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*Karen Elliott*

Date: December 19, 2002

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**INTERNAL HEALTH LOCUS OF CONTROL: A  
DESCRIPTION OF HIGH AND LOW ORIENTATION  
AND APPROACHES TO COPING WITH  
SCLERODERMA**

by  
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B.S., Carroll College, 1998  
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Presented in partial fulfillment of the requirements  
for the degree of  
Master of Science

Department of Health and Human Performance  
School of Education Graduate School  
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Missoula, Montana  
December 2002

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## **Thesis Abstract**

Elliott, Karen, M.S., December 2002

Health and Human Performance

**Internal Health Locus of Control: A Description of High and Low Orientation and Approaches to Coping with Scleroderma.**

Committee Chair: K. Ann Sondag, Ph.D. *KAS*

The purpose of this study was to describe individuals' approaches to coping with their illness as it relates to their health locus of control. Information was obtained through various sources. The Multidimensional Health Locus of Control Survey (MHLC) was used to identify a participant's health locus of control orientation within three subscales, internal, external and powerful others. Participants were sorted into two groups, High ILOC and Low ILOC. The Narrative Response Questionnaire was used to describe participants' approaches to coping with their scleroderma as it relates to either high or low internal health locus of control. A demographic page was also developed to collect demographics, length of diagnosis, type of scleroderma, length of support group attendance and overall health status.

Descriptive statistics were used to provide a summary of the results of the demographic page. The results of the NRQ were reported through qualitative analysis and described within the two groups. Themes or similar thoughts were identified with participants' responses in the High ILOC group and the Low ILOC group. Because of the uneven distribution of participants between the two groups, only limited comparisons and contrasts could be made between the High-ILOC Group and the Low-ILOC Group.

Information from this study provides the scleroderma support group members, group facilitators and the Scleroderma Foundation with a greater understanding of the role that the health locus of control plays in individuals' perceptions and coping behaviors related to their illness.

## **Acknowledgments**

**“If you have built castles in the air, your work need not be lost. That is where they should be. Now put the foundation under them.”**

**--Henry David Thoreau**

**I would like to express my sincere appreciation and gratitude to every person with scleroderma that shared part of their life with me during this project. I would especially like to thank my mom for sharing her knowledge and openness with me regarding scleroderma. Her strong spirit inspires me.**

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## **CHAPTER I**

### **Introduction to the Study**

Scleroderma affects approximately 300,000 people in the United States. The common age of onset ranges from 30-50 years old, with women approximately 4 times more likely to be affected than men. Within the past three decades, there has been an increase in incidence of the disease (Malcarne, 2002). People with this disease, diagnosed and undiagnosed, need to see a variety of health specialists and experiment with diverse medications and treatments (Scleroderma Research Foundation, 2002).

The cause of scleroderma is not known. There is no cure for scleroderma and there is no one standard treatment for the disease. There is also no specific test to diagnose scleroderma. Diagnosis requires a variety of tests and procedures. To diagnose the disease, it is important to piece together the various test results with the individual's symptoms. If this is not done, the disease remains undiagnosed, allowing for the possibility of many undetected cases in the United States (Scleroderma Research Foundation, 2002). More attention needs to be focused on scleroderma in order to create definitive diagnostic options and treatment plans (Wasko & Medsger, 2000).

While improving the diagnosis and treatment of scleroderma is important, it is also important to shed light onto the unexplored psychosocial dimensions of the disease (Malcarne, 2002). One approach to the study of the psychosocial aspects of chronic diseases like scleroderma has been through the application of the Health Locus of Control Theory. This theory, derived from the Social Learning Theory, states that individuals' perceptions of control over their health is

either predominately internal or external and affects their coping behaviors (Sanders & Sul, 1982). This location or “locus” of a person’s control can be measured by the Multidimensional Health Locus of Control Survey (MHLC). The MHLC was used in this study to categorize participants into one of two groups. The first group, High ILOC, consisted of individuals who scored high on the internal health locus of control scale. The second group, Low ILOC, consisted of those who scored low on the internal health locus of control scale.

In order to explore the relationship between locus of control and health related coping behaviors in people with scleroderma, the researcher developed the Narrative Response Questionnaire (NRQ). The NRQ asks respondents to explain the cause of their disease and to describe the various actions they are taking to cope with their disease. The NRQ was used to describe the coping actions of the participants for both the High ILOC and the Low ILOC groups. Awareness of coping behaviors of individuals as they relate to locus of control may provide information that can help scleroderma patients cope with their disease.

### **Statement of Purpose**

There is a lack of information regarding scleroderma patients and their ability to cope with their disease. The purpose of this study was to describe individuals’ approaches to coping with their illness as it relates to their health locus of control.

### **Research Questions**

1. High internal locus of control orientation on the MHLC:
  - a) How do participants who score high on internal health locus of control explain the cause of their disease?
  - b) How do participants who score high on internal health locus of control describe the effects of their disease in their lives?

- c) What actions do the participants who score high on internal health locus of control take in regard to dealing with their disease?
2. Low internal locus of control orientation on the MHLC:
  - a) How do participants who score low on internal health locus of control explain the cause of their disease?
  - b) How do participants who score low on internal health locus of control describe the effects of their disease on their lives?
  - c) What actions do the participants who score low on internal health locus of control take in regard to dealing with their disease?
3. What is the relationship between a high or low internal locus of control and perception of overall health status?

### **Significance of the Study**

Most research reviewed regarding scleroderma is focused on medically determining the cause and cure of the disease through exploring human physiology. In order, however, to gain a complete picture of scleroderma, this important emphasis needs to be coupled with an examination of the psychosocial dynamics of this disease. Information from this study provides the scleroderma support group members, group facilitators and the Scleroderma Foundation with a greater understanding of the role that the health locus of control plays in individuals' perceptions and coping behaviors.

### **Delimitations**

The delimitations of this study were:

1. The study was delimited to scleroderma patients attending support groups through the Scleroderma Foundation.
2. Data was collected via mailed surveys and questionnaires.
3. The data was restricted to participants' self report on the survey and questionnaire.

## **Limitations**

The limitations of this study were:

1. The results of this study depended on the participants' accuracy and honesty in filling out the survey and questionnaire.
2. Distribution of the survey and questionnaire was dependent on the facilitator. It is possible that not all support group members were asked to participate
3. Response was limited to the voluntary action of the participants filling out the survey and questionnaire and mailing it back in self-addressed stamped envelope.

## **Definition of Terms**

**Autoimmune Disease:** The immune system mistakenly attacks itself, targeting the cells, tissues, and organs of a person's own body (Scleroderma Research Foundation, 2001).

**Facilitator:** Any person who leads or serves a role in leading or organizing the respective support group meetings.

**Health Locus of Control:** "degree to which individuals believe that their health is controlled by internal or external factors" (Wallston & Wallston, 1981 ).

**Internal Locus of Control:** "belief that ones outcome is directly the result of ones behavior" (Wallston & Wallston, 1981 ).

**Multidimensional Health Locus of Control Survey (MHLC):** A survey consisting of eighteen statements used to identify locus of control in individuals with respect to health (Wallston & Grady, 1988).

**Narrative Response Questionnaire:** A questionnaire developed by the researcher to identify an individual's health actions.

**Scleroderma:** “Scleroderma is a chronic, degenerative disorder that leads to vascular deterioration, tissue loss and the overproduction of collagen in the body’s connective tissue” (Scleroderma Research Foundation, 1999).

**Support Group:** Any group of scleroderma patients, under the guidance and direction of the Scleroderma Foundation, who meet in person as a means of discussing, dealing and coping with their disease.

**Support Group Member:** Any person clinically diagnosed with scleroderma who is attending a respective Scleroderma Foundation support group.

## **CHAPTER II**

### **Review of Literature**

There is a lack of information regarding scleroderma patients and their ability to cope with their disease. The purpose of this study was to describe individuals' approaches to coping with their illness as it relates to their health locus of control.

#### **Scleroderma**

Scleroderma, or "hard skin", is defined by the Scleroderma Foundation as a "chronic, often progressive autoimmune disease in which the body's immune system attacks its own tissues". It is also defined as an individualized disease, in which the degree of severity varies with each person (Scleroderma Foundation, 2000).

There are two primary forms of scleroderma, localized and systemic. The localized form commonly occurs in children and affects mainly the skin. The systemic form is the more frequent type and also the more severe type, in which internal organs are affected in addition to the skin (Scleroderma Foundation, 2000). Therefore, depending on the type of scleroderma, and the person, the symptoms vary and may include thickening of the skin, joint pain, stiffness, loss of flexibility, fatigue, weakness, and discoloration of the skin (Arthritis Foundation, 2002).

Scleroderma affects approximately 300,000 people in the United States. The common age of onset ranges from 30-50 with women approximately 4 times more likely to be affected than men. Within the past three decades, there has been an increase in incidence of the disease (Malcarne, 2002). In addition, scleroderma is more prevalent than muscular dystrophy or multiple sclerosis (Scleroderma Society of Canada, 2002).



### Scleroderma and Diagnosis

Diagnosis of scleroderma is difficult because the symptoms overlap with many other autoimmune diseases such as lupus and rheumatoid arthritis (Scleroderma Foundation, 2000). There is currently no one specific test to diagnose the disease. Diagnosis is determined as a result of several tests, depending on the severity of the person's symptoms. Tests performed include pulmonary function tests, nail-fold capillary test, blood tests, x-rays, and electrocardiograms. Further research is necessary to determine more accurate means of diagnosing the disease and developing a specific test to diagnose scleroderma (Scleroderma Research Foundation, 2002).

### Scleroderma and Treatment

As with the diagnosis, there is no single drug or treatment that is proven or accepted to be effective in treating scleroderma (Wasko & Medsger, 2000). Treatment requires involvement of various specialists including rheumatologists, and dermatologists. In addition, treatment includes a combination of medications individualized for the patient based on the extent of the disease. Therefore, further research is also needed in order to develop more accurate treatment options for scleroderma patients (Scleroderma Research Foundation, 2002).

### Scleroderma and Cause

The fundamental cause of scleroderma is unknown, but researchers are identifying possible immunological, environmental and genetic components (Scleroderma Research Foundation, 2002).

Studies have identified abnormally high rates of scleroderma with specific geographical areas and certain toxic chemicals. South Boston, Massachusetts, Detroit and Northampton, Michigan, North Carolina have all been identified with a high incidence rates of the disease. Research is being conducted to identify

possible environmental factors or chemicals that might be responsible for these abnormally high rates of the disease in these areas. In addition, people who are highly exposed to specific chemicals such as silica dust and polyvinyl chloride may have a higher risk for developing scleroderma (Harvey et al., 1999).

The role of genetics remains questionable with scleroderma. Several studies have shown that some people may have a genetic predisposition to scleroderma. However, it is rare for direct family members to contract the disease. There is current research in studying the genome-wide gene expression patterns to further identify what role genetics plays in the disease. Some research has indicated that a gene, or genes, may create a greater risk for the disease, particularly if the person is exposed to an environmental trigger (Scleroderma Research Foundation, 2002).

There are several studies identifying biological characteristics common among scleroderma patients. One such aspect, is the accumulation of scar tissue, but it is not conclusive as to whether this was prevalent before or after the patients were diagnosed (Scleroderma Research Foundation, 2001). This area is currently being investigated to further identify these biological patterns present within those with scleroderma.

### Scleroderma and Psychosocial Dimension

In respect to research exploring the psychosocial dimensions of the disease, there are minimal studies. Past research includes the exploration of disability aspects and psychological distress such as depression, regarding scleroderma patients.

A current study is being conducted to develop a psychosocial profile of individuals with systemic sclerosis and their spouses and to identify medical and psychosocial predictors of both disability and psychosocial adjustment. Aspects that are being assessed in this study include disease severity and associated

symptoms, psychosocial adjustment self esteem and coping. Other studies have been done on rheumatic disease as a whole. However, Malcarne states the need to conduct studies specifically with scleroderma to identify whether the results can actually be generalized to pertain to all rheumatic diseases (Malcarne, 2002).

### **Social Learning Theory**

The Social Learning Theory was developed by Julian Rotter in 1966. The theory states that through a learning process, individuals develop beliefs regarding certain outcomes. According to the theory, individuals' behavior can be predicted from "a knowledge of how they view the situation, their expectancies about their behavior, and how they value the outcomes that might occur as a result of their behavior in that situation" (Sanders & Suls, 1982). Rotter stated that an individual who believes that certain outcomes are a result of their own actions have an internal locus of control. An internal locus of control is the belief that people are responsible for what happens to them and the outcome is under their control (Winstead-Fry et al, 1999). In contrast, those individuals who believe that certain outcomes are a result of outside forces such as fate, luck or chance have an external locus of control (Rotter, 1975). An external locus of control is the belief that people do not have control over the outcome, and what happens is out of their control.

From this theory, Rotter developed a Locus of Control construct to measure whether an individual has an internal or external locus of control. This became known as the Rotter I-E Scale and has been used extensively in all areas of research (Sanders & Sul, 1982). The purpose of the scale is to determine generally whether or not a person has a strong orientation towards either an internal or external locus of control (Wallston, 1992).

### **Health Locus of Control**

The Rotter I-E scale allows for general identification of a person's locus of control. However, the Rotter I-E Scale does not directly address locus of control related to one's health or illness (Levenson, 1973). Therefore, Wallston & Wallston developed health-specific measures of Rotter's scale to be used in studying health and illness (Wallston & Wallston, 1981). This new construct was called the Health Locus of Control Scale (HLC). The purpose of the HLC is to identify the degree to which individuals believe that their health is controlled by internal or external factors. The HLC is comprised of eleven statements, five directed towards internal locus of control, and six statements directed towards external locus of control. Responses to statements are recorded using a Likert Scale ranging from 1 (strongly disagree) to 6 (strongly agree).

High scores on the HLC Scale indicate agreement with the six external statements. Statements include, "When I stay healthy I'm just lucky." The individual responds to the statements based on the level they agree or disagree. A high score indicates a high orientation towards an external locus of control. This means that individuals are likely to believe that other factors such as fate, luck or chance control the outcome of their health or illness. A high score is considered any score above thirty four, the median. (Sanders & Sul, 1982).

Low scores on the HLC Scale indicate disagreement with the six external statements and agreement with the five internal statements. Internal statements include "I am directly responsible for my health." The individual responds to the statements based on the level they agree or disagree. A low score indicates a high orientation towards an internal locus of control. This means that the individual is likely to believe that they are responsible for the outcome of their health or illness (Wallston, 1992). A low score is considered any score below thirty four,

the median. (Sanders & Sul, 1982).

### **Multidimensional Health Locus of Control**

The HLC Scale does not measure the influence of other people on one's health or illness. Therefore, Wallston and Wallston expanded on the HLC to incorporate a powerful others category. This new construct is known as the Multidimensional Health Locus of Control Scale (MHLC). This construct is comprised of eighteen questions with three categories. Each category contains six belief statements, for a total of eighteen statements to make up the MHLC. The categories include Internal Health Locus of Control (IHLC), Chance Health Locus of Control (CHLC), and Powerful Others Locus of Control (POLC) (Wallston and Wallston, 1976).

The Internal Health Locus of Control Scale (IHLC) measures the degree to which individuals believe they are responsible for their health and the outcome is under their control (Winstead-Fry et al, 1999). The six belief statements in this category identify peoples' beliefs that they are responsible for their illness. This category consists of statements such as "I am directly responsible for my condition getting better or worse". The individual rates each statement using the same six-point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree) that was developed with the HLC.

The Chance Health Locus of Control (CHLC) measures the degree to which individuals believe that their health is controlled by external factors such as fate, luck or chance (Winstead-Fry et al, 1999). The six statements in this category identify the degree to which people believe that external variables are responsible for their illness. This category includes statements such as "Most things that affect my condition happen to me by chance". The individual rates each statement using the same six point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree).

The POLC has two subcategories, other people and doctors. The two subcategories consist of three belief statements each to make up six statements for the POLC. The other people subcategory measures the degree to which individuals believe people such as family or friends are responsible for their health. This category consists of statements such as “The type of help I receive from other people determines how soon my condition improves”. The doctor subcategory measures the degree to which individuals believe their doctor is responsible for their health. This category includes statements such as “If I see my doctor regularly, I am less likely to have problems with my condition”. Both subcategories are also answered using the six point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree) (Sanders & Sul, 1982).

### **Locus of Control Research Findings**

Previous research has found that a high internal locus of control is associated with an increased likelihood of healthier behaviors and actions (Lau, 1988). These behaviors include exercise, limiting fat intake, not smoking, dental care and sodium intake (Steptoe & Wardle, 2001). In addition, it was found that an internal locus of control is associated with a greater sense of psychological and physical well-being (Gfellner & Finlayson, 1988, Goldsmith et al, 1988). Several researchers have identified individuals who have high internal locus of control are more active in seeking information regarding their illness. Seeman and Evans (1962) studied tuberculosis patients and found that those with high internal locus of control knew more about their condition and questioned doctors and nursed more, regarding their condition, than those with low internal scores.

One study found that an internal health locus of control orientations was related to successful self-care practices at a general health center in London (McLean and Pietroni, 1990). In another study, researchers interviewed multiple sclerosis patients and identified that those with internal health locus of control

orientation had greater knowledge of their disease. Furthermore, they practiced more self-care behaviors than those with an external health locus of control (Wassem, 1991).

### Changeability of Internal Score

Several researchers within the academic setting identified the ability to change a person's locus of control, once it is known. One researcher found that college students who were engaged in a type of therapy emphasizing personal freedom and responsibility became more internal on the Rotter's locus of control scale. In another study, the researchers offered short-term therapy to college students to eliminate self-defeating behaviors. They re-tested the students, and their locus of control scores became more internal (Lefcourt, 1982).

Although most of the research pertaining to change involves the locus of control within academic settings, as identified with the attribution theory, these findings are significant. This information should be tested within the health setting with the health locus of control to identify if similar results occur.

## **CHAPTER III**

### **Methodology**

There is a lack of information regarding scleroderma patients and their ability to cope with their disease. The purpose of this study was to describe individuals' approaches to coping with their illness as it relates to their health locus of control.

#### **Sample Selection**

The target population for this study was scleroderma patients attending support groups associated with the Scleroderma Foundation. To ensure regional diversity, eight support groups were contacted through an initial email. The support group information was listed on the Scleroderma Foundation Website ([www.scleroderma.org](http://www.scleroderma.org)) and included email contact information for each support group. The support groups were selected based on geographical location to allow for representation of various regions within the United States. The selection process was also based on the support groups that listed their email contact information for their individual office and chapter on the website.

The support groups initially contacted included Arizona, Florida, Michigan, Minnesota, New England Chapter, Nevada, Oregon, and Texas. The New England Chapter consisted of five states which include Maine, Massachusetts, New Hampshire, Rhode Island and Vermont. The email consisted of a brief introduction about the research and asked if the respective support group was interested in participating in the study. A reply to the email was requested. Six of the support groups replied and agreed to participate in the study. The participating support groups included Florida, Michigan, Minnesota, Nevada, Oregon and Texas.



## **Instrumentation**

The study utilized both quantitative and qualitative methods. The two instruments used in this study were the Multidimensional Health Locus of Control Survey (MHLC) and the Narrative Response Questionnaire (NRQ). The MHLC is a quantitative method and provided scores to identify low versus high internal health locus of control. The NRQ is a qualitative measure developed by the researcher. The questionnaire consisted of questions about individuals' perceptions and actions towards their illness. A demographic page accompanied these two instruments.

### Survey

The Multidimensional Health Locus of Control Survey (MHLC) was developed to measure a person's locus of control in respect to their health (see Appendix) (Wallston et al., 1978). The MHLC was comprised of three categories. Each category contained six belief statements, for a total of eighteen statements to make up the MHLC. The categories included Internal Health Locus of Control (IHLC), Chance Health Locus of Control (CHLC), and Powerful Others Locus of Control (POLC) (see Appendix A).

Category I, the Internal Health Locus of Control (IHLC), measured the degree to which individuals believe they are responsible for their health and their health outcomes are under their control (Winstead-Fry et al, 1999). This category consisted of statements such as "I am directly responsible for my condition getting better or worse". The participant rated each statement using a six-point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree).

Category II, the Chance Health Locus of Control (CHLC), measured the degree to which individuals believed that their health was controlled by external factors such as fate, luck or chance (Winstead-Fry et al, 1999). This category

included statements such as “Most things that affect my condition happen to me by chance”. The participant rated each statement using the same six point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree).

Category III, the Powerful Other Health Locus of Control (POLC), had two subcategories, other people and doctors. The two subcategories consisted of three belief statements each to make up six statements for the POLC. The other people subcategory measured the degree to which individuals believed people such as family or friends are responsible for their health. This category consisted of statements such as “The type of help I receive from other people determines how soon my condition improves”. The doctor subcategory measured the degree to which individuals believed their doctor was responsible for their health (Sanders & Suls, 1982). This category included statements such as “If I see my doctor regularly, I am less likely to have problems with my condition”. Both subcategories were also answered using the six point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree).

For the purpose of this study, the main focus was on the IHLC. Previous researchers have found that a high internal locus of control is associated with an increased likelihood of healthier behaviors and actions. These behaviors include exercise and limiting fat and sodium intake (Steptoe & Wardle, 2001). In addition, research has related a high internal locus of control with behaviors that include being more actively involved in one’s health and health care. It has been determined that individuals with a high internal locus of control experience greater psychological and physiological benefits than those with low internal locus of control (Wallston & Wallston, 1982). Therefore, participants in this study were examined from the perspective of their orientation toward IHLC.

The POLC and CHLC categories were not emphasized in this study. However, individuals’ scores for the CHLC and POLC were identified and

described.

Reviews of previous studies provided evidence of survey reliability and validity (Wallston & Wallston, 1981, 1982). There is validity for the use of locus of control in research on individuals in regard to health behaviors. Researchers in one study identified a strong relationship between health beliefs, health locus of control and women's mammography behavior. They measured alpha reliabilities that indicated internal consistency of the MHLC that ranged from 0.673 to 0.767. Furthermore, a test of predictive validity found that the health status correlated positively with internal health locus of control ( $r=0.403$ ,  $p<0.01$ ) (Holm, Frank & Curtin, 1999). In another study, researchers identified a relationship between health behaviors such as smoking and diet and locus of control. They received similar alpha reliabilities for the MHLC scale as the previous study. They further identified a strong relationship between positive health behavior and internal health locus of control (Wallston et al., 1978). The MHLC Scales have been used extensively in health research and are shown to have adequate internal consistency (Furnham & Steele, 1993).

### MHLC Scoring

There is a scoring sheet detailing which questions on the survey belong in each category. The number the person selects is based on a range of 1 to 6 for each question. Each category is scored independently. A high score in one category is not indicative of a low score for a separate category. For example, a high CHLC score does not indicate that the IHLC score will be low. It is possible to have a high score in more than one category or a low score in more than one category. The CHLC and IHLC both have a maximum score of 36. A higher score in a category indicates a stronger orientation toward that dimension. For example, a score of 30 in the CHLC category indicates a high external locus of control belief towards one's illness. Whereas, a score of 10 in the CHLC category

would indicate a low external locus of control belief towards one's illness.

The POLC has two subcategories, other people and doctors. The two subcategories consist of three questions each to make up six questions for the POLC. Therefore, there is a possible maximum score of 18 for each of the two subcategories. If individuals have a score of 15 in the other people subcategory, that identifies a high belief that other people are responsible for their health. However, if they have a score of 5 in the other people category that identifies a low belief that other people are responsible for their health.

### Questionnaire

The Narrative Response Questionnaire (NRQ) was developed by the researcher for the purpose of identifying coping behaviors and perceptions of the participants in regard to their disease. Similar questions were asked in studies using Attribution Theory. The questions in these previous studies were designed to explore the component of Attribution Theory that relates to internal locus of control. In addition, The NRQ questions were developed based on a review of the literature of the Health Locus of Control. The HLC has been shown to influence individuals' perception of the cause of their disease, how their disease has affected their lives, and what actions they are taking to cope with their disease. Thus, questions on the NRQ were designed to illicit information in these areas.

The Narrative Response Questionnaire is comprised of three questions. The individual was instructed to answer each question using the provided space. The length of response to each question was dependent upon the individual. In addition, content and thoroughness of the answers were also dependent on the individual.

The first question asked participants to explain what they believe caused their scleroderma. The second question asked how scleroderma has affected their personal life in respect to family and work. The third question asked participants

to state what actions they were taking to cope with scleroderma. Examples were listed to give participants an idea of the of responses pertinent to the question.

### Demographic Page

A demographic page was also included for the participant to complete. The instructions stated that responding to each part of the study is voluntary, including the demographic page. Participants were asked for information about their age, gender, location, ethnicity, level of education, date of diagnosis with scleroderma, length of support group attendance, and various types of health professionals with who they are regularly seeing. They were also asked to rate their health status from 1 (excellent) to 4 (poor).

### **Data Collection**

After approval from the University of Montana Institutional Review Board, the surveys and questionnaires were sent to the support groups' main offices. The support group facilitators agreed to distribute them to the support group members. Each facilitator received a package consisting of a cover letter, an instruction page and individual packets for distribution to the participants (see Appendix D & E). The cover letter included background information about the researcher and the study. The instructions explained the facilitators' role and involvement in the study. The facilitator's main role was distribution of the enclosed individual packets. The distribution format was left to the facilitator's best judgment and varied with each support group. Approximately two weeks following packet distribution, the facilitator was asked to send out a general message to the members. This message served as a reminder for the members to send in their completed packets to the researcher, and it was dependent upon the facilitator's ability to contact members through a group email or phone message. This was left up to the facilitator. After this general reminder, the facilitator's role in the study was complete.

The individual packets included a cover letter to the individual support group member (see Appendix D). The cover letter included background information on the researcher and the study. The letter was accompanied by a page of instructions detailing the participant's role in the study (see Appendix E). The participants were asked to fill out the survey, questionnaire and demographic page and place them in the enclosed self-addressed stamped envelope and mail it back to the researcher. Participation was voluntary. No names were listed on any of the material that was sent back to the researcher. This ensured confidentiality. After the participant mailed the information back to the researcher, the participant's role in the study was complete.

### **Data Analysis**

Responses for each category on the MHLC were scored using a six-point Likert scale ranging from 1 (strongly disagree) to 6 (strongly agree). Scores were calculated for each category resulting in a health locus of control profile for each participant. Descriptive statistics were used to provide a summary of overall group results.

Participants were sorted into the two groups, High ILOC and Low ILOC. The High ILOC group consisted of those who scored above the median of 18, on the internal locus of control subscale. The Low ILOC group consisted of those who score below the median of 18, on the internal locus of control subscale.

The NRQ was used to describe participants' approaches to coping with their illness. This was accomplished through qualitative analysis of the NRQ. The responses to the NRQ were reviewed and divided into two groups. Responses of those individuals who scored high on the ILOC were analyzed separately from those who scored low. Themes or similar thoughts were identified, and described. The demographic page was analyzed descriptively. The SPSS program was used to obtain percentages for each response.

## CHAPTER IV

### Results

#### Packet Returns

A total of 100 packets containing the HLOC survey, NRQ and demographic page, were sent to 6 support groups. The distribution number was based on the group facilitators' estimation of their support group size. The distribution was comprised of 10 for Nevada, 15 for Oregon, 10 for Michigan, 30 for Minnesota, 20 for Florida, and 15 for Texas. Thirty-two packets were returned, from 3 of the support groups. Michigan returned 7, Nevada returned 3 and 22 were returned from Minnesota.

#### Demographics

##### Participants' Gender

Female (n=30)	93.8%
Male (n= 2)	6.2%

##### Age

40-49 (n=5)	15.6%
50-59 (n=13)	40.6%
60-69 (n=11)	34.5%
70-79 (n=3)	9.3%

##### Marital Status

Married	(n=19)	59.4%
Single	(n=12)	37.5%
Significant Other	(n=1)	3.1%

##### Race/Ethnicity

Caucasian	(n=29)	90.6%
Native American	(n=2)	6.3%
Hispanic/Latino	(n=1)	3.1%

**Educational Level**

High School	(n=4)	12.5%
Associate Degree	(n=5)	15.6%
Vocational/Technical	(n=1)	3.1%
Some College	(n=13)	37.5%
College/Degree	(n=6)	18.8%
Professional/Graduate	(n=3)	9.4%

**Length of Diagnosis**

0-5 years	(n=10)	31.2%
6-10 years	(n=16)	50.0%
11-15 years	(n=6)	18.7%

**Type of Scleroderma**

Localized	(n=4)	12.5%
Systemic	(n=27)	84.4%
Not Sure	(n=1)	3.1%

**Support Group Participation**

0-5 years	(n=21)	65.7 %
6-10 years	(n=10)	31.3 %
11-15 years	(n=1)	3.1%

**Type of Health Professionals Sought**

Rheumatologist	(n=29)	90.6%
Dentist	(n=25)	78.1%
Cardiologist	(n=16)	50.0%
Ophthalmologist	(n=14)	43.8%
Internist	(n=13)	37.5%
Other	(n=9)	28.1%
Pulmonologist	(n=8)	25.0%
Nutritionist/Dietician	(n=5)	15.6%
Dermatologist	(n=5)	15.6%
Physical Therapist	(n=4)	12.5%
Naturopathic	(n=1)	3.1%
Herbalist/Alternative	(n=1)	3.1%
Psychologist	(n=1)	3.1%

**Health Status**

Excellent	(n=3)	9.4%
Good	(n=18)	56.3%
Fair	(n=9)	28.1%
Poor	(n=2)	6.3 %



The perception of health status appeared to have somewhat of a pattern between the High-ILOC and the Low-ILOC groups. The two participants who rated their health as poor were both in the Low-ILOC Group. In addition, all three participants who rated their health as excellent were in the High ILOC Group. This could indicate a pattern between excellent health status with High ILOC and poor health status perception with Low ILOC. The remaining responses were distributed between the good and fair selections between the two groups.

The length of time in a support group and length of diagnosis appeared to have no relationship between the High ILOC and the Low ILOC groups. Participants' responses from both groups were distributed among the three selections for length of diagnosis. However, for the length of time in a support group, the two groups were distributed evenly among the first two selections. The last option, 11-15 years had only one response, which was from a participant in the High ILOC Group.

### **MHLC Survey**

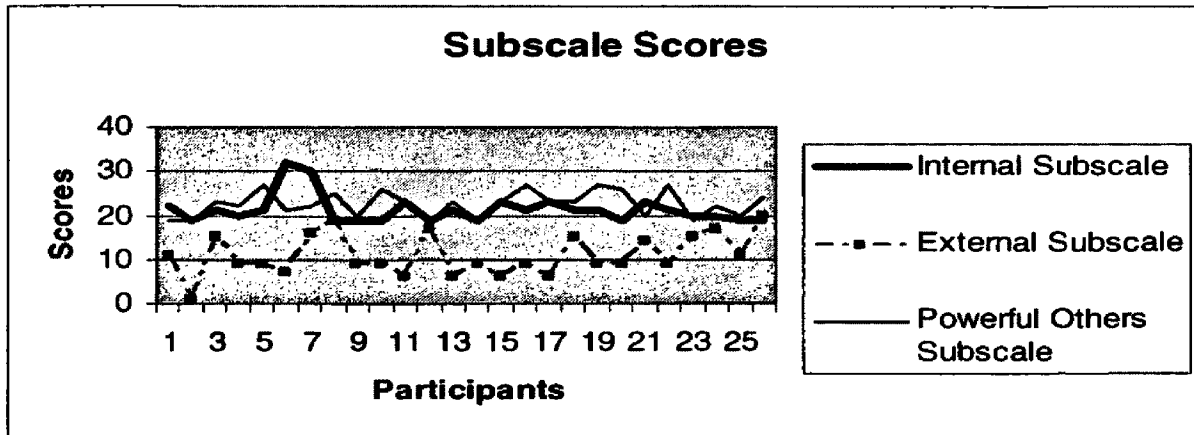
The surveys were scored using the standard score sheet. Of the 32 returned, 26 individuals scored high for internal locus of control (High ILOC, 18 or higher), and six scored low on internal locus of control (Low ILOC, less than 18). Each participant's scores on all subscales of the HLOC are reported in Table 1 below.

**Table 1: Health Locus of Control Score Profiles**

<b>HLOC SUBSCALE SCORES</b>			
<b>Participant</b>	<b>Internal</b>	<b>External</b>	<b>Powerful Others (Doctors, Other People)</b>
# 1	High (22)	Low (11)	High (19 - 11, 8)
# 2	High (19)	Low (17)	High (19 - 12, 7)
# 3	High (21)	Low (15)	High (23 - 10,13)
# 4	High (20)	Low (9)	High (22 - 12,10)
# 5	High (21)	Low (9)	High (27 - 11,16)
# 6	High (32)	Low (7)	High (21 - 16, 5)
# 7	High (30)	Low (16)	High (22 - 17, 5)
# 8	High (19)	High (19)	High (25 - 14,11)
# 9	High (19)	Low (9)	High (20 - 13, 7)
#10	High (19)	Low (9)	High (26 - 14,12)
#11	High (23)	Low (6)	High (23 - 16, 7)
#12	High (19)	Low (17)	High (19 - 12, 7)
#13	High (21)	Low (15)	High (23 - 10,13)
#14	High (19)	Low (17)	High (19 - 12, 7)
#15	High (23)	Low (6)	High (23 - 16, 7)
#16	High (21)	Low (9)	High (27 - 11,16)
#17	High (23)	Low (6)	High (23 - 16, 7)
#18	High (21)	Low (15)	High (23 - 10, 13)
#19	High (21)	Low (9)	High (27 - 11,16)
#20	High (19)	Low (9)	High (26 - 14,12)
#21	High (23)	Low (14)	High (20 - 12, 8)
#22	High (21)	Low (9)	High (27 - 11,16)
#23	High (19)	High (20)	High (24 - 16, 8)
#24	High (20)	Low (15)	High (19 - 14,5)
#25	High (20)	Low (17)	High (22 - 13, 9)
#26	High (19)	Low (11)	High (20 - 9, 11)
#27	Low (13)	Low (12)	Low (15 - 9, 6)
#28	Low (6)	High (23)	Low (11 - 8, 3)
#29	Low (9)	Low (15)	Low (8 - 5, 3)
#30	Low (9)	Low (17)	Low (9 - 6, 3)
#31	Low (11)	Low (13)	Low (13 - 9, 4)
#32	Low (10)	Low (12)	High (19 - 16, 3)

The distribution of HLOC subscale scores are further illustrated in charts 1 and 2 below. Chart 1 shows the subscale scores of participants with high internal locus of control, while chart 2 shows the subscale scores of participants with low internal locus of control.

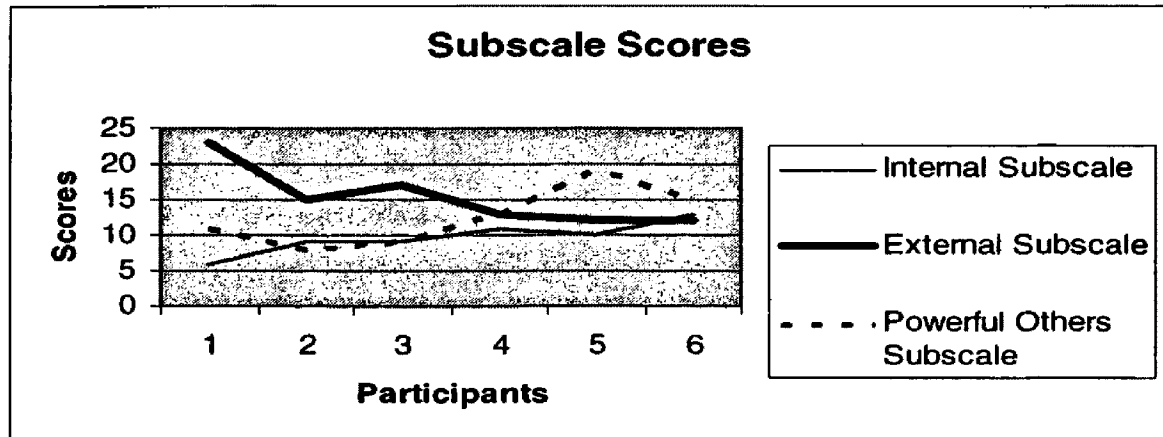
**Chart 1: Subscale Scores for Participants with High Internal Locus of Control**



For individuals with High Internal Locus of Control, mean scores and standard deviations for each subscale are as follows:

Internal subscale	m = 21.3	SD = .62
External subscale	m = 10.8	SD = .92
Powerful Others subscale	m = 22.6	SD = .55

**Chart 2: Subscale Scores for Individuals with Low Internal Locus of Control**



For individuals with Low Internal Locus of Control, mean scores and standard deviations for each subscale are as follows:

Internal subscale	m = 9.6	SD = .95
External subscale	m = 15.3	SD = 1.7
Powerful Others subscale	m = 12.5	SD = 1.6

### **Narrative Response Questionnaire**

Common themes arising from each question on the NRQ are described below. Commonalities among individuals who scored high on the Internal Locus of Control Sub-scale (n= 26) are described first, followed by a description of commonalities for individuals who scored low on the Internal Locus of Control Sub-scale (n=6).

#### **High Internal**

***Question 1: Please explain what you believe caused your scleroderma.***

#### **Theme #1: Stress**

Stress, participants stated, caused their immune systems to become compromised and thus more vulnerable and susceptible to diseases, such as scleroderma.

Responses included:

*“Stress, stress stress. I truly believe it had a major impact on the onset of Scleroderma”*

*“Stress, I think my job was a big “trigger” and wore down my immune system”*

*“I believe that stress had a huge impact on my disease, I had many family situations, deaths, in a short period of time and that was hard on me”*

### Theme #2: Genes/Hereditiy

Nearly half of the participants in the high internal locus of control category stated genes and or heredity played a factor in causing their disease. None of the participants described family members with scleroderma, but several reported other auto-immune diseases, such as arthritis and multiple sclerosis that run in their families.

Responses included:

*“I think it is in the genes, I think my family history of autoimmune diseases and there could be a gene making me more susceptible to scleroderma”*

*“I believe it was largely heredity. Arthritis runs in my family”*

*“I believe my case of scleroderma is due to a genetic predisposition to the disease”*

### Theme #3: Environmental Triggers

A few of the participants in the high internal locus of control group described environmental factors they believe contributed to causing their scleroderma. The factors included exposure to toxic fumes or viruses in the environment. The participants believed this exposure weakened their immune system, allowing for them to become susceptible to disease.

Responses included:

*“environmental triggers, painted house and fumes were unbearable and caused me to feel sick”*

*“After reading some opinions on the disease, I think there may have been “triggers” which created the onset. The summer before diagnosis, I painted the exterior of the house, using silicone caulk, latex paint, oil based paint and turpentine”*

*“One thought- I refinished a desk, couldn’t apply final finish because of severe headache from the fumes”*

## ***Question 2: How has Scleroderma affected your life?***

### **Theme #1: Physical Limitations**

The most common answers to this question were centered around physical limitations associated with scleroderma. Some of the limitations mentioned were fatigue, lack of mobility and sensitivity to cold. In addition, many participants stated they had to rely on supportive family members to assist them with many tasks, such as household chores because of these limitations.

Responses included:

*“I’m overly concerned about weather and ways to dress, to keep warm and comfortable”*

*“My family helps me with chores and daily tasks”*

*“I lost stamina and initially had joint pain, I lost mobility”*

*“Poor sleep with reflux problems”*

### **Theme #2: Work/ Job Related Changes**

Several participants stated that their ability to work was affected by scleroderma. Several participants stated they had to make changes such as decreasing their work hours, taking a temporary break from their job, or stopping work altogether.

Responses included:

*“I often missed work and eventually took advantage of an early retirement proposal”*

*“I can only work 20 hours a week”*

*“I switched to working in the office 2 or 3 hours a day instead”*

### Theme #3: Effect on Recreational Activities

Participants also stated they had to limit or eliminate recreational activities because of their physical limitations. These recreational activities included sports and personal interests/hobbies.

Responses included:

*“No longer able to do crafts and hobbies”*

*“I can no longer do some physical activities I once did such as snow skiing, tennis, golf and bowling”*

*“I can’t sing in the choir because of gastroesophageal difficulty.”*

*“I used to love to sail, but have curtailed that because it is too much work on me now”.*

***Question 3: Please describe in as much detail as possible, the actions you are currently taking to cope with your illness.***

### Theme #1: Social Actions

All of the participants mentioned the importance of social interactions through participating and belonging to a support group. The participants also commented on having a network of friends and family in addition to their support group. Some of the responses included:

*“We have a close knit support group and call each other often to hash over symptoms and remedies”*

*“I belong to a support group which is the best thing I could have done. I am also blessed with a wonderful support system of family and friends”*

*“My support group has really helped and my friends and family keep my spirits up”*

### Theme #2: Physical Actions

Participants described a variety of physical actions they are taking to alleviate their scleroderma symptoms. These physical actions included exercise, improving eating habits, getting enough rest, and taking medications. Some of the responses included:

*“I try to walk or exercise regularly and eat lots of veggies and fruit and get plenty of rest”*

*“I joined an exercise program and go with a friend 3-5 times a week for an hour, I also take a multi-vitamin and try to eat better”*

*“Pacing activities to preserve energy, allowing for nine hours of sleep per night”*

*“I have used and enjoyed paraffin baths for my fingers”*

*“I take my medications daily and keep close contact with my doctors”*

*“I get proper hours of sleep and take prescriptions and massage my fingers and hands”*

### Theme #3: Mental Actions

About half of the participants commented that they research and read information regarding their disease. Many commented on the importance of keeping up to date on the latest information regarding their illness. Some of the responses included:



*“read a lot and research on the internet”*

*“I try to keep current on status of research about scleroderma through publications, books, and on-line web sites”*

*“I read anything new about scleroderma”*

#### **Theme #4: Spiritual/Religious Actions**

Several participants stated that they engage in spiritual or religious activities such as meditating, praying or attending church. The participants stated that their religious beliefs are an important action they take to cope with their disease. In addition, many participants included actions they take to increase their spirituality, such as meditation. Some of the responses included:

*“prayer is an important part of my life.”*

*“We pray a lot for each other, I believe in prayer very strongly”*

*“I go to church and pray a lot”*

*“I meditate for my spirituality and overall well being”*

*“Meditating and prayer”*

#### **Low Internal**

This category consisted of only six participants making it difficult to identify themes for each question. Therefore, all six of the participants' responses for each question are described.

#### ***Question 1: Please explain what you believe caused your scleroderma.***

Most of the participants stated the cause of their scleroderma was due to either stress or heredity. Two stated they were not sure what caused their disease. The responses included:

*"I am inclined to believe that there was something in my genetics that malfunctioned."*

*"Perhaps a gene is present in scleroderma patients and stress starts the disease."*

*"unknown, probably a genetic predisposition"*

*"I have no idea"*

*"I have no idea what caused me to get scleroderma, my doctor doesn't know either"*

*"I really feel the stress in my life took its toll"*

**Question 2: How has Scleroderma affected your life?**

The responses for this group were physical limitations, work, and recreational limits. All of the responses are listed below.

*"It has caused me to lose my job, due to fatigue and pain. My husband is real good about trying to understand."*

*"For a time I could not work long hours"*

*"Feeling good enough to take trips have come to a halt"*

*"I try to be as active as I can but interest in things I once enjoyed has waned"*

*"It is hard to write and type"*

*"It has caused me to lose my job due to the fatigue and pain."*

**Question 3: Please describe in as much detail as possible, the actions you are currently taking to cope with your illness.**

The actions listed for this question were prayer, nutrition, exercise and support group attendance. Some of the responses included:

*"I attend a support group, walk and read."*

*"I really feel it is important to keep active with my support group"*

*" I pray daily"*

*“I attend church to enhance my spirituality”*

*“Try and exercise and stay flexible”*

*“I began to eat more nutritiously, adding more fruits and vegetables”*

## **CHAPTER V**

### **Summary of Findings**

The purpose of this study was to describe individuals' approaches to coping with their illness as it relates to their health locus of control.

Participants were all scleroderma patients and members of support groups affiliated with the Scleroderma Foundation. The researcher contacted six of these support groups through the Scleroderma Foundation Support Group Listing. Group facilitators agreed to approach their members with the information packets sent by the researcher. Information packets contained instructions and information regarding the researcher, the Multi-dimensional Health Locus of Control Survey (MHLC survey), the Narrative Response Questionnaire (NRQ) and the demographic page.

Out of one hundred packets sent to six support groups, thirty two were returned, resulting in a 32 percent return rate. Twenty-six of those returning the packets fell into the high internal locus of control group (High-ILOC Group), while only six fell into the low internal locus of control group (Low-ILOC Group). Because of the uneven distribution of participants between the two groups, only limited comparisons and contrasts could be made between the High-ILOC Group and the Low-ILOC Group.

### **Demographics**

The majority of the participants (93.8%) were women. Participants' ages ranged from 40 to 77. These demographics are somewhat congruent with those

found in the literature where women are four times as likely as men to be affected by scleroderma and the typical age range for scleroderma patients is between 30 and 50 years (Malcarne, 2002). Most of the participants were Caucasian (90.6%), married (59.4%), and had at least some college (65.7%).

Other information from the demographic page indicated that the majority of participants had been diagnosed for more than 6 years (68.7%), participated in a support group for less than 6 years (65.7%), and were diagnosed with the systemic form of scleroderma (84.4%). In addition, the majority of participants were seeing a rheumatologist (90.6%) and/or a dentist (78.1%) as their main health care professionals. Other health care professionals sought out by participants included: cardiologist (50%), ophthalmologist (43.8%), internist (37.5%), other (28.1%), pulmonologist (25%), nutritionist (15.6%), dermatologist (15.6%), physical therapist (12.5%), naturopathic (3.1%), herbalist (3.1%) and psychologist (3.1%). It was surprising that more participants were not seeing internists, since previous literature has indicated that they are also considered a primary health care professional for scleroderma treatment along with rheumatologists (Scleroderma Foundation, 2000).

The responses for health status indicated somewhat of a pattern related to ILOC. All of the participants who perceived their health as poor were in the Low ILOC Group (n=2) and all of the participants who perceived their health as excellent were in the High ILOC Group (n=3). The remaining responses for each group were distributed between the good and fair selections. The length of diagnosis and length of participation in a support group did not indicate a pattern

related to ILOC. However, the only person who had participated in a support group for more than 10 years was in the High ILOC Group.

### Discussion of High ILOC Group

As was expected, the majority of participants who scored high on the internal subscale (High ILOC Group) scored low on the external subscale on the Multidimensional Health Locus of Control survey (MHLC). The low score for the external subscale indicates that these participants do not believe that environmental factors control their health. Although some participants felt there were environmental or outside triggers involved in the onset of their disease, they stated on the NRQ that these factors did not control their health. When they were asked to write about the actions they were taking to cope with their illness, the majority of participants in this group listed numerous behaviors they were actively engaging in to take control of and responsibility for their health. This is consistent with the literature that describes high internals as more likely to engage in healthy behaviors and strive for physical well being (Wallston, 1976).

All of the participants in the High ILOC Group also scored high on the powerful others subscale on the MHLC. The powerful others subscale is divided into two categories, doctors and other people. A high score in either category indicates that individuals strongly believe that doctors or other people maintain control of their health. In this study, participants' scores indicated that they relied more heavily on doctors than they did on other people. And while a high score in the "doctors" category indicates that participants feel that doctors have control over their health (Malcarne, 2002), another interpretation of the meaning

of these scores may be reasonable. As previously stated, the literature shows that high internals are likely to strive for physical well being. In addition, past research has also shown that those with high internal locus of control are more likely to seek information regarding their condition (Malcarne, 2002). Thus, individuals with high internal locus of control might view powerful others, especially doctors, as a source of information as indicated by several people's responses. One participant stated, "I always ask my doctor for updates on new medications and treatments". Furthermore, they may view the gathering of that information as an important step in their quest to gain additional control over the course of their illness. This interpretation is supported by information from the NRQ where participants stated the importance of researching new information on scleroderma. Seeking information from doctors may be seen by High ILOC individuals as a means of conducting research on their illness.

A close connection between the powerful others and internal subscale also is illustrated in participants' responses to the second question on the NRQ. This question asks individuals to explain how scleroderma has affected their lives. It was interesting to note that the High ILOC participants stated that their lives had been affected in such a way that it was necessary for them to rely more heavily on others for support. This could further explain the high powerful others score among the High ILOC group. Reaching out to other people may possibly be another action they engage in to cope with and maintain control over their disease.

### High ILOC Profile

Analysis of data from this study indicates that participants with high

internal locus of control displayed several characteristics. First, they scored high in both the internal and powerful others subscales. They perceived powerful others, especially doctors, as sources of information and as a means of maintaining control of their health. Furthermore, they relied extensively on friends and family as a means of support and assistance in coping with their scleroderma. Finally, persons with high ILOC were able to describe a variety of actions that they were taking to cope with their illness and had a generally positive outlook towards their illness.

#### Discussion of Low ILOC Group

The following description should be interpreted with caution because of the minimal number of participants who fell into the Low ILOC category. Furthermore, information gathered from analysis of responses on the NRQ cannot be generalized to other individuals with scleroderma.

Most of the participants in this category scored low in all three subscales, internal, external and powerful others. It was surprising that the majority of individuals in the Low-ILOC group also scored low for both the external and powerful others subscales. It would seem reasonable that if individuals do not believe they have personal control over their health, they would believe either the environment or powerful others would have control. However, this was not the case. The majority of the Low ILOC group did not believe that they or any other identifiable source controlled their health. In fact, two of the participants stated on the NRQ that they did not know what caused their illness.



The responses of the Low-ILOC group to questions on the NRQ were somewhat ambiguous and were not written in as much detail as were the responses of the High ILOC group. For example, this group listed only a few actions they take to cope with their illness. There was no mention of seeking information or taking active responsibility in researching information on their illness. Furthermore, there was no mention of outreach to others, such as family or friends. There was a sense of isolation among this group, in regards to their illness and relationships to others. There was a tone of feeling alone and not being able to obtain support or help from loved ones.

#### Low ILOC Profile

Overall, analysis of data from this study indicates that a person with low internal locus of control would tend to display several characteristics. First, they scored low on all three subscales. Participants do not feel able to reach out to others for support or reassurance. Furthermore, they listed only a few actions they are taking to cope with their illness, and the actions did not directly relate to actively taking responsibility in controlling their illness and acquiring new information. Overall, they were unable to give detailed explanations of factors regarding their health, and they viewed their illness as a mystery they are unable to solve. Their outlook toward their illness was not as positive as those with a high internal locus of control.

#### **Limitations of the Study**

Results from this study apply only to those individuals who participated in the study and should not be generalized to all individuals who are afflicted with

scleroderma. Following is a discussion of various factors that may have affected the outcome of this study.

1) Only support group members of the Scleroderma Foundation were invited to participate. It might be reasonable to assume that individuals who participate in support groups are more likely to have high internal locus of control. This is because attending a support group may be considered an action individuals take to maintain control of their health.

2) The participants were all volunteers. This might also indicate a greater tendency towards a high internal locus of control since these volunteers demonstrated a willingness to be involved in activities that relate directly to their illness.

3) The low return rate also may have affected the results. It is highly likely that those individuals who chose to participate in the study were different than those who did not participate.

4) The unequal number of participants who scored in the High ILOC versus Low ILOC made it difficult to contrast or compare the two groups. The small number of Low ILOC participants made it particularly difficult to draw concrete conclusions regarding the general characteristics of the Low ILOC group.

### **Recommendations for Further Research**

Based on methodological lessons learned from this study, the researcher recommends two areas for further research.

1) Careful consideration should be given to how the powerful others subscale is defined. Currently, this subscale is defined as individuals' belief that

powerful others such as doctors or other people control their health. However, results from this study indicate that individuals with a high internal locus of control may perceive powerful others as sources of information. If this is the case, then individuals who score high on the powerful others sub-scale may not feel that doctors or other people control the outcome of their illness, rather, they may believe that by actively seeking information from “knowledgeable others” they have increased their personal control over the outcome of their illness. If this assumption is true then it would redefine the powerful others category and relate it closely with the internal locus of control subscale.

2) A second recommendation involves the use of a larger sample of scleroderma patients who are both in support groups and not in support groups. . A larger sample and the involvement of both types of participants would allow the researcher to draw more definitive conclusions regarding individuals with a low internal locus of control, and would also allow for comparisons and contrasts between the groups. In addition, it may be possible to identify whether those in support groups tend to have a higher internal locus of control, compared to those not in support groups.

### **Conclusions**

Ultimately, the value of examining health locus of control in relationship to coping with illness might be dependent upon the answer to two questions. First, are individuals with a high internal locus of control more likely to cope effectively with an illness than individuals with a low internal locus of control? Second, if individuals are found to have a low internal locus of control, are there

techniques available that have been proven effective in increasing their internal locus of control?

In regard to the first question, results from this study indicate that individuals with a high internal locus of control do indeed have a greater variety of positive coping mechanisms in relationship to their illness. The answer to the second question is not quite so clear, since studies related to changing locus of control have not been conducted in medical or health care settings with people suffering from chronic illness. However, previous studies in academic settings have indicated that an individual's locus of control can be changed through the use of therapeutic techniques.

Researchers in one study offered short-term therapy to college students who tested low for internal locus of control. The therapy was targeted toward eliminating self-defeating behaviors. After administering the short-term therapy, the students were re-tested, and their internal locus of control scores were substantially higher. Other studies within an academic setting have revealed similar findings (Lefcourt, 1982). These results are significant and should be applied within a health care setting. Studies directly investigating the ability to change a person's health locus of control should be conducted with individuals who suffer from chronic illness. Information from these studies could be applied to individuals with low internal locus of control scores, thus allowing them to develop a higher level of internal locus of control. Ultimately a higher internal locus of control would result in the development of more positive coping mechanisms.

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**Appendix A**  
**Multidimensional Health Locus of Control Survey**



## MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SURVEY

**Instructions:** Each item below is a belief statement about your illness with which you may agree or disagree. Beside each statement is a scale which ranges from 1 (strongly disagree) to 6 (strongly agree). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs, obviously, there are no right or wrong answers. Thank you!

**1=Strongly Disagree**  
**2=Moderately Disagree**  
**3=Slightly Disagree**

**4=Slightly Agree**  
**5=Moderately Agree**  
**6=Strongly Agree**

	Strongly Disagree	Mod. Disagree	Strongly Disagree	Strongly Agree	Mod. Agree	Strongly Agree
1. If my condition worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2. As to my condition, what will be will be.	1	2	3	4	5	6
3. If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4. Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5. Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6. I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7. Other people play a big role in whether my condition improves, stays the same or gets worse.	1	2	3	4	5	6
8. Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9. Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10. In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11. Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12. The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
13. I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14. Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15. If my condition worsens, its a matter of fate.	1	2	3	4	5	6
16. If I am lucky, my condition will get better.	1	2	3	4	5	6
17. If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18. The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6

**Appendix B**  
**Narrative Response Questionnaire**





## 2. How has Scleroderma affected your life?

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**Appendix C**  
**Demographic Information Page**

## Demographic Information



*Note: Completion of each question on this page is voluntary. Your responses will be greatly appreciated. Thank you!!*

**1. Gender**

Female

Male

**2. Age** \_\_\_\_\_

**3. Are you:**

Married

Single

Living with a significant other/domestic partner

**4. Race/Ethnicity**

Asian

Native American

Hispanic or Latino

Caucasian

African American

Other

**5. Highest level of education completed**

Some High School

High school

Associate Degree

Vocational/Technical

Some College

College Degree

Graduate/Professional

**6. How long have you been diagnosed with scleroderma?**

\_\_\_\_\_ Years

(continued on back)

**7. Have you been diagnosed with:**

- Localized Scleroderma - (localized involves only the skin)
- Systemic Scleroderma - (systemic involves the skin and internal organs)
- Not sure

**8. How long have you been attending a support group since your diagnosis? (This refers to all support groups, not just the current one you are attending)**

\_\_\_\_\_ Years

**9. How many doctors/health professionals you are currently seeing? (Within the past six months) Check all that apply**

- |   |   |
|---|---|
| <input type="checkbox"/> Rheumatologist             | <input type="checkbox"/> Dermatologist      |
| <input type="checkbox"/> Cardiologist               | <input type="checkbox"/> Internist          |
| <input type="checkbox"/> Pulmonologist              | <input type="checkbox"/> Physical Therapist |
| <input type="checkbox"/> Nutritionist/Dietician     | <input type="checkbox"/> Dentist            |
| <input type="checkbox"/> Naturopathic Physician     |   |
| <input type="checkbox"/> Herbalist/Alternative      |   |
| <input type="checkbox"/> Ophthalmologist/Optomtrist |   |
| <input type="checkbox"/> Psychologist/Therapist     |   |
| Other (please specify)                              |   |
- 

**10. How would you rate your overall health?**

- Excellent
- Good
- Fair
- Poor



**Appendix D**  
**Participant and Facilitator Cover Letter**

July 9, 2002

Dear Facilitator:

Thank you for agreeing to participate in my study and distribute the enclosed information. I want to provide you with a little more information about myself. I am a graduate student in Health Promotion at the University of Montana. I am conducting a study in order to receive my Master's Degree at the end of the summer. I became interested in the subject of scleroderma when my mother was diagnosed with the disease several years ago. My study focuses on exploring individuals' approaches to coping with scleroderma as it relates to their perceptions of control over their illness.

I appreciate your willingness to distribute the enclosed individual packets to members of your support group who agree to voluntarily participate. You also have the option of participating by filling out a packet. Each individual packet has instructions and will guide the members through the process of filling out the information.

You are not responsible for collecting or mailing the completed information. Participants are provided with a stamped self addressed envelope. I have enclosed instructions for you regarding distribution. Feel free to contact me if you have additional questions or comments. I would be happy to provide the results of my study once it is complete. Thank you again for your participation in my study.

Sincerely,

Karen Elliott

July 9, 2002

Dear Participant:

My name is Karen Elliott and I am a graduate student in Health Promotion at the University of Montana. I am currently conducting a study in order to receive my Master's Degree at the end of the summer. I became interested in the subject of scleroderma when my mother was diagnosed with the disease several years ago. My study focuses on exploring individuals' approaches to coping with scleroderma as it relates to their perceptions of control over their illness.

I would appreciate your participation in the study through completion of the information in the enclosed packet. Instructions are included with the survey, questionnaire and demographic page. I will provide the results of my study to your support group facilitator once it is complete. Thank you again for your participation in my study.

If you have questions about the study or would like to contact me for more information, I can be reached at:

Karen Elliott  
1500 McDonald Avenue 16B  
Missoula, MT 59801  
(406) 829-0363  
kelliott01@msn.com

Sincerely,

Karen Elliott

**Appendix E**  
**Participant and Facilitator Instructions**



## **PARTICIPANT INFORMATION**

### **INFORMATION REGARDING STUDY**

You are asked to participate in a research study conducted by Karen Elliott from the University of Montana, Department of Health and Human Performance. Results from this study will be assessed in my master's thesis.

You were selected as a possible participant because you are a current member of a scleroderma support group affiliated with the Scleroderma Foundation.

### **THE PURPOSE OF THE STUDY**

There is a lack of information regarding scleroderma and individuals' abilities to cope and deal with their disease. The purpose of this study is to describe individuals' approaches to coping with scleroderma as it relates to their perceptions of control over their illness.

### **PROCEDURES**

1. Read the instructions.
2. Complete the survey.
3. Complete the questionnaire, use additional pages if necessary.
4. Place the survey, questionnaire responses, and demographic page into the self-addressed stamped envelope.
5. Mail the envelope back to me. Please do not put your name on any of the information, including the envelope.

Thank You!

### **POTENTIAL RISKS AND DISCOMFORTS**

The survey and questionnaire ask participants to respond to questions based on their perceptions of their illness. These questions may be sensitive or uncomfortable to some.

(continued on back)

**ΓPOTENTIAL BENEFITSΓ**

This study will provide greater understanding of scleroderma by explaining the role that perceptions of control of the disease affects individuals' ability to cope with the disease. Information from this study will be shared with scleroderma support group members, group facilitators and the Scleroderma Foundation.

**ΓCONFIDENTIALITYΓ**

Participants are asked to not put their name on any of the information to be sent back. In addition, since the participants are approached by the support group facilitator, the researcher has no information regarding members' names.

**ΓPARTICIPATION AND WITHDRAWALΓ**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of kind. Participation is strictly voluntary.



## **PACKET DISTRIBUTION INFORMATION**

### **INFORMATION REGARDING STUDY**

There is a lack of information regarding scleroderma and individuals' abilities to cope and deal with their disease. The purpose of this study is to describe individuals' approaches to coping with scleroderma as it relates to their perceptions of control over their illness.

You are asked to participate in a research study conducted by Karen Elliott from the University of Montana, Department of Health and Human Performance. Results from this study will be used in my master's thesis.

### **PROCEDURES**

1. Please make the enclosed individual packets available to your support group. How you distribute them is up to you.
2. Please ask them to follow the instructions contained in each packet.

That is the extent of your role in this study, thank you for agreeing to distribute the information to individual members. You are not responsible for collecting or mailing any completed information, that is the responsibility of the participant.

If you have any questions or concern regarding your role or the information please feel free to contact me.

Results from this study will be made available to you to share with your support group members.

**Thank you!**

Karen Elliott  
 1500 McDonald Avenue 16B  
 Missoula MT 59801  
 (406) 829-0363  
[kelliott01@msn.com](mailto:kelliott01@msn.com)

**Appendix F**  
**Institutional Review Board Approval**



RECEIVED

Form RA-108  
JUN 28 2002

The University of Montana *484-02*  
INSTITUTIONAL REVIEW BOARD (IRB)  
CHECKLIST

UNIVERSITY OF MONTANA  
VICE PRESIDENT FOR RESEARCH

Submit one completed copy of this Checklist, including any required attachments, for each course involving human subjects. The IRB meets monthly to evaluate proposals, and approval is granted for one academic year. See *IRB Guidelines and Procedures* for details.

Project Director: Karen Elliott Dept.: HHP Phone: 829-0363

Signature: *Karen Elliott* Date: 6-28-02

Co-Director(s): \_\_\_\_\_ Dept.: \_\_\_\_\_ Phone: \_\_\_\_\_

Project Title: Internal Health Locus of Control: A Description of High and Low Orientation and Approaches to Coping with Scleroderma

Project Description: The purpose of this study is to describe individuals' approaches to coping with their illness as it relates to their health locus of control.

All investigators on this project must complete the NIH self-study course on protection of human research subjects.

Certification: I/We have completed the course - (Use additional page if necessary)

Signature	Date	Signature	Date
<u><i>Karen Elliott</i></u>	<u>6-26-02</u>	_____	_____
_____	_____	_____	_____

Students Only:

Faculty Supervisor: Dr. K. Ann Sondag Dept.: HHP Phone: 243-5215

Signature: *[Signature]*  
(My signature confirms that I have read the IRB Checklist and attachments and agree that it accurately represents the planned research and that I will supervise this research project.)

For IRB Use Only

IRB Determination:

Approved Exemption from Review

Approved by Administrative Review *(see memo on back)*

*Jana Ralback*

*July 1, 2002*



The University of  
**Montana**

Office of the Vice President  
Research and Development  
University Hall 116  
243-6670  
243-6330 FAX

**To: Investigators with research involving human subjects**  
**From: J. A. Rudbach, IRB Chair**  
**RE: IRB approval of your proposal**

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This study has been approved on the date that the "Checklist" was signed. If the study requires an Informed Consent Form, please use the "signed and dated" ICF as a "master" for preparing copies for your study. Approval is granted and continues for one year; if the study runs more than one year a continuation must be requested. Also, you are required to notify the IRB if there are any significant changes or if unanticipated or adverse events occur during the study. Please notify the IRB when you complete this study.



Jon A. Rudbach

attachment(s)