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Coping Behaviors of Individuals with Autoimmune Disorders

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ABSTRACT

Over the past 50 years, chronic illness has become the principal cause of disability and the need for health care services in the United States (Schattner, Shahar, & Shakra, 2012). Chronic illness currently accounts for 78 percent of health care costs in the United States and affects 45 percent of the population. Due to this extreme growth, it is important to have an understanding of the disorders themselves and the individuals living with them.

An online survey was used to measure perceived stress and coping behaviors in participants diagnosed with lupus, fibromyalgia, rheumatoid arthritis, any chronic illness, and "healthy" adults. Illness intrusiveness was also measured in the autoimmune sample. Illness activity was be measured using the Illness Intrusiveness Rating Scale (IIRS). The Perceived Stress Scale (PSS-10) was used to measure perceived stress. Coping behaviors were measured using The COPE Inventory.

It was expected that those with autoimmune disorders would use more positive coping behaviors than "healthy" individuals, but that the two samples would use similar levels of negative coping behaviors. In both samples, it was hypothesized that perceived stress levels would be similar, but that elevated levels of perceived stress would relate negatively to the use of effective coping behaviors, and positively to less effective coping behaviors. Among the autoimmune sample, it was expected that higher level of illness intrusiveness would positively relate to perceived stress, but negatively affect positive coping behaviors. It was also expected that the longer that participants had been diagnosed with the autoimmune disorder, the more effective their coping behaviors would be.

Although autoimmune diagnosis and preferred coping behaviors were found to be unrelated, elevated levels of perceived stress were found to be significantly related to the use of less effective coping behaviors in all diagnostic categories. The study looked at the relationship between illness intrusiveness and perceived stress, and the two variables were found to be significantly related in all three of the autoimmune samples.

The possible implications of this study can be extensive. Clinicians will be better able to understand individuals living with autoimmune disorders and how these disorders influence the individual's perceived stress and coping behaviors.

Keywords: autoimmune disorder, coping behavior, perceived stress, illness intrusiveness

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INTRODUCTION

Over the past 50 years, chronic illness has become the principal cause of disability and the need for health care services in the United States (Schattner, Shahar, & Shakra, 2012). Chronic illness currently accounts for 78 percent of health care costs in the United States and affects 45 percent of the population. However, there has been minimal investigation into autoimmune disorders in general, let alone the influence of autoimmune disorders on coping behaviors. The purpose of this study was to address this gap in the literature. It was expected that being diagnosed with an autoimmune disorder would have a positive outcome on coping behaviors. The first portion of the literature review will examine the three different types of autoimmune disorders included in the study, and how each disorder is defined and diagnosed. Next, the basic stress model and perceived stress will be discussed. The literature review will then conclude with information regarding different coping behaviors.

Autoimmune Disorders

An autoimmune disorder is a condition that occurs when the immune system mistakenly attacks and destroys healthy body tissues (Devins, 2010). To date, there are 80 different types of autoimmune disorders affecting approximately 14 to 23 million people in the United States. Considering the number of individuals affected by autoimmune disorders, there is a surprisingly small amount of documented research on the topic. Autoimmune disorders come in many shapes and sizes including: rheumatoid arthritis, fibromyalgia, and systemic lupus erythematosus. These disorders are the most well known autoimmune disorders to the general population (Devins, 2010).

Rheumatoid Arthritis

Rheumatoid arthritis is a progressive disorder that has the potential to cause functional disability and joint destruction (Scott, Wolfe, & Huizinga, 2010). This disorder is three times more common in women than in men. It affects 0.5 to one percent of adults worldwide, and 0.66 percent of people in the United States (Lundkvist, Kastang, & Kobelt, 2008). According to Scott et al. (2010), the prevalence of rheumatoid arthritis increases with age, and is highest in women ages 65 and older.

Signs and symptoms. Active rheumatoid arthritis can cause disability, joint damage, decreased quality of life, and cardiovascular or other co-morbidities (Scott et al., 2010). Fifty to eighty percent of people with rheumatoid arthritis will have ACPA, rheumatoid factor, or both. ACPA is an antibody that is directed against citrullinated antigens; it is more specific and sensitive for diagnosis when compared to the rheumatoid factor antibodies. The ACPA is also a better predictor of poor prognosis for disease progression.

Diagnostic criteria. Currently there are two sets of criteria used for diagnosing rheumatoid arthritis. The first set of criteria was established by the American College of Rheumatology in 1987 (see Table 1). Four of the seven following criteria must be present for a diagnosis, and items one through four must have been present for at least six weeks. Criteria set 1: (a) morning stiffness for at least one hour, (b) arthritis of three or more joint areas, (c) arthritis of hand joints, more than one swollen joint, (d) symmetrical

Table 1

Rheumatoid Arthritis Criteria (Criteria Set 1: ACR 1987)

Four of these seven criteria must be present for diagnosis of rheumatoid arthritis. Criteria 1-4 must have been present for at least six weeks.
Morning stiffness for at least one hour.
Arthritis of three or more joint areas.
Arthritis of hand joints, more than one swollen joint.
Symmetrical arthritis.
Rheumatoid nodules.
Serum rheumatoid factor.
Radiographic changes (erosions).

arthritis, (e) rheumatoid nodules, (f) serum rheumatoid factor, and (g) radiographic changes (erosions).

Morning stiffness is described as a physical sign of reduced range of motion predominately occurring after waking (Scott et al., 2010). Symmetrical arthritis is pain occurring symmetrically on the body. For example if you experience pain in your right thumb, you will also experience similar pain in your left thumb. Rheumatoid nodules are described as a local swelling or tissue lump that is firm to the touch. Serum Rheumatoid factor is an antibody that reacts against globulins and is found in the blood of patients suffering from rheumatoid arthritis. And finally, radiographic changes or erosions are described as a change in density or shape of the area being observed.

The second set of criteria was developed by the American College of Rheumatology and the European League Against Rheumatism in 2010 (Scott et al., 2010) (see Table 2). The following criteria are used for all new diagnoses following 2010. The criteria are separated into four sections and are based on a points system. To be diagnosed with rheumatoid arthritis a patient must have six or more points. Scoring is explained in Table 2.

Section one consists of joint involvement, and can receive a score ranging from zero to five. This section is separated into the following severities: (a) one medium-to-large joint, (b) two to ten medium-to-large joints, (c) one to three small joints not including large joints, (d) four to ten small joints not including large joints, and (e) more than ten joints including at least one small joint. Medium-to-large joints include joints such as the knee or elbow. Small joints include joints such as those within the fingers or toes.

Section two consists of serology, and can receive a score ranging from zero to three. This section is separated into the following severities: (a) negative Rheumatoid Factor (RF) and negative Antibodies against Citrullinated Peptides (ACPA), (b) low positive RF or low positive ACPA, and (c) high positive RF or high positive ACPA. Rheumatoid factor is described as an antibody that reacts against globulins and is found in the blood. ACPA is an antibody that is directed against citrullinated antigens, it is more specific and sensitive for diagnosis when compared to the rheumatoid factor antibodies.

Section three consists of acute-phase reactants, and can receive a score ranging from zero to one. This section is separated into the following severities: (a) normal C-

reactive protein (CRP) and normal erythrocyte sedimentation rate (ESR) and (b) abnormal CRP or abnormal ESR. C-reactive protein is a globulin that is in the blood in cases of acute inflammation. Erythrocyte sedimentation rate is the rate at which red blood cells settle in a tube of blood, a high rate typically indicates inflammation.

Section four consists of duration of symptoms, and can receive a score ranging from zero to one. This section is separated into the follow severities: (a) less than six weeks and (b) six weeks or more.

Patients should be assessed every few months in the early active stages of their disease (Scott et al., 2010). They should then establish a stable record of their rheumatoid arthritis by being assessed on a yearly basis.

Treatment options. Disease-modifying anti-rheumatic drugs (DMARDs) are the typical go-to medication for treating rheumatoid arthritis. These medications reduce joint swelling and pain, limit progressive joint damage, decrease acute-phase markers, and improve function (Scott et al., 2010). Serious side effects include: hepatotoxicity – toxicity of the liver, interstitial lung disease, blood dyscrasia – abnormal blood mixture, and mild nausea. Patients are typically prescribed the DMARD Methotrexate when they are first diagnosed and they will remain on this medication unless their disease progresses.

Non-Steroidal anti-inflammatory drugs (NSAIDs) are also used to decrease pain and stiffness. Originally, NSAIDs were the first line treatment; however, there is now concern about their limited effectiveness, gastrointestinal and cardiac toxic effects, and inability to alter the long-term course of the disease (Scott et al., 2010). Analgesics have also been used to reduce pain, but the evidence for these medications is modest at best.

Table 2

Rheumatoid Arthritis Criteria (Criteria Set 2: ACR/EULAR 2010)

Points are shown in parentheses, must have six points or more for diagnosis of rheumatoid arthritis.
Section 1 – Joint involvement (0-5)
One medium-to-large joint (0)
Two to ten medium-to-large joints (1)
One to three small joints (large joints not counted) (2)
Four to ten small joints (large joints not counted) (3)
More than ten joints (at least one small joint) (5)
Section 2 – Serology (0-3)
Negative RF and negative ACPA (0))
Low positive RF or low positive ACPA (2)
High positive RF or high positive ACPA (3)
Section 3 – Acute-phase reactants (0-1)
Normal CRP and normal ESR (0)
Abnormal CRP or abnormal ESR (1)
Section 4 – Duration of symptoms (0-1)
Less than 6 weeks (0)
6 weeks or more (1)

Nonpharmacologic treatments are also strongly suggested for patients with rheumatoid arthritis (Berube & Carruthers-Czyzewski, 1998). Examples of these include exercise, psychological assistance, joint protection, and foot care. Suggested exercise includes cardio and weight-bearing activities. Excess body weight increases stress on joints, such as the knees and hips. It is also suggested that individuals with rheumatoid arthritis protect their joints by avoiding excessive stress on the joints and by using appropriate body mechanics or devices to make daily tasks easier.

Fibromyalgia

Fibromyalgia is a medical disorder which occurs when the central nervous system abnormally processes pain, this leads to pain being amplified (Arnold, Clauw, Dunegan, & Turk, 2012). Due to this low pain threshold, a person with fibromyalgia may experience pain with a lower stimulus. This disorder is the third most prevalent rheumatologic disorder in the United States affecting approximately 6 million individuals (Jones, Clark, & Bennet, 2002). Currently there is no cure for fibromyalgia; because of this multimodal treatment focuses on alleviating symptoms.

Signs and symptoms. Fibromyalgia is a chronic condition characterized by widespread pain, generalized morning stiffness, persistent fatigue, and non-restorative sleep (Patkar, Bilal, & Masand, 2003). Although the etiology, or cause, of this disorder is unknown and poorly understood, potential causes include: (a) abnormalities in the neuroendocrine systems, (b) alterations in the substance P levels, and (c) low levels of growth hormones, cortisol, serotonin, and norepinephrine (Peterson, 2007)

Diagnostic criteria. Diagnosis is determined using a combination of physical examination, patient history, and laboratory evaluations (Peterson, 2007). It is also

necessary to evaluate and rule out other possible causes for current symptoms; these include: drug-induced myopathies, hypothyroidism, and autoimmune, connective tissue, or rheumatologic disorders.

Criteria according to the American College of Rheumatology (ACR) includes a history of widespread pain at least or greater than three months, and pain in 11 of 18 predetermined tender points when evaluated (Peterson, 2005) (see Table 3). These tender points are typically located over muscle or areas where muscle inserts bones or tendons. The tender points include the following (a) occiput, (b) trapezius, (c) supraspinatus, (d) gluteal, (e) low cervical, (f) second rib, (g) lateral epicondyle, (h) greater trochanter, and (i) knee.

The occiput is at the insertions of one or more of the following muscles (a) trapezius, (b) stemocleidomastoid, (c) splenlus capitus, and/or (d) semispinalis capitus. The trapezius is at the midpoint of the upper border. The supraspinatus is above the scapular spine near the medial border. The gluteal is at the upper outer quadrant of the buttocks at the anterior edge of the gluteus maxiumus. The low cervical is at the anterior aspect of the interspaces between the transverse processes of C5 through C7. The second rib is lateral to the second costochondral junctions. The lateral epicondyle is two centimeters distal to the lateral epicondyle. The greater trochanter is posterior to the greater trochanteric prominence. The knee is at the medial fat pad proximal to the joint line.

Treatment options. Common treatments include: medications, cognitive behavioral therapy, physical activity/ exercise, and sleep hygiene (Arnold et al., 2012). To date, three medications have been approved by the FDA: Pregabalin, Duloxetine, and

Table 3

Fibromyalgia Criteria (American College of Rheumatology (ACR) Criteria)

Must have both of the following for diagnosis of fibromyalgia.
A history of widespread pain for at least three months or longer.
Pain in 11 of 18 predetermined tender points, left or right.
Occiput
Trapezius
Supraspinatus
Gluteal
Low cervical
Second rib
Lateral epicondyle
Greater trochanter
Knee

Milnacipran. According to Quisel et al. (2004), patients treated with antidepressants are four times more likely to improve than those treated with a placebo. These same patients also had additional short term benefits when the antidepressant was given with a low dose muscle relaxant.

The American Pain Society also stresses the benefits of nonpharmacologic therapies (Peterson, 2007). These therapies include exercise, cognitive behavioral

therapy (CBT), and intensive patient education. Patients are encouraged to focus on sleep hygiene and tracking of their progress (Arnold et al., 2012).

Systemic Lupus Erythematosus

Systemic lupus erythematosus is an autoimmune disorder in which the body produces pathogenic antibodies and inflammatory cells that can affect tissues in any part of the body (Schattner et al., 2012). This disorder varies from individual to individual in regards of symptoms and severity, and follows an unpredictable course. Patients are typically diagnosed between the ages of 14 and 64. Eighty-five percent of patients are women, and patients with this disorder have a death-rate that is two to three times higher than the general population.

Signs and symptoms. Dominant symptoms of systemic lupus erythematosus include: extreme fatigue, headaches, weight change, depression, rashes, joint pain, renal disease, anemia, muscle aches, and general malaise (Schattner et al., 2012). Patients may also experience a malar or butterfly-shaped rash across their nose, sensitivity to sunlight, oral ulcers, kidney issues, or hair loss (Wallace, 2009).

Diagnostic criteria. The following criteria were developed by the American College of Rheumatology (see Table 4). A patient must have at least four of the eleven criteria either at the present time or at some point in the past (Wallace, 2009). The criteria include: (a) malar rash, (b) discoid rash, (c) photosensitivity, (d) oral ulcers, (e) arthritis, (f) serositis, (g) kidney disorder, (h) neurological disorder, (i) blood disorder, (j) immunologic disorder, and/or (k) abnormal antinuclear antibody (ANA).

A malar rash is a rash over the cheeks and nose, often in the shape of a butterfly. A discoid rash is a rash that appears as red, raised, disk-shaped patches. Photosensitivity is a

reaction to sun or light that causes a skin rash to appear or get worse. Oral ulcers are sores appearing in the mouth. Arthritis is joint pain and swelling of two or more joints in which the bones around the joints do not become destroyed. Serositis is inflammation of the lining around the lungs (pleuritis) or inflammation of the lining around the heart that causes chest pain that is worse with deep breathing (pericarditis). Kidney disorder is persistent protein or cellular casts in the urine. Neurological disorders consist of seizures

Table 4

Systemic Lupus Erythematosus Criteria (American College of Rheumatology Criteria)

Must have at least four of the eleven criteria either at the present time or at some point in the past for diagnosis of systemic lupus erythematosus.
Malar rash
Discoid rash
Photosensitivity
Oral ulcers
Arthritis
Serositis
Kidney disorder
Neurological disorder
Blood disorder
Immunologic disorder
Abnormal antinuclear antibody (ANA)

or psychosis. Blood disorders consist of anemia (low red blood cell count), leukopenia (low white blood cell count), lymphopenia (low level of specific white blood cells), or thrombocytopenia (low platelet count). Immunologic disorders consist of abnormal anti-double-stranded DNA or anti-Sm, positive antiphospholipid antibodies. Abnormal antinuclear antibody (ANA) is detected by a blood test.

Treatment Options. Medications are the typical treatment for patients with systemic lupus erythematosus (Wallace, 2009). The most common are non-steroidal anti-inflammatory drugs (NSAIDS), corticosteroids, anti-malarials, and immunosuppressives. NSAIDS and anti-malarials have anti-inflammatory effects. Corticosteroids counter inflammation. Immunosuppressives reduce the autoimmune response; these are prescribed if multiple organs are involved.

Nonpharmacologic treatments are strongly suggested for patients with systemic lupus erythematosus (Schattner et al., 2012). Examples of these include exercise, psychological assistance, and acupuncture. Acupuncture is a system that involves pricking the skin or tissue with needles; this is believed to alleviate pain in patients with systemic lupus erythematosus.

The Basic Model of Stress

Individuals living with autoimmune disorders also live with additional stressors. Ciminero's (2012) Basic Model of Stress will be used to understand stress and coping in these individuals. According to Ciminero, stress is "a combination of various physical and psychological reactions that occur whenever there is some demand placed on an individual that requires some kind of action by the person" (p. 18). The basic model of

stress consists of stressors, mental processing, stress reactions, and coping responses (Ciminero, 2012).

Stressors

Typical stressors include short-term events, long-term problems, and cognitions such as thoughts, beliefs, and memories (Ciminero, 2012). It is important to note that anything can be a stressor depending on how the individual perceives the situation; even positive events can be stressful. Stressors can also be considered complex, multiple stressors adding up on top of each other, or simple, a single event. Those with autoimmune disorders face the typical stressors of everyday life, in addition to the stressors that come along with their disorder.

Mental processing

Following a stressor, an individual's mind will react, almost automatically, to the situation (Ciminero, 2012). This process can either work as a "magnifier" or a "filter." If the process works as a "magnifier," the stressor will seem more demanding and more serious which appears to make the stress more severe. If the process works as a "filter" the stressor is kept in perspective and the individual is less likely to overreact to the situation. Due to the extra stress that individuals with autoimmune disorders experience, they many learn to process stress more effectively.

Stress reaction

Stress reactions consist of the various responses that individuals have when they are faced with a stressor (Ciminero, 2012). The four primary types of stress reactions include: (1) physiological, (2) emotional, (3) cognitive, and (4) behavioral.

The physiological reaction consists of the basic concept of fight-or-flight response (Ciminero, 2012). During this process the heart rate speeds up, muscles tense, blood pressure increases, perspiration occurs, acid in the stomach and digestive system increases, and the blood vessels in the hands and feet constrict. Some people will even experience a change in their breathing pattern.

Allostatic load is a term coined by McEwen (2000) to describe the impact of stress on an individual's health. Allostatic load is defined as the cumulative physiological strain of repeated adaptation to stressful situations. McEwen later proposed that sleep deprivation should be considered as a major contributor to allostatic load (McEwen, 2006).

Due to these physiological reactions, the body can experience physical damage (Ciminero, 2012). Gastrointestinal examples include: colitis, ulcers, diarrhea, and constipation. Examples of cardiovascular complications include: heart attacks, migraine headaches, and high blood pressure. Other additional complications include: lower back pain, TMJ, tension headaches, and fatigue. The research states that the physiological effects of acute stress may differ greatly from those of chronic stress (Bosch, de Geus, Ring, & Amerongen, 2004). Chronic stress tends to have more of an effect on the immune system's functioning (Ellard, Barlow, & Mian, 2005).

The emotional reaction is controlled by an individual's perception of the situation or how that individual interprets the stressor (Ciminero, 2012). Common emotional responses include: anxiety, depression, fear, and anger. Anxiety is typically the primary and most physically damaging emotional response to a stressor.

Cognitive reactions include any and all intellectual and mental processes such as attitudes, decision-making, thoughts, memory, and attention (Ciminero, 2012). Behavioral reactions consist of the external expression of an individual's response to a stressor (Ciminero, 2012). Examples of a behavioral reaction include: pacing, feet tapping, nail biting, teeth grinding, and fist clenching.

If those with autoimmune disorders more effectively process stressors mentally, they may experience lower levels of physiological, emotional, and cognitive reactions. They may also be better able to control their reactions and perceive their multiple stressors as less stressful.

Coping response

A coping response can be anything that you do to help manage the stress that you are experiencing (Ciminero, 2012). Coping responses can be either effective (problem-focused or emotion-focused) or less effective. The purpose of this study is to better understand the coping responses of individuals with autoimmune disorders. These responses will be discussed in detail in the Coping Behaviors section.

Quality of Life

To further explore the effects of the stressors discussed in the basic stress model; quality of life, perceived stressors, and stressors specific to autoimmune disorders will be discussed. Interest in quality of life grew in the second half of the 20th century (Devins, 2010). In turn, people also became interested in how this was affected by chronic disorders. Illness intrusiveness is a concept concerning illness and treatment-induced interruption to a patient's lifestyle, interests, and valued activities (Schattner et al., 2012). Increased severity of symptoms and the treatment process have been associated with

increased illness intrusiveness (Devins, 2010). Illness intrusiveness has also been found to be more distressing to young individuals as opposed to older individuals; this is because the life stages present different challenges.

The Psychomedical Vortex

Stressful life events have been found to be associated with declining psychological and physical health (Orucu & Demir, 2009). The Psychomedical vortex explains this by showing that psychological issues can lead to a decrease in physical health; however a decrease in physical health can also lead to a decrease in psychological wellbeing if the right risk factors are in place (Bruns & Disorbio, 2005). Psychological vulnerability risk factors include: history of depression or anxiety, inability to identify feelings, pain magnification, history of substance abuse, and failure to cope with symptoms. Whereas psychosocial and environmental risk factors include: lack of support, dissatisfaction with medical care leading to noncompliance, lack of outlets for frustrations, and lack of multidisciplinary treatment.

The Psychomedical vortex begins at the onset of illness or injury (Bruns & Disorbio, 2005). Common reactions to this onset include: difficulty adjusting to symptoms, loss of function or disfigurement, and possible outcomes of the illness; major depression; anger; financial and work issues; lifestyle changes; and changes in family dynamics. If the individual experiences any of the earlier mentioned psychological vulnerability risk factors, they may also experience psychological complications. Psychological complications include: magnification of physical symptoms, conversion of emotions into the experience of physical symptoms, and psychophysiological changes. If the individual experiences any of the psychosocial risk factors, they may also experience

a failure to cope with their current symptoms. This may lead to an exaggeration of symptoms in an attempt to gain support, depression, anger, exhaustion and resignation, and identity fragmentation.

Many factors can prevent a patient from escaping this vortex (Bruns & Disorbio, 2005). Examples include unrealistic patient expectations; feelings of depression, fear, or anger vented toward the physician; and a social environment that does not support attempts at adjustment or the lack of a multidisciplinary treatment plan. However, if a patient can use his or her frustration with their current situation and their desire to be healthy, they can persevere in treatment and likely escape the vortex.

Individuals are likely to cycle through this vortex many times during the course of their illness. This is mainly due to the longevity of autoimmune disorders and their cycling yet unpredictable patterns. It is possible that this cycling could cause a psychologically sound person to become even stronger and better prepared for the next cycle of their disorder, or for the individual already experiencing psychological issues the cycling could break them down even further.

Perceived Stress

Perceived stress is an individual's estimated interpretation of the amount of stress that their experiencing at any given time and their ability to cope (Federenko, Schlotz, Kirschbaum, Bartels, Hellhammer, & Wust, 2006). A high illusion of control is an individual's belief that they have control over a situation that is uncontrollable (Bogdan, Pringle, Goetz, & Pizzagalli, 2012). This is typically associated with motivation, happiness, effective task performance, and adaptive coping behaviors (Thompson, Kyle, & Osgood, 2004). Low illusion of control, or the lack of believed control over a situation,

has been linked to elevated depressive symptoms and Major Depressive Disorder. Low illusion of control may also lead to an increased stress perception (Pizzagalli, Bogdan, Ratner, & Jahn, 2007).

Rudolph and Flynn (2007) found that women are typically more reactive to stress than men are. The difference in this situation seems to be related to the level of control perceived (Shih, Eberhart, Hammen, & Brennan, 2006). Women are also more likely to engage in stress generation, this means that they contribute to the stressors that are already causing them issues.

Physical stresses of an autoimmune disorder

Individuals living with an autoimmune disorder typically experience many stressors due to their disorder. Disruptions to activities, lifestyles, and interest due to a chronic illness or treatment of that illness are known as Illness intrusiveness (Devins, 2010).

Individuals living with autoimmune disorders tend to suffer from pain, aversive symptoms, disability, physical discomfort, and dysfunction (Devins, 2010). As mentioned in the diagnostic criteria sections of each disorder, individuals also experience many comorbidities, such as depression or anxiety, due to their disorders. Increased stress, possibly due to physical ailments, has been found to be directly related to weakened immune responses (Evans, Leserman, Perkins & Stern, 1995).

Mental stresses of an autoimmune disorder

Illness intrusiveness leads to psychological stress due to reducing gratifying outcomes from valued activities and by limiting an individual's personal control over the

ability to obtain positive outcomes or to avoid negative ones (Devins, 2010). Mental processing plays a major role in terms of "magnifying" or "filtering" a mental stressor.

One of the most common and serious consequences of chronic illness is depression, occurring between 9.3 and 23 percent (Schattner et al., 2012). There is a 35-85 percent comorbidity of systemic lupus erythematosus and depression; this is largely due to increased illness activity. Also, 20-25 percent of patients with rheumatoid arthritis will suffer from either anxiety or depressive disorders (Dickens, Jackson, Tomenson, Hay, & Creed, 2003).

It has been found that about 30 percent of patients diagnosed with fibromyalgia have also been diagnosed with depression (Peterson, 2007). These patients are also eight times more likely to experience personality changes, four times more likely to experience anxiety, and three times more likely to experience eating disorders.

Financial stresses of an autoimmune disorder

Individuals facing an autoimmune disorder typically experience economic hardships, unemployment or disability, financial strain, complex medical routines, and dependencies on medical technology and personnel (Devins, 2010). Health related economic evaluations divide costs into direct and indirect categories (Lundkvist et al., 2008). Direct costs include the cost of detection, prevention, and treatment. Indirect costs include the cost of lost productivity or wages.

Long-term follow-up care of patients with fibromyalgia in academic medical centers reportedly averaged one hospitalization every three years and ten outpatient visits per year for problems related to their diagnosis (Peterson, 2007). Whereas patients with rheumatoid arthritis have the highest cost in the year of diagnosis, that cost decreases in

the following three to five years (Lundkvist et al., 2008). Because new research is being done, new biological treatments are being introduced for rheumatoid arthritis, fibromyalgia, and systemic lupus erythematosus; this is drastically increasing the cost of medications and treatments for patients.

A major indirect cost that individuals with autoimmune disorders face is early retirement (Lundkvist et al., 2008). Up to 50 percent of patients suffering from rheumatoid arthritis will be forced to enter early retirement within ten years of being diagnosed.

Coping Behaviors

Zeitlin (1980) describes coping as "an active, adaptive process of using strategies to manage one's world" (p. 139). She then goes on to divide coping behaviors into Adaptive and Maladaptive. This section will cover both stress reactions and coping responses of the basic stress model. Adaptive coping behavior is "behavior that is appropriate to the environment or situation and/or that enhances efforts to care for oneself" (Zeitlin, 1980, p. 139). Maladaptive coping behaviors interfere with new learning, generate excessive stress, and increase vulnerability.

Carver, Scheier, and Weintraub (1989) divide coping strategies into: Problem-focused coping, Emotion-focused coping, and Coping behaviors that are less effective. Problem-focused coping includes five areas: active coping, planning, suppression of competing activities, restraint coping, and seeking of instrumental social support (Carver et al., 1989). Active coping is the process of taking active steps to attempt to remove the stressor or improve its effects. The process of thinking about how to best handle a stressor is identified as planning. Suppression of competing activities is a method of

attempting to avoid becoming distracted by other events and putting aside other projects. A method of waiting for an appropriate opportunity to act is known as restraint coping. Whereas, seeking of instrumental social support is a process of seeking out advice, information, or assistance.

Emotion-focused coping includes five areas: positive reinterpretation, acceptance, denial, seeking of emotional social support, and turning to religion (Carver et al., 1989). Positive reinterpretation is aimed at managing emotions of distress. The ability to see the reality of a stressful situation is identified as acceptance. Denial is the refusal to believe that a stressor is real or that it exists. A process of seeking moral support, understanding, and sympathy is known as seeking social support for emotional reasons. Whereas, turning to religion is the tendency to turn to a personal religion in times of stress.

Less effective coping behaviors consist of three subscales: focus on and venting of emotions, behavioral disengagement, and mental disengagement (Carver et al., 1989). Focus on and venting of emotions is the tendency to vent about and focus on the feelings that is causing distress. Reducing one's effort to deal with a stressor is identified as behavioral disengagement. Whereas, mental disengagement is a way of distracting one's self from thinking about the stressor.

It has been shown that reductions in psychological stress or improved coping behaviors can lead to improved health, including a slowing in disease progression (Antoni, Carrico, Duran, Spitzer, Penedo, & Ironson, 2006). Folkman (1997) also found that individuals using coping strategies that focus on positively reappraising a situation or pursuing a personally meaningful goal were likely to experience positive psychological states.

Osipow and Spokane (1987) found that the adequacy of an individual's coping strategies and personal resources directly affect the strain experience from a perceived stressor. This is why many people can experience the same exact stressor; yet react in many different ways.

Purpose

The purpose of the current study is to understand the link between autoimmune disorders and effective coping behaviors. The study will add to the current gap of literature and research on coping behaviors among those with autoimmune disorders. Therefore, the research question of this study is as follows: to what extent, if any, does experiencing the diagnosis of an autoimmune disorder affect coping behavior?

Hypothesis 1

Lazarus and Folkman (1984) state that stress consists of three processes: primary appraisal, secondary appraisal, and coping. Primary appraisal is the process of perceiving a threat. Secondary appraisal is the process of thinking of a potential response to the threat. And coping is the process of acting on the response. Because individuals with autoimmune disorders have experienced this process on a large scale, it is believed that they will execute the process more effectively than individuals from the "healthy" sample. Therefore it was hypothesized that *individuals diagnosed with systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, or any chronic medical condition would use more effective coping behaviors (problem-focused and emotion-focused coping) than "healthy" individuals in everyday life.* Schulz and Mohamed (2004) also found that individuals with a wide range of medical conditions reported gains and benefits from the adversity that they experienced.

Hypothesis 2

Significant differences have not been found regarding negative coping behaviors among any tested samples. Therefore it was hypothesized that *there would not be a significant difference among individuals diagnosed with systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical diagnosis, and "healthy" individuals regarding less effective coping behaviors used in everyday life.*

Hypothesis 3

Orucu and Demir (2009) found that individuals label themselves as stressed when their environmental demands are perceived to outweigh their abilities to cope. Alloy and Clements (1992) found that an individual who perceived his or her actions would influence the outcome were more likely to cope effectively in the situation. Therefore it was hypothesized that *elevated levels of perceived stress would relate negatively to the use of effective coping behaviors (problem-focused and emotion-focused coping) in the systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy" samples; and positively to the use of less effective coping.*

Hypothesis 4

It has been shown that an individual who perceived his or her actions would influence the outcome were more likely to cope effectively in the situation (Alloy & Clements, 1992). *Because of increased coping skills among those living with autoimmune disorders, it was hypothesized that perceived stress would not be significantly different among the systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy" samples.*

Hypothesis 5

According to Devins (2010) illness intrusiveness consists of disruptions to activities, lifestyles, and interest due to a chronic illness or treatment of that illness. It was hypothesized that *an elevated level of illness intrusiveness would negatively relate to effective coping behaviors (problem-focused and emotion-focused coping) and positively relates to the use of less effective coping behaviors in the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples.*

Hypothesis 6

Orucu and Demir (2009) found that individuals label themselves as stressed when their environmental demands are perceived to outweigh their abilities to cope. Illness intrusiveness consists of disruptions to activities, lifestyles, and interest due to a chronic illness or treatment of that illness (Devins, 2010). Therefore, it was hypothesized that *an elevated level of illness intrusiveness would positively relate to perceived stress.*

Hypothesis 7

Hsu, Schubiner, Lumley, Stracks, Clauw, and Williams (2010) found that individuals diagnosed with fibromyalgia became more self-aware as they learned to live with their illness. Therefore it was hypothesized that *time elapsed since diagnosis would positively relate to use of effective coping behaviors (problem-focused and emotion-focused coping) in individuals diagnosed with systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis; and negatively relate to the use of less effective coping behaviors.*

METHOD

Participants

Participants for this study initially consisted of 284 adults, ages 18 to 65, who participate in online discussion boards. The sample included 272 women and 12 men with a mean age of 42 (*SD*=12.22). In addition, 255 were Caucasian, 11 African American, 13 Hispanic/Latino, 3 Asian, and 1 American Indian or Alaska Native. Furthermore, 56 were single, 186 were married, 30 were divorced, 7 were separated, and 5 were widowed.

Participants were divided into five separate samples based on self-report diagnosis including: systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy". The "healthy" sample will consist of individuals who are lacking a chronic medical diagnosis. All discussion boards were accessed through facebook.com.

Discussion boards for participants diagnosed with rheumatoid arthritis included (a) Rheumatology News, (b) Rheumatoid Arthritis Information, (c) Rheumatoid Arthritis Warrior, and (d)Rheumatoid Arthritis Awareness. Discussion boards for participants diagnosed with fibromyalgia included (a) Fibro 360 Community – Fibromyalgia and Fatigue Centers, (b) Fibro Colors, (c) Fibromyalgia Network, and (d) Fibromyalgia Awareness. Discussion boards for participants diagnosed with systemic lupus erythematosus included (a) Lupus: SLE, Discoid, Drug-Induced, and Neonatal, (b) The Purple Rose Lupus Foundation, (c) The Hibbs Lupus Trust, and (d) Lupus Foundation of America, Inc. Discussion boards for participants considered "healthy" included (a) Craft, Home and Garden Ideas, (b) Crock Pot Moms, (c) Coupon Divas, and (d) Friends on a

Budget. Due to the fact that Facebook has a "share" function, there is a possibility that the link to the survey may be accessible outside of these 16 discussion boards.

Because those with autoimmune disorders are primarily female, it was expected that the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples collected would be predominately female. Due to this majority, the 12 males were eliminated from the study. Eight individuals above the age of 65 were also eliminated due to the constraints of IRB approval.

The resulting sample included 264 women and 0 men with a mean age of 41 (*SD*=11.28). In addition, 235 were Caucasian, 11 African American, 13 Hispanic/Latino, 3 Asian, and 1 American Indian or Alaska Native. Furthermore, 53 were single, 170 were married, 30 were divorced, 7 were separated, and 4 were widowed. Demographics for each diagnostic category are included in Table 5.

Measures

COPE inventory. The COPE Inventory consisted of five subscales measuring problem-focused coping, five subscales measuring emotion-focused coping, and three subscales measuring coping behaviors that are less effective (Carver et al., 1989) (see Appendix A). Refer to the Coping Behaviors section of the literature review for definitions.

Problem-focused subscales included: active coping, planning, suppression of competing activities, restraint coping, and seeking of instrumental social support. Active coping includes items: 5, 25, 47, and 58. Example of active coping included: (a) I concentrated my efforts on doing something about it, and (b) I take direct action to get around the problem. Planning included items: 19, 32, 39, and 56. Examples of planning

Table 5

Demographics by Diagnosis for Study Sample

Diagnosis	Lupus	Fibro	RA	Chronic	Healthy
Ethnicity					
Caucasian	39	18	65	47	66
African American	5	1	1	2	2
Hispanic or Latino	4	0	4	4	1
Asian	1	0	2	0	0
American Indian or Alaska Native	0	0	0	1	0
Marital Status					
Single	18	4	13	4	14
Married	28	11	46	44	41
Divorced	2	3	9	5	11
Separated	0	1	3	1	2
Widowed	1	0	1	1	1
Mean Age	34.63	44.74	45.17	42.04	40.91

included: (a) I think hard about what steps to take, and (b) I make a plan of action. Suppression of competing activities included items: 15, 33, 42, and 55. Examples of suppression of competing activities included: (a) I keep myself from getting distracted by other thoughts or activities, and (b) I focus on dealing with this problem, and if necessary

let other things slide a little. Restraint coping included items: 10, 22, 41, and 49. Examples of restraint included: (a) I make sure not to make matters worse by acting too soon, and (b) I force myself to wait for the right time to do something. Seeking of instrumental social support included items: 4, 14, 30, and 45. Examples of seeking of instrumental social support included: (a) I talk to someone who could do something concrete about the problem, and (b) I try to get advice from someone about what to do.

Emotion-focused subscales included: seeking of emotional social support, positive reinterpretation and growth, acceptance, denial, and turning to religion. Seeking of emotional social support included items: 11, 23, 34, and 52. Examples of seeking of emotional support included: (a) I discuss my feelings with someone, and (b) I get sympathy and understanding from someone. Positive reinterpretation and growth included items: 1, 29, 38, and 59. Examples of positive reinterpretation and growth included: (a) I try to grow as a person as a result of the experience, and (b) I learn something from the experience. Acceptance included items: 13, 21, 44, and 54. Examples of acceptance included: (a) I accept that this has happened and that it can't be changed, and (b) I get used to the idea that it happened. Denial included items: 6, 27, 40, and 57. Examples of denial included: (a) I pretend that it hasn't really happened, and (b) I act as thought it hasn't even happened. Turning to religious included items: 7, 18, 48, and 60. Examples of turning to religion included: (a) I seek God's help, and (b) I put my trust in God.

The less effective subscales included: focusing on and venting of emotions, behavioral disengagement, mental disengagement. Focusing on and venting of emotions included items: 3, 17, 28, and 46. Examples of focusing on and venting of emotions

included: (a) I let my feelings out, and (b) I feel a lot of emotional distress and I find myself expressing those feelings a lot. Behavioral disengagement included items: 9, 24, 37, and 51. Examples of behavioral disengagement included: (a) I just give up trying to reach my goal, and (b) I give up the attempt to get what I want. Mental disengagement included items: 2, 16, 31, and 43. Examples of mental disengagement included: (a) I turn to work or other substitute activities to take my mind off things, and (b) I sleep more than usual.

Additional subscales included substance use and humor. Substance use included items: 12, 26, 35, and 53. Examples of substance use included: (a) I use alcohol or drugs to make myself feel better, and (b) I try to lose myself for a while by drinking alcohol or taking drugs. Humor included items: 8, 20, 36, and 50. Examples of humor included: (a) I make jokes about it, and (b) I make fun of the situation.

To score the COPE Inventory items for each scale needed to be added (Carver et al, 1989). Subscale scores range from four to sixteen; higher scores on a scale indicate that this method of coping is used more. The Problem-focused, Emotion-focused, and Less effective scales are figured by adding the appropriate subscales. Problem-focused and Emotion-focused Scale scores range from twenty to eighty. The less effective scale scores range from twelve to forty-eight. The COPE Inventory has an internal consistency reliability of 0.45 to 0.92 and a test-retest reliability of 0.42 to 0.89 (Carver et al., 1989). It also shows evidence of broad convergent and divergent validity.

Perceived Stress Scale (PSS). The Perceived Stress Scale is a measure of perceived stress in one's life instead of a measure of specific life events (Cohen, Kamarck, & Mermelstein, 1983) (see Appendix B). This method has been shown to

provide more accurate predictions of psychological and physical symptoms than measures of specific life events (Cohen, Kessler, & Gordon, 1995).

The original scale was a 14-item measure based on Lazarus's concept of appraisal (Lazarus & Folkman, 1984). Since then, the measure has been revised and there are now three different versions: PSS-14, PSS-10, and PSS-4. Because of its psychometric superiority, the 10-item version is recommended (Cohen & Williamson, 1988). A factor analysis of this version revealed a two factor structure measuring perceived distress and perceived coping abilities (Hewitt, Flett, & Mosher, 1992).

Participants used a five-point Likert scale, ranging from zero (never) to four (very often) to describe how often they have experienced these feeling in the last week (Orucu & Demir, 2009). Possible scores range from 0 to 40 and are calculated by adding up the ratings for the 10-items, after reverse scoring items: 4, 5, 7, and 8 (Benham, 2010). Higher scores on the PSS indicate higher perceived stress.

The PSS-10 has strong psychometric properties. The Coefficient alpha reliability ranges between .84 and .86 (Cohen et al., 1995). This measure also correlates well with physical (between .52 and .70) and depressive (between .65 and .76) symptomology measures.

Demographics. The demographics section consisted of six self-report items (see Appendix C). Participants were asked about their gender, age, diagnosis or lack thereof, and any traumatic life events. Traumatic events included, but were not limited to: (a) car accident, (b) death of a loved one, or (c) near-death experience.

The Illness Intrusiveness Rating Scale (IIRS). The Illness Intrusiveness Rating Scale consisted of 13 self-report items that measure the extent to which chronic illness

and/or its treatment interferes with activities, routines, and interests (Schattner et al., 2012) (see Appendix D). Illness intrusiveness was measured in the following domains of everyday life: (a) health, (b) diet, (c) work, (d) active recreation, (e) passive recreation, (f) financial situation, (g) relationship with partner, (h) sex life, (i) family relations, (j) other social relations, (k) self-improvement/ self-expression, (l) religious expression, and (m) community and civic involvement (Devins, 2010).

Participants used a seven-point scale, ranging from one (not very much) to seven (very much), to rate how their illness affects each section of their life (Devins, 2010). If a participant believed that an item is not applicable they simply mark that box and a score of one is used. The IIRS total score was created by adding the ratings provided, this score can range from 13 to 91. Higher scores indicate elevated illness intrusiveness.

The IIRS has an internal consistency reliability of .89 among patients with fibromyalgia, .87 among patients with rheumatoid arthritis, and .94 among patients with systemic lupus erythematosus (Devins, 2010). It also has a nine-month test-retest reliability of .85, and an eighteen-month test-retest reliability of .80.

Procedure

A link was posted on several online discussion boards and support groups (see Participants section). Participants then followed the link from their particular discussion board to the questionnaire. After electronically signing the consent form, participants were directed to a self-report questionnaire consisting of the following scales in the following order: The COPE Inventory, The Perceived Stress Scale, a demographics section, and The Illness Intrusiveness Rating Scale (IIRS). Participants only completed The Illness Intrusiveness Rating Scale if they reported living with an autoimmune

disorder (lupus, fibromyalgia, and rheumatoid arthritis) in the demographics section. Following completion of the questionnaire, participants were directed to a debriefing statement about the nature of the study.

RESULTS

Hypothesis 1. It was hypothesized that *individuals diagnosed with systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, or any chronic medical condition use more effective coping behaviors (problem-focused and emotion-focused coping) than "healthy" individuals in everyday life.* This hypothesis was not supported.

A one-way between sample ANOVA was done to compare the mean scores on a problem-focused coping scale for participants in each of the five diagnostic categories (systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy"). Prior to the analysis, the Levene test for homogeneity of variance was used to examine whether there were serious violations of the assumption of homogeneity of variance across the groups, but no significant violation was found, $F(4, 259) = .74$, $p > .05$.

The overall F for the one-way ANOVA was not statistically significant, $F(4, 259) = 1.56$, $p > .05$. The means and standard deviations for the five diagnostic categories are shown in Table 6.

A one-way between sample ANOVA was done to compare the mean scores on an emotion-focused coping scale for participants in each of the five diagnostic categories (systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy"). Prior to the analysis, the Levene test for homogeneity of variance was used to examine whether there were serious violations of the assumption of

Table 6

Hypothesis 1 – Problem-Focused Coping by Diagnosis

Diagnostic Category	*n*	M	SD
Lupus	49	53.06	8.40
Fibromyalgia	19	48.26	9.91
Rheumatoid Arthritis	72	53.82	8.55
Any Chronic Condition	55	52.36	7.93
"Healthy"	69	53.20	9.89

homogeneity of variance across the groups, but no significant violation was found, $F(4, 259) = .35$, $p < .05$.

The overall F for the one-way ANOVA was statistically significant, $F(4, 259) = 2.42$, $p < .05$. The means and standard deviations for the five diagnostic categories are shown in Table 7. In addition, a post-hoc was run using the Scheffe test. Based on this test (using $\alpha = .05$), it was found that there was no significant difference between the diagnostic categories on the emotion-focused coping scale.

Hypothesis 2. It was hypothesized that *there would not be a significant difference among individuals diagnosed with systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical diagnosis, or "healthy" individuals regarding less effective coping behaviors used in everyday life.* This hypothesis was partially supported.

Table 7

Hypothesis 1 – Emotion-Focused Coping by Diagnosis

Diagnostic Category	*n*	M	SD
Lupus	49	50.10	8.61
Fibromyalgia	19	44.84	8.66
Rheumatoid Arthritis	72	49.35	7.11
Any Chronic Condition	55	49.07	8.98
"Healthy"	69	51.39	8.97

A one-way between sample ANOVA was done to compare the mean scores on a less-effective coping scale for participants in each of the five diagnostic categories (systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy"). Prior to the analysis, the Levene test for homogeneity of variance was used to examine whether there were serious violations of the assumption of homogeneity of variance across the groups, but no significant violation was found, $F(4, 259) = .74$, $p > .05$.

The overall F for the one-way ANOVA was statistically significant, $F(4, 259) = 4.28$, $p < .01$. The means and standard deviations for the five diagnostic categories are shown in Table 8. In addition, a post-hoc was run using the Scheffe test. Based on this test (using $\alpha = .05$), it was found that the systemic lupus erythematosus group scored significantly higher than the any chronic medical condition group and the

Table 8

Hypothesis 2 – Less Effective Coping by Diagnosis

Diagnostic Category	*n*	M	SD
Lupus	49	29.67	4.88
Fibromyalgia	19	27.05	5.92
Rheumatoid Arthritis	72	27.31	5.18
Any Chronic Condition	55	25.96	4.48
"Healthy"	69	26.43	4.97

"healthy" group. There were no other significant differences between the diagnostic categories on the less effective coping scale.

Hypothesis 3. It was hypothesized that *elevated levels of perceived stress would relate negatively to the use of effective coping behaviors in the systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy" samples; and positively to the use of less effective coping behaviors.* This hypothesis was partially supported.

Pearson correlations were performed to assess whether levels of problem-focused coping, emotion-focused coping, and less effective coping could be predicted from level of perceived stress among the five diagnostic categories. The Pearson correlations are reported in Table 9.

Table 9

Hypothesis 3 – Perceived Stress Correlations with Coping by Diagnosis

Diagnostic Category	Problem-Focused	Emotion-Focused	Less Effective
Lupus (*n* = 49)	-.33*	-.28*	.57**
Fibromyalgia (*n* = 19)	-.08	.02	.52*
Rheumatoid Arthritis (*n* = 72)	-.42**	-.16	.67**
Any Chronic Medical Condition (*n* = 55)	.03	-.11	.29*
"Healthy" (*n* = 69)	-.27*	-.19	.48**

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

For the systemic lupus erythematosus sample, all three correlations were statistically significant. The correlation between problem-focused coping and perceived stress was statistically significant, $r(47) = -.33$, $p < .01$ (two-tailed). This shows that as perceived stress increases, problem-focused coping decreases. The correlation between emotion-focused coping and perceived stress was statistically significant, $r(47) = -.28$, $p < .05$ (two-tailed), meaning that as perceived stress increases, emotion-focused coping decreases. The correlation between less effective coping and perceived stress was statistically significant, $r(47) = .57$, $p < .01$ (two-tailed). This shows that as perceived stress increases, less effective coping also increases.

For the fibromyalgia sample, only one correlation was statistically significant. The correlation between less effective coping and perceived stress was statistically

significant, $r(17) = .52$, $p < .05$ (two-tailed). This means that as perceived stress increases, less effective coping also increases.

For the rheumatoid arthritis sample, two correlations were statistically significant. The correlation between problem-focused coping and perceived stress was statistically significant, $r(70) = -.41$, $p < .01$ (two-tailed). Showing that as perceived stress increases, problem-focused coping decreases. The correlation between less effective coping and perceived stress was statistically significant, $r(70) = .67$, $p < .01$ (two-tailed). This means that as perceived stress increases, less effective coping also increases.

For the any chronic medical condition sample, only one correlation was statistically significant. The correlation between less effective coping and perceived stress was statistically significant, $r(53) = .29$, $p < .05$ (two-tailed). This shows that as perceived stress increases, less effective stress also increases.

For the "healthy" sample, two correlations were statistically significant. The correlation between problem-focused coping and perceived stress was statistically significant, $r(67) = -.27$, $p < .05$ (two-tailed). Showing that as perceived stress increases, problem-focused coping decreases. The correlation between less effective coping and perceived stress was statistically significant, $r(67) = .48$, $p < .01$ (two-tailed). This means that as perceived stress increases, less effective coping also increases.

Hypothesis 4. It was hypothesized that *perceived stress would not be significantly different among the systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, or "healthy" samples.* This hypothesis was partially supported.

A one-way between sample ANOVA was done to compare the mean scores on a perceived stress scale for participants in each of the five diagnostic categories (systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy"). Prior to the analysis, the Levene test for homogeneity of variance was used to examine whether there were serious violations of the assumption of homogeneity of variance across the groups, but no significant violation was found: $F(4, 259) = .83$, $p > .05$.

The overall F for the one-way ANOVA was statistically significant, $F(4, 259) = 3.86$, $p < .01$. The means and standard deviations for the five diagnostic categories are shown in Table 10. In addition, all possible comparisons were made using the Scheffe test. Based on this test (using $\alpha = .05$), it was found that the systemic lupus erythematosus group scored significantly higher than the "healthy" group on perceived stress. There were no other significant differences among the diagnostic categories on the perceived stress scale.

Hypothesis 5. It was hypothesized that *an elevated level of illness intrusiveness would negatively relate to effective coping behaviors (problem-focused and emotion-focused coping) and positively relate to the use of less effective coping behaviors in the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples.* This hypothesis was partially supported.

Table 10

Hypothesis 4 – Perceived Stress

Diagnostic Category	*n*	M	SD
Lupus	49	24.61	7.63
Fibromyalgia	19	24.58	7.09
Rheumatoid Arthritis	72	22.14	8.07
Any Chronic Condition	55	20.24	7.22
"Healthy"	69	19.99	7.69

Pearson correlations were performed to assess whether levels of problem-focused coping, emotion-focused coping, and less effective coping could be predicted from level of illness intrusiveness among the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples. The Pearson correlations are reported in Table 11.

Table 11

Hypothesis 5 – Illness Intrusiveness Correlations with Coping by Diagnosis

Diagnostic Category	Problem-Focused	Emotion-Focused	Less Effective
Lupus (n = 48)	.03	.11	.42**
Fibromyalgia (n = 18)	-.50*	-.24	-.06
Rheumatoid Arthritis (n = 70)	-.23	-.12	.51**

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

For the systemic lupus erythematosus sample, only one correlation was statistically significant. The correlation between less effective coping and illness intrusiveness was statistically significant, $r(46) = .42$, $p < .01$ (two-tailed). This means that as illness intrusiveness increases, less effective coping also increases.

For the fibromyalgia sample, only one correlation was statistically significant. The correlation between problem-focused coping and illness intrusiveness was statistically significant, $r(16) = -.50$, $p < .05$ (two-tailed). This shows that as illness intrusiveness increases, problem-focused coping decreases.

For the rheumatoid arthritis sample, only one correlation was statistically significant. The correlation between less effective coping and illness intrusiveness was statistically significant, $r(68) = .51$, $p < .01$ (two-tailed). This means that as illness intrusiveness increases, less effective coping also increases.

Hypothesis 6. It was hypothesized that *an elevated level of illness intrusiveness would positively relate to perceived stress.* This hypothesis was supported.

Pearson correlations were performed to assess whether levels of perceived stress could be predicted from level of illness intrusiveness among the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples. The Pearson correlations are reported in Table 12.

For the systemic lupus erythematosus sample, the correlation between perceived stress and illness intrusiveness was statistically significant, $r(46) = .39$, $p < .01$ (two-tailed). This shows that as illness intrusiveness increases, perceived stress also increases.

Table 12

Hypothesis 6 – Illness Intrusiveness/ Perceived Stress Correlations by Diagnosis

Diagnostic Category	Perceived Stress
Lupus (n = 48)	.39**
Fibromyalgia (n = 18)	.52*
Rheumatoid Arthritis (n = 70)	.57**

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

For the rheumatoid arthritis sample, the correlation between perceived stress and illness intrusiveness was statistically significant, $r(68) = .57$, $p < .01$ (two-tailed). This shows that as illness intrusiveness increases, perceived stress also increases.

Hypothesis 7. It was hypothesized that *time elapsed since diagnosis would positively relate to use of effective coping behaviors (problem-focused and emotion-focused coping) in individuals diagnosed with systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis; and negatively relate to less effective coping.* This hypothesis was not supported.

Pearson correlations were performed to assess whether levels of problem-focused coping, emotion-focused coping, and less effective coping could be predicted by time elapsed since diagnosis among the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples. The Pearson correlations are reported in Table 13.

Table 13

Hypothesis 7 – Years Since Diagnosis Correlations with Coping by Diagnosis

Diagnostic Category	Problem-Focused	Emotion-Focused	Less Effective
Lupus (n = 49)	-.15	-.09	.31*
Fibromyalgia (n = 19)	-.16	.15	.39
Rheumatoid Arthritis (n = 72)	.11	-.12	.18

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

For the systemic lupus erythematosus sample, only one correlation was statistically significant. The correlation between less effective coping and years since diagnosis was statistically significant, $r(47) = .31$, $p < .05$ (two-tailed). This means that as the number of years since diagnosis increased, less effective coping also increased. For the fibromyalgia and rheumatoid arthritis samples, no correlations were statistically significant.

DISCUSSION

Hypothesis 1

Previous research has shown that stress consists of three processes: primary appraisal, secondary appraisal, and coping (Lazarus & Folkman, 1984). Primary appraisal is the process of perceiving a threat. Secondary appraisal is the process of thinking of a potential response to the threat, and coping is the process of acting on the response. Because individuals with autoimmune disorders have experienced this process on a large scale, it is reasonable to believe that they will execute the process more effectively than individuals from the "healthy" sample. It has also been found that individuals with a wide range of medical conditions reported gains and benefits from the adversity that they experienced (Schulz & Mohamed, 2004). It was expected in the current study that individuals diagnosed with systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, or any chronic medical condition would use more effective coping behaviors (problem-focused and emotion-focused coping) than "healthy" individuals in everyday life.

Not as hypothesized, it was found that problem-focused coping behaviors were not significantly different by diagnosis. This may be because individuals in all diagnostic categories (including "healthy" individuals) reported being highly problem-focused in their coping behaviors. However, diagnosis and emotion-focused coping behaviors were found to be significantly related as a whole without any significant differences among the diagnostic samples. It was expected that the autoimmune samples would report an elevated level of both problem-focused and emotion-focused coping behaviors. Interestingly, though not significant, the "healthy" sample reported the highest mean on

the emotion-focused coping scale. This could be due to the autoimmune and chronic illness samples having to come to terms with the facts surrounding their illness and cope with those facts in a problem-focused manner as opposed to emotion-focused. Though scoring high on one scale of the COPE Inventory does not mean that you will score low on the other scales, it is typical that individuals will report using one type of coping behaviors over the others.

Hypothesis 2

Previous studies have not found significant differences regarding negative coping behaviors among any tested samples. Therefore it was expected that there would not be a significant difference among individuals diagnosed with systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical diagnosis, or "healthy" individuals regarding less effective coping behaviors used in everyday life.

However, it was found that the systemic lupus erythematosus sample used significantly more negative coping behaviors than the any chronic medical condition sample and the "healthy" sample. This could be due to the fact that the mean age for the systemic lupus erythematosus sample is lower than those of the other samples. Younger individuals, due to lack of maturity, are more likely to use less effective coping behaviors in addition to the problem-focused and emotion-focused behaviors (Devins, 2010). Younger individuals also experience higher levels of distress due to illness intrusiveness. In additions, systemic lupus erythematosus has a less predictable pattern in terms of illness progression and this could also have played a role in these results.

As hypothesized, there was no significant difference found among the individuals diagnosed with fibromyalgia, rheumatoid arthritis, any chronic medical diagnosis, and

"healthy" individuals regarding negative coping behaviors used in everyday life. This could possibly indicate that being diagnosed with an autoimmune disorder does not affect an individual's likelihood to use negative coping behaviors.

Hypothesis 3

Previous research has found that individuals label themselves as stressed when their environmental demands are perceived to outweigh their abilities to cope (Orucu & Demir, 2009). Additionally, studies have found that an individual who perceived his or her actions would influence the outcome was more likely to cope effectively in the situation (Alloy & Clements, 1992). The hypothesis in the current study was that elevated levels of perceived stress would relate negatively to the use of effective coping behaviors (problem-focused and emotion-focused coping) in the systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy" samples; and positively to less effective coping.

It was found that elevated levels of perceived stress significantly correlated with increased use of less effective coping behaviors in all of the five diagnostic categories. However, elevated levels of perceived stress only correlated negatively with problem-focused coping behaviors in the systemic lupus erythematosus, rheumatoid arthritis, and "healthy" samples. This could be due to the smaller sample sizes collected for the fibromyalgia and any chronic medical condition samples as compared to the rheumatoid arthritis, systemic lupus erythematosus, and "healthy" samples. In addition, elevated levels of perceived stress only correlated negatively with emotion-focused coping behaviors in the systemic lupus erythematosus sample. This could be because the systemic lupus erythematosus sample reported the highest levels of perceived stress with

a mean of 24.61. This sample also reported the highest mean on the emotion-focused coping scale aside from the "healthy" sample. In addition, the systemic lupus erythematosus sample had one of the smaller samples sizes; this may have played a role in elevating the mean scores. It is possible that an elevated level of perceived stress may cause certain individuals to focus in on their emotions whereas other individuals avoid them all together.

Hypothesis 4

It has been shown in previous research that an individual who perceived his or her actions would influence the outcome were more likely to cope effectively in the situation (Alloy & Clements, 1992). Because of increased coping skills among those living with autoimmune disorders, it was expected that perceived stress would not be significantly different among the systemic lupus erythematosus, fibromyalgia, rheumatoid arthritis, any chronic medical condition, and "healthy" samples. However, it was found that the systemic lupus erythematosus sample reported a significantly higher amount of perceived stress than "healthy" sample. This is likely due to the unpredictable illness progression of systemic lupus erythematosus. In addition, the younger age of those in the systemic lupus erythematosus sample may be playing a role due to lack of maturity and experience. As hypothesized, there were no significant differences among the rheumatoid arthritis, fibromyalgia, any chronic medical condition, and "healthy" samples regarding perceived stress.

Hypothesis 5

Previous research defines illness intrusiveness as disruptions to activities, lifestyles, and interest due to a chronic illness or treatment of that illness (Devins, 2010).

It was hypothesized that an elevated level of illness intrusiveness would negatively relate to effective coping behaviors (problem-focused and emotion-focused coping) and positively relate to less effective coping behaviors in the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples.

As hypothesized, it was found that elevated levels illness intrusiveness correlated with increased use of less effective coping behaviors in the systemic lupus erythematosus and rheumatoid arthritis sample. This may be due to the fibromyalgia sample's small sample size. Additionally, illness intrusiveness only correlated negatively with problem-focused coping behaviors in the fibromyalgia sample. This is likely due to the fact that the fibromyalgia sample reported a lower, though not significantly lower, mean than the other samples on the problem-focused coping scale. Furthermore, not as hypothesized, illness intrusiveness did not significantly correlate negatively with emotion-focused coping behaviors in any of the samples. It is reasonable to interpret from this information that illness intrusiveness is most likely to affect the use of less effective coping behaviors. The psychomedical vortex explains this by showing that psychological issues can lead to a decrease in physical health; however a decrease in physical health can also lead to a decrease in psychological wellbeing (Bruns & Disorbio, 2005).

Hypothesis 6

Previous studies have found that individuals label themselves as stressed when their environmental demands are perceived to outweigh their abilities to cope with said demands (Orucu & Demir, 2009). Illness intrusiveness consists of disruptions to activities, lifestyles, and interest due to a chronic illness or treatment of that illness (Devins, 2010).

Therefore, it was expected that an elevated level of illness intrusiveness would positively relate to an elevated level of perceived stress in the systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis samples. As hypothesized, the two variables were found to be significantly correlated among all three samples.

Hypothesis 7

Previous research has found that individuals diagnosed with fibromyalgia became more self-aware as they learned to live with their illness (Hsu et. al., 2010). Therefore it was expected in the current study that time elapsed since diagnosis would positively relate to use of effective coping behaviors (problem-focused and emotion-focused coping) in individuals diagnosed with systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis; and negatively relate to the use of less effective coping behavior.

However, it was found that years since diagnosis only correlated positively with less effective coping behaviors, not as hypothesized, in the systemic lupus erythematosus sample. This is likely due to the unpredictable path of illness progression in systemic lupus erythematosus. It could also be related to increased illness intrusiveness as the illness progresses. In addition, not as hypothesized, none of the correlations were found to be statistically significant for the fibromyalgia or rheumatoid arthritis samples. This is likely due to increased illness intrusiveness and increased ability to cope effectively canceling each other out. This means that even though individuals are learning to live with and cope effectively with their disorder as time goes on, their disorder is also becoming more intrusive as the illness progresses and causing the individual more stress, physical and emotional.

Limitations and Directions for Future Research

This study had several limitations. First, the participants used in this study were already participating in online support groups specific to their illness. These individuals are already taking an additional step towards coping with their diagnosis. This method of sampling also excludes a portion of the autoimmune population who is not using online discussion boards as a way of working through their diagnosis. This could ultimately eliminate individuals using diverse coping behaviors that do not include discussion boards.

Additionally, this study lacked a diverse population, 96% of participants were female and 90% of participants were Caucasian. Although individuals diagnosed with autoimmune disorders are primarily female, about 10 percent of individuals diagnosed with autoimmune disorders are men. By not including men in the current study, 10 percent of the entire autoimmune population is not accounted for. In addition, individuals who are African American, American Indian, and Latino are far more likely to be diagnosed with an autoimmune disorder than Caucasian individuals. This demonstrates that a large portion of individuals is not accounted for regarding ethnicity. Also, it is likely that cultural background can play a role in coping behaviors.

In terms of diagnostic category samples, the lupus sample had a much lower mean age of 34 whereas the whole sample had a mean age of 42. Lack of maturity and experience can play a role in use of coping behaviors. Also these individuals can be experiencing different life stages which in turn effect coping behaviors. In addition, the sample size of the fibromyalgia sample was much smaller than those of the other diagnostic categories. Within the autoimmune population, fibromyalgia is not diagnosed

less often than the other disorders examined in the current study. Therefore this is an inaccurate representation of the autoimmune population as a whole. Additionally, the small sample size has the potential to affect the statistical results. Furthermore, when participants described themselves as having a chronic medical diagnosis it would have been beneficial to have asked what diagnosis they were referring to.

Future directions include examining coping behaviors using a more diverse population with additional sampling options. The current study focused on systemic lupus erythematosus, fibromyalgia, and rheumatoid arthritis; to gain a better understanding of the autoimmune population as a whole it would be worthwhile to include additional autoimmune disorders.

In addition, it would be productive to examine the relationship between autoimmune disorders and post-traumatic growth. Post-traumatic growth occurs as a result of coping with or adapting to a major life crisis. This would be worthwhile because even though diagnosis may not affect type of coping behaviors used, it may affect growth experienced due to the process of diagnosis.

Implications

The possible implications from this study are considerable and will have importance in many different fields. It is known that medical disorders tend to have both physical and psychological effects on those individuals diagnosed with them. This study provides both medical doctors and clinicians with valuable information on coping behaviors, perceived stress, and illness intrusiveness. This information may help these professionals identify the underlying causes of impaired day-to-day functioning that their clients are experiencing. Though conclusive information was not found in the current

study, the measures used in this study can be very effective when used with individual clients. The use of the measures can give a clinician a wealth of information about their client and areas to focus on in treatment.

This study will be useful for a clinician with clients struggling with an autoimmune disorder. It could help both the clinician and the client to better understand how the disorder is affecting the individual in different areas of his or her life. The illness intrusiveness rating scale is a very effective measure in terms of determining the extent to which the illness is affecting the individual in everyday life.

In addition, this study will also be useful for a clinician working with a client who is struggling with the use of appropriate coping behaviors. This study could help both the clinician and the client to better understand why the client may be choosing to use less effective coping behaviors. The current study found that the use of less effective coping behaviors was significantly related to perceived stress in all diagnostic samples. Clinicians can use this information to further explore perceived stress in their clients and ultimately address the less effective coping behaviors.

This study provides clinicians the opportunity to better understand a wide variety of clients. The measures used and the findings of the current study lend well to the holistic approach of examining clients and their presenting problems, including the psychomedical perspective. This will lead to a better understanding of the whole person as opposed to focusing on individual issues.

Conclusions

This study aimed to measure the relationship between autoimmune disorders and coping behaviors. Although the primary hypothesis was not supported, this study

produced interesting results. Even though autoimmune diagnosis and preferred coping behaviors were found to be unrelated; the relationship between the two should be explored further.

This study also examined the relationship between illness intrusiveness and coping behaviors, along with the relationship between perceived stress and coping behaviors. Elevated levels of perceived stress were found to be significantly related to the use of less effective coping behaviors.

Finally the study looked at the relationship between illness intrusiveness and perceived stress, and the two variables were found to be significantly related in all three of the autoimmune samples.

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Appendix A

IRB Exemption Approval

FORT HAYS STATE UNIVERSITY

Forward thinking. World ready.

OFFICE OF SCHOLARSHIP AND SPONSORED PROJECTS

DATE:	March 11, 2014
TO:	Lyndsey Gilmore
FROM:	Fort Hays State University IRB
STUDY TITLE:	[580127-1] Coping Behaviors of Individuals with Autoimmune Disorders
IRB REFERENCE #:	14-083
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
DECISION DATE:	March 11, 2014
REVIEW CATEGORY:	Exemption category # 2

Thank you for your submission of New Project materials for this research study. The departmental human subjects research committee and/or the Fort Hays State University IRB/IRB Administrator has determined that this project is EXEMPT FROM IRB REVIEW according to federal regulations.

Please note that any changes to this study may result in a change in exempt status. Any changes must be submitted to the IRB for review prior to implementation. In the event of a change, please follow the Instructions for Revisions at http://www.fhsu.edu/academic/gradschl/irb/.

The IRB administrator should be notified of adverse events or circumstances that meet the definition of unanticipated problems involving risks to subjects. See http://www.hhs.gov/ohrp/policy/AdvEvntGuid.htm.

We will put a copy of this correspondence on file in our office. Exempt studies are not subject to continuing review.

If you have any questions, please contact Leslie Paige at lpaige@fhsu.edu or 785-628-4349. Please include your study title and reference number in all correspondence with this office.

Appendix B

Recruiting Statement

Recruitment Statement – "Healthy" Sample

Hi, I am Lyndsey Gilmore, a Graduate student at Fort Hays State University. I am conducting a survey regarding coping behaviors. This is an 82-question survey that takes about 20 minutes to complete. This study is completely voluntary. The following link will take you to a consent form followed by the survey. This study should not cause you any harm, but should you become overwhelmed contact information for a nationwide hotline, the chair of the Psychology Ethics Committee, my faculty advisor, and myself will be provided. Thank you. https://www.surveymonkey.com/s/PZZVCBL

Recruitment Statement – Autoimmune Sample

Hi, I am Lyndsey Gilmore, a Graduate student at Fort Hays State University. I was diagnosed with Lupus in 2009. I am conducting a survey regarding coping behaviors. This is an 82-question survey that takes about 20 minutes to complete. This study is completely voluntary. The survey will ask about how being diagnosed with an autoimmune disorder has affected different parts of your life. This study should not cause you any harm, but should you become overwhelmed contact information for a nationwide hotline, the chair of the Psychology Ethics Committee, my faculty advisor, and myself will be provided. The following link will take you to a consent form followed by the survey. Thank you. https://www.surveymonkey.com/s/PZZVCBL

Appendix C

Informed Consent

CONSENT TO PARTICIPATE IN RESEARCH

Department of Psychology, Fort Hays State University

Coping Behaviors of Individuals with Autoimmune Disorders

Lyndsey Gilmore, (785) 650-7269

Carol Patrick, (785) 628-4406

You are being asked to participate in a research study. It is your choice whether or not to participate.

Your decision whether or not to participate will have no effect on benefits or services to which you are otherwise entitled. Please contact the individuals listed above if there is anything you do not understand.

What is the purpose of this study?

The purpose of the study is to better understand coping behaviors in general, and how being diagnosed with an autoimmune disorder can affect coping behaviors.

What does this study involve?

This is a 82-question survey that takes about 20 minutes to complete.

If you decide to participate in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you. The length of time of your participation in this study is around 20 minutes. Approximately ---- participants will be in this study.

None of the questionnaires used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for analysis.

Are there any benefits from participating in this study?

There will be (or may be) no benefits to you should you decide to participate in this study. Your participation will help us learn more about coping behaviors. It will also allow you the opportunity to think about your own coping behaviors and learn about new ones.

Will you be paid or receive anything to participate in this study?

You will not receive any compensation if the results of this research are used towards the development of a commercially available product.

What about the costs of this study?

There are no costs for participating in this study other than the time you will spend completing the survey.

What are the risks involved with being enrolled in this study?

It is unlikely that participation in this project will result in harm to participants. Sometimes talking about these subjects cause people to be upset. You do not have to talk about any subjects you do not want to talk about, and you may stop participating at any time. If you feel distressed or become upset by participating, please contact the nationwide hotline at 1-800-273-TALK or your community mental health center.

How will your privacy be protected?

The information collected as data for this study includes: coping behaviors, perceived stress, and general demographics. The data will be used to better understand coping behaviors. The data will be stored under lock and key in the investigators office, de-identified, and maintained according to the APA guidelines.

The information collected for this study will be used only for the purposes of conducting this study. What we find from this study may be presented at meetings or published in papers but your name will not ever be used in these presentations or papers.

Other important items you should know:

• **Withdrawal from the study:** You may choose to stop your participation in this study at any time. Your decision to stop your participation will have no adverse effects to the participant

• **Funding:** There is no outside funding for this research project.

Whom should you call with questions about this study ?

Questions about this study may be directed to the researcher in charge of this study: Lyndsey Gilmore at (785) 650-7269 or Dr. Carol Patrick at (785) 628-4406.

If you have questions, concerns, or suggestions about human research at FHSU, you may call the Office of Scholarship and Sponsored Projects at FHSU (785) 628-4349 during normal business hours.

CONSENT

I have read the above information about Coping Behaviors of Individuals with Autoimmune Disorders. You are under no obligation to participate in the study. Your completing this questionnaire will be taken as evidence of your willingness to participate and your consent to have the information used for purposes of the study. You may keep this cover letter and explanation about the nature of your participation in this study and the handling of the information you supply. I am 18 years or older.

Appendix D

Debriefing Statement

The purpose of the current study is to better understand the link between autoimmune disorders and coping behaviors. The study will add to the current literature and research on coping behaviors among those with autoimmune disorders.

It is expected that those with autoimmune disorders will use more positive coping behaviors than "healthy" individuals, but that the two groups will use similar levels of negative coping. In both groups, it is hypothesized that perceived stress levels will be similar, but that elevated levels of perceived stress will relate negatively to the use of effective coping behaviors, and positively to less effective coping behaviors.

Among the autoimmune sample, it is expected that higher level of illness intrusiveness will positively relate to perceived stress, but negatively affect positive coping behaviors. It is also expected that the longer that participants have been diagnosed with the autoimmune disorder, the more effective their coping behaviors will be.

The possible implications of this study can be extensive. Clinicians will be better able to understand individuals living with autoimmune disorders and how these disorders influence the individual's perceived stress and coping behaviors.

If you would like a copy of the results or have any questions about this study, please contact myself at (785-650-7269), my faculty advisor Dr. Carol Patrick at (785-628-4406), or the chair of the Psychology Ethics committee, Dr. Hill at (785-628-4404). If you are experiencing any distress please contact the nationwide hotline at (1-800-273-TALK) or your local community mental health center.

Appendix E

COPE Inventory

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by blackening one number on your answer sheet for each, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU--not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1 = I usually don't do this at all

2 = I usually do this a little bit

3 = I usually do this a medium amount

4 = I usually do this a lot

1. I try to grow as a person as a result of the experience.

1 2 3 4

2. I turn to work or other substitute activities to take my mind off things.

1 2 3 4

3. I get upset and let my emotions out.

1 2 3 4

4. I try to get advice from someone about what to do.

1 2 3 4

5. I concentrate my efforts on doing something about it.

1 2 3 4

6. I say to myself "this isn't real."

1 2 3 4

7. I put my trust in God.

1 2 3 4

8. I laugh about the situation.

1 2 3 4

9. I admit to myself that I can't deal with it, and quit trying.

1 2 3 4

10. I restrain myself from doing anything too quickly.

1 2 3 4

11. I discuss my feelings with someone.

    1 2 3 4

12. I use alcohol or drugs to make myself feel better.

    1 2 3 4

13. I get used to the idea that it happened.

    1 2 3 4

14. I talk to someone to find out more about the situation.

    1 2 3 4

15. I keep myself from getting distracted by other thoughts or activities.

    1 2 3 4

16. I daydream about things other than this.

    1 2 3 4

17. I get upset, and am really aware of it.

    1 2 3 4

18. I seek God's help.

    1 2 3 4

19. I make a plan of action.

    1 2 3 4

20. I make jokes about it.

    1 2 3 4

21. I accept that this has happened and that it can't be changed.

    1 2 3 4

22. I hold off doing anything about it until the situation permits.

    1 2 3 4

23. I try to get emotional support from friends or relatives.

    1 2 3 4

24. I just give up trying to reach my goal.

    1 2 3 4

25. I take additional action to try to get rid of the problem.

    1 2 3 4

26. I try to lose myself for a while by drinking alcohol or taking drugs.

    1 2 3 4

27. I refuse to believe that it has happened.

    1 2 3 4

28. I let my feelings out.

    1 2 3 4

29. I try to see it in a different light, to make it seem more positive.

    1 2 3 4

30. I talk to someone who could do something concrete about the problem.

    1 2 3 4

31. I sleep more than usual.

    1 2 3 4

32. I try to come up with a strategy about what to do.

    1 2 3 4

33. I focus on dealing with this problem, and if necessary let other things slide a little.

    1 2 3 4

34. I get sympathy and understanding from someone.

    1 2 3 4

35. I drink alcohol or take drugs, in order to think about it less.

    1 2 3 4

36. I kid around about it.

    1 2 3 4

37. I give up the attempt to get what I want.

    1 2 3 4

38. I look for something good in what is happening.

    1 2 3 4

39. I think about how I might best handle the problem.

    1 2 3 4

40. I pretend that it hasn't really happened.

    1 2 3 4

41. I make sure not to make matters worse by acting too soon.

    1 2 3 4

42. I try hard to prevent other things from interfering with my efforts at dealing with this.

    1 2 3 4

43. I go to movies or watch TV, to think about it less.

    1 2 3 4

44. I accept the reality of the fact that it happened.

    1 2 3 4

45. I ask people who have had similar experiences what they did.

    1 2 3 4

46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.

    1 2 3 4

47. I take direct action to get around the problem.

    1 2 3 4

48. I try to find comfort in my religion.

    1 2 3 4

49. I force myself to wait for the right time to do something.

    1 2 3 4

50. I make fun of the situation.

    1 2 3 4

51. I reduce the amount of effort I'm putting into solving the problem.

1 2 3 4

52. I talk to someone about how I feel.

1 2 3 4

53. I use alcohol or drugs to help me get through it.

1 2 3 4

54. I learn to live with it.

1 2 3 4

55. I put aside other activities in order to concentrate on this.

1 2 3 4

56. I think hard about what steps to take.

1 2 3 4

57. I act as though it hasn't even happened.

1 2 3 4

58. I do what has to be done, one step at a time.

1 2 3 4

59. I learn something from the experience.

1 2 3 4

60. I pray more than usual.

1 2 3 4

Appendix F

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

0 = never

1 = almost never

2 = sometimes

3 = fairly often

4 = very often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

0 1 2 3 4

Appendix G

Demographics

Gender: M F

Age _____

Marital Status:

___ Single

___ Married

___ Divorced

___ Separated

___ Widowed

Ethnicity:

___ Caucasian

___ African American

___ Hispanic or Latino

___ Asian

___ American Indian or Alaska Native

___ Native Hawaiian or Other Pacific Islander

___ Other (please list)_____

Are you currently married? Yes No

Do you have children? Yes No

If so, how many? _____

What are their ages? ____

Have you experienced a traumatic life event (stressors beyond what could be considered normal day-to-day events, that continue to have a lasting impact on you)?

____Yes

____No

Have you been diagnosed with any of the following (please check the appropriate one):

___Systemic Lupus Erythematosus

___Fibromyalgia

___Rheumatoid Arthritis

___Any Chronic (long term) Medical Disorder

___None

If so, how many years since you were first diagnosed? _____

Appendix H

Illness Intrusiveness Rating Scale

The following items ask about how much your illness(es) and/or its treatment interfere with your life. **Please circle the one number that best describes your current life situation.** If an item is not applicable, please check ( ) the box to indicate that this aspect of your life is not affected. Please do not leave any item unanswered.

How much does your illness(es) and/or its treatment interfere with:

1. Your feeling of being healthy? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

2. The things you eat and drink? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

3. Your work, including job, house work, chores, or errands? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

4. Playing sports, gardening, or other physical recreation or hobbies? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

5. Quiet recreation or hobbies, such as reading, TV, music, knitting, etc.? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

6. Your financial situation? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

How much does your illness(es) and/or its treatment interfere with:

7. Your relationship with your spouse or domestic partner? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

8. Your sex life? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

9. Your relationship and social activities with your family? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

10. Social activities with your friends, neighbors, or groups? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

11. Your religious or spiritual activities? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

12. Your involvement in community or civic activities? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much

13. Your self-improvement or self-expression activities? Not applicable

Not very much► 1 2 3 4 5 6 7 ◄Very much