

## ABSTRACT

Title of Dissertation:           ROLE OF BIOPSYCHOSOCIAL VARIABLES IN  
PREDICTING POSITIVE WELL-BEING AND  
HEALTH-PROMOTING BEHAVIORS IN  
INDIVIDUALS WITH AUTOIMMUNE DISEASES

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This project investigated the role of biopsychosocial variables in predicting positive well-being and health-promoting behaviors in individuals with autoimmune diseases. The predictors included disease severity, depression, arthritis self-efficacy, and social support. The dependent variables were positive well-being and health-promoting behaviors. Participants included 175 individuals with connective tissue or musculoskeletal autoimmune diseases who were over age 18. Participants were recruited through various health agencies and clinics serving people with autoimmune diseases and eligible respondents completed the survey online. Results of the study showed that disease severity and social support are not related, suggesting that an individuals' ability to access and utilize social support is unrelated to the severity of their autoimmune disease. Second, a significant relationship was found between self-efficacy and depression suggesting that individuals who believe they can handle the consequences of their disease report lower depression. Third, it was found that depression and social support predict both positive well-being and health promoting behaviors. Depression and social support added significant contributions to the regression model predicting well-being and healthy behaviors. Self-efficacy and disease severity did not add significant contributions to this model. It was found that self-efficacy does not mediate the

relationship between depression and positive well-being but social support does. Fourth, a cluster analysis revealed four different clusters of participants that react to their autoimmune disease in four different ways. The cluster analysis suggested that, in general, people may react strongly favorably, strongly unfavorably, or not at all to their autoimmune disease. Finally, qualitative data for three open-ended questions related to perceived causes of disease, openness to counseling or psychotherapy, and positive consequences of autoimmune diseases were analyzed by three independent raters. Implications for research and practice are discussed.

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AUTOIMMUNE DISEASES

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## Dedication

This project is dedicated to my Grandmother, Bernice “Beets” Trizulny, who died on March 13, 2008, just a few weeks before the completion of this project. My grandmother did not have the same opportunities I have had, so it is with great honor that I completed this project in her memory. She lived for many years with Rheumatoid Arthritis, while serving as a caretaker to others. She was filled with positive energy, hope, optimism, and lived her life with light and joy. I dedicate this to her in loving memory.

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## Chapter 1

### Introduction

Why study autoimmune diseases? What is so unique about autoimmune diseases that the research on other chronic illness cannot just be applied to the experiences of people with autoimmune diseases? Previous research and anecdotal evidence suggest: there is a unique experience common to individuals with autoimmune diseases. As Ellyn Kaschak writes, “For autoimmune diseases, the question of the medical profession has been, ‘Is it real or is it psychological?’ This is entirely the wrong question, one based not only in a dualistic epistemology, but even more deeply in a bias against ‘women’s illnesses’.” (Kaschak, 2001, p.1).

Imagine this situation: a young woman is experiencing significant pain in her joints and feels tired and achy all the time. Her knees, shoulders, and knuckles have been swollen for a few months and she has been perpetually exhausted. A former marathon runner, she was forced to stop running due to excruciating pain in her knees. The pain in her shoulders has made it difficult for her to pick up her young children and the joint swelling in her hands makes writing nearly impossible. She is a single mother and the burden of caring for her two young children alone, while she is in so much pain, is causing her to experience significant anxiety about whether she will still be able to support her family on her limited income. The pain alone makes it difficult to get out of bed in the morning, but recently, she has been feeling so down that she has to force herself to go to work each day.

Although this woman has limited financial resources, she consults a doctor who tells her that she has rheumatoid arthritis. She is immediately confused: arthritis is what her grandfather has, not something that a woman in her early thirties should have. She leaves her doctor's office and shares her diagnosis with friends and family and is met with more uneasiness. They do not know how to help her and they have a hard time understanding how much pain she is experiencing. She begins to think seriously about the lifestyle changes that must occur, including perhaps quitting her job because standing on her feet all day is just exacerbating her pain. She contemplates a future filled with having to explain her complicated symptoms to others and the many barriers she may encounter in her social life. In addition, she worries about who she will rely on for help. She has already drifted away from some of her closest friends because they socialized while training for marathons together. This woman is aware of the difficulty she has asking for help from friends and she is resolved not to burden other people with what she considers to be her problem.

While the above scenario is entirely fictional, many of the problems that the woman is experiencing are common among individuals with autoimmune diseases like rheumatoid arthritis. Significant physical impairment, psychological difficulties, and changes in social support are all commonly associated with this class of disorders (White, Lemkau, & Clasen, 2001). She had difficulty getting out of bed in the morning, anxiety about how she will support her family, and fears about asking other people for help, experiences that are common among people with physical illness.

Like this woman, individuals face many biological, psychological, and social consequences after being diagnosed with an autoimmune disease. In many cases, severe

physical impairments and debilitating symptoms force people to drastically change their occupational and social lives to account for the physical disability that accompanies their disease (Chrisler, 2001). Psychologically, these individuals can experience depression and anxiety, with the physical diagnosis either exacerbating an underlying predisposition for these psychological symptoms or bringing about psychological distress due to the stress and transition that accompanies the chronic illness. People with autoimmune diseases may struggle to rely on others for help, both physically and emotionally; asking for help can be in stark contrast to their previous ways of relating to the world (Chrisler, 2001).

Previous studies have shown that individuals who are recently diagnosed with rheumatoid arthritis (an autoimmune disease) are more depressed than the general population (Mangelli et al., 2002). Though the causal relationship between depression and autoimmune diseases has not been established, some previous studies have investigated variables associated with psychological well-being.

For example, research has been conducted on how depression and anxiety can affect pain and other disease symptoms in individuals with autoimmune diseases, though these studies have not incorporated the biopsychosocial model. Consistent findings have linked depression and pain in individuals with autoimmune diseases (Barsky, Orav, & Ahern, 1999; Mangelli et al., 2002; Westbrook & Nordholm, 1986). In a study of individuals attending a rheumatology clinic, positive well-being was found to be an important moderating variable between pain and depression, such that people with a higher positive well-being were less likely to get depressed even with pain levels that were similar to those of participants who did ultimately become depressed (Mangelli et

al., 2002). Other studies have used more objective measures of disease severity (joint measurements, immunological assays) and found that individuals with more severe symptoms are also more depressed (Cohen & Herbert, 1996).

Depression may also be due to individuals' attributions about their disease etiology. Westbrook and Nordholm (1986) investigated individuals' attributions about the cause of their chronic illness. They found that individuals with diseases with a low lifestyle component (i.e., diseases where health behaviors were not likely to influence the development of the disease) were less depressed when they accurately blamed chance causes for the development of the disease. The low lifestyle component diseases that they investigated were arthritis and cancer. On the other hand, when those same individuals blamed themselves for the development of their disease, they were more depressed and coped poorly. The opposite was true for diseases with a high lifestyle component (stroke, heart disease), where they were less depressed and coped better when they accurately blamed themselves and their lifestyle choices for the development of their diseases (Westbrook & Nordholm, 1986).

The emotional toll that these physical symptoms can have is highlighted by the loneliness that comes with the diagnosis of a relatively rare disease, concerns about one's future prognosis, and self blame for the development of the disease (Chrisler, 2001). The most common types of autoimmune diseases are connective tissue diseases. Connective tissue diseases include specific types of autoimmune disease in which the body attacks its own connective tissue (ligaments, cartilage, tendons, skin and any other substance that serves to bind together, support, and protect organs); a painful process just to imagine. Because each individual autoimmune disease is relatively rare, people may

not have the same level of social support garnered by a more prevalent and understandable disease such as cancer (White, Lemkau, & Clasen, 2001). Social changes may occur due to the necessary lifestyle changes that accompany an autoimmune disease as well as the difficulties that are associated with asking for and giving and receiving help in social and romantic relationships. Autoimmune diseases are generally progressive and have no cure. Some periods of ups and downs will recur but the general course of the disease worsens over time. Studies on the social support of individuals with autoimmune diseases show that people with more severe diseases and who have been diagnosed for longer periods of time have less social support than their newly diagnosed and less severe counterparts, perhaps due to the necessary lifestyle changes that one must make after a diagnosis (Fyrand et al., 2002).

Connective tissue diseases include the most common autoimmune diseases like rheumatoid arthritis, lupus, and multiple sclerosis. In addition, it is an umbrella term that encompasses other types of arthritis syndromes, rheumatic diseases, and musculoskeletal disorders. Autoimmune connective tissue diseases were included in the current study as were all autoimmune disorders, including autoimmune endocrine disorders, autoimmune gastrointestinal disorders, and other organ and tissue specific autoimmune diseases. Individuals with autoimmune disease represent the fourth largest group of people with chronic illness (Chrisler, 2001) and commonly face personal challenges due to the physical and psychosocial effects of autoimmune syndromes. Autoimmune diseases have an overall prevalence of 3-4% of the population, but, due to differences in diagnosis and a lack of standardization in criteria, the exact population and lifetime prevalence estimates are not available. Also, many individuals are diagnosed with multiple types of

autoimmune diseases, contributing to variability in prevalence estimates (Gaubitz, 2006). Sjogren's Syndrome, for example, is one of the most common autoimmune diseases and its estimated prevalence range is 0.5-3% in the population, and it is often diagnosed alongside other autoimmune disorders (Gaubitz, 2006).

Individuals with autoimmune diseases often face a more difficult adjustment to a new diagnosis due to the isolation that comes with having a rare disorder that may not be widely recognized by friends and family. For example, friends may respond differently when told about a diagnosis of cancer compared to Hashimoto's Thyroiditis (a type of autoimmune disease). Cancer treatments are more familiar to the general public and many people have developed a cognitive schema for understanding cancer based on their previous experiences. People with autoimmune diseases may not be easily identifiable and may not look sick. Since the course of autoimmune diseases is often unpredictable, including periods of relapse and remission, supportive others may have a difficult time understanding that these individuals can sometimes function well and at other times be completely debilitated. These individuals cannot be easily categorized, which can make accessing and maintaining social support more complicated endeavors (Gaubitz, 2006).

If social support is available from someone else with a similar disease, like in a support group, their experience of the disease is often vastly different due to factors such as differing periods of relapse and remission and greater or lesser symptom severity. In addition, it often takes many years to get an accurate diagnosis of an autoimmune disorder, which can cause emotional turmoil as people start to believe that their symptoms are "all in their heads," or are not taken seriously by their medical professionals. Individuals with autoimmune diseases tend to blame themselves for their



illness, which has been proven to relate to negative outcomes, both physically and emotionally (Barsky et al., 1999). In summary, autoimmune diseases are difficult to diagnose, physically painful, socially and vocationally limiting, and are often associated with psychological symptoms like anxiety and depression, especially when individuals blame themselves for their disorder.

A common course of disease progression includes bouts of severe impairment interspersed with periods of remission, though some individuals experience a more gradual prognosis without punctuation. The insidious nature of the disease is heightened by their incurable nature, treatment side effects, general unfamiliarity or ignorance from the general population, and the isolation associated with the disease (Chrisler, 2001).

Aside from all of the difficult symptoms and life changes that accompany autoimmune diseases, some positive benefits can result from the diagnosis. Finally having a name to put to one's varied symptoms, starting treatment, and re-evaluating one's priorities have been benefits that individuals have reported in the past. Some sense of increased positive well-being and decreased pain is associated with individuals being able to find benefits after their diagnosis (Katz et al., 2001; Mohr et al., 1999).

Investigating the impact of chronic physical illness has been difficult due to the numerous factors that affect psychosocial adjustment to illness as well as the varied physical impairments that can have an impact on an individual's adjustment to their disease. The biopsychosocial model (Hoffman & Driscoll, 2000) provides a good framework for integrating the various biological, psychological, and social factors that influence health outcomes and progression. It also takes a positive psychology approach to chronic illness and does not rely solely on the disease focus of the medical model. For

these reasons, the biopsychosocial model was chosen as the theoretical framework for the current study. The biopsychosocial model has been applied to a number of diseases and contexts including HIV, cancer, and community interventions (Schmidt, Hoffman, & Taylor, 2006). In the current study, the biopsychosocial model was applied to understanding how people respond to living with autoimmune diseases. Autoimmune diseases were chosen as the disease model for the current study because they have many psychological, emotional, and social considerations and accompanying concerns.

The link between physical and mental health has become increasingly clear in recent years, however, individuals with chronic physical illness often find the psychosocial aspects of their disease ignored and do not get interventions such as psychotherapy that they may need (Goodheart, 2006). The aim of the biopsychosocial model (Hoffman & Driscoll, 2000) is to better understand how biological, psychological, and social factors contribute to overall health status and to consider health factors in a multi-level analysis. Some research has been done on how one or two of the factors contribute to a given area of health, but few studies have investigated all three types of variables and their impact on health. Specifically, the focus of the biopsychosocial model is on positive well-being and few studies have applied the biopsychosocial model to investigating positive health outcomes.

Unlike previous studies on autoimmune diseases, this study investigated all three components of the biopsychosocial model at the same time. The current study investigated how biopsychosocial variables affect positive well-being and health-promoting behaviors in individuals with autoimmune diseases. These two variables have been shown to have a significant impact on both physical and mental health. In the

current study, specific biological, psychological, and social variables have been chosen to fully investigate the relationship between those specific health factors on well-being and health promotion. It was hoped that the variables that affect well-being and health-promoting behaviors can be isolated to determine how to enhance prevention in the future.

In response to the dearth of information about the factors that affect individuals with chronic illness, the current study investigated health-promoting behaviors (e.g. involvement in exercise, eating healthfully, and reducing stress levels) and positive well-being in a population with autoimmune diseases. Health promoting behaviors and positive well-being were selected as criterion variables in the current study due to their direct impact on quality of life. Major goals for health promotion include finding ways to encourage people to engage in healthy behaviors and improving overall well-being and life satisfaction. These two variables best encompass these goals. They are closely aligned with the leading health indicators set forth by the government task force to improve overall health called Healthy People 2010 ([www.healthypeople.gov](http://www.healthypeople.gov), 2007).

This study attempted to address the paucity of information on the biopsychosocial factors of individuals with chronic illnesses in general. The participants in this study were individuals with chronic illness, specifically autoimmune diseases, a population whose *physical* health needs are often the focus of research but whose *psychosocial* health needs are understudied and often ignored.

## Chapter 2

### Review of the Literature

People with autoimmune diseases may note that their physical ailments and pains impact their overall well-being and even their willingness to engage in social interactions. For example, someone with arthritis might say, “I just feel like staying in bed today.” Even though some individuals may draw connections between their physical and mental health, psychological and medical research has been slow to examine these important connections. Although the important relationship between mind and body is often acknowledged (Barsky et al., 1999, Mangelli et al., 2002, Westbrook & Nordholm, 1986), research has not been able to examine this integration in a manner that allows professionals in both medical and psychological fields to translate findings to help people adjust both physically and psychologically to their disorders.

The basis for this study grew out of several different bodies of literature, each understudied in their own way. This study investigated how biopsychosocial factors can affect individuals with chronic physical illness. Research on individuals with physical disease usually has a focus on either the medical treatment of the disease or, if it is more psychologically oriented, addresses issues like treatment adherence and outcome rather than exploring how biological, psychological, and social factors intersect to predict positive health behaviors and well-being.

This review of the literature will start with an overview of autoimmune diseases so the reader can understand the symptoms and prevalence of the disorders that are included in the current study. In addition, the justification for choosing these diseases as the model for the current study will be presented. The theoretical foundation of the

paper, the biopsychosocial model, will then be discussed. Previous research on each of the variables of interest that comprise the biological, psychological, and social components of the model will then be presented. Finally, since there has been limited research on the biopsychosocial effects of chronic illness in general, other research on this area will be briefly explored. This literature review will provide a comprehensive grounding in the rationale for the current study.

### Autoimmune Diseases

Autoimmune diseases were chosen as the model for chronic illnesses in the current study because they incorporate a variety of diseases and symptoms, yet they have similarities in their levels of debilitating effects and comorbid psychosocial symptoms. Stress and emotion have long been proven to have an effect on one's immune system, thus suggesting a natural link between autoimmune diseases and psychological health (O'Leary, 1990). Though no direct causes of autoimmune disease are known, stress is often viewed as a precipitating factor in all autoimmune diseases (O'Leary, 1990).

“Autoimmune disease” is an umbrella term for over 80-100 diseases that affect the immune system in humans. Various parts of the body are affected in each disease, with the immune system turning against its own tissues and organs and failing to distinguish between “self” and “non-self” when attacking cells. Each of the 80 diseases is not extremely prevalent in the US population, however, taken as a whole autoimmune diseases represent the fourth largest cause of disability in women (www.wrongdiagnosis.com, 2006). The prevalence of autoimmune diseases as a whole, their unusual disease progression, and the confusion around accurate diagnoses leading to feelings of isolation and depression are just a few of the many reasons why autoimmune

diseases were chosen as the model disease group for the current study. The psychological and emotional symptoms that are often associated with diagnosis of an autoimmune disease make this choice even more appropriate.

Autoimmune diseases are more prevalent in women than men. In general, women are three times more likely to have an autoimmune disease than men are (www.wrongdiagnosis.com, 2006). Table 1 lists the most common autoimmune diseases and their ratio of prevalence in women to men.

| <b>Table 1: Autoimmune disease prevalence in women compared to men</b> |      |
|--|------|
| Hashimoto's disease/hypothyroiditis (ages 40-60)                       | 50:1 |
| Systemic lupus erythematosus (ages 20-40)                              | 9:1  |
| Sjogren's syndrome (age 50)  | 9:1  |
| Antiphospholipid syndrome  | 9:1  |
| Primary biliary cirrhosis  | 9:1  |
| Mixed connective tissue disease  | 8:1  |
| Chronic active hepatitis   | 8:1  |
| Graves' disease/hyperthyroiditis (ages 20-40)                          | 7:1  |
| Rheumatoid arthritis (ages 30-50)                                      | 4:1  |
| Scleroderma  | 3:1  |
| Myasthenia gravis (ages 20-30)   | 2:1  |
| Multiple sclerosis (age 30)  | 2:1  |
| Chronic idiopathic thrombocytopenic purpura                            | 2:1  |
| Sources: www.aarda.org; Chrisler, 2001                                 |      |

The overall prevalence of autoimmune diseases in the US is 1 in 31. That is, just over 3% of Americans are diagnosed with some type of autoimmune disease. Once a person is diagnosed with the disease, they are considered to have the disease for the rest of their lives and there is no cure. Table 2 shows some of the most common autoimmune diseases. There are over 80 diseases that are currently classified as autoimmune diseases, with more under consideration. Diseases in question include chronic fatigue syndrome, irritable bowel syndrome, vasculitis, and others (Chrisler, 2001). It is interesting to note how common autoimmune disorders are in comparison to other types of chronic illness. The National Institutes of Health estimates that about 23.5 million Americans have an autoimmune disease, while only 9 million are affected by cancer and 22 million by heart disease. Research on autoimmune diseases is sorely underfunded, receiving only \$591 million in public funding compared to \$6.1 billion for cancer and \$2.4 billion for heart and stroke related diseases (www.aarda.org, 2008).

Autoimmune diseases are either organ-specific (e.g. Hashimoto's thyroiditis attacks the thyroid, pernicious anemia attacks the stomach, Addison's disease attacks the adrenal glands, and insulin-dependent diabetes mellitus attacks the pancreas) or non-organ specific (e.g. rheumatoid arthritis, systemic lupus erythematosus (SLE), and dermatomyositis (www.aarda.org, 2006). Individuals with one autoimmune disease are prone to developing others and disease progress and prognosis is often varied, causing significant psychological distress. Even though there are periods of relapse and remission, autoimmune diseases do not go away.

| <b>Table 2: Percent of population affected by autoimmune diseases</b>  |                   |
|--|-------------------|
| Rheumatoid arthritis (RA)  | 0.92%, 1 in 108   |
| Type I diabetes mellitus   | 0.12%, 1 in 800   |
| Hashimoto's Thyroiditis  | 0.55%, 1 in 182   |
| Systematic Lupus Erythematosus (SLE)   | 0.51%, 1 in 194   |
| Multiple Sclerosis (MS)  | 0.14%, 1 in 700   |
| Crohn's Disease  | 0.18%, 1 in 544   |
| Sjogren's Syndrome   | 0.37%, 1 in 272   |
| Pernicious anemia  | 0.15%, 1 in 680   |
| Grave's Disease  | 1.12%, 1 in 89    |
| Celiac Disease   | 0.40%, 1 in 249   |
| Glomerulonephritis   | 0.02%, 1 in 4,428 |
| Scleroderma  | 0.11%, 1 in 906   |
| Myasthenia gravis  | 1 in 20,000       |
| Source <a href="http://www.wrongdiagnosis.com">www.wrongdiagnosis.com</a> , <a href="http://www.aarda.org">www.aarda.org</a> |                   |



The etiology of autoimmune diseases is largely unknown. The best understanding at this point is that bacteria, viruses, toxins, or drugs may act as a trigger in individuals who have a genetic predisposition to develop a disorder. An inflammation response is typically involved such that the body may become sensitized to the inflammation response, which then transfers to a “self” system or organ rather than just attacking the “non-self” foreign body (www.aarda.org, 2006). Additionally, some people believe that defective T-lymphocytes may misregulate the immune system (Chrisler, 2001).

With the increased frequency of autoimmune diseases in women (See Table 1) and the most common age of diagnosis during childbearing years, some question the possible endocrinological involvement in the etiology of autoimmune diseases. Stress is believed to play a role in disease development and severity, which is common in women of childbearing age especially as they try to balance work and family. Family members are more likely to develop an autoimmune disease if another family member has one and some believe a genetic component is responsible for a 20% penetrance rate (www.aarda.org, 2006). Some autoimmune diseases vary by ethnicity, geographic region, and exposure to various toxins like airplane fuel, hair dyes, silicone breast implants, and vinyl chloride (Chrisler, 2001).

Symptoms of autoimmune disease vary depending on the disease but are often hard to diagnose and it is difficult to make accurate differential diagnoses among the subtypes. The variability and inconsistency of these symptoms may cause some psychosocial consequences which are of interest in the current study. A common course of disease progression includes bouts of severe impairment interspersed with periods of remission, though some individuals experience a more gradual prognosis without

punctuation. The insidious nature of the disease is heightened by their incurable nature, treatment side effects, general unfamiliarity or ignorance from the general population, and the isolation associated with the disease (Chrisler, 2001). Individuals often report significant loneliness or stigma associated with their disease because they do not know anyone else with a similar diagnosis, though others suggest that being a part of a community with others who are aware of their disease can be difficult due to the different levels of impairment, potential for remission, and varying treatments associated with the disease. Since not all individuals with SLE are equal, for example, an individual with a more severe case may not feel optimistic when supported by a friend with the disease who faces less functional impairment.

Treatment of individuals with autoimmune diseases is complex both medically and psychologically. No common treatment procedure exists and use of complementary and alternative medical (CAM) treatments is prevalent among individuals with autoimmune diseases with estimates ranging from 28-90% of individuals with rheumatic conditions, depending on the types of treatments that are included in the definition. CAM is more popular with individuals with autoimmune individuals than other types of chronic illnesses, perhaps due in part to the complexity of the disease symptoms and the lack of standardized treatment (Taibi & Bourguignon, 2003).

The most common autoimmune diseases (shown in Table 2) can be classified into different categories. Connective tissue diseases include Systemic Lupus Erythematosus (SLE), which is an inflammation of the connective tissues; Rheumatoid Arthritis, in which immune cells inflame and attack the cartilage and membranes around joints and occasionally the heart, lungs, and eyes; Scleroderma which produces scar tissues in the

skin, internal organs, and blood vessels and skin thickening; Sjogren's Syndrome in which individuals slowly become unable to secrete saliva and tears. Neuromuscular diseases include Multiple Sclerosis (MS), which attacks the central nervous system and leads to numbness and tingling in the limbs and Myasthenia Gravis which is characterized by progressive muscle weakness. Endocrine diseases include Hashimoto's Thyroiditis in which the immune system destroys the thyroid; Grave's Disease in which the body produces an excessive amount of thyroid hormone, and Type I Diabetes in which too little insulin is produced by the pancreas. Gastrointestinal diseases include Crohn's disease and ulcerative colitis in which the small intestine is attacked. Other autoimmune diseases attack blood vessels (Vasculitis); red blood cells (Hematologic Autoimmune Diseases); and the skin (www.aarda.org, 2006).

Autoimmune diseases are particularly important to study from a psychological perspective because they are extremely disempowering. Individuals with autoimmune diseases face debilitating pain, a myriad of symptoms that are difficult to diagnose and often face years of medical consultations before receiving a diagnosis (Chrisler, 2001). Friends, family, and colleagues of individuals with autoimmune diseases may believe that the symptoms are "all in their heads" and not be supportive of accommodations that need to be made. The pain associated with the diseases is debilitating and can lead to significant functional impairments. The etiology of autoimmune diseases is basically unknown though theories of genetic predispositions, bacterial causes, psychiatric connections, comorbid diseases, and neuroendocrinological factors have been studied (White, Lemkau, & Clasen, 2001). Due to the diffuse potential causes, diagnosis and treatment are difficult. The conditions can be managed through biopsychosocial

interventions such as education, pharmacological treatments, exercise, stress management, and therapy (White, Lemkau & Clasen, 2001) or complementary and alternative medicine (Taibi & Bourguignon, 2003).

An alternative explanation for psychological symptoms that are associated with autoimmune disease is that immune system over-responding can lead to depression (Dantzer et al., 2008). Some researchers suggest that uncontrolled activation of the peripheral immune system, such as in a systemic infection like an autoimmune disease, may lead the pro-inflammatory cytokines that are released by the immune system to trigger the brain to exaggerate sickness behaviors. Cytokines have been linked to depression-like sickness behaviors including withdrawal from the physical and social environments, pain and malaise, and anhedonia, so these researchers suggest that cytokine-triggered brain changes and depression may be indistinguishable. They state that, “Inflammation is therefore an important biological event that might increase the risk of major depressive episodes, much like the more traditional psychosocial factors (46)” Dantzer et al., 2008).

Similarly, the field of psychoneuroimmunology, or the study of interrelations between the central nervous system and the immune system, has begun to investigate the interplay of stress and immune system changes that can lead to autoimmune diseases. This perspective is more biomedical than biopsychosocial and some interesting studies exist which have examined the biological and immune system changes with psychologically stressful events. They have shown in retrospective studies that stressful life events and non-supportive atmospheres can exacerbate autoimmune diseases (Cohen & Herbert, 1996). One benefit of these studies is that they use objective information

about disease severity rather than self-report data to draw connections between psychological stressors and autoimmune symptoms.

One study found that individuals with rheumatoid arthritis who underwent a cognitive-behavioral intervention program had reduced pain intensity, inflammation, and serum levels of rheumatoid factor post-treatment compared to a control group and a social support group (Cohen & Herbert, 1996). Similar results were found by O'Leary et al. (1988) when individuals with RA went through a cognitive-behavioral intervention and were given joint swelling ratings by rheumatologists who were blind to their treatment or control group status. These objective rheumatologists rated the CBT treatment group as having significantly improved joint conditions compared to the control group (O'Leary et al., 1988).

Another explanation for the accompanying psychological symptoms found in many autoimmune diseases is that the process of diagnosis and treatment can be excruciating. The relief that someone feels when a diagnosis is finally reached may not outweigh the significant emotional toll that the wait takes on a person. With fibromyalgia, a disease with some autoimmune components, individuals wait an average of 6.7 years to receive an accurate diagnosis (Liller, 1994). Even though they may experience some relief at being able to put a name to their symptoms, these individuals still have to face living with a chronic disease and integrating that into their identity.

Feminist scholars suggest that there are societal explanations for disease that are important to consider including a biased scientific method and a fascination with fashionable explanations for inexplicable symptoms (White, Lemkau, & Clasen, 2001). Autoimmune diseases continue in the infamous tradition of women being marginalized

by medicine. Dating back to the days of 19<sup>th</sup> century diagnoses of hysteria and neurasthenia, autoimmune diseases like fibromyalgia continue to limit women. Women are assumed to be avoiding work, showing psychological weakness, shirking their duties, or resisting gender roles and expectations (Shorter, 1992). It is essential that researchers and therapists consider the range of biopsychosocial factors that affect people with autoimmune diseases and work from an adaptive framework in which they do not limit or stigmatize the individuals they study or with whom they work.

### Theoretical Foundation

The theoretical foundation for this study, the biopsychosocial model, is based on the belief that the body and mind are profoundly connected and should be treated as such by medical and mental health professionals (e.g. Engel, 1977, Hoffman & Driscoll, 2000). So often emotional and social concerns are not addressed in a physical exam and conversely, a client's physical distress is not addressed by mental health professionals. Integrating physical health issues into our understanding of mental health issues may be key to providing the best treatment possible for individuals with autoimmune diseases.

Individuals with disabilities or chronic illnesses experience marginalization in their daily lives, which can have a profound effect on mental health. A significant article in setting up the theoretical foundation of this study was written by Chrisler in 2001. She set forth some ideas about how autoimmune diseases should be evaluated from a feminist and systems approach and discussed how medical professionals should recognize the personal and societal impact of autoimmune diseases. Based on her extensive personal experience with autoimmune diseases, research on the psychological effects of the diseases, and clinical practice with clients with the diseases, Chrisler explicated ideas for

future research and theoretical conceptualizations necessary for studies on autoimmune diseases.

Often, research on biomedical issues tends to take a diagnostic perspective that works from a pathology perspective rather than a strengths perspective. Engel (1977) was the first to propose a biopsychosocial model, in contrast to the biomedical models in existence at the time. He posited that adjustment to a physical illness involves more than just which antibodies are being produced by the body or what part of the body hurts. Engel moved to include psychological and social factors in our understanding of medical illnesses (1977).

Expanding upon Engel's work, Hoffman and Driscoll (2000) propose a biopsychosocial model that emphasizes strengths and moving towards health and well-being, rather than focusing on deficits and disease. Their perspective is firmly differentiated from a classic medical model and has many implications for the current study.

Historically, common models of adjustment to chronic illness include the biomedical, psychosocial, and biopsychosocial models (Walker, Jackson, & Littlejohn, 2004). For the current study, it is important to not just understand the biomedical underpinnings of autoimmune diseases, which are the focus of most medical research, but to instead integrate knowledge of biological factors with important psychosocial factors that are known to be present in individuals coping with chronic illness. The biopsychosocial model encompasses aspects of both the biomedical and psychosocial models but also incorporates environmental and cultural contributors to health, thus extending the previous understanding of illness adjustment (Hoffman & Driscoll, 2000).

The biopsychosocial model embraces a strengths perspective that emphasizes empowerment, in contrast to the medical model, which typically focuses on deficits.

The biopsychosocial model has become more popular in conceptualizing chronic illness and as a framework for some research studies. Nicassio & Smith (1995) collected writings on the biopsychosocial perspective in their book, *Managing chronic illness: A biopsychosocial perspective*. The book uses the biopsychosocial perspective throughout to enhance clinical work, assessments, and treatment from a psychological perspective. It has more of a focus on mental illness than chronic physical illness but offers some valuable ideas about how to apply the biopsychosocial model in practice (Nicassio & Smith, 1995).

Another popular application of the biopsychosocial model is in understanding chronic pain. Chronic pain is associated with high personal and public costs in both physical and mental health care throughout the world. Recent advances in treating chronic pain have embraced the biopsychosocial model since many pain-related symptoms have biological/neurological, psychological, and even social underpinnings. In an excellent review of the current biopsychosocial understanding of chronic pain, Gatchel et al. (2007) summarize the ways that biopsychosocial issues can contribute to pain. The authors included a detailed review of how findings related to genetics, neuroscience, emotion, anxiety, depression, anger, cognitive factors, control, and self-efficacy can help explain levels of chronic pain and suggest ways for treatment. Contrary to early biomedical work in this area, Gatchel et al. (2007) suggest that “total biopsychosocial functioning must be carefully considered in order to maximize the probability of treatment success (607).”



Rheumatoid arthritis has been the most popular of all autoimmune diseases to study with the biopsychosocial perspective (Cohen & Herbert, 1996). Earlier researchers were struck by the important contributions of psychological components in predicting disease activity in RA. Parker et al. (1991) examined joint counts of painful/swollen joints taken by an experienced nurse clinician, peripheral blood immunophenotypic counts of lymphocyte subpopulations known to be associated with inflammatory responses, and self-reports of health status as biological variables. They also examined helplessness and depression as psychological measures in individuals with RA. Finally, age and education level were the social variables they considered. The researchers controlled for the biological variables so they could examine the unique contributions that the psychosocial variables played in predicting disease activity. They found that the psychological variables predicted worsening joint swelling over time. Depression and helplessness were significant predictors of decreasing health status at three and six month intervals (Parker et al., 1991). The Parker et al. study offered support for further research using the biopsychosocial model for research on autoimmune diseases.

Researchers have also begun to conceptualize their research with the biopsychosocial model in mind. For example Schoenfeld-Smith et al. (1996) chose both biological (disease activity, pain, and physical functioning) and psychological (helplessness, psychological functioning, and depression) variables to evaluate a model of progressive disease disability. They found that both pain levels and helplessness mediated the relationship between disease activity and future disability in people with rheumatoid arthritis, which was a significant contribution to the field at the time when biomedical perspectives were still most accepted (Schoenfeld-Smith et al., 1996).

The biopsychosocial model was applied to the current study with the goal to determine which biopsychosocial factors influence health behaviors and well-being of persons with autoimmune diseases. In other words, understanding which factors contribute to people's perception of positive outcomes about their health and well-being will be a major emphasis of the current study.

### Biopsychosocial Factors Associated with Chronic Illness

#### *Biological Issues Associated with Chronic Illness.*

A basic understanding of the physical effects of living with an autoimmune disease is important in understanding the individual's entire experience of these diseases. A description of some of the common symptoms of autoimmune diseases was provided in the previous section on autoimmune diseases to help delineate among the different diseases. Given the biopsychosocial framework that is used for the current study, it is difficult to totally separate each of the variables, however, in this section, some research on how disease severity and symptoms affect other psychological and social variables will be explored.

Some studies suggest that those with more severe disease experience decreased psychological well-being, while others suggest the opposite. An example of increased psychological well-being was found in studies of individuals with cancer and lupus (Katz et al., 2001) and multiple sclerosis (Mohr et al., 1999) who reported less pain and more benefit finding, suggesting that disease severity limits benefit finding.

Fyrand, Moum, Finset, and Glennas (2002) studied disease variables and duration on social support in 264 women with rheumatoid arthritis and found that women with

longer disease duration had less emotional support than those who had not been diagnosed for as long. Also, women with more severe rheumatoid arthritis reported less social support. In addition, extroverts and people who scored low on neuroticism reported having more daily social support than introverts and those low on neuroticism. Unfortunately, a strongly significant relationship between disease duration (longer) and disease severity (worse) and social companionship existed such that individuals with more severe and longer disease duration had lower levels of companionship and problem-focused emotional support (Fyrand et al., 2002). The current study will assess disease severity and duration to account for its impact on psychosocial adjustment to living with an autoimmune disease.

The biological or biomedical issues associated with autoimmune diseases were discussed above in the section explaining the types of diseases that will be included in this study. This study will focus on the physical symptoms that an individual is experiencing. Although some studies have used objective measures of disease severity like joint measurements to assess the swelling (Barsky et al., 1999) or immunological assays of the synovial fluid in joints (Friedman, Hayney, Love, Singer, & Ryff, 2007) to examine the level of inflammation factors present, these are beyond the capabilities of the researcher and outside the scope of the current study. Though the instruments used to assess physical symptoms in the current study were self-report measures, they have been shown to accurately assess general physical functioning in individuals with autoimmune diseases.

The overall conclusion that can be drawn from these previous studies on the biological factors in autoimmune diseases is that many studies have explored the link

between physical symptoms and psychosocial factors and have made the clear correlation that as physical health declines, positive well-being and psychological health also decline. This will be explored in more depth in the following sections.

*Psychological Issues Associated with Chronic Illness.*

Of particular interest to researchers studying chronic illness is developing an understanding of how people adjust to the psychosocial stressors associated with the disease. This section will address the psychological variables chosen for the current study: depression and self-efficacy.

Studies have shown that there is a large psychosocial impact associated with having a chronic illness. Depression and anxiety are often comorbid conditions with chronic illness. The psychological impact of chronic illness has been well documented in the literature (e.g., Taylor, 1983; Afflect & Tennen, 1996 as cited in Katz, Flasher, Cacciapaglia & Nelson, 2001).

Many studies have found that living with a chronic illness is often associated with decreased psychological well-being. Depression and anxiety increase and individuals have a more difficult time coping. One psychological factor that is more prevalent in individuals with autoimmune diseases is self-blame, which has been shown to have an impact on depression and anxiety. Research on these areas will be discussed in this section. Contrary to these findings that psychological health always decreases with negative changes in physical health, a brief overview of research on positive benefit finding will also be presented here.

A study by Mangelli et al. (2002) reported that individuals with rheumatoid arthritis are more likely to be depressed or anxious, thus suggesting that newly diagnosed

individuals with RA may need counseling interventions immediately following their diagnosis. Similar results were found in a study by Nagyova, Stewart, Macejova, vanDijk, & van den Heuvel (2005). They called for more attention to the emotional factors associated with RA, a link that has been missing from the treatment recommendations for individuals with RA commonly made by physicians. In their study of 160 recently diagnosed European individuals with rheumatoid arthritis, they employed structural equation modeling to determine what mediates the relationship between pain and positive well-being, as demonstrated by Mangelli et al. (2002). They found that an individual's self-esteem and adjustment mediated the correlation between pain and positive well-being. The personality variables of self-esteem and adjustment had a profound effect on the pain and positive well-being link. This finding suggests that counselors can help people with chronic disease boost their self-esteem and adjustment to the disease in order to improve their outlook on life (Nagyova et al., 2005). Both the Mangelli et al. (2002) and Nagyova et al. (2005) studies emphasize the importance of monitoring depression and anxiety in individuals with autoimmune diseases.

### *Self-efficacy.*

Self-efficacy is a concept that was originally introduced by Bandura in 1977 and has been widely applied to many contexts. Bandura defines self-efficacy as "Beliefs in one's capabilities to organize and execute the course of action required to produce given attainments" (Bandura, 1997, p.3 as cited in Barlow, Cullen, & Rowe, 2002). Dealing with a chronic illness requires much coordination of appointments, accommodation in one's schedule, balancing of various roles, and a huge amount of flexibility. Also, in the

case of autoimmune diseases, individuals must face physical debilitation and some psychological consequences.

In previous studies of individuals with autoimmune diseases, low self-efficacy has predicted depression (Wright et al., 1996), low self-efficacy has been significantly correlated with psychological distress and worse physical functioning (Beckham, Rice, & Talton, 1994), and that self-efficacy and pain predict physical functioning (Dwyer, 1997). Lorig et al. (1989) developed a self-efficacy scale specifically designed for use in individuals with arthritis and arthritis-related diseases like autoimmune diseases. Arthritis self-efficacy has been defined as the “perceived ability to control, or manage, various aspects of arthritis, such as pain, fatigue, and emotional distress” (Barlow et al., 2002, p. 12).

In a study of 60 individuals with rheumatoid arthritis in the UK, self-efficacy about perceived ability to manage disease symptoms mediated the relationship between pain and psychological well-being (Barlow, Cullen, & Rowe, 2002). For clients who believed in their own ability to manage their health, they were likely to experience less depression or anxiety (Barlow, Cullen, & Rowe, 2002). Participants completed inventories on depression, anxiety, positive mood, and disease characteristics. They also completed the Arthritis Self-Efficacy Scale. Lower arthritis self-efficacy was associated with worse physical disability, more pain and fatigue, a less positive mood, and more anxiety and depression. They also found that depression (as measured by the Hospital Anxiety and Depression Scale) was correlated with worse disease symptomatology, pain, and fatigue. Barlow, Cullen, and Rowe (2002) found weak correlations between the physical and psychological variables and when they controlled for arthritis self-efficacy,

they found that those correlations did not remain statistically significant, thus indicating that disease self-efficacy may play a mediating role in the relationship between physical and psychological health.

Similarly, perceptions of illness were linked to worse depression, less life satisfaction, and longer morning stiffness in a study of 154 individuals with rheumatoid arthritis with varying lengths of diagnosis. This was found to be especially pronounced in those individuals who had been diagnosed for less than six months. Optimism was significantly correlated with lower reported pain and social support was correlated with less fatigue in these individuals (Treharne, Kitas, Lyons, & Booth, 2005).

Self efficacy is a construct that has been investigated in a variety of different contexts. In a study of 235 older adults, Callaghan (2005) found that self-efficacy in general and self-efficacy for one's ability to take care of one's self (self-care) was significantly related to health promotion (as measured by the Health-Promoting Lifestyle Profile II). They found a direct link between people's beliefs about their ability to take care of themselves and their actual behaviors they engaged in.

In another study of individuals with MS, self-efficacy was evaluated as a mediator of the relationship between physical activity and quality of life (Motl, McAuley, & Snook, 2007). This study was unique in that it measured physical activity by having participants wear a pedometer and accelerometer for a week rather than relying on self-reports of activity, which are often unreliable. They measured self-efficacy using the Exercise Self-Efficacy Scale and the Barriers Self-Efficacy Scale, both situation-specific measures. They found that both self-efficacy and functional limitations mediated the

relationship between physical activity and quality of life. These relationships were independent of perceived social support (Motl et al., 2007).

Self-efficacy has been shown to be an important predictor of outcome variables, mediator of physical and psychological variables, and relevant factor to consider for individuals with autoimmune diseases.

*Other psychological variables.*

In one study of individuals with Multiple Sclerosis, three factors were found that described their ways of adjusting to the disease. They were demoralization, deteriorated relationships, and benefit-finding (Mohr et al., 1999). Demoralization encompasses the feelings of helplessness and vulnerability that come with having MS. Deteriorated relationships address the changes in social relationships and feelings of victimization that were associated with MS. Conversely, benefit-finding covered the positives that grew out of a diagnosis with a chronic illness which include things like deeper relationships, appreciation of life, and spirituality (Mohr et al., 1999). This same factor structure is believed to exist in other chronic illnesses, as Mohr et al.'s results were replicated by Katz, Flasher, Cacciapaglia, and Nelson (2001) who used Mohr's chronic illness psychosocial measure with individuals with both cancer (N=56) and lupus (N=31).

The Katz et al. (2001) study found that an individual's pain rating was inversely related to their benefit-finding score suggesting that those in more pain are less likely to see the bright side of their diagnosis. Without proving causality, the inverse that individuals who see more benefits experience less pain could also be true. Katz et al. raise the question of how this might relate to an intervention such that if clients are asked to find the silver lining to their disease, will they actually do better and perceive that they



have less pain? That question inspired the current study to look at what affects individual's positive well-being.

Surprisingly to some, benefit finding and other positive coping variables are consistently found in the chronic illness literature. Constructs like post-traumatic growth (Tedeschi & Calhoun, 1995) have repeatedly emerged from studies with individuals with chronic illness. In the present study, health promoting behaviors and positive well-being will be investigated.

The three factors that emerged from Mohr et al.'s study of 94 individuals with MS illustrate the variability in responses that individuals have to chronic illness. Certainly, some people experience the entire range of reactions from demoralization to benefit finding, but others tend towards one extreme or another. Just like there is variability in whether we are optimists or pessimists, it is easy to picture individuals in a hospital ward who have decided to fight their disease, live each day as if it's their last, and advocate for other individuals as well as those who are so depressed they do not want to live another day. The personality factors that affect an individual's reaction to a chronic illness are important to study and the current study will investigate how these variables also affect behavior choices. According to Taylor (1983), most individuals who suffer through a traumatic event regain their original level of happiness or even surpass it within a year after the event. Cognitive adaptation theory proposes that regained happiness is caused by a combination of three factors: searching for meaning in the experience, regaining mastery over the event and life in general, and struggling to regain self-esteem after the setback. Individuals who have faced a serious illness or trauma often discuss how the

experience forced them to reconsider their priorities and find meaning in their lives, especially in their relationships.

Two factors that are unique to autoimmune diseases and the psychological impact of these diseases warrant consideration here. These factors are self-blame and attributions of one's illness. Self-blame has been associated with depression and anxiety and inaccurate attributions have also been linked to poor well-being.

One of the factors that differentiates autoimmune diseases from other types of chronic illness is that, by definition, the body is attacking itself. Whereas other diseases with a known origin like a specific type of bacteria or virus are more understandable, individuals with an autoimmune disease are typically left with many questions about why they have developed their disease. People with autoimmune diseases tend to blame themselves more than individuals with other types of chronic illness (Westbrook & Nordholm, 1986) and this self-blame has huge consequences for the psychological well-being of these individuals. Self-blame is associated both with depression and anxiety, the psychological variables of interest in the current study.

Self-blame plays a large role in determining how an individual with an autoimmune disease will adjust to their illness. When an individual blames herself or himself for the development of disease, they often experience poorer well-being and depression. In diseases where lifestyle factors are not believed to be at blame for the development of the disease, individuals who blame themselves are especially worse off. A study by Westbrook and Nordholm (1986) compared individuals with diseases with either high or low lifestyle involvement. The high lifestyle involvement individuals had strokes or heart attacks and the low lifestyle involvement group had arthritis or cancer;

meaning that the factors contributing to the development of the disease had very different levels of lifestyle-contributing factors causing the disease. Individuals made attributions about the development of the disease that were either self-focused or chance-focused.

Individuals who blamed themselves when there was actually a medical basis for that attribution (i.e. the self-blaming group with strokes or heart attacks) were rated as coping better and acting more appropriately and typically by the rating health care practitioners. On the other hand, individuals who blamed themselves for the development of their cancer or arthritis were rated as more depressed, poorly adjusted, coping poorly, not accepting their disability, and needing counseling and information. Also included in the study were accident victims; when they were self-blaming, they were judged as more dependent, less likeable, and having poorer prognoses than accident victims who accurately blamed chance for their accident. In individuals who had realistic self-blame when they had a disease with lifestyle factors, they coped better but self-blamers who had low lifestyle involvement diseases felt stigmatized. These results indicate that having realistic self-blame, when appropriate, is helpful to an individuals' well-being (Westbrook & Nordholm, 1986).

Individuals with autoimmune disorders may be influenced by their doctor's misattributions about the etiology of their disease, which may increase the individual's self-blame. When physical health issues *are* addressed by psychologists, there is a tendency to blame the client for her/his role in the development of the disorder. For example, people with lung cancer are chastised for smoking, individuals with HIV for their risky sexual behaviors, and people with heart disease for their poor diet and lifestyle habits. Few health care practitioners take time to think about the societal issues that

affect the individuals who are sick—tobacco companies targeting children with advertising at a young age, a lack of safer-sex education and widespread homophobia, and an emphasis on long work days and the importance of financial security in exchange for healthy lifestyle practices, just to name a few. When individuals are blamed for their choices, their sense of empowerment decreases and they adhere less to their health care regimens (Goodheart, 2006). This will be examined through asking participants in the current study about their health-promoting behaviors.

Some research has been done on what individuals attribute to be the cause of their disease. To investigate how individuals with chronic illness attribute the causes of their disease, Benedict (1995) studied 203 individuals with chronic illnesses. Participants had a variety of diseases themselves and were asked to rank the contributing causes of their own disease and then rank the causes of an illness that an anonymous other person had. A pilot study was first conducted in a different population to determine common causes that people mention for generic chronic illnesses. This list was given to the 203 participants in the study so they could choose from a predetermined list. Causes were divided into “blaming” (bad habits, diet, lack of exercise, and stress), “not blaming” (accidents, bad luck, genetic predisposition, location/weather), and “neither” (emotional suffering/life crisis, natural aging process, problems associated with work, and other).

The results of the study indicate that older participants used more blaming attributions than did younger ones. Also, individuals who had more concomitant health problems (which was surveyed through an extensive health inventory) were less likely to use blaming attributions for themselves but more likely to blame others for their illnesses.

Benedict (1995) also found that individuals who used blaming attributions for themselves were more likely to be depressed than those who believed non-blaming causes.

A critique of the Benedict (1995) study is that participants were not separated by disease or even type of disease. Individuals with more serious ailments may react differently than those with less debilitating diseases. Since the participants were asked to rank the causes of an anonymous other's illness, it would have been impossible for the participants to separate their own previous knowledge during that task. If a participant had a strong family history of a certain illness, they might think of that disease first when asked to list attributions of someone else's disease whereas a person without much exposure to chronic illness would have more of a blank slate when choosing attributions. The Benedict (1995) study could have been improved with significant methodological changes.

The consistent findings about the psychological impact of living with a autoimmune disease is that most people will develop psychological symptoms like depression and anxiety unless they reduce self-blame for the development of their disease and try to engage in positive benefit-finding. It is unclear how much biological variables like pain and restriction of activities will contribute to depression and what the directionality of that relationship is. For example, does increased pain cause increased depression or does depression cause increased pain? The relationships among these variables will be examined in the current study. There is limited support on the effectiveness of seeking psychotherapy for these psychological symptoms, though previous studies have shown that social support is an important factor in the well-being of

people with autoimmune diseases. This will be further explored in the next section of this review of the literature.

### *Social Support*

Across many studies of individuals with chronic illness, those who have more social support do better. Social support is important in a number of different forms, specifically emotional support and logistical support. An individual who is sick needs someone to listen to them and help them talk about their problems just as much as they need someone to help drive them to doctor's appointments or bring them food. Some of this support can come from a counselor, but friends and family members often are the first line social support providers when someone is facing a chronic illness.

Some research on the importance of social support has already been discussed in the previous sections. For example, the Fyrand et al. (2002) study found that women with less social support had more severe rheumatoid arthritis. They also found that levels of social support deteriorated over time. This finding supports the anecdotal evidence that individuals with autoimmune diseases have a difficult time asking for help and that friends and family members are not able to understand how to help and what to do.

Another study about social support that was previously discussed was the Mohr et al. (1999) study, which found that people with Multiple Sclerosis commonly experienced deteriorated relationships after their diagnoses and they had feelings of victimization after being diagnosed.

Some general studies have been conducted that show that individuals experience a better immune system response when they have social support and that they do better

overall with a cancer diagnosis when they have a sense of perceived social support. Immunologic studies have been conducted that show clear links between good levels of social support and an improved immune response (in diseases like cancer and infectious diseases where an improved immune response is desired unlike the current study). These general studies are outside the realm of this review of the literature but are nicely reviewed in Cohen and Herbert (1996).

Previous studies have shown that individuals with a strong social support network do not seek therapy as often. Perceptions about the availability of social support may actually be more significant than whether those individuals are available to them when they are in need (Phillips & Murell, 1994). Social support has been shown to have a significant relationship with psychological well-being in previous studies (Phillips & Murell, 1994).

For example, Kettmann and Altmaier (2008) found that social support was an important predictor of depression in individuals who had undergone a bone marrow transplant. In a study of 86 individuals who had undergone bone marrow transplants, social support (as measured by the MOS-SSS) taken before the transplant predicted depression after the transplant (as measured by the CES-D), even more accurately than pre-transplant levels of depression (Kettmann & Altmaier, 2008).

These biopsychosocial variables are believed to have an impact on the overall sense of positive well-being and health-promoting behaviors in individuals with autoimmune diseases. These two variables were chosen as criterion variables in the current study because of their impact on overall health status. An overview of these variables is provided below.

## Outcome Variables

### *Positive well-being*

The overall goal for both medical and mental health professionals is to improve the well-being of individuals with autoimmune diseases. As was discussed in the previous sections, overall well-being can be affected by biological, psychological, and social factors as well as the interaction among these variables.

Positive well-being has been studied in many different populations in previous research. The importance of positive well-being in individuals with physical health problems has been validated in different studies. A high correlation between physical health status and psychological well-being ( $r = 0.66$ ) was observed, such that individuals with poor physical health also reported doing worse psychologically (Phillips & Murell, 1994). In that study, which was comprised of older adults (over age 55), individuals who expressed emotional and psychological difficulties were more likely to talk to their medical doctor about those problems than to any other type of health care or mental health provider.

The concept of well-being is broad, far-reaching, and encompasses many different topics ranging from happiness to satisfaction to positive growth. Ryff (1989) attempted to consolidate the various ideas about positive well-being into a more parsimonious theoretical structure. She views self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth as being the main components of positive well-being. Ryff compared her ideas about positive well-being to the structure of other measures of well-being and found that her structure was robust and held many opportunities for research applications. Positive and significant correlations



with past measures of well-being were found to range from 0.25 to 0.73. The previous measures used were life satisfaction, affect balance, self-esteem, internal control, and morale (Ryff, 1989).

Part of psychological well-being is resilience, or one's ability to handle and recover from a crisis. Resilience is an important adaptive factor for people diagnosed with chronic illness. Individuals who are able to find positive meaning in their lives, and to "bounce back" from significant life setbacks like chronic illness, experience better mental health. Positive well-being appears to measure resilience, as defined by Ryff (1996). Subscales of positive well-being (PWB) include autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. These scales have been shown to change with age, such that older individuals experience less purpose in life and personal growth and more environmental mastery (Mangelli, Gribbin, Buchi, Allard, & Sensky, 2002). In the current study, positive well-being will be evaluated using the Psychological Well-being Scale (Ryff, 1989).

In a study of 104 individuals with rheumatoid arthritis, the participants reported significantly lower positive well-being scores on all of the subscales, especially in the personal growth and purpose in life subscales as compared to a community sample drawn from the United States. Low scores on positive well-being were correlated with higher levels of depression and anxiety and higher levels of pain were associated with more depression and anxiety (Mangelli et al., 2002). These findings highlight the difficulty that many individuals with rheumatoid arthritis experience and the importance of encouraging resilience and positive growth in clients with autoimmune diseases. The

results also indicate that positive well-being is associated with chronic disease in general but the disease-specific effects of rheumatoid arthritis were less significant. This finding gives support to the current study, which will investigate autoimmune diseases as a whole rather than as specific diseases. Mangelli et al.'s findings illustrate the importance of attending to general psychosocial factors with individuals with chronic illness.

One additional study of psychological well-being in individuals with autoimmune diseases bears discussion here. A study conducted by Friedman, Hayney, Love, Singer & Ryff (2007) investigated the relationship between psychological well-being and levels of plasma inflammatory factors in aging women. In a study of 135 women between the ages of 61 and 91, interleukin-6 (IL-6) levels were measured along with giving participants a number of psychological measures to complete. IL-6 has been associated with inflammation associated with Alzheimer's disease, osteoporosis, rheumatoid arthritis, cardiovascular disease, and some forms of cancer. Previous research had shown IL-6 levels to be easily affected by psychological stresses, for example depression is often associated with elevated IL-6 levels. The Friedman et al. (2007) study found that IL-6 levels were lower in individuals who had higher levels of psychological well-being, specifically lower IL-6 levels were related to higher scores on purpose in life scales. In addition, participants who had high social support had lower levels of IL-6. These results are especially significant because the researchers controlled for other demographic variables.

Positive well-being encompasses a number of different types of variables and has been shown to be related to life satisfaction and other measures of well-being in

numerous studies (Ryff, 1996). Another well-researched outcome variable in the current study was health promoting behaviors.

### *Health Promoting Behaviors.*

The definition of health has expanded beyond the physical to include mental health, as well as other nuanced areas of well-being. Positive health is defined as physical, mental, and social well-being and negative health is disease and infirmity. Research on positive health is scarce and the current study will expand on some of the limited existing research available.

In order to improve overall health, individuals with chronic illness need to choose healthy behaviors and follow the medical recommendations made for them. In addition, effective coping skills and attitudes such as having a sense of optimism and psychological well-being are important. Individuals with chronic disease must also make choices that will benefit their mental health. Health promotion has been cited as a goal of the biopsychosocial model (Hoffman & Driscoll, 2000) and some research has been done on what characteristics comprise healthy behaviors. “A multidimensional pattern of self-initiated actions and perceptions that serve to maintain or enhance the level of wellness, self-actualization, and fulfillment of the individual (p.77)” is how Walker, Sechrest, and Pender (1987) define a health promoting lifestyle. Those authors went on to research what behaviors contribute positively to a healthy lifestyle. The main goal of the Walker et al. model of health promotion is increasing autonomy over health and educating others about ways to increase good health practices.

Previous studies have found that scores on the HPLP II are correlated with population health determinants and individual risk factors for a variety of diseases, suggesting that the HPLP is measuring what it claims to measure. In a study of women at risk for cardiovascular disease, the HPLP II encompassed many of the risk factors that predicted women's risk for heart disease and was correlated with physical measures given to the participants (Sawatzky & Naimark, 2005).

Health promoting behaviors have been researched across cultures and the Health Promoting Lifestyle Practices Profile II (HPLP II) contains questions about behaviors such as exercise, eating fruits and vegetables, and believing that life has purpose that have been validated in multiple samples. One study of the HPLP II compared the health practices of nursing students in both Canada and Jordan (Haddad, Kane, Rajach, Cameron, & Al-Ma'aitah, 2004). The results showed that Canadian students took more personal responsibility for their health and felt better about their interpersonal relationships. Those two areas represent two of the subscales of the HPLP II; others are physical activity, nutrition, spiritual growth, and stress management. The HPLP II has been used in many different samples and has been shown to be a useful measure of health promotion.

In a study conducted in the UK, researchers designed an intervention aimed at increasing the level of health-promoting activities in people with Multiple Sclerosis, as well as enhancing self-efficacy and quality of life (Ennis et al., 2006). Participants in the program were 62 adults with any kind of MS who completed an eight-week interdisciplinary program. It was an outpatient health promotion and education program

aimed solely at increasing the knowledge, skills, and self-efficacy needed to improve one's level of health-promoting activities.

They found that the treatment group (compared to the control group which only completed the paper measures) reported significantly higher levels of health promoting activities after the program. This was measured using the HPLP II and they also had higher self-efficacy for completion of those activities. Those levels of increased health-promoting behaviors were maintained for three months after the program. Individuals in the treatment group also reported higher levels of mental health and general health immediately after the program and three months later, compared to the control group. Many of the participants also expressed positive feedback about the intervention and the assistance they received in improving their health-promoting behaviors (Ennis et al., 2006).

### Conclusion

This review of the literature has covered an overview of autoimmune diseases and discussed the important biological, psychological, and social factors involved in adjusting to these disorders. It is clear from the presentation of the existing research in these areas that these factors have an effect on each other, for example, decreased physical functioning was shown to affect psychological well-being and a lack of social support is associated with disease severity. The distinct contributions of these factors to the overall picture of well-being has not been examined and, in keeping with the biopsychosocial model, the goal of this study is to provide a more integrative model of how well-being and health promoting behaviors are affected by living with an autoimmune disease.

Many different biopsychosocial variables exist that can be considered in investigating how someone copes with their autoimmune disease. For the current study, the relationship of disease severity, depression, self-efficacy, and social support to the selected outcome measures were examined. These variables were chosen because of their commonality among the population of individuals with autoimmune diseases and because it was believed that they would have a significant impact on the outcome variables chosen for the current study: positive well-being and health promoting behaviors.

The goal of the biopsychosocial model (Hoffman & Driscoll, 2000) is to enhance health promotion and improve health status. The outcome variables chosen for the current study addressed two different aspects of positive health. Positive well-being is associated with overall adjustment and life satisfaction, obviously an important part of positive health. Health-promoting behaviors serve to prevent the development of further illness and allow individuals to take control of the lifestyle components of their illness. Taken together, these two outcome variables contribute important information about the overall health status of individuals with autoimmune diseases. The broad scope of the biopsychosocial variables chosen for the current study enhance our ability to tease apart the contributions that each variable makes to overall health.

## Chapter 3

### Statement of the Problem

Taken as a whole, autoimmune diseases represent the fourth most common type of chronic illness (www.aarda.org, 2008) and the unique clinical presentation of autoimmune diseases made them an ideal disease model for the current study.

Individuals with autoimmune diseases in particular are often marginalized through their interactions with medical professionals and are underserved by mental health care services (Chrisler, 2001) because of the difficulty receiving an accurate diagnosis of an autoimmune disease, the cycles of remission and relapse that make treatment challenging, and the complicated psychological and physical symptoms. Because of this, it is crucial that we better understand variables that predict engaging in health-promoting behaviors for individuals with autoimmune diseases and those that have an effect on their sense of positive well-being.

Chrisler's (2001) article was the only theoretical article found that investigated the psychosocial issues facing individuals with autoimmune disease. This is an understudied population and limited empirical work has been done investigating biopsychosocial factors that influence positive well-being and health promoting behaviors. Because there is a paucity of research examining biopsychosocial variables that predict positive well-being and health promoting behaviors, no theoretical justification could be found to support some of the questions of interest in the current study; therefore research questions rather than hypotheses formed the foundation for this research. Several hypotheses are presented as well preceding the research questions.

Hypotheses:

*Hypothesis 1: A negative relationship will exist between disease severity and social support, such that the more severe the reported disease symptoms, the lower the level of social support.*

Fyrand et al. (2002) found that individuals with longer courses of rheumatoid arthritis had less social support and this hypothesis will attempt to confirm that finding. This hypothesis will measure disease severity based on symptom self-report rather than longevity of the disease.

Fyrand, along with other researchers, studied the impact of rheumatoid arthritis on social support using a number of different methods in multiple studies. First, they looked at the size of social networks of women with autoimmune diseases. They believed that the sheer number of social contacts would decrease as a result of having rheumatoid arthritis (Fyrand et al., 2000).

Next they studied social support using self-report inventories in women with autoimmune diseases (Fyrand et al., 2001). In the 2000 and 2001 studies, they compared individuals with autoimmune diseases to control groups without such diagnoses. In a follow-up study, they looked at rheumatoid arthritis duration and disability in women with rheumatoid arthritis to see how the disease impacted their social support. All three studies found significant evidence that social support worsened after a diagnosis of an autoimmune disease, regardless of how social support and disease disability were measured (Fyrand et al., 2000; Fyrand et al., 2001, Fyrand et al., 2002).

*Hypothesis 2: A negative relationship will exist between Arthritis self-efficacy and*



*depression, such that the higher the reported level of self-efficacy, the lower the level of depression.*

Previous research by Barlow, Cullen and Rowe (2002) found that psychological health was correlated with self-efficacy and physical disability status was also correlated with self-efficacy in a sample of 82 individuals with rheumatoid arthritis. They examined interventions aimed to increase self-efficacy and found that those interventions improved depressive symptoms as well.

A debate about how to study self-efficacy has existed in the literature. Should it be measured as a global construct or is it best studied through specific measures? Bandura (1997) indicated that self-efficacy is best studied using a specific task or goal. In the current study, the Arthritis Self-Efficacy scale (Lorig et al., 1989) measured specific self-efficacy about one's perceived ability to decrease disease symptoms. This hypothesis was designed to replicate the findings of the Barlow et al. (2002) study to investigate the link between specific self-efficacy and depression.

### *Research Questions*

*Research Question 1: How do biopsychosocial variables affect positive well-being in individuals with autoimmune diseases?*

Previous studies have shown that individual biological, psychological, and social variables do have an impact on positive well-being in individuals with autoimmune diseases, though few studies have evaluated the unique contributions of multiple biopsychosocial variables on well-being.

Studies like Mangelli et al. (2002), Barsky et al. (1999), and Westbrook and Nordholm (1986) found significant correlations for objective measures of disease severity with depression, self-blame, and overall well-being, suggesting that biological variables like disease severity do play a role in influencing positive well-being.

Psychological variables like depression, illness intrusion, and self-efficacy are also believed to be related to positive well-being. By definition, positive well-being involves positive affect and not symptoms of depression (Ryff, 1989) and illness intrusion has been shown to have a negative effect on well-being in other types of illnesses (Devins et al., 1997).

The connection between social support and positive well-being was explored by Friedman et al. (2007), where they found that participants with more social support scored higher on positive well-being. In addition, the participants who had higher well-being had lower levels of inflammatory factor in their blood, again suggesting a relationship between biological factors and well-being. However, psychological variables were not investigated in this study.

Therefore, the current study used all three components of the biopsychosocial model (Hoffman & Driscoll, 2000) to explore relationships to well-being in greater depth.

*Research Question 2: How do biopsychosocial variables affect health-promoting behaviors in individuals with autoimmune diseases?*

The foundation of the Health Promoting Behavior Profile which was used in this study to examine health behaviors is based in the idea that the measured behaviors help individuals promote their health and decrease the effects of their disease. Extensive

research on correlations between the items in the HPLP-II and health promoting activities was conducted (Walker, Sechrist, & Pender, 1987). This research question examined the relationship between selected biopsychosocial variables and health-promoting behaviors to help clarify factors that predict self-report of engagement in healthy behaviors.

Walker, Sechrest, and Pender (1987) define health-promoting behaviors as: “A multidimensional pattern of self-initiated actions and perceptions that serve to maintain or enhance the level of wellness, self-actualization, and fulfillment of the individual (p.77).” The relationship between the biopsychosocial variables examined in the current study and wellness, self-actualization, and fulfillment had not been studied in persons with autoimmune diseases but it was believed that these variables would play a role in health-promoting behaviors based on studies conducted in women with cardiovascular disease (Sawatzky & Naimark, 2005).

*Research question 3: Do psychosocial variables mediate the relationship between the biopsychosocial variables and positive well-being?*

*Research question 3a: Does self-efficacy mediate the relationship between depression and positive well-being?*

Previous studies have shown that self-efficacy has played a role in mediating other psychological variables (Lowe, 2008). In the current study, disease-specific self-efficacy was examined to see if it mediated the relationship between depression and self-efficacy. Previous studies have demonstrated the link between autoimmune diseases and depression (e.g., Mangelli et al., 2002), so it was expected that this sample would report a high level of depression. Depression has been linked to decreased levels of well-being

(Ryff, 1989), so it is expected that depression and low levels of well-being will be associated. The current study examined whether self-efficacy served to mediate that relationship between depression and well-being.

*Research question 3b: Does social support mediate the relationship between depression and positive well-being?*

The connection between social support and positive well-being was explored by Friedman et al. (2007), where they found that participants with more social support scored higher on positive well-being. Another study about social support that was previously discussed was the Mohr et al. (1999) study, which found that people with Multiple Sclerosis commonly experienced deteriorated relationships after their diagnoses and that they had feelings of victimization after being diagnosed.

The relationship between depression and social support has been shown in previous studies (Kettmann & Altmaier, 2008) and the current study attempted to follow-up on previous findings to see if social support was actually a mediator.

Previous studies have demonstrated the link between autoimmune diseases and depression (e.g., Mangelli et al., 2002), so was expected that this sample would report a high level of depression. Depression has been linked to decreased levels of well-being (Ryff, 1989), so was expected that depression and low levels of well-being would be associated. The current study examined whether social support served to mediate that relationship between depression and well-being.

*Research Question 4: How will natural groupings form among individuals with autoimmune diseases on the predictor variables of interest (disease severity, depression,*

*self-efficacy, and social support)?*

This research question served as an extension of the previous two research questions. Cluster analyses allow researchers to look at data in a different way by identifying groups of individuals who form clusters based on the variables of interest, and thus, some relationships among these variables may become clearer through this approach and add to the findings of the other analyses used in the current study (Borgen & Barnett, 1987).

The natural groupings that form may suggest a rationale for future studies, such as intervention studies, to group participants in specific ways. In other words, Ward's (1963) clustering method is designed to allow researchers to use exploratory data analyses to understand connections among variables that may differ from those found through regressions.

## Chapter 4

### Method

In this chapter, an overview of the study design, participants, procedures, and measures will be presented. Information about how the study was conducted, how measures were chosen, and how data were analyzed will be provided.

#### *Design Statement*

This study used a correlational, field-study, cross-sectional design. There were four predictor variables and two criterion variables. The predictor variables measured the three components of the biopsychosocial model (biological, psychological, and social). The biological variable was disease severity. The psychological variables were depression and self-efficacy. The social variable was social support. The criterion variables were positive well-being and health-promoting behaviors.

Data were analyzed using Pearson correlations and multiple regression analysis. Data were also analyzed using Ward's (1963) method of cluster analysis to identify natural groupings in the data. The goals of cluster analysis are exploration, confirmation, and simplification of data (Borgen & Barnett, 1987). Survey data and some brief qualitative data were collected from participants using an online survey.

#### *Power Analysis*

An a priori power analysis for a multiple regression design with a power equal to 0.80 and an  $\alpha$  level equal to 0.05 yielded a sample size of 75 to detect a medium effect size (0.20). Data needed to be collected from approximately 75-120 participants to ensure a large enough sample size to detect a medium effect size. Data were collected from 175 people, which was enough to detect even a small effect size.

### *Participants*

Participants in the current study were 175 individuals with autoimmune diseases. They were self-selected for the study and all of them reported being diagnosed with a valid autoimmune disease. See Table 3 for a summary of the participants.

Participants were all individuals who had been formally diagnosed with autoimmune diseases by a health care provider and were over age 18. Participants with non-connective tissue or non-musculoskeletal-type autoimmune diseases were eliminated from the final sample. More information about the diagnoses of the participants can be found in Table 14. In addition, participants who did not indicate a diagnosis were eliminated from the final sample. They ranged in age from 18-84. Most of them were female (90%) and white/European-American (94%). Participants represented at least five different ethnicities, even though the overwhelming majority of participants were white. Many were well educated with only 14% reporting a high school degree or less. Participants reported a wide range of occupations, disease symptoms, and ways that their autoimmune disease had impacted their lives. No restrictions were placed on the amount of time since the individuals were diagnosed with an autoimmune disease so the length of time since diagnosis ranged from within the past month (2%) to over 20 years ago (11%). See Table 3 for more information about the participants.

| Demographics                 | Groupings                       | Valid N (Percentage) |
|------------------------------|---------------------------------|----------------------|
| Age                          | 18-24                           | 10 (6%)              |
|                              | 25-34                           | 26 (15%)             |
|                              | 35-44                           | 34 (19%)             |
|                              | 45-54                           | 50 (29%)             |
|                              | 55-64                           | 38 (22%)             |
|                              | 65-74                           | 13 (7%)              |
|                              | 75-84                           | 4 (2%)               |
| Gender                       | Female                          | 157 (90%)            |
|                              | Male                            | 17 (10%)             |
| Race/Ethnicity               | Asian-American/Pacific Islander | 2 (1%)               |
|                              | White/European-American         | 165 (94%)            |
|                              | Hispanic/Latino(a)              | 1 (1%)               |
|                              | Biracial/Multiracial            | 2 (1%)               |
|                              | Black/African-American          | 4 (2%)               |
| Highest Education completed  | Middle school/Junior High       | 1 (1%)               |
|                              | High School                     | 24 (14%)             |
|                              | Technical School                | 10 (6%)              |
|                              | Two-year college                | 26 (15%)             |
|                              | Some college                    | 27 (15%)             |
|                              | Four year college degree        | 36 (21%)             |
|                              | Some graduate school            | 10 (6%)              |
|                              | Masters degree                  | 26 (15%)             |
| Time since diagnosis         | Doctoral/Professional Degree    | 15 (9%)              |
|                              | Within the past month           | 3 (2%)               |
|                              | 1-6 months ago                  | 8 (5%)               |
|                              | 6 months-1 year ago             | 4 (2%)               |
|                              | 1-2 years ago                   | 16 (9%)              |
|                              | 2-5 years ago                   | 36 (21%)             |
|                              | 5-10 years ago                  | 44 (25%)             |
|                              | 10-20 years ago                 | 44 (25%)             |
| Weekly hours worked for pay? | More than 20 years ago          | 20 (11%)             |
|                              | 0                               | 53 (30%)             |
|                              | 1-5                             | 13 (7%)              |
|                              | 6-20                            | 11 (6%)              |
|                              | 21-40                           | 42 (24%)             |
|                              | 41-60                           | 47 (27%)             |
|                              | Over 60                         | 3 (2%)               |

Note: Percentages do not add to 100% due to rounding



Participants were recruited through multiple online methods including snowball emails, emails sent through the Arthritis Foundation of Iowa, and publication through online list-servs with the Myositis Association, National Multiple Sclerosis Society, Lupus Foundation of America, American Thyroid Association (Hypothyroidism and Hashimoto's Disease), Celiac Disease Foundation, Sjögren's Syndrome Foundation and some of the smaller regional branches of these associations. Due to the mass emails that were sent out to many different contacts, it is impossible to tell how many people received the emails. Membership in these organizations is not just limited to individuals with the disease and also includes family members, friends, and health care professionals in the field. Participants were also recruited through in-person physician recommendations and posters at the National Institute of Arthritis and Musculoskeletal and Skin Diseases clinics in the Washington, D.C. metropolitan area and the Mercy Arthritis Clinic in Urbandale, Iowa.

### *Measures*

*Demographic Form.* (Appendix A) Clients were asked to describe their disease state and specific type of condition, when they were diagnosed, types of limitations they experience, type of medical treatment received, age, family structure, race, education, income, job, disability status, and history of counseling. A few open-ended questions were also included in the demographic form including, "What factors would affect your willingness to seek psychotherapy/counseling?" "What do you think caused your autoimmune disease?" and "What is a positive consequence you've experienced as a result of having an autoimmune disease?"

### *Biological Measure*

*World Health Organization Disease Assessment Schedule II (WHO-DAS II)* (World Health Organization, 2000). See Appendix B for more information about the WHO-DAS II. The WHO-DAS II is used to assess daily functioning in six domains. An overall score can be used to describe overall disability as well as functioning in each of the areas. The WHO-DAS II was designed to identify needs, match individuals to interventions, track functioning over time, and measure clinical outcomes and treatment effectiveness ([www.who.int/icidh/whodas](http://www.who.int/icidh/whodas), 2008). There are a few different versions of the WHO-DAS II available and the 36-item self-administered version was chosen for the current study due to its comprehensiveness and generalizability. The WHO-DAS II is not a disease-specific measure; instead, it is intended to give results of disability status that can be compared to other disease groups.

The WHO-DAS II has six subscales including Understanding and Communicating (sample item: In the last 30 days, how much difficulty did you have in: "Starting and maintaining a conversation), Getting Around ("Moving around inside your home?"), Self Care ("Washing your whole body?"), Getting along with people ("Dealing with people you do not know?"), Life Activities ("Getting all the household work done that you needed to do?"), Work ("Doing your most important work/school tasks well?"), and Participation in Society ("How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?"). Items are scored on a 5-point Likert scale ranging from 1=Not at all to 5=Extremely and all items have the prompt, "In the last 30 days, how much difficulty did you have in..." An overall score can be obtained without the work subscale for

individuals who do not work. In the current study, many participants reported not working so the overall score without the work subscale was used. A total score is obtained by using SPSS syntax, which contains algorithms that are inputted directly into SPSS, that scores the inventory by summing the scores on each of the items and dividing the scores by 100 and the resulting total score can range from 0-100. The work subscale included four items. The total scores still ranged from 0-100 without the work subscale because the scores were standardized relative to the total number of items (32 versus 36 on the subscale). This syntax was available directly from the World Health Organization. Most commonly, the total score is used to indicate an individual's perception of their disability status. Subscales can be used to describe functioning in specific areas but the total score was used in the current study (without the work subscale).

The WHO-DAS II is designed to serve as an indicator of one's perception of their disability and corresponds to functional impairment as measured by the International Classification of Disability system. It has been used as an estimate of disease severity, but is most effectively used as a marker of functional impairment.

Reliability and validity data have been collected in 16 testing centers across 14 countries with a wide range of populations. For the total scale, as described above and used in the present study, Cronbach's  $\alpha$  of .91-.93 were found by Adib-Hajbaghery and Aghanhoseini (2007) and .95 by Chwastiak and Von Korff (2003). Test-retest-reliability ranges from .65-.78 (Chwastiak & Von Korff, 2003). The WHO-DAS II has high levels of convergent validity with other scales measuring disease severity including the Medical Outcomes Study SF-36 ( $r=-0.77$ , Chwastiak & Von Korff, 2003); the Patient Health Questionnaire ( $r= 0.71$ , Chwastiak & Von Korff, 2003); and the Work Limitations

Questionnaire, physical subscale ( $r= 0.71$ , Chwastiak & Von Korff, 2003). Note that the negative correlation with the MOS SF-36 is due to a higher score on the SF-36 representing better functioning, whereas a higher score on the WHO-DAS II represents increased physical impairment. The Cronbach's  $\alpha$  for the current study was .95.

### *Psychological Measures*

*Center for Epidemiological Studies-Depression Scale* (Radloff, 1977). The CES-D is a 20-item scale that includes a list of items associated with depression like “I felt lonely.” And “I did not feel like eating, my appetite was poor.” Participants were asked to rate the items on a four point Likert scale with identifiers ranging from 0=rarely to 3=all of the time. A total score is obtained by summing the scores on all items. Scores range from 0 to 60 with higher scores indicating more depressed mood. The CES-D has been widely used in studies of depression based on its close relationship to components of depression that have been identified in the literature (Gignac et al., 2004). Because of its inclusion of some physical items, it has been ideal for investigating depression in individuals with physical health issues. It has been validated for samples with arthritis (Blalock et al., 1989) and is a well-validated and well-respected instrument. It has been shown to have good factorial, discriminant, and construct validity (Orme, Reis, & Herz, 1986). The original internal consistency  $\alpha$  for a general population was 0.85 and for a patient population was 0.90 (Radloff, 1977). Test-retest reliability was found to be 0.51 in a health comparison group and 0.57 in a patient population (Hann, Winter, & Jacobsen, 1999). Please see appendix C for a sample of the items.

The CES-D has been used in similar populations including a group of 54 individuals with Rheumatoid Arthritis who also had confirmed diagnoses of depression

(Parker et al., 2003) and 492 individuals with Rheumatoid or Osteoarthritis who were working (Gignac et al., 2004). The Parker et al. study found a Cronbach's  $\alpha$  of 0.89 and the Gignac et al. study found a Cronbach's  $\alpha$  of 0.92. Scores greater than 16 indicate evidence of depression. Recent studies have evaluated the CES-D for use in rheumatoid arthritis populations and have determined that 19 would be a more appropriate cut-off for levels of clinical depression due to the overlap of somatic symptoms (Covic et al., 2007). The Gignac et al. study of working people with arthritis found a mean of 10.88 and a standard deviation of 10.06 with an overall range of 0-48 (Scale range is 0-60). Parker et al. study compared groups with different kind of treatments for their depression. One group received cognitive-behavioral therapy and pharmacologic treatment, another group participated in a psychoeducational group to serve as a control for the cognitive-behavioral therapy and received pharmacologic treatment; another group received pharmacologic treatment and no therapy or psychoeducation. All of the groups continued to receive their ongoing rheumatologic care. The pre-intervention score for the three groups on the CES-D was 28.9, post-intervention was 14.9, at a six-month follow up was 15.8, and at a 15 month follow up was 11.9 (Parker et al., 2003) suggesting that this measure reflected response to treatment. The Cronbach's  $\alpha$  for the current study was .91.

*Arthritis Self-Efficacy.* (Lorig, Chastain, Ung, Shoor, & Holman, 1989) Please see appendix D for a copy of the measure. The Arthritis Self-Efficacy Scale (ASE) measures whether people feel confident in their ability to manage their pain, functionality, and other symptoms (including psychological symptoms). Many autoimmune diseases have arthritis-type symptoms and the scale has been designed for use in individuals with autoimmune and musculoskeletal disorders due to the similarity in symptoms. It has

been used in individuals with rheumatoid arthritis (Barlow et al., 2002), osteoarthritis (Hartman et al., 2000), fibromyalgia (Gowans et al., 2001) and general, non-specific musculoskeletal disorders (Malmgren-Olsson & Branholm, 1992).

It is a 20-item scale that has been used with people with arthritis and arthritis-related diseases. Since most autoimmune diseases have impairment that is similar to arthritis, it was chosen for the current study. Items are rated on a 10-point Likert scale ranging from 1=very uncertain to 10=very certain, with a total score ranging from 20-200. Higher scores indicate higher levels of self-efficacy. No items are reverse scored. Subscales include the 5-item Pain Self-Efficacy (PSE) subscale (sample item: “How certain are you that you can decrease your pain quite a bit?”), 9-item Functional Self-Efficacy (FSE) subscale (“How certain are you that you can walk 100 feet on flat ground in 20 seconds?”), and the 6-item Other Symptoms Self Efficacy (OSE) subscale (“How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?”). Previous research has shown that the FSE subscale is highly correlated with measures of severity and symptomatology (Lorig et al., 1989). The overall ASE total score was used in the current study.

Internal consistency for the ASE has been good. In a sample of 97 individuals with arthritis or arthritis-related diseases, Cronbach’s  $\alpha$  of .75 for the PSE, .90 for the FSE, and .87 for the OSE were obtained (Lorig et al., 1989). Test-retest reliability has also been good with .87 for the PSE, .85 for the FSE, and .90 for the OSE (Lorig et al., 1989). Many previous studies have omitted the FSE due to high correlations with other disability scales so internal consistency and test-retest reliability data are reported for the subscales here, though the full scale was used in the current study and that has been

shown to be an acceptable use of the scale as well (Lorig et al., 1989). Validity studies have shown high levels of correlation between the FSE and Health Assessment Questionnaire (Lowe et al., 2008). Readability and clarity of the scale have been adapted; creators of the ASE redesigned it so it had a 10-item Likert Scale to get a more complete range. Previous piloting by the creators of the scale showed that participants tended to circle the labels for the numbers if they were anchored in the middle so they changed the design to place anchors at the end of the scales. They recommended coding the lower number if two numbers were concurrently circled (Lorig et al., 1989), however, this was not a problem in the current study because the survey was available online and only one number could be selected. The Cronbach's  $\alpha$  for the current study for the total score was .94.

#### *Social Measures.*

*Medical Outcomes Study-Social Support Scale* (Sherbourne & Stewart, 1991).

The MOS-Social Support Survey is one part of the larger Medical Outcomes Study, which is a large-scale study of individuals with various medical problems. The MOS-SSS is made up of four subscales, which include emotional/informational support, tangible support, affectionate support, and positive social interaction, though a total social support score is determined by summing all items. The overall scale, used in the present study, consists of 19 items, which participants ranked on a five point Likert scale, ranging from 1=None of the time to 5=All of the time. Sample items include "Someone to confide in or talk to about yourself or your problems" and "Someone to help with daily chores if you were sick". Total scores can range from 19 to 95 with higher scores indicating more social support. Internal consistency estimates in previous studies are

above 0.91 for all of the subscales and 0.97 for the overall scale and test-retest reliability is 0.78 for the entire scale (Sherbourne & Stewart, 1991). The MOS-SSS has been widely used and has high levels of validity, showing strong correlations with indices of loneliness, role functioning, social activity, functional support, and marital functioning (Sherbourne & Stewart, 1991).

Previous studies have used the MOS-SSS in samples of newly registered people with HIV/AIDS (Burgoyne & Saunders, 2000), individuals who had undergone bone marrow transplants (Kettman & Altmaier, 2008), and women with postpartum depression (Surkan et al., 2006) among others. These studies show the consistent link between diminished social support and depression. Please see appendix E for a copy of the measure. The Cronbach's  $\alpha$  for the total scale which was used in the current study was .95.

#### *Outcome Measures.*

*Positive Well-Being* (Ryff, 1989). The Scales of Psychological Well-Being (SPWB) are made up of different aspects of positive functioning. There are six subscales, which represent self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. The total score is used to measure overall psychological well-being and was used in the current study. Each subscale was equally split between positively and negatively worded items. In the current study, 20 items were positively worded and 22 were negatively worded. The items are scored on a six-point Likert scale ranging from 1=strongly disagree to 6=strongly agree with higher scores indicating higher levels of positive well-being. Prior to analysis, the negatively worded items were reverse scored, such that higher scores



indicate increased well-being. Total scores can range from 42 to 252. Examples of items include “I enjoy making plans for the future and working to make them a reality” and “I have difficulty arranging my life in a way that is satisfying to me.”

Internal consistency  $\alpha$  coefficients for each of the six scales range from 0.82 to 0.90 (Schmutte & Ryff, 1997). The total scale has high internal consistency ( $\alpha$  range 0.86-0.93, Ryff, 1989) and test-retest reliability ( $\alpha$  range 0.81-0.88, Ryff, 1989) and has been widely used in studies of positive well-being (Ryff & Singer, 1996). The 42-item version of the scale was found to have enough items to support a six-item structure and had strong internal consistency. Though previous studies have used scales with varying numbers of items, the 42-item scale (7 items on each of the 6 subscales) was chosen for the current study (Abbott, Ploubis, Huppert, Kuh, Wadsworth, & Croudace, 2006). The total score on the SPWB has high correlations with other measures of happiness, satisfaction, and depression including the CES-D, Zung Depression Scale, Affect Balance Scale, single-item happiness measures, and Life Satisfaction Index (Ryff & Keyes, 1995). Please see appendix F for a copy of the scale. Cronbach’s  $\alpha$  for the current study was .92.

*Health-Promoting Lifestyle Profile II* (Walker, Sechrist, & Pender, 1987). The HPLP II is a revised version of the original Health Promoting Lifestyle Profile. It was revised to incorporate more recent research about health promoting behaviors and to accurately reflect what is known about the health benefits of different activities.

It is a 52-item scale that is scored on a four-point Likert scale (responses are never, sometimes, often, or routinely). Items were scored so that 1=never, 2=sometimes, 3=often, and 4=routinely. Total scores can range from 52 to 208 with higher scores indicating more health promoting behavior practices such as exercising more frequently

and eating more fruits and vegetables. The overall score, which was used in the present study, can be used as an index of health promoting behaviors and the subscales (health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management) can be used individually. Items include things like “Choose a diet low in fat, saturated fat, and cholesterol” and “Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling).

Validity and reliability were measured in a sample of 712 adults (Walker & Hill-Polerecky, 1996). Construct validity has been supported by factor analyses in various samples that support a six-factor solution. Cronbach’s  $\alpha$  for the entire scale was 0.94 and ranged from 0.74 to 0.87 for the subscales. Three-week retest stability was 0.89 (Walker & Hill-Polerecky, 1996). High correlations with the Personal Life Questionnaire and other measures of quality of life and perceived health status were observed (Walker & Hill-Polerecky, 1996). Please see appendix G for a sample of the items. Cronbach’s  $\alpha$  for the current study was .94.

*Summary of Measures.* Information about the measures and their psychometric properties is provided in Table 4 for reference.

| <b>Table 4: Psychometric and scoring information about measures</b> |                          |   |  |  |
|---|--------------------------|---|--|--|
| <i>Name of Measure</i>  | <i># of items; Range</i> | <i>Scoring</i>  | <i>Previous Cronbach's <math>\alpha</math></i>   | <i>Test-Retest</i>   |
| Arthritis Self-Efficacy (ASE)                                       | 20; 20-100               | Likert scale 1-10; 1=very uncertain to 10=very certain; higher scores indicate higher self efficacy                             | 0.75, 0.90, and 0.87 for pain, function and other symptoms subscale (Lorig et al., 1989) | 0.87, 0.85, and 0.90 for pain, function, and other symptoms subscale (Lorig et al., 1989)          |
| Center for Epidemiologic Studies Depression Scale (CES-D)           | 20; 0-60                 | Likert scale 0-3 with 0=Rarely or none of the time and 3=All of the time; higher scores indicated more depression               | 0.92 in working arthritis population (Gignac et al., 2004)                               | 0.51 in a health comparison group and 0.57 in a patient population (Hann, Winter & Jacobsen, 1999) |
| Health Promoting Lifestyle Profile (HPLP-II)                        | 52; 52-208               | Likert scale 1-4 with 1=Never and 4=Routinely; higher scores indicate more health promoting behaviors                           | 0.94 (Walker & Hill-Polerecky, 1996) in a large sample                                   | 0.89 (Walker & Hill-Polerecky, 1996)   |
| Medical Outcomes Study-Social Support Scale (MOS-SSS)               | 19; 19-95                | Likert scale with 1=None and 5=All; higher scores indicate more social support  | 0.91 (Sherbourne & Stewart, 1991)  | 0.78 (Sherbourne & Stewart, 1991)  |
| Scale of Positive Well-Being (SPWB)                                 | 42; 42-252               | Likert scale with 1=Disagree Strongly and 6=Agree Strongly; higher scores indicate more well-being                              | 0.86-0.93 (Ryff, 1997)   | 0.81-0.88 (Ryff, 1989)   |
| World Health Organization-Disability Assessment Schedule (WHO-DAS)  | 36; 0-100                | Likert Scale 1-5 with 1=Very Good or no problems and 5=Extreme/Cannot Do/ Very Bad; higher scores reflecting greater disability | 0.95 (Chwastiak & Von Korff, 2003)   | 0.65-0.78 (WHO-DAS II, 2002)   |

*Procedures.*

*Participant Recruitment.* Participants who had been previously diagnosed with an autoimmune disease and were over age 18 were eligible for the study. Participants were recruited through online and in-person methods. Participants were told that they could enter their email address at the end of the survey to have a chance of winning one \$50 Target gift card. One participant was selected at random and contacted via email to inform them that they had won the gift card, which was subsequently mailed to the address they provided.

The Arthritis Foundation of Iowa assisted in recruitment and requested an online survey that could be sent to potential respondents via email, list-servs, and in online newsletters rather than paper surveys. Participants were also recruited from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), at the National Institutes of Health (NIH) through posters placed at their clinics directing them to the survey website link.

Recruitment of participants occurred at two sites through NIAMS (Cardozo Clinic, located in Washington, D.C. and the National Institutes of Health main campus located in Bethesda, Maryland) via posted announcements of the study. The Community Health Center provides health care services to individuals primarily from the Cardozo community that is approximately 40% African-American, 40% Latino(a), and 20% Caucasian and Asian-American. The Clinical Center located in Bethesda, MD reaches an international population and also includes individuals from the Washington D.C. metropolitan community. Participants were directed to participate in the study by posters placed around the clinic. The results of the study indicate that very few participants from

the NIAMS clinics participated in the study because the online methods of recruitment were far more successful than were the posters soliciting participation.

Participants were also recruited through the Arthritis Foundation of Iowa. The Director of the foundation requested that an online survey be made available to their sample because he believed that the participants would complete an online survey more readily than paper surveys. Through the foundation list-servs, the director sent an email to 180 individuals with Rheumatoid Arthritis and invited them to participate. The hyperlink to the survey was made available in the email so participants could click on the link and be directly connected to the survey. The staff of the Arthritis Foundation of Iowa was also extremely helpful in recruiting participants. Many of them sent personal emails to their friends and colleagues with Rheumatoid Arthritis or Lupus and encouraged them to participate. This strategy was highly effective in getting eligible individuals to fill out the survey.

Physicians and research staff at the Mercy Arthritis Clinic in Urbandale, IA were helpful in previewing the survey and verifying that it would be relevant for people with autoimmune diseases. The Mercy Arthritis Clinic was willing to help with recruitment but the other methods were successful so quickly that their population was not utilized. Also, due to the initial demographic bias towards white, female participants, it was determined that adding participants from the Mercy Arthritis Clinic would not diversify the sample at all. This population is largely Caucasian and from a rural background. These individuals have a higher SES, on average, than the participants that were recruited from the Cardozo Clinic. They received similar types of medical care as the participants from the NIAMS clinics but are not enrolled in other research studies.

Emails were sent to the major national foundations for the most common autoimmune diseases. These included the Myositis Association, National Multiple Sclerosis Society, Lupus Foundation of America, American Thyroid Association (Hypothyroidism and Hashimoto's Disease), Celiac Disease Foundation, Sjögren's Syndrome Foundation and some of the smaller regional branches of these associations. The National Multiple Sclerosis Society and Myositis Association responded that they sent out the website link to their members, and there was a large representation of those individuals in the final sample.

Finally, participants were recruited through snowball techniques through the researcher's personal and professional contacts. Friends, family members, colleagues, and students sent out the website hyperlink to others and encouraged them to participate. This was the method by which the majority of participants were recruited. Collectors were set-up in Survey Monkey to differentiate among the means by which people heard about the survey. This did not track IP addresses or contact information of the participants but was able to record the most popular recruitment methods.

Participants that were recruited via the internet were also given the opportunity to receive a paper copy in the mail or receive an email with an attachment with the survey to mail back in an envelope. Five participants requested this method of survey submission. These individuals indicated that they were not "internet-savvy," did not have a computer, or had disability that impaired with their ability to use a computer. These participants were given a stamped and addressed envelope in which to mail back the survey after they completed it.

*Survey Development.* The survey was created using Survey Monkey

([www.surveymonkey.com](http://www.surveymonkey.com)). Survey Monkey is a website that is designed to help researchers input their survey questions directly and it formats the webpage for users. Some customization is available but the program has a similar format for each survey, which aided in the ease of survey design. Unfortunately, Survey Monkey does not allow for counterbalancing of measures so all participants took the measures in the same order.

*Participant Protocol.* After participants received the website hyperlink via email or after seeing it on a poster, they were directed to the specific website for this study. The first page of the survey was the consent form. Participants had to read through the consent form and click on a button at the bottom of the page indicating that they had read the entire page and agreed to participate (over age 18 and diagnosed with an autoimmune disease). They were made aware of the risks and benefits of participation and that they could discontinue at any time. They were also informed that the survey was anonymous and their responses would not be linked to their contact information or names.

The entire survey had a graphic at the top of the page that allowed participants to see how much of the survey remained (e.g. after page one, they could see that had completed 11% of the survey). The survey was designed so that participants could always read the question prompts and item anchors, even if they scrolled down the page because the prompts and anchors were repeated midway through each page. The survey took approximately 30 minutes to complete.

After the introduction and consent form, participants filled out the Arthritis Self Efficacy Survey, Scales of Psychological Well-Being, Medical Outcomes Survey-Social Support Scale, Health Promoting Lifestyle Profile II, Center for Epidemiological Studies-Depression Scale, World Health Organization Disability Assessment Schedule, followed

by the demographic form which included the open ended questions. The last page of the survey was the place for participants to leave their email address if they wanted to register for the gift card lottery. The order of measures was chosen to alternate longer and shorter measures.

A total of 362 individuals visited the survey website and participated or perused the survey past the first page. Of these, 216 individuals completed the survey, which was 60% of the site visitors. It is important to note that health care professionals and others could visit the survey website so it is difficult to ascertain what percentage of those visiting the website actually met the criteria for participation. A total of 22 individuals did not indicate a diagnosis and were eliminated from the final sample. A total of 16 individuals were eliminated from the final sample for having autoimmune diseases that were not considered connective tissue diseases or musculoskeletal type autoimmune diseases. A final 3 participants were eliminated for leaving large portions of the survey blank (an entire measure or more), resulting in a final sample of 175 participants.

A hit counter was created for the various methods of distributing the survey, tracking participants via a different website link sent to participants from each recruiting source. The website links directed participants to the same copy of the survey but tracking of the differential recruitment rates occurred through the different links that participants originally received. This counter tallied responses after individuals clicked past the first page of the survey. Posted signs at the Mercy Arthritis Clinic, NIAMS, and the Arthritis Foundation only generated 2 survey hits. Emails sent to the primary investigator's students generated 26 responses, snowball emails generated 217 responses, and emails sent to the primary investigator's professional contacts generated 117



responses. Clearly, the recruiting methods distributed to personal contacts via email were most effective. Emails sent to the online support groups of the various organizations were linked to the snowball email collector.

After participants completed the surveys and demographic form, which followed the surveys, they were given the opportunity to enter their email address for a chance to win a \$50 gift certificate. Participants were made aware that this was not connected to their responses and was not mandatory. Out of the 216 participants, 152 included their email address into the lottery. Following that, a thank you page appeared to let participants know they were finished and that their participation was appreciated.

*Description of an analysis of open-ended questions.*

To further be able to describe and explore the characteristics and experiences of the participants, nine open-ended questions were included in the survey and four were analyzed. The five questions that were not analyzed were: “How has your autoimmune disease affected your ability to work?” “How has your autoimmune disease affected your relationships?” “What types of treatments have you received for your autoimmune disease(s)” and “What other health problems do you have?” and “What else would you like to tell us about your experience?” These questions were not analyzed for a few different reasons. In the case of the last question, very few participants answered “What else would you like to tell us about your experience?” and no common themes were found among those that did respond. The questions about work and relationships were deemed too far beyond the scope of the current study and the questions about treatments and other health problems provided a context for the individual’s experience but it was determined that analyzing the type of autoimmune disease that an individual gave enough

qualitative background for the current study (See Table 14).

The questions that were chosen for analysis were: “What do you believe caused your autoimmune disease?” “Have you been given a medical explanation for the cause of your autoimmune disease?” “What is a positive consequence you have experienced as a result of having an autoimmune disease?” and “What would affect your willingness to seek counseling or psychotherapy?” The questions that were not coded were deemed outside the realm of the study (e.g. effects on work and relationships, other medical problems and treatments) and because responses to the questions were too diffuse. The final question included some interesting responses but was difficult to code due to participants’ wide range of comments.

Participants’ responses to these questions were coded by three raters. First, the researchers (a professor in the Counseling Psychology department and a graduate student in Counseling Psychology) came to consensus about the coding categories. Then, the questions were rated by the graduate student researcher and two other graduate students in Counseling Psychology with extensive experience in qualitative research. Inter-rater agreement on the three questions was calculated in SPSS using Cohen’s kappa. This statistic is commonly used in qualitative research to explore inter-rater agreement and is designed to compare raters two at a time. Those kappa statistics are shown in Table 5.

| <b>Table 5: Kappa inter-rater agreement for open-ended questions</b> |        |       |
|--|--------|-------|
| Question   | Raters | Kappa |
| 1  | 1-2    | .95   |
| 1  | 1-3    | .94   |
| 1  | 2-3    | .94   |

|   |     |     |
|---|-----|-----|
| 2 | 1-2 | .79 |
| 2 | 1-3 | .79 |
| 2 | 2-3 | .84 |
| 3 | 1-2 | .80 |
| 3 | 1-3 | .87 |
| 3 | 2-3 | .84 |

Overall, the raters had higher levels of agreement on question 1 compared to the other questions (“What do you believe caused your autoimmune disease?”) and lower levels of agreement on questions 2 (“What is a positive consequence you have experienced as a result of having an autoimmune disease?”) and question 3 (“What would affect your willingness to seek counseling or psychotherapy?”). The average kappa score for all three raters on question 1 was .94, on question 2 was .81, and on question 3 was .84. Further description of the results of is found in the next chapter. Kappa values over .61 are generally believed to acknowledge agreement while values over .80 are deemed very good (Landis & Koch, 1977). Kappa values are generally higher when fewer categories are present, which was found in the current study because the first qualitative question had only five categories and a higher kappa while the other two questions had more categories and slightly worse inter-rater agreement.

Raters discussed the answers to questions in pairs when agreement was not present. For many questions, consensus was reached after a short deliberation among the raters. When raters could not agree, a fourth independent rater, unaware of the study’s

hypotheses, was brought in to offer another opinion. When the fourth rater agreed with at least two out of three of the original raters, it was deemed that consensus was reached.

A description of the categories that emerged from the data and summary of the results of the analyses conducted on the open-ended questions can be found in the results chapter.

Further discussion of these categories can be found in chapter six. A full explanation of the results is found in the following chapter. All other results of the analyses conducted in the current study are also found in the following chapter.

## Chapter 5

### Results

#### *Data Analysis*

Descriptive data for the sample were collected and are shown in the previous chapter (See Table 3). The sample was predominantly female, as is typical of the population of individuals with autoimmune diseases although this sample's proportion of females was higher than in the general population of individuals with autoimmune disease, mostly well-educated, and primarily white. Autoimmune diseases are typically more common in women so the results of this study are not surprising. Autoimmune diseases in general are also more common in whites but Systemic Lupus Erythematosus affects African-American and Hispanic individuals at a higher rate than other autoimmune diseases ([www.cdc.gov](http://www.cdc.gov), 2008). Previous studies have found similar discrepancies between the number of women and men participants and the number of white vs. non-white participants (Barlow et al., 2002). Some studies select only female participants and may not collect data on race/ethnicity (e.g. Fyrand et al., 2002; Plach, Heidrich & Waite, 2003).

Most participants in the current study were between ages 45-54 (29%) and most were between ages 35-64 (70%). The sample was 90% female and 94% white/European-American. Overall, they were highly educated with 85% of the participants having completed at least a two-year college degree or some college. Most of the participants had been living with their autoimmune disease for at least 5 years (61%). There were a

substantial number of participants who were not working for pay (30%), but similar numbers who were working 21-40 hours per week (24%) and 41-60 hours per week (27%). The majority of participants (119; 68%) reported that their autoimmune disease had not affected their ability to work. Generally, 63.9% of the population over age 16 in the United States is part of the workforce, according to the results of the 2000 census ([www.census.gov](http://www.census.gov)), so the results of the current study are not dramatically different than what would be expected to be found in the general population, although it is notable that a large proportion of those working in the present study were not working full-time. Only 71 (41%) reported that someone else in their family also had an autoimmune disease.

Descriptive data is shown in Table 3 in the previous chapter. The means, standard deviations, and ranges of the measures are reported in Table 7 in this chapter. In Table 8, the reliability data for the current study is reported. All measures showed adequate to excellent reliability. Correlations between the variables of interest are shown in Table 6 of this chapter.

| <b>Table 6: Correlation matrix of key variables</b>  |        |        |        |       |       |      |       |      |     |
|--|--------|--------|--------|-------|-------|------|-------|------|-----|
|  | 1      | 2      | 3      | 4     | 5     | 6    | 7     | 8    | 9   |
| 1. CES-D   |        |        |        |       |       |      |       |      |     |
| 2. ASE   | -.38** |        |        |       |       |      |       |      |     |
| 3. SPWB  | -.54** | .35**  |        |       |       |      |       |      |     |
| 4. SSS   | -.28** | .17*   | .44**  |       |       |      |       |      |     |
| 5. HPLP  | -.34** | .20**  | .41**  | .40** |       |      |       |      |     |
| 6. WHO-DAS II  | .48**  | -.67** | -.34** | -.13  | -.17* |      |       |      |     |
| 7. Age   | -.19*  | -.08   | .15*   | .12   | .12   | .04  |       |      |     |
| 8. Sex   | -.03   | .01    | -.08   | -.10  | -.17* | -.00 | .14   |      |     |
| 9. Educ  | -.13   | .18*   | .06    | -.04  | .15   | -.07 | .16*  | .01  |     |
| 10. Length   | -.11   | .04    | .20    | .02   | -.01  | -.10 | .22** | -.06 | .01 |
| <p>Key to abbreviation in Table 6: CES-D (Center for Epidemiologic Studies-Depression), ASE (Arthritis Self-Efficacy), SPWB (Scale of Psychological Well-Being), SSS (Medical Outcomes Study-Social Support Scale), HPLP (Health Promoting Lifestyle Profile II), WHO-DAS II (World Health Organization Disability Assessment Schedule II), Educ (Highest education level completed), Length (Length of time since diagnosis)</p> <p>*=significant at the p&lt;.05 level, **=significant at the p&lt;.01 level</p> |        |        |        |       |       |      |       |      |     |

| <b>Table 7: Means, standard deviations, and ranges of the measures of interest in the current study (N=175)</b> |        |       |         |
|---|--------|-------|---------|
| MEASURE   | MEAN   | SD    | RANGE   |
| Arthritis Self-Efficacy (ASE)   | 130.89 | 38.07 | 28-200  |
| Center for Epidemiologic Studies Depression Scale (CES-D)   | 16.34  | 10.27 | 0-48    |
| Health Promoting Lifestyle Profile (HPLP-II)  | 142.25 | 20.21 | 84-192  |
| Medical Outcomes Study-Social Support Scale (MOS-SSS)   | 76.47  | 14.27 | 33-95   |
| Scale of Positive Well-Being (SPWB)   | 196.20 | 25.13 | 109-242 |
| World Health Organization-Disability Assessment Schedule II (WHO-DAS)   | 60.81  | 18.03 | 0-100   |



| <b>Table 8: Reliability data of measures for current sample</b>              |                        |   |
|--|------------------------|---|
| <i>Name of Scale</i>   | <i>Number of Items</i> | <i>Cronbach's <math>\alpha</math><br/>(current study)</i> |
| <b>Arthritis Self-Efficacy (ASE)</b>   | 20                     | 0.94  |
| <b>Scale of Positive Well-Being (SPWB)</b>                                   | 42                     | 0.92  |
| <b>Medical Outcomes Survey-Social Support Scale (MOS-SSS)</b>                | 19                     | 0.95  |
| <b>Health Promoting Lifestyle Profile II (HPLP II)</b>                       | 52                     | 0.94  |
| <b>Center for Epidemiologic Studies (CES-D)</b>                              | 20                     | 0.91  |
| <b>World Health Organization Disability Assessment Schedule (WHO-DAS-II)</b> | 36                     | 0.95  |

### *Primary Analyses*

Given the large sample size, an alpha level of 0.01 was used to determine statistical significance for the correlation and regression analyses. Effect sizes are included to provide more robust support for the findings, as called for by recent guidelines (e.g. Frazier, Tix & Barron, 2004). Effect sizes will be reported throughout the results using the following conventions. When  $r$  is used as the effect size indicator for correlations, a small effect size is  $r=0.1$ , a medium effect size is  $r=0.3$ , and a large effect size is  $r=0.5$ . When  $f^2$  is used as the effect size, convention indicates that a small effect size corresponds to  $f^2=0.02$ , a medium effect size is  $f^2=0.15$ , and a large effect size is  $f^2=0.35$ . Effect sizes were calculated by using Pearson correlation coefficients for the  $r$  values and using the following formula for  $f^2$ . The effect size  $f^2=R^2/(1-R^2)$  where  $R^2$  is the population squared multiple correlation. These guidelines were established by Cohen (1988).

Missing data was a problem in the original sample of 216 respondents. Following the elimination criteria for the current study, individuals who did not list a diagnosis or who did not have a connective tissue or musculoskeletal autoimmune disease were eliminated from the final sample. Some missing data was still present in the sample of 175 and was replaced using linear interpolation.

*Hypothesis 1: A negative relationship will exist between disease severity and social support, such that the more severe the reported disease symptoms are, the lower the level of social support will be.*

This hypothesis was tested by calculating a Pearson's  $r$  correlation between the total score on the WHO-DAS II and the total score on the MOS-SSS.

This hypothesis was not supported. Disease severity, as measured by the WHO-DAS II total score was not correlated with social support, as measured by the MOS-SSS. As indicated in Table 6, a correlation of  $r=-.13$ ,  $p=.09$  was found. To evaluate this hypothesis in another way, a Pearson's  $r$  correlation was calculated between the total score on the one-item severity item "How severe is your disease?" and the total score on the MOS-SSS. This correlation was not significant ( $r=-.01$ ,  $p=0.91$ ).

*Hypothesis 2: A negative relationship will exist between self-efficacy and depression, such that individuals with high levels of self-efficacy will show lower levels of depression.*

This hypothesis was tested by calculating a Pearson's  $r$  correlation between the total score on the ASE and the total score on the CES-D. This hypothesis was supported. As indicated in Table 6, a correlation of  $r=-.38$ ,  $p\leq .00$  was observed suggesting that higher levels of disease self-efficacy are associated with lower levels of depression. This level of correlation corresponds to a medium effect size ( $r>0.3$ ).

#### *Tests of Research Questions*

*Research Question 1: How do biopsychosocial variables affect positive well-being in individuals with autoimmune diseases?*

A linear regression analysis was used to analyze this research question. Each of the biopsychosocial variables (symptomatology, depression, self-efficacy, and social support) was entered into the model to determine their unique contribution to positive well-being. Multicollinearity was first examined to determine if any of the variables should be omitted from the regression and it was determined that none of the variables met criteria for elimination. By examining the tolerance values and variation inflation factors, multicollinearity was not determined to be a problem. No tolerance values were below

.20 and VIF values were not above 5, so multicollinearity was not a problem. These guidelines are explicated by Mansfield and Helms (1982).

The overall model was significant  $F(4,170)=28.26, p=.000$ . Social support, as measured by the MOS-SSS, made a significant contribution to the model as shown in Table 9 as determined by the  $\beta$  weight (.55) for the MOS-SSS in the regression model. ( $R^2$  for MOS-SSS is .20,  $f^2$  is .25). Depression, as measured by the CES-D also made a significant contribution to the model as determined by the  $\beta$  weight (-.94) for the CES-D in the regression model. ( $R^2$  for depression is .29,  $f^2 = .41$ ). The overall model was significant and demonstrated a large effect size of  $f^2=.67$ . In other words, lower levels of depression and higher levels of social support were unique predictors of positive well-being in this sample. Disease severity and self-efficacy did not contribute significantly to the model.

| <b>Table 9: Linear multiple regression analysis testing predictor variables effects on subjective positive well-being (SPWB)</b> |         |                |                      |       |                  |
|--|---------|----------------|----------------------|-------|------------------|
| Predictor Variables  | $\beta$ | Standard Error | Standardized $\beta$ | t     | Significance (p) |
| (constant)   | 160.33  | 14.97          |                      | 10.71 | .00              |
| ASE  | .09     | .05            | .14                  | 1.67  | .20              |
| SSS  | .55     | .11            | .31                  | 4.98  | .00              |
| CES-D  | -.94    | .17            | -.39                 | -5.48 | .00              |
| WHO-DAS  | -.03    | .12            | -.03                 | -.29  | .77              |

Note: N=175,  $R^2=.40^{**}$ , effect size  $f^2=.67$   
 ASE= Arthritis Self Efficacy; SSS= Social Support Scale; CES-D= Center for Epidemiological Studies-Depression Scale; WHO-DAS=World Health Organization-Disability Assessment Schedule

*Research Question 2: How do biopsychosocial variables affect health-promoting behaviors in individuals with autoimmune diseases?*

A simultaneous linear regression analysis was used to analyze this research question. Each of the biopsychosocial variables (symptomatology, depression, self-efficacy, and social support) were entered into the model to determine their unique contributions to the model. Multicollinearity was first examined to determine if any of the variables should be omitted from the regression and it was determined that none of the variables met criteria for elimination. Health-promoting behaviors were measured by the Health Promoting Lifestyle Profile II, which measures all health-promoting behaviors; it is not just limited to autoimmune diseases.

The overall model was significant  $F(4,174)=12.03, p=.000$ . Social support, as measured by the MOS-SSS, made a significant contribution to predicting health promoting variables as shown in Table 10 as determined by the  $\beta$  weight (.33) for the MOS-SSS ( $R^2=.16, f^2=.19$ ), as did depression ( $R^2=.11, f^2=.12$ ), as measured by the CES-D determined by the  $\beta$  weight (-.23). The overall model was significant and demonstrated a medium effect size of  $f^2=.28$ . In other words, health promoting behaviors can be predicted by lower levels of depression and higher levels of social support in this sample. Disease severity and self-efficacy did not contribute significantly to the model.

| <b>Table 10: Linear multiple regression analysis testing predictor variables effects on Health Promoting Lifestyle Profile (HPLP)</b> |        |                |                   |      |              |
|---|--------|----------------|-------------------|------|--------------|
| Predictor Variables   | Beta   | Standard Error | Standardized Beta | t    | Significance |
| (constant)  | 105.96 | 13.72          |                   | 7.73 | .00          |

|  |      |     |      |       |     |
|--|------|-----|------|-------|-----|
| ASE  | .04  | .05 | .08  | .85   | .40 |
| MOS  | .47  | .10 | .33  | 4.66  | .00 |
| CES-D  | -.46 | .16 | -.23 | -2.91 | .00 |
| WHO-DAS  | .04  | .11 | .04  | .39   | .70 |
| <p>Note: N=175, <math>R^2=.22^{**}</math>, effect size <math>f^2=.28</math><br/> ASE= Arthritis Self Efficacy; SSS= Social Support Scale; CES-D= Center for Epidemiological Studies-Depression Scale; WHO-DAS=World Health Organization-Disability Assessment Schedule</p> |      |     |      |       |     |

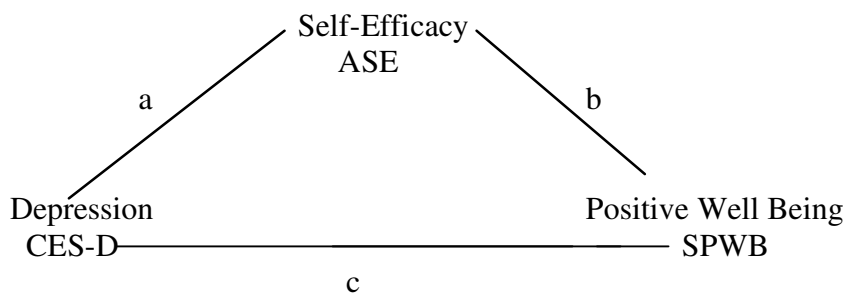
*Research question 3: Do psychosocial variables mediate the relationship between the biopsychosocial variables and positive well-being?*

*Research question 3a: Does self-efficacy mediate the relationship between depression and positive well-being?*

Using the methods suggested by Frazier, Tix, and Barron (2004), the mediating effects of self-efficacy were tested. Frazier, Tix, and Barron (2004) explicate a checklist for evaluating mediation analyses. The answers to these questions are shown in Table 11.

| <b>Table 11: An evaluation of the criteria necessary for mediation in the current study (From Frazier, Tix, &amp; Barron, 2004)</b> |  |                                   |
|---|--|-----------------------------------|
| Question from Frazier, Tix, and Barron (2004)   | Self-efficacy as a mediator (Research question 4a) | Social support as a mediator (4b) |
| Was the predictor significantly related to  | Yes, depression was correlated with SPWB           |                                   |

|   |   |                               |
|---|---|-------------------------------|
| the outcome?  | at $r = -.54^{**}$  |                               |
| Was there a theoretical rationale for the hypothesis that the predictor causes the mediator? Can mediator be changed?   | Yes, Yes  | Yes, Yes                      |
| What is the “effective sample size” given the correlation between the predictor and the moderator?                      | 140.31  | 155.36                        |
| Was relation between the mediator and the outcome greater than or equal to the relation between predictor and mediator? | No, .41 is not greater than -.44 (but comparable in size and thus will be considered) | Yes, .55 is greater than -.37 |
| Were the mediators adequately reliable (above $\alpha = .90$ ); (See Table 3)   | Yes, $\alpha = .94$   | Yes, $\alpha = .95$           |
| Was predictor significantly related to outcome?   | Yes   | Yes                           |



For this equation:

Depression  $\rightarrow$  Self-efficacy = path a ( $r = -.38$ )

Self-efficacy → SPWB = path b ( $r=.17$ )

Depression → SPWB= path c ( $-.54$ )

Depression → Self-efficacy → SPWB= path c' ( $-.47$ )

The effects of self-efficacy as a mediator were analyzed using the procedures described by Frazier et al. (2004) using multiple regression. The resulting beta weights are shown above.

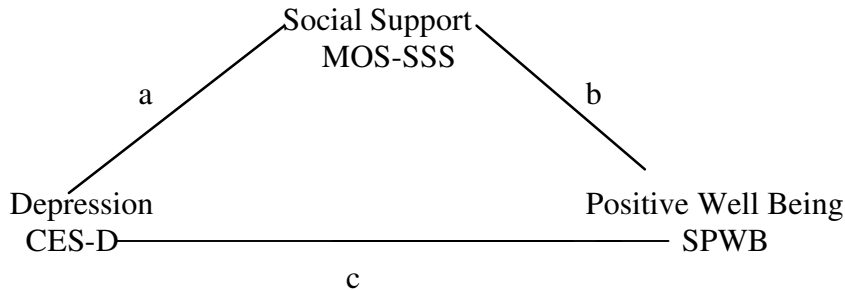
ASE is not a significant mediator of the relationship between depression and positive well-being. According to Frazier et al. (2004), one can calculate the significance of the effect by multiplying the unstandardized coefficients (a and b) and dividing that by the standard error term (calculated using the procedures explained by Baron and Kenny, (1986). The standard error term for this mediation equation is .0675. To test for significance, Frazier et al. (2004, p.131) suggest multiplying a (-1.6) times b (.072) and dividing that by the standard error term (.0675). That produces a z-score of the mediated effect. If that number is greater than 1.96, the effect is significant at the 0.05 level. In this mediation equation, that z-score is 1.71. Thus, the mediating effects of self-efficacy are not significant. In this equation  $c = -.54$  and  $c' = -.47$ , suggesting that the relationship between the predictor (depression) and the outcome (spwb) is weaker when self-efficacy is considered as a mediator.

*Research question 3b: Does social support mediate the relationship between depression and positive well-being?*

Using the methods suggested by Frazier, Tix, & Barron (2004), the mediating effects of social support were tested. Frazier, Tix, and Barron (2004) explicate a checklist



for evaluating mediation analyses. The answers to these questions are shown in Table 11 above.



For this equation:

Depression  $\rightarrow$  Self-efficacy = path a (-.38)

Social support  $\rightarrow$  SPWB = path b (.31)

Depression  $\rightarrow$  SPWB = path c (-.54)

Depression  $\rightarrow$  Social support  $\rightarrow$  SPWB = path c' (-.45)

The effects of social support as a mediator were analyzed using the procedures described by Frazier et al. (2004) using multiple regression. The resulting beta weights are shown above.

Social support is a significant mediator of the relationship between depression and positive well-being. Using the same procedures described above (Frazier et al., 2004 and Baron & Kenny, 1986), the standard error term for this mediation equation is .0359. To test for significance, a (-.49) was multiplied by b (.77) and divided by the standard error term (.0359). The z-score of the mediated effect was 10.52, thus it is significant at the .01 level, according to the guidelines set forth by Frazier et al. (2004).

*Research Question 4: How will natural groupings form among individuals with connective tissue autoimmune diseases on the predictor variables of interest (disease*

*severity, depression, arthritis self-efficacy, and social support*)?

This question was explored using Ward's (1963) cluster analysis method, which is a hierarchical clustering method that allows researchers to see how natural groupings form among the participants. ANOVA analyses will be conducted after the clusters are formed to see if significant differences exist between the clusters of the selected variables.

Ward's (1963) method was used to group the participants who had responded to all questions necessary for the cluster analysis (N=110). The Ward method is included in the Statistical Package for the Social Sciences (version 11.0) and is a common clustering method used in psychology. Clusters were constructed into branches of the most closely related individuals (graphically represented by a dendrogram) from n-1 clusters until they are all linked. In essence, the analysis begins by pairing together the two most similar participants, then adds new pairings, combining those pairings into clusters and combining clusters into increasingly larger clusters. Thus, the clusters are created in such a way that within-cluster variability is minimized and between-cluster variability is maximized at each stage of grouping (Borgen & Barnett, 1987).

After analyzing the resulting dendrogram and graph of squared coefficient changes (similar to a scree plot), a 4-cluster solution seemed to best fit the data. The cases where data was missing from any of the measures were removed, thus the cluster analysis was completed with N=110 while 107 cases were removed. This method for determining the number of clusters was based on the technique used by Heppner et al. (1994). Tukey post-hoc comparisons were used to control for the number of tests and to examine the differences between means. The results of those comparisons for the continuous variables included in the cluster analysis are shown in Table 13. Comparisons

on other demographic variables are shown in Table 12.

Cluster comparisons are shown graphically in Figure 1. This figure shows how the four clusters differ on each of the 6 continuous variables used in the cluster analysis. To distinguish between the groups, clusters that differed from the mean of the sample on each variable by  $\pm 0.5$  Z-score (a half standard deviation) were considered different than the others. In the description column in Table 12, trends are listed based on demographic questions that were analyzed, however, since there was a small number of individuals who were male and non-white, this information is just provided as an observation of the trends and was not analyzed statistically.

| <b>Table 12: Tukey post-hoc comparisons between clusters on other variables</b> |                            |                           |  |
|---|----------------------------|---------------------------|--|
| Variable  | Cluster differences        | p value                   | Description                            |
| Age   | 2 < 4                      | p=.013*                   | 4=oldest cluster<br>2=youngest cluster |
| Gender  | 3>1, 3>4                   | p=.049, p=.059            | 3=most men                             |
| Race  | No significant differences |                           | 1,3=all white                          |
| Education   | No significant differences |                           | 2=highest education level              |
| Length since diagnosis  | No significant differences |                           | 1=longest since diagnosis              |
| Therapy   | No significant differences |                           |  |
| Severity  | 4>1, 4>2, 4>3              | p=.014, p=.000,<br>p=.027 | 4=most severe<br>2=least severe        |

| <b>Table 13: Means, standard deviations, and comparisons by clusters</b> |                     |                 |                 |               |                          |
|--|---------------------|-----------------|-----------------|---------------|--------------------------|
| <i>Name</i>  | <i>N in cluster</i> | <i>Variable</i> | <i>Mean (Z)</i> | <i>SD (Z)</i> | <i>Tukey comparisons</i> |
| <b>Cluster One</b><br><i>(Healthy Exemplars)</i>                         | 31                  | ASE             | .51             | .72           | 1>3, 1>4                 |
|  |                     | SPWB            | 1.01            | .46           | 1>2, 1>3, 1>4            |
|  |                     | MOS-SSS         | .69             | .49           | 1>2, 1>3                 |
|  |                     | CES-D           | -.92            | .40           | 1<2, 1<3, 1<4            |
|  |                     | HPLP            | .88             | .80           | 1>2, 1>3, 1>4            |
|  |                     | WHODAS          | -.53            | .79           | 1<3, 1<4                 |
| <b>Cluster Two</b><br><i>(Efficacious Managers)</i>                      | 37                  | ASE             | .63             | .58           | 2>3, 2>4                 |
|  |                     | SPWB            | .06             | .52           | 2<1, 2>3, 2>4            |
|  |                     | MOS-SSS         | -.00            | .80           | 2<1, 2>3                 |
|  |                     | CES-D           | .26             | .69           | 2>1, 2<4                 |
|  |                     | HPLP            | .09             | .65           | 2<1, 2>3                 |
|  |                     | WHODAS          | -.42            | .69           | 2<3, 2<4                 |
| <b>Cluster Three</b><br><i>(Maladjusted Unwell)</i>                      | 22                  | ASE             | -.41            | .99           | 3<1, 3<2                 |
|  |                     | SPWB            | -1.07           | .69           | 3<1, 3<2, 3<4            |
|  |                     | MOS-SSS         | -1.41           | .81           | 3<1, 3<2, 3<4            |
|  |                     | CES-D           | .63             | .80           | 3>1                      |
|  |                     | HPLP            | -1.17           | .60           | 3<1, 3<2, 3<4            |
|  |                     | WHODAS          | .61             | .91           | 3>1, 3>2                 |
| <b>Cluster Four</b><br><i>(Impervious Moderates)</i>                     | 20                  | ASE             | -.94            | .65           | 4<1, 4<2                 |
|  |                     | SPWB            | -.58            | .71           | 4<1, 4<2, 4>3            |
|  |                     | MOS-SSS         | .30             | .59           | 4>3                      |
|  |                     | CES-D           | .80             | .91           | 4>1, 4>2                 |
|  |                     | HPLP            | -.03            | .78           | 4<1, 4>3                 |
|  |                     | WHODAS          | .83             | .67           | 4>1, 4>2                 |

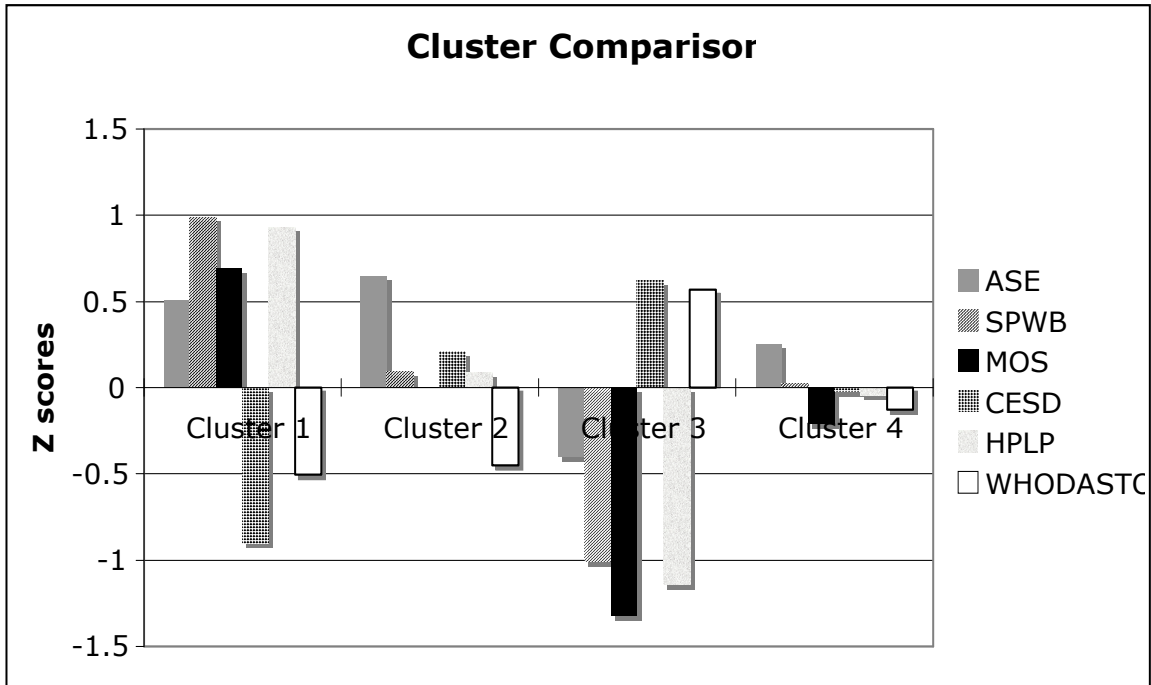


Figure 1: Graphical Representation of Four Cluster Solution

ASE=Arthritis Self Efficacy

SPWB=Scales of Psychological Well-Being

MOS=Medical Outcomes Study-Social Support Scale

CESD=Center for Epidemiologic Studies-Depression Scale

HPLP=Health Promoting Lifestyle Profile II

WHODASTO=World Health Organization Disability Assessment Schedule Total Score

Participants in Cluster One (N=31) had higher levels of self-efficacy, higher levels of positive well-being, higher scores on social support, lower levels of depression, higher levels of health promoting behaviors, and lower disease severity than the other clusters. Participants in cluster one had been diagnosed for the longest period of time. All of the members of cluster one were white. Cluster One is named the Healthy Exemplars.

Participants in Cluster Two (N=37) had higher levels of self-efficacy (the highest of all of the clusters) but moderate levels of all other variables. Cluster Two is the youngest cluster and has the highest education level. They reported the least severe autoimmune disease in the one-item measure. Cluster Two is named the Efficacious Managers. They differ from Cluster One, the Healthy Exemplars, because they have even higher levels of self-efficacy without the low levels of disease severity and depression that was notable in Cluster One.

Participants in Cluster Three (N=22) had very low levels of positive well-being, lower levels of social support, and lower levels of healthy behaviors, higher levels of depression and disease severity, and moderate to low levels of self-efficacy, compared to the other clusters. Cluster three had more men than any of the other clusters. All of the members of cluster three were white. Cluster Three is named the Maladjusted Unwell.

Participants in Cluster Four (N=20) had moderate scores on all of the variables. They did not meet any of the cut-off scores (.5 Z-score above or below the mean). Cluster 4 is also the oldest cluster and reported the most severe levels of autoimmune diseases on the one-item measure. Cluster Four is named the Impervious Moderates.

*External variable ANOVAs.* Clusters were compared on other variables to see if significant differences existed between clusters. One way ANOVAs were conducted on continuous (or nearly continuous variables) to further examine the differences between the clusters. Some significant differences emerged on the demographic variables. Age:  $F(3, 102)=4.27, p=.007$ ; and severity (as measured by the one item demographic question):  $F(3, 101)=7.95, p=.000$ . Other demographic variables were not significant between clusters. Tukey HSD post-hoc analysis revealed that there were significant differences between clusters (See Table 12).

*Additional Analyses.*

*ANOVA differences on continuous variables.*

To provide a better description of the sample, the participants were compared on their demographic variables (age, gender, race, length of time since diagnosis, and education levels) using One Way ANOVAs. The groups did not differ significantly by age on their levels of social support, health promoting behaviors, overall disease severity, positive well-being, or level of depression. They were significantly different on levels of self-efficacy  $F(6,172)=3.61, p=0.002$ . This suggests that the older a participant was, the less efficacious they felt about their ability to manage their disease.

When participants were compared on all of the continuous variables by gender, they did not differ by gender on levels of social support, self-efficacy, overall disease severity, positive well-being, or level of depression. They were significantly different on the overall HPLP-II score, suggesting that women are far more likely than men to engage

in health promoting behaviors  $F(1,151)=14.89$ ,  $p=0.000$ ,  $r=.30$ , indicating a medium effect size.

Due to the small number of participants from racial/ethnic backgrounds other than white/European-American, the continuous variables were compared between white vs. non-white participants. The only significant difference that emerged was on social support  $F(1,179)=12.52$ ,  $p=0.001$ ,  $r=.26$  indicating a small effect size. This suggests that participants who were white had somewhat more social support than the non-white participants.

No significant differences emerged when participants were compared on how long ago they were diagnosed, suggesting that the length of time since diagnosis is not a key factor in determining how well someone is functioning. No significant differences emerged on education level but a trend was observed that participants who had completed a higher level of education reported more social support,  $F(8, 180)=2.32$ ,  $p=0.020$ ,  $r=.11$  indicating a small effect size.

The autoimmune diseases with the most representation were Multiple Sclerosis and Rheumatoid Arthritis. Many other participants had Myositis or Systemic Lupus Erythematosus. There were many other autoimmune diseases with fewer representative participants. These results roughly correspond to the general population, though there were more individuals with Myositis that participated than in the general population. This may be due to the responsiveness of the Myositis Association and their publicity of the survey. Also, many individuals with Myositis responded that they had not had an opportunity to participate in research, so they were enthusiastic about their participation. It is also interesting to note that many of the participants had more than one autoimmune



disease. The individuals that were included in this category in Table 14 had to list multiple autoimmune diseases, not just multiple types of chronic illness. For example, a few individuals listed an autoimmune disease and breast cancer and they were not included in the “multiple” category. Please note that the total number of participants included in the analysis was 175, however the percentages in Table 14 do not add to 100 due to some individuals citing multiple autoimmune diseases.

#### *Description of the sample*

Some results of the primary analyses did not support the hypotheses, especially when disease specific factors were part of the hypothesis or research question. The disease-specific variables included in this study were disease severity and arthritis self-efficacy. The other variables (health-promoting behaviors, depression, social support, and well-being) were not unique measures for this population. Results including the autoimmune-specific variables were not significant. For example, disease severity and arthritis self-efficacy did not add a significant contribution to the regression models and arthritis self-efficacy was not a significant mediator of the relationship between depression and well-being. Overall, the results of the current study did not differentiate this population of individuals with autoimmune diseases from other populations with chronic illness. The sample seemed to report higher levels of social support and lower levels of depression than previous studies of individuals with autoimmune diseases. Because of these unexpected differences, further analyses were conducted to describe the sample on their reported levels of depression and social support.

Very few studies have focused on the psychosocial impact of autoimmune diseases so some of the unique aspects of the current sample will be described in this

section. Some findings will be briefly discussed in order to supplement the paucity of psychosocial information that is available about individuals with autoimmune diseases. Most research on autoimmune diseases have focused on one individual diseases (e.g. Rheumatoid arthritis (e.g. Covic et al., 2007) or Multiple Sclerosis (e.g. Mohr et al., 1999)) but this background information is provided here to aid in understanding the larger population of individuals with autoimmune diseases and the context of the results of the current study.

| <b>Table 14: Types of autoimmune diseases in current sample</b>  |          |                |
|--|----------|----------------|
| <i>Type</i>  | <i>N</i> | <i>Percent</i> |
| Multiple Sclerosis   | 42       | 24%            |
| Rheumatoid Arthritis   | 42       | 24%            |
| Myositis (Includes Polymyositis, Dermatomyositis, Inclusion Body Myositis)   | 33       | 19%            |
| Systemic Lupus Erythematosus   | 27       | 15%            |
| Fibromyalgia   | 7        | 4%             |
| Mixed Connective Tissue Disease (MCTD)   | 4        | 2%             |
| Graves' Disease  | 4        | 2%             |
| Sjögren's Syndrome   | 3        | 2%             |
| Hashimoto's Disease  | 3        | 2%             |
| Vasculitis   | 3        | 2%             |
| Psoriasis/Psoriatic Arthritis  | 3        | 2%             |
| Gout   | 2        | 1%             |
| Chronic Inflammatory Demyelinating Polyneuropathy  | 2        | 1%             |
| Pernicious Anemia  | 2        | 1%             |
| Antiphospholipid Antibody Syndrome   | 2        | 1%             |
| Scleroderma  | 2        | 1%             |
| Meinere's Disease, Primary Biliary Cirrhosis, Myofascial Pain Syndrome, Reynaud's Disease, CVID, Lyme's Disease, Crohn's Disease, Polymyalgia rheumatica, Ankylosing Spondylitis | 1 ea     | .5%            |
| Undetermined/Undifferentiated  | 3        | 2%             |
| Multiple Diseases  | 18       | 10%            |
| Other  | 3        | 1.4%           |
| Total  | 175      |                |
| **Does not add to 100% due to multiple diagnoses   |          |                |

*Analyses of qualitative data.*

There were three qualitative questions that were also analyzed for this project to get a better understanding of the experience of the participants. Each question was categorized by the primary investigators (this author and a Counseling Psychology faculty member) by discussing refinements to the categories until consensus was reached. Next, three independent coders rated each question. Inter-rater agreement was measured using Cohen's kappa scores and those were reported in the previous chapter in Table 5. A more detailed explanation of the methods used in the qualitative analysis is described in the previous chapter. A total of 5 categories were developed for the first question, 8 for the second question, and 7 for the third question. A description of the categories as well as the number of participants placed in each category by the three raters is found in table 15.

For the first question, the causality question, five categories emerged from the data. The percentage of respondents endorsing each category are presented in Table 15 in the following chapter. Findings are discussed further in the Discussion chapter. The first category was related to genetics and included responses like "heredity," comments about the illnesses running in their family, or mentioning a specific family member with the disease. The second category was entitled "physical stress" and included attributions like viruses, bacteria, toxins, pregnancy, other illnesses, and exposure to certain environmental triggers. It also included individuals who mentioned that where they lived (e.g. Pacific Northwest or Midwest) and having a lack of sunlight affected them getting their disease. The third category was emotional stress and included responses that were

limited to “stress” or when participants mentioned other types of emotional stressors or psychological distress. It also included individuals who indicated that “overworking” caused their disease. The fourth category was reactions to medications or vaccines. Participants who indicated a specific medication or vaccine that they took, mentioned drug abuse, flu shots, antibiotics, or “statin” drugs fell into this category. A response that was observed multiple times in this category was “Statin cholesterol-reducing medications” or “Lipitor”. Finally, participants who indicated that they did not know what caused their disease were in category five. Participants who left the question blank were coded as missing.

As a follow up to the first open-ended question, another open-ended question was asked about whether participants had received a medical explanation for the cause of their disease. Most of the respondents indicated simply “yes” or “no” in response to this question so it was determined that involving multiple coders for this question was not necessary, thus, it was coded solely by the primary investigator. The categories that emerged for this question were: yes, without a response given; no or don’t know; genetics; physical causes like a bacteria, virus, or environmental exposure; and emotional stress. Participants who left the question blank were coded as missing.

For the second question about positive consequences, eight categories emerged from the data. The first category was personal growth and included responses about increased positive personal characteristics of any sort, self-efficacy or determination, patience, or the ability to rely on one’s self. This category did not include responses about growth as it related to other people or growth around learning more about the disease. The second category was related to helping others with autoimmune diseases.

Many participants indicated that they were more sympathetic towards others with autoimmune diseases or having the disease helped them relate better to other people. They indicated an increased motivation to give back or help others. This category was disease-specific and did not include overall social support. The third category was re-evaluating one's priorities and included individuals who wrote about having a greater appreciation of life or learning about what was important to them. The fourth category was awareness of self-care and the body's limits and included discussions of being more able to say "no," ability to take care of one's body (including diet changes and exercise changes), the ability to ask for help, and other comments related to setting boundaries and taking care of one's self. The fifth category was social support and included mentioning specific individuals that respondents felt closer to as well as indicating disease support-groups or online communities as beneficial consequences of their diagnosis. The sixth category was religious/spiritual beliefs and included comments like "Becoming closer to God". The seventh category was all other responses. Some individuals indicated that a positive benefit was getting out of things (e.g. the military, carrying heavy things, physical labor) and these responses were included here. Finally, the last category was none/don't know. This category included all people who responded that they didn't know or were not able to think of any positive benefits. Participants who left the question blank were coded as missing.

For the third question about willingness to seek counseling, seven categories emerged from the data. The first category was responses that indicated the participant was currently in therapy or had been previously and had positive views of therapy. The second category included responses that pointed to characteristics of a potential therapist

or therapy in general. This included comments about not being able to access specific types of therapy in their location, looking for a specific theoretical orientation, looking for a Christian therapist, being worried that taking another pill would not be helpful, and wanting to work with someone who could understand having a chronic illness because they had “walked in their shoes”. Others indicated familiarity with the process of therapy and gave well-articulated reasons for not wanting to seek therapy (e.g. not wanting to talk about their emotions). The third category was worsened symptoms. These participants indicated that they would seek therapy if they became more depressed or suicidal, if their physical symptoms worsened or became terminal, if family members encouraged them to go, or if their distress was affecting their relationships. The fourth category was if barrier removal. The most common barriers were related to cost, transportation, time, and mobility. The fifth category was at the suggestion of medical professionals. The presence of this category indicates that participants trusted their doctors to direct them to psychotherapy if necessary. The sixth category was responses that indicated that participants did not believe it was necessary for them to seek therapy at this time. It conveyed a general willingness to go to therapy if they needed to in the future. Also, respondents who were coded in the sixth category conveyed an openness to therapy and did not make negative statements about their likelihood of seeking therapy. Finally, the last category was if participants were not interested or conveyed that no factors would change their adamancy that they would not seek therapy. Respondents who indicated “nothing” were also put into this category. Though, “nothing” could have multiple meanings in the context of this question, it was impossible to determine the intended meaning of “nothing,” so the participants who stated it were grouped with the seventh

category. Participants who left the question blank were coded as missing.

One Way ANOVAs were conducted on some of the open-ended questions for further analysis. On the positive consequence question, participants were grouped into two categories based on the benefit they indicated. Individuals who responded with a benefit that was not related to personal growth were grouped together. These included the groups that stated that a benefit was increased awareness of the disorder or a desire to help others since these categories were very disease-specific, that they had learned the importance of self-care which were focused on exercise and diet, other, none, or had missing data. These were categorized together since it was judged that they had not determined a significant positive and personal consequence of their disorder. Individuals who responded with a significant personal quality, that they had re-evaluated their life priorities, gained social support, or increased religious or spiritual benefits were grouped in the other category. These two groups were compared, using ANOVAs on depression, well-being, and social support. No significant difference emerged between the two groups. Depression:  $F(1, 186)=.726, p=.395$ ; Overall well-being:  $F(1, 172)=.372, p=.543$ ; Social Support:  $F(1, 196)=1.279, p=.259$ .

Further analysis was conducted on individuals who had been given a medical explanation versus those who had not. Individuals who answered that they had not received a cause from a medical professional were in one category and all other responses were in another category. One way ANOVAs were conducted on these cases to determine if there were any differences between the groups on depression, well-being, health promoting behaviors, or disease severity. No significant effects were found. Depression:  $F(1, 185)=.103, p=.749$ ; Well-being:  $F(1,171)=.073, p=.787$ ; Health promoting behaviors:

$F(1, 163)=.324, p=.570$ ; Disease severity:  $F(1,124)=1.511, p=.221$ .

A more extensive description of what fell into each category was discussed in the Methods chapter. Overall, participants reported many causes of their disease, some interesting positive consequences, and a variety of reasons why they would or would not seek psychotherapy. A further discussion of these results is found in the following chapter.

Participants were also asked if they had received a medical explanation for their disorder. The answers to this question were coded by the graduate student researcher. An overwhelming majority of the participants had not received a medical explanation for the cause of their disease, indicated that they did not know, or stated that they were told that there was no known cause. 132 participants, or 61.1% responded in this way. Another 33 left this question blank (15.3%). Some 29 (13.4%) of the participants just indicated “yes” but did not elaborate on the given cause of the disorder. The remaining participants explicated the medical cause that was told to them with 9 (4.2%) stating that it was due to genetics, 8 (3.7%) indicating that it was from a toxin, bacteria, or virus, 5 (2.3%) claiming it was due to emotional stress or overworking. Taken together, only 51 (23.6%) had been given any kind of medical explanation for the cause of their disease, yet 121 (56.0%) indicated a personal belief that a particular attribution was responsible for their autoimmune disease.



| <b>Table 15: Responses to the qualitative questions</b>   |                        |             |
|---|------------------------|-------------|
| Description of category   | Number of participants | % of sample |
| <i>Question 1: “What do you believe caused your autoimmune disease?”</i>  |                        |             |
| Missing   | 37                     | 17.1%       |
| Genetics/Hereditry  | 39                     | 18.1%       |
| Physical stress (bacteria, virus, environmental exposure)   | 42                     | 19.4%       |
| Emotional stress/overworking  | 26                     | 12.0%       |
| Reactions to medications or vaccines  | 14                     | 6.5%        |
| Don’t know  | 58                     | 26.9%       |
| <i>Question 2: “What is a positive consequence you have experienced as a result of having an autoimmune disease?”</i> |                        |             |
| Missing   | 41                     | 19.0%       |
| Personal growth   | 23                     | 10.6%       |
| Helping others with autoimmune diseases   | 24                     | 11.1%       |
| Re-evaluating one’s priorities  | 23                     | 10.6%       |
| Awareness of self-care and body’s limits  | 30                     | 13.9%       |
| Social support  | 26                     | 12.0%       |
| Religious/spiritual beliefs   | 12                     | 5.5%        |
| Other (e.g. getting out of things)  | 6                      | 2.8%        |
| None/Don’t know   | 31                     | 14.4%       |
| <i>Question 3: “What would affect your willingness to seek counseling or psychotherapy?”</i>                          |                        |             |
| Missing   | 53                     | 24.5%       |
| Currently in therapy/positive views   | 5                      | 2.3%        |

|  |    |       |
|--|----|-------|
| Characteristics of therapist/therapy               | 21 | 9.7%  |
| Symptoms worsen                                    | 17 | 7.9%  |
| Barriers removed (e.g. cost, transportation, time) | 47 | 21.8% |
| Medical personnel suggest it                       | 2  | 0.9%  |
| Don't need it but willing if situation changes     | 37 | 17.1% |
| Not interested/don't believe it would help         | 34 | 15.7% |

*Summary of Findings.*

A few of the findings will be highlighted here with more discussion to follow in the next chapter. First, it was found that disease severity and social support are not related, suggesting that an individuals' ability to access and utilize social support is unrelated to the severity of their autoimmune disease.

Second, a significant relationship was found between self-efficacy and depression suggesting that individuals who believe they can handle the consequences of their disease report lower depression or individuals with lower depression believe they can handle the consequences of their disease.

Third, it was found that depression and social support predict both positive well-being and health promoting behaviors. Depression and social support added significant contributions to the regression model predicting well-being and healthy behaviors. Self-efficacy and disease severity did not add significant contributions to this model. It was found that self-efficacy does not mediate the relationship between depression and positive well-being but social support does.

Fourth, a cluster analysis revealed four different clusters that react to their autoimmune disease in four different ways. The cluster analysis showed that people may react really well to their disease, like the Healthy Exemplars, or they may react really poorly, like the Maladjusted Unwell. It also showed that individuals may still have high levels of arthritis self-efficacy with moderate to low levels of the other biopsychosocial variables. Specifically, the first cluster, the Healthy Exemplars, do everything right, as their name indicates. They engage in high levels of health promoting behaviors, have high self-efficacy and positive well-being, low levels of depression and disease severity, and high levels of social support. They could be considered a model of how to cope with an autoimmune disease. Second, the Efficacious Managers, were significant based on their high levels of self-efficacy without any other significant variables. Third, the Maladjusted Unwell, reacted exactly the opposite as the Healthy Exemplars of cluster one. They had very low-levels of positive well-being, not a lot of social support, low self-efficacy and healthy behaviors, and high levels of depression and disease severity. In effect, they did everything wrong in coping with their autoimmune disease. Finally, cluster four had moderate scores on all of the variables, which could suggest that having an autoimmune disease had not changed their ways of reacting to the world or that they had already integrated their autoimmune disease into their identity. The cluster analysis suggests that, in general, people may react strongly favorably, strongly unfavorably, or not at all to their autoimmune disease. The variables that predict these reactions will be discussed more in the following chapter.

Finally, qualitative data for three open-ended questions were analyzed by three independent raters. These results will be explored in more detail in the following chapter.

In addition, a discussion of how these results compare to the results of previous studies will occur.

## Chapter 6

### Discussion

This study was designed to explore the role of biopsychosocial variables in affecting well-being and health promoting behaviors in individuals with autoimmune diseases. Another purpose was to further explore the psychosocial health of these individuals and determine if there are factors that define living with an autoimmune disease. Because there has been little research on the psychosocial health of people living with autoimmune diseases, it was hoped that this study would lay the groundwork for future studies research in this area.

This chapter will begin with a discussion of the results of the research questions, hypotheses, and additional analyses. Limitations of the study, implications for research and practice, conclusions, and other reflections on the study will then be discussed.

#### *Overall summary of results.*

There were three overarching findings of the current study that are worth highlighting to frame the discussion. First, only depression and social support, representing psychological and social aspects of the biopsychosocial model, uniquely predicted positive well-being and healthy behaviors whereas disease severity (biomedical variable) did not, when all three components of the model were considered together. Previous studies have also shown depression and social support to predict well-being in other chronically ill populations (e.g., Kettman & Altmaier, 2008) but it was hypothesized that the demographic and biological variables in the current study would predict well-being, which was not found. Previous studies have consistently found links between disease severity and well-being, so the finding from the current study is an

anomaly (Westbrook & Nordholm, 1986, Barsky et al., 1999; Mangelli et al., 2002). As discussed later in the chapter, variation on how disease severity was measured in the current study as well as the variety of disorders that were represented may partially explain this unexpected result.

Second, a cluster analysis was conducted in the current study and it was found that individuals with autoimmune diseases form natural groupings based on their data that provide additional information about how biopsychosocial factors covary with this disease. For example, one group of participants reported lower levels of physical, psychological, and social distress across the selected variables while another group reported consistently higher levels of distress. A third group reported moderate levels of all of the biopsychosocial variables of interest. Thus, we can conclude that reactions to autoimmune diseases can take many forms and reported levels of negative symptoms tend to show some uniformity in terms of being low, medium, or high.

Third, the sample in the current study reported slightly higher psychosocial functioning than expected based on previous studies on similar populations. Contrary to expectations, much of this sample reported levels of depression that did not meet the cut-off for clinical depression. This was surprising because previous studies have shown higher rates of clinical depression in populations with autoimmune diseases than found in this sample (e.g. Mangelli et al., 2002, Nagyova et al., 2005). Unfortunately, though, many participants did report levels of depression that would meet clinical criteria and the overall rate of depression was still higher than what has been found in the general population. Approximately 42% of this sample reported clinical levels of depression, whereas only 5-10% of the general population would qualify for clinical depression at

any point in time and 16% will be depressed at some point during their lifetime with higher levels expected for women (Kessler et al., 2003). It is clear that depression is still an issue for individuals with autoimmune diseases.

The sample also appeared to have higher levels of social support than reported by previous studies conducted on individuals with autoimmune diseases, which have typically concluded that social support and social networks are negatively affected after autoimmune diagnoses (Fyrand et al., 2000; Fyrand et al., 2001; Fyrand et al., 2002; Evers et al., 1998). Based on the lower than expected levels of distress found in the present study, as compared to what was expected based on the findings of previous studies, it might be that there are characteristics of the present sample that differ from previous samples of this population. Relationships between the variables of interest will be explored more in a discussion of the results.

#### *Discussion of Results: Hypotheses*

##### *Hypothesis One*

It was hypothesized that there would be a negative relationship between disease severity and social support. Contrary to the hypothesis, disease severity and social support were not correlated. Previous studies found that the longer people had been diagnosed with an autoimmune disease, the less social support they reported (Fyrand et al., 2002). Typically, greater lengths of time since diagnosis are associated with worsened severity, however length and severity are not always the same construct. Disease severity and longer disease length were also related to smaller social networks (an important component of social support) and decreased quality of social support (Fyrand et al., 2000; Fyrand et al., 2001).

The current findings may be explained by a number of factors. First, a wide range of diseases were represented in the current study. Though they were all similar in that they were classified under the general umbrella diagnosis of autoimmune diseases, with some commonality among symptoms, perhaps the variation in diseases might explain why this hypothesis was not supported. The previous studies were conducted primarily on groups of individuals with rheumatoid arthritis, while the current sample was comprised of individuals who had many different diagnoses. It is possible that current respondents had a wider range of symptoms than previous studies and may not respond to their social support networks in the same ways. For example, individuals with gastrointestinal autoimmune diseases may be able to manage their symptoms more consistently than individuals with significant pain or deformity from a connective tissue autoimmune disease so that social plans are not as disrupted due to disease symptoms.

The current finding may also be due to the measurement methods chosen since previous studies used different tests of social support. Since the Medical Outcomes Study-Social Support Scale examines social support from a variety of perspectives, as long as participants had social support that was positive in one area (e.g. supportive spouse but no close friends), they could score highly on the scale. People may report high levels of support if they became closer to a few significant people in their lives, even if they were more distanced from friends and acquaintances. This quote from a participant illustrates this point.

I don't share my illness with many people outside my husband and children. I look so fit, hail and hearty--even when I am not. People don't want to hear about it. They don't believe I am ill. So why share. Most people who I have shared with act like I am putting on an act. My husband and children can tell when I am well and they know when I am not. I don't have many friends--friends take time and effort. There are times when I sleep 12 hours a day for a few months. It is hard to



maintain friendships when you "drop out" for months over and over again. I really try to concentrate on what is most important relationship-wise...I don't have a huge amount of energy to give to relationships so I choose to concentrate what I have on only the most important people--my husband, children, a special nephew, my brothers. Others I deal with only as much as necessary--including my sister, aunt, cousins, old friends.

Overall, this participant scored highly on the MOS-SSS, even though she had high levels of physical impairment and felt more distant from her friends through the disease process. She shared that she became closer to her immediate family but more isolated from friends. She chose to focus her limited energy on relationships that mattered the most to her, which still gave her a high level of social support. Measuring social support using the MOS-SSS in the current study might have contributed to higher scores for the sample if many participants had areas of both strength and weakness in their social support networks to which other inventories may have been more sensitive.

Another explanation for these results might be related to other mediators or moderators between physical health and social support. For example, Plach, Heidrich, and Waite (2003) found that role quality was a mediator of the relationship between physical health and social support. They surveyed women with rheumatoid arthritis and found that women in poor health reporting high role quality were less depressed than women reporting a poor role quality. Another result of the Plach et al. study was that women with high levels of pain along with high role quality had more purpose in life than corresponding women with high levels of pain and low role quality. Regardless of physical health status, role quality had a significant impact on psychological well-being. Like the participant who was quoted above saying that she chose to spend time with people close to her who could understand her situation, the results of the Plach, Heidrich, and Waite (2003) study suggest that the relationship between disease severity and social

support may be more complicated than hypothesized.

It is possible that the current sample had higher levels of social support compared to previous samples, but quotes from participants indicated that social support was still an area of concern for many of the participants. Many individuals wrote about how others did not understand what they were going through, suggesting that there may be something other than the biomedical factors of the disease itself that affect the relationship between disease severity and social support. For example, quality of social support may be related to having close friends understand the full experience of one's struggles in life including chronic illness. In the process of recruiting participants, I received over 40 questions via email asking if a certain kind of disease that a friend had qualified as an autoimmune disease or not. This suggests that at the same time that friends and acquaintances may be aware that a friend or family member has some type of an autoimmune disease and may find it easy to pass on information, they may not be aware of the details of the disease like others who were more closely connected to the individual or who are more knowledgeable about the disease. It is possible that people with autoimmune diseases share the intimate details of their disease only with people in their inner circle, so most friends and some relatives may not have an accurate perception of the disease process.

Two quotes from participants illustrate the possibility that individuals may not share the full experience of their disease with friends. For example, “[My disease is...] often a lonely, frustrating journey. Since RA is experienced differently by everyone, there is not one path to follow. So visiting with others with the disease can often be scary, if someone is more disabled, or dismissed if not as serious as my RA.” This idea is also

supported by quotes like “[In my family] we focus on the positives. Friends: It is hard for people who have not experienced chronic illness to really ‘get it’. I don't look sick so it can be hard to understand my lack of energy, my need to pick and choose the things I spend my energy on - from the outside it looks like laziness I'm sure.”

Technological advances have also changed the way that individuals can receive social support. Online support groups, reference websites, emails, and cell phones may have increased access to social support for individuals whose autoimmune disease has left them housebound. Previous studies that showed that increased disability was associated with decreased social support were conducted before the widespread use of technology-aided forms of social support. In addition, since the survey was conducted online, the current sample may have been even more likely to access support through newer, high-tech forums.

The finding that disease severity and social support were not correlated in the present study does not support Fyrand et al. (2002)'s study, which showed that individuals who had rheumatoid arthritis for a longer period of time reported less social support. Though longevity and severity are correlated, the current study examined disease functionality rather than disease longevity, which also may partially explain the difference between these findings and the Fyrand et al. (2002) study. The WHO-DAS II investigated impact of disability on functionality and may not have been the best measure of disease severity.

Overall, social support may be based on a number of individual factors rather than anything that can be generalized across individuals with autoimmune diseases. Future research should explore the relationship between disease severity and social support to

clarify the complexities that may be unique to living with an autoimmune disease.

### *Hypothesis Two*

The second hypothesis predicted that there would be a negative relationship between self-efficacy and depression. This hypothesis was supported, suggesting that individuals with higher levels of disease self-efficacy had lower levels of depression. This finding suggests that perceived depression is related to how well individuals believe they can manage their disease. Further analyses revealed that self-efficacy was correlated with disease severity, suggesting that people viewed their ability to manage their disease relative to their perceived disease severity. In other words, higher levels of disease severity were related to lower levels of perceived disease self-efficacy and this relationship was demonstrated with a medium effect size.

These results support the findings of Barlow, Cullen, and Rowe (2002), who found that psychological health was correlated with self-efficacy and physical health status was also correlated with self-efficacy in a sample of individuals with rheumatoid arthritis. Previous studies have examined the important link between self-efficacy and well-being, depression, and performance in a variety of settings.

The connection between self-efficacy and depression has been strongly supported in other samples of people with chronic illness. Orengo et al. (2001) found that psychosocial factors like depression and self-efficacy were highly correlated and contributed to disability in individuals with rheumatoid arthritis. Using a regression model, pain, depression, and self-efficacy accounted for 67% of the variance in predicted disability status. Unlike the current study, pain added a significant contribution to the regression model. The relationship between self-efficacy and depression has been widely

studied in individuals with rheumatoid arthritis, more than other autoimmune diseases.

Evidence suggests that this relationship holds important promise for increasing overall well-being and has the potential for beneficial interventions. The relationship between self-efficacy and depression has been evaluated in some studies including Smarr et al. (1997) where an intervention designed to improve stress management and self-efficacy was successful in raising scores on depression and self-efficacy measures in individuals with RA and showed relevance to other clinically important measures of disease severity (Smarr et al., 1997). The general effects of self-efficacy have been found in pain management as well, such that higher self-efficacy for managing pain is associated with less disability and depression and use of better pain coping strategies (Turner et al., 2005).

Though previous studies have also found similar results as the current study, Lowe et al. (2008) pointed out that self-efficacy can be a factor that is variable in terms of how it affects outcomes for different individuals. For some, self-efficacy contributes to more effective coping mechanisms, but for others, self-efficacy does not seem to translate to coping. Lowe et al. also suggested that self-efficacy might be related to the manner in which cognitive coping strategies are implemented. Specifically, they found that the relationship between coping and emotional outcome variables differed according to global self-efficacy appraisals (Lowe et al., 2008). Though depression and self-efficacy have been consistently shown to be associated with one another, the relationship between depression and self-efficacy is complex and holds promise for many other studies on the impact of these psychological variables in chronic illness.

The relationship between self-efficacy and other variables was explored in further

analyses to examine the potential mediating effects of self-efficacy. These results will be discussed later in this chapter.

### *Discussion of Results: Research Questions*

#### *Research Questions One and Two*

The first research question investigated how biopsychosocial variables affect positive well-being in individuals with autoimmune diseases. The second research question examined these same variables' effect on health-promoting behaviors. The biopsychosocial variables that were examined as predictors were disease severity (biological variable), depression (psychological variable), arthritis self-efficacy (psychological variable) and social support (social variable). For both Research Question 1 and Research Question 2, depression and social support were the only variables that were unique predictors of positive well-being and general health promoting behaviors. This suggests that higher levels of social support and lower levels of depression may be more important than perceived pain or disease severity in predicting overall outcome variables like well-being and health-promoting behaviors. Disease severity and self-efficacy did not uniquely predict either well-being or health promoting behaviors. The results for both research questions were similar so an overview of each predictor variable will be discussed briefly followed by a discussion of the separate outcomes of each regression analysis.

Previous studies have found that depression and social support are the most meaningful contributors to predicting outcome variables such as well-being for individuals with chronic disease. The findings of the present study support these previous findings. For example, Kettman and Altmaier (2008) found that social support

was the most important predictor of depression in individuals who had undergone a bone marrow transplant. Social support (as measured by the MOS-SSS) before the transplant predicted depression after the transplant (as measured by the CES-D), even more accurately than pre-transplant levels of depression (Kettman & Altmaier, 2008). The predictive validity of depression and social support in predicting well-being and health-promoting behaviors in the current study as well as post-transplant levels of depression in the Kettman and Altmaier (2008) study suggest that psychosocial variables may be even more important than biomedical variables in understanding the experience of living with a chronic illness.

Although studies like Mangelli et al. (2002), Barsky et al. (1999), and Westbrook and Nordholm (1986) also found significant relationships between depression, well-being, and social support, unlike the present study, they also found that biomedical measures of disease severity were significant predictors. However, it is important to note that these studies used clinician ratings and blood samples to indicate disease severity. The results of the current study differ from these studies because disease severity was not a significant predictor of well-being or general health promoting behaviors.

The broad range of diseases that was included in the current study and the measurement of disability may explain these findings. The measure of disease severity used in the current study (WHO-DAS II) was designed to be broad enough to capture a variety of sources of disability, but it may not had enough specificity to capture the specific autoimmune-related symptoms that most affect well-being and health promoting behaviors in this population. Also, since the data was self-report in nature whereas previous studies had clinicians give severity ratings or used blood tests, it is possible that

the current study did not measure disease severity as accurately as past research.

Unlike the current study, previous studies have found concurrent links between both psychosocial and biomedical factors in predicting well-being. Friedman et al. (2007) found that participants with more social support scored higher on positive well-being. In addition, the participants who had higher well-being had lower levels of inflammatory factor in their blood, again suggesting a relationship between biological factors and well-being. However, psychological variables were not investigated in the Friedman et al. (2007) study.

Neither of the regression models for research question one and research question two showed a significant contribution from the biomedical variable, disease severity, or the psychological variable, self-efficacy. This study utilized self-report ratings of physical symptoms. It is possible that the results of this study differ from some previous research because of the manner in which symptoms were measured. Specifically, pain and even some common symptoms of autoimmune diseases like joint stiffness can be subjective from person to person. In contrast, some previous studies used objective measures of severity like measuring levels of severity indicators in the blood (e.g. Friedman et al., 2007). Since previous studies have shown that individuals who are more depressed also report higher levels of pain (Barsky et al., 1999), using self-report indicators of biological variables may be fraught with confounds, however both methods for measuring disease severity do have their place in research. Individuals with lower well-being may already perceive their pain as worse or experiencing more severe pain may go hand in hand with depression. Future studies could measure levels of interleukins or joint synovial fluid for an objective disease-severity measure of the



importance of depression and social support in disease outcomes.

Self-efficacy did not predict well-being or health-promoting behaviors in either regression. The relationship between self-efficacy and depression was significant in the previous hypothesis but self-efficacy did not add any predictive validity to the current research questions. The Arthritis Self-Efficacy measure that was used in the current study was specific for use with autoimmune diseases that have a musculoskeletal component but it may not have effectively detected self-efficacy for other disease-related variables. It may have been too general of a measure for the broad range of diagnoses in the current study, thus explaining its lack of significance in these regression models. Also, the Functional Self-Efficacy subscale of the ASE has been highly correlated with other measures of disease severity, perhaps making this more of a measure of severity rather than psychological self-efficacy.

Given that the biomedical variables did not add predictive value to the regression models, it raises the question of the value of the biopsychosocial model (e.g. importance of examining all three components) in understanding chronic disease. The findings of the current study suggest that psychosocial variables may be more predictive of health status than biomedical variables, at least for a general population of individuals with autoimmune diseases. Although the biopsychosocial model was developed to emphasize the importance of considering psychological and social factors in addition to biological variables in predicting health outcomes, it was expected that the biomedical variables would account for unique variance in predicting outcomes in the current study. However, the diffuse sample and self-report severity indices may have contributed to the results and make it difficult to draw conclusions about the usefulness of the biopsychosocial model

in investigating this population. This issue is discussed further in the implications for research section of this chapter.

### *Research Question Three*

#### *Role of Self-Efficacy as a Mediator*

The third research question examined whether possible mediating variables existed in the relationship between the biopsychosocial variables and positive well-being. The first analysis examined self-efficacy as a mediator between depression and well-being and found that self-efficacy was not a significant mediator of the relationship between depression and positive well-being. This finding differs from previous research because self-efficacy has been shown to play a role in mediating psychological variables in other studies (e.g. Lowe, 2008). One difference in the current study may have been that the self-efficacy variable that was used was Arthritis Self-Efficacy. Since the Arthritis Self-Efficacy measure encompasses three types of self-efficacy (pain, function, and other symptoms), its mediating effects may have been limited by its broad definition of self-efficacy. More focused measures, like the Pain Self Efficacy measure used in Turner et al. (2005) study have found evidence for mediation. The instrument measures individual's beliefs that they can manage the pain, functional impairment, and other symptoms of their disease. Since the two variables of interest here were depression and well-being and the ASE measure focuses more on the physical symptoms than on cognitive appraisal of a situation as do most other measures of self-efficacy, the lack of a mediation effect may be partially explained.

In previous studies, the functional self-efficacy subscale has been so highly correlated with actual functionality that it has been used as a proxy for disease severity

(Lowe et al., 2008). In this study, psychological predictor variables seemed to predict outcomes but disease severity did not have a relationship with outcome. That the ASE measure has overlap with both disease severity and psychological constructs like self-efficacy and disease severity variables but did not predict outcomes in this study may partially explain the lack of mediation in this study.

The Arthritis Self-Efficacy measure incorporates both physical and psychological items where previous studies on self-efficacy in other disease groups focus on one or the other. For example, Edwards et al. (2001) found that high levels of self-efficacy predicted low levels of disease severity in African Americans with Sickle Cell Disease, and self-efficacy also predicted psychological symptoms like anxiety and depression. They used a more general measure of self-efficacy than the disease-specific one used in the current study, leading to a more clear prediction model.

It is clear that self-efficacy has a relationship with both depression and well-being based on their significant correlations but its role as a mediator was not supported in this sample. Given that self-efficacy as a construct has been found to be important in predicting well-being in other samples, the role of self-efficacy, using a different measure, would be worth investigating in future research.

### *Research Question Three*

#### *Role of Social Support as a Mediator*

The next research question evaluated whether social support was a mediator of the relationship between depression and positive well-being. Results showed that social support was a significant mediator of the relationship between depression and well-being. Frazier, Tix, and Barron (2004) state that mediator variables help explain “how or why

one variable predicts or causes an outcome variable...a mediator is the mechanism through which a predictor influences an outcome variable (116).” Given that definition, social support can be interpreted as one mechanism through which depression influences positive well-being. In other words, social support may influence how or why depression predicts well-being.

The connection between social support and positive well-being was explored by Friedman et al. (2007), where they found that participants with more social support scored higher on positive well-being. Another study about social support that was previously discussed was the Mohr et al. (1999) study, which found that people with Multiple Sclerosis commonly experienced deteriorated relationships after their diagnoses and that they had feelings of victimization after being diagnosed.

This relationship has been shown in previous studies (Kettman & Altmaier, 2008) and has important implications for the study of chronic illness. If one’s level of social support directly impacts well-being, future research should explore ways to improve well-being through social interventions.

#### *Research Question Four*

The fourth research question examined how natural groupings would form among individuals with autoimmune diseases on the predictor variables of interest (depression, self-efficacy, social support, and disease severity) using cluster analysis.

Cluster analysis helps to simplify data and allows researchers to interpret participant responses in grouped form. It is important to recognize that the clusters do not include all of the richness of the participant’s data and by using a reductionistic technique, the statements that can be made about the clusters are just generalizations.

However, cluster analyses can help see the ways that variables tend to cluster together in groups of participants, allowing us to make judgments about possible interventions or implications that can be helpful for groups of people with autoimmune diseases. They also allow us to see what natural groupings tend to form in the data.

One of the most interesting findings about the clusters that resulted from the current study is that there were two groups who represented the extremes on the biopsychosocial variables. Cluster One was doing relatively well while Cluster Three was doing relatively poorly. Cluster One, the healthy exemplars, reported doing well on all variables as compared to the other clusters, while Cluster Three, the Maladjusted Unwell reported doing poorer on all of the variables compared to all of the other clusters. The other two clusters fell somewhere in between.

These clusters helped elucidate the patterns through which the participants tended to vary in similar ways. Unlike the group data, which was used in the regressions, correlations, and in determining the overall means and standard deviations for the study, the cluster analysis showed that groups of participants reacted similarly in overwhelming positive, negative, or neutral ways.

Overall this cluster solution helps point to an important issue for individuals with autoimmune diseases; there is not one way of adjusting to being diagnosed with an autoimmune disease. Based on individual characteristics like depression and social support, people will react either really well or really poorly. The other clusters had moderate scores on almost all of the variables, suggesting that another type of reaction to autoimmune diseases can be fairly moderate, when compared to other individuals with the diseases.

Cluster One, the Healthy Exemplars, report ideal levels of distress and symptoms compared to the other clusters. Future research could explore what factors affect membership in cluster one since they reported doing so well. This cluster reported significantly better scores on all of the variables than the other clusters. Interestingly, this was true for each of the six variables. The members of this cluster had a positive attitude about their ability to get through difficult times or “flare-ups” of their diseases. When asked what a positive consequence of having an autoimmune disease is, these individuals said things like, “I’ve learned to take one day at a time and try to get the most joy out of it you can. And people that truly care and love you will be there to help out when you need it. You find out who you can truly count on.”

Even when negative or stigmatizing comments were made to individuals in cluster one, they found a way to stay positive. For example, “I always found it amusing when people would ask me about what disease I had and I would answer lupus, I would get that “what is it and are you contagious” question. When I would explain it was an autoimmune disease almost every time they would back away from me like I had just said AIDS or leprosy! You gotta see the humor in life and people. I’m glad I have a great sense of humor!”

In sharp contrast, participants in Cluster Three, the Maladjusted Unwell, perceived that they were not doing well on the selected variables. When asked what a positive consequence of having an autoimmune disease is, one member of this cluster said, “What? Stupid question!” and “There has not been any positive consequences to having any autoimmune disease!” These individuals reported poor health and high levels of depression. They reported low levels of social support and low levels of disease self-

efficacy. They scored low on overall well-being as well as in their amount of health-promoting behaviors. Cluster Three seems to represent the opposite end of the continuum of functioning compared to Cluster One, which was doing so well. In many ways, this cluster exemplifies the “worst case scenario” for people with autoimmune disease. One implication for future research is to find ways to reduce the negative emotions and symptoms of individuals in this group.

Cluster Two, the Efficacious Managers, had the highest levels of self-efficacy of all of the clusters. They had relatively low levels of disease severity, but not as low as Cluster One. The high level of disease self-efficacy in Cluster Two was the only variable of interest that did not vary with the other variables as expected. Cluster One had high levels of all of the desirable variables (social support, self-efficacy, well-being, and health promoting behaviors) and low levels of the less-than-desirable variables (depression and disease severity), while Cluster Three had low levels of those desirable variables and high levels of the less-than-desirable variables. Cluster Four had moderate levels of all of the variables. In Clusters One, Three, and Four, the variables “hung together” as expected but Cluster Two had the only example of an elevated level on one variable, compared to the other clusters, with moderate levels on the others. Due to this one unexpected finding, their name emphasizes that they thought they could do well in managing their health: the Efficacious Managers. A quote from a member of Cluster Two illustrates the value of self-efficacy for this group: “I have learned that if you put your mind to it, you can accomplish anything that you want to, even if it is difficult. When I feel good I try to do the things that I want to do, even if the next day I know I will suffer.” Her quote indicates that she believes she can do anything she wants to, but that

she may have to pay the consequences (either physical, psychological, or both) the following day. The moderate levels of the variables besides self-efficacy may be due to them averaging out over time (e.g. some good days, some bad days).

Cluster Four, the Impervious Moderates, reported moderate levels of all of the variables. There are many possible explanations for this. Perhaps they are not affected by autoimmune diseases as much as the other clusters are, perhaps they have integrated their disease into their identity, or perhaps they are just individuals who were more moderate on the variables before having an autoimmune disease and have not changed much. It is really not possible to speculate on why this cluster was moderate compared to the other clusters since a complete analysis of this was not conducted. There is no way to compare clusters on their levels of these variables before having an autoimmune disease so it is difficult to know which ways of reacting (or not-reacting) are due to their autoimmune disease, other factors in their life, other medical issues, or their personality in general.

When asked about a positive consequence of her autoimmune disease, this Impervious Moderate wrote, “Just one. I am much more aware and understanding of others with any kind of disability.” She did not indicate that she was positively or negatively affected in any extreme ways and she was only able to come up with a short positive explanation for the question. Her answer was not about herself but that she had learned too be more aware of others.

Interestingly, the clusters that resulted from the current study were straightforward in that participants tended to react in expected ways. No clusters appeared where participants were doing really well on some variables and really poorly on others. This



may also be because there were high levels of correlations found between many of the biopsychosocial variables (See Table 6). Given that many doctors (and participants in the study) mentioned stress as a cause of autoimmune diseases, perhaps autoimmune diseases are more linked to psychological functioning. As was true with the clusters, if one thing is good, the rest is good, and if one thing is bad, the rest is bad too.

#### *Qualitative Data.*

There were three questions analyzed using qualitative methods. These questions were included in the study to give a more detailed view of the sample and were not intended to be used for quantitative analyses. Since rigorous qualitative methods were not applied in the current study, the data are presented here for descriptive purposes. Future studies should expand on the qualitative questions used here in semi-structured interviews or focus groups.

Because people with autoimmune diseases often misattribute the cause of their disease or blame themselves for their illness, the first question was included to assess the causal attributions that individual respondents held and if they were supported by medical professionals. For the first question, “What do you believe caused your disease?” the category where 27% of the respondents were placed was “don’t know.” Since the causes of autoimmune diseases are largely unknown, this was not a surprising result. However, over half of the sample (56%) indicated a specific cause for their disease. Interestingly, only 24% of the sample had received a medical explanation for the cause of their disease, yet many still had personal attributions for their disorder. The number of participants who responded “genetics” (which could be viewed as something beyond their control) and “some kind of physical or psychological stress” (which could be viewed as somewhat

within their control) was approximately equal. It is important to note that there was a tone of self-blame in some individuals in the physical stress group and especially in the next largest category, emotional stress. These individuals in the emotional stress group in particular seemed to blame themselves for working too much or not dealing with the psychological or emotional stressors in their lives, which they believed led to the development of their disease. Though the completeness and reliability of the corresponding question about participants' knowledge of a medical cause for their disease was lacking, it did become clear that some participants had been given a medical explanation for their disease but still believed it was due to something they had done wrong (e.g. "drinking too much Diet Pepsi"). Further analysis of this question, through a more complete qualitative research study, would be beneficial in understanding if and when people blame themselves for the etiology of their disease.

The difference between the number of participants who articulated a cause (56%) and those who had received a medical explanation (24%) illustrates a gap that has also been observed in previous literature. It is possible that holding a belief that a specific factor caused one's disease may allow people to make sense out of something that has happened to them or to feel protected against other types of illness or believe that their family members will not be similarly affected if they are able to avoid the perceived cause.

It is important to think about the results of this causality question in light of previous research on attributions for illness. Westbrook and Nordholm (1986) found that accurate attributions were tied to lower levels of depression, more positive coping, and less need for counseling. They compared people with high-lifestyle involvement diseases

(heart attack and stroke) to people with low-lifestyle involvement diseases (arthritis and cancer). They found that people who were more accurately blaming themselves for some lifestyle-related reason that they developed heart disease or strokes were doing better. Conversely, when individuals with low-lifestyle involvement diseases blamed themselves, they were doing worse (Westbrook & Nordholm, 1986). Since the causes of autoimmune diseases are unknown and not likely due to lifestyle involvement, self-blame in this population is likely to have harmful effects.

One response from this study demonstrated this paradox. When asked what she thinks caused her autoimmune disease, she responded: “I am not sure, I have heard that maybe a virus can cause MS. When I am really depressed, I can talk myself in to a punishment from sins of my past. I am really not sure.” When asked if she had received a medical explanation for her disorder, she responded, “Most doctors will say that they don't know for sure what the cause is.” Another individual had been told by her doctor that the explanation was genetics and she thought, “Well besides my father having it, I being in recovery have also seen a number of people getting clean who were cocaine addicts have also been DX with MS. I also am a recovering cocaine addict.” She, like other participants, blamed themselves for decisions or lifestyle choices they had made in the past, yet at the same time seemed to be aware that these attributions were not supported by the medical profession.

For the second question about positive benefits of their diagnosis, a wide range of responses was observed. The largest group of respondents indicated that having an autoimmune disease had allowed them to be more aware of their limits, their own body, and how to balance their time. Many people in this group discussed making changes to

their lifestyles to improve their overall health through diet, exercise, and stress management. They also learned how to ask for help and recognized their limits.

The next categories had roughly similar numbers of participants. First, social support was often cited as a benefit of their diagnosis. This tended to take the form of specifying a relationship (e.g. with a spouse) that had improved or that the participant felt closer to a specific person as a result of their disease. This category was similar to the one about helping others with autoimmune diseases. Respondents who indicated that they benefited through developing empathy for others, an ability to relate to family members or friends with autoimmune diseases, or that they had a different view of disability fell into the category of helping others. They differed from the social support respondents because the focus of their positive benefits was towards other people rather than receiving help from others or becoming closer to specific people.

Another positive benefit reported was personal growth, when people indicated a specific way that they had grown or changed as a result of their disease. Similarly, about the same proportion of participants indicated that they had re-evaluated their priorities or focused on what was most important in their lives. With many of these responses, the positive benefits had some relationship to social support. That was observed directly with the fifth category and indirectly by helping others with autoimmune diseases. Some personal growth was related to improvement on individual characteristics that improved relationships (e.g. became a better listener) and re-evaluating one's priorities often meant that the respondent was choosing to spend more time with their families or other important people in their lives. Since the sample as a whole reported high levels of social support, as indicated in the results section and measured by the MOS-SSS, it is not

surprising that so many participants cited positive benefits that had a relationship to social support. The other category of benefits is religious/spiritual beliefs. Just under 6% of the participants indicated that they became closer to God, more spiritual, or more committed to their religious faith.

Previous studies have found that individuals who are able to find more positive-benefits as a result of having a chronic illness report less severe levels of pain (Katz et al., 2001). Though no significant differences were found between participants who were able to identify positive benefits and those who did not in the current study, further analysis of this relationship between benefit-finding and disease severity is warranted.

Finally, for the third question about willingness to seek psychotherapy, the largest number of responses related to the removal of barriers like cost, transportation, and not having enough time to go to therapy. Approximately equal numbers of participants indicated that they did not need it but would be willing to go if something changed but for now are not interested. These responses were from people who were generally willing to seek therapy and did not express resistance or reasons not to go to therapy. Some of the answers to this open-ended question were rather short (e.g. “nothing”) so it was difficult to interpret which category to place these responses in. It was determined that these answers would be categorized together, though without a more complete context for understanding them, it is unclear if that was the correct decision. A more complete discussion of this issue will follow in the limitations section. It is also important to note that this open-ended question had more missing data than the other questions. It is possible that respondents were less willing to answer questions about counseling than other issues or considered these questions less germane to the purpose of

the study.

Other responses to this question included specific comments about therapist characteristics or the therapy process, which were categorized together. Another category was related to worsening symptoms, such that respondents would seek psychotherapy or counseling if they became more depressed or suicidal or their emotional state started to affect their relationships. Overall, since the sample reported slightly less depression and reported more social support than expected, it is not surprising that many respondents indicated a reluctance to seek therapy.

The findings from the open-ended questions give a fuller picture of the sample. From the first question about causes of one's disease, it is clear that people with autoimmune disease have a variety of different explanations for the cause of their disease, regardless of if what is espoused by their doctors. Secondly, some individuals with autoimmune diseases have been able to find a silver lining to their experience with their disease, while other respondents had difficulty answering that question. Finally, willingness to seek psychotherapy was found in some of the participants but significant barriers (both personal and logistical) exist for a large portion of the sample. Some of the barriers to seeking therapy that were mentioned were unique to individuals with autoimmune diseases and suggest some important implications for practice which will be discussed later in this chapter.

These three questions that were included in the study to give a more detailed view of the sample and were not intended to be used for quantitative analyses. Since rigorous qualitative methods were not applied in the current study, the data were presented here for descriptive purposes. Future studies should expand on the qualitative questions used

here in semi-structured interviews or focus groups to include follow up questions that help clarify the context of the answers. Overall, the results from the open-ended questions did present some interesting findings for future research and implications for practice. These will be discussed after a description of the limitations in the current study.

*Limitations.*

Several limitations existed in the current study. First, the sample was overwhelmingly white. While there are some autoimmune diseases that are more common among white individuals, the proportions of white participants do not match the norms for the diseases. A number of explanations exist for this including the population demographics of Iowa, where most of the participants were recruited, being primarily white. The 2000 census estimates that the population of Iowa as a whole is 94.6% white, which is similar to the 94% white in the current study ([www.quickfacts.census.gov](http://www.quickfacts.census.gov), 2008). Also, since snowball sampling was used as one of the methods of data collection, many people who participated in the study shared the information about the survey with individuals they were related to or whom they knew, who would likely be of the same race. This limitation should be addressed in future research. One way of addressing this discrepancy in future research is to oversample from minority populations. More involvement from clinics like the NIAMS Cardozo Community Health Clinic, which serves less than 10% white clients, would be a great improvement to the body of research that currently exists on autoimmune diseases.

All sampling methods have some limitations. Conducting an online survey has its

own unique pitfalls as well as its benefits. Some of the problems with online research in general are difficulty determining a response rate, especially when participants are recruited in part through snowball techniques. This was a problem for the current study but the limitations of this method were outweighed by the ability to collect a larger sample size from individuals with a variety of different diagnoses. Some online research uses password-protected websites to collect data but that was not done in the current study due to the desire to collect data from a wide-range of participants that may not have access to the passwords. This was a limitation because data was missing on many items, which may have been attributed to people who were not serious about the study. Though it is doubtful that participants contaminated data in large numbers, it is a consideration that many people viewed the survey without following through on completing it.

Some benefits of online surveys were apparent as well. Data collection was a relatively fast process, and a sample from a large geographic range of participants was possible. A broad range of diagnoses with good representation of the population of autoimmune diseases as a whole was collected. Collectors were created in Survey Monkey to track the number of participants. Some people clicked on the first page of the survey to agree that they would participate but did not fill out the survey. Though there are some limitations to collecting data through online surveys, the number of surveys collected in a short period of time was a benefit in the current study.

One other limitation is that the variety of diagnoses represented were fairly broad but represented few enough individuals that analysis of the differences between the subgroups was not possible. Though the “umbrella” of autoimmune diseases that were represented in the current study was discussed in detail with physicians from the National



Institutes of Arthritis and Musculoskeletal and Skin Diseases, there was still enough variability in the types of symptoms represented among the diseases that the sample was fairly broad. Diseases that were not connective tissue or musculoskeletal autoimmune diseases were dropped from the final sample.

The WHO-DAS II was not the best measure of disease severity. It is a better estimate of perceived impairment and is used to correspond with levels of functional impairment. The WHO-DAS II had good sensitivity for pain and functional impairment, but may have allowed for under-representation of the severity of other autoimmune symptoms. In future studies, the range of disease severity could be more limited or a specific type of disease or length of time since diagnosis could be specified. Most of the measures were not disease-specific but future studies should include a measure of biological symptoms of severity that is not self-report data to fully determine the impact of the disease.

Another limitation is that the current study was cross-sectional. Future studies could benefit from utilizing a longitudinal perspective. No significant effects for time since diagnosis were found in the current study but a longitudinal study may do a better job of capturing the highs and lows of remission and relapse associated with autoimmune diseases. A possible way of doing this would be to use journaling at various time-points to capture variation in symptoms across time. Also, since this study was self-report in nature, participants were only reporting their own experience. This is a significant limitation of the current study because participants may have under- or over-reported their disease severity.

As discussed earlier, depression may skew the experience of disease symptoms or

pain levels and some people may not have given an accurate representation of symptoms of autoimmune diseases. People with more severe depression may not have elected to participate in the study. Since many individuals with autoimmune diseases are used to interacting with people who are not familiar with the nature of their symptoms or even the name of their diagnosis, it also might be that people living with autoimmune diseases become used to “putting on a happy face”. When given the opportunity to report on their symptoms, they may be so used to trying to fit in with others or avoid complaining, that they simply did not accurately report their symptoms.

Overall, participants indicated that their health was similar to levels reported in previous studies. When asked, “Based on what you know about your disease (or compared to others), how severe is your autoimmune disease?” on a scale of 1-10, the mean was 4.58 with a  $SD=2.46$ . As part of the WHO-DAS II, when asked, “How do you rate your overall health in the past 30 days?” on a scale of 1-5, the mean was 2.64 with a  $SD=0.971$ . This suggests that the current sample was similar to previous samples on biomedical issues but had some better psychological and social outcomes.

Missing data was also a limitation in this study. A detailed explanation of the decision-making process associated with the missing data is provided in the results section. The length of the survey may have led to an increased amount of missing data in this sample. Although there was a substantial amount of missing data in this sample, the results were not different when missing data was replaced using the common methods recommended by Allison (2008) and available in SPSS. Perhaps some participants were skipping select items or scales with confusing wording; hopefully a shorter survey would be beneficial in reducing the amount of missing data and individuals who were deterred

from taking the survey in the first place. In addition, counterbalancing of the measures may aid in reducing missing data.

A limitation was present in the analysis of the qualitative data as well. First, the open-ended questions were designed for participants to write answers to the questions in detail but many participants were terse with their responses. Better qualitative data would have been gathered through in-person interviews or a survey that was solely focused on open-ended responses. The qualitative data was at the end of the survey and respondents may have developed some survey fatigue by that point, thus limiting their answers. In addition, since participants became accustomed to filling out Likert-scale questions, it may have been difficult and burdensome to change question modalities to respond to the open-ended questions.

In the qualitative coding process, there was some difficulty interpreting the answers that participants had to some of the items due to their short answers. For example, on the question about willingness to seek psychotherapy, many participants indicated “nothing”. They could mean that “Nothing would ever change my mind about not wanting to go to therapy” or “I’m already in therapy and so nothing would change my willingness to do it” or that “Nothing affects my willingness to seek therapy.” Though another question about history of counseling/therapy was asked, the data on that question was not thorough enough to analyze, nor would it be appropriate to make judgments about the intention of a given response just because it was matched to data about their history of therapy.

#### *Implications for future research.*

The current study was largely exploratory in nature because there is a lack of

research on autoimmune diseases in general and the psychosocial impact of these diseases in particular. The purpose of this study was to evaluate the impact of biopsychosocial variables on well-being and health-promoting behaviors.

Future research should expand on the findings from the current study. One area of research that should be investigated is whether the unique contributions of individual diseases matter when doing psychosocial research or if the common factors that are significant across studies are more relevant to future research. Many studies on chronic illness in general have similar results that show that social support and depression are both important predictors of well-being and other outcomes but there has been little evidence differentiating how those processes are different for individuals with different diseases. In other words, does it make sense for us to research psychosocial issues for different disease groups separately (e.g. studies on breast cancer, HIV, autoimmune diseases, etc...) or are the experiences of individuals with chronic illness similar enough that we can group them together? The results of the current study were almost identical to those of Kettmann and Altmaier (2008) in that depression and social support were the only variables of interest that accounted for unique variance in predicting the outcome variables, yet their study was conducted with individuals who had undergone a bone marrow transplant—an entirely different physical experience. It is possible that the within-group differences for one type of disease are greater than or equal to the between-group differences for individuals with different types of chronic illness. Perhaps the biomedical differences between groups are not as important as the psychological and social factors and people's perceptions of their situations (e.g. pain perception).

The findings of the current study and those of the Kettman and Altmaier (2008)

study may be similar because some psychosocial variables, like depression and social support, consistently predict well-being and other outcome variables and are relevant across multiple situations. A strength of the biopsychosocial model is that it allows researchers and clinicians to recognize the importance of psychological and social factors in the context of biomedical factors; in a way, the true strength of the biopsychosocial model is providing a lens through which biomedical variables can be considered in a psychosocial light. However, a limitation is that variables like depression and social support seem to be “common factors” that predict positive life outcomes and positive health outcomes in general, regardless of the specifics of the situation. These can be likened to the “common factors” approach in understanding therapy process and outcome research; meaning that factors like having a positive relationship with one’s therapist and symptom reduction are beneficial regardless of the type of therapy studied (Wampold, 2001). Perhaps among the common factors in predicting health outcomes are depression and social support.

Another implication is whether the biopsychosocial model should be modified to encompass this finding that depression and social support have the largest impact on individuals’ experiences with their chronic illness. It may be that a body of evidence has shown that quality of life can be improved by reducing depression and increasing social support, both of which represent areas that are possible to intervene and are appropriate for counseling psychologists to focus on with their clients. One benefit of research examining the biopsychosocial model is that it supports Engel’s view that a medical model alone may not be the best way to predict the effects of disease (Hoffman & Driscoll, 2000).

Not only does it appear that psychosocial issues are at least as important, if not more important in dealing with a chronic illness but psychosocial issues have also been shown to have a large impact on physical symptoms. For example, Barsky et al. (1999) found that individuals who were less depressed reported less pain but also had significantly less joint swelling, when objective measures were used to measure that biomedical outcome. Their study showed a clear impact of the psychosocial issues surrounding a chronic illness and proved that helping individuals feel better psychologically had a drastic impact on their health. Even if similar examples of psychosocial factors improving biomedical health are not found across all disease categories, greater perceptions of well-being and increased quality of life are substantial benefits for all individuals. The current study provided support for continued use of the biopsychosocial model as a way of conceptualizing and interpreting research on chronic illness.

Future research should also aim to encompass different ways of understanding disease severity including objective measures as well as self-report data (like measuring blood levels of interleukins or monitoring joint swelling) as well as asking family members to share their experiences too. Some benefits exist in using multiple types of data. In the current study, the self-report nature of the survey might have skewed the results to show a more positive view of the individuals with autoimmune diseases because they did not self-report that they were depressed or doing badly as often as they wrote about it in the open-ended questions.

Future research could streamline the measurement of disease severity, perhaps creating instruments that are more robust for use in different populations that also have

high levels of specificity. There were three different measures of functionality and severity that were used in the current study. First, previous studies have shown that the Arthritis Self-Efficacy: Function scale correlates significantly with people's actual functionality (Barlow et al., 2000); belief in one's ability to manage symptoms seems to be an important construct in understanding disability. Second, the measure that was used to assess symptomatology in the current study was the WHO-DAS II, which assesses physical as well as some psychological and social impairment related to disability. Finally, participants were asked one item in the demographics section where they had to rank the severity of their disease, as compared to other individuals with autoimmune diseases, on a scale of 1-10. These three different indicators can all be used to describe the functionality of the sample. Along with objective measures of severity like joint counts, interleukin levels in the bloodstream, or physician ratings of symptoms, there is much room for improvement in measuring the biomedical factors associated with autoimmune diseases. Combining self-efficacy, self-report symptom, comparisons to others with objective measures could be a productive direction for future research.

*Implications for practice.*

The psychological symptoms that were investigated in the current study, depression and self-efficacy, are commonly associated with psychological distress among people with chronic physical illnesses. The ongoing and higher levels of distress associated with autoimmune diseases versus adults in general and the promising results of psychosocial interventions with individuals with other types of chronic illnesses suggest that psychosocial and psychotherapeutic interventions could be extremely valuable for autoimmune populations. One avenue for improving the significant life stressors that

may be associated with autoimmune diseases is psychotherapy (Westbrook & Nordholm, 1986) as seeking psychotherapy generally has the implicit goal of enhancing one's psychological well-being. The current study found support for the predictive role of depression and social support in enhanced well-being, factors which psychotherapy is designed to help improve. This study found that around 42% of the participants would reach clinical levels of depression, suggesting that there are many individuals in this population who could benefit from psychotherapy.

The results of the cluster analysis showed that people tended to have low, medium, or high levels of impairment on all of the biopsychosocial variables that were included in the current study. This might suggest that individuals who are doing poorly on one variable may have other areas of functioning that could benefit from remediation. An implication for clinicians is that poor functioning in one area may serve as a “red flag” that other areas may also be worse than expected. For example, if an individual with autoimmune disease reports high levels of depression; low levels of social support and self-efficacy and high levels of disease severity may also be found. This finding should encourage clinicians to look beneath the surface and do a full investigation of well-being if individuals appear to be doing poorly in one area.

Previous studies have found that psychotherapy can be effective with individuals with autoimmune diseases. Therapy interventions have helped individuals with rheumatoid arthritis reduce pain and joint swelling (O'Leary et al., 1988) as well as ease the psychological and social distress associated with autoimmune diseases (Astin et al., 2002). The significance of depression and social support in the current study could suggest important therapy interventions. Individual or group therapy could be helpful in



reducing symptoms of depression while group therapy could aid in providing social support and teaching participants the skills they need to access support elsewhere.

Disease-specific support groups, either in-person or online, may be especially helpful in assisting individuals with autoimmune diseases in improving their perceived levels of social support.

One clinical application of the current study is that the recruitment for this survey happened online and a wide variety of individuals participated with different diseases. As shown in Table 14, many different autoimmune diseases were represented. The utility of the internet for connecting individuals with different diseases was clearly demonstrated in the current study based on the variety of diseases that participants reported having. At least one online support group through the Multiple Sclerosis Society encouraged their members to participate in this research. Many respondents had similar comments in the open-ended question section of the study and could benefit from open dialogue through chat rooms, blogs, or other online mechanisms of communicating with others. Given the results that social support functioned as a significant mediator in the current study, it would be beneficial to form online support groups and encourage medical professionals to endorse them too.

Although this study did not examine the benefits of specific interventions, some practice implications can also be gleaned through analysis of the qualitative question about psychotherapy. Participants were asked what factors would affect their willingness to seek psychotherapy and a large number of them mentioned that barriers that have deterred them from entering therapy. The sample was split almost evenly among those who had been in therapy and those who had not. Many people commented that they

would go to therapy “if depressed or suicidal” or “if necessary,” suggesting that they were open to it if they felt worse.

A couple of participants stated that they felt comfortable talking to their physicians about everything they needed or would go to counseling if their doctor recommended it. For example, “Neither [psychotherapy or counseling] have been suggested by my physicians. If necessary, I would be willing.” This could be problematic for many individuals with autoimmune diseases considering that one study found that only 10% of individuals in therapy were referred by their doctors (Cunningham & Edmonds, 1996). Though all of the participants had some contact with medical doctors, only two individuals mentioned anything about them in any of the qualitative questions, perhaps an indication of the mind-body dualism that is still present in medical treatment.

The most common response to “What would affect your willingness to seek psychotherapy or counseling?” was “nothing could”. Many of them were disinterested and indicated that there were no factors that could change their minds. Others did not think it could be helpful in dealing with their autoimmune disease. About half of the participants had previously participated in therapy or counseling of some sort, and some of those who had participated reported having a negative experience that had affected their future willingness to seek therapy again. Others mentioned financial issues or logistical issues like finding the time, being able to get out of the house, “finding a qualified person,” and transportation problems. Some of the logistical issues related to transportation and mobility may be unique to individuals with autoimmune disease, such that innovative therapeutic interventions that incorporate technology may be especially helpful for this population.

As discussed in the review of the literature, seeking therapy may also be uniquely difficult for individuals with a chronic physical illness because they have so many medical appointments that they must attend to monitor their physical health that they do not have the time or energy left to talk to a therapist. As one participant put it, “Time and health [would affect my decision to seek counseling or psychotherapy]. It takes a great deal of time going to all my doctors so I do not have much more time for extras.” Some were able to recognize their personal difficulties in seeking out or participating in therapy to the fullest extent stating, “I struggle with the ability to discuss my personal problems, so it is difficult for me to cooperate in therapy.” And, “It's hard to want to work through all that stuff emotionally it is very draining and finding the strength and courage to do it is very hard.”

Others did not believe that a counselor could understand their perspective on living with an autoimmune disease, perhaps addressing some of the alienation and misinformation they have received from other professionals: “[I] do not believe it would help unless they have walked in my shoes.” Building empathy for chronic physical illness among therapists is especially important so that when a physically ill individual does seek out therapy, the therapist is ready for the case. Given the unique presentation of autoimmune diseases, mental health professionals should make an effort to educate themselves about chronic illness, especially if a client presents with an unfamiliar disorder.

Some individuals responded that they received enough support from their families and friends and did not need therapy, while others indicated that they would rely on their doctors to refer them to counseling if needed. In the current study, no participants

mentioned a positive benefit of their autoimmune disease being related to attention from their doctors. Many individuals talked about the beneficial support of family members or friends or even disease-related support groups but no one mentioned the care from or relationship with their doctors as being a positive benefit. One implication of this finding is that since people are relying on their doctors for psychological referrals, or at least some psychosocial guidance, it is imperative that medical professionals be made more aware of the importance of psychosocial issues in the process of chronic disease. Another implication is that the participants in the current study were not overwhelmingly excited about traditional therapy but other modalities, perhaps even online psychoeducational support groups would be beneficial.

The results of the current study suggest that depression and social support are predictors of psychological well-being, so doctors and nurses need to be more attuned to the psychosocial wellness of the individuals with whom they work. As a corollary, counselors, psychologists, and psychotherapists also need to be more educated about how chronic physical illness takes a toll on one's emotional health.

### *Conclusions.*

In response to the lack of information about how biopsychosocial variables affect positive well-being and health-promoting behaviors in individuals with autoimmune disorders, the current study investigated the impact of depression, self-efficacy, disease severity, and social support on those important outcome variables. Because of the importance of positive well-being and health-promoting behaviors on overall mental and physical health, they were chosen as the outcome variables of interest in this study. In addition, well-being and health-promotion are both important variables because of they

have implications for prevention and clinical interventions.

In the current study, psychological and social variables predicted unique variance in outcomes whereas biomedical variables did not. These results suggest that the psychological and social aspects that go along with the diseases may be more important than disease symptoms. Though people with autoimmune diseases commonly report being told their disease is “all in their head,” the results of this study suggests that how individuals perceive and react to their disease may be based more on psychosocial variables than on characteristics or symptoms of their disease. In other words, psychological and social variables may be the lens through which the actual symptomatology, disease progression, or severity is viewed. It is possible that actions to alleviate depression and to stay connected to friends, family, and significant others through the ups and downs of an autoimmune disease may be most helpful in improving well-being and staying healthy. It is easier to intervene with these psychosocial variables than with disease symptoms.

Though individuals with autoimmune diseases may go through the cycles of relapse and remission, lengthy and difficult diagnosis processes, isolation and stigmatization, and painful physical symptoms; the results of the current study indicate that having friends and significant others, and alleviating stress and depression are important objectives that seem to be an important part of doing well. For the individual described in the introduction chapter who was attempting to balance the many demands in her life as well as struggling with rheumatoid arthritis, hopefully the results of this study will encourage medical professionals to acknowledge the importance of her psychological and social needs in addition to the biomedical symptoms they are already treating. In summary,

autoimmune diseases have significant biomedical, psychological, and social consequences and costs for affected individuals, their loved ones, and society as a whole.

Appendix A

Demographic Form

Age: (Select One) [18-24; 25-34; 35-44; 45-54; 55-64; 65-74; 75-84; 85 or above]

Gender: [Female or Male]

Race/ethnicity: [Asian/Asian-American/Pacific Islander; White/European-American; Middle-Eastern/Arab; Asian Indian/Pakistani; Hispanic/Latino(a); Biracial/Multiracial; Black/African-American; Native American/Native Alaskan]

Other (please specify) \_\_\_\_\_

Highest degree completed: (Select One) [Elementary School; Middle School/Junior High School; High School; Technical School; Two-Year College; Some Four-Year College; Four Year College Degree; Some Graduate School, Masters Degree, Doctorate or Professional Degree]

What type of autoimmune disease(s) do you have: \_\_\_\_\_

How long ago were you diagnosed with this disease(s)? (Select One) [Within the past month; 1-6 months ago; 6 months-1 year ago; 1-2 years ago; 2-5 years ago; 5-10 years ago; 10-20 years ago; more than 20 years ago]

What symptoms do you experience? \_\_\_\_\_

Occupation: \_\_\_\_\_

Number of hours per week that you work for pay: (Select One) [0; 1-5; 6-20; 21-40; 41-60; more than 60]

Has your autoimmune disease(s) affected your ability to work? [No/ Yes]

If yes, how? \_\_\_\_\_

How has your autoimmune disease affected your relationships (e.g. partner/spouse, children, friends, etc...)? [No/ Yes]

If yes, how?

What types of medical treatment have you received for your autoimmune disease?

\_\_\_\_\_

Who do you live with?

If children, please list ages. \_\_\_\_\_

Does anyone else in your family have an autoimmune disease? [No/ Yes]

If yes, who and what kind? \_\_\_\_\_

Based on what you know about your illness (or compared to other people you know with the disease), how severe is your autoimmune disease?

|                      |   |   |   |   |   |   |   |   |                     |
|----------------------|---|---|---|---|---|---|---|---|---------------------|
| 1                    | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10                  |
| Not at all<br>severe |   |   |   |   |   |   |   |   | Extremely<br>severe |

What do you believe caused your autoimmune disease?

Have you been given a medical explanation for the cause of your disease?

What other health problems do you have?

What is a positive consequence you've experienced based on having an autoimmune disease?

Have you ever been in therapy/counseling before? [No/ Yes]

If yes, please describe how long ago, length of time in therapy, and type of therapy (if known).

What would affect your willingness to seek counseling or psychotherapy?

Is there anything else you would like to tell us about your experience?



## Appendix B

### WHO-DAS II

How do you rate your overall health in the past 30 days?

Very good      Good      Moderate      Bad      Very Bad

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the last 30 days, how much difficulty did you have in:

#### Understanding and communicating

1. Concentrating on doing something for ten minutes?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

2. Remembering to do important things?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

3. Analyzing and finding solutions to problems in day to day life?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

4. Learning a new task, for example, learning how to get to a new place?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

5. Generally understanding what people say?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

6. Starting and maintaining a conversation?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

#### Getting around

1. Standing for long periods such as 30 minutes?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

2. Standing up from sitting down?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

3. Moving around inside your home?

None Mild Moderate Severe Extreme/ Cannot Do

4. Getting out of your home?

None Mild Moderate Severe Extreme/ Cannot Do

5. Walking a long distance such as a kilometre (or equivalent)?

None Mild Moderate Severe Extreme/ Cannot Do

In the last 30 days, how much difficulty did you have in:

Self Care

1. Washing your whole body?

None Mild Moderate Severe Extreme/ Cannot Do

2. Getting dressed?

None Mild Moderate Severe Extreme/ Cannot Do

3. Eating?

None Mild Moderate Severe Extreme/ Cannot Do

4. Staying by yourself for a few days?

None Mild Moderate Severe Extreme/ Cannot Do

5. Dealing with people you do not know?

None Mild Moderate Severe Extreme/ Cannot Do

6. Maintaining a friendship?

None Mild Moderate Severe Extreme/ Cannot Do

7. Getting along with people who are close to you?

None Mild Moderate Severe Extreme/ Cannot Do

8. Making new friends?

None Mild Moderate Severe Extreme/ Cannot Do

9. Sexual activities?

None Mild Moderate Severe Extreme/ Cannot Do

10. Taking care of your household responsibilities?

None Mild Moderate Severe Extreme/ Cannot Do

11. Doing most important household tasks well?

None Mild Moderate Severe Extreme/ Cannot Do

12. Getting all the household work done that you needed to do?  
None Mild Moderate Severe Extreme/ Cannot Do

13. Getting your household work done as quickly as needed?  
None Mild Moderate Severe Extreme/ Cannot Do

IF YOU WORK (PAID, NON-PAID, SELF EMPLOYED) OR GO TO SCHOOL,  
COMPLETE QUESTIONS 1-4 BELOW. OTHERWISE, SKIP TO THE NEXT PAGE.

In the last 30 days, how much difficulty did you have in:

1. Your day to day work/school?  
None Mild Moderate Severe Extreme/ Cannot Do

2. Doing your most important work/school tasks well?  
None Mild Moderate Severe Extreme/ Cannot Do

3. Getting all the work done that you need to do?  
None Mild Moderate Severe Extreme/ Cannot Do

4. Getting your work done as quickly as needed?  
None Mild Moderate Severe Extreme/ Cannot Do

In the last 30 days:

Participation in Society

1. How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?  
None Mild Moderate Severe Extreme/ Cannot Do

2. How much of a problem did you have because of barriers or hindrances in the world around you?  
None Mild Moderate Severe Extreme/ Cannot Do

3. How much of a problem did you have living with dignity because of the attitudes and actions of others?  
None Mild Moderate Severe Extreme/ Cannot Do

4. How much time did you spend on your health condition, or its consequences?  
None Mild Moderate Severe Extreme/ Cannot Do

5. How much have you been emotionally affected by your health condition?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

6. How much has your health been a drain on the financial resources of you or your family?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

7. How much of a problem did your family have because of your health problems?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

8. How much of a problem did you have in doing things by yourself for relaxation or pleasure?

None      Mild      Moderate      Severe      Extreme/ Cannot Do

## Appendix C

### Center for Epidemiologic Studies Depression Scale (CES-D)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week: (circle one number on each line)

| Rarely or none<br>Of the time<br>(less than 1 day)<br>0 | Some or<br>a little of the time<br>(1-2 days)<br>1 | Occasionally or a moderate<br>amount of time<br>(3-4 days)<br>2 | All the time<br>(5-7days)<br>3 |
|---|--|---|--------------------------------|
|---|--|---|--------------------------------|

During the past week...

- |  |   |   |   |
|--|---|---|---|
| 1. I was bothered by things that usually don't bother me.....0                     | 1 | 2 | 3 |
| 2. I did not feel like eating; my appetite was poor .....0                         | 1 | 2 | 3 |
| 3. I felt that I could not shake off the blues even with help from my family.....0 | 1 | 2 | 3 |
| 4. I felt that I was just as good as other people .....0                           | 1 | 2 | 3 |
| 5. I had trouble keeping my mind on what I was doing.....0                         | 1 | 2 | 3 |
| 6. I felt depressed .....0   | 1 | 2 | 3 |
| 7. I felt that everything I did was an effort .....0                               | 1 | 2 | 3 |
| 8. I felt hopeful about the future .....0  | 1 | 2 | 3 |
| 9. I thought my life had been a failure .....0                                     | 1 | 2 | 3 |
| 10. I felt fearful .....0  | 1 | 2 | 3 |
| 11. My sleep was restless.....0  | 1 | 2 | 3 |
| 12. I was happy .....0   | 1 | 2 | 3 |
| 13. I talked less than usual .....0  | 1 | 2 | 3 |
| 14. I felt lonely.....0  | 1 | 2 | 3 |

|   |   |   |   |   |
|---|---|---|---|---|
| 15. People were unfriendly .....        | 0 | 1 | 2 | 3 |
| 16. I enjoyed life .....                | 0 | 1 | 2 | 3 |
| 17. I had crying spells .....           | 0 | 1 | 2 | 3 |
| 18. I felt sad.....                     | 0 | 1 | 2 | 3 |
| 19. I felt that people disliked me..... | 0 | 1 | 2 | 3 |
| 20. I could not "get going" .....       | 0 | 1 | 2 | 3 |

## Appendix D

### Arthritis Self-Efficacy

For each of the following questions, please circle the number that corresponds to how certain you are that you can do the following tasks regularly at the present time.

#### Self-Efficacy Pain Scale

Very 1 2 3 4 5 6 7 8 9 10 Very  
Uncertain Certain

1. How certain are you that you can decrease your pain quite a bit?
2. How certain are you that you can continue most of your daily activities?
3. How certain are you that you can keep arthritis pain from interfering with your sleep?
4. How certain are you that you can that you can make a small-to-moderate reduction in your arthritis pain by using methods other than taking extra medication?
5. How certain are you that you can make a large reduction in your arthritis pain by using methods other than taking extra medication?

#### Self-Efficacy Function Scale

Very 1 2 3 4 5 6 7 8 9 10 Very  
Uncertain Certain

1. How certain are you that you can walk 100 feet on flat ground in 20 seconds?
2. How certain are you that you can that you can walk 10 steps downstairs in 7 seconds?
3. How certain are you that you can get out of an armless chair quickly, without using your hands for support?
4. How certain are you that you can button and unbutton 3 medium-size buttons in a row in 12 seconds?

5. How certain are you that you can cut 2 bite-size pieces of meat with a knife and fork in 8 seconds?
6. How certain are you that you can turn an outdoor faucet all the way on and all the way off?
7. How certain are you that you can scratch your upper back with both your right and left hands?
8. How certain are you that you can get in and out of the passenger side of a car without assistance from another person and without physical aids?
9. How certain are you that you can put on a long-sleeve front-opening shirt or blouse (without buttoning) in 8 seconds?

Self-Efficacy Other Symptoms Scale

|           |   |   |   |   |   |   |   |   |   |    |         |
|-----------|---|---|---|---|---|---|---|---|---|----|---------|
| Very      | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very    |
| Uncertain |   |   |   |   |   |   |   |   |   |    | Certain |

1. How certain are you that you can control your fatigue?
2. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis?
3. How certain are you that you can do something to help yourself feel better if you are feeling blue?
4. As compared with other people with arthritis like yours, how certain are you that you can manage arthritis pain during your daily activities?
5. How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?
6. How certain are you that you can deal with the frustration of arthritis?



## Appendix E

### MOS-SSS

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

None of the time=1  
A little of the time=2  
Some of the time=3  
Most of the time=4  
All of the time=5

1. Someone you can count on to listen to you when you need to talk  
1      2      3      4      5
2. Someone to give you information to help you understand a situation  
1      2      3      4      5
3. Someone to give you good advice about a crisis  
1      2      3      4      5
4. Someone to confide in or talk to about yourself or your problems  
1      2      3      4      5
5. Someone whose advice you really want  
1      2      3      4      5
6. Someone to share your most private worries and fears with  
1      2      3      4      5
7. Someone to turn to for suggestions about how to deal with a personal problem  
1      2      3      4      5
8. Someone who understands your problems  
1      2      3      4      5
9. Someone to help you if you were confined to bed  
1      2      3      4      5
10. Someone to take you to the doctor if you needed it

1      2      3      4      5

11. Someone to prepare your meals if you were unable to do it yourself

1      2      3      4      5

12. Someone to help with daily chores if you were sick

1      2      3      4      5

13. Someone who shows you love and affection

1      2      3      4      5

14. Someone to love and make you feel wanted

1      2      3      4      5

15. Someone who hugs you

1      2      3      4      5

16. Someone to have a good time with

1      2      3      4      5

17. Someone to get together with for relaxation

1      2      3      4      5

18. Someone to do something enjoyable with

1      2      3      4      5

19. Someone to do things with you get your mind off things

1      2      3      4      5

## Appendix F

### SPWB

Please choose one response per row that best represents how you feel.

| Disagree<br>Strongly<br>1 | Disagree<br>Moderately<br>2 | Disagree<br>Slightly<br>3 | Agree<br>Slightly<br>4 | Agree<br>Moderately<br>5 | Agree<br>Strongly<br>6 |
|---------------------------|-----------------------------|---------------------------|------------------------|--------------------------|------------------------|
|---------------------------|-----------------------------|---------------------------|------------------------|--------------------------|------------------------|

1. I am quite good at managing the many responsibilities of my daily life
2. I generally do a good job of taking care of my personal finances and affairs
3. I am good at juggling my time so that I can fit everything in that needs to be done
4. I have been able to build a home and a lifestyle for myself that is much to my liking
5. I do not fit very well with the people and the community around me
6. I often feel overwhelmed by my responsibilities
7. I have difficulty arranging my life in a way that is satisfying to me
8. I think it is important to have new experiences that challenge how you think about the world
9. I have the sense that I have developed a lot as a person over time
10. I am not interested in activities that will expand my horizons
11. I don't want to try new ways of doing things – my life is fine the way it is
12. When I think about it, I haven't really improved much as a person over the years
13. I do not enjoy being in new situations that require me to change my old familiar ways of doing things

14. There is a truth in the saying that you can't teach an old dog new tricks
15. Most people see me as loving and affectionate
16. I enjoy personal and mutual conversations with family members or friends
17. People would describe me as a giving person, willing to share my time with others
18. I know that I can trust my friends and they know that they can trust me
19. I often feel lonely because I have few close friends with whom to share my concerns
20. I don't have many people who want to listen when I need to talk
21. It seems to me that most other people have more friends than I do
22. I am an active person in carrying out the plans I set for myself
23. I enjoy making plans for the future and working to make them a reality
24. I tend to focus on the present, because the future nearly always brings me problems
25. My daily activities often seem trivial and unimportant to me
26. I don't have a good sense of what it is I am trying to accomplish in life
27. I used to set goals for myself, but that now seems a waste of time
28. I sometime feel I have done all there is to do in life
29. I have made some mistakes in the past, but feel that all in all everything has worked out for the best
30. The past had its ups and downs, but in general I wouldn't want to change it
31. When I compare myself with friends and acquaintances, it makes me feel good about who I am

32. In general, I feel confident and positive about myself
33. I feel that many of the people I know have got more out of life than I have
34. In many ways, I feel disappointed about my achievements in life
35. My attitude about myself is probably not as positive as most people feel about themselves
36. I am not afraid to voice my opinions even when they are in opposition to the opinions of most people
37. My decisions are not usually influenced by what everyone else is doing
38. I have confidence in my opinions even if they are contrary to the general consensus
39. Being happy with myself is more important than having others approve of me
40. I tend to worry what other people think of me
41. I often change my mind about decisions if my friends and family disagree
42. It is difficult for me to voice my own opinions on controversial matters

## Appendix G

### HPLP II

**DIRECTIONS:** This questionnaire contains statements about your *present* way of life or personal habits.

Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behavior by circling:

N for never                      S for sometimes      O for often      or R for routinely

1. Discuss my problems and concerns with people close to me.
2. Choose a diet low in fat, saturated fat, and cholesterol.
3. Report any unusual signs or symptoms to a physician or other health professional.
4. Follow a planned exercise program.
5. Get enough sleep.
6. Feel I am growing and changing in positive ways.
7. Praise other people easily for their achievements.
8. Limit use of sugars and food containing sugar (sweets).
9. Read or watch TV programs about improving health.
10. Exercise vigorously for 20 or more minutes at least three times a week.
11. Take some time for relaxation each day.
12. Believe that my life has purpose.
13. Maintain meaningful and fulfilling relationships with others.
14. Eat 6-11 servings of bread, cereal, rice and pasta each day.
15. Question health professionals in order to understand their instructions.
16. Take part in light to moderate physical activity (such as sustained walking 30-40 minutes 5 or more times a week).

17. Accept those things in my life which I can not change.
18. Look forward to the future.
19. Spend time with close friends.
20. Eat 2-4 servings of fruit each day.
21. Get a second opinion when I question my health care provider's advice.
22. Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling).
23. Concentrate on pleasant thoughts at bedtime.
24. Feel content and at peace with myself.
25. Find it easy to show concern, love and warmth to others.
26. Eat 3-5 servings of vegetables each day.
27. Discuss my health concerns with health professionals.
28. Do stretching exercises at least 3 times per week.
29. Use specific methods to control my stress.
30. Work toward long-term goals in my life.
31. Touch and am touched by people I care about.
32. Eat 2-3 servings of milk, yogurt or cheese each day.
33. Inspect my body at least monthly for physical changes/danger signs.
34. Get exercise during usual daily activities (such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking).
35. Balance time between work and play.
36. Find each day interesting and challenging.
37. Find ways to meet my needs for intimacy.
38. Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and nuts group each day.

39. Ask for information from health professionals about how to take good care of myself.
40. Check my pulse rate when exercising.
41. Practice relaxation or meditation for 15-20 minutes daily.
42. Am aware of what is important to me in life.
43. Get support from a network of caring people.
44. Read labels to identify nutrients, fats, and sodium content in packaged food.
45. Attend educational programs on personal health care.
46. Reach my target heart rate when exercising.
47. Pace myself to prevent tiredness.
48. Feel connected with some force greater than myself.
49. Settle conflicts with others through discussion and compromise.
50. Eat breakfast.
51. Seek guidance or counseling when necessary.
52. Expose myself to new experiences and challenges.



## References

- Abbott, R. A., Ploubis, G. B., Huppert, F. A., Kuh, D. Wadsworth, M. E. J., & Croudace, T.J. (2006). Psychometric evaluation and predictive validity of Ryff's psychological well-being items in a UK birth order cohort sample of women. *Health and Quality of Life Outcomes*, 4, 76-92.
- Adib-Hajbaghery, M., & Aghahoseini, S. (2007). The evaluation of disability and its related factors among the elderly population in Kashan, Iran. *BMC Public Health*, 7, 261-268.
- Allison, P. (2008, March). Convergence failures in logistic regression. Presented at the SAS Global Forum, San Antonio, TX.
- American Autoimmune Related Diseases Association. (2008). [www.aarda.org](http://www.aarda.org).
- Applebaum, S. A. (1973). Psychological mindedness: Word, concept, and essence. *International Journal of Psychoanalysis*, 54, 35-46.
- Astin, J. A., Beckner, W., Soeken, K., Hochberg, M. C., & Berman, B. (2002). Psychological interventions for rheumatoid arthritis: A meta-analysis of randomized controlled trials. *Arthritis & Rheumatism*, 47(3), 291-302.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: Freeman.
- Barlow, J. H., Cullen, L. A., & Rowe, I. F. (2002). Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis. *Patient Education and Counseling*, 46, 11-19.
- Baron, R. M., & Kenny, A. A. (1986). The moderator-mediator distinction in social psychological research: Conceptual, strategic, and statistical

considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.

- Barsky, A. J., Orav, E. J., & Ahern, D. K. (1999). Somatic style and symptom reporting in rheumatoid arthritis. *Psychosomatics: Journal of Consultation Liaison Psychiatry*, 40(5), 396-403.
- Beckham, J. C., Rice, J. R., & Talton, S. L. (1994). Relationship of cognitive constructs to adjustment in rheumatoid arthritis patients. *Cognitive Therapy Research*, 18(5), 479-498.
- Benedict, A. (1995). Attributions of causes for chronic illness among aged persons. *Activities, Adaptation, and Aging*, 19(4), 49-59.
- Billings, D. W., Folkman, S., Acree, M., & Moskowitz, J. T. (2000). Coping and physical health during caregiving: The roles of positive and negative affect. *Journal of Personality and Social Psychology*, 79(1), 131-142.
- Blalock, S. J., DeVellis, R. F., Brown, G. K., Wallston, K. A. (1989). Validity of the Center for Epidemiological Studies Depression Scale in arthritis populations. *Arthritis and Rheumatism*, 32, 991-997.
- Boland, C. S. (2000). Social support and spiritual well-being: empowering older adults to commit to health-promoting behaviors. *Journal of Multicultural Nursing and Health*, 6(3), 12-23.
- Borgen, F. H., & Barnett, D. C. (1987). Applying cluster analysis in counseling psychology research. *Journal of Counseling Psychology*, 34(4), 456-468.
- Burgoyne, R. W. & Saunders, D. S. (2000). Perceived support in newly registered HIV/AIDS clinic outpatients. *AIDS Care*, 12(5), 643-650.

- Callaghan, D. (2005). Healthy behaviors, self-efficacy, self-care, and basic conditioning factors in older adults. *Journal of Community Health Nursing, 22*(3), 169-178.
- Centers for Disease Control Website. (2008). [www.cdc.gov](http://www.cdc.gov)
- Chrisler, J. C. (2001). How can feminist therapies support women with autoimmune disorders? *Women & Therapy, 23*(1), 7-22.
- Chwastiak, L.A., & Von Korff, M. (2003). Disability in depression and back pain: Evaluation of the World Health Organization Disability Assessment Schedule (WHO DAS II) in a primary care setting. *Journal of Clinical Epidemiology, 56*(6), 507-514.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences (2nd ed.)*. Hillsdale, NJ: Erlbaum.
- Cohen, S. & Herbert, T. B. (1996). Health psychology: Psychological factors and physical disease from the perspective of human psychoneuroimmunology. *Annual Review of Psychology, 47*, 113-142.
- Covic, T., Pallant, J. F., Conaghan, P. G., & Tennant, A. (2007). A longitudinal evaluation of the Center for Epidemiologic Studies-Depression scale (CES-D) in a Rheumatoid Arthritis Population using Rasch Analysis. *Health and Quality of Life Outcomes, 5*, 41.
- Cunningham, A. J. & Edmonds, C. V. (1996). Group psychological therapy for cancer patients: A point of view and discussion of the hierarchy of options. *International Journal of Psychiatry in Medicine, 26*, 51-82.

- Dantzer, R., O'Connor, J. C., Freund, G. G., Johnson, R. W., & Kelley, K. W. (2008). From inflammation to sickness and depression: When the immune system subjugates the brain. *Nature Reviews: Neuroscience*, 9, 46-57.
- Devins, G. M. (1981). Helplessness and depression in end-stage renal disease. *Journal of Abnormal Psychology*, 90(6), 531-545.
- Devins, G. M., Hunsley, J., Mandin, H., Taub, K. J., & Paul, L. C. (1997). The marital context of end-stage renal disease: Illness intrusiveness and perceived changes in family environment. *Annals of Behavioral Medicine*, 19(4), 325-332.
- Dwyer, K. A. (1997). Psychosocial factors and health status in women with rheumatoid arthritis: Predictive models. *American Journal of Preventative Medicine*, 13(1), 66-72.
- Edwards, R., Telfair, J., Cecil, H., & Lenoci, J. (2001). Self-efficacy as a predictor of adult adjustment to sickle cell disease: One-year outcomes. *Psychosomatic Medicine*, 63(5), 850-858.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129-136.
- Ennis, M., Thain, J., Bogglid, M., Baker, G. A., Young, C. A. (2006). A randomized controlled trial of a health promotion education programme for people with multiple sclerosis. *Clinical Rehabilitation*, 20(9), 783-792.
- Evers, A. W. M., Kraaiaat, F. W., Greenen, R., & Bijlsma, J. W. J. (1998). Psychosocial predictors of functional change in recently diagnosed

- rheumatoid arthritis patients. *Behavioral Research and Therapy*, 36, 170-193.
- Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology research. *Journal of Counseling Psychology*, 51, 115-134.
- Friedman, E. M., Hayney, M., Love, G. D., Singer, B. H., & Ryff, C. D. (2007). Plasma interleukin-6 and soluble IL-6 receptors are associated with psychological well-being in aging women. *Health Psychology* 26(3), 305-313.
- Fyrand, L. Moum, T., Finset, A., Wichstrom, L., & Glennas, A. (2000). Social network size of female patients with rheumatoid arthritis compared to healthy controls. *Scandinavian Journal of Rheumatology*, 29, 38-43.
- Fyrand, L., Moum, T., Finset, A., Wichstrom, L., & Glennas, A. (2001). Social support in female patients with rheumatoid arthritis compared with health controls. *Psychology, Health and Medicine*, 6, 429-439.
- Fyrand, L., Moum, T., Finset, A., & Glennas, A. (2002). The impact of disability and disease duration on social support of women with rheumatoid arthritis. *Journal of Behavioral Medicine*, 25(3), 251-268.
- Gatchel, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychological Bulletin*, 133(4), 581-624.
- Gaubitz, M. (2006). Epidemiology of connective tissue disorders. *Rheumatology*, 45(1), iii3-iii4.

- Gignac, M. A. M., Badley, E. M., Lacaille, D., Cott, C. C., Adam, P., & Anis, A.H. (2004). Managing arthritis and employment: Making arthritis-related work changes as a means of adaptation. *Arthritis & Rheumatism*, 51(6), 909-916.
- Goodheart, C. D. (2006). An integrated view of girls' and women's health: Psychology, physiology, and society. In: J. Worell & C. Goodheart, *Handbook of girls' and women's psychological health: Gender and well-being across the lifespan*, 3-14. New York, NY: Oxford University Press.
- Gowans, S. E., deHueck, A., Voss, S., Silaj, A., Abbey, S. E., Reynolds, W. J. (2001). Effect of a randomized, controlled trial of exercise on mood and physical function in individuals with fibromyalgia. *Arthritis & Rheumatism: Arthritis Care & Research*, 45(6), 519-529.
- Haddad, L., Kane, D., Rajacich, D., Cameron, S., & Al-Ma'aitah, R. (2004). A comparison of health practices of Canadian and Jordanian nursing students. *Public Health Nursing*, 21 (1), 85-90.
- Hann, D., Winter, K., & Jacobsen, P. (1999). Measurement of depressive symptoms in cancer patients: Evaluation of the Center for Epidemiological Studies Depression Scale (CES-D). *Journal of Psychosomatic Research*, 46, 437-443.
- Hart, S., Fonareva, I., Merluzzi, N., & Mohr, D. C. (2005). Treatment for depression and its relationship to improvement in quality of life and psychological well-being in multiple sclerosis patients. *Quality of Life Research*, 14, 695-703.

- Hartman, C. A., Manos, T. M., Winter, C., Hartman, D. M., Li, B., & Smith, J. C. (2000). Effects of T'ai Chi training on function and quality of life indicators in older adults with osteoarthritis. *Journal of the American Geriatrics Society, 48*(12), 1553-1559.
- Healthy People 2010. (2007). [www.healthypeople.gov](http://www.healthypeople.gov).
- Heppner, P.P., Kivlighan, D.M., Good, G.E., Roehlke, H.J., Hills, H.I., & Ashby, J.S. (1994). Presenting problems of university counseling center clients: A snapshot and multivariate classification scheme. *Journal of Counseling Psychology, 41*(3), 315-324.
- Hoffman, M. A. & Driscoll, J. M. (2000). Health promotion and disease prevention: A concentric biopsychosocial model of health status. In: S.D. Brown & R.W. Lent (Eds.), *Handbook of counseling psychology (3<sup>rd</sup> ed.)*, 532-567. New York: John Wiley & Sons, Inc.
- Kettmann, J. D. J. & Altmaier, E. V. (2008). Social support and depression among bone marrow transplant patients. *Journal of Health Psychology, 13*(1), 39-46.
- Kafka, G. J. & Kozma, A. (2002). The construct validity of Ryff's scales of psychological well-being (SPWB) and their relationship to measures of subjective well-being. *Social Indicators Research, 57*, 171-190.
- Kaschak, E. (2001). Minding the body: Psychotherapy in cases of chronic and life-threatening illness. *Women & Therapy, 23*(1), 1-5.
- Katz, R. C., Flasher, L., Cacciapaglia, H., & Nelson, S. (2001). The psychosocial impact of cancer and lupus: A cross-validation study that extends the

generality of “benefit-finding” in patients with chronic disease. *Journal of Behavioral Medicine*, 24(6), 561-571.

Kelly, P. T. (1983). Counseling persons who have cancer. In Newell, G. R. (Eds.), *Cancer Prevention in Clinical Medicine* (pp.147-158). New York: Raven Press.

Kessler, R.C., Berglund, P., Demler, O., Jin, R., Koretz, D., Merikangas, K.R., Rush, A.J., Walters, E.E., & Wang, P.S. (2003). The epidemiology of major depressive disorder: Results from the national comorbidity survey replication (NCS-R). *Journal of the American Medical Association*, 289, 3095-3105.

Kettmann, J. D. J. & Altmaier, E.M. (2008). Social support and depression among bone marrow transplant patients. *Journal of Health Psychology*, 13(1), 39-46.

Landis, J. R. and Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33, 159-174.

Liller, T. K. (1994). *Expanding horizons: An exploration of fibromyalgia syndrome*. Fibromyalgia Association of Greater Washington, Inc.

Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure self-efficacy in people with arthritis. *Arthritis and Rheumatism*, 32(1), 37-44.

Lowe, R., Cockshott, Z., Greenwood, R., Kirwan, J. R., Almeida, C., Richards, P., & Hewlett, S. (2008). Self-efficacy as an appraisal that moderates the



coping-emotion relationship: Associations among people with rheumatoid arthritis. *Psychology and Health*, 23(2), 155-174.

Malmgren-Olsson, E.B., Branholm, I. B. (1992). A comparison between three physiotherapy approaches with regard to health-related factors in patients with non-specific musculoskeletal disorders. *Disability and Rehabilitation: An International Multidisciplinary Journal*, 24(6), 308-317.

Mangelli, L., Gribbin, N., Buchi, S., Allard, S., & Sensky, T. (2002). Psychological well-being in rheumatoid arthritis: Relationship to 'disease' variables and affective disturbance. *Psychotherapy and Psychosomatics*, 71, 112-116.

Mansfield, E.R., Helms, B.P. (1982). Detecting multicollinearity. *The American Statistician*, 36(3), 158-160.

Mast, M. S., Kindlimann, A. & Langewitz, W. (2005). Recipients' perspectives on breaking bad news: How you put it really makes a difference. *Patient Education and Counseling*, 58, 244-251.

Mohr, D. C., Dick, L. P., Russo, D., Pinn, J., Boudewyn, A. C., Likosky, W., & Goodkin, D. E. (1999). The psychosocial impact of multiple sclerosis: Exploring the patient's perspective. *Health Psychology*, 18(4), 376-382.

Motl, R. W., McAuley, E., & Snook, E. M. (2007) Physical activity and quality of life in multiple sclerosis: Possible roles of social support, self efficacy, and functional limitations. *Rehabilitation Psychology*, 52(2), 143-151.

- Nagyova, I., Stewart, R. E., Macejova, Z., van Dijk, J. P., & van den Heuvel, W. J. A. (2005). The impact of pain on psychological well-being in rheumatoid arthritis: The mediating effects of self-esteem and adjustment to disease. *Patient Education and Counseling, 58*, 55-62.
- Nicassio, P. M., & Smith, T. W. (1995). *Managing Chronic Illness: A Biopsychosocial Perspective*. Washington, DC: American Psychological Association.
- O'Leary, A. (1990). Stress, emotion, & human immune function. *Psychological Bulletin, 108*(3), 363-382.
- O'Leary, A., Shoor, S., Lorig, K., & Holman, H. (1988). A cognitive-behavioral treatment for rheumatoid arthritis. *Health Psychology, 7*(6), 527-544.
- Orengo, C. A., Wei, S. H., Molinari, V. A., Hale, D. D., & Kunik, M. E. (2001). Functioning in rheumatoid arthritis: The role of depression and self-efficacy. *Clinical Gerontologist, 23*(3 – 4), 45-56.
- Orme, J. G., Reis, J., & Herz, E. J. (1986). Factorial and discriminant validity of the Center for Epidemiological Studies Depression (CES-D) scale. *Journal of Clinical Psychology, 42*, 28-33.
- Parker, J. C. Smarr, K. L., Walker, S. E., Hagglund, K. J., Anderson, S. K., Hewett, J. E., Bridges, A. J., & Caldwell, C. W. (1991). Biopsychosocial parameters of disease activity in rheumatoid arthritis. *Arthritis Care and Research, 4*(2), 73-80.
- Parker, J. C., Smarr, K. L., Slaughter, J. R., Johnston, S. K., Priesmeyer, M. L., Hanson, K. D., Johnson, G. E., & Hewett, J. E., et al. (2003).

Management of depression in rheumatoid arthritis: A combined pharmacologic and cognitive-behavioral approach. *Arthritis & Rheumatism*, 49(6), 766-777.

Phillips, M. A. & Murrell, S. A. (1994). Impact of psychological and physical health, stressful events, and social support on subsequent mental health help seeking among older adults. *Journal of Consulting and Clinical Psychology*, 62(2), 270-275.

Plach, S.K., Heidrich, S.M., & Waite, R.M. (2003). The relationship of social role quality to psychological well-being in women with rheumatoid arthritis. *Research in Nursing and Health*, 26, 190-202.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.

Radloff, L. S. (1991). The Use of the Center for Epidemiologic Studies Depression Scale in Adolescents and Young Adults. *Journal of Youth and Adolescence*, 20(2), 149-166.

Ryan, K. A., Rapport, L. J., Sherman, T. E., Hanks, R. A., Lisak, R., & Khan, O. (2007). Predictors of subjective well-being among individuals with multiple sclerosis. *The Clinical Neuropsychologist*, 21, 239-262.

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069-1081.

- Ryff, C. D. & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69(4), 719-727.
- Ryff, C. D. (1995). Psychological well-being in adult life. *American Psychological Society*, 4(4), 99-104.
- Ryff, C. D., Keyes, C. L. M., & Hughes, D. L. (2003). Status Inequalities, perceived discrimination, and eudaimonic well-being: Do the challenges of minority life hone purpose and growth? *Journal of Health and Social Behavior*, 44, 275-291.
- Ryff, C. D., & Singer, B. (1996). Psychological well-being: Meaning, measurement, and implications for psychotherapy research. *Psychotherapy and Psychosomatics*, 65, 14-23.
- Sawatzky, J. V. & Naimark, B. J. (2005). Cardiovascular health promotion in aging women: Validating a population health approach. *Public Health Nursing*, 22(5), 379-388.
- Schmidt, C. K., Hoffman, M. A., & Taylor, N. E. (2005). Social justice related to working with HIV/AIDS from a community health psychology perspective. In: R. Toporek, L. Gerstein, N. Fouad, G. Roysircar, & T. Israel (Eds.), *Handbook for social justice in counseling psychology: Leadership, vision, and action*. New York: Sage Publications.
- Schmutte, P. S. & Ryff, C. D. (1997). Personality and well-being: Reexamining methods and meanings. *Journal of Personality and Social Psychology*, 73(3), 549-559.

- Schoenfeld-Smith, K., Petroski, G. F., Hewett J. E., Johnson J. C., Wright, G. E., Smarr, K. L., Walker, S. E., Parker, J. C. (1996). A biopsychosocial model of disability in rheumatoid arthritis. *Arthritis Care & Research*, 9(5), 368-375.
- Sherbourne, C. D. & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, 32(6), 705-714.
- Shorter, E. (1992). From paralysis to fatigue: A history of psychosomatic illness in the modern era. New York: The Free Press.
- Smarr, K. L., Parker, J. C., Wright, G. E., Stucky-Ropp, R. C., Buckelew, S. P., Hoffman, R. W., O'Sullivan, F. X., & Hewett, J. E. (1997). Arthritis & Rheumatism: Arthritis Care & Research. *Arthritis Care & Research*, 10(1), 18-26.
- Surkan, P. J., Peterson, K. E., Hughes, M. D., & Gottlieb, B. R. (2006). The role of social networks and support in postpartum women's depression: A multiethnic urban sample. *Maternal and Child Health Journal*, 10(4), 375-383.
- Taibi, D. M., & Bourguignon, C. (2003). The role of complementary and alternative therapies in managing rheumatoid arthritis. *Family and Community Health*, January-March, 41-52.
- Taylor, S. E. (1983). Adjustment to threatening events. *American Psychologist*, 1161-1173.
- Tedeschi, R. G. & Calhoun, L. G. (1995). *Trauma & transformation: Growing in the aftermath of suffering*. Thousand Oaks, CA: Sage Publications, Inc.

- Toporek, R. L., Gerstein, L., Fouad, N., Roysircar, G., & Israel, T. (in press). *Handbook for social justice in counseling psychology: Leadership, vision, and action*. Thousand Oaks, CA: Sage Publications.
- Treharne, G. J., Kitas, G. D., Lyons, A. C., & Booth, D. A. (2005). Well-being in rheumatoid arthritis: The effects of disease duration and psychosocial factors. *Journal of Health Psychology, 10*(3), 457-474.
- Turner, J. A., Ersek, M., & Kemp, C. (2005). Self-efficacy for managing pain is associated with disability, depression, and pain coping among retirement community residents with chronic pain. *The Journal of Pain, 6*(7), 471-479.
- United States Census Webpage. (2008). [www.quickfacts.census.gov](http://www.quickfacts.census.gov)
- Walker, S. N., & Hill-Polerecky, D. M. (1996). Psychometric evaluation of the Health-Promoting Lifestyle Profile II. Unpublished manuscript, University of Nebraska Medical Center.
- Walker, J. G., Jackson, H. J., & Littlejohn, G. O. (2004). Models of adjustment to chronic illness: Using the example of rheumatoid arthritis. *Clinical Psychology Review, 24*(4), 461-488.
- Walker, S. N., Sechrist, K. R., & Pender, N. J. (1987). The health-promoting lifestyle profile: development and psychometric characteristics. *Nursing Research, 36*(2), 76-81.
- Walker, S. N., Kerr, M. J., Pender, N. J., & Sechrist, K. R. (1990). A Spanish language version of the health-promoting lifestyle profile. *Nursing Research, 39*(5), 268-273.

- Wampold, Bruce E. (2001). *The great psychotherapy debate*. New Jersey: Lawrence Erlbaum.
- Ward, J. H. (1963). Hierarchical Grouping to Optimize an Objective Function. *Journal of the American Statistical Association*, 58, 236-244.
- Westbrook, M. T. & Nordholm, L. A. (1986). Effects of diagnosis on reactions to patient optimism and depression. *Rehabilitation Psychology*, 31(2), 79-94.
- White, M. T., Lemkau, J. P., & Clasen, M. E. (2001). Fibromyalgia: A feminist biopsychosocial perspective. *Women & Therapy*, 23(1), 45-58.
- Wright, G. E., Parker, J. C., Smarr, K. L., Schoenfeld-Smith, K, et al. (1996). *Arthritis Care Research*, 9, 264-272.
- World Health Organization Website (2008). [www.who.int/icidh/whodas](http://www.who.int/icidh/whodas)
- Wrong Diagnosis Website (2006). [www.wrongdiagnosis.com](http://www.wrongdiagnosis.com)