some organic diseases in addition to a specific pathophysiology, may have a specific psychopathology and vice versa (Helman, 1985; Engel, 1975). Other theorists have also emphasized the role of social factors as definitional of vulnerability, pointing to increased levels of certain illness in populations characterized by poverty, marginality, isolation, inadequate social support etc. (Shuval, 1981; Cassel, 1976; Tolman, 1979).

Physiologically-oriented researchers such as Wolff (1950), have underscored the importance of a biological and genetically determined response pattern to stress. When the person is exposed to sufficient amounts of stress he or she will respond in accordance to this genetic pattern. In the same fashion, Lacey and Lacey (1958) introduced the idea of the specificity of the physiological reaction to stress, as when a person responds to stress by increasing the blood pressure, but not respiration or vice versa (Beck, 1977).

A somewhat different strategy is taken by behaviorists who traditionally have insisted on looking at behavior as the significant unit of study and have disregarded the notion of dynamic conflict, personality styles or cognitive mediation. These approaches stress the role of the environment in shaping behavior. Illness, is also a specific type of behavior that has physiological correlates but that nevertheless is subject to the same sorts of contingencies as other behaviors (Norton, 1982; Bakal, 1979). Some cognitive-behaviorists, although agreeing with the importance of the environment, have stressed the need for a model that includes perception, evaluation and behavioral aspects of illness (Mechanic, 1978; Lazarus, 1976).

Finally there are those approaches stressing the role of social categories in understanding illness. Starting with the seminal work of Parsons (1951), researchers have focused in the social aspects of illness (Gerhardt, 1989). Parsons (1951), analyzed the theoretical concepts underlying what he called the "Sick role," and the implications it had upon the expression of illness. By doing this he opened a new perspective in medicine which has come to be known as

medical sociology (Gerhardt, 1989). An alternative to the traditional mind-body dualism of traditional psychosomatic illness, it emphasizes the role of social categories by which physical and psychological states are "cognized, labelled, ordered and acted upon" (Helman, 1985). In this view, concepts such as "illness," "emotions," "personality" etc., are the result of social categorization and, thus, the product of personal experience, interpersonal relations and social institutions (Helman, 1985; Katon et al, 1982). Among family therapists, this view is widely held especially in regard to the role of the family in originating and maintaining psychosomatic disorders (Minuchin, 1978).

Empirical studies strongly support the contention that psychological factors have a significant effect upon physiological responses (Lipowski, Lipsitt & Whybrow, 1977). Some of the areas most frequently studied include disorders such as bronchial asthma (Aitken et al, 1972), heart disease (Cay et al, 1972) and pain (Sternbach, 1977; Mersky & Spear, 1967). More recently there has been an increased interest in the immune system and its relation to psychological factors and the development of illness. Amkraut and Solomon (1977) provide an extensive review of this literature. Backus and Dudley (1977) have also reviewed the relevant data concerning the relationship between psychological factors and organic disease.

The psychological perspective offers a different view of illness from that of the traditional pathophysiological paradigm. Although widely divergent in theoretical assumptions, it agrees in the need to expand our conceptualization of illness into a more holistic

perspective. This perspective ought to include the psychological, social and interpersonal aspects of human beings as essentially significant in the task of understanding and treating illness.

This study will emphasize the phenomenological perspective. In contrast to previously considered approaches, in which the "phenomenon" under study is extracted from experience and divested of all personal meanings, phenomenology aims at describing the world as is lived by the person in their everyday experience (Heidegger, 1962). The phenomenological approach focus on the person's conscious experience and in the meanings this experience has for the individual. Phenomenology, therefore, offers new possibilities for a broader understanding of the phenomenon of illness. Being ill is not just something that happens to the patient's body and can be clearly formulated and understood in the language of biology; but it becomes part of the persons' life. That is, the disease has a significance for the sufferer that goes beyond the particular signs and symptoms described in medical textbooks. As this study will indicate, illness becomes, for some patients, a way of life, a totally different perspective from which they experience the world; for others, illness becomes a forced identity which dominates their life and consumes every aspect of their selves (Nerenz & Leventhal, 1983).

As a friendly critic of the medical model, the present work takes the position there is a need to expand this model, not because it has failed or because it is wrong, but because it offers too narrow a conceptualization of the phenomenon of illness. Therefore, the following study represents an effort at describing and understanding

Lupus from a different perspective. In pursuing this approach, we hope to obtain a better understanding of this illness as well as to suggest ways in which this illness' symptoms may become more manageable for both the patient who suffers them and for the clinician who treats them.

CHAPTER 2

LITERATURE REVIEW

Physiological and Psychological Aspects of Lupus

Lupus Erythematosus is usually defined as a chronic, multisystem, inflammatory disease of the connective tissue, characterized by periods of exacerbations and remissions (Wallace & Dubois, 1987; Hall & Stickney, 1984). The first researcher to study this disorder systematically was the French dermatologist Bielt in 1828 and his "erythema centrifugum" was the first published report of this disease (Botzer J.W., 1983).

Although this work is of relative early date, the disorder itself was observed as far back as the time of Hippocrates (Lahita, 1987). He was the first to describe skin lesions resembling lupus with the term "Herpes Esthiomenos." It was during the middle ages that the term Lupus was first applied to skin diseases, circa 916 A.D. The name Lupus was given because skin lesions were thought to resemble the bite of the wolf (Hall & Stickney, 1984). From that time on Lupus was one of the terms used, together with herpes ethiomenos, to describe skin lesions (Smith, D.C. & Cyr M. 1989). Willan (1757-1812) used the term Herpes for vesicular diseases and Lupus for destructive and ulcerative disorders of the face. In 1872, Kaposi subdivided Lupus into discoid and systemic disorder and discussed the potentially fatal aspects of the systemic forms of Lupus (Smith & Cyr, 1989).

Today, lupus has ceased to be the mysterious illness of the past with as many as one million people suffering from it in the United States alone (Blau, S.P, 1978). It is more common among females, with nearly 90% of all cases. There is also a reported higher incidence of Lupus among blacks, Indians and hispanics (Dubois, 1964).

Etiological Considerations

There is no known etiology for Lupus Erythematosus. Some have suggested that Lupus may be multifactorially determined, and that the search for a single cause may prove futile (Wallace & Dubois, 1987). In addition, others have proposed that Lupus may be the expression of a common pathogenetic mechanism set off by a variety of different factors, similar to disorders such as asthma (Zvaifler & Woods, 1985). It has also been suggested that Lupus may not be a single disease but a syndrome of different signs and symptoms caused by various factors (Zvaifler & Woods, 1985). What these theories have in common is the realization of the complexity of the phenomena and the likelihood of several causative factors, rather than one single pathogenetic element. Talal (1985), notes:

Systemic Lupus Erythematosus (SLE) is not a disease: It is a syndrome with striking diversity regarding clinical patterns, pathophysiology and prognosis . . . etiological or inducing factors have not been identified . . . There is a high probability that the clinical heterogeneity of SLE reflects not only host variables but different etiological stimuli (Norman Talal, 1987 p. 39).

Of all the factors that have been identified with the pathogenesis of Lupus, there are at least some that should be mentioned:

Immune Dysregulation

Zvaifler and Woods (1985), write that practically every aspect of the immune system in SLE patients has been reported as abnormal, although the specific abnormality may vary from patient to patient. The typical finding is the creation of autoantibodies, a decrease of the activity of T-Lymphocyte suppressor cells together with normal antibody response to exogenous antigens (Zvaifler & Woods, 1985).

Genetics

There is evidence to suggest a genetic component in Lupus; for instance, SLE occurs among relatives of those with the disease with a frequency of .4 to 5%, representing a several-fold increase over the frequency in the general population (Leonhardt 1964; Arnett & Shulman, 1976; Lehman et al., 1979). Immunological disorders are more frequent among relatives of Lupus patients than among controls (Leonhardt, 1980). Twin studies show a greater concordance rate for monozygotic twins, while the frequency of SLE among dizygotic twins is no different than among first degree relatives (Block et al., 1975).

The Viral Connection

Early attempts at finding a viral etiology for Lupus have proven unsuccessful. Many still believe that it is a matter of time before a virus or viruses will be found (Wallace & Dubois, 1987). Some evidence for this view comes from findings of increased viral antibodies among Lupus patients (Zvaifler & Woods, 1985). Despite this, direct virus isolation using more sensitive methods have not been successful (Phillips et al., 1978). Other clues include the high

levels of Interferon in the serum of SLE patients with acute disease. This is often associated with viral infections, although it may just be the result of a hyperactivity of the immune system (Zvaifler & Woods, 1985). Finally others researchers have pointed out similarity between certain findings concerning Lupus and AIDS (Talal, 1987), such as B-cell activation, serum immune complexes, acid labile interferon, and natural killer cell activity. It has been advanced that if AIDS is caused by a virus, Lupus may also be caused by a virus or viruses (Talal, 1987).

Sex Hormones

It is well established that Lupus is ten times more common among females than males (Wallace & Dubois, 1987), although this prevalence is not found among children or the aged (Maddock, 1965). It is believed that the action of estrogens increase immune reactivity while androgens decreases it. It has been found that experimental manipulation of sex hormones in mice alters the outcome and expression of Lupus. Specifically, an increase in the male hormones in mice suppresses the disease, while an increase in the female hormones augments it (Zvaifler & Woods, 1985; Roubinian et al., 1977). It is thought that the effect of estrogen may be due to its action over anti-DNA antibody production, transforming benign immunoglobulin (IgM) to a more toxic one (IgG) or by preventing the clearance of immune complexes (Zvaifler & Woods, 1985).

Psychoneuroimmunology

During the mid 1970's, Ader and Cohen were able to condition murine rats to suppress their immune system (Ader, 1981). This was the first time anyone successfully regulated the immune system by means of "learned behavior." It opened the door to the possibility of behavioral and psychological factors in the pathogenesis of SLE, including consideration of the effects of stress, mood and emotions in the development and expression of the disorder (Talal, 1987).

Advances in psychoneuroendocrinology, and psychoimmunology have brought us much closer to understanding how the psyche influences the soma. These discoveries point to an exiting frontier for future investigation and are directly applicable to patients with SLE. We know for instance, that stress can alter the sympathetic-adrenal-medullary system and that epinephrine and norepinephrine affect cutaneous hypersensitivity. We also know that loss can depress lymphocyte function, that stress can decreased responses of the immune system and that autoimmune disease in mice can be dramatically modified by behavioral conditioning. Most interestingly, people vary in their physiologic responses according to their particular psychological styles . . . (Samuel Perry, 1987 p. 822).

There are many findings suggesting that Lupus may very well be a disease in which there is an interaction of biological, environmental and psychological factors. Still, it will become necessary to clarify and understand the relationship between those factors and that will be the hardest task. Talal expresses it best when he writes:

In the mid-1970's, the immunology world was excited about suppressor cell deficiency and C-type viruses as the probable explanation for SLE. Answers to important questions such as autoimmunity seemed close at hand.

Since that time the impact of the new biotechnology exemplified by gene cloning, cell sorting, and monoclonal antibodies has been felt in biomedical research. We know so much more now, but we seem sure of so much less. The infinite complexity and interrelatedness of biologic systems inspire awe but does not move us closer to our

destination. Rather we see how far we still must travel, and we remain asking the same questions, this time with more humility (Norman Talal, 1987 p. 43).

Clinical Presentation and General Systemic Symptoms

The mode of onset of Lupus varies significantly from patient to patient. An acute onset has been observed in about 20% of all the cases. Of this group as many as 50% may die within three years (Richardson, 1966). The most common presentation, however is an insidious onset which frequently escapes diagnosis for several years. There is a better prognosis associated with this type of clinical presentation (Hall & Stickney, 1984).

The first early symptoms of Lupus are often very vague and generalized (Hall & Stickney, 1984). They frequently include fatigue, fever, weight loss and muscle and joint pain. Of 209 patients studied by Rothfield (1985), 76% presented with chronic fatigue. She found that complaints of fatigue preceded the onset or more objective signs of the disease. It was also found that the fatigue disappeared after other symptoms became evident, and when treatment was made available. Other findings indicated that 63% of the patients had experienced weight loss, and 83% had fever at the time of diagnosis. Fever is always suggestive of underlying infection, and before the use of steroids to treat lupus, infections were the leading cause of death (Ropes, 1976).

Involvement of the joints is the most frequent symptom in Lupus. Pain in the joints may precede the onset of the other systemic manifestations by as much as five years (Rothfield, 1985; Labowitz &

Schumacher, 1971). Cronin (1989), reports that 76% of patients develop arthritis. In Rothfield's study, 86% had arthritis and 95% had either arthritis or arthralgias (Rothfield, 1985). Muscle pain and tenderness is present in about one third of the patients at time of diagnosis (Rothfield, 1985). Extreme muscle weakness with marked atrophy and paralysis was reported by Ropes (1976) in 8 % of his patients. Klemperer et al. (1942), found abnormalities in 25% of patients in post mortem examinations.

Generalized and vague symptoms, in the absence of more clearly defined clinical or laboratory findings, make the diagnosis of Lupus a difficult one. Patients are frequently misdiagnosed or worse yet, labeled hysterics or hypochondriacs. Hall and Stickney write:

Because of the vagueness and variability of these complaints, it is not uncommon for the lupus patient to be labeled "psychoneurotic." Following medical rebuffs and labeling, the patient may undertake a round of "doctor shopping" in an effort to obtain relief, only to be confronted with more frustration and increasing self doubt if the initial psychiatric diagnosis is upheld. One SLE patient summed it all well when she said: "I jumped up and down in the parking lot when I was finally diagnosed. It may sound funny that I was happy to discover that I was sick, but I could finally put a name on what was making me feel so lousy (Hall & Stickney, 1984 p. 288).

In the light of the multiplicity of signs and symptoms associated with this disorder, the American Rheumatism Association has adopted some specific diagnostic criteria for Lupus Erythematosus. In order to make a diagnosis of Lupus, 4 of the following 11 signs must be present:

- 1- Facial erythema (butterfly rash)
- 2- Discoid rash

- 3- Photosensitivity
- 4- Oral ulcers
- 5- Arthritis
- 6- Serositis: pleuritis or pericarditis
- 7- Renal disorders:proteinuria or cellular casts
- 8- Neurologic disorder:seizures or psychosis
- 9- Hematologic disorder:anemia or leukopenia or lymphopenia or thrombocytopenia.
- 10- Immunologic disorder:positive LE cell preparation or anti-DNA antibody or anti-SM or false positive test for syphilis.
- 11- Antinuclear anti-body.An abnormal titer of anti-nuclear antibody by immunoflourescence method.

Multisystem Involvement

Skin Disorders

Cutaneous lesions are a very common characteristic of Lupus.The most frequently observed is the "butterfly rash." As many as half of the patients present with this symptom (Rothfield, 1985), although others report it occurring only in a third of the patients (Cassidy JT, 1977). The rash is located on both cheeks and across the bridge of the nose. It may also be the first sign of the disorder. It is usually brought about by exposure to sun light but it can occur without it. Other skin disorders include alopecia, mucosal ulcers and purpura (Larson, 1961).

Kidney Impairment

Kidney impairment occurs in about half of all Lupus patients and it is one of the least favorable prognostic signs (Cassidy, 1977). Although only half of the patients with Lupus come to develop clinical signs of renal disease, post-mortem examinations and/or immunofluorescent studies of biopsies show abnormalities in nearly all cases of SLE (Rothfield, 1985). Renal involvement includes the entire spectrum of glomerular, tubular and vascular diseases (Balow and Austin, 1989). Early kidney disease is usually subtle and difficult to notice. The first signs include nocturia and edema, rapidly progressing to glomerulonephritis (Balow & Austin, 1989). There are two forms of proliferative glomerulonephritis: focal and diffuse. In focal glomerulonephritis, changes are observed in about half of the nephrons with active inflammatory lesions; ie;cellular crescents, fibrinoid necrosis, and interstitial inflammatory infiltrates (Grishman & Churg, 1982). Severe or diffuse proliferative lupus nephritis is characterized by more than 50% kidney involvement, with marked hypercellularity, necrosis, sclerosis and capillary loop thickening (Rothfield, 1985; Balow & Austin, 1989). Typically immunofluorescent studies show an increased deposition of immunoglobins, complement components and occasional fibrin. Clinically, there is an increased in proteinuria, hematuria, and mild to severe renal insufficiency (Rothfield, 1985).

Vascular Manifestations

Raynaud's phenomenon is the most frequent vascular manifestation of Lupus. In her study, Rothfield (1985) reports finding 20% of her

patients with Raynauds. In some patients it is the first manifestation of the disease (Ropes, 1976).

Gastrointestinal Disorders

Gastrointestinal disorders are also common among lupus patients, and any area of the gastrointestinal tract may be involved. Ulcerative lesions of the mucous membranes are frequently found (Hall & Stickney, 1984). Anorexia, nausea and vomiting are also present. Abdominal pain may be the result of infarction of small or large bowel which may result in perforation and death (Rothfield, 1985). Other disorders may include ascites, dysphagia and pancreatitis.

Liver, Spleen and Lymph Nodes Disorders

Hepatomegaly is usually present in lupus as a result of fatty infiltrations in the liver (Hall & Stickney, 1984). This is a finding corroborated by post-mortem examination of the liver (Ropes, 1976). Liver biopsies of patients with clinically evident liver disease may show chronic active hepatitis, cirrhosis, acute hepatitis and cholestasis (Runyon et al., 1980).

Mild to moderate splenomegaly is reported by Rothfield to be present in about 20% of SLE patients. Splenomegaly is said to be usually present without hemolytic anemia (Rothfield, 1985).

Lymph nodes are also frequently enlarged especially during periods of active disease. Tender lymph nodes are commonly an indication of infection, and may be one of the early signs of the impending generalized flare for some patients (Rothfield, 1985).

Ocular Manifestations

Cyroid bodies have been noted in as many as 20% of SLE patients, although some have reported lower numbers (Hall & Stickney, 1984; Cohen et al., 1971; Tumulty, 1962). The presence of cyroid bodies in the absence of essential hypertension or vasculitis is virtually a diagnostic sign of Lupus (Cohen et al., 1971). Some have reported an association between cyroid bodies and central nervous system activity (Rothfield, 1985). Loss of vision has been reported as an initial manifestation of the disease although vision returns to normal after treatment with steroids (Wong et al., 1981).

Cardiac Manifestations

Pericarditis is the most common cardiac manifestation in SLE, occurring in 20 to 30% of all lupus patients (Baduie et al., 1985). Histological examinations in post mortem studies reveal an incidence of 50 to 60% (Carette, 1989). The usual clinical manifestation includes substernal or precordial pain. The pain may be mild or severe and it is often aggravated by breathing, coughing or swallowing and relieved by bending forward (Carette, 1989). ECG findings show abnormal T waves, which tend to disappear as the disease is treated (Ropes, 1976; Rothfield, 1985). Myocardial involvement is less frequent than pericarditis. Ropes (1976), reports that 10% of his patients developed myocardial complications. Clinically, its manifestations include tachycardia, enlargement of the heart, congestive heart failure, arrhythmias and conduction defects (Rothfield, 1985). Other complications include valvular disease and coronary artery disorder.

Pulmonary Involvement

There are a host of pulmonary complications associated with SLE. Pleuritis with or without effusion is by far the most common problem in SLE, occurring in approximately 45 to 56% of Lupus patients. (Wallace & Dubois, 1987; Estes & Christian, 1971; Carette, 1989). It also may occur with pericarditis. Pleuritic pain is often present even in the absence of radiographic evidence of pleural effusion (Rothfield, 1985). Disorders of the lung parenchyma are also evident. Acute Lupus Pneumonitis was found in 12% of the patients in a study published by Matthay and colleagues in 1974 (Matthay et al., 1974). Recently it has been acknowledged that diffuse interstitial fibrosis is a complication of SLE (Eisenberg et al., 1971), leading to chronic Lupus pneumonitis (Carette, 1989). Other complications include pulmonary hypertension and pulmonary embolism (Carette, 1989).

Drug Induced Lupus

Finally some drugs produce symptoms of Lupus where the clinical presentation is very similar to the natural occurring disorder (Hall & Stickney, 1984). Some of the drugs found to precipitate these symptom include antibiotics, anticonvulsants and birth control pills among others (Richardson, 1966). Usually the symptoms disappear after the medication is discontinued (Hall & Stickney, 1984).

Psychological Factors

One of the most frequently observed phenomenon in Systemic Lupus Erythematosus is the presence of psychological disorders. How common these disorders are cannot be accurately determined from the research

done to this date. Dubois, for instance, in his review of the literature, reports the incidence of psychological disorders to be between 12 and 71% (Wallace & Dubois, 1987). Other researchers have reported similar findings, ranging from as low as 3% to as high as 82% (Johnson & Richardson, 1968; Andrew, 1975; Feinglas, 1976; Liang et al., 1984; Rupe, 1959; Sergeant, 1975).

Several factors seem responsible for these widely different findings; one of these seems to be the discipline of the researcher, with psychiatrists and psychologists finding a higher incidence of psychopathology than other medical researchers (Gurland, 1972). This in part may be explained by the kinds of patients psychiatrists and psychologists are more likely to see compared to other medical professionals. Another important factor is the method by which psychological disorders are determined. Most research has consisted of retrospective study of patients charts. When, on the other hand, patients were clinically interviewed or psychologically tested (which has been the exception), the reported incidence has been higher (Grade & Zeagans, 1986).

Beginning in the early 1950's, researchers have traditionally divided the neuropsychiatric disorders into either organic or functional (Perry, 1987). Organic disorders are usually associated with abnormalities in the brain, and are revealed by impaired neurological functioning. Clark and Bailey (1956) reported organic neuropsychiatric disorders found in Lupus including: convulsions, hemiplegia, diplopia, choked disk, polyneuritis, subarachnoid hemorrhage, nystagmus, vertigo, choreiform movements, monoplegia,

paraplegia, quadriplegia, aphasia, intention tremors, Bell's palsy, cortical blindness and decerebrate states. Central nervous system involvement is only second to nephritis as the leading cause of death among lupus patients (Hall & Stickney, 1984). Others have reported "mental disturbances" and "frank psychosis" as the most common manifestation of neurological impairment (Cassidy, 1977).

The incidence of psychosis in Lupus patients has been reported in many studies. Brody (1956), for example reports in his work with SLE patients that 52% were psychotic. Clark and Baily (1956), reviewing the records of 100 SLE patients seen at the Mayo Clinic from 1948 to 1951 found "severe" psychosis in 17% of the patients. O'Connor (1966), in his study, found that 21 patients had serious psychotic episodes. He was able to obtain autopsies in 11 of these patients with demonstrable CNS involvement. Ten of those showed pathologic changes in the central nervous system especially the cerebrum. Some of these changes included: hemorrhage, foci of necrosis, thickened and hyalinized arterial walls, cellular degeneration, areas of infiltration with mononuclear and polymorphonuclear cells (O'Connor, 1966; Wallace & Dubois, 1987). A significant conclusion arising from this research was the poor correlation between brain pathology and the psychiatric manifestation exhibited by the patients. O'Connor writes:

The relationship between the clinical findings and the findings at autopsy remains quite confusing. Patients with evidence of gross impairment of CNS function can show no lesions at autopsy. Patients with no evidence of CNS disease, clinically, can have gross and microscopy lesions evident in the brain, spinal cord and peripheral nerves . . . We were unable to correlate clinical findings with

pathologic changes observed on postmortem examination
(O'Connor, 1966 p. 158).

Wallace and Dubois (1987), reports an incidence of 29% of psychosis among patients in their study. They believe all the cases resulted from vasculitis and found that they responded well to treatment with steroids. Stern and Robbins (1960), studied 53 cases admitted to a hospital and found half were psychotic. They classified the psychotic episodes into organic mental disorders, schizophrenia, unclassified psychosis, psychotic depression and steroid induced psychosis. They found that administration of steroids relieved some of the psychotic symptoms and suggested that the psychoses were the result of organic brain reactions (Stern & Robbins, 1960).

Guze (1967) found a higher incidence of psychiatric disorders among Lupus patients than among the general medical population. He classified these disorders as organic brain syndrome, affective illness, and schizophreniform disorders. He used the term schizophreniform to distinguish from schizophrenia due to its better prognosis. He was also the first to recognize a higher risk of psychiatric disturbances among black women and he cast some doubts on the then prevalent notion that psychotic disorders in Lupus were caused by steroid administration. Finally he suggested that psychiatric disturbances may be the result of chemical or anatomical alterations in the brain.

Of the more "functional" disorders, depression and anxiety are also very prominent in Lupus. Clark and Bailey (1956) identified depression and anxiety as the most common personality changes

associated with SLE. Dubois (1987) reports incidences ranging from 2 to 51% . He writes:

Depression is particularly common in SLE. Most is reactive although endogenous and psychotic depression occurs. It is characterized by a sense of helplessness, hopelessness, loss of body image, worthlessness, loss of pleasure, anorexia, constipation, and sometimes, suicidal ideation. Anxiety reactions overlap to some extent with depression and includes symptoms of palpitation, diarrhea, sweating and hyperventilation. Hypomania, conversion reactions, panic attacks, hypochondriasis, phobias and obsessive compulsive behaviors are occasionally seen (Dubois, 1987 p. 492).

In O'Connor's study only 12% of Lupus patients were found to have "functional disorders" and their difficulties often were associated with anxiety and depression. The anxiety seemed to reflect a generalized anxiety condition with intermittent or sporadic flares. Increasing anxiety was also closely linked to the administration of steroids. Depression, on the other hand was more chronic and manifested itself in terms of feelings of hopelessness and anxiety (O'Connor, 1959; Wallace & Dubois, 1987). Other studies have found a significant incidence of depression, anxiety and related disorders (Stern & Robbins, 1960; Estes & Christian, 1960). Stern and Robbins (1960) suggested that one of the most problematic aspects of managing Lupus patients was the difficulty in understanding the degree to which the symptoms reflect a reactive response to the physical condition. They were one of the first to call attention to the fact that non-organic factors may be playing a very important role in the manifestation of psychiatric disorders of SLE.

In a study by Ganz and colleagues (1972), SLE patients were compared to patients with rheumatic arthritis. Using an structured

psychiatric interview, they found that although there were striking similarities among both groups of SLE patients showed significantly higher levels of depression. They also found that 57% of the SLE patients had at least one organic, depressive or schizophreniform symptom. Depressive symptoms were more than twice as common as organic symptoms and seven times as common as schizophreniform symptoms.

Liang and associates (1984) studied a group of SLE patients and a group of rheumatic arthritic patients and found that in both groups there was a significant level of psychological distress. The study consisted of standardized psychological tests, such as the MMPI and interviews. Loss of physical function, independence and decreased social interactions were found in both groups. Lupus patients showed an increased awareness and fear of death, a finding not present in the other group. Both groups had almost identical MMPI profiles with marked elevations in the Depression, Hysteria, and Hypochondriasis scales. Liang and associates suggest that the similarity between the two groups casts doubts on the assumption that an organic process is the basis for psychological disorders in SLE. They suggest that the psychological problems may reflect an adaptive rather than a neurotic process.

Liang's study (1984) is one of the few in which qualitative data were incorporated in the analysis. His findings are significant because they represent a major step in trying to understand the illness from the perspective of the patient. Among his findings, Liang reported that as many as 76% of Lupus patients complained they

had difficulty obtaining a diagnosis of Lupus. They also reported "loss of function" as one of their biggest problems as well as strong "emotional reactions" and/or mood swings. As previously mentioned, the theme of death was present in the Lupus patients (23%), while for the greatest fear for the Rheumatic Arthritis group was physical disability.

Another significant finding was that although most patients reported being content with their interpersonal relationships, 21% felt that their doctor could do more to understand their illness. In addition, they reported a conflict between accepting the disease and the "sick role" versus hiding it and pretending to be normal. Liang suggests that the loss of physical function and independence are "major themes in both groups." He also suggests that the large number of patients who had altered relationships with friends, family and spouses may be indicative of "isolation and conflict." He also reports that as many as 50% of the patients in both groups experienced their illness as positive in their lives, a process that Liang suggests is similar to the "transcendental redirection" described in patients surviving cardiac arrests.

Another study that used qualitative data was conducted by Kinash (1983), at the University of Saskatchewan in Canada. Her sample consisted of 52 patients who had Lupus for a minimum of one year and who were undergoing therapy at the Rheumatic Disease Unit of the University Hospital. She obtained data from 31 patients by means of a semi-structure taped interview and from 21 patients by mail questionnaire. In her sample, 85% of the patients reported mood

swings which included "overt anger, frustration and depression," and nearly 50% complained of memory deficits and confusion. All patients had a "flare" episode although the length, severity and general pattern changed from patient to patient. The most common symptom (69%) was pain and fatigue followed by fever and chills (30%). Many patients (42%) also reported a loss of control either temporary, as when they experienced a "flare-up" of the disease, or as a permanent condition in their lives. The majority of the patients (75%), described themselves as satisfied with themselves, although 60% reported the disease set limits and that interfered with their lives, their goals and their aspirations. Finally, in the area of interpersonal relationships, some patients reported significant problems and felt distant from others because they "did not understand."

There is very little empirical data regarding personality style of the SLE patient. Most evidence reflects inferences based on studies of patients with rheumatic arthritis, or on clinical interviews of SLE patients. Grade and Zeagans (1986) report characteristics such as passivity, self-sacrifice, masochism and denial, and cite studies by Goodwin et al. (1979) and McClary (1955) to support their contention. Goodwin (1979) reports that physicians who treat Lupus patients find them immature and uncooperative, anxious, depressed, cruel, seductive, impatient and unreliable. McClary reports that SLE patients display a "characteristic air of self assurance" and "an extreme degree of artificial cheerfulness." Based on the evidence they present in their

article, it does not seem that Grade and Zegans have much to go on, however they write the following:

The tentative conclusion suggested to us by these studies is that those individuals susceptible, for example, to the "low pathogenicity of the LE virus"(if one were to accept the viral theory of SLE) or prone for example to physiological intolerance for and/or lack of recognition of the components of the "self"(if one were to emphasize the autoimmune process), are those people who have a "primitive" psychological make up. They are people who sense of self is not adequately integrated. They are people whose tendency is towards the splitting of the "good" and "bad" self. Given this way of perceiving themselves, they understandably tend to see others in extreme of good and bad. In the face of confrontation (or stress), they are prone toward denial, undoing, projection, and somatization. Their emotional displays frequently take on extreme forms; they often manifest as caricatures of a modulated response (Grade & Zeagans, 1986 p. 34).

Although exaggerated claims as the one just quoted have poor empirical validation, the evidence does seem to suggest a strong psychological component in SLE. There is also strong support for anatomical and physiological alterations in the central nervous system in SLE. Finally, the social and interpersonal adjustments brought about by the disease may cause by itself strong emotional reaction.

In summary the empirical findings suggests the following conclusions:

- 1) Psychological disturbances seem to be an intrinsic aspect of SLE. Psychosis, depression and anxiety appear to be the most prominent symptoms (Lahita, 1987; Wallace & Dubois, 1987; Hall & Stickney, 1984; O'Conner, 1960; Guze, 1967; Estes, 1971; Ganz, 1972; Feinglass, 1977, and others).

- 2) There is significant CNS involvement directly attributable to SLE. The relationship between those anatomical and/or physiological changes and the overt psychiatric disorders has not been substantiated by research (O'Connor, 1960; Johnson & Richardson, 1968; Glasser, 1952; Rudin, 1981; Carr et al., 1978; Wienfield et al., 1978; Hadler et al., 1971).
- 3) Psychiatric symptoms may be caused by systemic disorders not directly associated with CNS, such as hypertension, uremia, infections metabolic abnormalities, etc. Once again, no clear relationship had been established between systemic disorders, brain dysfunction and psychiatric symptoms (Baker et al., 1973; Sargent et al., 1973; Feinglass et al., 1976).
- 4) In the past, steroids had been linked to the appearance of psychiatric symptoms, especially that of psychosis (Broday, 1956; Cares & Weinberg, 1958; O'Connor, 1959). Although this may occur in some cases, the current evidence is that steroids are a source of potential cure rather than the cause of neuropsychiatric complications (Lahita, 1987; Carr, 1978; Grigor et al., 1978; Guzee, 1967 ; Bennet et al., 1972; Baker et al., 1973; Cade et al., 1973 and others).
- 5) There is no clear evidence for a "Lupus Personality." Grade & Zeagans (1986) have suggested a pattern characterized by masochism, denial, passivity and self-

sacrifice. Lahita (1987), believes that the premorbid personality, education and pattern of interpersonal relationships may modify the presentation of Lupus. Others (Liang et al., 1984; Kinash, 1983) have viewed the so called "neurotic personality" found in Lupus as an adjustment to the stressors and limitations of this disease.

CHAPTER 3

METHODS AND PROCEDURES

Most psychological studies of Lupus, have been characterized by inconsistent findings, different selection criteria and, to a degree, deficient methodologies (Grade & Zeagans, 1986; Guze, 1967; Liang et al, 1984; Morbidelli et al, 1986). There is a good reason for this since one of the most distressing aspects of Lupus is the problem of establishing a definitive diagnosis. Throughout the years advances in biotechnology have provided clinicians with powerful tools to aid in the diagnosis of Lupus and the American Rheumatism Association has set a criteria with that end in mind (Rothfield, 1986). Nevertheless, of the studies I reviewed, the majority did not specifically define what criteria they used in determining the diagnosis of Lupus and, therefore, how they selected patients for study. It is very likely that when we look at studies done since the early 1950's we will find a "mixed bag" of patients; that is, although diagnosed as having Lupus, they probably represented several related disorders aside from Lupus. Even today, many patients diagnosed as having Lupus may in fact be suffering from some other disorders (Dr. Sheib, Personal Communication, 1990). This may be a potential source of biases, especially in regards to the generalizability of findings.

Another problem with psychological studies of Lupus is the classification of what constitutes "neuropsychiatric abnormalities" (Grade & Zeagans, 1986). Here again there is significant variability among studies; some accept minor changes in mood and cognition, while

others insisting in including only symptoms which represent a major alteration of psychological functioning. (Johnson & Richardson, 1968). The manner in which the symptoms have been shown to "exist" has also been inconsistent. Many studies have relied on examination of patient charts, others in clinical interviews, others on observation of neurological function and, only until recently, psychological tests have been utilized (Liang et al, 1984). Thus, it is not surprising to find a large difference in the reported prevalence of neuropsychiatric disorders, from as low as 3% to as high as 82% (Perry, SW in Lahita ed, 1987).

Psychological studies of Lupus have also been characterized by a specific research program which usually involves a comparison of group means between Lupus patients and a control group; either normals or some other kind of chronically ill patients. These studies also attempted to establish causative relationships between psychological symptoms and either a pathological or a functional abnormality (Grade & Zeagans, 1986). Although this approach has proven effective, as the need for control groups is well established in research (Burish & Bradley, 1983), it is not without some problems. Comparison of means, assumes certain homogeneity in the sample; if this is not the case, as is likely in Lupus, the obtained group means may be very misleading at best and it may not reflect at all the "true" status of the sample (Naliboff & Cohen, 1983).

A different approach is to study differences within the group, and to describe unique characteristics. This method, should provide information concerning what the patients are like not just how they

differ from some control group. Aiming at understanding the characteristics or differences within the group will provide the very best possible description of the phenomenon and, ultimately, a better grasp of the problem. This is not a mere academic point but a very significant one. For instance, in recent psychological studies of Lupus, MMPI profiles of Lupus and control groups are reported. When chronic arthritis patients are used as controls, the profiles are similar although Lupus patients' profiles are slightly more elevated (Laing et al, 1984; Morbidelli et al, 1986). The usual elevations are in scales 1,2 and 3 with a characteristic conversion "V" profile. Although these findings are useful and intriguing, they fail to reveal how many patients had such a profile (which is the "classic" neurotic profile), and what the reasons for such elevations may be, although the Liang study did try to explain the elevations). By averaging and comparing groups, we may in fact be mislead or left in the dark regarding the original intentions of the study, that is, we may fail to "understand" the psychological phenomena in Lupus. Although the tendency to aggregate data had been criticized in the past it is still frequently used (Baloff & Becker in Schultz ed, 1970).

Another characteristic of current methodological approaches to the psychological study of Lupus, concerns the use of linear models of causation. Many researchers have set out to look for the "causes" of psychological disturbances, either in specific brain pathology or in a particular "personality" style. Such efforts have not been without merit although they have not delivered the promised outcome. Most recently there has been an attempt at understanding Lupus from a

multicausal rather than a unicausal perspective (Grade & Zeagans, 1986). Cause-effects models of science are not the only ones available, and an emphasis on such an approach may obscure useful and important information. Viable options may include interactive, transactional or synergetic models and many researchers are beginning to adopt such models (Burish & Bradley, 1983).

The use of "subjective" data in the form of patient reports of their experience has been largely overlooked in Lupus research despite the fact that they have been very useful in other types of illness research such as pain research (Burish and Bradley, 1983). This situation may reflect the suspicion traditional psychological research has towards "subjective" data and the fear of poor validity or reliability. This need not be so; In fact, subjective reports are considered highly desirable in some medical research because of the privileged epistemic position of the patient (Watson & Kendall, 1983). The patient feelings and sensations, as well as his understanding of the impact of the illness in his life, are uniquely in the province of his "subjectivity." Because we can not "observe" the patients' pain, we need him to tell us about it; but we also need a method that would provide the means to do so in a rigorous manner. Psychological phenomenology, as a method of investigating human experience, may prove a good perspective from which to undertake this study.

Psychological phenomenology traces its origins to the philosophical investigations of Edmund Husserl (1931/1970). Husserl insisted in the primacy of consciousness as the starting point for any investigation (Polkinghorne, 1989). The individual for Husserl does

not "grasp" reality by being a passive recipient of sense data, but objects appear in consciousness as a "meaningful whole." The character of perception has the quality of "intentionality, that is, consciousness is directed towards its objects. For Husserl there is no pure consciousness, but there is always "consciousness of" something. Thus perception is inherently world-oriented and meaningful. The process by which we elucidate the meanings or "essences" (to use Husserl's term), is phenomenological or a rigorous approach to the analyses of human experience (Colaizzi, 1978).

Husserl has had a significant impact on the philosophical thought of the 20th Century. Both Heidegger and Sartre as well as the philosophy of existentialism have been heavily influenced by him (Sahakian & Sahakian, 1974). His influence, however is not limited to philosophy. Many psychologists have for sometime now utilized his insights and method in the study of human experience (Giorgi, 1970/1985; Aanstoos, 1984; Colaizzi, 1978).

The importance of phenomenology for psychological research rests on the assumption that human experience is meaningful, intelligible and communicable to others. Furthermore, it emphasizes conscious human experience as a proper realm for psychology and it investigates such experience in a methodical, empirical and systematic manner (Polkinghorne, 1984). For those interested in illness research, and in particular, in the totality of the person's experience of his disease, phenomenology is an invaluable tool because it describes the world as lived by the sick person in his everyday experience (Valle &

King, 1978; Heidegger, 1962; Schrag, 1970). This study will attempt to do just that regarding the experience of the Lupus Patient.

Purpose of the Study

The purpose of the present study is to describe the experience of being ill with Lupus Erythematosus, including the everyday experience of living with Lupus and the meaning it has for the patient. A significant effort in this work is aimed at understanding this disease from the perspective of the patient. Its basic premise concerns the view of illness as a phenomenon which includes not only pathological and/or biological processes, but the inherently human experience of suffering and of giving meaningful expression to that suffering. In addition, this study emphasizes the need to expand our concept of what illness "is," lifting it from a purely biological reductionism to a more comprehensive and, hopefully, more useful definition which will provide a better understanding and more effective treatments.

There will also be an attempt to relate psychological characteristics of Lupus to variables previously identified in the research literature. The first part of the study will use phenomenological interviews, while the second part of the study will make use of the Minnesota Multiphasic Personality Inventory-2 (MMPI-2), and Cattell's 16 Personality Profiles test (16 PF). In addition, social, medical, and behavioral information will be collected from the participants. These data will then be analyzed using One-way Analyses of Variance, Pearson Product Moment correlations and Student's t-test.

Participants

The participants were all volunteers and were solicited through the Lupus Foundation Chapter of East Tennessee. To participate in the study, the patients were required to have a diagnosis of SLE. In addition a Symptom Checklist Form was developed to determine if the participants met criteria set by the American Rheumatic Association for the diagnosis of Lupus. Finally, medical information was requested from the patients' physicians in order to establish more stringent laboratory parameters for SLE diagnosis. Demographic information on the subjects is presented in Table 1 of the Appendix.

Comparison groups within the Lupus sample were used in order to investigate relationships among variables of interest. Comparisons with normal or non-Lupus population were not done, except in the case of psychological test scores. In this case, the scores reported in the normative sample of both the MMPI-2 and the 16 PF Form A were used. Norms for the 16PF were obtained from the Tabular Supplement No1 to the 16 Pf Handbook; Norms for the MMPI-2 were obtained from Appendix H of the MMPI-2 handbook.

Forms and Instruments

In addition to the two previously mentioned psychological tests, participants filled out two consent forms. The Informed Consent Form was their agreement to participate in the study; the Release of Information Form, was used to request medical information from the patients' private physicians. Social information was also collected using the Biographical Information Form, which was adapted from the

Biographical Information Form utilized in the MMPI Restandardization Project (Butcher, J.N., Graham, J.R., Williams, C.L. & Ben-Porath, Y.S., 1990). The nature of life stressors was assessed by means of the Life Event Form. This form was also adapted from Holmes and Rahe's Social Readjustment Scale (Holmes, T.H. & Rahe, R.H. 1967). Finally, participant reports of medical symptoms and illness behavior were obtained through the Symptom Checklist Form which was developed using an standard medical text in Lupus (Wallace & Dubois, 1987), and with the collaboration of a nurse and physician. Samples of all forms are presented in Appendix A.

Data Collection

Selection of Participants

All participants were members of the Lupus Foundation of America, East Tennessee Chapter. Patients were first informed of the project through the monthly newsletter of the foundation. Initially, over fifty people showed interest in participating in the study and called the Foundation's office inquiring about it. Each of the volunteers was personally contacted by the researcher, and the nature and purpose of the study explained to them. Because the study required having a diagnosis of Lupus, some volunteers were not able to take part in the project, since they had not been "definitively diagnosed" with Lupus. The final pool included 37 females and 2 males, which is consistent with the general ratio in the Lupus population. Participants then signed the Informed Consent Form, and were assigned numbers to protect confidentiality. From that point on, all test data was identified by

means of that number. The names and phone numbers of the subjects were written in a master list which was kept at the Lupus Foundation Office in Knoxville.

Phenomenological Data

Phenomenological data were obtained from 27 participants. Although there was no special criteria for selection in this part of the study, not all patients participated in it. There were several reasons for this. Some participants felt they did not express themselves well, either written or orally, and declined. Others became very sick and could not participate and one person, regretfully, died of complications from Lupus.

Two of the most frequently used methods of data collection in phenomenological research include written descriptions and dialogal interviews (Colaizzi, 1978). Both provide sources of descriptive data of a particular experience. Written protocols offer the advantage of shorter clear descriptions but lack the depth of information often obtained in dialogal interviews. Dialogal interviews provide the researcher with an opportunity to clarify the co-participants' statements, reduce ambiguity and allow for a more sensitive understanding and, perhaps, a more comprehensive description of the phenomena. Both methods are frequently used at the University of Tennessee Phenomenological research group and have been found within its limitations, to be effective and useful. Both methods were used in this study.

The phenomenological data consisted of 12 in-depth interviews and 15 written protocols. Each participant was asked to describe as fully

as possible his or her experience of being ill with Lupus. Specifically, they were asked to: "Think of a time in which you have become very aware of having Lupus or of being a Lupus patient; What were you aware of?" The same question was used in the written protocol. All interviews were audio-recorded later transcribed.

Psychological Tests and Other Data

The collection of test data and other information took place at the Lupus Foundation offices. Normally an appointment was made for a certain date and time. Usually one or two participants were tested at the same time. The researcher gave directions and waited until subjects understood the procedure before starting.

The tests and other materials consisted of the following:

- a) Minnesota Multiphasic Personality Inventory(MMPI-2)
- b) 16 Personality Profiles Test, Form A (16 PF)
- c) Biographical Information Form
- d) Symptom Checklist Form
- e) Life Events Form
- f) Release of Information Form

After the testing was completed, all materials were placed in a sealed envelope with all identifying data removed, except for the participant's number. Because of the nature of their illness, and the length of the testing procedure, some participants required two testing sessions to finish. In that case they would return at their convenience and complete the testing. All test materials remained sealed in their packets until they were collected for analysis. Mrs Julie Scott, Director of the East Tennessee Chapter, assisted in

collecting the test materials. She also was the only person with access to the participants' names and telephone numbers.

Data Analysis

Phenomenological Data

The procedure used in the analysis of protocols was adapted from Colaizzi(1978) and included the following steps:

- 1) Reading protocols in order to obtain a "holistic" grasp.
- 2) Extract significant statements.
- 3) Formulate meanings.
- 4) Organize meanings into clusters of themes.
- 5) Validate themes by checking back with the original protocols.
- 6) Validate meanings by checking back with subjects.

Step 1. A Holistic grasp of the Data

The first approach to the data, requires that the researcher becomes familiar with the protocols. Colaizzi (1978), speaks of "acquiring a feeling" for it and beginning to develop a sense for what the subject is describing. In later stages of the research this knowledge becomes essential in understanding aspects of the protocols that may appear confusing or ambiguous.

Step 2. Extract significant statements

In this stage, in order to facilitate reading and understanding, all repetitions, false starts or deviations from the topic are deleted from the protocol. The protocol is then divided into significant statements which are phrases or sentences pertaining to the experience

of the person. This step is basically one in which the protocol is changed into main ideas and careful attention is paid to the words, metaphors and expressions used by the participant. Each section or paragraph of the protocol is carefully read in this fashion and is then transformed into significant statements. The procedure involves making photocopies of the written protocol (in order not to damage the original) and either writing on the margin next to the text, or in a separate page of paper (after appropriately coding the section) the significant statements. For instance, part of one protocol reads:

I have been in the hospital numerous times and it is hard but my main goal is to fight and keep fighting as much as I can. I also pray a lot. I am a very Christian person and fighting and the power of the Lord is very helpful to me. My church and family is very supportive of me and that keeps me going.

When the paragraph is changed to significant statement it reads:

- Despite being hospitalized and acknowledging that "it is hard" she keeps fighting.
- She prays
- Fighting and "the power of the Lord" is very helpful.
- Support of family and church keeps her going.

Step 3. Formulate meanings

This is the first "interpretative" step. Colaizzi (1978) describes this step as the "creative insight" or the "leap" from what participants say to what they mean. The meanings, however, have to be either clearly stated in the protocols or strongly suggested by them and they *must refer to the person's experience and to his or her unique ways of perceiving and describing the experience.* The

procedure involves reading the significant statements, paying careful attention to shifts in meaning. All significant statements that share a common meaning are summarized in the words of the researcher. This is done throughout the protocol therefore reducing the original protocol to a series of "summaries" or "meaning units." This step produces the basic data from which the themes of the experience of "being ill with Lupus" are to be extracted. The summary need not be very extensive and sometimes a short description or phrase is used; however, it must describe accurately what the person is experiencing. In the example above, the summary or "meaning unit" was described as follows:

This person seems to be very aware of her fighting and the support she receives from family and religion.

Step 4. Organize meanings into cluster of themes

Once protocols have been analyzed into "meaning units" or "summaries," they are aggregated into "clusters of themes." A theme is an aspect of the experience that encompasses several meanings and which constitutes the basic structure of that experience, something akin to Husserl's ideas (*eidos*).

Husserl (1931/1970), believed that human experience had a "transcendental structure," an "essence" which is accessible to human consciousness. This essence he called *eidos*. The means by which this "essence" was determined was a form of intuition, the "eidetic reduction" or "eidetic seeing" and required a suspension of judgement in which all preconceived notions, ideas, dogmas etc, were set aside to allow for an unbiased perception of the phenomenon as it appears

and reveals itself in consciousness. Psychological phenomenology, appropriates Husserl's basic insight, but attempts to describe this structure as a phenomenon of consciousness based on the experience of the real world. This science of experience, "treats phenomena as real existence of real subjects who belong to the spatio-temporal world" (Sahakian and Sahakian, 1974). This step then, is an attempt at describing the particular human experience ie, "being ill with Lupus" and to elucidate its basic existential structure or themes.

The process of searching for fundamental themes involves grouping of "meaning units" or "summaries" into general themes or "cluster of themes" that best express the meaning of the experience as it is found in the summaries. The method is described by Polkinghorne (1989) as requiring the "researcher to move back and forth between the meaning statements and the successive revised hypothetical "exhaustive" lists until the themes are accurately reflected in the cluster. The final result . . . is the finding of the research, the essential structural definition." This description suggests a process by which "meaning units" are grouped and regrouped in different clusters until a comprehensive and coherent general theme is formulated. Once such general theme is formulated, the most frequent word, phrase or metaphor used by the participants in describing their experience is selected to name the theme. For instance, in the example we have been considering so far, there was a sense of "struggle," of "fighting," and of not giving up. Participants also referred to this experience as "coping" and "adjusting," and frequently used those

words. This experience was consistent across protocols and it was revealed in meanings that were described as follows:

RESOLUTENESS (FIGHTING/COPING)

This theme refers to the experience of struggling and fighting against the disease. Some patients refer to it in terms of "fighting" as implying an adversarial relationship to the disease. Others talked about "coping" as if the quality of the struggle was that of adjustment. This theme was found in 44% of all protocols. Frequently people mentioned their individual faith or religion, their family and friends and others a positive attitude towards their illness as a source of help and support.

The next two steps in analyzing phenomenological data are concern the validation of the themes.

Step 5. Validate themes by checking back with the original protocols

In this step one looks at the themes and compares them to the original data in the form of written protocols. The question asked is if these themes faithfully reproduce the experience of being ill with Lupus as it was described in the protocols. Again, in phenomenological research, the main goal is to describe the experience of the person. Sometimes, changes are made when a theme does not faithfully describe the person's experience. For instance, one of the five themes found in this study, *Isolation/ Invisibility*, was originally named *Alienation*. When the protocols were read again, it seemed that it was not the best description of the kind of experience patients were talking about. Certainly, some patients spoke of their loneliness and withdrawal in such a way as to suggest a sense of profound alienation, something akin to an "schizoid withdrawal" (Simms, 1989). But for most patients, their sense of loneliness and separation was more characteristic of Barrell's (1989) description of

a Barrier experience than that of alienation. This experience described by Barrell (1989) in his study of loneliness is based in a sense of separation from other people and an awareness of a barrier that stands between the person and the world. After further work with the data, and discussions with other members of the phenomenology research group, it seemed that Isolation/Invisibility much more accurately captured the meaning of the experience than that of Alienation.

Step 6. Validate meanings by checking back with subjects

This is a "must" in phenomenological research. One of the fundamental ways in which phenomenology differs from traditional psychological research is that the "subjects" are seen as "co-participants" or "co-researchers." In each phenomenological study, the co-participant is in some ways responsible for the results of the study. In addition, this step insures that the researcher keeps an open and non-dogmatic attitude over his or hers findings and that he or she would be willing to change them if necessary. It is also a way of clarifying or gaining a deeper understanding into the themes themselves.

In this study, after the thematic analysis was completed, the researcher went back and contacted the people who had participated in the project and shared with them the results. At this point, they were asked how accurately these themes described their experience of having Lupus or of being a Lupus patient. They also were asked to clarify or expand on the same themes. This was done over a period of two months, and led to a more clear understanding of the data.

Validity and Reliability in Phenomenological Research

Phenomenology offers a radically different approach to the study of human life in the context of daily, everyday experience. In this sense it departs from traditional views in psychology, specifically from laboratory based experimental and behavioral approaches. Since psychology, from its beginning, became associated with natural science in an attempt to separate itself from philosophy, any deviation from this type of "traditional method" is viewed with suspicion. Frequently, questions are raised regarding issues of reliability and validity in phenomenological research. Phenomenologists have addressed those issues from two perspectives: (1) by emphasizing the different philosophical assumptions underlying both phenomenological and natural science research as applied to psychology and (2) by describing how validity and reliability are conceptualized and evaluated in phenomenological research (Romanyshym, 1978; Coliazzi, 1978; Giorgi, 1970; Polkinghorne, 1989).

Romanyshym (1978) charges that the natural science approach represents a fundamental bifurcation of the world between the world as it appears to the naive observer, and the world as "it really is," the world which is discovered by science. According to Romanyhsym, the natural science approach has made a fundamental error in dismissing the former and elevating the latter to a level of supremacy. Similar criticism have been raised by Giorgi (1970). He asserts that psychologists who work under the natural science paradigm, have failed to appreciate the meanings implicit in those behaviors and the

richness of the human experience. Polkinghorne (1989) also contrast the two perspectives in the following way:

Research methods are plans used in the pursuit of knowledge . . . the map developed by western science during the past three centuries is based on the notion that reality consists of natural objects and that knowledge is a description of those objects as they exist on themselves. The purpose of the path laid out on this map is to eliminate the distorting influences of personal perspectives and the subjective properties of researchers . . . The phenomenological map is not antithetical to the mainstream natural sciences map but it marks different features of the terrain. It locates geological features of human awareness and remind us that the research journey needs to attend to the configuration of experience before moving on to assumptions about independent natural objects (Polkinghorne, 1989).

With these arguments, phenomenologists have indicated that the differences between the natural science approach and phenomenology is grounded in their particular point of departure. What emerges from these two perspectives is that the natural science approach will be concerned with discovering universal laws and developing theoretical models while emphasizing objectivity, experimentation and measurement. The phenomenological approach, in contrast, will be concern with situated and contextualized descriptions (Coliazzi, 1978). Therefore, reliability and validity are conceptualized differently in phenomenological research than in natural science research. For phenomenology, reliability is not defined in terms of seeking and establishing consensus among researchers but in understanding the perspectives of the researcher. If another researcher assumes this perspective, he or she should be able to "perceive and understand the same meanings" (Giorgi, 1975; Barrell, 1988). Validity is viewed as the realization and description of the phenomenon as it is lived and experienced by an individual (Coliazzi, 1978).

In addition to describing differences between both approaches, phenomenologists have also paid close attention to methodological matters. Frequently, phenomenological studies are subject to scrutiny and validation. For instance, many have conducted reliability studies of the phenomenological method. The results have indicated high levels of agreements among raters. These studies have reported values of reliability ranging from .75 to 1.0 (Dapkus, 1982; Ridgeway, 1985; Young, 1986; Seidner, 1987; Barrell, 1989; Khanna, 1989). Other methods include the use of a group of people familiar with the phenomenological method of protocol analyses. Protocols are brought into the phenomenological research group where they are read and thematize by all the members of the group and the results then discussed and discrepancies resolved. The members of the group, in this fashion, function as independent raters providing multiple reliability checks. That was the method of choice for this study (Fisher, 1978).

Validity is also of importance to the phenomenological researcher. That is, validity as the faithful description of the person's experience, what phenomenologists describe as "being present to the experience." In order to achieve this, "validity checks" are always incorporated into every phenomenological study (Colaizzi, 1978). Although the specific method may be differ from one researcher to another, at least two are kept constant; checking results with the original protocols as well as with the specific individuals who participated in the study. In the first instance, results are validated against the data; in the second they are validated by the

interviewees themselves. The goal of the researcher is to describe the person's experience; to the extent he or she is successful in doing this, the study is valid.

In the final analysis, it seems that a valid understanding of man's psychological experience should not be restricted to one particular method. Science, as Popper (1975) has pointed out, is a constant movement of "conjectures" and "refutations." There is no "meaning criterion" which in one simple stroke will separate science from non-science, except for a critical and rigorous attitude towards one's theories and one's research. This has been recently strongly supported by some psychologists as the "proper scientific attitude" (Bartley, 1984; Rorer, 1989).

According to May (1958), the early existential-phenomenologists, believed they were more rather than less scientific in assuming a first person perspective in psychology, because such a perspective had been completely ignored in psychology. The human being is both subject and object, and our methods should reflect and encompass this unique characteristic; as Burt (1970) has indicated, we need to incorporate in our research what he calls "external" and "internal" observational methods. The problem with the empirical tradition in psychology, best represented by the radical behaviorists and experimental psychologists, is that their description of man was incomplete and ultimately misleading. By describing the human being only in terms of "object" and by eliminating subjectivity, they failed to realize the very crucial element that make humans, and the scientific study of humans, unique.

Today there is a greater awareness among behaviorists of the importance of "organism variables" and "cognitive processes" (Martin & Pear, 1988). We are also much more aware that experimental studies conducted under laboratory conditions are limited in their applications, because of limited "ecological validity" (Chapanis, 1970). That is I believe, an step in the right direction. Perhaps the best position is that expressed by Pollio (personal communication, 1989) when he said "let the phenomenon dictate the method."

Psychological and other Test Data

In this part of the study the aim was to describe the psychological characteristics of the Lupus patients as reflected in the MMPI-2 and the 16 PF. In addition, medical, social, and behavioral data also were collected, described and compared to clinical measures of psychopathology.

Step 1. General Description of Sample

Psychological Data. Scores on the clinical scales of the MMPI-2 and the personality dimensions of the 16PF were described for the sample as a whole.

Social Data. The sample was described in terms of demographic and social variables. This information was obtained from the Biographical Information Form that subjects had filled out.

Medical and Behavioral Data. The sample was described in terms of the medical information and the behavioral data provided in the Symptom Checklist Form and the Life Event Form.

Step 2. Individual Profile Analyses

Each MMPI-2 and 16 PF protocol was interpreted using well established clinical guidelines (Karson & O'Dell, 1976; Graham, 1990; Greene, 1980). Because specific psychiatric diagnosis are difficult to make when based only in test data another approach was used. Clinical descriptions were sorted out according to four major categories: Normal, Neuroticism, Psychotism and Other. These categories were chosen for descriptive purpose and were defined as follows:

Normal: A protocol was described as "normal" when the validity scales on both MMPI-2 and 16 PF indicated a valid test and the clinical scales were within normal limits.

Neuroticism: A protocol was classified as "neurotic" if it indicated a condition in which a person reported emotionally distressing and enduring symptoms; these symptoms were experienced as ego dystonic and reality testing was fairly intact. In addition, the condition could not be a reaction to situational stress. In the MMPI-2 elevations in scales 1,2,3 and 7 or a combination thereof are generally viewed as indication of a neurotic condition. Similarly, in the 16PF scales C-, L+, O+, Q3- and Q4+ are also indicative of neurosis. This category will include most depressive and anxiety disorders.

Psychotism: A condition in which the primary focus is severe disturbances in perception, thinking and reality testing. In the MMPI-2 elevations in scale 8, alone or in conjunction with other scales such as 4-8, 6-8, 7-8, 9-8 etc often are associated with psychotic disorders. There is no specific pattern in the 16 PF associated with psychosis.

Other: Basically, subjects whose profiles did not meet any of the above mentioned categories were included in this one. An example of this category includes transient reactions to stress or a pattern indicative of CNS disturbances.

Some profiles seemed to point to both neurotic and psychotic conditions. Those individuals would most likely be classified today as severe character disorders. Since there was no need to create an additional category, these profiles were grouped either with the "Neuroticism" or the "Other" category. The "Psychotism" category was used only in clear cases of psychotic profiles. However, all the participants who admitted to psychotic symptoms were noted regardless of their particular category. This was necessary because otherwise the results would have been misleading. For instance, in the present sample only 8% of all the participants met criterion of "Psychotism," a rather small percent. However, if all the individuals who reported psychotic symptoms are combined this percent increases to 33%.

Step 3. Group Comparisons and Sample Correlations

Lupus Diagnosis. The sample was divided into three groups based in the likelihood of Lupus diagnosis. These groups were designated as Low Likelihood, High Likelihood and Unknown. The groups were then compared on different clinical variables of the MMPI-2 and the 16 PF and a One-way Analysis of Variance was performed. Group selection for the above categories was based on information obtained from the patients' private physicians. This information consisted of medical history and laboratory data. The researcher sought the help of a Rheumatologist who on the basis of the information available assigned participants to

these groups. Although all patients who participated in the study had a previous diagnosis of Lupus, and according to the history provided by them, met guidelines for Lupus diagnosis set by the American Rheumatic Association, not all of them met a more stringent laboratory criteria consistent with a Lupus diagnosis. Therefore, a question was raised in terms of possible psychological differences among patients with definitive diagnosis and those who may or may not be afflicted with Lupus. The "unknown" category was added when medical and laboratory information was not available to make a decision .

Social, Medical and Phenomenological Variables. Subjects were first divided in groups representing several social variables such as marital status and ability to work and then compared on clinical scales in the MMPI-2 and the 16PF. Medical and behavioral variables also were compared to clinical scales of psychopathology. These variables included: stress level, years with Lupus, amount of Prednisone taken per day, total number of other medications taken per day, number of hospitalizations in the last two years, number of symptoms reported by patient, number of "flare ups" in the last two years, number of physician contacts in the last six months and total number of hours of activity per day. Phenomenological data also were compared to clinical variables of "neuroticism." Themes 1,2, 4 and 5 were used for this purpose. For each theme, participants were assigned to either of two groups: a group in which the theme was present or a group in which the theme was absent, and then, both groups were compared to the neurotic scales on the MMPI-2 and the 16 PF. Theme 3 was not used because of the small number of participants in the "absent" group. Student's t-test

and Pearson Product Moment Correlation were performed to describe relationships among the variables and to evaluate the significance obtained between the groups.

CHAPTER 4

RESULTS

General Description of the Sample

Social and Demographic Data

The total number of subjects who participated in this study was 39. The mean age was 45.6 years (SD=10.71), with an age range from 25 to 76 years. The majority of participants were white (77%), female (94%), married (56%) and protestant(64%) Fifteen percent of the participants reported having no religious preference and 41% reported family incomes of over \$30,000 a year. Thirty six percent reported receiving Social Security benefits. Table B-1 in Appendix B summarizes the demographic data.

Phenomenological Study

Transcripts of the interviews averaged seven pages in length, while written protocols averaged two. Themes appeared with a frequency of 3.80 in the interviews and 2.98 in the written protocols. The phenomenological analysis of the experience of "being ill" with Lupus yielded five major themes. These are:

- 1) Isolation/Invisibility
- 2) Constricted Existence (Losses/Limitations)
- 3) Vulnerability/Helplessness
- 4) Transformation(Changes)
- 5) Resoluteness(Fighting/Coping).

These themes revealed different aspects of the experience of being ill with Lupus as found in this group of patients. Not all themes were present in every participant's experience. The percentage of participant protocols expressing the same themes ranged from 44% for Theme 5 to 88% for Theme 3. Theme 1 was expressed by 60% of participants; Theme 2 by 80%; Theme 3, as noted, by 88%; Theme 4 by 52% and Theme 5, as noted, by 44%. These percentages indicate the frequency of themes in all the participant protocols. Thus, the most common experience among the participants of this study, was indicated by Theme 3 Vulnerability/Helplessness; the least common was Resoluteness indicated by Theme 5. The following examples will illustrate each theme.

Theme 1. Isolation/Invisibility

This theme includes the experience of isolation from other people, a awareness of other people's lack of understanding and acceptance of their illness, and the feeling of self-alienation. This theme was found in 60% of all the protocols. It is described as a deep sense of loneliness and separation. In some patients the experience of isolation seems to reflect more of a feeling of estrangement or self- alienation. Patients refer to a lack of understanding by others coupled with their inability to see them as really "sick." They become isolated and their illness is "invisible" in the eyes of others. An emotion frequently associated with this experience is depression. They also talked about frustration and anger. The following examples are taken from the protocols:

Example 1. [015]. This is a young married woman who had been having "vague" symptoms for several years and who finally was diagnosed with SLE.

I had known that there was something wrong with me and I had been to the doctor several times for the last few years. I knew that something was wrong, that I was too tired. Well one day I looked at the mirror and I started having signs of the Lupus blush and then things started clicking. It was a year before I went back to the doctor. I just didn't want to face another doctor looking at me and saying: "This is another Nutty nurse diagnosing herself again." So I waited over a year and then went to a Dermatologist . . . You know when you haven't gotten over the feeling that a doctor will look at you and go: "Well a part of this is just your imagination". . . Ok when the label was attached to the symptoms it was . . . a vindication, and also a relief like I am not crazy, or that I am not a neurotic. There is a good reason for me to behave in this way. So in a way the diagnosis has been helpful . . . I am very sensitive to how other people think about me. I guess what you would say I don't have a super self-image . . . and then I get irritated at them for not accepting me for the way I am and for what I still can do . . .

Example 2.[040] From an older woman who feels that the only one who really understands is her doctor. She sees herself as "The stick-in-the-mud grandmother."

I just have the feeling that when people ask you how you are they don't really want to know. It is just a social greeting, you know, and they expect you to answer "fine." If you answer anything other than that they don't really care. They don't want to hear. If you are feeling badly, it tends to make them feel badly. So you just don't tell them . . . I have told my friends when they ask that I am fine, because I realized that the only one who really wants to know is my physician . . . I find that my son who was still at home when I was first diagnosed and when I first became ill, understands much more of my limitations than the son who had finished school and moved away from home. He still does not understand. I think with my grandchildren, I am compared with the other grandmother who, even though she is years older, she has much more energy and much fewer responsibilities and she can do things for them. I feel

sometimes that they think I am the stick-in-the-mud grandmother because I don't have the energy to keep up with the things she can do with them.

Example 3.[036] From another elderly woman who feels no one understands.

It is like being in an invisible glass box of pain which only I can see and feel. No one can understand the ups and downs of this disease.

Example 4.[019] This excerpt is by a young woman who had been seriously ill on various occasions. After it was discovered that she had Lupus, life became very difficult for her. Eventually she divorced and now lives by herself.

I have had friends who have come up to me . . . and they told me one time: "you know we just really can't be around you anymore because we can't believe the way you are now and the way you use to be and we feel so bad ourselves and we feel guilty we can't do anything for you." I quit even trying to make friends. You know, I thought, unless they were like in a group, or there was somebody I knew some other way . . . personal relationships with men and so forth became extremely difficult, because I just got tired of explaining." I am essentially alone even though I have two brothers, really they are my brothers but I have really never known them . . . I am essentially alone.

Example 5.[011] This is another young woman who in a moment of despair attempted suicide.

Your friends are gone, most of them, and eventually those who aren't will go after a few years. I didn't want to live. I just plain flat out did not want to live, and the only reason I hadn't done it before, I think, was for my family, and I thought well, you know my family wasn't there anymore, so I thought, well that is what I am going to do, and I had me one of those boxes of wine, and drank most of that, and then took all of the pills I could find, and locked the door . . .

Example 6.[013] This is an elderly woman who had been suffering from Lupus for many years before it was diagnosed.

The fact that my family does not accept the fact that I have Lupus has been a real drawback. They know I have it but as my younger son said to me, "I don't really believe that you are as sick as you say you are. I think that it is just an act." So by this time with all the medical problems that I was having, I was beginning to think that I was a hypochondriac, and that I didn't have all of those things wrong with me. I knew that I had something wrong, but what?

...Nobody believed that I was sick. They knew I fell a lot because I was falling all the time, and I was breaking different things, different bones in my body. And then when I was able to talk to my sister, she told me they had found she had both Discoid and Systemic Lupus..and bells went off in my head..When the diagnosis of Lupus was finally made, things started coming together and I felt better . . . It was a relief to know I had a specific illness.

As all of these examples suggest, this theme reflects the patients experience of loneliness and isolation in the context of relationship. They spoke of being rejected, misunderstood and isolated. They also referred to the fact that their illness was not "accepted" by others, including, sometimes, their own family physicians, although this was not true of every case.

An additional phenomena appeared in the protocols. The "other" was either very understanding or very rejecting. If the "other" was understanding it meant that he or she believed in the patient's illness and accepted the patient as "sick." He would then be perceived as supportive by the patient. If the "other" was not understanding, it meant that he or she would not believe in the patient's illness, nor he or she would accept the patient as "sick." In this case, the "other" was perceived by the patient as rejecting and indifferent and contributing to the patients' isolation and despair. Therefore, the patients experienced "visibility," that is, whether people could see

them as "sick" rather than "fakes" or "hysterics," was the determining factor in their feelings of isolation. In the interviews and in follow-up conversations, patients explained how important it was to have the "diagnosis" because it was a way for them to be "validated." Only 30% of the people interviewed and 14% of those who wrote about their experience specifically mentioned being supported and understood by others.

Theme 2. Constricted Existence (Losses and Limitations)

This theme includes an awareness of losses and the limitations imposed by the illness, and was found in 88% of the protocols. It encompasses different aspects of the patients' lives; from physical losses and limitations to emotional, financial and interpersonal ones. It is as one patient put it: "the whole world turned upside down." The following are examples of this theme.

Example 1.[002] This is a young high school teacher, who most of his life had been very active in various organizations and in the theater. He still works, but his life and his activities have been drastically reduced.

I am particularly aware of having Lupus when I missed those activities that were so much part of me, that I would really like to be doing . . . it limits all sorts of activities . . . I think how we approach life has to do with our perceptions of ourselves things like: "I Was." I was happy with whom I was and confident. I saw the things that I accomplished as measure of myself as being successful and having worth, and now I have mistakenly tied the completions of my projects, like a Play etc, to my being successful, but I can't do those things anymore . . . I don't perceive myself as a good person, as a whole human being because of those limitations.

Example 2.[007] An older man, a very active businessman all of his life, said the following:

I am very cognizant of the disease and the limitations it produces for me . . . it limits the hours of work . . . it limits[my traveling anymore] . . . I would find myself crying because I was a healthy person all my life and to think, all of the sudden, here I am like I am, you know . . . I am grateful that it is not more serious than what it is with me. When I hear about some of the women and the problems they have, psychologically, I just get a little upset . . . and when I get a flare up and I am highly restricted I kind of get mad and say "why does this have to happen?".

Example 3.[006] This patient is a middle aged woman, who has had severe "flares" and who lost her job and career after she developed Lupus.

It makes you stop and think about where you are at, and accepting where you are at, and knowing that some things you can't do and you know you want to . . . I had to quit that and then everything I try to do I end up quitting because of the illness. . . It does a lot to your self-worth. You feel like you can't hold a job and it gets you down . . . It governs everything I do.

Example 4.[003] A young married woman who sometimes feels like an old woman, wrote:

What's been hardest mentally is the comparison/contrast of what I am like and able to do versus to what people around me are like and able to do. The people more similar to me in abilities, stamina and bodily condition . . . are in their 80's!(Other Lupus people not included) . . . In very distinct ways "I am losing ground.

Example 5.[004] This is a young woman who was diagnosed with Lupus as a young teenager. She talks about the most important aspect of being a Lupus patient in the following manner:

I guess there is one thing. There is one major thing. I do blame the Lupus for, to some extent, not entirely, for the failure of me to be able to follow some of the

dreams I had for my life. I did always want a family. Of course I have my adopted son now, but not being able to have children because of the Lupus, was a horrible, horrible disappointment to me, and that hit very hard, and I think contributed to the depression down deep . . . I blamed the loss of that on Lupus, and I didn't finish school, and I feel bad about that . . . I felt that Lupus affected my marriage tremendously, that my husband was extremely disappointed because of the disease on me . . . I think Lupus has affected my life tremendously, really. A lot of loss.

The previous examples revealed some of the experience of loss and limitations in the lives of the Lupus patients. Some of the examples also included aspects of other themes. For example, patients often spoke of limitations or losses in relation to their pains or bodily symptoms. Pains and bodily symptoms, however, could (and were) coded under the Vulnerability /Helplessness theme. In sections of the protocols where it was clear that the patients were referring to their physical and emotional vulnerabilities as well as to the limitations they produce, they were considered as both themes.

There were aspects of the Lupus experience that had to do with not only actual losses, but with what many experienced as "potential" losses. Such potential losses took two forms: (1) fearing an event which was going to imply a loss or a limitation such as "going psychotic" or losing a job; (2) the awareness that there were things in their lives that they were never going to have or to experience, such as "having a baby" or "getting a suntan." The experience of losses and limitations was also described as pertaining to a "loss of self-esteem," a "loss of self-worth or agency," "financial limitations," "physical limitations" "forced adjustments and limitations" etc. Precisely because losses and limitations referred not only to physical the aspects

of illness, but included many other aspects of the patients' lives as well, the best descriptor of this theme seemed to be "Constricted Existence."

Theme 3. Vulnerability/Helplessness

The majority of the patients (88% of the protocols) referred to their awareness of physical and mental symptoms, and to the very strong sense of vulnerability that they produced, which was aggravated by the unpredictability of the disease. Many patients also referred to a feeling of lack of control and/or helplessness. Patients are very aware of their symptoms, especially pain and tiredness. They also reported severe mood swings and cognitive difficulties such as memory loss, delusions etc. The following are examples from patient protocols.

Example 1.[006]. This patient was introduced before. She is the middle aged woman with a history of severe "flares."

I would say mostly the headaches, the joint pains, the flu-like symptoms . . . It comes and goes. Even different parts of the day. You can get up feeling pretty good, then you just have a headache. As the day wears on I loose my energy and get this real terrible headache. I have to lay down and take pills for the pain . . . That's one thing that it is real frustrating. It is something I got and I can't do anything about it, and it feels like I am out of control and I am ever going to be able to do the things I want to do . . .

Example 2.[003] This patient was also introduced before. she is the young married woman that feels like an 80 year old person. She writes:

. . . The disorder makes me sick with aches and pains, which does make it tough to be cheerful, patient with other people and so on. Life gets to be very draining getting up each day, hurting here or hurting there, limping through a demanding day and then feeling

exhausted in the evening, unable to sleep because of the aches, pains and stiffness. Sometimes the fatigue is so much of it too. To wear out so quickly into any activity makes it hardly worth beginning the activity at all. The unpredictability of the ups and downs is maddening . . . I keep "cutting corners" and fight my way through the bodily pain each day, but it gets to be a big game of "beat the clock." Lupus creates (in me anyway) a chronic anxiety/insecurity, a state of constant instability brought about by something which I have little or no control over, and it is not some other person but my own body that betrays me again and again.

Example 3.[005] This excerpt is by a middle age woman, once very active in family and business affairs. She writes:

Probably the thing that I feel most strongly with whatever is wrong with me is a sense of disintegration and loss of control in my life, both personally and in my abilities to nurture and maintain good positive relationships with friends and family and to maintain and organize and keep orderly our household and our business affairs. I use to be a very career oriented person but have been unable even to entertain the idea of working for ten years . . . This last year I seem to have lost so much ground mentally that I feel totally overwhelmed in all aspects of my life.

Example 4.[042] This young woman is very aware of her loss of control and the unpredictability of Lupus. She said:

In addition to the physical problems caused by Lupus are the non-physical problems that greatly multiply the stress-load for the Lupus-patient . . . Never knowing if you are receiving the appropriate care and having no way of knowing is a very helpless feeling. It is an area of your life which becomes increasingly vast over which you have little or no control . . . Lupus affects ones' total life style, always demanding modification and reconciliation..

As can be seen, this theme refers to the physical symptoms, "lupus in the body," such as the pains, fatigue etc. Patients experienced the illness in their body, and they felt vulnerable and "sick." But the feeling of vulnerability involves more than the physical symptoms; it

includes other aspects of their existence as well. Lupus they report, is unpredictable, attacking different organs, presenting different symptoms, often allowing them little choice in the things they could do to help themselves. Such unpredictability makes them feel out of control and helpless.

Of the patients interviewed, 100% described being aware of a physical or mental symptom, in contrast to 80% among the patients who wrote about their experience. There was also some overlap with the previous theme of "Constricted Existence." There was, however, a crucial difference. In one, the patient's world becomes, as the result of losses and limitations, "narrower," "constricted," and the persons' actions upon his or her world are significantly reduced or limited. In the other, their awareness is directed towards their own person and they become "vulnerable."

This theme may be compared to an awareness of "non-being" that is, an existential understanding of one's mortality and fragility. As one patient put it, she becomes vulnerable to the "assaults" of Lupus. Patients become targets and "prey" and feel "totally overwhelmed." Finally, it was also found, that some patients talk about feeling vulnerable in terms of the treatment and assessment of their disease such as the frequency of tests, changes of medications, doctors visits etc. One patient described her experience as "frustration, negative tests, positive tests, I feel like a guinea pig."

Theme 4. Transformation (Changes)

A little over half of the patients (52%) spoke of changes in their personality, moods, and lifestyle. Some of these changes and

transformations were experienced as "positive," others were seen as more negative or alien to the self. The following are excerpts from protocols in which these themes were found.

Example 1.[025]. This is a young married woman who reports Lupus has brought positive changes in her life. She writes:

Oddly enough I feel that in a lot of ways Lupus has brought positive changes in my life and done me some favors . . . It drew my husband and I very quickly in our married life and I feel certain that the intimacy and friendship we share has been boosted by my having a chronic disease . . . I am more involved in church than I would probably have been . . . all the visits to the doctors and my concern for my health has probably made me more healthier in some ways . . . [I have learned] to enjoy life on a day to day basis and don't live much for the future and I am more apt to "seize the moment."

Example 2.[002] This is the young high school teacher, who talks about changes in his personality, actually becoming "a different person."

Pretty much so, and it is mentally disturbing, yeah, I am not the same. I can't do what I use to do and it bothers me, yes there is something there about being different . . . I think that having Lupus would make me less, would diminish me in some ways, so I am not happy with it, not being effective . . . There is a lot of anger about becoming a different person . . . I do resent having become the person that I am now. I don't want to be this person . . . I don't like this person that I have become. A very difficult adjustment . . .

Example 3.[013] The older lady who has suffered with Lupus for many years before it was diagnosed. She said:

It is a very serious thing and to make them understand how Lupus works and why it works the way it works . . . the personality changes that I have undergone over the past three or four years, from calm to wild behavior. I don't realize I'm doing it but I can't stop it. I don't know if it is actually the Lupus or the medication that causes that . . . It has brought about a complete slow down, it has brought about a lot of changes, a lot of adjustments.

Example 4.[037] This is another patient who finds that Lupus has also brought positive changes in her life. She writes:

In a way Lupus has made me a better person. I enjoy things more and I take nothing for granted . . . I tend to live life now and not think about tomorrow or 10 or 20 years from now.

These descriptions illustrates the different ways patients experience change and transformation in their lives. Some regard the impact of Lupus as a positive event which has brought certain important changes for them. Most of the times, they describe an increased awareness of the present, of living for today and trying to enjoy what they have. They also refer to a different kind of attitude towards problems in their daily living, becoming more "accepting," less rigid and more tolerant of others. One patient, for instance, speaks of "becoming calmer," "less fearful" and "more analytical" than before having Lupus. Others also expressed an increased appreciation for "life in general." For those who experienced these transformations as something negative, a common complaint was their difficulty controlling their moods, or their drastic change in their personality, specifically in terms of their ability to tolerate stress, or with changes in self-image.

Theme 5. Resoluteness (Fighting/Coping)

This theme refers to the experience of struggling and fighting against the disease. Some patients refer to it in terms of fighting, as implying an adversarial relationship to the disease. Others talked about coping as if the quality of the experience is one of adjustment. This theme was found in 44% of all protocols. Frequently people

mentioned their individual faith or religion, their family and friends , and others mentioned a positive attitude towards their illness as a source of help and support. The following are examples of this theme.

Example 1.[011] The young woman who had attempted suicide once shared this with me at the end of our interview:

Yes I have, like I said, I am getting away from it now. I don't want to go through those sick periods. It is not worthy for anybody. Like with _____ I thought if this had happened five or ten years ago, I would have been ready to take another overdose. [But], nothing is worth that; it is just not worth it. Nothing is worthy making myself sicker. Convincing myself it is time to have a little bit of fun, and somebody else doesn't like it, it is their problem. Their own contentment is their responsibility, not mine. That is where I am now.

Example 2.[007] An older businessman said the following:

I think that another thing that has been important to me, I have had an awful good support from my family . . . what they have done is to make themselves knowledgeable about the disease, and they know me now too, almost as well as I know myself. . . and they understand . . . and another thing I for sure learned to do, and I have been fortunate to be in that position, I have eliminated almost all the business stress almost totally . . . there is no question that I believe that your psychological make up and your demeanor can upset your disease. I know stress does, and of course that is a part of your psychological make up, how stress manifests itself on you and how you handle it . . . if somebody does not learned to put those things on perspective they can aggravate their illness.

Example 3.[002] The high school teacher referred to his experience in the following manner:

There is a lot of fighting and sometimes I think I should not be fighting which is weird. I guess what I should to is some kind of adjustment. How do you call it? -Cognitive rehabilitation, positively adjust and concentrate in ways to feel more happy and complete and be happy with myself and I am probably struggling

against it and is not being very effective and is not a positive thing but a negative thing.

Example 4.[013] Finally the elderly lady who had suffered with

Lupus for several years said:

As far as the Lupus is concern I try to deal with it the best I can. I think it is all anybody can do. I am not happy with the prospect of having Lupus, or having to deal with the problems that relate to it, but really again, there is nothing I can do about, and I have learned to live one day at a time and if some of the emotional pressure would lift I know that I would feel better than what I do now . . . I think I could do a lot better.

These descriptions represent a sample of the sort of experience people talked about in their struggle and their coping with this illness. Taking one day at the time, relying on friends, on family and/or on the support of their church, changing their perceptions, learning about the disease, controlling stress etc., all describe an experience of Resoluteness.

Psychological Study

Medical and Behavioral Data

The most frequently reported symptoms within the last six months were fever(86%) and pain (86%), followed by skin rashes and arthritis, each being reported by 78% of the patients. Photosensitivity and depression both were reported by 65% of patients, and mouth ulcers and hair loss were both reported by 51% of subjects. Table B-2 of Appendix B shows frequency of reported symptoms.

The patients reported taking more than one hundred and twenty different medications. The mean number of different medications taken was 6.78(SD= 5.19). Prednisone was by far the most frequently reported

medication with 54% of the patients saying they were currently taking it and the average dose of Prednisone was 10.33 mg per day (sd= 32.74 mg). Other frequently reported medications included: Aspirin(22%), followed by Vitamins, Xanax and Imuran(all 16%); then Lasix (15%), Prozac(13%), Calcium (10%), and Lanoxin and Procardia with 8% each.

The mean number of years with Lupus reported by the patients was 7.48 years, with a range of 0.6 to 24 years. Patients reported an average of 6.96 visits to a physician during the previous 3 months and 2.02 hospitalizations in the past 5 years. It was not clear, however, if all the hospitalizations were due to Lupus or something else. Patients also reported a mean of 1.69 "flares" in the last 2 years although a few of the patients said they had one "lasting 6 months" or even longer. The average number of reported symptoms in the last six months was 10.89 (SD = 7.06). Forty one percent of the patients reported working while 56% were either retired or disabled(there was no data regarding the other 3%). The average number of hours of activity per day was 6.6 with a deviation of 4.0 hours. Finally, the average "stress level" as measured by the Life Event Form was 182. Table B-3 of Appendix B summarizes medical and behavioral data.

Psychological Test Data

The results from the test data revealed significant elevations in scales 1, 2, and 3 of the MMPI-2, as well as moderate elevations in scales 7 and 8. In the 16 PF, there were significant deviations in scales C, M, N, Q2 and Q4. All scales in the MMPI-2 with the exception of K and 6 were statically different($P < .05$) from the normative sample. In the 16 PF, scales A, B, C, G, M, N, Q1, Q2 and Q4 were also

statistically different($p < .05$) than the normative sample. Tables 1 and 2, and Figures 1 through 4 of Appendix B summarize results.

Individual Profile Analyses

Individual profile analysis for the present set of patients revealed that only 10% (N=4), of the subjects could be categorized within the "Normal" category. Even within this group, however, there was evidence of a moderate elevation in anxiety. The largest group was that of the "Neurotic" category; with 74% (N=29) of the patient group showing a pattern characteristic of a neurotic adjustment. Most of the depressive and anxiety disorders were found here. However, this group could be subdivided into two groups, with one subgroup containing 38% (N=11) of the "neurotic" cases, or 28% of the total group; and the other subgroup containing 62% (N=18) of the "neurotic" group, or 46% of the total patient group. The subgroup containing 38% of the Neurotic group was characterized by an increase in depression, anxiety and a moderate to severe withdrawal from people. The MMPI-2 profile for this group was 1-2/2-1, 1-7, and 2-3, while the 16PF profile was C-,L+,O+Q4+. This group was labeled Type I Neurotic. Nearly one fourth (23%) of this group also reported psychotic symptoms.

The second subgroup containing 62% of the Neurotic group was characterized by a denial of psychopathology and by "repression." These patients are often described as more socially outgoing but superficial and dependent in their interpersonal relationships. In addition they are thought to be converting psychological problems into physical complaints (Greene, 1980). The MMPI-2 profile for this group was 1-3/3-1 and 3-2. Their 16 PF profile was (C-,Q4) or (C-) or (Q4) or an

TABLE 1
MEAN RAW-SCORES FOR THE MMPI-2

Scale	Normative Sample		Lupus Sample		t
	M	SD	M	SD	
L	3.44	1.96	4.97	2.41	4.35**
F	3.35	2.73	5.38	3.33	4.15**
K	15.50	4.15	14.73	4.66	-1.05
1	5.28	4.00	18.65	6.40	17.72***
2	20.28	5.08	28.43	8.40	8.44***
3	22.02	4.33	32.81	5.75	13.47***
4	15.68	4.51	17.78	4.99	2.64*
6	10.17	2.97	10.84	3.26	1.28
7	12.23	6.89	20.73	7.74	6.97***
8	10.18	6.70	19.57	10.19	7.52***
9	15.42	4.67	17.13	4.87	2.09*
0	27.81	8.82	32.55	8.43	3.09*

* p < .01
 ** p < .001
 *** p < .0001

TABLE 2
MEAN RAW SCORES FOR THE 16 PF

Scale	Normative Sample		Lupus Sample		t
	M	SD	M	SD	
A	11.27	3.22	10.19	3.73	-1.97*
B	7.04	2.17	8.22	2.52	3.18**
C	15.58	3.96	12.35	3.62	-4.85**
E	11.26	4.55	10.76	3.32	-0.66
F	13.54	4.34	12.27	4.75	-1.62
G	12.80	3.31	14.19	2.72	2.44**
H	12.91	5.65	12.03	5.41	-.93
I	13.36	3.39	13.68	2.77	.564
L	6.21	3.36	7.03	4.04	1.43
M	13.12	3.91	10.73	4.54	-3.58**
N	10.36	2.89	11.59	2.47	2.54*
O	10.74	3.96	12.03	4.20	1.93
Q ₁	7.67	3.05	6.35	2.70	-2.61**
Q ₂	10.17	3.61	12.43	3.67	3.71**
Q ₃	12.45	3.27	13.46	2.44	1.85
Q ₄	12.93	4.77	16.78	5.14	4.76**

* p < .05
** p < .01

otherwise abnormal profile with no reported anxiety. This group was labeled Type 2 Neurotic. More than half of this group (54%) reported psychotic symptoms, a significant finding in light of their denial of psychopathology. Eight percent of the patients (N=3), showed a profile consistent with a primary psychotic process. This group was categorized under the Psychotism group. The typical MMPI-2 profile of this group was 7-8, 6-8 and 1-8 and there was no consistent 16PF profile. It is important to note, however, that one third of all participants in the study reported having some sort of psychotic symptom. Finally, eight percent of the participants (N=3), were categorized under the Other category. Their MMPI-2 profiles were 1-9, 4-2 and 2-0 and their 16 PF was characterized by an elevation in the scale C. Table B-4 of Appendix B summarizes the findings.

Group Comparisons and Sample Correlations

Lupus Diagnosis. Laboratory and Medical history was obtained for 22 patients. Of those individuals, 11 showed high likelihood of having Lupus, while 11 did not. For the remainder, medical information was incomplete or not obtained; therefore, participants were divided into the following groups: High Likelihood (N=11), Low Likelihood (N=11) and Unknown (N=17). Analysis of Variance for these three groups, showed no statistically significant differences among any of the clinical scales of the MMPI-2 and the 16 PF. Table B-5 of Appendix B summarizes the results.

Social, Medical and Behavioral Variables

Results of statistical comparisons among groups on medical, behavioral, social and phenomenological variables as well as scale elevations in the MMPI-2 and the 16 PF revealed the following: Whether the person was married or not, did not have a significant effect in scale elevation on both the MMPI-2 or the 16 PF. People who reported they were working, including part-time work, showed a statistically meaningful difference ($p < .05$) on the MMPI-2 profile for neuroticism (scales 1, 2 and 3), with all of these being decreased. On the other hand, results of the relationship between phenomenological themes and the clinical scales indicated that groups in which Theme 1 was "present," had significant elevations in scale 2 ($p < .01$) of the MMPI-2; and scales C ($p < .10$), L ($p < .05$) and Q4 ($p < .05$) of the 16 PF. Results also showed Scale Q4 (High Tension), was elevated when Theme 1 and Theme 2 were "present" and decreased when Theme 5 was "absent." As previously mentioned, Theme 3 was not included for analysis due to the small number of participants in the "absent" group (see Tables B-6, B-7, B-8 and B-9 of Appendix B).

Turning now to correlational data, Tables 3 and 4 present correlation between medical and behavioral data and clinical scales on the MMPI-2 and the 16 PF. Correlations above $r = .32$ are statistically significant ($p < .05$). These findings indicate that the number of years with Lupus, the number of stressful events reported, the amount of Prednisone taken and the number of hospitalizations, showed little or no correlation with the clinical scales of the MMPI-2 and the 16

PF(i.e., $r = -.20$ to $.24$ for the MMPI-2 and $r = -.22$ to $.19$ on the 16 PF).

The total number of medications taken had a small correlation ($r = .30$) with the Depression scale of the MMPI-2, and little or no correlation with other clinical scales. The number of "flare ups" had a correlation of $.34$ with the Schizophrenia scale of the MMPI-2 and a correlation of $.36$ with scale Q4 (High Tension) of the 16 PF. The total number of visits to a physician had a negative correlation with the Paranoia scale in the MMPI-2 ($r = -.40$), and a small or no correlation with other scales in the MMPI-2 and the 16 PF.

The strongest correlations, were found with the number of symptoms reported by the patient. The number of symptoms reported had a correlation of $.47$ with the Hypochondriasis scale, $.59$ with the Depression scale, $.52$ with the Hysteria scale and $.36$ with Schizophrenia scale of the MMPI-2, and a $.39$ correlation with scale C (Low Ego strength) of the 16 PF. Finally, the total number of hours of activity per day had negative correlations with the Hypochondriasis scale ($r = -.57$), the Depression scale ($r = -.34$), and the Hysteria scale ($r = -.52$) of the MMPI-2 and a positive correlations of $.43$ with scale Q3 (strong social image) of the 16 PF. Tables B-6, B-7, B-8 and B-9 of Appendix B, and Tables 3 and 4 summarize these results.

TABLE 3

CORRELATION OF MEDICAL AND BEHAVIORAL VARIABLES AND MMPI-2

Medical and Behavioral Variables	MMPI-2 Variables								
	1	2	3	4	6	7	8	9	
Stress	.03	-.02	.14	.03	-.01	.07	-.07	.22	
Years with Lupus	.07	.09	.05	.07	-.02	.09	-.09	.09	
Amount of Prednisone	.05	.20	.22	-.03	.03	.06	.08	.05	
Number of Medications Taken	.08	.30	-.02	-.27	-.08	-.03	.11	.18	
Number of Hospitalizations	.05	-.20	.12	-.11	.23	.18	.24	.13	
Number of Symptoms Reported	.47	.59	.52	.11	.01	.27	.36	.03	
Number of Flares	.07	.21	.12	-.10	.04	.23	.34	.13	
Visits to Physician	.30	-.12	.21	-.08	-.40	.13	.24	.24	
Hours of Activity per day	-.57	-.34	-.52	-.07	-.05	-.17	-.14	-.05	

Note: Critical values of the correlation coefficient for two-tailed test: $r > .32$; $p < .05$ with 35 df.

TABLE 4

CORRELATION OF MEDICAL AND BEHAVIORAL VARIABLES AND 16 PF CLINICAL SCALES

Medical and Behavioral Variables	16 PF Variables				
	C*	L	0	Q ₃ *	Q ₄
Stress	-.14	.03	.15	-.07	-.00
Years with Lupus	.00	-.21	.17	-.07	-.22
Amount of Prednisone	-.19	.11	-.16	.16	-.10
Number of Medications Taken	.01	-.01	-.20	.21	-.01
Number of Hospitalizations	-.11	.18	-.12	.07	-.08
Number of Symptoms Reported	-.39	.02	-.00	-.05	.21
Number of Flares	-.13	.11	.19	-.14	.36
Visits to Physician	.13	-.13	-.02	.25	-.01
Hours of Activity per day	.21	.04	.11	.43	-.01

*Negative number indicates direction of pathology in these two scales

Note: Critical values of the correlation coefficient for two-tailed test: $r > .32$; $p < .05$

CHAPTER 5

DISCUSSION

The primary objective of this study was to provide a description of the experience of being ill with Lupus. Once this description was obtained, a second purpose was to understand the psychological phenomena of Lupus in the context of the patient's experience of this disease. In addition, this work sought to investigate the relationship of psychological phenomena present in Lupus to certain medical, social, and behavioral variables. In this section, results of the phenomenological and psychological studies will be discussed as well as their relationship to relevant literature. Also to be discussed are the theoretical and practical implications of this study in order to achieve a better understanding of this disease as expressed by the patient.

Patient Selection and Sample Characteristics

It is a well established fact that studies based on selection criteria other than random sampling may be problematic (Shaughnessy and Zechmeister, 1990). Random sampling, it has been pointed out, insures the greatest probability of having a representative sample. That condition, however, is often difficult to meet, especially in illness research conducted in outpatient settings (Watson and Kendall, 1983). In this study every effort was made, given the settings and resources available, to obtain a representative sample of Lupus patients. In terms of patient characteristics, it is quite consistent

with other studies of Lupus patients; ie, the majority of patients were white(77%), female (94%), and married(56%). This has been similar to other recent studies such as the one by Liang et al (1984), which reported patient characteristics as 94% white, 90% female and 69% married. Kinnash (1983), reports 96% female , and 71% married (no race reported).Although some studies seem to indicate a higher incidence of Lupus among blacks and hispanics, the current available data indicates that the majority of Lupus patients in America are white, married and female (Wallace & Dubois, 1987).

In regards to sample size, this study consisted of 39 subjects, a possible small sample, especially for purposes of statistical analysis. Most of the published research to date, however, has studied comparable sample sizes, such as Johnson (1968), 24; Seargent (1975), 28; Liang (1984), 75; Kinnash (1983),52 etc. Finally, the results of the psychological study (which will shortly be reviewed), may indicate that the sample in this study represents a somewhat more seriously afflicted Lupus population, than the average study conducted with an outpatient population.

There is also the question of diagnosis, so critical in research as well as in clinical practice. All of the studies reviewed did not specify how the diagnosis of Lupus was established; thus there is no way to compare results. Although all patients who participated in this study had a prior diagnosis of Lupus, not all of the medical and laboratory data received supported the diagnosis of Lupus for every patient. So, for example, of the 22 patients whose medical and

laboratory records were available, half were classified as "low-likelihood " Lupus (based on that data).

At first sight, these findings represent a problem, since it implies that a large percent of the patients may in fact, not be Lupus patients. This is a question that deserves further attention and which shows the difficulties encountered in diagnosing this disease. For the purpose of this study it may not be as critical as would be expected for the following reasons. (1) a lack of highly discriminatory laboratory data for Lupus diagnosis does not necessarily mean that the person was not suffering from Lupus, since some of those tests have a great number of false negatives, and some patients who may have initially tested negative, may test positive at a later date.(2) The diagnosis of Lupus is also based in the presence of many different signs and symptoms of which such lab data is only part of. In fact, Zvaifler and Woods (1985), have recommended, in light of Lupus' unknown etiology, to use "the broadest definition of the disease and consider the greatest range of possibilities." They have also based on animal models of Lupus, the probability that this disease may represent a syndrome of various etiologies rather than a discrete disease entity. If a broad definition is used based on all the data rather than a narrow one based on highly discriminatory lab data, all of the patients in this study could confidently be classified as having Lupus. (3) this sample most represents the "typical Lupus patient," those whose diagnosis was based mainly on well informed clinical judgement and a likely limited availability of laboratory evidence. If only patients with highly discriminatory lab

data were used, they would be a unique sample or subset of the total "Lupus population," something that would not be desirable for this study.(4) from a psychological perspective, there was no difference between those patients with high, low and unknown likelihood of Lupus, suggesting that either the sample is homogeneous in regards to diagnosis, or that having an specific laboratory sign is not of fundamental importance for the psychology of Lupus.

Despite these reasons, the finding of a high percent of diagnosed Lupus patients with poor laboratory evidence of Lupus is of concern, especially in regards to the medical treatment of this disorder. Such a finding also raises the important question of whether these patients are being misdiagnosed. If that is the case, Why? Is it a problem with the diagnostic criteria? Are we looking at a syndrome of highly related disorders, rather than to a discrete disease entity? Are physicians influenced in their diagnosing by the despair and anxiety they detect in their "undiagnosed" patients? These are some of the questions which would be worthwhile to consider in future research.

Phenomenological Study

The World of the Lupus Patient

The basic themes that describe the experience of "being ill with Lupus" can be seen as describing the "world" of the Lupus patient as lived by the Lupus patients. Patients in the present study reported experiencing a deep sense of isolation from others; an awareness that other people-- sometimes close significant people in their lives-- do not understand them or their disease . It is as if they and their the

disease were invisible to others. Lupus patients are continuously confronted with a number of losses, both real and symbolic, and become acutely aware of their own limitations leading to the experience of a constricted existence. They are very familiar with their own anxiety and feel very vulnerable, in body and mind, and think they have little control over their lives. Ultimately, their own sense of self is transformed by this disease, and they are confronted with the task of coping and adjusting and of facing their disease with courage and resolve.

Isolation and Loneliness in the Lupus Patients

As already mentioned, among Lupus patients there seem to be a deep sense of isolation and the awareness that the "other" does not understand. This is a common experience found in qualitative studies of Lupus (Liang et al, 1984; Kinnash, 1983). This sense of isolation was very graphically depicted by the patient who said her experience was like being in "an invisible glass box of pain." Some Lupus patients feel their disease creates a separation between them and the other people in their lives. Barrell (1988), in his study of loneliness, found that this was a frequent theme in the experience of being alone. He writes:

. . . one feels isolated, disconnected and cut-off from others; as if there were a wall or distance between the self and others. The person may feel as an outsider; he or she may feel outside the activities that others are engaged in. One may also feel caught in the inside where others have no access to their unique experience . . . (p. 123).

Barrell's insight seems to describe very accurately a type of experience that also is evident in Lupus patients. They feel both

"outsiders" in the sense that they find themselves unable to participate in the normal activities and life of others, and "insiders" in the sense that others do not "have access" to the unique way they are experiencing and living their own lives. Related to their feelings of isolation, patients spoke of having a disease that was "invisible" in the eyes of the other. This seems to be, the result of a disease that often lacks clear outward "signs" for others to see. The "visibility" of an illness is, as Mechanic (1978) has pointed out, an important factor in the social validation process of the person's illness. If I claim to be sick and expect to receive the attention of others as well as the benefits associated with being ill, I need first to be validated as being "really sick" (Cockherman, 1989; Mechanic, 1978).

Thus, crutches, walking sticks, guide dogs, missing limbs, etc; are not only "part" of a person's illness, but serve as means to communicate to others the status of the bearer of the "sign" as a "sick person." When a person is "sick," one of the social expectation is that others will accept their "deviance", either when their disease is clearly visible and/or when a physician, in the absence of signs, has validated their illness (Goffman, 1959).

Mechanic writes:

When a patient complains frequently, and when it may be difficult to find tangible evidence either to substantiate or to account for the complaint, questions may be raised concerning the patients' desire to avoid obligations and use illness as an excuse. Similarly, the patient's significant others (dependents and intimates) are less likely to accept such complaints, as compared with more clear cut physical signs, unless they are diagnosed as "true illness" by a doctor. The visibility of illness play some part in others accepting a definition of "sickness." . . . (p. 51)

Frequently, although not always, the symptoms exhibited by many Lupus patients are vague and "invisible." They feel tired, weak, have fevers, pains etc. As many patients reported, they first go to the doctor when they began to feel sick, and after the normal screening procedures nothing was found. This pattern was repeated several times, and after a while, the family, the doctor and by this time even the patient began to believe that their illness was in "their head." Eventually, either as a result of a severe "flare" or a referral to a specialist or other physician who believed they were really sick, and was not willing to give up, their illness was diagnosed. They spoke of "being validated" and of "being relieved" when the diagnosis was finally made. Henrietta Aladjem (1982) also writes about this experience:

Despite the growing awareness of Lupus and the increased knowledge that the scientists have gained about it, the disease can still be a lonely experience. Many patients still go from one doctor to another, only to be told that they suffer from recurring cold, or a lingering virus. Some patients are told that the disease is in their mind . . . in their search for understanding, some patients become increasingly confused and emotionally distraught, questioning even their own sanity (p 18-19).

For the patient, the disease becomes a constant struggle with employers, acquaintances and relatives who frequently say: "but you look so good." There is a dissonance between how the person feels and how others perceive her. They feel that others do not understand and begin to isolate themselves. Complicating this is the array of psychological and neurotic symptoms present in many of the Lupus patients making many to question if they are dealing with a neurotic who has developed Lupus or a Lupus patient who has developed a

neurosis(Aladjem, 1982). Lupus becomes the "barrier," "the glass box of pain" that separates the patient from others.

On Losses and Limitations

A common experience in chronic illness is the reality of severe losses and the ever-present limitations the patient suffers (Lipowski, 1978; Kleinman, 1988). Liang(1984), in his study of Lupus and rheumatic arthritic patients found that "loss of physical function, of independence and of social interactions were major themes found in interviews." Similarly, Kinnash (1983) reports 60% of the Lupus patients in her study suffered losses and limitations in their daily life. Depression is believed to be one of the most prominent symptoms in Lupus (Clark and Baily, 1956; Dubois and Wallace, 1987) and, in depression, the experience of loss is prominent(Beck, 1979). This was also very clear in the present study.

Many of the patients in this study mentioned losses in their lives. Their losses, however, were expressed in terms of "actual"losses such as the loss of function, lack of energy etc., and potential losses such as the loss of future possibilities. Lipowski(1978) also found among people with physical illness this same pattern. He writes:

The losses encompass not only concrete ones of body parts or function endowed with affective value for the patient, but also illness related symbolic functions of gratifications of biological or social needs, self esteem, status and so on (p 179) .

One significant finding in the present study was that some patients, when talking about their losses, talked about a "loss of self." They felt as if something of themselves had been lost in the

process. This experience of feeling a "loss of self" provides one clue to the understanding of the depression and the pain so prevalent among the Lupus patients. William James(1890), spoke of the "self" as the self-as-knower(the I) and the self-as-known (the Me). The self as object is constituted by one's body and one's possessions, ie family, friends, clothes, cars etc.This self as object is also constituted by the social roles a person plays. Thus the self in James' view, exists "over-there" and extends over the range of the person's concerns and activities.

Similar ideas were expressed by Heidegger (1962), in his view of the person (Dasein) as extended or, to use his words, "Being-in-the-world." Others, such as Mead(1934) and Cooley (1922) saw the self as the "interaction" of the person and his/her environment (Schlenker, 1985). If one accepts these views , then the intense losses experienced in Lupus become comprehensible. The patient's pain thus, seem to mean that he or she, in losing different aspects of the world, experiences it as losing different aspects of one existence as a person.

Lupus and Vulnerability

Nearly 90% of the patients who participated in this study referred to some current awareness of physical and or mental symptoms. Paradoxically, the most distressing part was not the pain or the physical handicap but the lack of control experienced coupled with the unpredictability of not knowing what to expect from this disease.

Patients talked about feeling "helpless" and "out of control." One person put it very graphically when she said she felt "hostage" to

the disease. The psychological experience frequently associated with this theme is that of anxiety and fear. Participants reported having great difficulty managing their illness. One patient said: "not knowing what to do is a very helpless feeling." This feeling of vulnerability also was well expressed by Aladjem(1982) when she wrote about her experience:

For those of us who are patients, Lupus remains a bizarre, cruel disease with a difficult name to pronounce. It is a disease of unknown cause/causes, with an unpredictable prognosis and symptoms difficult to explain. It is intermittent, recurrent and it can destroy the will to live and the ability to cope. It can threaten life and prevent its victim from functioning as a normal human being (p 18).

From a psychological perspective, Lupus patients could indeed be seen as victims. A victim has been defined as a person who suffers a change in general life condition, as a result of a physical or psychological "loss"(Weary, Stanly &Harvey, 1989). Typical reactions to victimization include an attempt to maintain control of one's life and one's environment (Kelly, 1971; Walster, 1966).

Bandura (1982, 1986), has called the ability to gain control over one's environment and one's life "self-efficacy." Constant frustration and failures in controlling emotion and behavior will result in decreased self-efficacy and despair. Seligman(1975), has described the experience of repeated frustration and failures which lead to the condition called "learned helplessness." Once the person has learned that nothing he or she can do will change the outcome, he or she will give up and try no more. Learned helplessness reduces the attempt to control the environment, interferes with learning new strategies, and produces fear and depression (Weary,

Stanley and Harvey, 1989). The sense of vulnerability and helplessness that many Lupus patients experience is not only accentuated by their "victimization," but also by their subsequent inability to gain control over their condition leading to decreased feelings of self-efficacy and further despair.

Another way to understand this experience of vulnerability has been described by existentialism. Existential thinkers have made anxiety a cornerstone in their understanding of human experience and human suffering (Schrag, 1970). From this perspective, it could be said that the Lupus patient is anxious because he or she has become aware of the possibility of "non-being." Anxiety discloses the reality of death in a very personal manner. To die means not just the abstract concept of death but "my dying" (Schrag, 1970). Although only two patients in this study mentioned being aware of death, Liang (1984) found a much higher proportion (23 %) in his study. The experience of vulnerability does seem to indicate an awareness of human fragility and mortality, thus lending some validity to the existential view. As one patient remarked: "It is the perception of being old, that I don't feel the same way, that I don't move as fast, that I am more fatigued, that I just can't do things and that I am wearing out..[the same thing] as of being aware of one's mortality . . . I guess that is just it."

Transformation and Change

One of the themes which appeared consistently in the protocols of the Lupus patients was that of transformation and change. Frequently the changes were experienced in terms of alterations in lifestyle.

The most striking aspect of the experience of change, however, seemed to be associated with a transformation in personality. This is a finding which was surprising. It was expected that having a chronic illness would have had significant impact in the person's life and also important changes would have necessarily taken place (Kleinman, 1989). Yet, in some patients, it seemed much more than "just an adjustment," but seemed better described as a whole new perspective, a complete change in their lives.

When we approach a sick person as someone who "caught" a disease, for instance, in the same way all of us now and then experience catching a cold, we tend to see illness as something incidental to the person's life. The doctor approaches the sufferer armed with knowledge gained from years of hard training and with a whole armamentarium of technological tools to aid in diagnosis and treatment. The disease is treated as something "alien" to the patient and that needs to be eliminated. In cases where cure is possible, the patients usually experience only a temporary alteration of daily routine. When the condition becomes chronic and not curable, the disease becomes an intimate part of the patient's world. It ceases to be something "alien" and becomes "part of the person," imbued with particular meanings for the patient. Illness becomes in a sense, a sort of identity for the patient. As Kleinman (1989) says: "in the context of chronic disorder, the illness becomes embodied in a particular life trajectory, envired in a concrete life world" and "acting like a sponge illness soaks up personal and social significance from the world of the sick person." This phenomenon has

been reported by others in different kinds of illness (Helman, 1985; Siegel, 1986). The person is not only sick in the sense of having symptoms, but becomes, due to the nature of the illness, "the sick person."

Burish and Bradley (1983), have suggested four reasons why the experience of chronically ill people is different from those with acute illness: cause, time, identity and outcome. The causes of chronic illness are generally unknown and often are related in some ways to the "personality" or "behavior" of the sick person. Chronic illness, unlike acute ones, usually has an insidious onset and is endured over long periods of time. The third dimension, identity, refers to the sort of ideas patients have about what is wrong with them. In chronic illness, the "identity" of the illness is much more difficult to describe due to the unknown causes as well as the "diffuse" symptoms the patient experiences. Finally, the outcome of chronic illness means a life of adjustment to the disease which, most times, ca not be cured. Faced with this set of circumstances, the patients find themselves in a situation which involves an alteration of the way they see themselves as well as in the way they are seen by others. Such changes occur at the most fundamental level, that is, at the level of the "self" or "personality." This was frequently reported by participants in this study.

Some patients spoke of transformations brought about by their illness as a positive event and, although they were experiencing pains and frustrations, they found the disease to have "made them better persons." They used examples such as how the disease brought them

closer to their families and how they had learned to enjoy the present, to "seize the day." From a negative perspective that can be seen as a form of rationalization. On the other hand, as Frankl (1977) has pointed out the greatest transformations in the character and personality of a person takes place in the midst of suffering and despair. Such experiences may make people "better" in the sense that they provide the opportunity to create meaning in their lives.

Other patients believed that they had become a different person, but one who they disliked and refused to accept. They reported seeing themselves as weaker, more emotional and less able to control themselves or their thoughts. One patient said that he was becoming "less of a person," another commented: "I can't tolerate the changes in my personality." What all of the patients had in common, whether they saw it as positive or negative, is that they were aware of becoming a different person, of somehow being absorbed, taken up by an identity which becomes defined by the illness they suffer. In the words of Herzlich and Pierret (1987):

To be sick, then, more and more frequently means to live with an illness or with a handicap, and illness tend to become an identity for the sufferer, and a category of social perception for the others. But the sick person has to master this identity, accept it, and make others accept it (p 53).

Coping with Lupus Erythematosus

Less than half of the patients interviewed made direct reference to their experience of coping with their illness. Although, at first sight, this may not appear to be a significant number, considering the importance of coping in chronic illness (Burish and Bradley, 1983),

the experience of coping was actually reflected in the way Lupus patients tried to understand their illness. In a sense, all of the patients were involved with coping. For the purpose of the study, however, only those protocols in which the person talked about coping, and reported being aware of attempts to struggle with Lupus were coded as specific examples of coping.

In general, those patients who talked about coping either referred to it as a "fight" with the disease,(ie, the disease was an enemy that needed to be overcome) or they talked about adjustment(ie, the disease is here and I better learn to accept it). Some referred to "internal" strategies such as changing attitudes, developing different ways of thinking about themselves and their illness or obtaining information about the disease . Others described coping more in terms of "external" strategies, such as doing things they like, seeking the help of friend and family and participating in church activities . Similar strategies have been noted in the clinical literature as two distinct forms of coping; one reflecting an "inner directed," ideational style, and the other an "outer directed," interactional one (Rorschach, 1921; Exner, 1986; Mechanic, 1977; Nerenz and Leventhal, 1983).

Psychological Study

Lupus and Its Symptoms

Consistent with current literature, this study suggests the presence of various physical and psychological symptoms among Lupus patients. Wallace and Dubois(1987), reported fever and arthritis as

the most frequent clinical manifestations in their sample of Lupus patients, followed by LE cells and skin changes. Nearly half of his sample also reported pain(48.2%), and a quarter had CNS involvement (25.5%). Rothfield (1985), in a review of the literature also reported arthritis and LE cells as most frequent, followed by erythema and alopecia. All of those symptoms with the exception of LE cell were reported as most common in this sample as well. The absence of LE cell reported in this study may be a result of the fact that patients reported "symptoms" and did not included laboratory results.

Despite the frequency of symptoms among Lupus patients, it is clear from this study, and others, that the most common abnormalities in this disease are those which are either "vague" and "non-specific" and which present the clinician with a serious challenge for treatment and diagnosis. A patient who complains of fever and arthritis (which in Lupus is often present without the deformity seen in Chronic Arthritis), or diffuse pains and weakness , by the time he or she goes to the physician may present a totally different "clinical picture." Even within the same day, some of the symptoms may vary. Wallace and Dubois(1987) also acknowledge this situation among the patients they treated. They write:

Patients frequently complain of morning stiffness with diffuse puffiness of the fingers and dorsum of the hand. These conditions subside from 10 minutes to several hours after arising. Fleeting pains may be present in both joints and muscles. At the time of physical examination, usually later in the day, no objective abnormality may be seen, resulting in the patients being labeled "psychoneurotic." . . . We have shown that SLE is diagnosed a mean of 4.1 years after the onset of symptoms (p 320).

This situation has been found to be one of the most prominent complaints expressed by Lupus patients. It was also interesting to see that they believe a good physician is not necessarily the most knowledgeable one, but one who would listen to them, and believe they were in fact "sick."

Another finding was the apparently high frequency of health care utilization among the present sample of patients. They reported a mean of approximately 3 visits to the doctor per month, and one hospitalization per year. They also reported a great number of symptoms and more than half said they were unable to hold a job because of their disease. As a group they reported taking more than 120 different medications, Prednisone being the most frequently named.

Whether this represents the true "medical status" of the patient or not is impossible to ascertain from the information gathered in this study. One major difficulty is that all of the information is based on self reports. There was no independent confirmation of the status of their illness. As it has been already mentioned, medical information from physicians was not available on all patients. In addition, the study concentrated on present symptoms which, as we know, may vary considerable from one time to another. Assuming that the patients had no reason to deceive, this result either points to a seriously ill group of Lupus patients or to an attempt by these patients to emphasize the "sick role" (Parson, 1951), or both.

The Psychology of Lupus Patients

Group Profiles

Group profiles for both the MMPI-2 and 16 PF were consistent with significant emotional distress. The MMPI-2 showed elevations in scales 1, 2, 3 and 8; the 16 PF profiles showed deviations in scales C, M, N, Q2 and Q4. The findings in the MMPI-2 are essentially the same as the ones reported in the literature (Grade and Zeagans, 1986; Liang et al, 1984, Morbideli et al, 1986), unfortunately, there has been no study of Lupus using the 16 PF and consequently no comparisons can be made.

The first three scales in the MMPI-2 comprise what has been called the neurotic scales, and the pattern evidenced by this group of patients (the conversion "V"), the neurotic triad (Greene, 1980; Graham, 1990). The interpretative analysis of this pattern has traditionally been identified with patients who "convert" (ie transform) psychological problems into physical complaints. They are described as immature, egocentric and selfish. They also are described as insecure, dependent and with great need for affection and they are thought to make use of denial, rationalization and projection (Graham, 1990). On the other hand, the pattern suggested by the 16PF indicates high emotional instability, tension, frustration, apprehension, an attitude of reserve and mistrust towards others, high self-reliance, preference for own decisions, avoidance of others and concern with practical down-to-earth issues (Cattell, 1989).

There are two major difficulties in interpreting present results in this way. One concerns the use of aggregated data as means to

understand the "typical individual" (Baloff and Becker, 1970).

Although the most common pattern on the MMPI-2 for Lupus patients is the 13/31 profile, the majority of patients in this study (54%) did not have it. Thus for 54% of the patients interpretations based on the 13/31 profiles were not valid. Instead, individual and cluster pattern analyses of data should provide a better method of describing groups of patients.

The second difficulty deals with the interpretation of psychological test profiles in special populations such as medical patients. To conclude that a person is converting psychological symptoms into physical symptoms because of his or her endorsement of items included in scales 1 and 3 of the MMPI-2 may be misleading, since research shows that medical patients generally have elevations on these scales (Osborne, 1985; Lair and Trapp, 1962; Gilberstadt and Jancis, 1967). Osborne (1985), cites a large study conducted at the Mayo Clinic in which 50,000 medical patients were given MMPIs, and the results show elevations on scales 1, 2 and 3 above those of the normative sample. In addition it was impossible to distinguish (on the bases of the test alone) between patients with "functional" diagnosis and patients with "organic" diagnosis. Therefore, elevation on these profiles, while indicating serious emotional disorder, may either suggest the "conversion" of psychological conflict into physical symptoms, or the development of psychological conflict as result of a physical disorder. Most of the psychological literature, has traditionally interpreted the psychological disturbances in medical illness as resulting from inner conflicts, which,

incidentally, were often associated with the development of the illness , as the illness became the bodily expression of the intrapsyche conflict (Lipowski, 1977). Although the field of psychosomatic medicine has matured, and few today will hold on to this view, the tendency remains to associate psychopathology in medical disorders with the "character" of the person; thereby minimizing the effects of social and interpersonal factors in the development of emotional disorders. In addition, this view also has brought negative consequences such as blaming the patient for his or her illness and limiting the extent of possible interventions (Lipowski, 1977). In chronic illness such as Lupus, it is worthwhile to consider neuroticism as effect rather than cause, and psychopathology, as the result of a failed attempt to adjust to a very difficult life situation rather than the expression of some inner conflicts.

Individual Profile Analysis

If we move from describing the group as a whole to more individualized or cluster profile analysis, we obtain a better psychological picture from the test data. Ten percent of this sample did not show significant deviation in their tests profiles from the normative sample. This group was labelled "normal." On the other hand, ninety percent of all patients showed changes indicating some level of psychopathology. This is much higher than previous studies, which may suggest that this particular group of patients represent a more dysfunctional "sample" of Lupus patients .

The largest percent (74%) of all the patients were classified under the "neurotic" category. Within this group, however, an

interesting pattern was revealed. There was a group of patients whose profiles indicated the presence of depression, anxiety, and a severe withdrawal from people; there was second group essentially denied psychopathology, was much more extroverted, and surprisingly had the largest frequency of psychotic symptoms. This finding appears to lend support to the introversion-extroversion dimension in neuroticism. Eysenck and Claridge (1962), conducted a large study with a group of neurotics and normals and found that introversion-extroversion was a major dimension of personality, and when applied to neurotics gave rise to meaningful distinctions he called hysterical (extroverted) and dysthymic(introverted).

Horney (1937, 1945, 1950), in her description of strategies used by neurotic individuals, defined two she called "moving towards people" (dependent, hysterical and extroverted) and "moving away from people" (depressed and introverted). Her view of neurosis resulting from interpersonal conflict, and of the neurotic person developing specific strategies to decrease anxiety, offers good insight into understanding people in situations of threat to the self. Her strategy of "moving against people, which refers to an attempt to regain mastery through aggressiveness was not found in this study.

Similar views of the interpersonal causes of neurosis have been addressed by Fromm(1947, 1976) and Sullivan(1953). More recently both Beck(1989) and Millon (1986) have included in their views of personality, the interpersonal as well as the "basic strategy" concepts of personality disorders. This view provides good insight into the behavior and personality styles of Lupus patients. Basically

neurosis could be seen as a dysfunctional adjustment or strategy used to deal with a host of conflicts and the need to maintain self-esteem in a threatening world. Although the question remains as to whether Lupus patients are neurotics who develop Lupus or Lupus patients who develop neurosis can not be answered by this study, the most parsimonious position seems to be the last one. A position that will be discussed shortly.

The last two groups found in this study were those who appeared to have a fundamentally "psychotic" dysfunction, and those who failed meet any of the above criteria, the "Other" category. Psychotic symptoms appear with relatively high frequency among Lupus patients and they have traditionally been associated with either CNS involvement or medication (Wallace & Dubois, 1987). Although there is evidence to support the relationship between psychotic symptoms and CNS involvement (O'Connor, 1957), the incidence of psychosis due to medication, such as steroids, is significantly less than previously thought (Wallace & Dubois, 1987). There is a danger of automatically ascribing the presence of psychosis symptoms to underlying organic disorders. First of all, despite the fairly well established correlation between psychotic symptoms and organic disorders, there is no conclusive "proof" that the psychotic symptoms are "caused" by the organicity (Grade and Zeagans, 1986). Secondly, as this study suggests, there is a great number of patients with apparent "functional" disorders who are reporting psychotic symptoms, a finding that at least raises the possibility of non-organic psychotic disorders. Looking at "Lupus psychosis" only in terms of underlying

organic processes, may prevent the clinician from acknowledging other potential sources of conflict which may be "causing" the psychosis.

Medical and Social Variables and Psychopathology

As mentioned previously, the likelihood of Lupus diagnosis does not seem to be an important factor in the kind or degree of psychopathology, as evidenced in the MMPI-2 and the 16 PF. The group, who on the bases of confirmatory lab data for Lupus, showed a high likelihood of having the disorder, did not suffered from more psychopathology than the group with low-likelihood or the group with unknown likelihood. These findings suggests either that this group is in fact very homogeneous, despite the lack of good confirmatory lab data, or that the presence of particular auto-antibodies does not play an important role in the psychological disorders seen in Lupus.

In general, most of the social and medical variables used in this study did not showed strong correlations with clinical scales in the MMPI and the 16 PF. Of the medical variables, the total number of medications taken by the patient had a moderate correlation with depression, while Prednisone by itself did not. The number of "flares" had also some relation to the schizophrenia scale in the MMPI-2 and the Tension/anxiety scale in the 16 PF. In addition, the number of visits to a physician was related to the Hypochondriasis scale and negatively related to Paranoia scale.

These findings must be interpreted with caution, especially in the context of a correlational and descriptive study. Consistent with recent thinking about the effects of Prednisone in psychological symptoms (Wallace and Dubois, 1987), it seems that the effects are

minimal, and in general it may be safe drug (from a psychological perspective) to take. On the other hand, if a patient is taking a large number of medications, there is a possibility for depression. This may be due to the potentiation effect of the drugs or just that the patient is in fact "more sick" or perceives himself/herself to be so, increasing the sense of pain or suffering for the patient.

The experience often associated with "flares" of the disease is one of "loss of control" or "vulnerability." It is not surprising then that there is an association between the number of flares and the schizophrenia scale in the MMPI-2, and the Tension/Anxiety scale in the 16PF. This association may be much stronger than the numbers indicate since the strength or duration of the flare may have an even stronger effect than the number of flares.

The relationship of Hypochondriasis to the number of visits to the physician does not seem very surprising in the context of the meaning of that scale. There is also the suggestion that the patient who visits a physician is less likely to be suspicious of other people.

One of the surprising findings was that the number of years with Lupus showed little or not relationship to clinical scales in the MMPI-2 and the 16 PF. Also, and contrary to expectations, the amount of "stress" as measured by the Life Event Form had little effect on the levels of psychopathology measured by the MMPI-2 and the 16 PF. Thus, people who reported increasing number of stressful events in their lives did not necessarily show increased psychopathology. It seems that what was "measured" was not the amount of psychological

stress, but the "number of events" that occurred in the person's life. In other words, this variable may be related more to "activity" rather than stress and, since in this group "activity" had a strong negative correlation with psychopathology, the measure of stress did not show the expected negative effects. For example, an intercorrelational matrix of the behavioral and medical variables used in this study (see Table B-10 Appendix B), shows "stress" (Str) as the only variable with a positive correlation (although not statistically significant) with the "activity" (Act) variable. Some authors have recently warned about the inherent weakness of inventories of life stress because of the "ambiguity" and "thin descriptions" of complex life events (Coyne and Downey, 1991; Geerwitz, 1973). In addition, it has been suggested that not only the interpretation of an event but the character and circumstances surrounding it differs among persons (Coyne and Downey, 1991). Further examination of this factor should be important to consider.

Among the social variables, whether the person was married or not did not show statistically significant differences. If the person was able to work, even part time, their "neurotic" scales were lower than those of patients who did not work. Originally it was expected that married people would do better due to potential social and emotional support. Liang (1984) even found a positive relation between being married, depressed and being Hypochondriac! Although in this study there was no negative effect of being married, it is possible that for many patients being married provides a greater opportunity for interpersonal conflict, thereby upsetting any positive effect obtained

from social support. In contrast, being able to work had some positive effects, probably due to enhanced self-esteem and to an increased sense of self-efficacy (Bandura, 1982, 1986). Other research shows that women who work, consistently report greater sense of self-esteem, decreased psychological distress and greater coping strategies (Betz, 1989).

Comparison of phenomenological data and neurotic scales on the MMPI-2 and 16 PF suggests that the experience revealed in Theme 1, that is, isolation and invisibility, has some effects in the levels of neuroticism among the Lupus patients. This may indicate an attempt by the Lupus patients to engage in "neurotic behaviors" as means to seek and gain attention from others and find validation for their illness. Results also indicate that the level of acute anxiety and tension as measured by scale Q4 of the 16 PF may be related to the experience of isolation, of losses and limitations and of lack of coping in their lives.

Not surprisingly, the two most important factors found were the number of symptoms reported by the patient, and the total number of hours of activity per day. Those two factors best typify what seems to be "health" and "illness." The person who sees herself as very sick (realistically or not), and is able to produce or recall a large number of symptoms will be more psychologically distressed. Symptoms serve as a way and means to communicate her suffering while the person who keeps him or herself active and/or keeps a job especially when Lupus makes people tired, may be communicating the opposite.

In conclusion, this study found, consistent with previous literature, a high incidence of psychopathology among Lupus patients. Nearly three fourths of the sample showed a pattern characterized by a neurotic adjustment to the disease, and one third reported having some psychotic symptoms. The strongest predictor of psychological dysfunction was the number of symptoms reported by the patient. This may be an indication of disease activity and/or a reflection of the degree to which the person perceives him or herself to be sick. The awareness of isolation and of the disease's invisibility showed also an effect on the levels of neuroticism on the MMPI-2 and 16PF. Acute situational anxiety was related to the experience of isolation, of losses and limitations and of lack of coping. Other medical and social variables did not show any strong correlation with psychopathology. A "health" factor, which included, decreased number of symptoms reported, holding a job and an increased physical activity showed the strongest negative correlations with psychopathology.

Theoretical and Practical Considerations

Illness as Meaning

A fundamental characteristic, as well as an objective of this study was an emphasis on the patient's meanings of her or his the illness. Illness can be described from two basic perspectives. One is the medical description characterized by the biological and physiological processes in the human body. Its objectivity is clearly formulated in clinical and scientific textbooks. There is a second perspective, however, from which illness can be viewed; that of the

patient. Illness as a scientific concept is abstract and theoretical; illness as a human affair is always lived in a concrete individual, who works, plays and suffers in a world of his own (Kleinman, 1989). We can further say that illness becomes "real" not in the "objective" biological processes, those are only the necessary markers of the "disease." The "real" illness is always found in a living person. The identity and meaning of a disease is always related to the activities and meanings of the individual who suffers it.

Kleinman(1989) and Engel (1977), have suggested a distinction between "illness" and "disease." Disease is the description of medical and biological processes. Illness, on the other hand, is the patient's experience of a disease in the context of a particular life situation. When a patient comes to see a physician he or she brings "illness complaints," which are often translated into the technical and scientific language of the medical or psychological science. This state of affairs allows for a basic misunderstanding between what the patients needs are, and what the physician, or other health care provider, thinks is wrong with the patient. Kleinman writes:

Disease is what practitioners have been trained to see through their theoretical lenses of their particular form of practice. That is, the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems . . . The healer- whether a neurosurgeon or a family doctor, a chiropractor or the latest breed of psychotherapist- interprets the health problem within a particular nomenclature and taxonomy, a disease nosology, that creates a new diagnostic entity, an "it"- the disease (Kleinman, 1988 p 5).

But illness has meanings which are intimately related to the course of the illness in the patient's life as well as to the particular and unique interpretations the patient gives to it in the

context of their "life-world." Because social reality is construed in a fashion that sees illness only as the result of biological processes, a legacy of Pasteur and Virchow, any inquiry into its social and psychological meanings is automatically precluded. An emphasis on the biological and technological have dampen our awareness of the social and psychological. When illness is recast only in terms of the biological, we fail to recognize that illness does not reside in the body alone, but in all the aspects of human existence.

What the Lupus patient experiences, goes beyond a particular set of bodily symptoms. She experiences isolation and loneliness as well as limitations and losses, which may include her job, her friends, family and even her self-esteem and self-respect. Some patients struggle to keep hold of a reality that becomes, at times, difficult to bear and accept. When she goes to the physician she talks about her pains and aches, when in fact, she may be expressing her fears, her despair and her terrifying sense of vulnerability.

One of the patients in the study, a woman in her sixties, talked about a life of frequent illness followed by periods of "remission." For years, visits to her doctor failed to bring any relief to her suffering, because nothing was ever found to be wrong with her. Her family did not believe that she was sick, but that she was only "pretending." Her sister, however, after a severe illness that required hospitalization, found she had Lupus and told her to have herself checked for it. She did, and after the appropriate medical work-up she was also diagnosed as having Lupus.

The diagnosis did more than just validate her, it also validated her mother. She told me that during the 1930's her mother began to show strange behaviors which had been preceded by periods of severe weakness and complaints of bodily pains. Her mother was eventually diagnosed as schizophrenic, but in the process she had done a VDRL test which came positive. The implication was that she had contracted syphilis "outside the marriage." Her father divorced her mother and she ended up, in the last days of her life, in a mental institution. When the diagnosis of Lupus was made both sisters realized that their mother most likely also suffered from Lupus (in Lupus one gets false positive VDRL). For many years she lived thinking she was a "fake" just as her mother had been. In her tears there was relief of knowing she was not a fake but also a lot of anger and disappointment towards herself, her family and the medical community. Her illness was more than symptoms, it was the fabric that gave coherence to her life history.

The Self, Society and Psychopathology

A fundamental principle of human behavior is that people are purposive, and are always involved in the task of making sense of their experience and their world (Schlenker, 1985; Frankl, 1977; Harre, 1980). To achieve their goals people construct and develop plans and strategies. These plans involve beliefs, attitudes, roles and sets of behavioral options for specific situations (Kelly, 1963; Schank and Abelson, 1977). Central to this point of view is the idea of a "self" or "self-system" which directs, selects and guides

behavior(Allport, 1937; Buguental, 1952; Rogers, 1951; Epstein, 1973). From the very beginning of psychology in America, the self was a central concept (James, 1889). It was soon forgotten as academic and experimental psychology became behavioristic. On the other hand clinicians were captivated by the drive theories of psychoanalysis which left very little room for the concept of the self(Schlenker, 1985). But things have changed , and today there is no school of psychology that does not have some concept of self, from psychoanalysis (Kohut, 1971, 1977), to cognitive psychologists (Greenwald and Pratkanis, 1984).

The view of self that I found important to consider here, is what has been variously called the phenomenal self, the interactional self or the field theory self (Kelly, 1963; Schelenker, 1985). Consistent with personal experience, as well with a theory of existence which sees man always in interaction with others and the environment, this self is presumed to developed in the context of social life. Such a theory of self was further developed by Symbolic Interactionists such as Mead(1934) and Cooley(1920). The self as a product of the social interaction must always be construed and negotiated in the process of interacting with others. The person is not passive in those encounters but actively evaluates, censors, and interprets and gives meaning to these situations.

The actions of other people always reveal information about my self, shaping and transforming it in the process. From this perspective, the self or self-system is a dynamic process which changes, develops and adjusts in constant interaction with others (Markus and

Wurf, 1987). The person's behavior at any particular point in life is the product of the individual and the situation (Schelenker, 1985). This basic insight would seem to provide a way to understand the so called "neurotic" behavior exhibited by many Lupus patients as their behavior and self-identity are continuously affected by the interactions with others. A fundamental theme in the experience of the Lupus patients is the lack of validation, and the dissonance they experience in their dealings with others. Others, they report, don't believe they are sick, or at least not to the point that allows them to "be sick" (Mechanic, 1978). Their disease is "invisible" and they become "fakes." In this context, is not surprising to find patients who reported an awareness of this experience exhibiting an elevated "neurotic" profile in comparison to those who did not reported it.

In addition, the deep sense of vulnerability, the losses and limitations and the changes and transformations imposed by their illness, restrict the sorts of goals and the range of meaningful activities they can engage in. Many of the patients reported a constant feeling of dread or anxiety and, some, experienced what they refer to a "loss of self" or a loss of identity, suggesting that one of the primary goals they face is an attempt at achieving a new definition of self in the context of their illness.

To understand the psychological problems found among the Lupus patients we need go beyond the psychiatric nosology, towards an understanding of life-situations. That does not mean that the effects of the disease process, ie CNS involvement, or specific medications such as prednisone, do not play a role in the development of psychiatric

symptoms. They do, as research seems to indicate, but they are not the only, or primary cause of suffering. On the other hand, trying to imply that a certain personality style has causative factors in Lupus(Grade and Zegans, 1986), has not found support in the empirical literature, and further stigmatizes a patient by making him or her "responsible" for the disease. A most parsimonious explanation is that following the development of the disease, the patient is confronted with a whole new set of situations and circumstances that demand a different adjustment(Turk and Salovey, 1984). Some of the factors involved will be physical or biological, others will be socially or psychological. This does not excludes the possibility of psychological factors in the development of the disease itself, but for that we will need to wait before more evidence is available. Neurosis does not produce Lupus or we would have millions of Lupus patients; what is more likely is that such style of life is the result of having Lupus.

Future Directions and Treatment Considerations

One of the issues that remain problematic in Lupus is that of diagnosis. Although essentially a medical problem, we have seen the negative impact that lack of (or incorrect) diagnosis may have on the patient. While we wait for an improved ability to diagnosed Lupus, it is very important not to lose sight of the human factor. What the doctor tells a patient goes beyond the nosological tag, and unlike a veterinarian, what he or she says directly affects the patient (Cockherham, 1989). Greater sensitivity, on the part of the medical practitioner and a greater awareness of the meaning of illness will

certainly provide better communication between the physician and the patient. At a more significant level it will aid treatment and healing, and above all it will help the patient to be relieved , to some degree, of her pain.

Another area which deserves further attention in terms of both intervention as well as research, has to do with helping the patient ameliorate the negative emotional effects of her disease. Based on the themes found in this study, it will be possible to devise potential interventions. Family involvement and education as well as support groups for patients may help with the feelings of strangement and isolation. Helping patients to develop greater sense of control, focusing their limited energy into meaningful activity, and gaining greater knowledge about their illness and greater participation in their treatment may help the patient to feel less vulnerable and less victimized. A technique which was suggested by one of the Lupus patients, is to symbolize their energy by means of marbles. Letting one marble stand for a certain amount of energy, they can then set aside so many marbles for planned activities. Once the marbles are spent, the patient should rest. This "game" is designed to help the Lupus patient pace herself and feel in control of her activity. Another useful technique would be to teach them to talk to physicians in terms of letting them know what sorts of interventions seem to help the most. Getting involved will also increased their sense of self-efficacy and do for them what Kleinman(1988) calls "remoralizing."

To be involved in psychotherapy may prove effective for some patients. Finding a redirection in their lives now that they have a

chronic illness, and developing a "new self" may be worked on in the therapeutic relationship. Care should be taken, however, in involving the patients in psychotherapy, in terms of not giving them the message that they are "crazy." A referral to a psychiatrist or psychotherapist, may be harmful if the patient perceives it as one more sign her problems are in her "head." Future research may focus on some of these interventions to find the viability in reducing distress and increasing the patients' sense of well being. While a cure may not be in sight, we can provide a greater understanding and a better quality of life for the patient with Lupus Erythematosus.

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APPENDIXES

APPENDIX A

LIFE EVENTS FORM

Please circle the numbers if any of the events have happened to you within the last six(6) months.

- 1-Death of spouse
- 2-Divorce
- 3-Marital separation.
- 4-Jail Term.
- 5-Death of a close family member.
- 6-Personal injury or illness.
- 7-Marriage
- 8-Fired at work.
- 9-Marital Reconciliation.
- 10-Retirement.
- 11-Change in health of family member.
- 12-Pregnancy.
- 13-Sex difficulties.
- 14-Addition of new family member.
- 15-Business difficulties or loss.
- 16-Change in Financial status.
- 17-Death of a close friend.
- 18-Change to different line of work.
- 19-Change in number of arguments with family member.
- 20-Assume high mortgage.
- 21-Unable to pay mortgage or loan.
- 22-Change in work responsibilities.
- 23-Son or daughter leaving home.
- 24-Trouble with in-laws.
- 25-Outstanding personal achievement.
- 26-Wife or husband begins or stops work.
- 27-Begin or end school.
- 28-Change in living conditions.
- 29-Change of personal habits.
- 30-Trouble with boss.
- 31-Change in work hours or conditions.
- 32-Change in residence.
- 33-Change in schools.
- 34-Change in recreation.
- 35-Change in church activities.
- 36-Change in social activities.
- 37-Take out small loan.
- 38-Change in sleeping habits.
- 39-Change in number of family get-together.
- 40-change in eating habits.
- 41-Vacation.
- 42-Christmas.
- 43-Minor violations of the law.

Symptom Checklist

Have you been diagnosed as having Lupus?

How long ago?

Do you have SLE or Discoid Lupus?

Have you experience any of the following?

Last 5 yrs Last 2 yrs Last 6 mo

Fever

Skin Rashes

Pain

Arthritis

Hair Loss

Mouth Ulcers

Photosensitivity

Kidney Involvement

Pleurisy

Seizures

Anemia

Cardiac Arrhythmias

Pericardiatis

Myocardic Disease

Pulmonary Infection

High Blood Pressure

Psychosis

Anxiety Disorders

Depression

Organic Brain Disease

How many hospitalizations have you had in the last 5 years?

Are you able to work?

If you do, how many hours per week?

How often do you feel fatigued or tired?

How many hours of activity per day are you able to tolerate?

How often do you go to see a physician?

How many "flare-ups" have you had in the last 2 years?

List any medications you may be taking and the dosage.

What other symptoms are you experiencing?

BIOGRAPHICAL INFORMATION FORM.

NUMBER:

AGE:

SEX:

1-Current marital status:

Married
Widowed
Divorced
Separated
Never Married

2-How many years has your current marital status lasted?

3-Have you been married before?

yes
no

4-How did your last marriage ended?

Divorce
Death of spouse

5-How many children do you have?

0 1 2 3 4 5 6 or more

6-What is your birth order?

Only child
Oldest
Middle
Youngest

7-How many siblings did you have?

0 1 2 3 4 5 6 or more

8-How many are there alive?

0 1 2 3 4 5 6 or more

9-What was your father's occupation?

Laborer	Clerical worker	Skilled craftperson
Manager	Professional	None of the above

10-What was your mother's occupation?

Laborer	Clerical worker	Skilled craftperson
Manager	Professional	None of the above

11-What is your ethnic origin?

Asian	Native American
Black	White
Hispanic	Other

12-Is English your native language?

yes no

13-Where have you lived most of your life?

City Town Rural area

14-What is your present dwelling?

Own home	Condominium	Rented apt or house
Rooming house	Dormitory	Other

15-Are you able to work?

yes	no
-----	----

16-How many hours per week?

1-5	6-10	11-20
21-30	31-40	none

15-What is your present occupation?

Laborer	Clerical worker	Skilled craftperson
Manager	Professional	None of the above

16-Estimated family income:

5000 or less	5001-10000	10001-15000
15001-20000	20001-25000	25001-30000
30001-35000	35001-40000	40000 or greater

17-Do you receive any of the following:

SSI	Social Security	Medicaid
AFDC	VA	Medicare
Other		

18-What is your religion?

Roman Catholic	Baptist	Other Protestant
Jewish	Other	None

19-Please complete what best describes you: "I have used alcohol"

Never	Almost never	Occasionally
Frequently	I have a problem with alcohol	

20-Please complete what best describes you: "I have used drugs"

Never	Almost never	Occasionally
Frequently	I have a problem with drugs.	

PSYCHOLOGICAL AND EXPERIENTIAL ASPECTS OF LUPUS.

The study in which you will be participating is a study which seeks to understand the psychological factors in Lupus as well as the way Lupus patients understand their experience of this disease.

You will be required to take two personality assessment tests: The Minnesota Multiphasic Personality Inventory-2 (MMPI-2), and the 16 Personality Factor Test (16 PF). You will also fill out a short symptom checklist, a biographical information form and a life event form. Finally, you will participate in a recorded interview about your experience of having Lupus.

The risks in this study are minimal. The testing part will take approximately 2-3 hours depending on how fast you read. The interview will take about 30-60 minutes. You will be assigned a number to protect your privacy and assure confidentiality. If at anytime during the study you wish to withdraw you are free to do so by simply informing the researcher. The researcher will be happy to answer any question you may have. The persons to contact are:

Mr. Luis Fernandez
401 Austin Peay Bldg
University of Tennessee
Knoxville, TN 37996
(615) 974-6060

Dr. Howard Pollio
Dissertation Director
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At the end of this project, feedback will be provided to all the participants regarding the results of this study.

I have read the above paragraphs and fully understand their meaning, and hereby give my consent to participate in this study.

SIGNED _____

APPENDIX B

TABLE B-1
DEMOGRAPHIC INFORMATION

SEX: . Females = 37	Males = 2	
AGE: Mean = 45.6 years	Sd. = 10.71 years	Range: 25-76 years
RACE: White: 30	African American: 2	
Native American: 3	Unknown: 4	
MARITAL STATUS:	Married: 22	Single: 1
	Divorced: 6	Widowed: 3
	Separated: 2	Other: 5
OCCUPATION:	Laborer or Clerical Workers: 7	
	Skilled Craftsperson: 1	
	Manager: 1	
	Professional: 6	
	Not working: 17	
	Other: 7	
ESTIMATED FAMILY INCOME:	<10,000 = 3	10,000-20,000 = 5
	21,000-30,000 = 5	31,000-40,000 = 7
	>41,000 = 9	Not reported = 10
RELIGION:	Roman Catholic = 3	Jew = 1
	Baptist = 17	Other = 2
	Other Protestant = 8	None = 6
NUMBER OF PARTICIPANTS OWNING OR RENTING HOUSE:		
Owning = 29	Renting = 5	Other = 5
NUMBER OF PARTICIPANTS RECEIVING GOVERNMENT ASSISTANCE:		
SSI = 2	Social Security = 14	Medicaid = 1
Medicare = 12	Other = 4	

TABLE B-2
MOST FREQUENTLY REPORTED SYMPTOMS

1. Fever	86%	13. Anemia	30%
2. Pain	86%	14. Headaches	28%
3. Skin rashes	78%	15. Raynauds	26%
4. Arthritis	78%	16. G.I. disturbances	21%
5. Photosensitivity	65%	17. High blood pressure	21%
6. Depression	64%	18. Loss of memory	18%
7. Mouth ulcers	51%	19. Pulmonary infection	18%
8. Hair loss	50%	20. Pericardiatis	15%
9. Weakness	38%	21. Pleurisy	15%
10. Anxiety	38%	22. Seizures	13%
11. Kidney involvement	32%	23. Loss of coordination	10%
12. Cardiac Arrythmias	30%	24. Organic brain disease	8%

TABLE B-3
MEDICAL AND BEHAVIORAL DATA

Variable	Mean	Standard Deviation
Years with Lupus	7.48	6.09
Number of Hospitalizations ¹	2.03	3.57
Visits to Physician ²	6.96	5.40
Number of Symptoms Reported	10.89	7.06
Number of Medications Taken	6.78	5.19
Amount of Prednisone	10.33	32.74
Number of Flares ³	1.69	1.70
Hours of Activity per day	6.56	4.0
Life Change Units (LCU)	182	114.2

¹In the last 5 years

²In the last 3 months

³In the last 2 years

TABLE B-4
SUMMARY INDIVIDUAL PROFILE ANALYSIS

Category	N	Percent
Normal	4	10%
Neuroticism	29	74%
Type I	11	28%
Type II	18	46%
Psychotism	3	8%
Other	3	8%
Total	39	100%
Total Percent with Psychotic Symptoms = 33%		

TABLE B-5

RESULTS OF ANALYSIS OF VARIANCE IN LIKELIHOOD OF LUPUS
DIAGNOSIS AND CLINICAL SCALES ON THE MMPI-2 AND 16 PF

Variable	High	Low	Unknown	F-test
MMPI-2 Scale 1	25.1	26.2	26.2	.103
MMPI-2 Scale 2	29.0	30.0	30.5	.200
MMPI-2 Scale 3	31.5	34.7	32.0	1.05
MMPI-2 Scale 7	35.3	35.3	33.9	.268
MMPI-2 Scale 8	35.9	35.3	32.9	.470
16 PF Scale C	11.7	11.5	12.3	.156
16 PF Scale L	7.4	6.8	8.1	.380
16 PF Scale 0	10.9	12.27	11.9	.286
16 PF Scale Q ₃	11.9	12.4	14.2	2.634*
16 PF Scale Q ₄	15.4	16.3	16.8	.223

*p > .08

TABLE B-6
IMPACT OF MARITAL STATUS AND EMPLOYMENT ON MMPI-2 SCALES

Scales	Work	Not/Working	t	Married	Not/Married	t
1	22.5	28.2	2.92*	26.8	24.9	.76
2	27.2	31.2	2.22**	29.5	30.2	.71
3	30.3	34.3	2.23**	32.9	31.9	.51
7	34.44	35.22	.35	35.20	34.50	.31
8	33.75	34.9	.417	35.3	33.0	.77

*p < .01

**p < .05

TABLE B-7
IMPACT OF MARITAL STATUS AND EMPLOYMENT ON 16 PF NEUROTIC SCALES

Scales	Work	Not/Working	t	Married	Not/Married	t
C	12.94	11.26	1.68	12.05	11.31	.59
L	6.93	7.69	.76	7.09	8.19	.89
O	12.50	11.17	.94	11.59	12.38	.57
Q ₃	12.20	13.40	1.15	12.86	13.13	.26
Q ₄	15.20	17.00	1.01	16.41	16.50	.09

TABLE B-8

PHENOMENOLOGICAL THEMES AND NEUROTIC SCALES IN MMPI-2

	Theme I			Theme II			Theme IV			Theme V		
	Present	Absent	t	Present	Absent	t	Present	Absent	t	Present	Absent	t
MMPI-2												
Scale 1	28.20	25.77	.875	26.83	27.33	.867	26.66	28.25	.596	27.00	26.57	.157
Scale 2	33.73	25.78	3.55*	31.05	29.83	.391	31.00	29.83	.443	31.20	31.40	.076
Scale 3	34.80	32.33	1.16	33.61	34.66	.417	33.50	34.07	.273	33.40	31.85	.635

*p < .01

TABLE B-9

PHENOMENOLOGICAL THEMES AND NEUROTIC SCALES IN 16 PF

16PF	Theme I			Theme II			Theme IV			Theme V		
	Present	Absent	t	Present	Absent	t	Present	Absent	t	Present	Absent	t
Scale C*	10.80	13.33	1.87**	11.83	10.67	.750	11.67	11.83	.167	11.60	11.86	.179
Scale L	9.13	5.55	2.31***	8.47	5.40	1.57	8.25	7.38	.867	7.10	8.28	.706
Scale O	11.87	10.44	.863	11.53	10.60	.466	10.33	12.33	1.28	11.00	11.57	.348
Scale Q ₄	18.60	14.44	2.18***	17.95	13.60	1.87**	16.50	17.58	1.08	11.00	17.21	3.29*

*In this scale Low Ego Strength is indicated by the lower number.

*p < .01

**p < .10

***p < .05

TABLE B-10

INTERCORRELATIONAL MATRIX OF MEDICAL AND BEHAVIORAL VARIABLES

	YL	Pdn	Mds	DrV	Hosp	Sym	Flr	Act	Str
YL	x	.011	.152	-.182	-.018	-.135	-.284	-.173	.039
Pdn	.011	x	.023	.144	.855*	.305	.049	-.326	-.312
Mds	.152	.023	x	.075	-.118	.517*	.111	-.453*	-.264
DrV	-.182	.144	.023	x	.449*	.215	.318	-.216	-.022
Hosp	-.018	.855*	-.118	.449*	x	.135	.051	-.118	-.097
Sym	-.135	.305	.517*	.215	.135	x	.430*	-.386	.164
Flr	-.284	.049	.111	.318	.051	.430*	x	-.166	-.019
Act	-.173	-.326	-.453*	-.216	-.118	-.386	-.166	x	.232
Str	.039	-.312	-.264	-.022	-.097	.164	-.019	.232	x

*p < .05

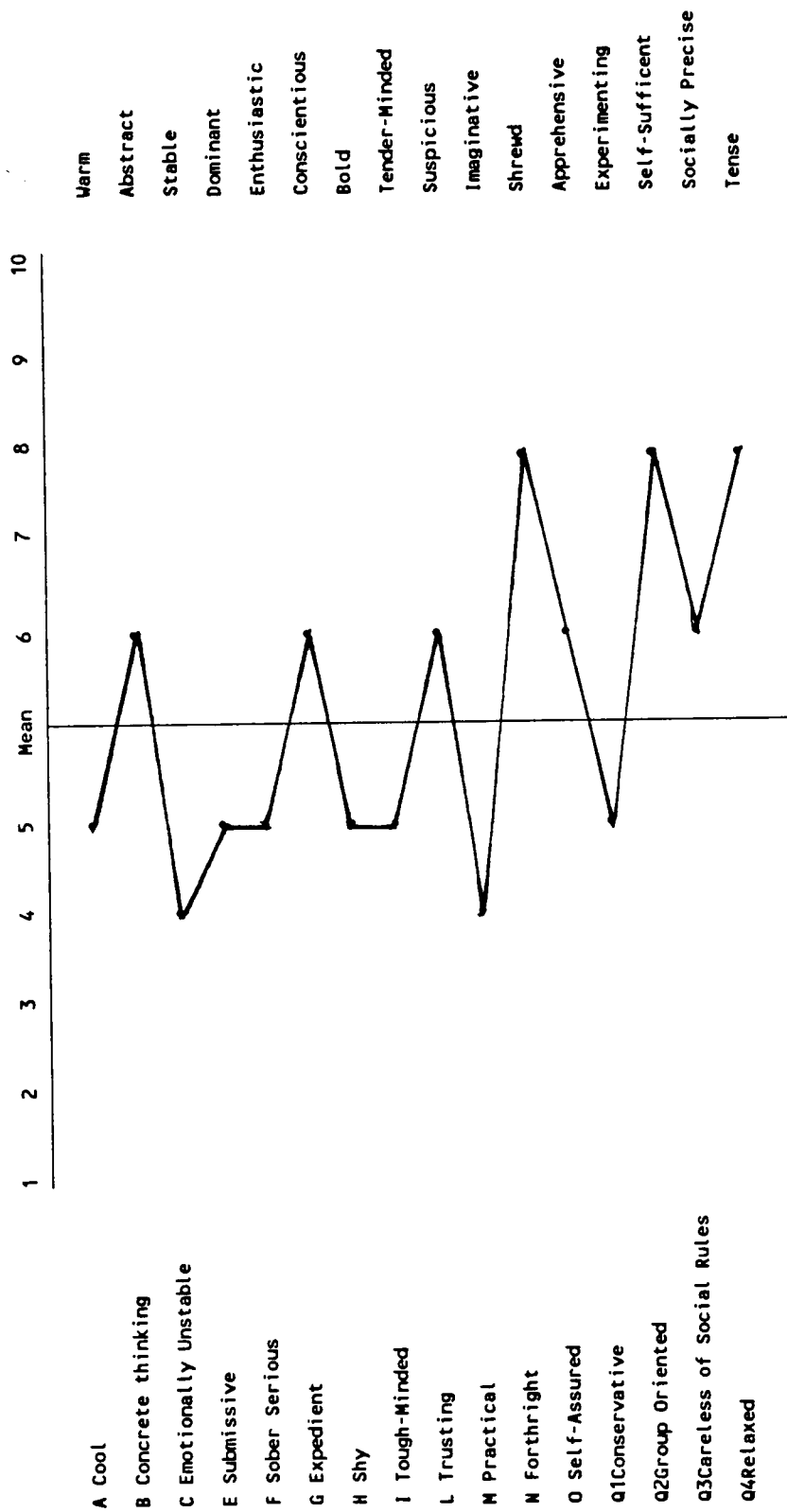


FIGURE 1
GROUP MEAN PROFILE OF THE 16 PF

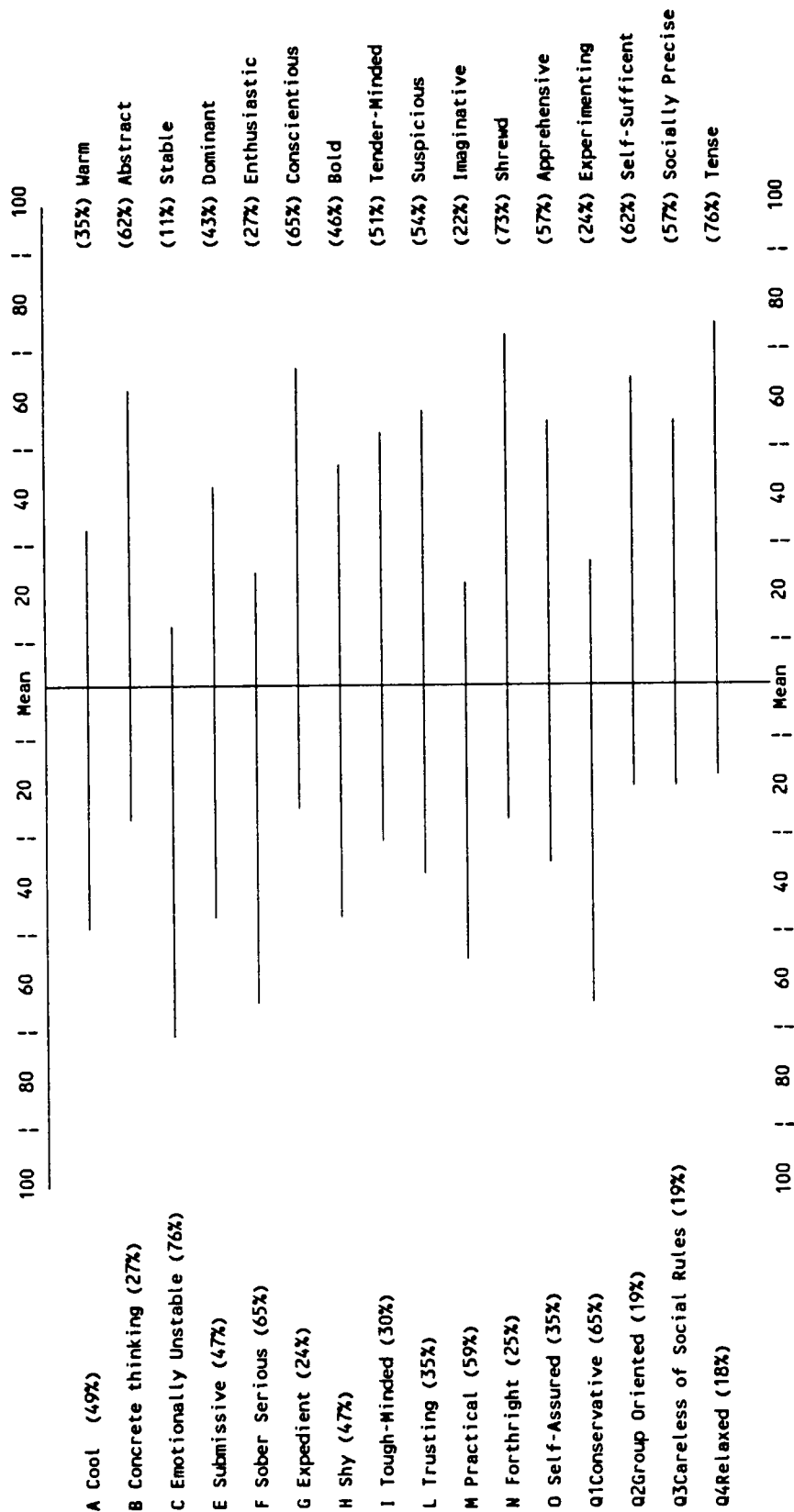


FIGURE 2

GROUP PERCENTAGE PROFILE OF THE 16 PF

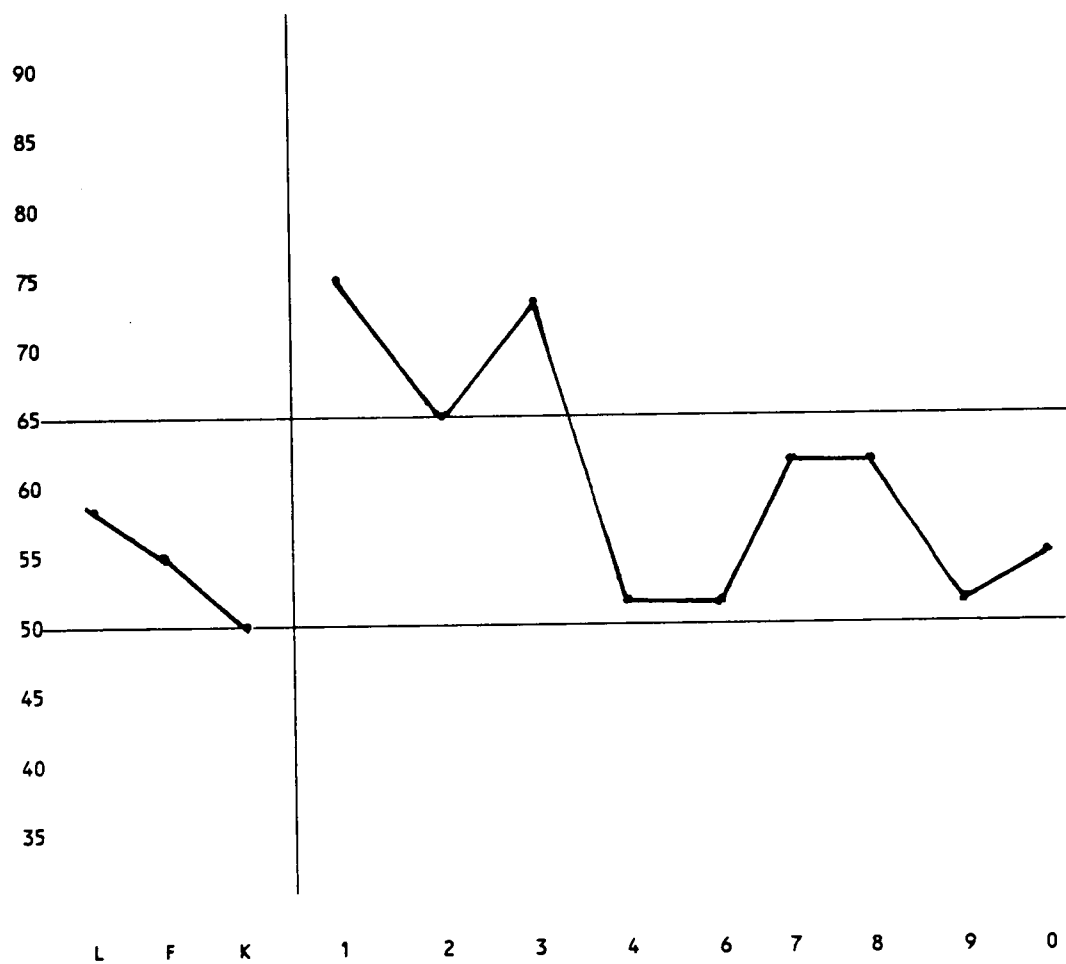


FIGURE 3
GROUP MEAN PROFILE OF THE MMPI-2

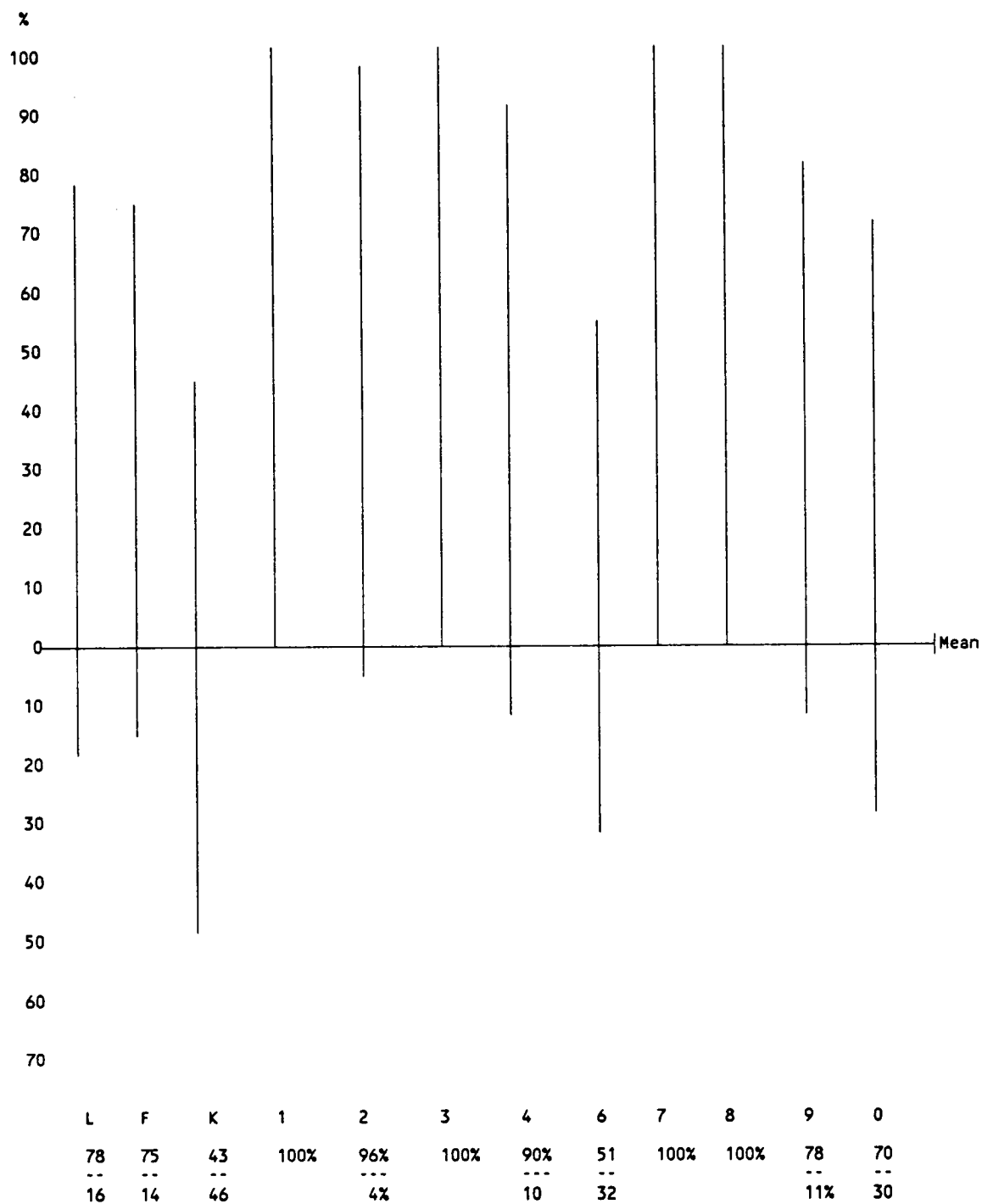


FIGURE 4
GROUP PERCENTAGE PROFILE OF THE MMPI-2

APPENDIX C

Sample Interview

Female 004, 9/9/89

I: I would like for you to think of a time or times in which you have become very much aware of being a Lupus patient. What are you aware of at those times?

P: Most of the time I don't think about it and I am not aware of it most of the time. I think the last time I really felt aware of being a Lupus patient was a little over a year ago shortly before I took a class last summer at UT evening school, and I was very afraid to take the class, because I - and I was working part time at that time - but even that, plus taking care of the home and my son, and taking this evening class, I was afraid would be too much stress and might cause the Lupus to reoccur. It was the first class I had taken, a college class, since I had left college in 1968, and I didn't graduate back then. And I had always wanted to go back and finish, but people had been telling me over the years, you don't want to overdo, you don't want to work full time, you don't want to do this, you don't want to do that because the Lupus will act up, so when I finally made the decision to take this english class last summer, I was looking forward to it, but when it came right down close - within a few days of the class starting - I had just tremendous anxiety. I was afraid and I tore up my registration forms at one point because I thought, No I can't do this. I felt depressed about it, and then I said, no and I went without the registration forms. I told them I had lost them. I didn't tell them I had torn up. They were still able to get me registered but even the weekend before the class started on Monday, I cried a lot and had tremendous anxiety and was afraid I was doing something that would reactivate the Lupus. Well I did take the class. It was a tremendous strain with had work, you know, a tremendous amount of work, and late hours studying, etc. But I got through it just fine. I got an A in the class, the Lupus did not reoccur. In fact some of my tests after that were better than they had ever been, and that was a real turning point as far as being afraid of the Lupus. And since that class I have not really been afraid of it, and prior to that, the only other time, I remember was right before Charlie came, my son. That was five years ago, and people said that will be much for you to take him on, and that will cause you to get sick again, and I remember thinking, I don't care. I may get sick. Maybe they are right, what they have been telling me all these years, if I do too much I will get sick. I was so compelled to bring him that I didn't care if the Lupus made me - killed me. I thought, I am at least going to try, because his alternative was to go into the foster care system out in California, and I thought, well I hope it doesn't happen, but if it reoccurs, and I get really sick, and even if I die, I decided it was worth trying this particular thing. But people had scared me pretty badly.

I: You became aware of being a Lupus patient basically when other people remind you of your limitations, or remind you of your-what would be the word-the things that may precipitate a flare up.

P: Yes, in the earlier years-over the years of my marriage, for instance, I wouldn't think about it a lot except my husband would say, don't go out in the sun or remember to wear your hat, you know, little things like that or I myself might think I better put the hat on and I am at the beach and I would cover up. Time when I was doing very specific things to prevent the Lupus from recurring, the doctors had said don't go out in the sun, so I was taking reasonable precautions and I would put on the hat. But most of the time, and really as I look back at my life I have not thought about it. Days and weeks go by and I don't even think about Lupus. It does not enter my mind unless I am going to have an outing, which would put me in the sun on a weekend, or something, I would prepare for that, or if I am going to attempt something difficult and stressful. I have internal fears and people also say, you shouldn't maybe do that.

I: So it is not only people also, but when you are going to face situation that would be demanding or stressful from inside yourself, so to speak, you become aware of your Lupus.

P: Yeah, but since the class and getting through that, and also since Charlie, and Charlie was very stressful on me, especially the first two years, but I went through all that and I didn't have a relapse. I have had little problems but nothing major happened, and that has given me more confidence. I'm not foolish enough to think, Well I am completely immuned to a relapse, but I am less afraid now, having accomplished these difficult things than I was before I accomplished them. But before I accomplished these things I felt like a very dependent person who couldn't accomplish anything of significance because the Lupus was inactive. I just thought it would be automatic and it did keep me down, it did keep me from doing things.

I: So actually being able to do what you feared or faced your fear, so to speak, has been beneficial for you.

P: Yes it has, because it makes me feel like I am more a part of life, you know, living, and before I was just existing, really afraid to try anything challenging.

I: When you said before, before -?

P: Well let's see, I was fairly young when I got the Lupus, back when I was in college, and college is very stressful. This was the thing. I think this is why I had so much anxiety with this class, because it was while I was taking classes that I first became ill with the Lupus, and I was working part-time at college, plus taking lots of classes, and just generally feeling a lot of stress and I had a boyfriend who became my husband, but we weren't able to spend a lot of time together because he was working too, and I was living at home, and really, what happened I

think was when they first announce that I had the Lupus, I had started feeling bad, fatigued, stomach aches, the arthritis started, and became worse and worse, and I heard you say other people were relieved to know that it was something, I felt the same way. It was relief to know it was something, but I knew nothing about Lupus or what was ahead of me or what it was. I just liked having a diagnosis. It was a medical thing that was causing all these problems, and so that was a relief. I was very naive, young and naive about what it could mean to my life, so I wasn't really very afraid of the Lupus when I first heard that I had it. And to be perfectly honest in a sense I was relieved because it meant I could cut back some of my classes at school, and I think I was feeling overwhelmed. I was able to stop working part-time and cut back on my classes, and I saw it as kind of a convenient out from being overwhelmed and very stressed. Gee this was convenient. I was sick with a real medical disease. I am just being honest. I remember feeling some relief that I had a good excuse to cut back on my activities, but then it just got a little worse, and worse, and I stayed naive about it for quite a while, even when I was really quite sick and probably closer to dying than I realized and without proper care I really could have very easily, but I felt indestructible at the time.

I: How old were you then?

P: I must have been about 19, 20 and I was already engaged to be married, but we had decided not to marry until Mike finished and got his Bachelors degree, but I knew I was sick, and I was in the hospital a lot, but I never, for a minute thought I would die at that point, and then I still felt, had times when I felt cheerful and hopeful, and then we got married and it really seemed like shortly after I got married that things started to get worse. I had been on a lot of medications and they brought me to a point where it was, not gone, but under control. Suddenly I began noticing the limitations more, in terms of being married, being responsible for my own home. I had never lived away from home, and my husband was in graduate school, and he was gone a lot, and working very late, and I had never been alone before, cause I grew up in a family with 6 people, so I was by my self a lot. We moved to a different town. I had never lived away, and I was alone. It made me nervous to be alone at night. I started working part-time because we needed the money, and I began to get more fatigued. I would have little set-backs. I was having side effects from the medication. I began to get heart arrhythmies and high blood pressure, and things started happening to me that were related to the Lupus in some respect. Some of it was anxiety I think, but a lot of it was the Lupus causing-when it started to affect my heart that was the most frightening thing of all. Then I-my heart had always been very healthy but I went through long spells of irregular heart beats where I would almost pass out, and they finally documented these on twenty-four hour EKG etc., and I became very afraid of dying all of a sudden and felt like, when I most needed my husband because of this tremendous fear, he was not available. In fact if I would say, I feel frightened because of this or that, I would call him at the school, you know, he would say, I can't come home. I have waited all day to get on this equipment. I have research to do, and the

only time the graduate students get to use it is at night, so he would be angry. Not angry, he would be irritated that I was asking him to come home because I was afraid. So after a while I realized that I couldn't count on him to be there, and in fact if I did say anything he would react with resentment and that kept on going for years and years and then the depression started after that, and I was living away from my family. We always lived in cities away from my family. I was alone a lot. Didn't have a good support group, knew nobody else with Lupus, didn't go to Lupus support groups, didn't know of any back then, didn't even consider counseling, didn't realize that I was depressed, but I did at some level but I couldn't even label it with that word. I knew things didn't feel right, I was sad a lot.

I: So you felt very isolated?

P: Very isolated, and my husband would want to go on back packing trips—he is an outdoors person, liking to do things out doors in the sun a lot, things that took a lot of energy, and I couldn't always do those sort of things and I couldn't always do those things and he seemed disappointed and I began to feel like I was really letting him down, and also the thing about, we weren't able to have children. We found that out before we were married and his family seemed to be disappointed about that and I was aware that they were, and I was aware that his grandparents had tried to talk him out of marrying me when they found out I had the disease, but they never talked to me directly about it and we truly never, I never talked about it with anybody. Not with my own family, or with his family or anyone. I just had a sense of my own family being very protective and being very worried about me and his family being kinda disappointed. They had a daughter-in-law who had this illness and couldn't have children, a couldn't lead what they thought was a normal life. So that—then I tried to pretend that I didn't have it. And I just tried to as much as I could, work as much as I could without letting people know that I had the illness, or tried to pretend that I didn't have it. But I did and I would keep getting these little problems and the panic attacks started, and I developed agoraphobia, afraid of going out, for a while I couldn't go out even to the laundry mat or the grocery store. If I tried my hands would shake so badly I couldn't write the check. I don't how that all—it just seemed like not getting enough support, and these scary little things like the heart, my heart felt like such a vital part of me. The arthritis I could deal with and this and that, and the kidneys, but it wasn't until physically it hit my heart that I really got scared. Then I just went a long time not doing very well, and we moved to TN about 12 years ago. My first year I stayed at home and felt depressed. I didn't know anyone here, then I had played violin before, before I got married, 4th grade into college, and so I didn't work my first year here and so I though I will take violin lessons again. My violin teacher encouraged me to join the orchestra and she said I needed a new violin bow and the only way we could pay for that was if I went to work again. So I went to work out at the lab part-time, and I started to get more confidence from that, just little by little. Just playing in the orchestra was fun for me, so little by little I felt my strength and my confidence coming

back, sort of physically, but I knew I still wasn't real happy in the marriage. I knew I was still depressed, but I didn't really know what to do about it, and I still felt my husband's resentment. It seemed like for being sick.

I: Right at this moment, I know there has been some changes in your life recently, how do you see yourself, how are you experiencing yourself as a Lupus patient? If there any change from the past?

P: Well one big change from the past is I am not having the panic attacks any more, and I think due a lot to the medication they put me on earlier this year when I was hospitalized for the depression which just became so bad, I couldn't function, and my physician put me over at Peninsula. I just fell apart, and I had some panic attacks at the hospital, then I told them about my history of having these attacks, they put me on the medication, and I haven't had any since then, and that has eased a lot of the fear and distress that I have had and I have not had any real physical symptoms that I am aware of of the Lupus. My tests have been good this year from Dr. Hembry. I don't think about the Lupus again, even starting the full-time job again, people, my husband, said we don't know if you should do that, but I had to do it because I was going to be separating from my husband and I needed to support myself. I felt some confidence in doing that, and it has been a very difficult, stressful job, and I'm not sure if it will be the right job for me to stay in but I have been doing alright so far, and I don't feel like it is making me sick.

I: Now, before you said you basically deny that you have Lupus, is this the same experience now or are you saying that you just don't think about it. Is there any difference from the past or you are basically -

P: It seems to me that when I am not having symptoms, I feel as though I don't really have the Lupus. I know that I do because the tests still show positive, but my other tests are pretty good. It is not really active in my body right now, that I am aware of, causing arthritis or something. I don't quite why that is. I haven't really thought about it till you asked me, but I petty much don't think of myself as a Lupus patient.

I: Let me just put this final question to you, OK? You know the purpose of this study is to help other people understand how Lupus patient's feel about themselves and the disease. It is to try to understand the disease from the perspective of the patient, OK, and in this you are teaching us how it is like to be a Lupus patient, if you were to let us know something that would be really important for us to understand about Lupus, from your experience, what would that be like?

P: OK, I guess there is one thing. There is one major thing. I do blame the Lupus for, to some extent, not entirely, for the failure of me to be able to follow through with some of the dreams I had for my life. I did always want a family. Of course I have my adopted son now, but not being able to have children because of the Lupus was a horrible,

horrible disappointment to me, and that hit very hard, and I think attributed to the depression down deep, but it wasn't something I talked about to people for many years. I blame the loss of that on the Lupus, and I didn't finish school, and I feel bad about that. And I always had a dream to go back and finish, at least up until recently, I've felt it was because of the Lupus that I wasn't able to finish, but then I was able to take that class last summer, so maybe it was my fears of what the Lupus might do, and not the Lupus itself, but I felt that the Lupus affected my marriage tremendously, that my husband was extremely disappointed because of the disease in me, and I think, I don't know, our marriage might have been - he might have been sort of a non supportive person even without the Lupus. He likes me best when I'm healthy and active and so on. It had tremendous impact, especially in the earlier years of our marriage in giving us a very bad start in our marriage. Maybe if I had married someone who was very understanding and supportive that might have been different, but I think the Lupus has affected my life tremendously, really. A lot of loss.

I: A lot of loss and disappointment.

P: And fear, fear of really living.

I: Is there anything else that you think might be important that maybe we have not talked about?

P: The uncertainty of what might happen with the disease, the unpredictability of it caused a lot of fear. I began to realize what it's potential was and various strange things did happen to my body. The uncertainty of it and the never-ending possibility that it could just go on forever was not good. That really through me off. I couldn't see an end to it and I never knew what it might do next. I think that is why it scared me so much to think about that, that I kinda just tried not to think. I think that is why, even when I first heard about the support group, I didn't want to I didn't want to come because I didn't want to be reminded of what could happen with Lupus, and I do see some of these people very sick and sometimes it is upsetting in some respects, because it reminds me of how sick a person can get with it. It was a little psychological thing I just do where I just don't think.

I: Thank you very much. If you think of anything later that you would like to add, just let me know.

VITA

Luis Fernandez was born in Habana, Cuba on February 8, 1955. His grandparents were Spanish immigrants . His father was a physician and his mother an artist. From them he learned an appreciation for the sciences as well as for the humanities as expressions of man's reason and creativity. In 1969, he left Cuba for political reasons and lived in various countries including the United States. He became an American citizen in 1975 and joined the Army's 82nd Airborne Div.

After the military service, he obtained an Associate in Science Degree in Respiratory Therapy from Miami Dade Community College, graduating with Honors and receiving the Max Glasser Award for academic excellence. He married in 1980, had a son and returned to college. In 1984, he received a Bachelor of Arts degree in History from Florida International University with Honors. In September of 1987, he entered the Clinical Training Program in Psychology at the University of Tennessee, Knoxville. In 1991, he was offered a predoctoral internship at Bethesda Naval Hospital in Maryland, and a commission as a Lieutenant in the United States Navy.

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