This is to certify that the

dissertation entitled

A STUDY OF LIFELONG TRANSITIONS, EXPERIENTIAL LEARNINGS, AND COPING RESPONSES OF SIX FEMALE SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS BETWEEN THE AGES OF 20 AND 51 YEARS

presented by

James J. Scott

has been accepted towards fulfillment
of the requirements for

Ph.D. degree in Educational Administration

James E. Hoddy
Major professor

Date November 6, 1991

DATE DUE	DATE DUE	DATE DUE
OCT 2 6 1993		

A STUDY OF LIFELONG TRANSITIONS, EXPERIENTIAL LEARNINGS, AND COPING RESPONSES OF SIX FEMALE SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS BETWEEN THE AGES OF 20 AND 51 YEARS

By

James J. Scott

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Department of Educational Administration

1991

ABSTRACT

A STUDY OF LIFELONG TRANSITIONS, EXPERIENTIAL LEARNINGS, AND COPING RESPONSES OF SIX FEMALE SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS BETWEEN THE AGES OF 20 AND 51 YEARS

By

James J. Scott

The purpose of this study was to understand the life histories and experiential learnings of six persons with systemic lupus erythematosus (SLE) and to determine the kinds of transitions, losses, and coping behaviors that were prevalent in this group. The limiting factors for involvement included: female, ages 20 to 51, and 5 years diagnosed with SLE.

The study incorporated a combination of research techniques. Each subject was given three survey instruments and a series of interviews. The interviews were based in part on preliminary data obtained from the survey instruments. The survey instruments included the Lifeline Inventory, Life Changes Inventory, and Response to Loss Inventory. These instruments helped identify and record significant events in the lives of the subjects. In addition, attitudes and perspectives related to their losses were identified.

The data were reported in three major sections: subject profiles providing a brief life history of each participant, summary

of the Response to Loss Inventory, and assertions that evolved as a result of the interviews and inventories. Quotations and vignettes were used to frame this section. The assertions section had two parts--original assertions and new findings.

Four categories of conclusions were identified. The key factors contributing to coping and management of stress were:

1. Beliefs of the subjects--a belief in a higher power as a source of strength and energy.

2. Factors related to establishing and maintaining hardiness: (a) clear priorities create order, and (b) letting go is a source of power.

3. Actions taken by the subjects related to coping--positive self-care can lead to more effective commitments.

4. Transformations and experiential learnings related to loss: (a) some events in life cannot be anticipated or planned, (b) there is always more than meets the eye, (c) where there is commitment there is power, (d) what you focus on grows, (e) live now, and (f) love can heal.

Committee chairperson: Dr. James E. Snoddy

ACKNOWLEDGMENTS

This research would not have been possible without the support, effort, and love of a number of very special people. First of all, a special thanks to those unnamed subjects who shared their life stories and whose vision it was to contribute to others who are faced with chronic illness with their own stories. They are truly heroes.

Second, I would like to thank Cheryl Saylor for being the inspiration to venture into this project and John Schneider, who provided access to his sensitive tools for investigating loss and transformation and for his support in the interpretation of the data. I would further like to thank Dr. Richard Gardner, Dr. Doug Campbell, and Dr. William Hinds, who as a committee contributed to my efforts with positive evaluation and support for the duration of this research. They also were my guides in a number of courses that prepared me for this journey. I would especially like to thank Dr. Jim Snoddy, whose coaching and input I valued most highly of all. He was always there in positive, supportive, and constructive ways.

Finally, I would like to thank my loving wife, Lisa, and my children for their unending patience and encouragement as I have worked through this process. Their conditional love has provided me with the commitment and effort to complete this dissertation.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER I

INTRODUCTION

As an instructor for at least 15 years of stress management for college traditional and adult nontraditional students, this researcher has wanted to understand more completely how people deal with the transitions of life. Marriage, birth, divorce, illness, and personal failure are just a few of the kinds of transitions that people are confronted with daily. It was understanding how people deal with these transitions that interested this researcher.

The central focus of the writer's teaching has been sharing stress-management concepts and techniques by using parables or stories. As an adult educator and learner, he has found that the intimacy of his stories and the students' involvement in their own learning have significantly contributed to the students' ability to understand stress-management concepts on a more profound level. In undertaking this research, it was important that it:

1. Be a source of intimate stories that reflect people being confronted with significant life transitions.

2. Involve individuals who had been forced to face life's challenges over a long period of time. Systemic lupus erythematosus (SLE) is a chronic degenerative disease that is difficult both to diagnose and to treat. These factors are important because in many

ways this disease characterizes and parallels the transitions of life in general. All people are confronted with losses that cause them to adjust.

3. Involve narrative opportunities rather than quantitative information.

4. Look at the participants' life histories. The researcher was interested in the relationship between one's illness and wellness and his/her outlook on life.

After a series of interviews with allied professionals, a preliminary review of the literature, and communication with various support agencies, SLE patients were chosen as subjects for this research. The nature of the disease and its correlation to chronic illness make this research very transferable. Currently, there are more than 500,000 diagnosed SLE and discoid lupus patients in the United States. Most experts believe that this number may be low because of the difficulties encountered in attempting to diagnose the disease accurately. SLE is also part of a greater disease category known as chronic illness. Approximately 22 million Americans have been identified as having chronic illness. In addition to these factors, the disease has other characteristics that make the research as it relates to stress, coping, and loss very generalizable, including the following:

1. The disease is chronic and difficult to diagnose.

2. Because of the nature of the illness, there are often periods of remission and recurrence. This leads an individual through significant periods of transition and loss.

3. The disease is a result of an overly responsive immune system. Immune-system-related diseases are on the rise, cancer and acquired immune deficiency syndrome (AIDS) being the most visible.

4. The disease may attack and even tear down any organ in the host's system. This means a SLE patient could mirror symptoms of many other chronic illnesses, which might include kidney disease, rheumatoid arthritis, and heart disease, to name a few.

There is a strong parallel between chronic illness in general and SLE. In both, individuals are forced to face many unplanned transitions that force them to cope and adjust to changing circumstances.

A number of the basic elements of society are in turmoil. The structure of the family has changed significantly in the last 40 years. Now, approximately one of every two marriages ends in divorce. This revolutionary change of the family unit and American society is leading to recurring generations of dysfunction (Barna, 1989). Divorce, abuse, and violence have reached staggering levels in recent years (Bureau of Census, 1988). Given these changes in the family unit, we are seeing a basic change in societal values and structure. Support for the individual from the family unit is diminishing. The closely knit family is becoming a support group of the past. Dysfunction breeds dysfunction.

Added to these changes has been an ever-increasing distancing from each other. Individuals' skill in communicating at intimate levels, in sharing their innermost thoughts, is being compromised.

Television and radio are adding to this problem. Through provocative, highly targeted advertising and program production, adults and children are being exposed to a multi-layered value system that is different from past values (Barna, 1989). The powerful realities of life are being replaced by fantasy and tremendous amounts of superfluous information. These changes in access to media and the deterioration of the family unit are providing less opportunity for youths and adults to grow and mature in positive environments. The images that are constantly being flashed on the screen are becoming the new realities and values of today's generation. One can begin to see how these significant changes can contribute to confusion and increasing levels of individual transition.

The emergence of new levels of drug abuse, addiction, and violence is presenting a dilemma that is unique to American society (Smith & Smith, 1990). All these are reflections of growing levels of dysfunction.

For these reasons, this study was focused on the lives of SLE patients.

Importance of the Study

The researcher's purpose in this study was to understand the life histories of six persons with SLE and to determine the kinds of transitions, losses, and coping strategies that were prevalent in this group. Very little work of this kind has been done in the area of SLE and coping. Furthermore, most of the support agencies for

SLE have been in existence for fewer than 20 years. The present research was undertaken to provide some insight for others into what life is like for a SLE patient and how a person with this chronic illness survives.

As the world becomes more complex, there seem to be fewer examples to which we, as evolving individuals, can look for models of healthy behavior. The understanding of how one copes with life and how one can survive with joy is clouded. The need to examine how people face transition, cope, and survive the losses of life with joy is greater now than ever before.

In addition, a number of diseases related to life style and the environment are on the increase. Chronic illness is becoming an ever-increasing factor in American society. At present, more than 22 million Americans suffer from chronic illness (Pitzele, 1985). As technologies and abilities to prolong life increase, so does the presence of those afflicted increase. SLE and discoid lupus patients now number more than 500,000 and are in the category of chronic illness (National Lupus Foundation, 1990). Many of these diseases are related to how individuals handle their internal environments, their ability to cope, their ability to develop systems of eustress, and how they confront the world around them (Krantz, Grunberg, & Baum, 1985).

The incidence of other immune-system diseases is on the rise. Cancer is the most prevalent. More than 400,000 people annually die from cancer (American Cancer Society, 1989). It is now believed that all illness is, in part, stress related, and cancer is one of

the most significant (Davison & Neale, 1990). The use of tobacco and alcohol is an example of how people choose to cope and how their lives are negatively affected as a result of their choices. According to the American Cancer Society, close to 90% of all lung cancer is related to tobacco use. A significantly high percentage of all cirrhosis of the liver is related to alcohol consumption (Morra & Potts, 1987).

In addition, the presence of AIDS is contributing to the already staggering problems with health care. AIDS is an immune-system disease that is chronic and difficult to treat. There is no known cure, and the disease is ultimately fatal. AIDS is forcing society to examine an entire set of very difficult issues and concerns. Many of these issues deal with people's basic values and morals. AIDS may force people to reestablish values that are very different from the mainstream of society as it is known today. The choices and the issues are quickly approaching. In 1980, the disease AIDS was not even present in the medical books. In 1989, the National Institutes of Health projected that there would be more than 270,000 cases of AIDS in the United States by 1992. The World Health Organization (1991) has predicted that there will be more than 40 million cases of AIDS worldwide by the year 2000. This is an increase of 10 million over previous predictions. If current levels of the illness continue, these projections will be accurate, and the year 2000 will be a very different time in the United States and the world.

The present study was intended to provide a glimpse at how people faced with recurring life-threatening transitions survive in light of a changing society. If even a minimal sense of understanding what SLE patients are confronted with is gained, and how they may have developed systems for survival as a result of their transitions, society can benefit. There is a possibility that, as a result of this research and the sharing of experiences, people can begin to see how others cope and learn from the transitions of illness. A number of intimate samples of behavior will be provided in this study. From these samples, readers may gain a more personal perspective for their own behaviors.

Major Assertions

The assertions included below were developed from the initial readings, the researcher's work in the area of chronic illness, and conversations with health professionals. These assertions provided a starting point for this research.

1. Illness forces people to evaluate their lives in profound and lasting ways. As a society, we have a great number of cultural norms concerning how our lives should be and where our greatest lessons in life originate. The effect that illness has on one's life is not always evident, nor is it often discussed. This assertion concerns the depth to which one's life is affected by illness.

2. There can be a positive relationship between a person's illness and the quality of life as he/she perceives it. There is a

perception that as one becomes ill the quality of his/her life decreases. The researcher was not sure one can make that assumption. The quality of one's life may be relative to the particular point in the individual's experience. The essential question in life is how one can be happy, and whether one has to be healthy to be happy is a real concern for many people.

Research Questions

In light of the researcher's interests as an educator, he began to look at some of the issues facing individuals with SLE and chronic illness. The writer did a preliminary review of the literature and spoke with a number of researchers and educators regarding the purpose of this study. Those individuals included a graduate studies support group. The researcher developed a number of preliminary questions and submitted them for the support group's review. Additional questions were developed through the guidance of the writer's research committee, with a specific focus on loss. These questions focused on four areas:

1. What kinds of transitions and experiences do SLE patients face as they mature with their illness?

This category of questions helped in examining life transitions in general and disease-related transitions in particular, i.e., diagnosis, remission, and related problems. The focus was on looking at all transitions, not only those of the factors related to illness. This line of questioning helped to frame the individuals' life stories and to look at their illnesses in light of the whole of

who they were. In illness, one is confronted with a number of issues that may be placed above other kinds of transitions in life. The researcher sought to understand to what extent these complicated and increased stress-related factors.

2. What kinds of life skills related to coping appear to be most helpful?

Understanding the skills these subjects had used and trying to get a sense from them as to which skills or support issues had been most helpful was an important element of this research. All too often, we see only the results of someone's coping skills, but we do not have the opportunity to understand what is occurring and how it is functioning.

3. How are most effective coping skills learned?

The further implications of this study include how these skills were learned and how they can then be transferred to other people. The issues surrounding transference are key to involvement of this kind of learning in an educational environment.

4. Are certain skills more meaningful at different stages in one's illness?

The notion that stages of illness and skills of coping are standard throughout the various life spans needs to be looked at more completely. How experience promotes healing and how insight promotes well-being are two complementary questions.

5. Are there periods in which loss is identified as a significant factor in the quality of one's life with chronic illness?

There is a great deal of literature on the elements of loss and its effect developmentally. The question of how loss relates to chronic illness is important because it may provide understanding that influences one's approach to coping and treatment.

6. What social support is encountered, and how is the individual affected?

The role of social support in chronic illness has been discussed, but little has been written about the development of social support systems. Researchers usually have addressed only group perspectives and not the perspective of the individual.

7. Are there common threads that can be identified related to coping and surviving with SLE?

The Sample

In this study the researcher focused on six individuals who had had SLE for at least five years and had experienced recurring periods of illness and remission. The age group was from 20 to 51 years. The sample included individuals who were married with children, single, and single parents. Sample members had varied levels of involvement both in terms of the disease and the length of time with symptoms and diagnosis. Members of the group were all females. The process for selecting SLE patients for involvement in this study is described in Chapter III.

Sources of Data

Data were collected on two levels, primary and secondary. Primary sources of data were those that provided information in its

raw form, without interpretation from the subject. These included interviews and reflective materials such as journals and art work. Secondary sources were used to draw information of a more quantitative nature from and about the subjects. Examples include interviews with significant others and survey instruments. These sources are described in the following paragraphs.

Primary Sources

Primary source identification is described in Chapter III. Taped interviews were structured with the use of a tool called a Lifeline (see Appendix A). Each participant was asked to create a Lifeline. The individual was then asked to outline the events that were significant to her life. The periods of life were identified in the following manner: pre-illness, initial stages of illness, illness/wellness stages, and major learnings from their experiences. The interviews focused on describing the experiences that the participant outlined and that were discovered in the interview process. As part of the researcher's teaching, he had used this technique with well over 500 students. The technique provides a powerful opportunity for intimate dialogue and rich glimpses of a person's life.

Other primary sources included the review of those journals, drawings, or articles the subjects had created. The Lifeline was included in this category because it was a first-person narrative.

The following procedures were included in this study.

1. The life story was developed through interviews with each person.

2. Personal journals and written reflections were reviewed.

3. Site visits were made to the participants' homes and work places to understand better the environments in which they spent their time.

Secondary Sources

The secondary sources used in this study were developed to provide an additional perspective on the subjects, their experiences, and the effect of those experiences on their lives, as perceived by others or through exploratory surveys. These sources helped in the triangulation of data and provided a means of validating the perspectives of the subjects. These sources were as follows:

1. Taped interviews were conducted with one or more significant others in the SLE patients' lives. The persons involved were family members, friends, or a therapist (Appendix B).

2. Schneider's Life Change Inventory (Appendix C) was used to help each participant review her life transitions and their perceived value.

3. Schneider's Response to Loss Inventory (Appendix D) was used to evaluate the subject's stage of loss or recovery. This instrument was designed to identify the various elements of grief

(Appendix E). It has been validated and helped to provide another picture of the subjects' lives at a particular time (Appendix F).

4. A limited review of literature was conducted on the following general topics: stress, coping, transition, managing, SLE, and holistic approaches to treatment for SLE patients.

Analysis of Data

The data were analyzed in the following manner:

1. The interviews were taped and reviewed in a systematic manner. Vignettes and data were extracted from interviews to verify or challenge the initial assertions. In addition, new findings evolved from the data. This also helped contribute to the evolution of new assertions.

2. This information was then triangulated with other written materials provided by the participants. The additional written materials included the Lifeline, the Response to Loss (RTL) Inventory, the Life Change Inventory (LCI), and journals and/or other reflective work.

Definition of Terms

Coping. Efforts to master conditions of harm, threat, or challenge when a routine or automatic response is not readily available (Lazarus & Folkman, 1984; Murphy, 1962; White, 1974). Coping refers to things people do to avoid being harmed by life strains (Pearlin & Schooler, 1978). Coping has been defined as the overt and covert behaviors individuals use to prevent, alleviate, or respond to stressful situations. Coping can occur before, during,

or after a stressful or challenging situation (George & Sielger, 1981).

Dysfunction. Disordered or impaired behavior related to relationships with others. The term frequently is used to describe an individual's behavior in a social or family setting (Black, 1983).

Illness. A sickness with mind or body. Illness has been defined further as a disease and has been broken down in the following manner: "dis-ease, ill at ease with one's mind or body. . . . Illness is any departure from health" (Webster's New World Dictionary, 1968).

Remission. The act of lessening a degree of illness. There are two types of remission, serological and clinical. Serological pertains to test parameters in the blood. Clinical pertains to observable parameters (Guyton, 1966).

Stress. Determined by the perception of the situation rather than by the situation itself. Pascal (cited in Lazarus, Deese, & Osler, 1952) defined stress as "a perceived environmental situation which threatens the gratification of needs" (p. 177). Lazarus clarified the concept by saying, "Stress occurs when there are demands on the person which tax or exceed his adjustive resources." "Stress is a state which arises from an actual or perceived demand-capability imbalance in the organism's vital adjustment actions which is partially manifested by a non-specific response" (Monat & Lazarus, 1964).

Systemic lupus erythematosus (SLE). An inflammatory autoimmune disorder. The disease affects many body organs, especially the heart, lungs, spleen, and kidneys, About 85% of all SLE patients are female, most of them between the ages of 10 and 50. Although the cause of SLE is unknown, it is believed that people with the disorder manufacture antibodies that attack their own body tissue (Phillips, 1986). Onset of SLE is often during periods of emotional crisis or during severe exposure to sunlight or X-ray. Several drugs, including hydralazine, isoniazid, and certain anticonvulsive medications, may cause the disorder as a side effect. Viruses also may play a causative role (Grossel, Stansloski, & Kramer, 1980).

Transitions. Periods marked by relational and personal changes, including attempts to deal with upset, tension, or fatigue and attempts to find new sources of support (Weis, 1976). Transition may be further defined as positive or negative (Moos & Tso, 1976; Schlossberg & Leibowitz, 1980).

Triangulation. A data-collection and analysis process through which a subject can be studied by the use of varied types of data (Biklen & Bogdan, 1982).

Wellness. A process or life style that promotes making choices and taking actions that allow one to work toward his/her physical, emotional, and spiritual potential (Travis & Ryan, 1988).

Organization of the Dissertation

Chapter I included an introduction to the study, the importance of the research, major assertions, research questions, a description of the sample, sources of data, the risk-to-benefit ratio, the data-analysis methods, and definitions of terms.

Chapter II is a review of literature. The chapter is organized so as to help the reader understand the nature of SLE and explore some of its correlations with chronic illness. A brief overview of stress and coping is included, with specific attention to chronic illness and coping.

The research methodology and procedures are described in Chapter III. The data-collection procedures, interview process (questions and settings), environmental scanning issues, and qualitative-analysis factors are discussed.

Subject profiles, a summary of the RTL responses, responses to initial assertions, the identification of new findings, and additional insights are presented in Chapter IV. Chapter V contains observations and recommendations for further study, implications of the study, conclusions, and closing observations.

CHAPTER II

REVIEW OF THE LITERATURE

The Picture of Lupus

The amount of information in the fields of lupus, chronic illness, coping, stress, and lifelong transitions is extensive. The writer did not try to be all encompassing but focused on some of the significant literature on the interrelatedness of SLE to loss and chronic illness to stress. Its relationship to coping was explored. The following review of literature has been organized to help the reader understand the nature of SLE and to explore some of its correlations with chronic illness and lifelong transitions. After this relationship has been established, a brief overview of stress and coping is provided, with specific attention to chronic illness, loss, and coping.

Systemic Lupus Erythematosus (SLE)

Chronic illness can be a real and significant part of life (Pitzele, 1985). In reading this section, one should keep in mind that the presence of illness is a part of this journey of life for all people. Illness has to be faced and embraced like all other parts of life if we are to achieve our potential for high-level well-being (Pelletier, 1977; Schuller, 1983). Part of understanding our potential is to explore the unknown that weaves our lives into a

web of the mysterious. This understanding can help us embrace the adventure, the joy, the sadness, and the beauty of life. The intention of this review is to explore a few elements that we will most likely be confronted with as we mature.

Twenty years ago, SLE was a rare disease. Only 40% of all SLE patients were expected to live three years following diagnosis. Now more than 90% will survive ten years or more (Phillips, 1986). Today, SLE is recognized to be more prevalent than muscular dystrophy, multiple sclerosis, cystic fibrosis, rheumatic fever, pernicious anemia, Hodgkin's disease, and leukemia (National Lupus Foundation, 1990). Optimistically, one can extrapolate from these statistics that increasingly more effective treatments will continue to improve not only life expectancy but, more important, the quality of life.

SLE is a chronic inflammatory immune complex disease of unknown cause. SLE can affect virtually any body organ or system. Organs that can be affected may include skin, joints, kidneys, brain, lungs, and heart. Diagnosis is very difficult (LeMaistre, 1981; Ragan, 1988). Many SLE patients reported that they sensed vague aches or pains, or ran a fever with some frequency but not with any predictability. Others reported that they stumbled unexpectedly while walking. Stairs became increasingly difficult to navigate. Some had weakened hands. Virtually all reported that they were hesitant to face their physicians with such undefined problems (Aladjem, 1985).

Part of the problem with the diagnosis of SLE is that it is a chronic illness with many nonspecific symptoms that occur intermittently and are similar to a number of other chronic illnesses. Communicating these symptoms and their inconsistent nature is difficult (Blum, 1972; Boyle, 1970; Francis, Korsch, & Morris, 1969; Permut, 1989). Many of the symptoms create their own anxiety because of their perplexing look-alike nature with a multitude of other illnesses (Aladjem, 1985; National Lupus Foundation, 1986).

Symptoms may include many of the following but generally do not include all of them: chronic low-grade fever, chronic fatigue that can easily be aggravated, aches and pains, loss of appetite, weight loss, swollen glands, nausea and vomiting, headache, depression, easy bruising, hearing loss, edema, and swelling. Other symptoms that often are evident include a rash over the cheeks and bridge of the nose, discoid lupus lesions, developing rashes after exposure to the sun or ultraviolet light, ulcers inside the mouth, seizures, anemia, Raynaud's disease, bald spots, and organ involvement (Lupus Lifeline Book, 1988; Spelman, 1977). Symptoms involving organs may include chest pain due to pleurisy and irritation of the membranes lining the inside of the chest around the lungs, and pain due to pericarditis. Muscular system and joint involvement may include primary muscle weakness and aching pain along with arthritis-like pain, swelling in the joints, redness, and stiffness. The blood may also be affected with low red blood cell counts. White counts may also decrease, thereby increasing the person's susceptibility to

infection. Increased amounts of gamma globulin in the blood may also be a problem with SLE, and blood tests may indicate a false-positive test for syphilis. There is also possible involvement in the heart and circulatory systems, nervous system, digestive system, and kidneys. What is incredible is that the types of symptoms are so varied that they mask the specific issues related to SLE (Phillips, 1984).

Patients with SLE also develop distinct abnormalities of the immune system. In addition to making antibodies (specific substances that help destroy foreign material entering the body against bacteria and viruses), the bodies of lupus patients make antibodies to their own cells. They are called antinuclear antibodies. A diagnosis of SLE is likely to follow the discovery of these antinuclear antibodies. The antibodies are also related to one's DNA (Aladjem, 1985; Lupus Erythematosus, 1985; Phillips, 1984).

The degree of symptomology that a patient may have will vary significantly, depending on the intensity and the amount of involvement the patient has with the disease ("Lupus Erythematosus," 1985). Many also experience arthritic or swollen, inflamed joints. Lungs and kidneys are involved about 50% of the time (Phillips, 1984).

Many times these symptoms come and go without pattern, warning, or explanation (Lupus News, 1986). The adage, "well until proven sick," is more often than not the case with SLE patients. The

notion of hypochondria is very often alluded to. In texts by Aladjem (1985), Permut (1989), and others, this was mentioned repeatedly. SLE is usually easier to diagnose when an individual has many of the characteristic symptoms and signs, and, as may be expected, diagnosis is made more difficult if none or only a few are present. Aladjem ascribed the confusion about whether neurotics fall prey to SLE, or whether SLE creates neurotics, to a combination of factors:

> The frequent lag time in diagnosis, the intense emotions triggered by the disease and the potential for direct involvement of the brain through inflammation all promote this veil of deceit when it comes to trying to diagnosis Lupus. (p. 76)

In the book Understanding Lupus, Aladjem provided a check list and medical paths that help delineate the symptoms and issues related to diagnosis.

During the child-bearing years, females have a significantly higher rate of incidence than males. Females who are having menstrual cycles are ten times more likely to contract the illness than are males (Facts About Lupus, 1988). During premenstrual and postmenstrual periods, females are only two and one-half times more likely to contract the illness. Eighty-five percent of all persons afflicted with SLE are female. Approximately 16,000 new cases are diagnosed annually, and more than 500,000 Americans have been identified with SLE of various types and degrees of involvement. Minorities, including Blacks and Asians, have a higher incidence of involvement (What Is Lupus, 1988). There is no cure for SLE, but

medical treatment can lead to control of the disease (What Is Lupus, 1988).

There are three types of lupus:

1. Discoid lupus affects the skin, causing a rash and lesions, usually across the face and upper part of the body. The skin may become quite disfigured as a result of this form of lupus.

2. SLE, usually more severe than discoid, can attack any body organ or system, such as joints, kidneys, brain, heart, and lungs. If not controlled, SLE can be life threatening.

3. Drug-induced lupus, caused by reaction to medication, is the third form of the disease. Generally, when medication is discontinued, the lupus symptoms becomes less significant or disappear (National Lupus Foundation, 1990).

SLE can be characterized as a roller-coaster type of disease. It is frequented by periods of remission with varying degrees of flare-ups and organ involvement. Many times, when patients think they have gotten through it and are in remission, they have a "flare-up" and are right back where they started (Hogan, 1988). Flare-ups can vary in terms of intensity. The word *flare* is a poor descriptor for the actual reality of what may happen. A flare-up may consist of mild joint pain and fatigue that may last a few days. It may also consist of very severe joint and muscle pain with all the other types of symptoms that have been described. It is not uncommon for these flare-ups to force a person to be heavily medicated and bedridden or hospitalized for a month or more. Flare-ups may even result in death (Aladjem, 1985).

It is not uncommon for a person to feel perfectly normal one day and that night become severely ill. Equally so, some SLE patients who experience flare-ups may not do so overnight, but rather they might experience progressive decreases in their well-being over a period of several days, weeks, or months. Because the major complications of lupus may be preceded by milder symptoms, the patients may be in a position to inform their physicians about what is occurring. Fatigue and insensitivity to one's bodily responses may be a factor contributing to this, but this is not always the case. Nobody knows his/her body better than the patient. The one person who is in the best position to feel if the disease is flaring up is the patient (Luc Senecal, 1986). Each person's response is unique.

The following excerpt from Embracing the Wolf (Permut, 1989) is an example of the kinds of varied responses one might see with SLE:

> Over a period of four years, my lupus had grown from a case with no organ involvement to central nervous system lupus with minor brain involvement. We just had to hope that the seizures would not increase but would remain relatively manageable. (p. 37)

Descriptors similar to this one were common in a number of the books and pamphlets that were reviewed for this study (Aladjem, 1972; Phillips, 1985).

Little information is available on the possible relationship between the incidence and duration of combined serologic and clinical remission (Heller & Schur, 1985; Luc Senecal, 1986). There seems to be a great deal of initial evidence that the onset of

illness is accelerated due to stressful environments and chaotic life styles (DeLongis et al., 1982; LeShan, 1959; Locke, Hurst, Heisel, et al., 1979).

The odds of a quick, clear diagnosis and prognosis are not very good. When the laboratory test results remain within the "normal" range and the examination reveals nothing unusual, it is difficult for even the finest diagnostician to name this elusive illness (Pitzele, 1985).

Additional indicators that can help provide a clearer diagnosis include antinuclear antibody tests and antibody to DNA tests, blood counts focusing on white blood counts and related indices, and kidney-function tests. There is a great deal of difference between the narratives and written materials describing diagnostic options of even five years ago and the new materials being published by the national organization.

In a small percentage of cases, clinical and serologic remission occurs, often without medication and sometimes lasting for years (Heller & Schur, 1985).

Given all this information, scientists now believe that SLE develops in individuals predisposed to it and that a viral infection or similar stress can alter the delicate balance between normal immunity to foreign substances and reaction to one's own cells (Aladjem, 1985). Finding and removing such disease triggers would have the potential to be therapeutically more definitive and far more satisfying than the current option of trying to manipulate the immune response of the host (Heller & Schur, 1985). A patient whose

disease remits "spontaneously" and who stays well deserves the closest epidemiological scrutiny.

Chronic Illness

Many of the issues related to lupus are very similar to those of other chronic illnesses (Pitzele, 1988). SLE is clearly a chronic illness whose presence seems to be increasing (Lupus Foundation of America, 1988). Part of this apparent increase is due to the ability of the medical community to diagnose SLE more accurately. The chronically ill face a great number of factors. This is unique to SLE (Hogan, 1986). These common links may include:

1. Chronic fatigue. Fatigue from chronic illness can actually cause "fatigue of chronic illness." Inactivity inhibits the functioning of the autonomic nervous system. The blood circulates more slowly, the poisons in the blood are not oxidized, and the system becomes more sluggish (Aladjem, 1972; Jackson, 1979; Nguyen, 1984).

2. Loss. The losses of chronic illness are endless. The ability to whistle, to walk, to play, and to live in the same ways can be destroyed (Aladjem & Schur, 1972). Any loss includes more than one dimension (Schneider, 1984). In Schneider's (1989) Response to Loss Inventory, these dimensions are explored. They help provide a framework for understanding the transformative processes of loss. They further help define the interrelatedness of loss and grieving by providing a model for understanding loss.

3. Changes in relationships. Any relationship that meets important needs, or through which lasting patterns of behavior are developed, can be lost when changes occur, especially those related to chronic illness (Schneider, 1984). The stress of chronic illness can create a tremendous amount of uncertainty in a relationship. Coping with a serious illness is a hardship for both the patients and their loved ones (Ragan, 1988). Chronic illness creates a situation in which there is little certainty except the illness and questionable circumstances related to health (Pitzele, 1987).

4. Diagnosis is difficult. The journey from health through lupus is a confusing diagnosis and is riddled with questions and confusion (Aladjem & Schur, 1972).

5. Life style issues. The chronically ill especially recognize that there may be times when activities may have to be cut back and immobility will result. By planning ahead and having relaxing activities on hand to engage in during these times, boredom can be avoided (Lewis, 1985).

Additional concerns can include pain management, changes in expectations, and the ability to communicate both symptoms and responses to one's illness (Gould, 1977; Schneider, 1990; Viorst, 1986; Weenolsen, 1988). Losses can be compounded not only by illness, but by developmental issues related to loss and maturation as well (Schneider, 1990). Death, too, is present in a more real and frequent way. All of these concerns can be significant contributors to stress at many different levels (Pitzele, 1985).

Common to all persons with significant illness and especially related to newly diagnosed patients is an enormous craving for a reliable guide to their condition. It needs to be written in clear, accurate, sensible, compassionate, and practical terms. Seldom can physicians and health care professionals be accessible enough to satisfy the patient's emotional need for reassurance and to answer the countless questions that arise (Ley, 1967; Luc Senecal, 1986). According to current estimates, more than 55 million Americans suffer from chronic illnesses. Approximately 30% of America's adult population suffers from a chronic illness at varying levels of intensity (Pitzele, 1985). The following list of chronic illnesses (Pitzele, 1985) is extensive and varied. It does not represent all such illnesses.

Rheumatoid arthritis	16,000,000 patients
Osteoarthritis	16,000,000 patients
Stroke	8,700,000 patients
Heart disease	4,600,000 patients
Other arthritics	4,000,000 patients
Lung disease	3,150,000 patients
Diabetes	2,500,000 patients
Gout	2,500,000 patients
Parkinson's disease	1,500,000 patients
Lupus	500,000 patients
Diabetes Type I	500,000 patients
Multiple sclerosis	250,000 patients
Adult-onset dystrophies	200,000 patients

Other chronic illnesses that are not represented on this list, such as human immuno virus/acquired immune deficiency syndrome (HIVB/AIDS) and sexually transmitted diseases syndrome (STD), are not even considered in these numbers but are increasing at incredibly high rates (National Centers for Disease Control, 1988).

SLE is clearly a chronic illness that shares many of the same patterns and problems of other chronic diseases. Many of the issues related to diagnosis, treatment, and coping are interrelated (Pitzele, 1985).

Stress, Loss, Lupus, and Chronic Illness

Coping with the losses related to chronic illness is an extremely complicated and difficult process to understand and define (Hobfoll, 1988). Many times people are unaware of the possible alterations in one's view of life that may occur as a result of loss (Silver & Wartman, 1980). Often individuals who are experiencing a loss are asked to limit their responses to grief and not to dwell on their problems (Glick, Weiss, & Parks, 1974; Maddison & Walker, 1967). To limit the responses to loss and avoid grieving has a potential for grave problems (Schneider, 1984). Our society often is insensitive and ill prepared to address the needs of those who have experienced a loss or who are chronically ill (Wright, 1983). If people could identify their needs and the needs of those around them related to loss, meaningful interventions could be developed and positive support groups could be more effectively designed (Bracken & Shepard, 1980). Coping with illness and loss involves all of the major systems of the body, occurs in all social systems, and plays a vital role in one's development (Schneider, 1984). Words like worries, fears, goals, hopes, and faith can all be included as descriptors of behaviors and responses to stress (Kasi, 1966). It expands beyond the known and includes the spirit in

indefinable and mystical ways (Simonton, Matthews-Simonton, & Crieghton, 1975). There seems to be no single absolute definition of stress. This may be an indication of the complexity and the diversity of thought on this subject.

The accumulation of perceived changes, both chronic and acute, that one encounters in the process of living can be used as an umbrella for discussion related to stress (Giradano & Everly, 1987). Research has supported the view that there are high positive correlations between the frequency of major events in one's life and illness (Dise, 1988; Holmes & Rahe, 1967; Kobosa, 1979; LaShaw, 1966; Rahe, Ryman, & Ward, 1980; Sarason, Johnson, & Siegel, 1978). There is further evidence to support the notion that the presence of frequent minor problems greatly affects one's ability to cope (DeLongis, 1982; Lazarus, 1984). A number of others, including Mueller, Eward, and Yarvis (1977) and Vinokur and Selzer (1975) have contributed to this body of knowledge related to the frequency of problems and their effect on coping. There is still a debate as to whether undesirable events are the only things affecting how one copes, versus change itself. Rose (1980) interpreted stress in this way:

> The adult portion of the life span . . . is peppered with socially generated life strains that differ with regard to their persistence and predictability. Many life strains may have their roots in the fundamental arrangements of society but societies are at the same time also the source of many efficacious devices people use to withstand the full impact of the strains. Indeed, as varied as the life strains are, the ways of responding to them are richer yet. One learns from his experiences, from his membership groups, and from his culture a vast array of acceptable modes of anticipating, appraising, and meeting challenges. If these modes fail him, either because of

> their inherent lack of coping efficacy or because the challenging circumstances are not amenable to individual coping efforts, then he becomes vulnerable to psychic distress. But if one copes effectively, as people typically appear to do, then life strains may even have a positive contribution to one's development through the adult portion of the life span. Although much is still conjecture, we can be quite certain that to understand the well-being of adults, we need to observe the unfolding of the circumstances and events they experience, the meaning of the experience for them, and their attempts to avoid being harmed by it.

Earlier stress theorists recognized the cognitive components of stress and the physiological processes of stress separately. They generally did not integrate these components into major stress theories (Cannon, 1935; Grace & Graham, 1952; Selye, 1974). They tended to present these components as independent, governed by separate sets of rules. Subconscious processes have also been given little attention in stress research, but this does not mean they have been disproven. For the most part, they have not been studied. Recent research in health psychology has pointed to the need to consider the integration of cognitive and biophysiological stressors as factors to be considered jointly (Gatchel & Barum, 1983; Greenburg, 1989; Wolff, 1988). Stress and its management clearly span all of these parameters.

The relationship of stress, chronic illness, loss, and coping is complex and significant to all people. Correlations with the onset of illness and disease have been established in various studies throughout the last 40 years (LeShan, 1966; Mechanic, 1966; Simonton & Matthews-Simonton, 1975; Wolf, 1953). Excessive stress can be harmful to the human organism at many levels, to both the nondiseased and the diseased person alike. Stress can exacerbate

many disease forms and may, in fact, be a significant marker as to the onset of the illness (Dohrenwend & Dohrenwend, 1974; LeShan, 1966; Mechanic, 1978; Wolff, 1988). The correlation with other illnesses has been identified many times. Wolf (1953) demonstrated the effects of stress on the digestive system, and LeShan (1966) studied its effects on the development of cancer. In 1975, Simonton and Matthews-Simonton did further work related to stress and cancer, and in subsequent years this work has expanded.

In 1955, Engel studied stress and ulcerative colitis. Friedman and Rosenman (1977) identified the relationship between stress and coronary heart disease. Later researchers included anger and hostility as components in the development of the disease. Ischemic heart disease was proven to be four times more frequent in subjects with Type A behavior than in those with Type B, and arterial hypertension was 1.6 times more frequent in anxious and aggressive subjects (Damsa, Moscu, Schioiu, & Cucu, 1988). Wolf and Wolff (1955) studied stress and headaches, and Benson and Peters (1977) looked at the effects of stress on blood pressure.

As one begins to explore the sources of stress, a number of elements must be considered. Factors such as perception of change, threat, and loss are all potentially significant stressors. Both the threat of potential loss and actual loss can be significant stressors (Felner, Farber, & Primavera, 1983; Schneider, 1986; Schonpflug, 1985). The effect of stressors can be related to a number of elements. The elements can be identified as chronic or

acute, positive or negative, and real or imagined. For SLE patients in particular, and people with chronic illness in general, a number of elements of loss carry the potential for being significant stressors. Loss is a key factor in illness and life (Thoits, 1983). Many elements of one's life change with illness (Baum & Gatchel, 1981; Kasi & Cobb, 1966; LeShan, 1966). These include, but are not limited to, one's ability to participate on a day-to-day basis in activities and functions (Permut, 1987), the ability to communicate and interact socially, the ability to sustain oneself with work or play in ways that have been basic to one's nature (Schneider, 1984), a diminished ability to anticipate and have expectations on a day-to-day basis, and compromises in intimate relationships (Aladjem, 1985).

Additional factors that contribute to the stresses that may be encountered as a result of the preliminary onset of illness may include the following:

1. A change in one's ability to trust his/her own health and therefore plan for the future, in some cases on a daily basis.

2. The onset of various symptoms, which creates continuously changing internal environments and predictable daily schedules.

3. The loss of one's freedom due to physical or emotional restrictions.

4. The intrusion of medical personnel into one's privacy. The physical and mental domains become open for the medical community to explore in their quest for well-being.

5. The type of personal paradigm an individual has related to health, and how it may be challenged (Hinds, 1983).

As time passes, a number of other concerns are presented to the chronically ill person. These include learning to live with change and unpredictability, the possibility of pain management, relationship changes related to expectation and illness, depression, financial and job-security issues, and the presence of chronic fatigue or being easily fatigued (Aladjem, 1985; Permut, 1989; Pitzele, 1985).

Coping

Kobasa (1979) found that people who did not get ill after undergoing many stress experiences had a strong sense of meaningfulness. They also had a commitment to self, a vigorous attitude toward life, and an internal locus of control. This Kobasa termed "hardiness," which she defined as a sense of emotional insulation. A number of factors seem to contribute to this sense of hardiness (Tang, 1987), but further investigation needs to be done in this area.

The lack of a secure and loving environment has been correlated to a breakdown in immunological systems that fight illness (Turk, Ruby, & Salovey, 1984). Social support has also been identified as a potentially important moderator of the stress-illness relationship (Dakof, 1987). People with high-level social support have less concurrent strain, future strain, concurrent illness, and future illness than do those without such support (Tang & Mammontree,

1989). Lack of exercise and nutritional deficits also can increase one's sensitivity to negative information from the environment. These deficits can influence the onset of depression and thus negatively affect the immune system. The emphasis in stress-illness research recently has begun to shift toward the study of resistance resources. For the person who is already chronically ill, many of these factors are exacerbated (Burckhardt, 1953).

A number of factors contribute to coping at multiple levels; some of them are:

Enhanced coping skills. Enhanced coping skills were related to enhanced mood and personal empowerment (Janis, 1985). These skills may promote the ability to manage one's life in positive ways. They may include but are not limited to relaxation training, meditation, exercise, proper nutrition, problem-solving skills, empowerment skills, time management, and assertion skills (Janis, 1985).

Family resources. Family resources were related to better immunological functioning (Simonton, 1978).

Patient responsibility. Patients who took responsibility for their own health and well-being and who had a strong sense of family social support were much better off than those who did not. This was especially true if the support started early in the disease process. These patients were more likely to adapt to and cope effectively with their illness, thus affecting the disease progression, morbidity, and mortality (Locke et al., 1979; O'Brien, 1987; Wolf, 1989).

Coping with chronic illness presents both a challenge and a threat for patients (Leventhal et al., 1987). Coping strategies, when effectively used, are powerful methods for influencing one's functioning and well-being. Understanding the processes patients go through when confronted with chronic illness can make a major difference (Burckhardt, 1987). The idea of coping simply means one is adjusting to his/her illness. To adjust simply means the person is accepting circumstances and making the best of the environment. From a perspective of establishing a higher level of well-being, one may view coping as an element of accepting a sense of powerlessness (Benson & Kennally, 1976). To seek a higher level of well-being may necessitate developing new skills. This development would most likely be both mental and emotional (LeMaistre, 1981). Issues related to self-responsibility and life force are powerful enhancements of one's well-being during crisis but are extremely difficult to pass on to others in a formal sense (Ardel, 1987; Cousins, 1986; Travis, 1988).

In looking at the issues of self-responsibility and spirit, it can be seen that the environment and social support play a large role in coping styles (O'Brien, 1987). There is a strong correlation between coping dispositions of individuals and the value system of the surrounding society (Pearlin, 1978). It seems fair to state that interest in coping far exceeds the knowledge about it. Mechanic (1978) argued that there are basically two components of adaptation: (a) dealing directly with the situation, or coping; and (b) dealing with one's feelings about the situation, or defending.

The amount of stress one experiences is therefore dependent on the availability and effectiveness of one's means for coping and defending.

A major problem with the concept of coping related to chronic illness is that people tend to focus on an "illness model" rather than a "wellness model." The illness model focuses on one adapting to one's situation, whether he/she likes it or not (LeMaistre, 1981). For the healthy person, this belief structure works reasonably well. It is when the individual becomes chronically ill that the system does not serve him/her well. Illness challenges one's basic belief system. Consideration needs to be given to an alternative to this kind of model. A true adaptation of a wellness model needs to be made. This adaptation suggests that development, emotional growth, and striving instead of surrender to a less-than-satisfying existence are important issues (Simonton et al., 1978).

Data suggest that individuals who have a locus-of-control orientation of powerful others respond to chronic illness with emotionally based behaviors. Chronically ill individuals who are physically dysfunctional tend to respond with palliative coping strategies (Keller, 1988). The statement "I am thankful that I have my health, at least" no longer means anything. A basic belief focused on "It could be worse" ultimately may take its place (Pitzele, 1985).

Understanding stress and how to manage it can be helpful to one's disease state (Mechanic, 1978). Literature on both humans and

animals seems to support the concept that the way one copes with stress is an important modifier of the stress-disease relationship (Coyne & Lazarus, 1980).

There is also evidence that the way people cope with illness or surgery can affect the process of their recovery (Roskies, 1987). Coping related to chronic illness can also be enhanced when the patient has a thorough education about his/her disease, the treatment options, and self-care concerns (Phillips, 1985). Such knowledge helps the patient with chronic illness learn to control elements of his/her illness instead of being controlled by it. Patients can learn to fight back, rather than be invaded by the disease, and join in with their physicians to gain an element of control over their illness or, if not their illness, their quality of life (Luc Senecal, 1986).

The range of possible interventions is great. No single stress-management approach is completely effective (Everly & Giradono, 1986; Gatchel & Baum, 1983; Greenberg, 1988). It is generally thought that a system of management that involves the individual at many levels and through several modalities has the best potential to affect his/her long-term well-being. The stress-management concept of wholism is one in which a collective approach is used, which intervenes at many levels to help a person recapture equilibrium (Greenberg, 1990; Hobfoll, 1988).

In approaching the negative elements of managing situations and responses, Lazarus and Launier (1983) divided coping techniques into two general categories: (a) instrument focused, which include

information gathering, problem solving, communication and social skills training, time management, mobilizing supports, and direct efforts to change the environment or to remove oneself from it; and (b) problem-focused and palliative actions, which are focused on regulating emotional distress. These include denial, diverting attention, searching for meaning, emotional distancing, expressing affect, cognitive restructuring, and relaxation training (Lazarus & Launier, 1978).

Stress-related transactions between the person and the environment play a significant role in one's ability to cope (Baum & Singer, 1981; Billings, 1983; O'Brien, 1987). Other models focus on creating positive consequences of stress. These models help individuals develop activities and methods that create elements of joy in one's life. This joy affects perceptions and responses to stressful life situations at many levels (Moss, 1976; Nguyen, 1984; Pearlin & Schooler, 1978). This can be described as an investment in and planning of resources for the future, thus providing hope and optimism.

Although little is known about the accumulation of resources, there is evidence that the accumulation of positive elements creates an insulating mechanism against stressor events (Cohen & Hobohman, 1983). The nurturing of positive events can contribute to an emotional uplifting that provides a basis of insulation for the individual as he/she encounters life situations that are perceived

as stressful. This kind of thinking is also consistent with the development of what Kobasa (1979) termed the hardy personality.

The sum total of these issues is not just with coping. These issues focus on helping individuals understand that they can survive positively and live at higher levels through acceptance and assuming a high degree of self-responsibility in their choices.

Although all stress management is destined to increase coping skills, for most stress problems no single outcome can be labeled perfect. Many stress problems have a range of possible acceptable outcomes. The teaching of coping skills borrows from both educational and psychotherapeutic environments (Roskies, 1987). The phases of acquiring coping skills include awareness of unmet needs, motivation to change, education, actual acquisition of skills, rehearsal of specific coping skills, and support for implementation of these new skills (Greenberg, 1989).

Findings have suggested that stress-management programs produce beneficial changes, even though the specific reasons for improvement might be difficult to assess (Wheeler & Munz, 1985). Given these design models, there are many intervention configurations. These interventions can be discussed in a variety of frameworks. Giridano and Everly (1987), Greenburg and Page (1988), and Gatchel and Baum (1983) all used basic variations of descriptors for interventions that are common in the field of managing stress. These interventions include a broad spectrum. Interventions are activities that block a stressor from resulting in negative consequences such as physiological discomfort, anxiety, illness, or

disease. These interventions may include biofeedback training, exercise, environmental engineering, social engineering, rational emotive therapy, and a number of other skills or processes (Greenberg, 1990).

In Anatomy of an Illness as Perceived by the Patient, Cousins (1989) stated: "I have learned never to underestimate the capacity of the human mind and the body to regenerate when the prospects seem most wretched. The life-force may be the least understood force on earth" (p. 248). James (cited in Healers on Healing, 1989) expanded on this thought when he stated:

> Human beings tend to live too far within self-imposed limits. It is possible that those limits will recede when we respect more fully the natural drive of the human mind and body toward perfectibility and regeneration. Protecting and cherishing that natural drive may well represent the finest exercise of human freedom. (p. 167)

CHAPTER III

METHODOLOGY AND PROCEDURES

Factors Influencing the Design

The study design was influenced by the following factors:

1. The researcher's experience in working with adults in the areas of managing stress, coping with loss, and transition.

2. Personal expectations and criteria related to the kinds of growth and educational experiences the researcher hoped to achieve through this study. These expectations included (a) that the research be a source of intimate stories reflecting people confronted with significant life transitions; (b) that the research involve individuals forced to face life's transitions over a long period of time; (c) that the research be primarily ethnographic in nature, the desired research tools being personal interviews; and (d) that the researcher look at the participants' life histories with the primary concerns focused on the relationship between one's illness and wellness and one's outlook on life.

Two more factors significantly influenced the development of this study:

1. Interviews and written communication with professionals whose work focused on coping with chronic illness, adult transitions, and loss.

2. A preliminary review of the literature.

The sequence had some variations because a number of these steps occurred simultaneously.

Continuing clarification of the problem areas in coping with chronic illness and SLE was developed on a number of levels:

1. Written communications with all identifiable national, state, local, and support organizations dealing with SLE. Appendix J contains a list of national and state organizations contacted for this study. Identification of local support-group involvement would have been a breach of confidentiality and thus is not included.

2. Involvement with a graduate student research support group that helped to focus on issues and clarify the intention of the study. The group critiqued proposals and provided suggestions for the refinement of these proposals.

3. Advice and guidance from members of the doctoral guidance committee.

A review of the literature was highlighted and aided by using the following services and technologies:

1. Direct data-bank searching on CD ROM at Jackson Community College, Jackson, Michigan. Data banks searched were Medline and ERIC, both produced and marketed under the trade name Silver Platter. Descriptors used to delineate and identify appropriate articles included lupus, SLE, chronic illness, coping, stress management, wellness, holistic health, well-being, emotional health, social support, adjustment, United States only, and family values. The focus was on literature published after 1980.

2. On-line data-searching services at Jackson Community College. The following data banks were used: Psychology Abstracts, Sociological Abstracts, Books in Print, and Dissertation Abstracts. The search was limited to those materials in print after 1970. Some stress-related documents went back to the 1930s, 1940s, and 1950s. Some of the descriptors and delineators used in the data-bank searches included chronic illness, emotional adjustment, support groups, well-being, loss, bereavement, holistic health, coping, adjustment, illness, stress management, and family issues.

In addition to these searching techniques, three other sources of data were used:

1. Recommended reading lists from the National Lupus Foundation of America.

2. Conversations with professionals relative to specific kinds of information and their location.

3. Books in print from 1970 to the present. All materials were received through interlibrary loans and personal purchases from various lupus-related organizations.

Interview and Data-Collection Process

The interview and data-collection processes were developed with the following intentions:

1. As a means of complementing existing data.

2. As a mechanism to develop a triangulation of different types of information that would create opportunities to learn about various elements of a subject's transitions.

3. As a form of cross-referencing types of changes in each subject's life related to transitions and loss. The criteria for selection of the subjects required that all subjects be (a) female, (b) positively diagnosed with SLE for 5 years or more, (c) between 20 and 55 years of age, and (d) voluntarily involved.

Quantitative Research Instruments

Three instruments were chosen to provide quantitative data from the subjects: the Lifeline, the Life Changes Inventory, and the Response to Loss Inventory (see Appendices A, C, and D for copies of all the instruments.) The Life Changes Inventory and the Response to Loss Inventory were developed by John Schneider. The Life Changes Inventory is comprehensive and provides for a wide variety of questioning. The format is easy to use, clear, and complete. Both an interpretation of the intensity of the change by the subject and a chronology of events are included. The Lifeline is a simple story line that duplicates the information in the Life Changes Inventory. The Life Changes Inventory, coupled with the Lifeline, provides a powerful tool for looking at one's life and developing dialogue.

The Response to Loss Inventory was chosen because it met a number of other criteria that were helpful in the interpretation and triangulation of the data. These criteria included the following:

1. The instrument provides a quantitative measurement of some of the changes and life positions of the subjects.

2. This quantitative measure provides a form of validation for some qualitative sources of information gained in the interviews (see Appendix E).

3. It helps the researcher gain a perspective on how the subjects are responding to the losses related to their illness. This is especially important in understanding some of the varieties of transitions and choices that individuals report.

4. The instrument helps the researcher understand some of the dynamics of loss that individuals may be experiencing because chronic illness has a great number of issues related to loss and grieving.

These instruments were chosen for the following three reasons, as well:

1. They provide a consistent format to review life transitions and responses beyond the interviews.

2. They can be used to stimulate a subject's recall vignettes.

3. The researcher had previously used all three instruments.

4. The potential to duplicate the research using these instruments is very good.

Qualitative Research Focus

A comprehensive interview process was developed, in which the Life Changes Inventory and the Lifeline were used to create a consistent framework for the interviews. The use of these tools in concert with the interviews created a format from which the interview was developed.

Chronological Steps in Conducting the Research

On October 3, 1990, the proposal for this study was accepted by the researcher's doctoral advisory committee. The application for Human Subjects was submitted immediately thereafter. (See Appendix K for a copy of the Risk-to-Benefit ratio.) On October 24, 1990, the Michigan State University Committee on Research Involving Human Subjects gave its approval to the study (see Appendix L). Also on October 24, 1990, letters expressing the researcher's intention in seeking subjects were sent to professional counselors, medical personnel, support groups, and related allied health professionals (see Appendix H). The closing date for all interviews was set at January 1, 1991. This was then extended to March 1, 1991, due to problems completing the interviews and finding sufficient subjects who met the guidelines. Six subjects completed the interview and survey process. The process and procedures for identification of subjects were as follows:

I. A letter of introduction was sent to the professionals describing the nature of the research and the purpose of the study (Appendix H). Copies of letters that were sent to persons interested in participating in the study and the informed consent forms are included in Appendices I and G, respectively.

II. Once interest was expressed by or on the part of an individual, a preliminary meeting was set up with the prospective subject. The purpose of the meeting was to

provide a more complete description of the research and procedures. Specific content included:

1. Purpose of the research
2. Overview of the types of data and research procedures:
    a. Interview process, sample questions, and taping procedures
    b. Survey instruments: Lifeline, Life Changes Inventory, Response to Loss Inventory
    c. Possible follow-up interview of significant others; how and why they might be helpful
    d. Any questions or concerns related to the research
    e. Review of informed consent and written permission from subject
    f. Upon informed consent, a time line was developed, with each participant outlining the various components of the study
    g. Survey instruments were given to each person

III. Between the first and second meetings, the two survey instruments, the Lifeline and the Life Changes Inventory, needed to be completed and returned. In some cases this step was eliminated, and the Lifeline and Life Changes Inventory were filled out before the first interview. This occurred because the researcher found that the extra meetings were not fulfilling a valid need.

IV. Once these instruments were received and reviewed by the researcher, a second interview was scheduled.

V. The second interview focused on understanding the chronology of the subject's life: what occurred, what kind of an early

life she had experienced, and some of the most significant times in her life.

VI. The Response to Loss Inventory was also completed between the first and second interviews. It was then reviewed by the researcher, with additional help from John Schneider.

VII. The third interview focused on significant transitions and the kinds of coping strategies that were used to get through those times. The questions focused on kinds of coping strategies used either overtly or covertly, with or without conscious awareness at the time. Individuals were also asked to identify which strategies would be most beneficial to them in the future. Some of the issues discussed included types of experiences they had encountered in past years that caused them to learn new coping responses and how these new responses had changed over the years. Depending on the length of the interview, the individual's fatigue factor, and personal schedule, a fourth follow-up interview was scheduled for some subjects.

VIII. The fourth interview focused on a review of the Response to Loss Inventory, discussion of any closing concerns, and identification of any significant others who might be helpful in providing perspective on the subject's approach to transitions. If a significant other was identified, the subject was then asked to sign a consent form to allow the researcher to contact the other person. In two cases the interview process was condensed to a longer session. That

had been preceded by preliminary and follow-up phone conversations. Also, as the researcher became more comfortable with the data collection, certain types of information were found to be insignificant and later interviews were modified.

IX. Significant others were then approached and an informed consent form acquired from each person willing to participate in the study.

X. Taped interviews with significant others included (a) clarification of relationship with the subject and (b) perceptions of the subject's coping responses and behaviors during and after times of transition.

Inventories and interviews were reviewed, and the results of each interview were screened for the following types of information:

1. Types and frequencies of transitions, and narratives describing these transitions.

2. Types and frequencies of coping responses or tools used to cope.

3. Vignettes that reflected coping responses.

4. Triangulations that were created using survey tools and interviews with significant others.

5. Comparison to the results from other participants related to their coping.

6. The types of transitions that were encountered.

The interview responses were entered into a data bank and coded by types of vignettes and transitions that were shared. The researcher reviewed the data from the Life Changes Inventory and the Response to Loss Inventory and discussed them with John Schneider because he had developed the LCI and RTL and understood both instruments best. Following these discussions and the review of data, each subject's responses were analyzed and reduced in summary form to assist the researcher in using the data. This summary of the data was then taken into account in developing the total data bank and in cataloging. Once the information was catalogued and organized, the process of clarifying major assertions to be drawn from the data was initiated. The researcher and John Schneider met twice to review the data. The focus of the conversations was on those statements in which there were significant levels of agreement and disagreement.

The RTL results were summarized in three ways. Areas of high agreement were summarized in individual statements. Areas of absolute disagreement were summarized. Next, areas of absolute unimportance were examined. These statements were then compared with the frequencies found in the interviews.

Summary

Six primary subjects were interviewed for this study; the interviews lasted a total of 35.5 hours. Four secondary interviews were conducted with significant others, lasting a total of 6 hours. In addition to the six subjects who completed the study, one person

completed about 80% of the process and then withdrew from the study. Three others volunteered to participate but did not meet the criteria. Of the total number of people who volunteered for the study, five were part of the regional support group for SLE and discoid lupus patients, three were referred by counseling professionals, and two were referred by medical personnel who were aware of the research.

CHAPTER IV

ANALYSIS OF THE DATA

Introduction

Illness, tragedy, joy, and pain are all elements of life. The question is not whether transitions will occur, but rather how we choose to deal with these transitions, specifically, chronic illness. What promotes well-being in times of illness? What learnings are gained from the presence of chronic illness in one's life? The data in this chapter present the reflections of the six subjects as they relate to SLE.

This chapter is organized in the following manner. The first section includes a profile on each of the subjects. The second section includes a summary of data gathered from the Response to Loss Inventory. The third section includes an identification and considerations of various assertions. Section three has two parts: (a) a look at the initial assertions as identified through the preliminary research proposal and (b) an identification of a number of additional assertions that evolved from the data.

Profiles of the Subjects

This section contains a brief profile on each of the six subjects who participated in the study.

Marilyn

Marilyn was young and searching, yet she had a depth of sensitivity about her that was way beyond her years. She was seeking a role as a helping professional and had begun the long journey. She was a 20-year-old student who had been diagnosed with SLE for six years. Her illness had been a significant part of her life in many ways. Developmentally, she was the youngest subject. She was a friendly, outgoing individual who looked the picture of health. (See Table 1 for Marilyn's subject profile.) (For a description of the subject profile informational breakdown, see Appendix L.)

Table 1.--Summary of individual subject profile data: Marilyn.

Subject	Marilyn
Age	20
Gender	Female
Current marital status	Single
Marriages	None
Divorce	None
Children--natural	None
Children--adopted	None
Miscarriages	None
Years diagnosed	Six
Years with possible symptoms before diagnosis	Five
Organ involvement	Lung, central nervous system
Joint pain	Yes
Fatigue	Yes
Allergies	Yes
Possible hereditary	Yes
Relationship	Mother
Medications	Yes
Past or present involvement in support group	Yes
Has had or was referred to counseling	Yes

Marilyn was raised in a traditional family. Both her parents were working at the time of the study. The presence of her mother's chronic illness was a part of her earliest memories. When Marilyn was three, her mother was hospitalized, and the child stayed with an aunt for a short while. When Marilyn was eight, her mother had a recurrence and was wheelchair-bound for almost three years. Gradually she regained her ability to walk, and when Marilyn was 11 her mother started to walk with a walker. Her mother demonstrated a great deal of courage and spirit in her own journey and was a real caretaker. She currently was managing her own business and was in remission. Marilyn's father had been very supportive to both Marilyn and her mother throughout this time. Other family members had also been significantly supportive during this time. Grandparents and aunts and uncles had been very helpful. Grandmothers, specifically, continued to be supportive.

Music was a part of Marilyn's early life, and at age seven she began to play the piano. By age 13, she was burned out from piano and tried to play the clarinet in the school band. That did not last long. She quit when she was 14. Music continued to be an important part of her life at the time of the study. She still liked to play, but at times the joint pain got in the way. Before age 12, Marilyn liked to play sports with family members and was fairly active.

Illness in Marilyn's own life became more evident with the onset of puberty. At age ten, she missed a lot of school because of unexplained illnesses. At age 12, she had very severe allergic

responses; that same year, her grandfather died. He was a special person in her life. At age 13, she missed a great deal of school, was sent to a rheumatologist, and was diagnosed as having arthritis.

This period was followed by a severe depression, and Marilyn was referred to a psychologist. This was followed by a diagnosis of lupus when she was 14. This was a particularly difficult time in that she was started on steroid therapy, had a breast tumor removed, and lost many friendships. Life was very difficult. Marilyn's grades fell, and she was hospitalized for an extended period of time. By then, she was 16 years old, and because of her physical condition she was placed in a class for youths with impaired health. Three positive things occurred at this time: (a) Marilyn became friends with a physical therapist who was very concerned and caring, (b) her mother went into remission and started walking well, and (c) she officially started to drive.

When Marilyn was 16, she had her first summer job, helped in her mother's business, and went on an extended trip. Half way through the year she had a flare-up of her lupus, was put on new medications, and was hospitalized. This pattern recurred throughout the following year, and at the end of her seventeenth year she was bedridden for a month. The positive parts of the year were that she purchased her first car and enrolled in a cadet teachers program. The year closed on a good note: She started to feel better. It seems that this pattern of January flare-ups had been consistent for the last three years.

Marilyn graduated from high school and enrolled at a local two-year institution. She also began an exercise program and found this to be helpful. She had a severe weight gain of 30 pounds right around the end of her eighteenth year but lost all 30 pounds by the middle of her nineteenth year. She also had seizures that began around this time and was diagnosed as having some central nervous system involvement. She had three good terms at school but had to maintain a limited schedule. Her goal of nursing was also clarified.

At age 20, Marilyn was continuing to take classes, seemed to think there was a good prognosis, and was involved in a lupus mutual support group that was helping a great deal. She was also looking for work. Her goal was to continue to build her endurance and strengthen herself. She still had recurring flare-ups that lasted anywhere from a day or two to a month, and this kept the presence of the illness in her life very great. She regulated her own medications and was seeking a new physician because she was not comfortable with the kind of care she was receiving. She had a good sense of her rights as a person, as well as her needs.

Anne

Anne was a pleasant 29-year-old mother of two. She had been married for more than 12 years. She was diagnosed with lupus nine years ago. Her first child was born naturally, and her second was adopted. Her 10-year-old son had had one positive and one negative test for lupus. Anne's mother also had lupus and had been diagnosed

for more than 20 years. Anne expressed many fears and concerns due to the severity of her mother's chronic illness but did not dwell on it, nor did she share that it was an all-consuming part of her childhood. Anne was married to a very supportive husband. She had a great deal of family support and lived in a loving environment. (See Table 2 for Anne's subject profile.)

Table 2.--Summary of individual subject profile data: Anne.

Subject	Anne
Age	29
Gender	Female
Marriages	Married
Number of marriages	None
Divorce	None
Children--natural	One
Children--adopted	One
Miscarriages	One
Years diagnosed	Nine
Years with possible symptoms before diagnosis	Eight
Organ involvement	Lung
Joint pain	Yes
Fatigue	Yes
Allergies	Yes
Possible hereditary	Yes
Relationship	Mother, child
Medications	Yes
Past or present involvement in support group	Yes
Has had or was referred to counseling	Yes

Anne was born in a farming community in the Midwest and continued to live in that same community. As an infant, she had many allergies. These included milk and eggs, to name just two. With these allergies, she had a great deal of mucous. In addition to these issues of early infancy, she had eczema on her face and

ears, which caused oozing. At six months, Anne had bursitis in her shoulder and could not move her arm away from her body. Later in childhood she developed asthma and lung problems. The lung involvement was significantly affected by her lupus. To complicate matters, she was vaccinated for measles, and due to her hypersensitivity, she contracted the disease. The illness caused a very high fever for more than a week. The doctor said that she was fortunate because if she had contracted a full-blown case of measles she would have had serious effects.

This sensitivity continued on throughout her life. In the first half of the 1971-72 school year, Anne missed 48 days of school. She had to go home every day about 10 a.m. because she felt unwell. Doctors said it seemed like morning sickness, but that was not even a remote possibility. In January of that same school year, she had exploratory surgery; an irregular appendix was revealed. Due to Anne's sensitivity, the surgeon let her go home early becuase they could not give her anything for pain without incurring a reaction.

In 1974, Anne twisted her knee. She also blacked out and fell while working outside with her father. This was only the beginning of several strange things that happened throughout her maturing years. She was always sensitive to the sun. Often, when riding a bicycle, she would go fast in the sun and slow in the shade, just to protect herself.

In her teenage years, Anne began feeling short of breath and would have to go to the emergency room for help and oxygen. It was

always the same scenario: gasping for breath, as if her lungs were fatigued and in need of rest. During the following six years, Anne was sent to all kinds of doctors for a multitude of tests. This was not before she had been recommended to a psychologist for counseling because her regular doctors and a specialist could not detect a specific cause for her illness. She said that, at that point, she was really beginning to doubt that there was anything there. Finally, a doctor told her what had been going on even before he finished listing her symptoms. What is ironic is that Anne's mother had had lupus for years. The possibility of Anne's having it was ruled out, so the doctors never made a connection in spite of all her history and symptoms.

One month after giving birth to her child, Anne became extremely ill. Her hair was falling out, her face became splotchy red, and she lost a lot of weight. This was a portent of things to come. She had a number of flare-ups since then. On December 31, 1984, Anne went riding on a three-wheel motorcycle and had a wonderful time. The next day, she was exhausted physically; her body was so fatigued that she could do nothing but lie there. Just breathing was tough. After another flare-up, Anne lost 25 pounds and became extremely skinny and shaky. She was so frail she could barely hold herself up for any length of time. At the time of the study, due to her lung involvement, she still could not suck a milkshake through a straw or bite a whole apple without having it cut up. That is just part of where she was in her life at the time.

In those times of flare-ups, Anne said she was so weak that she spent a month at a time in bed. She was so overcome with weakness that she could barely care for herself. Even in less difficult flare-ups, it was difficult to plan even one event a week, such as going shopping, because she was so weak.

Beyond these physical concerns, Anne had to overcome a number of fears related to illness and life. There were times when she was so withdrawn and depressed that venturing out and confronting people on a daily basis was difficult. These fears, she said, had been the most difficult part of her journey.

At the time of the study, she could maintain a normal schedule as long as she listened to her body and did not overdo things. If a week became too filled with stressful activities and responsibilities, she canceled everything that was not necessary, to protect her body and preserve her energy. Evenings were usually the most difficult.

A year before being interviewed for this study, Anne and her husband adopted an infant. Her primary focus was on maintaining balance in her life in as many ways as possible. She had an extremely clear sense of priorities. These lay with her life and family. She paid special attention to her diet, which included vitamin supplements. She also included some regular, moderate exercise and had positive outlets. Learning had become a key focus in her life. Anne also had a wonderful sense of spirituality that was very apparent.

Beth

Beth was 35 years old. She had been married twice and divorced once. She had three children, one from her first marriage and two from her second marriage. She had been diagnosed with lupus eight years before the study. Both of her parents were blue-collar workers. Little outward affection had been shown toward Beth as she grew up. (See Table 3 for Beth's subject profile.)

Table 3.--Summary of individual subject profile data: Beth.

Subject	Beth
Age	35
Gender	Female
Current marital status	Married
Marriages	Two
Divorce	One
Children--natural	Three
Children--adopted	None
Miscarriages	None
Years diagnosed	11
Years with possible symptoms before diagnosis	12
Organ involvement	None
Joint pain	Yes
Fatigue	Yes
Allergies	Yes
Possible hereditary	Yes
Relationship	Grandfather, cousin
Medications	Yes
Past or present involvement in support group	No
Has had or was referred to counseling	No

As a child, Beth was given piano, flute, voice, ballet, and skating lessons; she was also in the choir. She had a great deal of talent and was very bright. Her parents wanted everything for her

that they had not had. Beth shared that she seemed to grow up without a sense of what she wanted for herself.

Beth was very allergic to a number of things as a child and had various unexplained illnesses throughout her youth. She had her tonsils removed when she was about seven. She said she had a tough time adjusting to junior high school. She was raped when she was 15. At age 16, she traveled to Europe as part of a touring singing group. About that same time, she had an appendectomy. At the age of 17, Beth again had her tonsils removed.

Beth graduated from high school when she was 18 and entered college as an English major. She graduated at the age of 22, and some time during that period she aborted a baby.

She was married at the age of 23, and her first child was born when she was 28. Her marriage was rocky; the relationship encountered a great deal of conflict in the early years. Later on, Beth was betrayed and tried to reconcile the relationship, to no avail.

That period became a major turning point in her life. She realized that she hated her marital situation, and at the same time she was pregnant. In an attempt to lash back at her husband, Beth scheduled herself for an abortion. Just before the abortion, however, she decided that what she really wanted was the child; it was the marriage she did not want. Beth was divorced shortly after her first child's birth.

Beth said that once the child was born, she learned the most profound lesson of her life. She could be loved unconditionally by

someone, her child. It was through the unconditional love of her child that she eventually learned to love herself. During that time, she was diagnosed as having lupus. The road to diagnosis was a difficult one. She had many illnesses during that time that were hard to understand. Their origin was difficult, if not impossible, to pinpoint.

This created significant changes in Beth's life. She had a great deal of pain. Finances changed for the worse, and life was difficult. For a brief, two-year period she moved out of her native state. It was at that time that she lost her job and eventually had to move in with her parents until life could become stable after the divorce. She shared that life was difficult, but once she became adjusted to her new roles she enjoyed her freedom and living independently.

She remarried when she was 32. The person she married was an old friend she had known before her first marriage. Life became more stable in a number of ways. During the past year, she became the mother of twins. She worked as a clerk, a job for which she was not educated. She did not feel challenged or stimulated in her work but thought that was all right. She said the hours and benefits were good; she did not have to overextend herself physically. She shared that this had been one of the adjustments she had made since her lupus. She experienced a great deal of fatigue in the evenings and had to guard her time. She had a much clearer sense of priorities and felt good in her new role.

Geraldine

Geraldine was a 37-year-old single mother of an 11-year-old boy. She had been raised in a rural community in a traditional farm family setting. Geraldine was the oldest of three children; she had a brother and a sister. Her parents were farmers and lived a conservative life. Her father was hard-working and dominant; her mother was conservative and very traditional. Geraldine's perceptions of her family were that they were loving and that her home environment was secure and basically positive. She had had systemic lupus for at least 11 years. She had two miscarriages in the early 1980s, at which time her lupus manifested itself. Her involvement with SLE was mild but chronic and controlling. (See Table 4 for Geraldine's subject profile.)

Geraldine was on daily pain medications, had some joint involvement, and was confronted with fatigue daily. She also had skin rashes that had been especially bad when she was growing up. Seventh grade was a particularly difficult time. Schoolmates were nasty and teased her mercilessly about her skin. This continued for about a year, until someone else came along with a worse problem and the teasing was transferred to that child. High school and growing up was a lonely time. Geraldine lived on a farm and did not have any close friends during that time. She did not participate in any outside-school activities. Her life revolved around reading and her farm chores. Reading continued to be a favorite pastime at the time of this study.

Table 4.--Summary of individual subject profile data: Geraldine.

Subject	Geraldine
Age	37
Gender	Female
Current marital status	Single: live-in partner/ fiancé
Marriages	Two
Divorce	Two
Children--natural	One
Children--adopted	None
Miscarriages	Two
Years diagnosed	Eight
Years with possible symptoms before diagnosis	Eight
Organ involvement	No
Joint pain	Yes
Fatigue	Yes
Allergies	Yes
Possible hereditary	Yes
Relationship	Mother, grandmother
Medications	Yes
Past or present involvement in support group	Yes
Has had or was referred to counseling	Yes

At age 18, Geraldine graduated from high school, got her first job, was fired, and met the man she would marry three years later. Somewhere during that time she had two abortions. She was married at 21 and was divorced 14 months later. Geraldine met her second husband when she was 22 and was married two years later. She became pregnant and had a child at age 25. Her husband was not ready for children, and the burden of raising the child was hers. Subsequently, she had two miscarriages when she was 28 and 29. At that time, her lupus began to flare up, and the limitations of her illness became more apparent.

At age 30, Geraldine moved to the country. At 32 she caught her husband having an affair and sought a divorce. She also bought a horse, and horseback riding became a favorite pastime.

At the time of this study, Geraldine was living with a man she expected to marry. She had always dealt with difficult times by accepting her pain and discomfort and by withdrawal. Her hobbies included horseback riding, needlepoint, and reading, especially historical romance novels. The model who had influenced her the most was her mother. She believed the woman's role was to serve the man, be obedient, and attend to her own needs last. Not until her divorce four years before had she begun to question her role as a parent and spouse. The most significant changes in her life in the last four years had been a gradual evolution of her self-concept and a realization of her personal needs for expression and her ability to express those needs. Through mutual support and counseling, she had begun to clarify her rights, her needs, and her role as a person and a parent.

Sarah

Sarah was jovial and sensitive and a caretaker of the heart. She had a wonderful sense of her priorities and understood her message of sharing and loving those with whom she came into contact. She was absolutely committed to helping and supporting others. (See Table 5 for Sarah's subject profile.)

Table 5.--Summary of individual subject profile data: Sarah.

Subject	Sarah
Age	48
Gender	Female
Current marital status	Married
Marriages	One
Divorce	None
Children--natural	Two
Children--adopted	None
Miscarriages	None
Years diagnosed	Eight
Years with possible symptoms before diagnosis	Four
Organ involvement	Muscular pain
Joint pain	Yes
Fatigue	Yes
Allergies	Yes
Possible hereditary	No
Relationship	None
Medications	Yes
Past or present involvement in support group	Yes
Has had or was referred to counseling	Yes

Sarah, a 48-year-old woman, had been diagnosed with lupus eight years earlier. She was born in a large midwestern city. Her parents' formal education was limited; they had married when Sarah's mother was only 14 years old. Her mother was a positive influence in Sarah's life. Sarah shared that it was her unconditional love that provided her with a sense of who she was. Her father was very moody, had a chronic ulcer, and ultimately became an alcoholic. His presence in Sarah's life was a very negative one, for her father was the one she most wanted to please but she could not please him. He was the origin of a great deal of pain for her all the way into her early married life.

When she was ten, Sarah's family moved to the suburbs, and Sarah felt alienated. She gained weight. When she was 14, her father had corrective surgery for his ulcer, and this seemed to alleviate the problem; but alcohol became a bigger concern. Sarah very much wanted to please her father, and this was a constant source of pain for her. Eventually, he became a chronic user of alcohol. By the time Sarah was 15, her father was drinking heavily. There was a lot of tension in the house. From about age 15 to 17, Sarah's father did not speak to her because of her choice of boyfriend. The family was very much on edge as a result of her father's behavior.

At 18, Sarah graduated from high school but did not receive support to attend college, even though other family members had done so. At the age of 19, she was working as a data-processing clerk in a company and was becoming fairly independent. It was then she met her future husband. After three dates, he asked her to marry him. Four months later they were married; Sarah was pregnant. Both Sarah and her husband worked. Her father continued to drink chronically. By the time Sarah was 21, her first born had arrived. She stayed home for nine months and took care of her son. Her mother cared for him after Sarah returned to work. Leaving to go to work was difficult because of her commitment to her child.

At age 22, Sarah had her second son. Marital problems were beginning; her husband was becoming a chronic user of alcohol. Sarah experienced two miscarriages. At age 24 she was experiencing

severe headaches, she slept a lot, the marriage was becoming difficult, and she was feeling isolated due to a move to a smaller town. Their life continued. At age 27, Sarah had a daughter. The marriage improved, even though her husband was still drinking and his dislike of his work was becoming a problem. Sarah was doing free-lance work, but their social life was very limited and she was isolated.

At age 28, Sarah began doing data entry at a university. She made many nice friends. Her husband was drinking heavily at the time. Sarah came to the realization that anyone could go to college if they had the money and were willing to work. Her self-esteem was still low. "I don't feel very smart, but I do know how to work," she commented. She took an inventory of her life and her marriage and decided to register for college. That was a major turning point in her life. She was scared to death; as she said, "I didn't even know the language around education.

At age 29, Sarah finally come to grips with her relationship with her father. She identified that she was not responsible for his behavior. College began. Her husband was distanced and threatened by her attending school. Things did not look good. "I'll finish school, become a professional, and it can either help the relationship and me financially or it can be my way out," she said. By age 30, life and school were going well, and Sarah's attitude was one of commitment to the children and school. Her husband was still drinking a great deal, but "that's his problem,"

she realized. She loved school and was having a very successful experience.

When she was 30, Sarah discovered that her husband was having an extramarital affair. She shared that she had never felt so hurt. After a brief separation and a great deal of talking, Sarah and her husband decided to give their relationship a second chance. He began going to Alcoholics Anonymous, and she decided to drop out of school and focus her energies on the relationship. The marriage got stronger; life was good. Her husband decided to return to school. He quit his job, they sold the house and one car, and they moved into student housing. Their roles changed. Sarah became the provider, and her husband became the househusband. This entailed a lot of hard work. Life went on. A brother was divorced. A child had two minor surgeries and later was hit by a car; he was in a coma for three days.

At age 35, Sarah worked as an assistant manager of a restaurant, 60 to 70 hours a week. She was fired without explanation. She had a terrible upper-respiratory infection and was very sick for five days; they had no money. Finally, she had to go to the emergency room with a temperature of 105^{o} F. This was her perception of the beginning of her lupus. Her husband began drinking again, and she was devastated.

When Sarah was 36, a number of transitions occurred. Her husband graduated and was doing his internship in another town. Her son was caught doing drugs and was later arrested for breaking and entering. Sarah's mother decided at that time to separate from her

father. Sarah's father had a heart attack and died before her mother could tell him. Her husband came home on a weekend drunk and hating his job. Sarah was helpless and, in desperation, left the house frustrated and angry. She was driving in the country and crying uncontrollably. She screamed in a plea of helplessness: "Oh, God, help me." She said she was immediately overcome with a sense of peace. Life began to change. Christ became the focus of her life.

At 37, Sarah's life was a constant roller-coaster. Her son was heavily into drugs. Her husband was in denial with his drinking problem and working 70 hours a week. Chaos surrounded her. She was a prisoner in her own home.

When she was 40, the realities of lupus were realized, and Sarah was diagnosed. After six months of grieving, her realization of life was reborn. "I decided dying is easy; while I have life, I'm going to live it." Her son left home at about this time--"tough love." Her husband came to the realization that Sarah could die at any time. He started attending church with Sarah and their daughter.

Between ages 40 and 45, a number of things happened. A niece was killed in an accident. Sarah's daughter was dating seriously. Her son, who had been forced to move out of the house, entered college, became a Christian, and married. Sarah went back to work. Her husband was searching spiritually. She returned to school. Her daughter-in-law was hit by lightning and by a train. Her son and

daughter-in-law's house was burglarized. She learned that a cousin was dying of AIDS.

When Sarah was 46, her son was in an automobile accident in which one person was killed; alcohol was involved. Her son then moved back home. Sarah's husband converted to Christianity. That same year, their daughter broke up with her boyfriend of five years. Life went on.

Sarah categorized her life with her husband at the time of the study as follows: "He is my best friend, he is my love, he is everything!" About her children she said, "I do not have to like what they do, nor do I have to accept it, but they know I will always love them no matter what."

Teresa

Teresa, age 51, was married and had two adult children. Her daughter had lupus, and her daughter's son was also diagnosed with possible SLE. He had one positive test for lupus. Teresa had been diagnosed with lupus 20 years ago, after almost 20 years of ill-defined symptoms and illnesses. She had been raised in a rural environment and lived on a farm. (See Table 6 for Teresa's subject profile.)

Teresa's first symptoms occurred at the age of 10. After sledding one afternoon, she began running a low-grade fever. She had swollen joints and pain. The skin on her legs was mottled. This was the beginning of a lifelong series of ill-defined illnesses. Initially, these illnesses would cause her to miss

school up to six weeks at a time. Doctors could not find a cause. At age 12, she had her tonsils taken out by electric needle because she was such a heavy bleeder. At 14 years of age, she had her appendix out and almost died. She had to have a second surgery and was found to be bleeding internally. She had an incision from hip to hip and had to be transfused. Her blood type at that time was RH negative. This later proved to be very puzzling to her doctors because, after the birth of her first son, she was found to be RH positive.

Table 6.--Summary of individual subject profile data: Teresa.

Subject	Teresa
Age	51
Gender	Female
Current marital status	Married
Marriages	One
Divorce	None
Children--natural	Two
Children--adopted	None
Miscarriages	Two
Years diagnosed	20
Years with possible symptoms before diagnosis	20
Organ involvement	Heart
Joint pain	Yes
Fatigue	Yes
Allergies	Yes
Possible hereditary	Yes
Relationship	Daughter, grandson
Medications	Yes
Past or present involvement in support group	Yes
Has had or was referred to counseling	Yes

In January of that year, when Teresa was 16, her father died. The next month, she was taken to Ann Arbor for thyroid surgery.

Graves disease was the diagnosis. Her eyes bulged, and her throat was enlarged. She was in surgery for eight hours. The gland was large, hard, and wrapped around the windpipe. It had feelers down into her chest. At the time, the doctors thought it was malignant, but it was later found to be benign. Right after surgery, Teresa had what was labeled a thyroid storm; she almost died. This, too, was a rare occurrence. She shared that the doctors would not let her mother leave the hospital for three days because Teresa was so close to death. At age 18, she had damage to the mitral valve of her heart and was diagnosed as having rheumatic fever.

Shortly thereafter, Teresa was married. About a year later she had a miscarriage after carrying the fetus for about six weeks. At 19 she gave birth to her son, who was a normal weight. She had carried him for almost 11 months. Doctors tried everything, from inducing vomiting several times, to castor oil, to jumping off chairs; nothing worked. The baby was born in his own time. He was bluish and shriveled but normal. Teresa's heart problems were manifested again, and she was put on digitalis. Her blood was now retyped as RH positive. To say the least, her doctors were puzzled.

At the age of 20, Teresa again became pregnant; she started spotting at about three months. At six months she began hemorrhaging, and the baby was stillborn. A year later, Teresa gave birth to her daughter. The baby's birth weight--9 pounds, 13 ounces--was slightly above normal. She carried this baby almost 11 months, as well. At age 22, Teresa had a flare-up of her thyroid,

and her heart rate became very rapid. She was ultimately treated in a major hospital and given radioactive iodine. She had a monstrous dose of almost 14 rads. Teresa was very weak for a long time.

At age 23, despite fears she had become sterile from the radioactive iodine, Teresa became pregnant with twins. They were born two months prematurely, and both died a short time afterwards; their lungs were not fully developed. Teresa, also, almost died after her Caesarean section broke loose. She spent two months in the hospital recuperating.

Teresa described the next eight or ten years as relatively free of incidents. The exception was that she had significant allergies. Bee stings were especially frightening. She also started to develop reactions to the sun and did not realize the cause. She would collapse and get very weak, similar to heat stroke. She also would develop a butterfly rash that was never diagnosed. She was fine one moment, and the next she could be in turmoil. She would get terrible headaches and run a high temperature or even collapse. Illness was very present, but in comparison to the past she was doing better.

When Teresa was about 30, she began passing out from heart fibrillations. Her heart would stop beating for a few seconds at a time. She was then put on pronestyl. For a while, things went pretty well. She said she could bale and haul hay, do other work on the farm, and take care of the family. She also baby sat and cared for her sick mother. She was a real caretaker and did so for everyone but herself.

At age 32, Teresa had been working on the farm and had had a busy day. That night, at about 3:00 a.m., she got to the bathroom and passed out on the floor. She was in so much pain that it hurt for her husband to carry her to the couch. She was extremely ill and nauseated; her heart was still fibrillating. She was sent to the intensive care unit by her family doctor. After all this, a check was made for lupus cells, and Teresa was diagnosed as having lupus as well as heart-related complications. She was put on coumadin but could not be given enough to thin the blood. There were many ups and downs. It seemed as though she was hospitalized about every six weeks with heart-related problems.

Upon returning home from a short trip, Teresa stepped out of her pick-up truck and slipped on the pavement, breaking her ankle in three places. Because of the potential for complications, the doctor chose to set the ankle and put it in a cast, even though surgery was warranted. Teresa was told that she would never walk again, but the doctors were wrong. She was checked to see whether the pronestyl was a cause of her lupus, but that was not the case.

To make matters worse, Teresa's husband had two back surgeries and his plant was closed. Their income was limited, and life became tougher still. She said there was a lot of stress during that time. "Even though these were tough years, they were important years. We all bonded together and rolled with the flow." She even made most of the children's clothes. It was then she dreamed that she would make her daughter's wedding dress. That dream was later fulfilled.

At age 43, after lying in intensive care, Teresa dreamed of reaffirming her wedding vows on their twenty-fifth anniversary. This eventually occurred, with their family at hand, their original best man and maid of honor, and their grandchildren all in attendance. Just after that, Teresa had a terrible reaction to her medications and even some common foods like carrots. She said that, because of her extreme sensitivity, she even had trouble finding a dentist who would treat her.

Teresa's last hospital visit was two years before the interview, at age 49, when she had her second myocardial infarction. Her internist and five doctors all were unsure what to do for her. She needed a heart catheterization and a balloon, but the doctors decided she was not a candidate because of her vasculitis. She said that this had been initiated when she brought a baby calf into the barn out of a terrible blustery snowstorm and pulled muscles in her chest loose and also tore the pericardium. In addition to having a heart attack, her lupus flared up. After two and a half weeks in the hospital, Teresa had a spec thallium, rest, and a lot of tender loving care. She returned home for more rest. Her mother-in-law stayed and cared for her; she was so weak she could not even raise her arms. She had to take baby steps and had no breath to sing in church. Now, after two years, she could drive and do almost anything. She wanted to travel in Michigan and nearby states with her husband. She did some square dancing and enjoyed life and her family to the fullest. She said that, after the last visit to the hospital, she got her priorities in order. She cared for herself

much more, which she said she had never taken the time to do before. She said that she could see how this let her love others even more. She took vitamins and did a great deal of self-care.

Teresa said,

> I feel I have come a long way on my journey through life and that I can see God's purpose in my whole life. There was a time just after the second myocardial infarction that my son and daughter-in-law moved in to help.

She continued:

> I was so bad that they even had to feed me, and it hurt to hold my six-pound grandson in my arms. I feel that this was a turning point for me in my health. It gave me a different outlook and much more to fight for.

She put it this way:

> I think life is great and what you make of it. I also must say I would not have gotten this far without my husband's sense of humor and a family that has loved me all these years. It has brought me through many a bad day.

Summary of the individual profile data. Table 7 is a composite of the data for each subject, as reported in the preceding pages. From this table, the reader can gain a sense of the kinds of individual similarities and diversities each subject brought to the study.

Table 7.--Summary of individual subject profile data.

Characteristic	Subject					
	1	2	3	4	5	6
Age	20	29	35	37	48	51
Gender	F	F	F	F	F	F
Current marital status	S	M	M	S	M	M
Marriage(s)	0	1	2	2	1	1
Divorce(s)	0	0	1	2	0	0
Children--natural	0	1	3	1	2	2
Children--adopted	0	1	0	0	0	0
Miscarriage(s)	0	0	0	2	0	2
Years diagnosed	9	9	11	8	8	20
Years with possible symptoms before diagnosis	5	8	12	8	4	20
Organ involvement	CNS/ Lung	Lung	None	None	Musc. Pain	Heart
Joint pain	Yes	Yes	Yes	Yes	Yes	Yes
Fatigue	Yes	Yes	Yes	Yes	Yes	Yes
Allergies	Yes	Yes	Yes	Yes	Yes	Yes
Possible hereditary	Yes	Yes	Yes	No	No	Yes
Medications	Yes	Yes	Yes	Yes	Yes	Yes
Relationship	a	b	c	d	e	f
Involvement in support group	Yes	Yes	No	No	No	Yes
Have had or were referred to counseling	Yes	Yes	Yes	Yes	Yes	Yes

Key: 1 = Marilyn, 2 = Anne, 3 = Beth, 4 = Geraldine, 5 = Sarah, 6 = Teresa

Current marital status: S = single, M = married

Organ involvement: CNS = central nervous system

Relationship: a = mother, b = mother, child, c = grandfather, cousin, d = Mother, grandmother, e = None, f = daughter, grandson

The Response to Loss Inventory

The primary focus of this section is to summarize the information gathered with the Response to Loss Inventory (RTL). The highest level of agreement with a statement on the inventory represents an individual score of 5 on the inventory. This indicates the subject definitely thought the statement was true about her current responses to her losses related to lupus. For the group, the range of composite points could be from 30 to 0. A composite score of 30 reflects perfect agreement among all subjects with these statements. A composite score of 28 to 29 would represent a composite score in which there are more 5's than 4's. A composite score of 25 to 27 would reflect a scoring of greater than 4 but less than 5 and that there were more 4's than 5's. A score of 4 represents that the statement is true most of the time about the subject's responses to this loss. A composite of 24 would represent group agreement with these statements at a 4 level. A score of 3 represents that this is true some of the time and reflects a composite score of 18. A score of 2 represents that this is true occasionally and reflects a composite score of 12. A score of 1 reflects that this is not true about the subject's current loss and would have a composite score of 6. A score of 0 indicates that the statement is true about her but not as a response to the loss.

Highest Level of Agreement

The following statements reflect perfect positive agreement by all six subjects. Each person responded with a 5. The group composite score was 30 on these statements. These statements

reflect perfect agreement in each subject's response patterns and with each other as it relates to the various stages of loss as identified in this inventory to their illness. An asterisk indicates the statement is of a spiritual nature, as defined by John Schneider, author of the inventory.

Perspective

In the time since this loss:

There is at least one person I can count on for support.

I've found ways to enjoy myself.

I can think about other things than this loss.

*What I have left in my life is enough to keep me going.

In light of this loss:

My feelings make sense when I think about them.

I am able to express my feelings about the loss.

I have already passed the lowest point.

It feels good to be able to laugh again.

No one is really to blame for what happened.

*I've decided to go on living.

*There are quiet places in my life now.

All of the above statements concerning **perspective** reflected perfect agreement by the subjects. These statements reflected learning and insights gained since the illness and demonstrated healthy attitudes. Based on the perfect agreement with these statements, it can be said that the six subjects each had support, had learned to enjoy life, all liked to laugh, believed that they

had passed through the worst of their illness, and had the ability to express their feelings about their loss.

Integrating the Loss

In the time since this loss:

I've experienced this loss in ways that were healing.

I've had many feelings.

I like being with people.

I can make sense out of the messages from my body.

It's time for me to get on with my life.

Life is worth living again.

In terms of integrating the loss into their lives, the subjects shared that they had been able to see experiences from the loss that were healthy, they were able to enjoy other people, and they were able to be sensitive to their bodies' messages. They also agreed that their own lives had value and with the importance of getting on with their lives.

Self-Empowerment (Reformulation)

As a result of this loss:

I am not as hard on myself when I make mistakes.

I don't avoid admitting what I feel.

*I've discovered that there is more to me than what meets the eye.

I don't have to have all the answers for why I am alive.

My life has times of joy.

I know that things in my life can change and life can still be meaningful.

Relative to the issue of **self-empowerment**, the group showed that they could still have a meaningful life, despite the limitations of their illness, that they were not as hard on themselves, and that they understood a depth about themselves that they had not known before their illnesses.

Holding On

Because of this loss:

*I won't give up.

The preceding statement was the only **holding-on** issue with which each of the subjects indicated perfect positive agreement. Each person was unwilling to give up.

High Agreement

The following statements reflect an extremely high sense of positive agreement by the subjects. The group composite scores were in the range of 28 to 29 points. These numbers reflect a stronger presence of 5's, with one or two participants giving a score of 4. In contrast to the preceding section, there was very high agreement of belief in these statements, but not perfect agreement. This may reflect a number of factors, the most significant of which might be developmental in nature. These developmental issues may be related primarily to maturation and be categorized as physical, emotional, or intellectual. Many of the statements on which there was not perfect agreement came from those subjects at either end of the age spectrum.

Perspective

In light of this loss:

*My past will always be a part of me.

*A part of me will always be connected to what/who I lost.

Both of these statements reflect strong elements of acceptance relative to the subjects' illnesses and transitions.

Integrating the Loss

In light of this loss:

My life has more to it.

I know my life is important.

I have as good an understanding as I can right now.

Putting my thoughts into words has helped me recover.

In the time since this loss:

I've found effective ways to express my feelings.

I relax.

I don't neglect my body.

I sleep well.

I eat sensibly.

I feel better.

I take care of the way I look.

I feel confident enough in myself to move on to other things.

I am finding ways to fit this experience into the rest of my life.

I've restored or regained part of what I had lost.

The majority of the subjects reflected issues of how they had come to integrate their losses in positive ways. In the statements related to "in the time since the loss," the group had a very high level of consensus about their own self-care. They found time to relax and to take care of their bodies. They slept well, ate sensibly, and generally felt better. These are all attributes of a well-oriented person.

Transforming Loss

As a result of this loss:

What I own isn't as important.

*I can get along with less than I have needed in the past.

*I believe there is someone or something more powerful, loving, lasting and wiser than any single human being.

I know I want other people in my life.

*I feel connected to the world and to nature.

*I know I am in the right place for me right now.

*I realize that I can't live without loving myself.

*I have something important to share with others.

I listen to what my body tells me.

I feel strong.

I am active in caring for myself physically.

I enjoy touching and being touched.

I listen to music.

I live as fully as I can.

I can love and be devoted to another without losing myself.

I am more consistently aware of what's important.

I have rediscovered the essential part of me.

I want to help others who have this kind of life experience in common with me.

I have time for my family and friends and time for me.

I feel lovable.

When these statements are examined, they affirm a high level of change from loss. These statements on self-love, self-care, attention to personal needs, and clear priorities are all statements that are positive and powerful.

Self-Empowerment (Reformulation)

As a result of this loss:

I enjoy being alone.

I spend time by myself.

I feel challenged to keep on going.

I don't spend as much time thinking about the loss.

*I feel loving and affectionate.

I've learned to respect myself.

I am at peace.

I can feel both joyful and sad.

My feelings are valid.

This section on **self-empowerment** is a very strong segment as to how the subjects had reformulated their lives after their losses. They had learned to respect themselves, enjoyed being alone, and had

an acceptance of feelings related to love, joy, sadness, and affection.

Low Agreement

The following statements reflect a score of 1. With a composite score of 6, these statements reflect that this was not true about the subjects' current responses to the loss. These data are not absolute because of a problem that arose in the scoring mechanism. There were two levels of variances in the responses related to 0's and 1's:

1. Questions related to sex and relationships were responded to in a very different way by the 20-year-old subject. In the researcher's opinion, this reflects a developmental issue.

2. The score of 0 was in some cases misinterpreted by two subjects and used in place of 1 on the questions where they had a question about what was being asked. Upon review of these surveys, correlations with the past interviews, and follow-up questioning, these inconsistencies were validated. In a follow-up sampling, Subject 6 confirmed that 0's were used when 1's more accurately reflected her feelings. What is interesting is that, even with these possible errors, the scoring validated the earlier states to a great degree. It must be kept in mind that these statements reflect how the subjects currently did not perceive themselves. They might be more easily understood if the reader inserts the words "I do not" or "does not" in each phrase.

Holding On

In the time since my loss:

I look at reminders of my loss (e.g. pictures, mementos).

Until it is proven to be beyond any doubt that this loss is real, I will keep looking for it/him/her.

Almost anything can remind me of my loss.

I think I am responsible for this loss.

I feel that I should have done something to prevent this from happening.

My feelings are so intense I'm afraid I'm losing control.

I try to hold back the tears.

I dream that it never happened.

Because of this loss:

*Life seems unfair.

These statements reflect a healthy perspective. The individuals seemed not to be dwelling on the past or their illnesses. They seemed to believe that they did have some order to their lives and did not fantasize about what their lives would have been like had the illness not occurred.

Letting Go

Since the time of this loss, I have thought:

I cannot imagine how anything positive could have come out of this loss.

In the time since this loss:

I feel dissatisfied with everything.

I get upset with myself for the way I have behaved.

These statements reflect high levels of balance and very little focus on the need to let go. Because there were few statements in the area of letting go, one could reflect that these issues were no longer of concern for this group.

Awareness

Since the time of this loss:

It's been hard to concentrate.

I am less confident.

My friends have been avoiding me.

Because of this loss:

It's hard to express what I feel in words.

Being in certain places can unexpectedly stir up feelings.

I feel pangs.

I feel a great deal of hurt or emotional pain.

I don't know if I can stand the physical pain for one more day.

This section can be read to reflect that the individuals had gained a level of personal awareness and control.

The following statements reflect scores of less than 6 and could be considered in the range of 4 to 5. Given the possible variance related to the use of 0's in place of 1's, these statements would be even more significant. Due to the way the survey was written, it might help the reader to read these statements with the opposite intension; for example, "I believe that this loss really happened," or "Nothing could have been done to prevent this loss." Double asterisks indicate it would be very easy to misinterpret the statement as a function of lupus and not loss.

Holding On

In the time since my loss:

I would do almost anything to get back what I've lost.

I don't believe that this loss really happened.

Something could have been done to prevent this loss.

I think that I am good or perfect enough.

What was lost will return.

I wish things were the way they were before the loss occurred.

I keep thinking something could be done to bring back what I lost.

If I tried hard enough, I can bring back what I lost.

I hope that I am dreaming and I'll wake up and find out it never happened.

I'm scared to share what I've been thinking, feeling and doing.

I feel guilty or disloyal when I forget about this loss.

I want someone to be punished for this loss.

I feel guilty just thinking about enjoying myself.

I am afraid to think about anything else but my loss.

I'm afraid I'll forget my loss if I stop thinking about it.

I can't control my feelings when I'm with those who share my loss.

Unless something happens soon to change this, I don't know if I can control my feelings.

My feelings are so unpredictable I wonder if I am crazy.

I'm not ready to let go of my feelings about what happened.

I dream that it never happened.

I dream that something has happened to reverse my loss.

**I am sleeping less.

**I don't eat as much.

Because of this loss:

It would help if someone could help me understand this.

I am not able to forgive those who contributed to this loss.

I won't accept that this loss has happened.

I am determined to make those responsible pay for this loss.

This loss must be changed.

These statements reflect and affirm many of the statements related to transformation and self-empowerment. Issues concerning recovery from the loss, guilt, fear, and control are all positively reflected in these statements.

Letting Go

Since this loss happened:

I have kept secret what really happened.

I don't spend as much time with my family.

I refuse to discuss this loss.

Since the time of this loss, I have thought:

I deserve a better deal than I'm getting.

I can think of very few people worth my time and energy now.

That I'm better off without it/him/her.

In the time since this loss:

I feel confused and disoriented.

If I let myself, I get so unhappy I can't stand it.

People irritate me.

**I'm fed up with spending so much time on this.

I'm ashamed of the way I've behaved.

It's hard for me to trust anybody.

Nothing has really made any difference, so why do I bother?

Nobody cares how I am doing.

I lack the energy to make sense out of it.

Keeping in mind that none of these statements is true reflects the subjects' high level of freedom from the pangs of their losses.

Awareness

Since the time of this loss:

I've a not been interested in meeting anyone new.

I get so preoccupied that I forget where I am going.

I avoid being alone.

I lack love, affection and companionship.

It's hard for me to make decisions.

I avoid being in new situations.

I forget to do routine, everyday tasks.

When I think about this loss:

I am scattered and ineffective.

I am unable to find anything to look forward to.

Because of this loss:

I miss feeling happy.

I wake up during the night.

**It's like I've been hit in the stomach.

**I hurt all over.

I never seem to know what to do with myself.

My dreams remind me of my loss.

There is nothing positive or redeeming about this loss.

My beliefs don't give me the comfort they used to give me.

It seems like I have lost my desire to live.

I question the existence of the God I used to believe in.

I've lost my sense of innocence.

**When I'm convinced things can't get any worse, they do.

There are parts of me that are missing.

Given that all these statements were negative, the group consistently reflected a positive outlook.

Summary. The group affirmed a very high degree of (a) Integrating the Loss, (b) Self-Empowerment (Reformulation), and (c) Transforming Loss. These elements of loss are generally present in individuals who have lived through their losses, dealt with them, and transformed their losses into positive growth experiences. This kind of transformation is a powerful and developmentally appropriate place for individuals who have experienced a single loss and confronted it over time. What is interesting is that these subjects had diseases that were in progress and evolving. Their losses continued as we talked, and their losses related to this illness and health continued daily in some cases. Yet their perspective, their transformation, and their self-empowerment reflected a different perspective, one that seemed to separate them from the loss and allowed them to be objective and yet aware. It was one that acknowledged pain and suffering and yet allowed them to live rich, full lives that were limited by their disease but not by their perspectives of their ability to participate and find joy in life.

Significant Disagreement

The following statements reflect significant disagreement among the subjects. These are statements that reflected inconsistent responses or disagreement. In these statements a subject or two

were in disagreement with the majority. Composite scores were in the range of 6 to 12 but reflected one person who responded inconsistently with the group; this person was not always the same. Scoring was reflected in this manner. Most of the group would respond with all 0's or 1's, and one person would respond with a 5. It should be noted that variances in these responses could be related to a subject's physical status and not loss. These statements are summarized in totality at the end of this section.

Holding On

In the time since my loss:

I am smoking more.

I've increased my exercise.

I have lost weight.

Sex gets my mind off the loss.

The inconsistencies here may be more easily understood given the following factors: One subject could not exercise, one came from an abusive-compulsive family environment, and one was single.

Because of this loss:

I believe something good will happen.

Letting Go

Since the time of this loss, I have thought:

Something else is going to go wrong.

If I don't look out for myself, no one else will.

No one can change what's already happened.

Even if I could understand why it happened, it wouldn't change anything.

It's best not to dwell on the past.

In the time since this loss:

I avoid feeling too sad about this.

I'm gaining weight.

I don't remember any dreams.

I exercise less.

I'm more clumsy and accident prone.

I've realized that nothing could have prevented it.

It was difficult to understand the validity of these responses without knowing the current status of their diseases. That is, if a person was in remission, she might have been further along in the grief process. If her SLE was active, her losses may have been continuing.

Awareness

Since the time of this loss:

I have very little to say.

When I think about this loss:

I'm reminded how little I really control.

I remember what happened as clearly as if it happened yesterday.

I know I cannot bring it back.

Because of this loss:

I really miss it/him/her.

I lack a sex life.

It is easier to realize that someday I will die.

My faith has been shaken.

I cannot continue life the same way as before.

There is a great emptiness in my life.

No amount of money could ever replace my loss.

I know I will lose things and people important to me.

Perspective

In the time since this loss:

Activities like getting a massage, painting or music are soothing.

It helps when I don't have anything to do.

I think about the effects of this loss: how I have changed, what is different.

I realized that I've lost a lot, but I haven't lost everything.

I wasn't the only one who contributed to this loss.

In light of this loss:

I still hurt, but the pain has lessened.

My guilt has lessened.

My disgust over what happened has lessened.

The aches and pains I used to have with this loss have lessened.

I notice how things smell and taste again.

I enjoy being touched and held once again.

My dreams seem to help me understand and accept what happens.

It takes less energy to do things than it used to.

I believe there is some good in every person.

My life will continue.

My life does seem to have meaning.

Life seems more fragile and precious.

Whatever I contributed to this loss, I did not want to happen.

There are limits on what I lost.

The fond memories are there along with the painful ones.

One's perspective may be significantly influenced by the degree of involvement with his/her illness. A critically ill person may have a very different outlook than a person who is not ill or physically impaired at the time of responding to this inventory.

Integrating the Loss

In the time since this loss:

At least one person knows that I've forgiven myself.

I understand why it's important to have times of celebration and remembrance before it's too late.

I don't need to be so much in control of things.

I would not reverse this loss if it meant giving up my growth from it.

Self-Empowerment (Reformulation)

As a result of this loss:

I'm more assertive.

I'm able to take risks again.

It takes less effort and thought to do what I need to do.

I spend time by myself.

I'm not as serious a person.

I'm more creative in my approach to life.

I enjoy dreaming as much as I do reaching for them.

I'm more patient.

I see the past as just as important as what is happening now.

I've realized that I can do destructive things.

I am not as hard on myself when I make mistakes.

Sadness reminds me how important this loss was to me.

It's hard for me to be bored.

I've found new ways to express my feelings.

I enjoy the intimacy, closeness and pleasure of making love.

My dreams make sense.

I believe that death is only one of many transitions I'll make in life.

Some kind of "inner" wisdom has been guiding me.

Transforming Loss:

<u>As a result of this loss</u>:

I am sometimes surprised by what I know and say.

I've discovered that the most important parts of my loss remain alive inside of me.

I know the cycles of life have times of birth and death.

I am curious about what will happen after I die.

These components related to transformation, self-empowerment, and integrating loss can reflect personality and maturation factors.

If they were factored out through further analysis and possibly the use of an additional segment of this tool, the results may be even more dramatic.

The statements in this part are difficult to interpret in any absolute sense. It might be said that these kinds of variances reflect individual differences, developmentally and culturally. Furthermore, it could be stated that these statements might reflect variations in the intensity of one's transitions related to each subject's illness and life.

Summary

The composite of statements in this section provided the reader with a sense of those areas in which the subjects were in basic agreement as they viewed their lives. It also provided an overview of some elements on which there was a good deal of inconsistency. In addition, this part of the chapter further elucidated the nature of the group and demonstrated, to a strong degree, a high level of self-empowerment and transformation.

Furthermore, the group as a whole reflected a very positive perspective on life and had integrated their losses and gotten on with life. This might be due, in part, to the homogeneous nature of the group. Each subject was female, had 5 or more years since diagnosis, and had volunteered to participate in the study. They all expected that their involvement in the study might help someone else.

Assertions

This section is a composite of vignettes, LCI responses, and responses to the RTL inventory. The criteria used to address these assertions included (a) stated changes in beliefs as a result of the transitions, (b) demonstrated changes in behavior, (c) stated changes in priorities as a result of the transitions, and (d) demonstrated changes in priorities as a result of the transitions. It should be noted that these assertions evolved from the preliminary work that the researcher completed in preparation for this research.

This section has two parts. The first contains a discussion of the original assertions that were named in the initial proposal. The second part contains new assertions that evolved from the research process.

Original Assertions

Assertion 1. Illness forces people to evaluate their lives in profound and lasting ways.

There was a great deal of support for this assertion at many levels.

Marilyn. Marilyn had faced a great deal of illness throughout her short life. She was the youngest subject. Her early involvement with chronic illness made her experiences somewhat different. There were a number of developmental issues that were difficult to separate from her illness. Her illness had been the major controlling factor in her life. She was diagnosed at age 14, but she had many complications and some preliminary diagnoses of

other illnesses. Her access to relationships and her opportunities for relationships outside of the family were limited, in contrast to the other subjects. Marilyn was single, had never married, had never been engaged, and had no history of long-term relationships with males. Her lifetime reflected many flare-ups, some lasting six weeks or more. During these times, her symptoms ranged from mild to severe pain, to being bedridden and incapacitated. At times, she perceived herself to be near death. Some times were worse than others. She had to face not only her pain and physical changes, but also the issues of development and maturation at the same time. The relative isolation from peers and the possible lack of intimate dialogue with friends who could help her frame her experiences were issues. It seemed that she was alone in a crowd of adults. Many times she had feelings and fears, with no one her age to support her. Time had not permitted her to develop enduring relationships. It is difficult to determine which factors contributed most to her transformation and development.

> After I finally decided that I am going to focus on now, one day at a time, I have only had two sessions where the pain was so bad that I couldn't handle it. It seemed like no matter what I did it just continued to happen, it just happened. I just didn't believe it would happen again, but it did. That's when things get confusing. You think that all is going to be fine and life begins to get a little consistent and then this happens.
>
> I guess there are always going to be storms. There are no seasons, only life itself. I think if I hadn't gone through the last six years of finding myself I would definitely not be at this point I am now. I think the illness has opened me to seeing things in a different way. When your body is deteriorating around you, that is when you have to begin to separate your mind from your body and say things will be OK.

> I keep learning more and more. I think it gets difficult for my parents at times. It's been six years or maybe more, now that I look back at it. I learn more each time. It has helped me clarify my priorities. I am at a point of acceptance with my illness. I know that it will get worse at times, but I believe it will get better.

It should be remembered that Marilyn was only 20 at the time of the study. The statement, "I learn more each time," is an example of the depth of Marilyn's perception of her own growth.

> My philosophy of life has changed. Before, I never gave much thought about life or responsibility or death. I never really considered it. I always acted grown up, but now . . . now I am more focused on feelings and thoughts. My priorities are my family, their health and well-being, their happiness, my health, and school.

Anne. Anne had had a great deal of illness and change for a young person of 29. She had been very athletic, competitive, and hard-driving as a teenager. As her illness progressed, her lifestyle changed drastically. She could no longer be as competitive and hard-driving as she had been. Her goal orientation changed, and so did her expectations for her life. She had several years of transitions focused on compromised health and changing health. Included in this time was a year in bed. Her life was turned upside down, and she was forced to make many choices that she would not have considered before her illness. There was a gradual but profound change in her life. She stated:

> I gained a sense of who I am. I realized that I was more than a physical being. I realized that there is life beyond the visual. Dealing with my physical being was the hardest part. Where I am is where I am at. People's influence in my life became less. My physical features do not matter; I will smile and be me. I can't be anyone else. I am not a thin person nor a fat person; I am me! I realized that life is going to go on! I am different now. I don't know what would have been, but I

> do know what has been. Life has become much more simple. I do not have to keep up with anyone for any reason. My priorities are more clear. I can pace myself and feel OK about it. If I cannot get it done today, I will most likely get it done tomorrow. It will always be there. I know it sounds funny, but I am thankful for my lupus.

Anne's comments reflect changes in goals, expectations, and behaviors, all related to her illness. Her illness caused her to evaluate and change her behavior at very intimate levels.

Beth. Beth was at a point in her life where, she said, "[either] I curl up and die or go on living. I choose to live." Her life before SLE had been one of unhappiness. She had been bulimic for many years. She had been rebellious and unhappy with her life in general. She was in a marriage she did not want, and she was facing a difficult pregnancy. During that time, her SLE began to manifest itself in more significant ways than it had up to that point. The illness compounded her difficulties, but the real turning point came when she confronted the reality that she was pregnant and in a bad marriage. These two realities, her deteriorating marriage and her illness, became increasingly present in her life. She did not want to remain married and was confronted with a baby she thought she did not want.

The first reality was easier to solve: Get a divorce. Her second decision, about the baby, was a more powerful issue for her. She had been scheduled for an abortion when she decided to keep the baby. This action brought about a profound change in her life. After 11 years of bulimia, she started to take care of herself. As she began to move through this time, her SLE began to manifest

itself. The fatigue and the pain became more prevalent. She spoke of these times as follows:

> If I was to go on living, then I decided I was going to have the best life that I can have, and so that is what I did. I made the active choices. I found it's OK to look beyond. I think the turning point of choosing life for me was when I got pregnant. I filed for divorce. I made the decision I was going to have to do it for myself. It took a long time, but I did. It was the first time that I really took charge of my life. I really realized I was empowered just about the same time I was diagnosed with lupus. I was diagnosed after 12 years of active symptoms. When I became pregnant, life became even more hectic. I just didn't realize the power I had to control my own destiny. I think as I have become empowered my control over my lupus has improved. I think it has worked to my advantage. When I was forced to reevaluate my life, I became empowered.

In Beth's situation, part of what had an effect was a significant change in her relationships with her husband and the possibility of being responsible for another's life. The other factor was her lupus. The birth of her daughter further led to a powerful realization. She said she experienced unconditional love for the first time. It was through this realization of being loved that she shared:

> When I began to experience the love of my newborn and her unconditional acceptance of me, I began to learn to love myself. The illness just cemented my desire to keep on fighting and living the best I can.

In Beth's case, it would be difficult to separate the effects of her illness and the effects of the changes in her relationships. What is clear is that there was a major change in perception and self-esteem, which led to significant behavior changes. Her bulimia ended after 11 years, and she started a new page in her life. As she said,

> I like me now. . . . The birth of my daughter helped to get me there.

There were also significant changes in terms of her professional aspirations. She had been trained as an educator, but because of her health she thought she could not commit that much energy to teaching. She decided to take a job that required less of her energy and had benefits. She said that she would not accept more responsibility at work. She had to conserve her energy to help meet her other responsibilities--the family. She also had to rest a great deal.

> I am shot after 7:00 p.m. I just do not function. I also know when I have been pushing too hard, and I pay for it. I have to listen to my body.

Illness does cause change and requires adaptation for survival. Many times the choices are limited.

Geraldine. Of all the subjects, Geraldine had had the least involvement relative to her illness. Her life, although modified somewhat as a result of her illness, had been changed the least. She had pain and fatigue and definitely had to monitor her activities. But in comparison to the other subjects, she had the least involvement. Relationship issues had been the greatest influencing factors:

> I guess going through all the pain of divorce I realized I had to open up and let go. I couldn't go on living that way. I was really hurt, and I was lower than I had ever been before. It was probably the worst experience of my life. When I lost my job I was also really affected. I couldn't believe that they fired me. There wasn't anything there for a long time. I just had to open up and get it out. I am still learning. I take time out for my animals. I love to read. I am taking time for myself.

Sarah. Sarah's story revolved around issues of relationships. Her illness was a factor that contributed in many ways to who she was and the kinds of issues she was forced to confront, but it seems as if the realities of her confrontations with illness were not as significant as her concerns with her relationships. Her husband was in transition for many years. As an adult, he was not happy with his life. He had had a good job and was not happy, so he decided to go back to school. They sold their new house and their possessions, and Sarah went back to being the provider. She became the breadwinner, and her husband went to school and helped with raising their children and maintaining the household. Sarah said that, in spite of his problems, he was always a good father and a caring person.

The turning point for Sarah came after her husband had received his degree. He had started in his new profession, working in another town and living at home on the weekends. Their son was having problems with drugs and was in a great deal of trouble. Her father had just died. They had returned home to a weekend relationship. After all this disruption--the selling of their house, the moves, and the sacrifice and supporting the family--he was still having problems. What Sarah encountered was that he was still unhappy and reflected it. He had come home for the weekend. Sarah had been anticipating a nice time together and had made a special dinner. When he arrived home, he had been drinking and his alcoholism had returned. The roof came crashing in on Sarah:

> I hit bottom. My father had died. My son was on drugs. I had lost my job. I had lived in chaos, and I thought things were getting back to normal. My husband is still discontent and his alcoholism is returning. I was alone.

Sarah had been left to handle it all. She began to run into a significant problem dealing with what was happening.

> I was at my wits' end. I did not know what to do. I couldn't sleep, and I was angry. I got out of the house feeling really upset and helpless. I had put my life aside. We moved; we sold our house and everything for him to go to school. We lived in student housing, and when he finished nothing had changed. Everything was falling apart around me, and I was feeling worse and worse. I just got in the car and began to drive. I was just driving. It was about 3:00 a.m. I was crying and I was really confused. I yelled out at the top of my lungs, "Oh, God, help me." There was an immediate peace. I can't really explain the feeling. There was a feeling that I wasn't alone. I drove home, crawled into bed, and I know I wasn't alone and that I would make it. All I can say is that that peace has stayed with me to this day. I really believe that was a turning point for me. After that, nothing changed right away, but I felt better and I was able to confront the issues in my life. I had after that time a belief that everything would be OK. And you know what? That is exactly how it has worked out. The Lord really works in mysterious ways.

> What forced my growth was an alcoholic father who abused me psychologically. He did not talk to me for two years because I had a boy friend he did not like. My husband was a drinker, and my son was into drugs. He even killed someone with his car. I think a lot of my issues were clarified prior to my illness really getting bad.

Another factor that was present in Sarah's story was that illness causes people to evaluate their lives in profound ways.

> I think the most significant thing is that my illness brought my husband to the Lord. He had always loved me, and he was a good caretaker of the kids. He just had problems and was not a happy person. My illness scared him to death. When he thought I was going to die, that made a difference. "I don't want you to go somewhere I can't go." He did not want to die and be separated away from me. He knew that if he continued to live the way he was living, there was a good chance that we would end up in different places for eternity, and he couldn't handle

> that. The understanding that I could be somewhere without him was the turning point for him.

To completely separate Sarah's illness and its impact on her life and the significance of her relationships would be extremely difficult. No one lives with his/her life compartmentalized in such a way that one element does not affect another.

Teresa. The depth of Teresa's changes is hard to quantify. Throughout the interview process, she shared a continued changing and clarifying of priorities and spiritual understanding. The illness had been a long and continuing transformational issue in her life. Her subject profile reflected a never-ending series of illnesses. At three different times she was extremely close to death, and on innumerable occasions she was gravely ill by normal standards.

> All the time, since I was 16 or so I guess, way back, someone has been trying to tell me something all along, and I was too dumb to listen. You would have thought I would have woken up a long time ago, and I thought I had, but I guess I didn't. I finally made up my mind that I had to make the best of what life I had.
>
> I went through a time of grieving. I would ask, "Why me? Why me?" At times I would lie lifeless on the couch. I couldn't talk. I have come to live today, not in the past.
>
> I can see now that each time in my illness the Lord moved in many ways. I was saved when I was 16 after my father died, but it is different now. I don't let things bother me. I look at life differently.

Teresa's story was one of the most powerful. In listening to her recount the numerous sequences in her life around illness, the researcher was amazed that she was doing so well. She had been blind for a short period, bedridden for countless days and months at

various times, and so allergic to medications that she could not be treated when she had her last heart attack; yet she had persisted and flourished. Teresa's story is a testament to the power of the human spirit and faith. She persevered and lived in ways that few people could understand.

Summary. It should be noted that, although all of the subjects encountered profound changes during the development of their diseases, their diseases were not the only significant factor to affect their lives. The influence of relationships as a part of their life experiences was difficult to separate from their illness. This was especially demonstrated in the LCIs of Geraldine, Sarah, and Beth. Each stated that changes in relationships were significant factors in their lives and that these changes were as meaningful as the experiences their illnesses provided. Without exception, group members stated in the RTL the following affirmations of this assertion:

> What I have left in my life is enough to keep me going.
>
> I've decided to go on living.
>
> Life is worth living again.
>
> I've discovered there is more to me than meets the eye.
>
> I know that things in my life can change and life can still be meaningful.

Hence the assertion would be stated better in the following manner:

> Illness and significant changes in relationships with others or work appear to cause people to evaluate their lives in profound and lasting ways.

Assertion 2. There can be a positive relationship between a person's illness and the quality of his/her life as he/she perceives it.

This assertion has many implications related to quality of life. Many of the statements included in this section are best understood from the perception of the person speaking.

Marilyn. Generally speaking, Marilyn demonstrated excellent health and well-being skills. It should be kept in mind that she, of all the subjects, had significant impairment related to fatigue and recurring flare-ups. She reflected a high level of self-responsibility and caring that she believed had been mandated by her illness over the years.

> Exercise helps a lot. I meet people. It makes a difference in my self-esteem.
>
> Generally, I feel really like I can take care of myself.
>
> I have always kept my own medical records ever since I was a teenager. If there was a problem I would call the physician or the pharmacist and find out the answers.
>
> I feel I have a good sense of balance in terms of my self-care and energy; exercise creates a lot of joy.

Although Marilyn did not have the same clarity of priorities as the other subjects, she was very clear about what was important to her and where she wanted to go:

> Something I really need to do is balance my focus. Right now, I am really focusing on my schooling and professional growth. The only two things that are really important to me are my schooling and my family.

She had gained a number of profound understandings about herself. She said,

> Over time I gained a sense of hope. I have found that my flare-ups would improve over time, no matter what I did.

She also made a statement that none of the others shared in this way. One of the strengths she had was empathy. She said that when another person was in pain or doubt related to his/her illness, she could relate to that individual at a very deep level.

> Empathy for others who are ill is something I have a sense about that others may not understand. When I see a person who is sick, I think I have a different understanding than most.

Anne. Anne was one of three subjects who had experienced a profound series of SLE-related illnesses. Her disease involvement was significant at many levels. Her illness had not only challenged her physically, but she also had faced tremendous fears and had overcome them. The following statements give a picture of the kind of person she had become:

> I realized that I can contribute. I am capable. I am healthy. I can help people to understand more about my illness, and I can give back to others. Sure, I have ups and downs, but that's life! It's not anything more.

> I was internally focused before. Now I have moved my focus outwardly. I understand there will be health issues for me, but I am OK with that.

> I am accepting. I didn't fight on the illness. I didn't fight the illness I meant with more.

In terms of Anne's nature, a number of factors became evident. She had a clear sense of her priorities. She knew what was important to her and could manifest it in her life. There was no question in her mind as to what was important in her life, and this sense of priority created a simplicity and order that are not often seen.

> My priorities are totally clear. I know what is involved in the family. I don't get caught up in keeping up with anyone or any trivial thing that does not fit with my priorities. That's what is important to me.
>
> I don't get caught up in keeping up with anyone.
>
> The family is my focus, and I feel good about it. I have not always been clear on my priorities. Before my illness manifested, I did not have this same kind of clarity.
>
> My schedule is protected. I have to live my life by my priorities. I can't do it all.

In addition to a clear sense of priority, Anne had an intense interest in learning and growing as a person. She had a keen interest in reading and learning more about parenting skills.

> I am really interested in growing more and in helping others to really accept illnesses and grow more.
>
> I am excited to think about expanding and growing.

Given the intensity of Anne's illnesses, it is interesting that she could still make a statement like the one below. Her perceptions concerning health and well-being were different, and so was her sense of herself.

> I still view myself as well and healthy as anyone. I have a great deal of balance now that I did not have before. I have balance both physically and spiritually.
>
> After it's gone [a flare-up], I start to focus on what's left.

Beth. The most significant change for Beth was her realization of being empowered. Before her illness and transformation, she had a belief system that gave the responsibilities for her life to others. She was not happy, and she blamed others for her position in life. Now her perception of her own ability to influence her life and her directions was entirely different. She thought she had

a high level of control and that she could make decisions that were good for her.

> Previously to my being empowered, everything was done or decided by other college, marriage, and school activities. Now that's different.

She had learned to assert herself at many levels. She no longer allowed others to make important decisions for her.

> I learned to fight for me. If I was to survive, I had to learn to say "No" and make people understand that I had to stand up for me.
>
> I realized that each of us is responsible for our own lives.

Here, Beth reflected a high degree of self-actualization and confidence. As compared with the behaviors she had before her transitions, this statement was very different. Before, she had been bulimic; she was depressed and very disillusioned with life. Now she was a different person.

> I know what my priorities are. I learned that the sooner I took care of myself, the better I would survive.

Geraldine. The key factors in Geraldine's transitions were her relationships and the adjustments she had to make to her life related to fatigue and allergies. What she gained from her transitions was a different perspective on what was important to her to live. She expressed a strong need to reach out to others and not isolate herself as she had done in her relationships before her divorce.

> Since my divorce I have developed more anchors. Before the divorce I was isolated and alone. Now I have a lot more people who I can rely on and who support me in what I do. I feel a lot better.

> I went to counseling a couple of different times, and this last time I really think I gained from it. I definitely know that I would do it again if I felt I needed it.

Geraldine had the ability to understand more of what she needed and to seek help now that she did not have before. She thought she had a better self-esteem and was happier with her life.

> I found that if you can't do it totally, then maybe you can do it in part.
>
> I don't do many things that I don't want to do anymore. I did too much of that before. That was the way I was raised, and I was not happy.
>
> I have found for me that I need more than simple existing. I need joy in my life, and I am responsible.

Sarah. Sarah had lived a difficult life in many ways, beginning with her father's alcoholism and then her marital disappointments and culminating with the manifestation of her illness. She had expended tremendous amounts of energy trying to help all those around her: her mother, her husband, her son, and her father. She had a tremendous capacity to love, and in so doing she had to confront a lot of issues. Her understanding that she could not be responsible for the problems others had was a profound learning and one that very few people truly understand.

> I learned that I am not responsible for everyone's problems. I will do all that I can, and I know that you won't let it go.

The next statement sets the stage for understanding a part of Sarah's values and her belief system related to expectations. She demonstrated a clear sense of having some control over and optimism about her life.

> I look at the future. I look at work, at graduation, and if part of it may not happen, who cares? Part of the life joy is

> expectations. A bigger part [of life] is being where I want to be and moving toward that direction.
>
> I think if I were not in school I would not be so well off as I am. I get to see people whom I can love and who are worse off than me. I get to share and grow when I am there, and that's where I need to be right now.

In spite of the fact that Sarah was heavily medicated with pain killers, she shared this perception. She had learned to focus her energies away from her illness and onto more productive parts of her life:

> I think I am healthier now than I have been in a long time. I am aware of my body, but I do not dwell on me.

Subsequently, she shared that she could feel the effects of stress. She was sensitive to stress and its effects, and she listened to her body, a skill that few people really understand.

> I can feel it. Stress. . . . To me it is like taking a 2" x 4" and knocking me over the head. I really do listen, and I do protect myself.

Sarah's last statement again validated a clear sense of priority in her life. In talking with her, there was no question about what was important. To the very core of her being, she had a special energy and sense about her.

> My priorities are absolutely clear for this life. Love is the key to it all. I believe that I have been put here for a reason and that it is unfolding for me as it should.

Teresa. Of the six subjects, Teresa had been the most physically affected for the longest time by SLE. In the following statements, she shared a number of perspectives that she had gained and held related to her life and the effects her illness had had on her life. The specific statements reflect elements of her life that

could be identified as quality-enhancing. Teresa stated in hindsight:

> Lupus was my journey to wellness. What is interesting is that the people who grew up around me seem to gain these skills also. The gift is a different kind of gift.

As one reads this statement, there is an implicit understanding that Teresa's illness had not been a detriment to her being but had provided an enhancement.

> I don't have to worry about anything anymore. I am concerned and I care, but I am not going to let it get me down. I can remember the pits, but I believe I am over the hurdle now.

Teresa reflected a life position that was very different from that of most people. The duration and significance of her illness create a framework for this statement that is very powerful.

The following statements project a sense of clarity about Teresa's position in life and her understanding of how she worked best.

> My priorities got clearer and clearer.
>
> I always have goals, and they make a difference for me now. I have always set goals for myself. I believe that it makes a big difference for the kids. I always listen to my body.
>
> As I proceeded on, I got stronger and stronger inside. Any anger or hostility I may have had is gone.
>
> The doctor has said that he likes to treat people like me. People with intestinal fortitude, with a supportive family, and who can listen to their bodies.
>
> My illness has opened me up. In the hospital visits I have had over the years, I had to talk. You had to share and learn communication skills if you were to survive. This has made a difference for me.
>
> Because of my lupus, I have had to be very cautious about what I eat. It is so hard, but it makes a real difference in how hard I work and play.

These statements give the reader a sense of the effects Teresa's illness had had on her:

> I listen to my gut. It is something you did early, and I had a good sense of intuition. I always felt I would survive.
>
> I found the more I can help other people the better I feel.

Teresa further disclosed that said she had discovered she had gained a number of sensitivities to herself and life.

This assertion was further affirmed in the RTL sections pertaining to "As a result of this loss" and "In the time since this loss." Throughout the collections of statements in total agreement and very high agreement, there were reflections of this assertion.

In the section related to **Self-Empowerment** "As a result of this loss," the following statements further affirmed this assertion:

> I am at peace.
>
> I've learned to respect myself.
>
> I enjoy being alone.
>
> I can feel both joyful and sad.
>
> My feelings are valid.
>
> I feel challenged to keep on going.

In the section on **Integrating the Loss** "In light of this loss," further support for this assertion was found in the following statements:

> Life is worth living again.
>
> My life has times of joy.
>
> My live has more to it.
>
> I know my life is important.

I feel better.

I don't neglect my body.

I feel confident enough in myself to move on to other things.

Summary. It appears there was a great deal of support for the initial assertions. There was definitely a broad spectrum of responses that individuals made related to the effects of their transitions on their learnings and changes. There seem to be a number of relationships that were identified in the research process.

Additional Findings

Throughout the analysis of the data, a number of other assertions emerged. In the process of collecting and analyzing the data, a number of additional assertions emerged. These assertions were a natural extension of the findings. As the reader reflects on these assertions, he/she should keep in mind that there is a very strong interrelatedness with both the old and the new assertions. These assertions were related to three different areas of focus. Part 1 of this section is directly related to the original assertions and is an expansion of those data. Part 2 relates to issues based on new perspectives on the relationship of modeling, positive relationships, and love. Part 3 reflects a number of assertions based on issues related to chronic illness and the processes related to diagnosis. Part 4 is a collection of assertions related to the correlation with heredity, the autoimmune system, and the relationship of significant allergic reaction as a

precursor to SLE. Some of these assertions may be obvious to the chronically ill but not to the researcher.

Part 1. In this part, two assertions are identified that may reflect concepts that were developed from the original assertions.

> Assertion 1: The depth of the learning experience increased as the age of the subject and the intensity of the experience increased.

It was apparent that the intensity of one's transitions was not limited to one's illness but included transitions related to relationships. It was apparent that loss was a common denominator in all of these transitions at some level.

> Assertion 2: Interpersonal relationship issues were also a major influence in one's responses to life changes.

This assertion was especially true in the lives of Geraldine, Sarah, and Beth. Each of these subjects demonstrated this in the following ways.

Geraldine had had two marriages and two divorces. She was living with a man and stated,

> My illness was not as difficult to accept as the transitions related to my relationships.

Sarah had lived her life trying to support a husband who was unhappy with his life. She had a child who had drug-related problems, and she was struggling with her role and her own life directions. For Sarah, the turning point occurred one night after years of struggle and disappointment in her relationship with her husband. He had come home drunk. She stated,

> I left the house frustrated, angry and disappointed. I just drove. It was late [and] I was crying. I screamed at the top

> of my lungs, "God help me!" A peace came over me that is with me to this day.

Beth had an unhappy youth. She ultimately married and had a disappointing marriage. She was bulimic and became pregnant. She shared that once she accepted her pregnancy and realized her role in the relationship, she stopped being bulimic. She had been bulimic for 11 years. Beth commented:

> Once I decided to have the baby and I began to experience love, everything changed.

Although expressing the importance of relationships, Marilyn had a number of developmental issues that were occurring as a function of her age. These factors were difficult to separate from other factors associated with her illness process.

These two assertions are, in effect, related to the expansion of the original assertions. The RTL inventory and especially the LCI helped to expand these perspectives.

Part 2--Priorities, love, and modeling. The assertions in this part focus on changing priorities, the models of love the subjects had, and the importance of love in their lives.

Assertion 3: Clear priorities can lead to order.

Each of the subjects expressed or demonstrated this assertion a number of times. If they did not express it, they demonstrated it in their behaviors or actions. Most of the subjects controlled their schedules and knew where and when they were willing to dedicate time to a project or a relationship. From a stress-management perspective, this assertion has implications for all people.

Marilyn. In line with this new assertion, Marilyn stated:

> When you are ill as much I have been, you have a lot of time to think about what is important and how you want to spend the time you have when you are not ill. It makes a big difference.

Beth. When Beth was approached to be a part of this study, she was very emphatic about the notion of how she was willing to use her time:

> I only have so much energy and time, and I really try to use it effectively.

Geraldine. With regard to priorities, this subject stated:

> I protect my time. I like to spend my free time with my animals and reading. You only have so much energy.

Teresa. Teresa stated:

> I thought my priorities were clear before, but not like they are now. With each event they got more clear.

This assertion was manifested in a number of statements that were identified in the RTL:

> I know that things in my life can change; life can still be meaningful.
>
> I believe there is someone or something more powerful, loving, lasting, and wiser than any single human being.
>
> *I feel connected to the world and to nature.
>
> I have something to share with others.
>
> *I am consistently aware of what's important.
>
> I have rediscovered the essential part of me.
>
> *I have time for my family and friends and time for me!

The three statements marked with an asterisk are especially good examples of the subjects' understanding of order and their understanding of priorities.

Summary. The understanding and expression of this assertion by the subjects in their daily lives is a very powerful statement as to the profound effect their transitions have had on their lives.

Assertion 4: Love is a powerful influence in one's life.

Marilyn. Marilyn expressed the presence of love in her family:

> The most important thing to me is my family. They have always been there when I needed them. . . . My dad and I always have had a special relationship.

Anne. Anne had been raised in a loving, committed family environment. She spoke of the unconditional support she had received from her mother and her husband, saying that had made all the difference in the world:

> They were always there, and they made a difference. When I was ready to reach out, their hands were always there. There is nothing more important than a loving family.

Beth. Beth stated on various occasions that she was a very unhappy person. She was in a bad marriage, unhappy with her life, and very depressed. She was not taking responsibility for her life, and she was not in control. She shared that she had been trying to decide whether to get a divorce when she discovered she was pregnant. She was angry at life and her relationship and decided it would be best to abort the baby. She was scheduled for an abortion when she realized she was not angry with the baby but her husband. It was at that time she finalized her plans for her divorce and canceled the abortion. She shared that, as a result of that decision, some other things happened that were significant. She realized that if she was going to be responsible for another's life,

she had to stop being self-destructive. She had been bulimic for 11 years; she stopped this behavior and started to take care of herself.

Beth shared that, after the baby was born, she began to experience what being loved was all about. She said that the baby accepted her unconditionally, and therefore she began to love herself more. This was the first time in many years that she experienced unconditional love.

> I like me now! When the baby was born, she helped me get there. She accepted me unconditionally, and I wanted to be more. I was in a bad marriage. I got to a place that I couldn't stay. I dreamed about my future and saw myself in a grave, and I could not do that with the baby coming. That got me to change.
>
> Love is what keeps us going.
>
> I think support and love is what makes all the difference for me now!

Geraldine. The support of a loving mother had been a key issue for Geraldine. She said:

> I guess no matter what, I always felt I was loved. That has made a real difference.

Her grandmother was also a special person:

> I always had a special relationship with her. Up until she died a few years ago, we would always have dinner together a few times a month and talk and just be together. I miss her.

Sarah. Sarah's home life was very chaotic. Her father was an alcoholic, and her mother was a positive and powerful influence on her. She was a loving model who influenced Sarah throughout her life. Sarah described her mother in the following ways:

> She had a warm heart. She was a special friend that God gave to me. She always loved me unconditionally. She was a lover, and so am I.

This was demonstrated by a statement Sarah shared that her son had made. He was in Arizona, having been sent there because of his drug problems.

> I could not send him money because he would spend it on drugs. But every week I sent him a care package. Later, my son said, "While I was in Arizona there was no one who cared about anything, but I always knew I was loved in spite of who I was."

In reference to a number of tough but caring instructors she had, Sarah said:

> I had some really awesome instructors. They made me feel so special. . . . She made me feel really good.

In describing her relationship to God, Sarah said:

> My God was loving and gentle and good.

She later stated:

> I had a client when I was working on one of the floors at the hospital. He was in a psychiatry unit. I had been warned not to get too close to him because he was dangerous. After my supervisors left, I went in and started to talk with him. He had tattoos all over his body, and it was obvious that he was very alone. I asked him to tell me his story, and he did. He was from a completely different side of life. [When we parted], there was a tear in his eye. I knew that he had felt something that he had not felt in a long time.

In reference to another relationship, Sarah related the following incident. Her son was having a relationship with a pretty girl who had told the family that she was ill and dying. She had led the family on, sought a lot of attention, and hurt Sarah. Sarah's dialogue gave another indication of how she perceived love:

> I deal in honesty. How I could be so stupid. Her lies did not change a thing. I did not like what she had done. But that has nothing to do with how I feel about her as a human being.

> I got a hold of her and let her know that I still loved her. I am going to love you whether you like it or not.

She concluded by saying:

> It's hard to not like you when you are being loved. If I care about you and you are still angry, then that is your problem.

Teresa. Teresa was a highly spiritual person with a tremendous capacity for love. That capacity had provided her with a great deal of energy and motivation to keep on living.

> I believe we were placed on this earth to love. If you learn to love yourself, then you will be able to love and care for others in positive ways.

Teresa was a powerful caretaker. She said that her desire to get up in the morning often was motivated by her love of her family:

> I would make sure I got up with the kids to make them breakfast, and then I would have to lie on the couch after they had gone because of the fatigue or pain.
>
> I had to take care of myself for them. There is a sense of spiritualness in a loving relationship. Strength is what the spirit provides.

In referring to her family, she stated:

> There has always been love for everyone here. Love and spirituality are always here. I guess we are so fortunate.

The ability to model love in their own lives by their actions and the presence of love in the lives of the subjects were affirmed in the following ways related to the RTL. These statements are categorized in terms of self, others, and the influence of others.

In terms of self, these statements reflect a great deal of strength in the presence of self-love:

I feel lovable.

I realize that I can't live without loving myself.

I live as fully as I can.

There were also a number of statements about self-care that could be interpreted as self-respect and love.

In terms of others and their relationship to the SLE subjects, these statements seem to reflect the relationship to love and others:

I can love and be devoted to another without losing my self.

I want other people in my life.

I want to help others who have this kind of life experience in common with me.

Two additional assertions could also be developed from the previous statements. It appears, for these subjects, that love affects those who encounter it and influences their behavior. It is not clear whether love can heal people physically, but it seems to have a great potential to motivate people, provide hope, and affect the spirit in profound and positive ways.

Assertion 5: The love of significant others is an essential contributor to one's understanding.

Assertion 6: The models one has throughout his/her life are very powerful influences.

Summary. Part 2 began to examine some of the relationships and influences love has had on the subjects. The issues related to these assertions are very complicated. It should be noted that all of the subjects were compassionate. Each subject, in her own way,

talked about the models of love and the presence of self-love in her life.

Part 3--Illness, medicine, and communications. Another series of assertions was developed around the issues of SLE, illness, medicine, and communications. These issues were demonstrated frequently in the literature and were later validated in the interviews, the LCI, and the Lifelines. These assertions are as follows:

> Assertion 7: Access to caring, competent medical professionals makes a difference in the nature of the patient's perception of medical care.
>
> Assertion 8: The inability to communicate one's illness and symptoms or to have others understand one's feelings is frustrating and painful.

Each subject found a need to seek either counseling or a support group, or was referred to counseling for help during this time. Not all subjects used this kind of help. They ended up seeking help or being referred to help because their physicians or families thought their symptoms were not real, or they were having trouble coping with all the ambiguity in their lives around their illness.

In the literature reviewed that included personal encounters with SLE--Embracing the Wolf, Living With Chronic Illness, The Sun Is My Enemy, and Coping With Lupus--each of the individuals had a significant number of years in which they experienced symptoms and could not be diagnosed. They, too, had been referred to counseling and misdiagnosed over a number of years.

Marilyn. In reference to a situation in which she was very ill, Marilyn shared that her mother had difficulty understanding what she was experiencing. She stated:

> This is the most frustrating thing because that's who you deal with everyday. It's just like communicating with the doctor. We are on different wave lengths.
>
> I begin to doubt myself. Maybe I am not having the problems I thought I was having.
>
> Communicating where I am is a problem. Old stories get lost in new pain. It is so hard to communicate the issues. The response has been more than once, "You think we should go back to the psychologist?" or "Well, I am going to take you to the Mayo Clinic and the Cleveland Clinic so maybe we can get an answer once and for all."
>
> Part of the problem is that my flare-ups really vary, and to someone who is not going through it, it is hard to really understand. It may be localized in certain muscles or joints, and if I treat those and go on with life it might be OK. Many times I am left to regulate my medications and try to eliminate the symptoms I can. When I have a major flare-up, it's like the flu. I can't do very much. I really have to watch out. I can't do anything. Or I might end up in bed for a month, feeling near death. Sometimes I feel so close to death, and no one else really understands because they think it is like the last one, which may or may not have been as bad. They all seem to run together, from their eyes. And they are really not all the same.
>
> I was in the hospital a lot. I ended up at about the same time every year. I began to feel comfortable there.
>
> I can't believe I forgot this. When I started college in the spring, they said I was having central nervous system involvement, so I went out to a head injury center and they helped me. I went there for about a year. It was hard because I had seizures. That is what started it, and there was pain in the backs of my eyes.
>
> Just last week I had a really difficult flare-up. I was feeling really badly. I think it was the worst I had had in a very long time, and she did not understand.
>
> I was bedridden for a month in January. Then I was going to graduate. Everything was really difficult.

Anne. In reference to the same kind of situation Marilyn faced, Anne responded:

> The biggest thing in one's life is the biggest until something bigger comes along. It is still the biggest. It is all in your reference to pain and joy and life and death, and it cannot be understood in any other way by anyone else.

She also noted:

> On a number of occasions I had to go to the emergency room, and the nurses would put on the oxygen mask because I was having real difficulty breathing, but they did not turn on the oxygen because they wanted to see if I was really in need of oxygen or just faking it. My lips would be blue.
>
> There was a lot of doubt and skepticism. What was really amazing was that my mother had lupus and they had ruled it out. It took them almost eight years to diagnose me with lupus.
>
> Part of the problem is that no test is conclusive. Also that a number of the symptoms of SLE are similar to some other types of chronic illnesses. [It should be noted that testing is becoming more sensitive.]

Beth. In the interview, Beth stated:

> When I started having barline cysts again, I was told that I had to live with them again. I said, "No way!" They couldn't understand how I felt. I found a new doctor. I had ovarian cysts and barline cysts. My periods were all screwed up, and there was no help. They said I had to live with it.

Geraldine. In reference to the birth of her son, Geraldine said:

> He came two months early. Then came lupus. No one had said anything about the other miscarriages I had had. Thus just said, "Take it easy." After the miscarriages I had joint pain, but I thought it was just part of growing older. I couldn't walk for a few days. The pregnancies were the worst part.

Sarah. Sarah shared in the interview:

> When you hurt in so many places and so intently, you really cannot communicate what you feel like, and no one really knows.

Assertion 9: The diagnosis of SLE can be an extremely difficult and lengthy process.

As this assertion is considered, a number of other factors in addition to the interviews can provide the reader with a more complete picture of what occurred for this subjects. Table 7 on page 79 shows the number of years each of the subjects went before being diagnosed. The number of years before diagnosis a subject with symptoms had ranged from 2 to 20. The average for the six subjects was approximately 9 years.

All of the subjects had prolonged periods of illness and symptoms before a diagnosis. During those periods, there was a great deal of doubt concerning the authenticity of their problems.

Marilyn.

> I was diagnosed when I was 14, but I had been having problems since I was nine. I was recommended for counseling because they thought that I really wasn't sick; no one really understood. . . . No one could really pinpoint the problem. I had been first diagnosed with rheumatoid arthritis, and later it was a diagnosis of lupus.

In reference to a conversation with her mother, she said:

> Mom, I felt like I was losing control of my mind, I felt like I was having seizures again, and that's why I was so scared. It wasn't like all the other times. It just seemed that way to you. I am sorry that it seemed like the hundreds of other times this had happened, but it wasn't!

Anne.

> I was 20 or 21 when I was diagnosed with lupus, and yet I had been having significant problems for six or seven years prior to my diagnosis and the doctors even ruled out lupus. Looking back, they never seemed to make a link that Mom had it and that I might have it also. I guess what is hard about it is that Mom's lupus was heart related and mine was lung related.

Beth.

I had vague symptoms for years, but it was really hard to communicate what was going on. I had lots of fevers, too. I had a lot of problems earlier. I think my immune system was always shaky. They took my tonsils out and I was still sick. I also had chronic constipation. I also felt better with less food.

Geraldine.

When I had my first miscarriage, they said I probably should not attempt to have more children, but they never were able to tell my why. I wasn't diagnosed with lupus until after the birth of my daughter, and even then not a lot was said.

Sarah.

I was diagnosed six years ago, but I had been having vague symptoms for years. I just thought it was normal. I didn't realize what was going on.

Teresa.

I was diagnosed when I was 31. But as I look back, I had been having problems since my early teens and maybe before.

In many of the readings, the issues of obtaining a clear diagnosis, and communicating with people what the symptoms are and how one is feeling, have been demonstrated a variety of times. In books like Embracing the Wolf, Coping With Lupus, Coping With Chronic Illness, and My Enemy the Sun, diagnosis was always a difficult and vague process.

Part 4--Hereditary factors, autoimmune malfunction, and allergies.

Assertion 10: There seems to be a relationship among heredity, autoimmune malfunction, and SLE.

Although a medical issue, the role of hereditary factors, autoimmune-related chronic illness, and specifically SLE is not clear. Are there other factors related to heredity issues that

should be considered in qualitative studies? This question has been raised because five out of the six research subjects identified family members, parents, children, grandparents, or cousins who had either some form of lupus or other autoimmune-related problems. The problems ranged from other family members with very severe allergies to lupus and other autoimmune illness. The literature did not indicate that there had been any significant research focused on hereditary factors and SLE or other immune-malfunction diseases. Subjects' responses related to this issue included the following:

Marilyn:

My mother has M.S. She was chronically ill when I was a little girl. When she was ill, I stayed home with her a lot. We were afraid to leave her. She began to progress and eventually was able to walk again. On one occasion, she had had a preliminary diagnosis of lupus, but that has not been confirmed. She now has her own business. Illness was a big part of my early life with my mother. Now the roles are reversed; she is well and I am ill.

Anne:

Mom was diagnosed with lupus when I was nine years old. My son has also had one positive test for lupus, and he is nine.

Beth:

When I was six, I lost my cousin from aplastic anemia. That was the first time I had experienced death. Many years later, I learned that aplastic anemia is an autoimmune-system problem. Later that year, my grandfather died. They said it was from lupus. He was diagnosed the year before he died. He stayed with us, and he used my bed and bedroom. He had dry skin and always had to cover himself. He had to wear gloves and a hat all the time. I think he had discoid and systemic lupus. My grandma lost it totally after she had the twins. She ended up in a mental institution, and six years later she died of TB. During those years, she had a lot of vaginal bleeding, and I believed she was very depressed. She gave up. Now that I think about it, I had very similar problems related to bleeding

that had been in part as a result of bars cysts that were related to my lupus.

Geraldine:

I had really terrible dry skin when I was younger. I still have it. I used to be teased a great deal by the kids at school, and I hated it. They called me dragon lady. That was a tough year. My mother had the same kind of dry skin problems, and so did my grandmother.

Teresa:

My daughter has lupus. I sometimes wonder. . . . I have felt guilty in the past, but I now realize that there is nothing that I could have done. My grandson also has been positively diagnosed as having lupus once, but the diagnosis has not been duplicated.

Assertion 11: Allergies were an early response symptom of all the SLE subjects.

Marilyn:

My allergies got really bad. I wasn't able to go outdoors because of my allergies. Then the arthritis got really bad, and after that I was diagnosed with lupus.

Anne:

There were many times when I was brought in to the emergency room and I couldn't breathe.

Beth:

I had a lot of problems that went undiagnosed in high school and college. I had shingles in college and never knew it. I just thought they were allergies, too.

Geraldine:

I have always been highly allergic. I have had extremely dry skin. I have always seemed to have it. In seventh grade I was tormented by the other kids because I had extremely dry skin. I was just flaky and had rashes all over. My mother has the same thing and her mother, too. We all had allergies. Mine happened to be worse. My allergies really get bad sometimes when I am haying.

Sarah:

> I have always had super allergies. I had migraines since I was ten. I can remember headaches for two weeks at a time. Everyone had allergies. I just thought it was normal.

Summary. The relationship among SLE, heredity, and allergies was not discussed in the literature. The common presence of these factors in each of the subjects leads the researcher to believe there may be a link with all of these issues to SLE. What seemed obvious to the chronically ill was not obvious to the researcher and might not be obvious to the lay person. Issues and beliefs related to health, illness, and the ability of medical practitioners to deal with illness in clear, decisive actions are not always accurate. This sampling may be just a hint of some of the realities related to illness, diagnosis, and treatment.

Chapter Summary

In each section of this chapter, the researcher attempted to provide the reader with a different perspective of the data regarding each of the research subjects. Although no absolute conclusions can be gained from such a limited sample, there seem to be many subtle relationships and common experiences that were reflected in the data.

The first section focused on the personal histories of each of the subjects. The data were self-reported and might have a degree of error due to the subjects' ability to recall dates and experiences in a clear and accurate manner. The common experiences

and expressions of concern helped provide a glimpse of what their lives were like.

The second section focused on the responses that were collected from the RTL. The RTL provided a broad range of statements in relation to issues related to the losses of illness and their responses. The level of agreement in the areas of transformation and self-empowerment was a strong affirmation of the common beliefs and experiences shared by the subjects.

In the third section, the researcher attempted to connect some of the common threads of data into a number of assertions. These assertions were categorized into two major areas. These included two major categories: original assertions and additional findings. The additional findings included 11 new assertions. These new assertions were broken down into four parts, all reflecting different elements of the data and the review of literature.

CHAPTER V

IMPLICATIONS, DESIGN RECOMMENDATIONS, CONCLUSIONS, AND CLOSING OBSERVATIONS

Implications

Throughout the interviews and reflected in the survey information, a number of questions were raised that went beyond the design of this study.

The following questions were raised in the surveys and interviews and warrant consideration for further study. These include the following:

1. How can the level of stress be reduced in SLE patients and individuals with chronic illness who have symptoms that are very difficult to diagnose?

2. Where can one find the social support in times of chronic illness?

3. How effective are support groups for people with chronic illness?

4. How helpful are support groups for family members who have a loved one who has a chronic illness?

5. How can supportive environments be created for the chronically ill in a society of growing structural changes in the family and familial dysfunction?

6. What role does the use of vitamins play in bolstering the response of the immune system?

7. What role do self-care activities like exercise, good nutrition, meditation, and a strong prayer life have in affecting the quality of life of people with chronic illness?

8. Is depression induced in people with chronic illness because of a change in their physiology?

9. Is depression caused by the losses associated with chronic illness?

10. What is the relationship between physiological changes and losses related to depression for the chronic illness?

11. Can depression related to chronic illness be treated and approached from a perspective of loss?

12. Can the sharing of the significant learnings that people with chronic illness experience help people who are not ill live more effective lives?

13. What is the relationship between an early history of severe allergies and other autoimmune-related illnesses?

14. What role does one's sensitivity to his/her environment play in signaling the onset of immune-system diseases?

15. Are there environmental factors that stimulate the development of immune-system diseases?

In summary, this research project has identified a number of assertions related specifically to these six SLE patients that are possibly transferable to other people with chronic illness. The

project also has implications for the researcher as a teacher and a person.

We live in an era of medical technology and pharmacological approaches, one in which increased longevity and increased incidences of immune-system-related problems are creating growing populations of people with chronic illness. These demographic changes, as identified in Chapter I, are increasing the need to further examine questions related to chronic illness.

Design Recommendations

The format of this study permitted a great deal of in-depth exploration into the life histories of a limited subject population of six. A number of design factors may warrant examination if other investigators undertake this kind of research in the future.

1. The sequence of the research could be improved if an individual were asked to complete the Life Changes Inventory and the Response to Loss Inventory before completing the Lifeline. It is the researcher's experience that the Lifeline's function of promoting a narrative might be improved.

2. The amount of data collected was voluminous. A wealth of information was gathered. The indexing of statements and the cross-referencing of information were very time consuming and difficult to control. A comprehensive system of computerized information management would be helpful for future research.

3. The depth of the interviews might be strengthened if an individual were allowed to tell his/her life story uninterrupted,

using the Lifeline first. Once this initial interview was completed, the interview could then be reviewed and questions developed that would focus on extrapolating consistent lines of questioning and information collection.

4. Further studies might be valuable in helping people identify some of the common issues that all people struggle with in chronic illness. These factors might include depression, the effects of chronic illness on relationships, the effects of receiving unconditional love on remission and healing, the ability to communicate one's symptoms, isolation as a result of illness, and transitions related to relationships during illness.

5. The focus of this study was on subjects who had had a diagnosis of SLE for more than five years. The level of maturing of these subjects had, related to their illness, was very high. Further research related to the developmental issues surrounding loss and chronic illness needs to be done. Many of the statements made by the subjects and many of their actions reflected a high level of personal transformation. How people who are newly diagnosed with a chronic illness respond may be different and important. Understanding these differences might help in the development of treatments that are more developmentally appropriate.

Conclusions

The data produced by this research were very powerful. The interviews, use of the RTL, Lifeline, and LCI all contributed to a body of information that encapsulated the life stories of six people

who were living with SLE. The dysfunction, divorce, drug abuse, and bulimia are all reflections and true microcosms of the societal picture that was described in Chapter I. Their lives mirrored many of the issues related to chronic illness, stress, and coping that were presented in Chapter II. It is these stories that have led to the following conclusions. The conclusions are broken down into two categories. Category 1 is related to concepts presented in the review of literature. Category 2 focuses on additional observations.

Category 1

The literature discussed coping and loss, adjustment, and illness. The key factors that contributed to coping and the management of stress that were identified in the literature and are reflected in these conclusions were as follows: (a) beliefs of the subjects, (b) transformations related to losses, and (c) actions taken by the subjects related to coping.

Conclusions related to beliefs. In the literature, a number of elements were discussed about the relationship of people's beliefs to their ability to deal with their changing life positions. These conclusions focused on the relationship of people's beliefs, the effects of their beliefs on their behavior, and how they coped.

1. A belief in a higher power beyond one's self is a source of strength and energy.

"'God help me.' I screamed, and immediately a peace came over me that has been present in my life ever since." Similar statements were echoed throughout the interviews about the presence of a higher power in each of the subjects' lives. Two subjects reflected a strong belief in the presence of Christ in their lives. Two others shared renewed spiritual awakening and a belief in a higher power. All of the subjects reflected a belief in a higher order. What was interesting was that, despite the chaos related to their illness or relationships, their worlds reflected that they had order in their lives. There were no questions concerning their belief or their sense of order in the universe. The questions related to why they had contracted SLE and why they were forced to endure their transitions were no longer being asked.

Transformations related to losses. This section is a collection of some of the kinds of actions that occurred in the process of managing their transitions. Some of these conclusions were a result of individual transformations as they moved through their losses.

1. Clear priorities create order. In reading these stories, a consistent pattern arose. Despite the monumental problems, there was a sense of order in each of these subjects' lives. That order seemed to be a result of a gradual transformative process, in which each subject slowly eliminated those parts of her life that were no longer important. As the subjects let go of their losses and identified the important elements of their lives, they were able to

focus on and use their energy in ways they thought were positive. This is not to say that their lives were not without chaos. In those areas where choices existed, they were able to use their energy to create some joy and order in their lives.

2. Letting go is a source of power. The RTL reflected a strong tendency on the part of each subject to let go of her anger and the losses related to her illness. The group showed a high transformative sense about their lives. They all acknowledged that they were getting on with their lives, and their focus was positive. Each person chose to volunteer for this research project with the belief and intention that this work might help someone else. They all could have chosen to "hold on to" their daily pain, losses, or resentment for the way life has been played out to them, but they did not. They made a different choice--to "let go" and to use their energy positively. The letting go seemed to provide them with a source of energy. It allowed them to use the energy they had in ways that empowered and freed each of them.

Actions taken by the subjects related to coping. This section reflects actions that were taken by the research subjects that helped them more effectively manage the stresses they encountered. References to exercise, self-care, nutrition, and their own sensitivities to their needs were identified.

1. Positive self-care can lead to more effective commitments. SLE was described, both in the literature and the data, as an illness that talks to you through your body. It sends messages in

the form of pain and fatigue. These messages are part of what contributes to the lessons that illness teaches. For the SLE patient, listening to these messages was critical. It was within these limits that the researcher began to understand that if the SLE patient did not acknowledge the pain and the fatigue and pushed beyond a reasonable level, she was forced into a worsening of symptoms or a "flare-up." Each subject reflected modifications in her life style. They all rested more, some took vitamins or tried to exercise as much as possible, and in general they kept their relationships current. They did these things to help them meet their personal and work commitments. They also did this because it improved the quality of their lives. If these SLE patients did not do this and did not take the time for themselves, they could not have met their priorities. One subject said, "I have to listen to my body because if I don't, my body screams at me and I end up praying out of fear."

Category 2

There seemed to be a number of other related observations that were more difficult to pinpoint as to where they originated and how they affected one's ability to cope. The researcher believes these understandings contribute to the hardiness of the individual.

1. Some events in life cannot be anticipated or planned. An alcoholic husband, a train wreck, a child who is addicted, a miscarriage, a heart attack, an illness, a pain, a divorce, and flowers that did not wilt were all parts of what made life unique

for each of the subjects, yet reflected unpredictability. The chaotic world that confronted each of the subjects was a common threat that was present at many levels, both in the data and in the literature. Illness, loss, and despair are often like a thief in the night. They appear without warning and provide each of us with a set of circumstances we call life that is completely different and previously unimaginable. These changes, many of which involve loss, were a central part of each subject's life.

2. <u>There is always more than meets the eye</u>. So often we never really know the stories behind the people we live with and work next to. Assumptions are made about many parts of their lives. We may have little glimpses of who they are, but seldom are we allowed into their private domains. Seldom do we really understand who they are and what they are about. This cataloging of data provided the researcher with a multitude of stories, each describing elements of a subject's life. Even with the intensity of these stories, it is difficult to really comprehend the complete picture. Impressions create a powerful mask from the realities of life. Marilyn was a wonderful example. She was attractive, well dressed, 20, and a college student seeking a degree in an allied health occupation. Who could have really understood how much of her life had been centered on illness and loss? Sarah's story was vastly different, but her experiences were very similar. Externally, she was very jovial, happy, and caring. It seemed almost impossible that she could have faced so many obstacles on her journey. All of the subjects had their own stories. Their lives, like the lives of so

many, are much more complex than we can understand. This kind of complexity was a common link that was reflected in all of the subjects. Each profile validated how little we really know about others. All of these subjects could have been a neighbor, a friend, or a spouse to any one who reads this document.

3. Where there is commitment there is power. All of the subjects had a multitude of reasons to give up--recurring muscle pain, periods of immobility, organ involvement, central nervous system problems, heart attacks, and more--but they did not. In each case there was a commitment to something outside of themselves. It might have been a spouse, a child, an education, or a desire to learn. It did not seem to matter. Each was committed to something she felt positive about. What mattered was they had commitments that provided direction for their lives. The motivation to get out of bed, to make a quilt, to face life and make it positive was consistent. Teresa had two nearly fatal heart attacks and was highly allergic to medical treatments. Two others experienced recurring bouts with extended periods of forced bed rest of a month or more. Yet they recovered. Each said it was her commitment to something outside of herself that helped her move beyond her illness and limitations. Mitchell (1991) shared this perspective: "When one commits, strange and powerful things happen."

4. What you focus on grows. If one pays attention to his/her garden, what is cultivated usually grows and becomes plentiful. Illness and, in particular, pain can cause one to change focus. It

can cause one to divert thoughts, especially positive thoughts of life to thoughts of death. It can cause depression, apathy, and hopelessness. None of the subjects reflected these kinds of behaviors. Each had a focus. It may have been to grow intellectually, help others, or be a model for their children. They all had a focus beyond their own illnesses. Their focus was positive and dynamic.

5. Live now. Each person had a sense of presence that was very powerful. There was no doubt that they were highly focused. No one looked back on their lives with longing. They had accepted their past. They also did not project forward with any unfounded hopefulness or denial. Each had a belief that her life would continue to improve, but her focus was on now. Words like "when this changes," "if only," and "life shouldn't be this way" were not used. With each meeting, the researcher sensed their whole attention was focused on the task at hand. In his book Jonathan Livingston Seagull, Bach (1972) summarized it this way:

> If our friendship depends on things like space and time, then when we finally overcome space and time, we've destroyed our own brotherhood! But overcome space, and all we have left is Here. Overcome time, and all we have left is Now. And in the middle of Here and Now, don't you think that we may see each other once or twice? (p. 63)

In all the subjects' interviews and stories, they were present and focused. Their expressions and behaviors did not reflect urgency as much as a state of being into the moment.

6. Love can heal. The subjects shared a number of stories that demonstrated how unconditional love was experienced and how

that love changed their lives. A bulimic of 11 years started to eat healthfully, an alcoholic husband could not envision life without his spouse and stopped drinking, a grandmother's model of love gave strength. It should be noted that the healing was not always physical, but many times emotional or spiritual. The loving that was experienced by each of the subjects made a key difference in their lives. Where that love emanated from was not as important as was its presence. Elizabeth Kubler-Ross (1968), founder of the hospice movement, stated it this way: "Unconditional love can heal anything."

There are very few certainties in life, short of death. Each of these subjects was confronted with her mortality in ways that are foreign to many of us. The reality is that death is equally present for all of us. The only difference between these six subjects and most people is that they were possibly aware of their mortality at a greater depth. Yet they possess a zest for life that reflects courage, optimism, and hope.

Closing Observations

This study gave the researcher a sense of some of the kinds of issues and transitions SLE patients face daily. The subjects in this study provided the writer with yet another possible model of how one might live more closely to his/her potential as a human being.

To some extent, this study also provided the researcher with a sense of some of the issues that are faced by people with chronic

illness that he has not had. It is clear that each illness is unique and that not all chronic illness can be put into one generalized category. Obviously, even persons with SLE cannot be singularly categorized due to the varied nature of this illness, the individual's stage of development, and the level of involvement that a person may be encountering. Nonetheless, the experiences recorded in this study might be useful to others who are facing transition.

This research also revealed the kinds of similar experiences and perceptions that SLE patients have and provided the researcher with a wealth of stories related to these transitions. The subjects' stories reflect how people who are faced with recurring transitions can cope with loss, survive, and transform their lives in positive ways.

The subjects' stories were very common at some levels, and yet at other levels they reflected a type of heroism that is seldom discussed. Their heroism was demonstrated in how they faced the physical and psychological unknown of chronic illness, how they confronted their losses and pain daily, and how, despite these obstacles, they were willing to share their stories with others. All of the subjects showed a genuine concern and caring for others by sharing their stories in the hope that someone else might benefit. They seemed to have a special empathy for others who were in the transitions of chronic illness, loss, and life in general.

The subjects shared stories about their challenges and their obstacles that seldom are shared. These stories provided a glimpse at a part of life many people do not encounter. The subjects also

shared a number of fears and concerns related to life and chronic illness that most people do not take the opportunity to discuss.

More important, the participants shared a perspective that life can still be joyous and meaningful, no matter where one is on the continuum of physical health and illness. They demonstrated how their own sense of self-responsibility could make a difference in the quality of their experience. They further reflected how their sense of spirituality and commitment to having meaningful relationships had made a difference in their lives. Finally, they shared how love had been a powerful source of strength and, in some cases, healing for them.

Briefly in Chapter I, in the section on the Importance of the Study, and to a much greater extent in the Review of Literature in Chapter II, many of the recurring themes of life in America for people coping with chronic illness were reflected. Even though the data certainly echoed models of coping with loss in great detail, they went beyond the literature in providing intimate stories and relationships on how people cope with loss.

As shown in this study, there is an ongoing need among researchers, teachers, and lay people to establish a dialogue with people who are chronically ill. This dialogue might provide an opportunity to further understand the workings of the human spirit and the ability to live in joy despite illness and personal tragedy. Understanding the perspective of the chronically ill might well

provide a glimpse of life that can enrich one's own life and help people live closer to their potential.

The final implication is that the researcher, as a teacher of stress management, has been given a set of stories that might help provide models for future students regarding how others have survived and embraced life during transition.

APPENDICES

APPENDIX A

THE LIFELINE

LIFELINE

Introduction:

The purpose of this exercise is to help you prepare for your interview. This tool is designed to help you focus on meaningful transitions and major learning experiences in your life. Do not hesitate to share other events or feelings that are meaningful to you during this time even if they do not seem especially significant but are important to you.

Directions: Please plan to take sufficient, uninterrupted, time to create your lifeline. Beginning with your early childhood identify as many major and or meaningful experiences as you can. The measure of major or meaningful is to be defined by you. You may use a calender and list events chronologically or you may, through the use of stick figures, pictures or other types of drawings, outline your experiences. Please use the paper provided. The lifeline is not meant to be a detailed description of your experiences, but a tool by which we can initiate a meaningful dialogue. A great deal of detail is not necessary.

(If you have journals, scrapbooks or other reflective works, art, short stories, and or letters and are willing to share them please bring them to the first interview along with your lifeline.)

APPENDIX B

TAPED INTERVIEW FORMAT

Interview Preparation and Format

1) Please prepare your Lifeline as outlined in the attached form.
2) Please bring any journals, letters, scrapbooks or other materials that may help to get a clearer picture of what your life looks like during this period.
3) The interview will be informal.
4) Each interview will be taped to help capture the transitions and their meaning as accurately as possible.
5) Please read over the questions attached so that you may be able to give some thought to the flavor of the interview and anticipate some of your responses. Additional questions may evolve as a result of your responses.

Sample Questions:

1) Please describe your life for this period of time (use your own lifeline).
2) What have been the most significant events for you ?
3) Were there any specific events that were particularly stressful for you during this period?
4) Did any illness follow these stressful events?
5) Through your illness transitions, what helped you the most through these difficult times?
6) Please explain in as much detail as possible how you confront these transitions? What do you say to yourself?
7) Has your self-talk changed a great deal over the years?
8) Do you have any scrapbooks, journals or other materials that may help to understand what your life was like during this time of your life?
9) Please go over them with me!

APPENDIX C

THE LIFE CHANGES INVENTORY

LIFE CHANGES INVENTORY

●John Schneider, Ph.D.

NAME or CODE:_____
DATE:_____ AGE:_____ SEX:____
LIVING ARRANGEMENT(S):
ALONE:___ WITH SPOUSE:____WITH CHILDREN:___
WITH PARENTS_____
WITH OTHERS_____

The following is a list of changes which people can experience throughout their lives. These may include one or more which you have experienced. You are to 1) identify significant changes and to 2) rate their current impact on you.

First, select a change event which you have experienced. In the blank next to the item, indicate how long ago this event occurred (e.g. 6 mos.; 10 yrs.). Identify as many as apply to you.

Second, please rate each item you have checked with a number between -5 and +5, according to the following guidelines:

- 5 = this event is <u>right now</u> the most negative or equal to the most negative I've ever experienced.

0 = this event is neither positive nor negative <u>at the present time</u>

+5 = this event is <u>currently</u> the most positive experience or equal to the most positive experience in my life.

All information on this rating scale wil be kept confidential. Please use a code name if you wish to insure your anonymity.

Examples:		**Rate : (Circle)**	
How long?		**Negative**	**Positive**
____	19.06 = decreased drug use	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	19.07 = increased smoking	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
<u>2yrs.</u>	19.08 = decreased smoking	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
<u>6 mos.</u>	19.09 = increased drinking	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

EXTERNAL CHANGES

0 = Changes in relationships with spouse/significant other

How long ago? (mos./yrs.)		Rate (circle) Negative	Positive
____	0.01 falling in love	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.02 marriage/public commitment	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.03 death of a partner	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.04 divorce	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.05 separation	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.06 prolonged absence	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.07 reconciliation	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.08 betrayal of trust	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.09 changes due to partner's way of dealing with loss/grief	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	0.10 marital conflict	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

1 = Loss of a child:

How long ago?		Negative	Positive
	1.01 death:		
____	1.011 due to illness	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.012 due to injury	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.013 due to murder	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.014 SIDS	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.02 miscarriage	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.03 abortion	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.04 kidnapping	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.05 disappearance	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.06 placed for adoption	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.07 runaway	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.08 imprisonment	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	1.09 other: please elaborate: _____	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

2 = Other changes in relationships with our children:

How long ago?		Negative						Positive				
____	2.01 birth	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.02 starting child care	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.03 starting school	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.04 moving (as a family)	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.05 child leaving home	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.06 child's illness/disability	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.07 adult child living at home (returning)	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.08 becoming a single parent	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.09 loss/limitation of visitation rights	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.10 alienation	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.11 problems among children	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.12 problems with stepchildren	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5
____	2.13 Other: _____	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5

3 = Change involving parents

How long ago? **Negative** **Positive**

____ 3.01 parent death -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.02 leaving parent's home
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.03 change in custody -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.04 reconciliation of parents with each other
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.05 being disowned/alienated
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.06 returning to live at home
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.07 change due to parental separation or divorce
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.08 parental illness -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.09 reconciliation with one or both parents
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.10 parental remarriage -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.11 relation with step parent
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 3.12 relations with step siblings
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

4 = Changes involving brothers and sisters/close relatives:

How long ago? **Negative** **Positive**

____ 4.01 death of a sibling/relative (specifiy relationship):_____
_____ -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.02 loss of contact -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.03 living with sibling -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.04 estrangement from siblings/family members
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.05 reconciliation with siblings/family members
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.06 sibling problems (e.g. divorce, bankruptcy, imprisonment)
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.07 death of grandparent/great grandparent
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
____ 4.08 death of grandchild -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

5 = Changes involving friends

How long ago?	Negative	Positive
____ 5.01 friend's death	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 5.02 betrayal of friendship	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 5.03 moving	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 5.04 new relationships interfering	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 5.05 estrangement	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

6 = Other external losses or changes:

How long ago?	Negative	Positive
____ 6.01 loss of a pet	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.02 loss of home	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
6.03 moving		
____ 6.031 within the same community	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.032 within 250 miles	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.033 within the same country	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.034 to a new country	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.035 to better accomodations	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.036 to worse accomodations	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.037 eviction/foreclosure	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.04 loss of favorite mementos/photos	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.05 leaving homeland/culture/ethnic background	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.06 unable to use native language	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.07 living in unfamiliar/dangerous environment	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 6.08 natural disaster (e.g. tornado, flood, drought)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

7 = Other external losses (please specify):

How long ago?		Negative	Positive
____	7.01 - _____	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5	
____	7.02 - _____	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5	
____	7.03 - _____	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5	

Comments on external changes in your life:

INTERNAL LOSSES/CHANGES

10 = Changes due to traumatic experiences

How long ago? (mos./yrs.)		Rate (circle) Negative	Positive
____	10.01 being imprisoned	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.02 being abused	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.03 political torture	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.04 being in combat	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.05 rape	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.06 witnessing a murder or rape	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.07 injuring/killing someone accidentally	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.08 injuring/killing someone deliberately	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.09 victim of prejudice	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	10.10 victim of neglect	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

11 = my own life threatening or chronic illness/condition

How long ago?		Negative	Positive
____	11.01 AIDS (HIV positive)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.02 Cancer/Leukemia	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.03 Heart condition	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.04 Chronic lung	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.05 Diabetes	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.06 Multiple Sclerosis	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.07 Lupus	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.08 Environmental Illness	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.09 Cystic Fibrosis	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.10 Huntington's	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____	11.11 Other: _____	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

12 = job related changes:

How long ago?	Negative	Positive
____ 12.01 being fired	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.02 retirement	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.03 promotion	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.04 being hired	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.05 reassigned	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.06 demoted	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.07 being passed over for promotion	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.08 responsibilities curtailed	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.09 responsibilities increased	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.10 work lost its meaning or significance	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 12.11 work gained meaning or significance	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

13 = loss of physical function or ability to work due to:

How long ago?	Negative	Positive
____ 13.01 injury	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 13.02 illness	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 13.03 accident	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 13.04 treatment (e.g. drugs, surgery)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 13.05 aging	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 13.06 disability (e.g. hearing, sight impaired)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

14 = Loss of sexual function/attractiveness due to:

____ 14.01 injury	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 14.02 illness	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 14.03 accident	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 14.04 treatment (e.g. drugs, surgery)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 14.05 aging	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 14.06 disability (e.g. hearing, sight impaired)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

15 = Loss of mental functioning due to

How long ago?	Negative	Positive
____ 15.01 injury	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 15.02 illness	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 15.03 accident/trauma	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 15.04 treatment (e.g. drugs, surgery)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 15.05 aging	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 15.06 disability	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

16 = Pain

How long ago?	Negative	Positive
____ 16.01 long lasting pain (more than six months)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 16.02 effective control of long lasting pain	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 16.03 resolution with long lasting pain	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 16.04 ending of long lasting pain	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

17 = Financial changes:

How long ago?	Negative	Positive
____ 17.01 significant indebtedness	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 17.02 winning the lottery (more than 10,000)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 17.03 declaring bankruptcy	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 17.04 significant increase in salary/income	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 17.05 significant decrease in salary/income	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 17.06 living on a fixed income	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

18 = change in status or prestige:

How long ago?	Negative	Positive
____ 18.01 graduation	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.02 becoming famous (award, publication, etc.)	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.03 being arrested	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.04 publically "losing face"	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.05 winning a lawsuit	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.06 losing a lawsuit	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.07 being cleared (exonerated) of an accusation	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 1808 being convicted	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.09 entering a religious life style	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.10 leaving a religious life style or cult	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5
____ 18.11 Other: _____	-5 -4 -3 -2 -1	0 +1 +2 +3 +4 +5

19 = change in health habits (for longer than six months):

How long ago? **Negative** **Positive**

____ 19.01 increased exercise (by more than 3 hours/week)
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.02 decreased exercise (by more than 3 hours/week)
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.03 increased chances to relax (by more than 3 times/week)
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.04 decreased opportunities to relax (by more than 3 times/week)
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.05 increased use of street drugs
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.06 increased use of prescription drugs
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5____

____ 19.07 decreased use of street drugs
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.08 decreased use of prescribed drugs
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.07 increased smoking -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.08 decreased smoking-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.09 increased drinking -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.10 decreased drinking-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.11 weight gain -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 19.12 weight loss -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

20 = changes due to treatment

How long ago? **Negative** **Positive**

____ 20.01 counseling or psychotherapy
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 20.02 prescription drugs
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 20.03 being adopted/placed in foster care
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

____ 20.04 being hospitalized
-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

21 = other internal (self) losses: Please elaborate

How long ago?		Negative	Positive
____	21.01	_____	
		-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5	
____	21.02	_____	
		-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5	

Comments on internal changes:

11/16/89 jms

APPENDIX D

THE RESPONSE TO LOSS INVENTORY

RESPONSE TO LOSS

(TOTAL)

Taking the RTL is voluntary. You may choose not to participate at all, or not answer certain questions without penalty. You indicate your willingness to participate by filling out and returning the answer sheets.

John Schneider &
Diane Deutsch
Revised 17 September 1990

RESPONSE TO LOSS (RTL)

Questionnaire Instruction

This is an inventory of ways people respond to losses in their lives. All of the questions reflect the normal process of grieving, although, of course, none of us reacts in all of these ways to any given loss. Responding to this inventory may help you identify your current reactions to significant changes in your life, particularly losses. You may find responding to this questionnaire difficult because some questions may bring up memories or feelings which are painful. You may not wish to finish this inventory. You are not required to do so.

- Since this inventory asks you *only* how you are doing right now, you may find that you have changed from how you would have responded even a few days or a few months ago.
- It might be helpful to discuss your reactions with someone. You are invited to record your thoughts about taking the inventory at the end of your answer sheets.
- When possible, respond to only one particular loss or change in your life. The "Life Change Inventory" may have already helped you to select your most recent and/or most significant loss. Please note in the answer booklet which loss it is that you are considering.
- When it is not possible to focus on a single loss, please indicate all the losses which were involved in your response.
- As you read each question, ask yourself if the statement is true about you right now, or in the past few days or weeks. You can indicate the degree to which you are having these responses according to the following scheme:

1 = *this isn't true about my current response to this loss*
2 = *occasionally this is true about my responses to this loss.*
3 = *some of the time this is true about my responses to this loss.*
4 = *most of the time this is true about my responses to this loss.*
5 = *this definitely is true about my current responses to this loss.*

NOTE: If a statement is true about you, but is not a response to the loss, leave it blank.

Please respond to all questions, even if you leave some of them blank. You may find it helpful to take one or more breaks while you are filling out the questionnaire. It does not need to be filled out in one day, but within a few days. If the loss you are considering has occurred recently, or if filling out these items provokes strong feelings, you may postpone filling out this questionnaire.

The loss I am considering is (check one):

00 = my own life-threatening illness or condition
01 = death of a partner/spouse
02 = death of a child/
03 = death of a grandchild
04 = death of a parent
05 = death of a grandparent
06 = death of a friend
07 = death of a brother or sister
08 = loss of job (e.g., being fired, quitting, retirement)
09 = loss of partner/spouse other than by death (e.g. divorce, separation, severe conflict, prolonged absence)
10 = loss of health
11 = loss of home, homeland, culture (e.g., moving, war, intolerance, etc)
12 = financial loss (e.g., bankruptcy, foreclosure, business failure)
13 = loss of freedom (e.g., arrest, imprisonment)
14 = loss of parents other than through death (e.g., moving from home, being disowned, estrangement, conflicts, their divorce, separation)
15 = loss of children other than through death (e.g., their moving out of the home, illness, adoption, loss of visitation rights)
16 = loss of self due to traumatic experience(s) (e.g. accident, crime, war, natural disaster, rape, incest)
17 = other loss(es): Choose from the Life Change Inventory. Please specify on the answer sheet.
18 = Multiple losses. Please indicate all of the above losses which apply:

Mark your answers on the answer sheet provided with this questionnaire.

1 = *this isn't true about my current response to this loss*
2 = *occasionally this is true about my responses to this loss.*
3 = *some of the time this is true about my responses to this loss.*
4 = *most of the time this is true about my responses to this loss.*
5 = *this definitely is true about my current responses to this loss.*

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

HOLDING ON

In the time since my loss,

1. I find myself talking or acting as if nothing has changed.
2. Keeping active and busy helps me feel less anxious about this loss.
3. I look at reminders of my loss (e.g. pictures, mementoes).
4. I would do almost anything to get back what I've lost.
5. I am smoking more.
6. I keep busy to avoid thinking about what happened.
7. I want/need to tell others what happened.
8. Taking care of others distracts me from thinking about my loss.
9. I've been the one to make the necessary decisions.
10. Until it is proven to be beyond any doubt that this loss is real, I will keep looking for it/him/her.
11. I look just as good as I always do.
12. I go over the loss in my mind, trying to figure out how things could have been different.
13. I try to figure out why this loss happened to me.
14. This whole thing seems unreal.
15. Almost anything can remind me of my loss.
16. I think I am responsible for this loss.
17. I don't believe that this loss really happened.
18. Something could have been done to prevent this loss.
19. I think that if I am good or perfect enough, what was lost will return.
20. I wish things were the way they were before this loss occurred.
21. I keep thinking something could be done to bring back what I lost.
22. If I could just find the reason this loss happened, I wouldn't feel so bad about it.
23. If I tried hard enough, I can bring back what I lost.
24. I hope that I am dreaming and I'll wake up and find out it never happened.
25. I feel that I should have done something to prevent this from happening.
26. I am angry about this loss.
29. I'm scared to share what I've been thinking, feeling and doing.
30. I'm not sure I trust the feelings I have about what I did and/or didn't do just before the loss happened.
31. I feel guilty or disloyal when I forget about this loss.
32. My feelings are so intense I'm afraid I'm losing control.
33. I want someone to be punished for this loss.
34. I feel guilty just thinking about enjoying myself.

In the time since my loss,

35. Being in control helps me feel less overwhelmed.
36. I am afraid to think about anything else but my loss.
37. I'm afraid I'll forget my loss if I stop thinking about it.
38. I can't control my feelings when I'm with those who share my loss.
39. Unless something happens soon to change this, I don't know if I can control my feelings.
40. I try to hold back the tears.
41. My feelings are so unpredictable I wonder if I am crazy.
42. I'm not ready to let go of my feelings about what happen.
43. I dream that it never happened.
44 I've increased my exercise.
45. I ignore the physical pain just to keep going.
46. I dream that something has happened to reverse my loss.
47. I have lost weight.
48. Sex gets my mind off the loss.
49. It's obvious to others I've been upset.
50. I am sleeping less.
51. I don't eat as much.

Because of this loss,

52. It would help if someone could help me understand this.
53. Life seems unfair.
54. There are times when it feels like I am going through this same thing all over again.
55. I am not able to forgive those who contributed to this loss.
56. I wonder if I really deserve what I have.
57. I believe that if people could just love each other, no one would really have to suffer.
58. I won't give up.
59. I won't accept that this loss has happened.
60. I am determined to make those responsible pay for this.
61. I'm looking for a way out of this loss.
62. This loss must be changed.
63. I believe something good will happen.

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

LETTING GO

Since this loss happened,

1. I avoid telling anyone what I'm thinking, feeling and/or doing.
2. I avoid people who remind me of this experience.
3. I've been careless.
4. I have kept secret what really happened.
5. I act as though this doesn't really matter to me.
6. I drink to forget my loss.
7. I've put away anything which could remind me of this loss.
8. I avoid reminders of this loss.
9. I use drugs to forget my loss.
10. I'm less patient with people.
11. I don't see much of my old friends.
12. I don't spend as much time with my family.
13. I avoid getting involved in anything.
14. I refuse to discuss this loss.
15. I can be physically abusive when others remind me of the loss.
16. I can be verbally abusive when others remind me of this loss.
17. I lose or misplace things which are related to this loss.

Since the time of this loss, I have thought

18. Something else is going to go wrong.
19. It's easier when I can forget what happened.
20. This loss is evidence that I have failed as a person.
21. If I get too happy, something bad is bound to happen.
22. If I don't look out for myself, no one else will.
23. I deserve a better deal than I'm getting.
24. I can think of very few people worth my time and energy now.
25. That I'm better off without it/him/her.
26. No one can change what's already happened.
27. No matter what I do, what will happen will happen.
28. Even if I could understand why it happened, it wouldn't change anything.
29. It's best not to dwell on the past.
30. I cannot imagine how anything positive could come out of this loss.

In the time since this loss,

31. I feel confused and disoriented.
32. I feel detached and separate from others.
33. I feel dissatisfied with everything.
34. I feel overwhelmed.
35. People irritate me.
36. I get angry at myself.
37. I am scared by how unpredictable my feelings are.
38. I feel frustrated.
39. If I let myself, I get so unhappy I can't stand it.

In the time since this loss,

40. I get upset with myself for the way I have behaved.
41. I'm fed up with spending so much time on this.
42. I'm ashamed of the way I've behaved.
43. I feel bored with life.
44. I am revolted by the way people have responded.
45. It disgusts me to think of how it happened.
46. I avoid feeling too sad about this.
47. I try not to let anything affect me.
48. I refuse to wallow in self-pity.
49. I deserve to be punished for what I contributed to this loss.
50. I am less interested in sex.
51. I don't want to be touched.
52 I get hurt more.
53. I dream that I destroyed what/who I lost.
54. I am sick a lot.
55. I'm gaining weight.
56. I don't remembered any dreams.
57. I exercise less
58. I'm more clumsy and accident prone.
59. I sleep more.
60. I don't watch what I eat.
61. I wish I could be saved from having to deal with this experience.
62. I doubt that anything or anyone can give my life meaning again.
63. It's hard for me to trust anybody.
64. Nothing has really made any difference, so why do I bother?
65. Nobody cares how I am doing.
66. I wonder what point there is in going on.
67. I've lost respect for myself.
68. I can't imagine anyone ever being as important to me.
69. I've given up believing that my life has any particular significance.
70. My life doesn't seem to have a purpose.
71. I've had fantasies of being dead.
72. I wonder if I'm really a disgusting, worthless person.
73. There's no sense thinking or worrying about what happened.
74. I've realized that nothing could have prevented it.
75. I lack the energy to make sense out of it.
76. If people important to me knew my contribution to this loss, they would be shocked.
77. No one could ever pay enough for causing this loss to happen.

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

AWARENESS

Since the time of this loss,

1. It's been hard to concentrate.
2. I am less confident.
3. I've not been interested in meeting anyone new.
4. I have very little to say.
5. I've had no energy to do anything.
6. I get so preoccupied that I forget where I am going.
7. I avoid being alone.
8. I avoid getting close to others.
9. I lack love, affection and companionship.
10. I do less of the things I enjoyed before.
11. My friends have been avoiding me.
12. It's hard for me to make decisions.
13. I've lost friends.
14. My friends avoid talking about my loss.
15. I avoid being in new situations.
16. I forget to do routine, everyday tasks.
17. I talk about how it's been for me since the time of this loss.

When I think about this loss,

18. I am scattered and ineffective.
19. I am unable to find anything to look forward to.
20. My thinking has been slower than usual.
21. I can't imagine how things will get better.
22. It seems hopeless to try to understand what really happened.
23. I'm struck by how trivial everyday life seems.
24. I'm reminded how little I really control.
25. I am overwhelmed at how real and inescapable this loss seems.
26. There's no way I can fully understand why it happened.
27. I think about how my life has been changed.
28. I am aware of what is no longer a part of my life.
29. I remember what happened as clearly as if it happened yesterday.
30. I forget how it used to be before this happened.
31. I know I cannot bring it back.
32. I think about what's missing in my life.
33. I think about the dreams that will never come true.
34. I lose track of what's going on.
35. I'm struck by how other people seem to go on with their lives while I cannot.

Because of this loss,

36. I feel empty, like a shell, like I am just existing.
37. I feel lonely and alone.
38. I long for what (whom) I've lost.
39. The tears are hard to stop.
40. I miss expressing my love.
41. It's hard to express what I feel in words.
42. I cry.
43. I feel like I would rather die than go on experiencing this.
44. Being in certain places can unexpectedly stir up feelings.
45. I feel pangs.
46. I feel numb.
47. I feel a great deal of hurt or emotional pain.
48. I feel sad.
49. I am at the lowest point I have ever been.
50. I really miss it/him/her.
51. Music can stir up my feelings.
52. Looking at old photos stirs up painful feelings.
53. Certain odors (e.g. perfumes, old houses) can trigger feelings.
54. I feel helpless.
55. My feelings just come.
56. I miss feeling happy.
57. Joy is missing in my life.
58. I feel restless.
59. I feel tense.
60. I am exhausted by any effort.
61. My body feels heavy.
62. I wake up during the night.
63. I am more tired than usual.
64. I sigh.
65. I don't know if I can stand the physical pain for one more day.
66. I wake up feeling stiff and achy, as if I'd been tense all night.
67. I have difficulty getting to sleep.
68. It's like I've been hit in the stomach
69. I lack a sex life.
70. When someone touches me, my feelings come to the surface.
71. I have trouble getting up in the morning.
72. I feel sick.
73. I feel tight in my throat, like there is a lump in it.
74. I use up much more energy than I did before.
75. My stomach really churns.
76. I hurt all over.
77. I lack touching, holding and hugging.

Because of this loss,

78. I never seem to know what to do with myself.
79. My dreams remind me of my loss.
80. I have aches and pains which remind me of my loss.
81. The future seems empty.
82. It is easier to realize that someday I will die.
83. Everything else seems trivial and meaningless.
84. I've lost my fear of dying.
85. There is nothing positive or redeeming about this loss.
86. My beliefs don't give me the comfort they use to give me.
87. My faith has been shaken.
88. It seems like I have lost my desire to live.
89. I cannot continue life the same way as before.
90. I question the existence of the God I used to believe in.
91. I've realized that my life will never be completely free from pain and suffering.
92. My belief in myself as a basically good and honest human being has been shaken.
93. There is a great emptiness in my life.
94. I realize how fragile life is.
95. I've lost my sense of innocence.
96. I don't have the kind of love I had.
97. What I value most in life has been destroyed.
98. When I'm convinced things can't get any worse, they do.
99. No amount of money could ever replace my loss.
100. There are parts of me that are missing.
101. I am not the loving, caring, trusting person I was.
102. I know I will lose things and people important to me.

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

PERSPECTIVE

In the time since this loss,

1. Hearing about other's experiences with similar losses helps.
2. Being by myself has been healing.
3. Telling or writing my story about this experience gives me a feeling of relief and release.
4. It's easier to let myself just experience this loss.
5. It helps to be with a friend who accepts me as I am.
6. I like to be with friends who know what I've been through.
7. I take long walks and just daydream.
8. There is at least one person I can count on for support.
9. I've found ways to enjoy myself.
10. There is a special place which is healing for me.
11. Activities like getting a massage, painting or music are soothing.
12. It helps when I don't have anything to do.
13. I think about the effects of this loss; how I have changed, what is different.
14. I can take what comes.
15. I realize that I've lost a lot, but I haven't lost everything.
16. There are some things I will never understand about this.
17. I'm not as responsible as I thought I was for what happened.
18. I wasn't the only one who contributed to this loss.
19. I can think about other things than this loss now.
20. My imagination has returned.
21. I can let things turn out the way they will.
22. What I have left in my life is enough to keep me going.

In light of this loss,

23. My feelings make sense when I think about them.
24. I don't need to struggle to accept what has happened.
25. I still hurt, but the pain has lessened.
26. My feelings still catch me by surprise, but they don't last as long.
27. My guilt has lessened.
28. I'm not so sad.
29. I am able to express my feelings about the loss.
30. My feelings of anger are not as strong anymore.
31. My feelings can be ones of "sweet sadness".
32. My disgust over what happened has lessened.
33. My fears about dying are less.
34. I have already passed the lowest point.
35. It feels good to be able to laugh again.
36. I can enjoy simple pleasures of life again.
37. My body is healing from the stresses of this experience.

In light of this loss,

38. The aches and pains I used to have with this loss have lessened.
39. I notice how things smell and taste again.
40. I'm able to relax.
41. I enjoy being touched and held once again.
42. My dreams seem to help me understand and accept what happen.
43. I am more aware of myself physically than I was before the loss.
44. My energy level has improved since the time of the loss.
45. It takes less energy to do things than it used to.
46. I realize that sadness and peacefulness can co-exist.
47. Someone or something powerful and loving has helped me make it this far.
48. I have learned to accept that losses and changes are a part of life.
49. I believe there is some good in every person.
50. My faith, religious beliefs or spiritual understanding helped me with this experience.
51. Something good could come out of this.
52. My life will continue.
53. My life does seem to have meaning.
54. No one is really to blame for what happened.
55. Life seems more fragile and precious.
56. I've decided to go on living.
57. My past will always be a part of me.
58. There are quiet places in my life now.
59. Whatever I contributed to this loss, I did not want it to happen.
60. What I've lost will always have a place in my life.
61. There are limits on what I lost.
62. A part of me will always be connected to what/who I lost.
63. The fond memories are there along with the painful ones.

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

INTEGRATING THE LOSS

In the times since this loss,

1. At least one person knows that I've forgiven myself.
2. I've found ways to get back my integrity.
3. I've changed.
4. I've experienced this loss in ways that were healing.
5. I've said good-by to my loss.
6. I've taken steps to forgive those involved.
7. I've remembered what I really want to remember about it.
8. I've done everything I can do right now about this loss.
9. I don't depend as much on others.
10. I've finished things related to my loss as completely as I can.
11. I've restored relationships which were disrupted by it.

In light of this loss,

12. I realize how important it is to say good-by to what's (who's) gone.
13. My life has more to it.
14. I know my life is important.
15. I have as good an understanding as I can right now.
16. I understand why it's important to have times of celebration and remembrance before it's too late.
17. This experience has meaning for me.
18. I don't need to be so much in control of things.
19. There are ways that I have both gained and lost.
20. Putting my thoughts into words has helped me recover.

In the time since this loss,

21. I've felt all I can feel about this loss.
22. I no longer feel shame.
23. I've let go of the guilt.
24. I've let go of my sadness.
25. I've let go of the anger.
26. I no longer feel disgust.
27. I've had many feelings.
28. I've experienced the loss as fully as I can.
29. I've found effective ways to express my feelings.
30. I like being with people again.
31. I've learned a lot from my feelings about this loss.
32. I can make sense out of the messages from my body.
33. I have the energy I need.
34. I relax.
35. I don't neglect my body.
36. I sleep well.
37. I eat sensibly.

38. I don't push my body beyond limits.
39. I exercise.
40. I can be sexually or romantically interested.
41. I feel better.
42 I take care of the way I look.
43. My dreams are restful, playful and helpful.
44. I feel confident enough in myself to move on to other things.
45. I have forgiven myself for what happened.
46. It's time for me to get on with life.
47. This loss has opened me to bonds of love and friendship with at least one person.
48. I have been forgiven for what I contributed to this loss.
49. I have forgiven others for what happened.
50. I would not reverse this loss if it meant giving up my growth from it.
51. I've made peace with those involved in this loss.
52. Some of my dreams have survived this loss.
53. I am finding ways to fit this experience into the rest of my life.
54. Life is worth living again.
55. I've restored or regained part of what I had lost.
56 I feel the presence of what/who I lost.

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

SELF-EMPOWERMENT (REFORMULATION)

As a result of this loss,

1. I'm more self-disciplined.
2. I enjoy being alone.
3. I discovered what I want in life.
4. I can laugh at myself.
5. I'm more assertive.
6. I've started new relationships.
7. I'm able to take risks again.
8. I am more able to give to others.
9. I can take care of me and take care of others.
10. It takes less effort and thought to do what I need to do.
11. I do things on the spur of the moment.
12. Music has become very healing.
13. I like being challenged.
14. I spend time by myself.
15. I'm nicer to myself.
16. I'm not as serious a person.
17. I feel more confident.
18. I'm more creative in my approach to life.
19. I feel challenged to keep on going.
20. I enjoy dreaming as much as I do reaching for them.
21. I've changed in ways that would not have happened otherwise.
22. I'm more patient.
23. I've grown.
24. I see the past as just as important as what is happening now.
25. I don't spend as much time thinking about the loss.
26. I've realized that I can do destructive things.
27. Past, present and future are equally important.
28. I trust my ways of thinking.
29. I know what I need to do to move my life forward.
30. I am curious about a lot of things.
31. I feel like a whole person.
32. I feel loving and affectionate.
33. I've learned to respect myself.
34. I am not as hard on myself when I make mistakes.
35. I don't avoid admitting what I feel.
36. I am at peace.
37. I can feel both joyful and sad.
38. My feelings are valid.
39. Sadness reminds me how important this loss was to me.

As a result of this loss,

40. I can get angry.
41. It's hard for me to be bored.
42. I've found new ways to express my feelings.
43. I like the way I am.
44. I listen to what my body tells me.
45. I am efficient and creative at doing things.
46. I enjoy the intimacy, closeness and pleasure of making love.
47. I feel strong.
48. I am active in caring for myself physically.
49. I get the exercise I need.
50. I take my time.
51. I enjoy touching and being touched.
52. What I eat is healthy.
53. I make sure I have time to relax.
54. I listen to music.
55. I can express myself in many ways.
56. My dreams make sense.
57. I've discovered that there is more to me than what meets the eye.
58. I trust my intuition, dreams, fantasies or my inner sense to let me know what I need to know.
59. I feel a part of something much bigger than me.
60. I live as fully as I can.
61. I can love and be devoted to another without losing myself.
62. I am more consistently aware of what's important.
63. Some kind of "inner" wisdom has been guiding me.
64. I believe that death is only one of many transitions I'll make in life.
65. I feel connected to what I've lost in ways I never expected.
66. I want to help others who have this kind of life experience in common with me.
67. What is important to me has changed.
68 I have rediscovered the essential parts of me.
69. I want to have some degree of control over how and when I die.
70. I have time for my family and friends and time for me.
71. I feel lovable.

NOTE: If a statement is true about you, but is <u>not</u> a response to the loss, leave it blank.

TRANSFORMING LOSS

As a result of this loss,

1. I've found a balance between devoting energy to my personal growth and to my relationships.
2. I have peaceful moments.
3. I am sometimes surprised by what I know and say.
4. I've discovered that the most important parts of my loss remain alive inside of me.
5. What I own isn't as important.
6. I know the cycles of life have times of birth and death.
7. I feel a deeper connection to people who are no longer alive
8. I am curious about my death.
9. I can get along with less than I have needed in the past.
10. I believe there is someone or something more powerful, loving, lasting and wiser than any single human being.
11. I don't have to have all the answers for why I am alive.
12. I know I want other people in my life.
13. I feel connected to the world and to nature.
14. I know I am in the right place for me right now.
15. I realize that I can't live without loving myself.
16. I have something important to share with others.
17. I know that things in my life can change and life can still be meaningful.
18. I am curious about what will happen after I die.
19. My life has times of joy.

END OF QUESTIONS

APPENDIX E

DIMENSIONS OF RESPONSE TO LOSS

Dimensions of Response to Loss

This inventory includes the following dimensions:

Behavioral items included here are intended to assess the actual behavior responses the bereaved individual agreed happened as a response to the loss.

Cognitive items include ways of thinking which the person associated with the loss.

Emotional items include feelings and emotions which the person associated with the loss.

Spiritual items include the impact on the person's values, attitudes, beliefs and will to live which the person associated with the loss.

The inventory also includes the following or theoretically discrete phases of the grieving process:

Coping. Items included here are ones which the person identifies as ways to limit their vulnerability and their awareness of their loss. The adequacy of coping is seen in the ability to limit, delay or temporarily relieve the pressures and stressfulness of active grieving. The most productive balance between coping and active grieving may be one which allows for both times of awareness and times for function (coping). Two types of coping are included:

> Holding On: Items in this scale are ones which reflect the ways people attempt to overcome or to see themselves as "beating" the loss through such means as "keeping busy" (behavioral), being angry (emotional), or believing the loss is reversible (spiritual).
>
> Letting Go: Items in this scale are ones which the person indicates they use to escape from the stress and burden of their grief. They can include, for example, the use of drinking (behavioral), distraction (cognitive), disgust (emotional), or sleeping (physical).

Awareness. Items included here are ones which are traditionally associated with grieving and are almost entirely adapted from Deutsch's doctoral study.

Perspective. Items included here are those a person would associate with healing from the loss and the insights about the meaning and significance of the loss.

Growth. Items in this section relate to the extent to which the person attributes subsequent growth and realization of their potential to the loss. This section includes three parts:

Integration. These items relate to the ways people might use to mobilize their resources to actively remember their loss, to finish their business with it, or to make restitution, forgiveness, or rehabilitation.

Self-empowerment. These items are designed to associate different ways of increasing one's resourcefulness, flexibility, and responsivity as a reflection of the loss.

Transformation. Items in this section are designed to associate changes in one's world view and the nature of the losses in general as a function of this loss.

Source: J. Schneider, D. Deutsch, & T. McGovern (1990). Understanding the transformative potential of grief. Construct validation of the Response to Loss Inventory, TRL. Unpublished draft of an article.

APPENDIX F

TABLE OF VALIDATION (RESPONSE TO LOSS INVENTORY)

Table F.1.--Reliability coefficients for the RTL II (1988-89) (N = 207).

Category	Cronbach's Alpha	Guttman Split-Half
Holding On	.93	.91
Letting Go	.94	.94
Awareness	.97	.96
Perspective	.93	.90
Integration	.95	.93
Self-Empowerment	.97	.96
Transformation	.88	--

Source: J. Schneider, D. Deutsch, & T. McGovern (1990). Understanding the transformative potential of grief. Construct validation of the Response to Loss Inventory, TRL. Unpublished draft of an article.

APPENDIX G

INFORMED CONSENT FORMS

RESEARCH STUDY PARTICIPATION AGREEMENT
1990
SECONDARY SUBJECT

As an instructor of stress management, I have a strong curiosity to understand more completely what techniques and learning formats are most profitable to adults seeking programs of stress management. It has long been known that people manage stress in many ways and that each person adapts to life's circumstances in different ways. I am proposing to study this topic by interviewing female adult Systemic Lupus Erythematosus patients who are between the ages of 25-55. The intent of this study is to understand some of the kinds of transitions SLE patients are faced with and to learn about the types of coping mechanisms they rely on day-to-day.

This pilot project will run from August 1990 through December 1990. The project will include primarily participant interviews of SLE patients. Additional interviews will be obtained from willing significant others, both lay and medical personnel.

Confidentiality will be maintained (including community of origin) for all participants and any persons identified as a part of the interviewing process.

ALL IDENTIFICATION WILL BE REMOVED IN THE FINAL WRITTEN REPORT TO GUARANTEE ANONYMITY. THIS STUDY IS IN NO WAY INTENDED TO BE EVALUATIVE. THE STUDY IS FOR EDUCATIONAL PURPOSES ONLY. IT IS MEANT TO HELP BETTER UNDERSTAND AND INFLUENCE THE TEACHING AND DEVELOPMENT OF FUTURE PROGRAMS OF STRESS MANAGEMENT.

If you have any questions, please feel free to call me at home (784-1332) or at work (787-0800).

Jim Scott
4986 Country Manor
Jackson, Michigan 49201

I have read this proposal and I agree to participate as a significant other or medical personnel related to a SLE-primary subject in this study.

_____ _____

SIGNATURE DATE

APPENDIX H

LETTER OF INTRODUCTION TO PROFESSIONALS

Dear (Professional),

I am seeking research subjects who have Systemic Lupus Erythematosus, are female and are between the ages of 20 and 55 years.

The purpose of this study is to review the life stories of Systemic Lupus Erythematosus patients to examine the possible relationship of their illness to their life long transitions and their varied coping responses in life. The research will include personal interviews and the use of three survey instruments. In addition, possible additional information may include review of any reflective work like journals and writings, home or work visits and the interview of other significant persons in the participant's life. All participants will be required to sign an informed consent prior to involvement (See attached). All data collected will be held in total confidence. The reporting of data will not include the real identities or location identifications of any of the subjects or any other data that could indicate the identification of the participant.

If you have any clients, patients or friends who you feel would be interested in contributing to this kind of research or who you feel would benefit from sharing their life story please provide them with the attached overview letter, or have them call me. You could also send their name to me after you have talked to them and I would be excited to call to them personally.

Should you have any questions regarding this research or about the eligibility of a perspective subject please feel free to contact me. I can be reached at 1-517-784-1332. If it is long distance please feel free to call me collect. Thank you for your time and support in this research project.

Sincerely Yours,

James J. Scott
Professor of Health and Physical Fitness
Jackson Community College

APPENDIX I

LETTER OF INTRODUCTION TO PROSPECTIVE SUBJECTS

Dear Prospective Subject,

I am seeking research subjects who have Systemic Lupus Erythematosus, are female and are between the ages of 20 and 55 years.

The purpose of this study is to review the life stories of Systemic Lupus Erythematosus patients to examine the possible relationship of their illness to their life long transitions and their varied coping responses. If you choose to participate, your involvement will include personal interviews focused on your life story and the use of three survey instruments related to changing life circumstances. Possible additonal information may include a review of reflective journals or writing, home or work site visits, and the interview of other significant persons in your life. The interview with significant others, the review of reflective work and home or worksite observations will only occur if you are willing. An informed consent form for significant others is also required. All data collected will be held in total confidence. The reporting of data will not include the real identities or location identifications of any of the subjects or any other data that could reflect the identification of the particular participant. You will be required to sign an informed consent prior to involvement. Your approximate time involvement will be from 7-9 hours.

Should you have any questions regarding this research please feel free to contact me. I can be reached at 1-517-784-1332. If it is long distance please feel free to call collect. Thank you for your time and support in this research project.

Sincerely Yours:

James J. Scott
Professor of Health and Physical Fitness
Jackson Community College

APPENDIX J

NATIONAL AND STATE ORGANIZATIONS CONTACTED FOR THE STUDY

National and State Organizations Contacted for the Study

Organizations contacted by mail:

Bay Area Lupus Foundation
2635 North First Street, Suite #206
San Jose, CA 95134
(800) 523-3363
(Very extensive materials listing)

Lupus Foundation of America
1717 Massachusetts Avenue, N.W., Suite #203
Washington, D.C. 20036
(202) 328-4550

Michigan Lupus Foundation
26202 Harper Avenue
St. Clair Shores, MI 48081
(313) 775-8310

Organizations contacted by telephone:

American Lupus Society
(213) 542-8891

Lupus Erythematosus Support Club
(803) 764-1769

Lupus Network
(203) 372-5795

National Lupus Erythematosus Foundation
(408) 954-8600

APPENDIX K

RISK-TO-BENEFIT RATIO

Risk-to-Benefit Ratio

Three areas are discussed in this section. The first two areas concern possible benefits and risks. The third area considers how the risks may be minimized.

Possible Benefits

1. SLE patients had an opportunity to share their stories. This sharing provided other SLE patients with another point of reference as they encountered their own illnesses. Reports related to these interviews may provide friends, family, lay persons, medical personnel, and adult educators with an understanding of some of the types of transitions and insights that SLE patients have encountered as a result of their illness.

2. The study was a rich source of intimate narratives. These narratives may be useful in teaching concepts related to the management of stress.

3. This study allowed SLE patients the opportunity to share some of the experiences that they had been carrying for a long time.

Potential Risks

Due to the nature of this type of research, individuals were asked to self-disclose a great deal. When there is self-disclosing, there is a possibility that the information being shared might place the individual at risk. This kind of risk is at least at two levels:

1. There is a possibility that individuals who are willing to share at this level might expose very intimate experiences and

feelings that, if revealed, would compromise current relationships or positions.

2. A further possibility of risk exists through this sharing in that one might encounter past experiences that could be painful and create discomfort.

Minimizing Risks

In an effort to minimize the risks of this research, the following actions were taken:

1. The focus of the research was on a chronological and retrospective perspective of a person's life with chronic illness. No questioning designed to be therapeutic was developed intentionally. Questions were prescreened for appropriateness by an expert panel.

2. When questions or concerns arose, the research participants had direct access to the researcher. Recommendations for follow-up support and referral were then made as needed. Each participant had the right to withdraw without recrimination at any time she felt discomfort or her life circumstances changed and she saw a need to discontinue involvement.

3. Because of the manner in which this information was treated, there were no breaches of confidentiality. The actual reporting of all data maintained the anonymity of all persons involved. No real names, identities, or sites were used in any of the reporting or capsuling of the materials. Each person was given a fictitious name and identity that completely protected anonymity.

Informed consent was secured from the following individuals:

1. The individual whose life history was gathered.

2. The support and medical person who had connections with the individual whose life history was gathered.

The informed consent forms used for these purposes appear in Appendix G.

APPENDIX L

LETTER OF APPROVAL FROM THE UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS

MICHIGAN STATE UNIVERSITY

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

November 7, 1990

IRB# 90-429

James J. Scott
4986 Country Manor
Jackson, MI 49201

RE: A STUDY OF LIFE LONG TRANSITIONS, COPING RESPONSES AND EUSTRESS RESPONSES OF SIX FEMALE SYSTEMIC LUPUS ERYTHEMATOSUS PATIENTS BETWEEN THE AGES OF 20 AND 55 YEARS, IRB# 90-429

Dear Mr. Scott:

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on November 5, 1990.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to November 5, 1991.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

David E. Wright, Ph.D.
Chair, UCRIHS

DEW/deo

cc: Dr. James Snoody

APPENDIX M

SUBJECT PROFILE SUMMARY INFORMATIONAL BREAKDOWNS

Subject Profile Summary Informational Breakdown

Individual items include:

Subject: Item includes a first name that holds the subject's identity in confidence.

Age: Item reflects the age of the subject at the time of the study.

Gender: Item reflects the sex of the subject.

Current marital status: Item reflects the current marital status of the subject: single, married, divorced, or widowed.

Marriages: Item reflects the number of marriages.

Divorces: Item reflects the number of divorces.

Children--natural: Item reflects the number of children conceived and delivered by the subject.

Children--adopted: Item reflects the number of children adopted into the family by the married subject.

Miscarriages: Item reflects the number of pregnancies that were not completed due to natural complications.

Years diagnosed: Item refers to the number of years with a confirmed diagnosis of SLE.

Years with possible symptoms before diagnosis: Item reflects the number of years the subject had symptoms before diagnosis.

Organ involvement: Item refers to the types of organs that were involved as a result of SLE.

Joint pain. Item refers to the presence of joint pain on a daily basis.

Fatigue: Item refers to the presence of chronic fatigue.

Allergies: Item refers to the presence of significant allergies in the subject's life.

Possible hereditary: Item refers to the possibility of a hereditary link with SLE.

Relationship: Item refers to family members with SLE or similar illnesses.

Medications: Item refers to the presence of medications of SLE on a daily basis.

Past or present involvement in support group: Item refers to the subject's attendance at and/or involvement involvement in a support group at some time.

Has had or was referred to counseling: Refers to the subject's use of a counseling professional.

REFERENCES

REFERENCES

Aladjem, H. (1985). Understanding lupus (What it is, how to treat it, how to cope with it). New York: Charles Scribner's Sons.

Aladjem, H., & Schur, P. H. (1972). In search of the sun: A woman's courageous victory over lupus. Rev. ed. New York: Charles Scribner's Sons.

Bach, R. (1972). Jonathan Livingston Seagull. New York: Dell.

Baum, A., & Gatchel, R. J. (1981). Cognitive determinants of reaction to uncontrollable events: Development of reactance and learned helplessness. Journal of Personality and Social Psychology, 40, 1078-1089.

Baum, A., Singer, J. E., & Baum, C. S. (1981). Stress and the environment. Journal of Social Issues, 37, 4-35.

Benson, H. (1974). Beyond the relaxation response. New York: William Morrow.

Benson, H. (1975). The relaxation response. New York: William Morrow.

Benson, J. S., & Kennally, K. J. (1976). Learned helplessness: The result of uncontrollable aversive stimuli? Journal of Personality and Social Psychology, 34, 138-145.

Biklen, S. K., & Bogdan, R. C. (1982). Qualitative research for education: An introduction to theory and methods. Boston: Allyn & Bacon.

Billings, A. G. (1983, May). Social-environmental factors in unipolar depression: Comparisons of depressed patients and nondepressed controls. Journal of Abnormal Psychology, 92, 119-133.

Blum, L. H. (1972). Reading between the lines: Doctor-patient communication. New York: International University Press.

Boyle, C. M. (1970). Differences between patient's and doctor's interpretation of some common medical terms. British Medical Journal, 2, 286-289.

Bracken, M. B., & Shepard, M. J. (1980). Coping and adaptation following acute spinal cord injury: A theoretical analysis. Paraplegia, 18, 74-85.

Brown, B. B. (1978). Stress and the art of biofeedback. New York: Harper & Row.

Burckhardt, C. S. (1953). Coping strategies of the chronically ill. Springfield, IL: Charles C. Thomas.

Cannon, W. B. (1935). Stresses and strains of homeostasis (Mary Scott Newbold lecture). Journal of Medical Sciences, 189, 1-14.

Cannon, W. B. (1939). The wisdom of the body (2nd ed.). New York: Norton.

Carlson, R., & Shield, B. (1989). Healers on healing. Los Angeles: Jeremy P. Tarcher, Inc.

Claus, K. E., & Bailey, J. T. (Eds.). (1980). Living with stress and promoting well-being. St. Louis: C. V. Mosby.

Corley, K. (1985). Pathopsychology of stress. In S. Burchfield (Ed.), Stress (pp. 185-206). New York: Hemisphere.

Coyne, J. C., & Lazarus, R. S. (1980). Cognitive style, stress perspective, and coping. In J. L. Kutash & L. B. Schlesinger (Eds.), Handbook on stress and anxiety. San Francisco: Jossey-Bass.

Dakof, G. A., et al. (1987, August 28-September 1). Family support and the cancer patient. Paper presented at the 95th Annual Convention of the American Psychological Association.

Damsa, T., Moscu, I. K., Schioiu, L., & Cucu, F. (1988). Ischemic heart disease in relation with the type of behavior and the emotional state. Medicine Interne.

DeLongis, A., et al. (1982). Relationship of daily hassles, uplifts, and major life events to health status. Health Psychology, 1, 119-136.

Dise, L. (1988, September-October). The Life Events and Coping Inventory: An assessment of stress in children. Psychosomatic Medicine, pp. 484-499.

Dohrenwend, B. S., & Dohrenwend, M. (L974). Stressful life events: Their nature and effects. New York: Wiley.

Dusek, D., & Girdano, D. A. (1988). Changing health behavior. Scottsdale, AZ: Gorsuch & Scarisbrik.

Engel, G. L. (1955, August). Studies of ulcerative colitis III: The nature of the psychologic processes. American Journal of Medicine.

Engel, G. L. (1961). Is grief a disease: A challenge for medical research. Psychosomatic Medicine, 23, 18-22.

Facts about lupus. (1988). Lupus Foundation of America.

Francis, V., Korsch, B. M., & Morris, M. J. (1969). Gaps in doctor-patient communication. New England Journal of Medicine, 280, 535-540.

Friedman, M., & Rosenman, R. H. (1974). Type A behavior and your heart. Greenwich, CN: Fawcett.

Gatchel, R. J., & Baum, A. (1983). An introduction to health psychology. New York: Newberry Award Records.

Girdano, D. A., Everly, G. S., Jr., & Dusek, D. E. (1986). Controlling stress and tension: A holistic approach. Englewood Cliffs, NJ: Simon & Schuster.

Glasser, W. (1984). Taking effective control of your life. New York: Harper & Row.

Glick, I. O., Weiss, R. S., & Parkes, T. (1974). The first year of bereavement. New York: Wiley.

Grace, W. J., & Graham, D. T. (1952). Relationship of specific attitudes and emotions to certain bodily diseases. Psychosomatic Medicine, 14, 242-251.

Greenberg, J. S. (1990). Comprehensive stress management (3rd ed.). Dubuque, IA: Wm. C. Brown.

Guyton, A. C. (1966). Textbook of medical physiology. Philadelphia, PA: W. B. Saunders.

Haefner, D. P., & Kirscht, H. P. (1970). Motivational and behavioral effects of modifying health beliefs. Public Health Reports, 85, 478-484.

Heller, C. A., & Schur, P. H. (1985). Serological and clinical remission in systemic lupus erythematosus. Journal of rheumatology, 12, 916-918.

Henry, J. P., & Stephens, P. M. (1985). Stress, health, and the social environment. New York: Workman Publishing.

Hinds, W. C. (1983). Personal paradigm shift: A lifestyle inventory approach to health care management. East Lansing: Michigan State University.

Hiroto, D. S. (1974). Learned helplessness and locus of control. Journal of Experimental Psychology, 102, 187-193.

Hobfoll, S. E. (1988). The ecology of stress. New York: Hemisphere.

Hogan, S. M. (1988). Coping with depression in a chronic illness. Paper presented at the ACSW Annual Meeting, Michigan.

Janis, I. L. (1985). Stress inoculation in health care: Theory and research. In A. Monat & R. S. Lazarus (Eds.), Stress and coping: An anthology. New York: Columbia University Press.

Janis, I. L., & Leventhal, A. (1965). Psychological aspects of physical illness and hospital care. In B. Wolman (Ed.), Handbook of clinical psychology. New York: McGraw-Hill.

Jolly, M. G. (1975). Ethics of cancer management from the patient's perspective. Journal of Human Stress, 1, 22-36.

Kasl, S. V., & Cobb, S. (1966). Health behavior, illness behavior, and sick role behavior. Archives of Environmental health, 12, 531-541.

Keller, C. (1967, August). Psychological and physical variables as predictors of coping strategies. Perceptual and Motor Skills, 88, 95-100.

Kobasa, S. C. (1979). Stressful life events, personality and health. Journal of Personality and Social Psychology, 37, 1-11.

Kobasa, S. C., Maddi, S. R., & Kahn, S. (1982). Hardiness and health: A prospective study. Journal of Personality and Social Psychology, 42, 168-177.

Kubler-Ross, E. (1968). On death and dying. New York: Macmillan.

Lages, W. L. (1985, March). Diet and lupus. San Jose, CA: Bay Area Lupus Foundation.

Lazarus, R. S. (1966a). Psychological stress and the coping process. New York: McGraw-Hill.

Lazarus, R. S. (1966b). Story telling and the measurement of motivation: The direct versus substitutive controversy. Journal of Consulting Psychology, 30, 483-487.

Lazarus, R. S. (1976). Patterns of adjustment. New York: McGraw-Hill.

Lazarus, R. S. (1984). Puzzles in the study of daily hassles. Journal of Behavioral Medicine, 7, 375-389.

Lazarus, R. S., Deese, J., & Osler, S. F. (1952). The effects of psychological stress upon performance. Psychological Bulletin, 49, 293-317.

Leigh, H. (1982). Evaluation and management of stress in general medicine: The psychosomatic approach. In L. Goldberger & S. Breznitz (Eds.), Handbook of stress. New York: Free Press.

LeMaistre, J. (1981, July). The emotional impact of chronic physical illness. San Jose, CA: Bay Area Lupus Foundation.

LeShan, L. L. (1959). Psychological states as factors in the development of malignant disease: A critical review. Journal of the National Cancer Institute, 29, 1-18.

LeShan, L. L. (1966). An emotional life-history pattern associated with neoplastic disease. Annals of the New York Academy of Sciences.

Leventhal, H., Nerenz, D., & Leventhal, E. (In press). Feeling of threat and private view of illness: Factors in dehumanization in the medical care system. In A. Baum & J. E. Singer (Eds.), Advances in environmental psychology (Vol. 4). Hillsdale, NJ: Erlbaum.

Levi, L. (1974). Psychosocial stress and disease: A conceptual model. In E. K. Gunderson & R. H. Rahe (Eds.), Life stress and illness. Springfield, IL: Charles C. Thomas.

Lewis, K. (1985). Social or lifestyle engineering. San Jose, CA: Bay Area Lupus Foundation.

Ley, P., & Spelman, M. S. (1967). Communicating with the patient. London: Staples Press.

Locke, S. E., Hurst, M. W., Heisel, J., et al. (1979, March). The influence of stress on the immune responses. Paper presented at the Annual Meeting of the American Psychosomatic Society.

Luc Senecal, J. (1988). The patient's role in controlling lupus. Lupus Foundation.

Lupus News. (1986). 6(3) (Entire issue).

Maddison, D., & Walker, W. L. (1967). Factors affecting the outcome of conjugal bereavement. British Journal of Psychiatry, 113, 1057-1067.

Mechanic, D. (1976). Effects of psychological distress on perceptions of physical health and use of medical and psychiatric facilities. Journal of Human Stress, 2, 2-6.

Mechanic, D. (1978). Stress, illness and illness behavior. Journal of Human Stress, 4, 26-32.

Mitchell, W. (1991). Presentation at Star Commonwealth, Marshall, MI.

Monat, A., Averill, J. R., & Lazarus, R. S. (1972). Anticipatory stress and coping reactions under various conditions of uncertainty. Journal of Personality and Social Psychology, 24, 237-253.

Monat, A., & Lazarus, R. S. (Eds.). (1985). Stress and coping: An anthology (2nd ed.). New York: Columbia University Press.

Moos, R. H. (Ed.). (1976). Human adaptation: Coping with life crises. Lexington, MA: D. C. Heath.

Morra, M., & Potts, E. (1987). Choices: Realistic alternatives in cancer treatment. New York: Avon Books.

Mueller, D., Edwards, D., & Yarvis, H. (1977). Stressful life events and psychiatric symptomology. Journal of Health and Social Behavior, 18, 307-317.

Nguyen, C. (1984, June). Exercise and SLE. San Jose, CA: Bay Area Lupus Foundation.

O'Brien, R. A. (1987). Role of social support in bereavement outcomes. Paper presented at the Fourth Annual Meeting of Delegates in San Francisco, CA.

Patent, A. (1985). You can have it all. Pierpont, NY: Money Matters Publishing.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior, 19, 2-21.

Pelletier, K. R. (1977). Mind as healer, mind as slayer. New York: Dell.

Permut, J. B. (1989). Embracing the wolf. A lupus victim and her family learn to live with chronic disease. Trade Cherokee.

Peters, R. K., Benson, H., & Porter, D. (1977). Daily relaxation response breaks in a working population: II. Effects on blood pressure. American Journal of Public Health, 67, 954-959.

Phillips, R. H. (1986). Coping with lupus. A guide to living with lupus for you and your family. Avery Publishing Group.

Pitzele, S. K. (1985). We are not alone: Learning to live with chronic illness.

Ragan, G. R. (1988, Winter). The wolf within: A personal account of coping with systemic lupus erythematosus. Health and Social Work, 13, 11-19.

Rahe, R. H. (1975). Life changes and near-future illness reports. In L. Levi (Ed.), Emotions: Their parameters and measurements. New York: Raven.

Rahe, R. H., Ryman, D. H., & Ward, H. W. (1980). Simplified scale for life change events. Journal of Human Stress, 6, 22-27.

Rathbone, J. L. (1969). Relaxation. Philadelphia, PA: Lea & Febiger.

Roskies, E. (1987). A new approach to managing stress. Advances (Institute for the Advancement of Health), 4, 29-43.

Rossi, E. L. (1986). The psychobiology of mind-body healing. New York: W. W. Norton.

Sarason, I. G., Johnson, J. H., & Siegel, J. M. (1978). Assessing the impact of life changes: Development of the Life Experiences Survey. Journal of Consulting and Clinical Psychology, 46, 932-946.

Schneider, J. (1984). Stress, loss, and grief. Rockville, MD: Aspen.

Schneider, J., Deutsch, D., & McGovern, T. (1990). Understanding the transformative potential of grief. Construct validation of the Response to Loss Inventory, RTL (Unpublished draft of article).

Schuller, R. H. (1983). Tough times never last, but tough people do! New York: Thomas Nelson Publishers.

Seligman, M. E. P. (1975). Helplessness: On depression, development, and death. San Francisco: W. H. Freeman.

Selye, H. (1974). Stress without distress. New York: J. B. Lippincott.

Siegel, B. (1987). Love, medicine and miracles. New York: Harper & Row.

Silver, R. C., & Wortman, C. B. (1980). Coping with undesirable life events. In J. Gaber & M. E. P. Seligman (Eds.), Human helplessness: Theory and applications (pp. 279-340). New York: Academic Press.

Simonton, B. C., Matthews-Simonton, S., & Creighton, J. (1978). Getting well again. Los Angeles: J. P. Vacher.

Simonton, C. O., & Matthews-Simonton, S. (1975). Belief systems and management of the emotional aspects of malignancy. Journal of Transpersonal Psychology, 7, 29-48.

Smith, S. F., & Smith, C. M. (1990). Personal health choices. Boston: Jones & Bartlett.

Spielberger, C. D., & Sarason, I. G. (1986). Stress and Anxiety: A sourcebook of theory and research (Vol. 10). Washington, DC: Hemisphere.

Tang, T., & Mammontree, M. L. (1987). The effects of hardiness, job-related stress, and life stress on health and absence from work.

Tanner, O. (1976). Stress. New York: Time-Life Books.

Travis, J. W., & Ryan, R. S. (1988). Wellness workbook (2nd ed.). Berkeley, CA: Ten Speed Press.

Turk, D. C., Ruby, T. E., & Salovey, P. (1985). Implicit models of illness. Journal of Behavioral Medicine, 9, 453-474.

Vinokur, A. M., & Selzer, L. (1975). Desirable versus undesirable life events. Their relationship to stress and mental distress. Journal of Personality and Social Psychology, 32, 329-337.

Webster's new world dictionary of the American language (2nd ed.). New York: World Publishing, 1968.

Weis, R. S. (1976). The emotional impact of marital separation. Journal of Social Issues, 32, 135-145.

Wheeler, R. J., & Munz, D. C. (1985, August 23-27). Psychological and physiological effects of a stress management program. Paper presented at the 93rd Annual Convention of the American Psychological Association.

Wolf, S. (1965). The stomach. Oxford: Oxford University Press.

Wolf, S., & Wolff, H. G. (1953). Headaches: Their nature and treatment. Boston: Little, Brown.

Wright, B. A. (1983). Physical disability: A psychosocial approach (2nd ed.). New York: Harper & Row.